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Women's Health Legislation in the 107th Congress



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Women's Policy, Inc. (WPI) is a nonprofit (501)(c)(3) organization providing nonpartisan research and information on legislative actions affecting women and families. WPI is a special affiliate of The George Washington University.

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Introduction

The effort to improve women's health has probably received more attention from Congress during the 1990s than any other women's issue. Led by members of the Congressional Caucus for Women's Issues, this effort has been bipartisan.

Since 1990, Caucus efforts have resulted in the appropriation of several billion dollars for women's health research and prevention initiatives. This has led to the creation of several important public health programs designed to make mammograms and Pap tests more widely available, to ensure the safety and accuracy of mammography screening, to prevent infertility through better screening and treatment of sexually transmitted diseases, to increase awareness about osteoporosis and improve coverage for osteoporosis screening, and to prevent cardiovascular diseases in women through research and screening programs.

The majority of women's health bills considered by Congress between 1990 and 1996 were first introduced as part of the Women's Health Equity Act (WHEA), which combined more than 30 women's health bills into one omnibus package. First introduced in 1990, revised WHEA packages were reintroduced in three successive Congresses between 1991 and 1996. In all, 27 WHEA bills were enacted.

Beginning in 1997, the Congressional Caucus for Women's Issues decided to incorporate Caucus-backed provisions into legislation already under consideration by Congress. The strategy was pursued during the 105th, 106th, and 107th Congresses. To that end, the Caucus established a number of bipartisan legislative teams charged with developing an agenda and legislative strategy for their areas of emphasis.

Women's Health Legislation in the 107th Congress provides background information on a range of women's health issues from autoimmune diseases to HIV/AIDS prevention to insurance coverage for breast and cervical cancer treatment. It is not meant to be an

encyclopedic guide to women's health topics but rather a report on those health issues considered by the 107th Congress.

The first section of the report focuses on women's health research covering such topics as alcohol, autoimmune diseases, breast cancer, cardiovascular diseases, DES, environmental health, HIV/AIDS, ovarian cancer, and the treatment of women scientists.

The second section of the report focuses on preventive health services for women and covers adolescent pregnancy, domestic violence, eating disorders, family planning informed consent, minority health, mid-life and older women, HIV/AIDS, international women's health, osteoporosis, reproductive health, smoking, women veterans' health, and women's health offices.

The third section of the report focuses on health care coverage, detailing breast and cervical cancer treatment, bone mass measurement, clinical trials, contraceptive drugs and services, family caregivers and long-term care, genetic discrimination, mammography screening, mastectomy hospital stays, mental health services, access to obstetricians-gynecologists, prescription drugs, and reconstructive breast surgery. The report also includes two appendices: the first provides a summary of all legislative action on women's health in the 107th Congress and the second provides a selected listing of bills pertaining to women's health that were introduced in the 107th Congress.

Overall, the 107th Congress was stymied on a number of health issues, particularly in the wake of September 11, 2001, when the focus of congressional action turned to the war on terrorism and homeland security. Additionally, lawmakers were unable to reach agreement on 11 of the 13 FY2003 appropriations bills, including the Labor, Health and Human Services, and Education spending bill, pushing final action on those measures into the 108th Congress.

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Part One

Women's Health Research

Alcohol/Fetal Alcohol Syndrome

Alcoholism and diseases related to alcohol abuse are not commonly considered women's health issues. It is true that alcohol use is lower among women than among men, both in terms of the number of women who drink and the amount of alcohol they consume. However, particularly for the heaviest drinkers, drinking comparable amounts of alcohol has more severe effects on women than on men.

- Female alcoholics develop alcohol-induced liver disease over a shorter period of time and after consuming less alcohol, compared with men.¹
- Women are more susceptible to interpersonal violence as a result of alcohol abuse. According to the National Institute on Alcohol Abuse and Alcoholism (NIAAA) at the National Institutes of Health (NIH), one survey of female college students found a significant relationship between consumption of alcohol the women reported drinking each week and their experiences of sexual victimization.²
- Women are more likely to develop alcoholic hepatitis and to die from cirrhosis than men with similar drinking histories.³
- Heavy alcohol use increases risk of death from cardiovascular disease for women aged 55 and younger.⁴

According to the Centers for Disease Control and Prevention (CDC), 1 out of 7 women of childbearing age report risk drinking, which is defined as consuming seven or more drinks per week, or five or more drinks on any one occasion. Additionally, 1 out of every 30 women who know they are pregnant reports risk drinking.⁵

Alcohol use during pregnancy is a leading cause of birth defects and developmental disorders. It can cause head and facial deformities, organ dysfunction, growth retardation, learning disabilities, low IQ, behavioral problems, short attention span, poor coordination, and hyperactivity. This set of irreversible mental, physical, and neurobiological birth defects is

known as Fetal Alcohol Syndrome (FAS) and affects between 1,200 and 8,000 babies each year.⁶ Recent studies have shown that the prevalence of FAS is 0.5 to 2 cases per 1,000 births in the U.S.; however, true prevalence rates are difficult to ascertain due to inadequate data and differences in diagnostic criteria.⁷

Alcohol-related birth defect (ARBD) is used to describe individuals who have the physical characteristics of FAS minus the characteristic set of abnormal facial features. Alcohol-related neurodevelopmental disorder (ARND) refers to individuals who lack the physical defects associated with FAS but have induced mental impairments as a result of alcohol use.⁸ The prevalence of FAS and ARBD combined is roughly 10 per 1,000 births, or 1 percent of all births.⁹ The NIAAA estimates that the lifetime health care costs for a single child born with FAS in 2000 will total \$588,000.¹⁰

However, advocates believe that FAS is misdiagnosed and underdiagnosed due to a lack of health care provider training. As a result, the National Organization on Fetal Alcohol Syndrome (NOFAS) has developed a training curriculum for nursing, nurse midwifery, and physician assistant students on FAS and ARBD, and nine schools have implemented the curriculum.¹¹ Three additional medical schools have implemented the curriculum for medical students.¹²

FAS affects all races and socioeconomic groups. One of its puzzling aspects is that the occurrence of FAS among African Americans is 6 times higher than among Caucasians, even when the mothers have similar drinking habits during pregnancy.¹³ The occurrence is 33 times higher among some Native American tribes.¹⁴ Smokers, single women, young women, and less educated women are more likely to drink alcohol during pregnancy and are therefore at a higher risk of having babies with FAS.

To that end, the NIAAA issued a strategic plan to address health disparities in 2001. That plan included

a number of goals for research on FAS and prenatal alcohol exposure, including identifying biological, genetic, and environmental risk factors that lead to disproportionately high incidence of FAS among African Americans, Alaska Natives, and American Indians, establishing the incidence of FAS in minority communities, developing interventions for the prevention of FAS in minority communities, developing neurobehavioral assessment methods leading to techniques for improving awareness, and determining the extent to which high rates of alcohol consumption during pregnancy contribute to the high incidence of infant mortality and SIDS in some minority groups.¹⁵

Gender differences in the physiological effects of alcohol have not been well explored. For example, hormonal changes throughout the menstrual cycle may influence the metabolism of alcohol in women. Alcoholic women have higher rates of amenorrhea, miscarriage, early menopause, gynecologic surgery, and infertility than other women, but the mechanisms by which alcohol affects the female reproductive system are not well understood.¹⁶

Prevention and Surveillance Activities

In December 2001, the National Task Force on Fetal Alcohol Syndrome and Fetal Alcohol Effect issued 15 recommendations regarding FAS, ARBD, and ARND, including developing clinical case definitions for the diagnosis and surveillance of FAS and ARND, developing prevention and treatment strategies for women at risk for prenatal alcohol use, developing health services and basic science research agendas, developing a national standard of care for individuals with FAS/ARND, and developing and disseminating plans for system-wide education regarding prenatal alcohol-related disabilities.¹⁷

The Substance Abuse and Mental Health Services Administration's Center for Substance Abuse Prevention created the Partnership to Prevent Fetal Alcohol Syndrome in July 2001. The goal of the partnership is to unite communities in a public health response to FAS and ARBD. Initially, the partnership will implement programs in four communities: Erie

County, New York; Doña Ana County, New Mexico; East Baton Rouge Parish, Louisiana; and Sumter County, South Carolina.¹⁸

The CDC has developed the Fetal Alcohol Syndrome Surveillance Network (FASSNet), which monitors trends in the occurrence of FAS in five states—Alaska, Arizona, Colorado, New York, and Wisconsin.¹⁹ Also, beginning in 1997, the CDC awarded cooperative agreements to three universities—Nova Southeastern University, University of Texas Health Sciences Center, and Virginia Commonwealth University—to develop and study interventions aimed at preventing alcohol-exposed pregnancies. The first part of the study, dubbed Project CHOICES, included an epidemiological survey and a behavioral intervention. The second phase of the study consists of a randomized trial to test the efficacy of the behavioral intervention. This phase started in June 2002 and is slated for completion in June 2004.²⁰

Additionally in March 2002, the NIAAA and NOFAS launched a two-year multi-media public awareness campaign, “Play it Smart. Alcohol and Pregnancy Don’t Mix,” in Washington, D.C. The campaign will target African-American women between the ages of 21 and 29 with posters, brochures, transit announcements, and a local information phone line.²¹

Further Research Needed

Quantifying the prevalence of alcohol problems among women is hampered by the lack of recent data. Women have historically been underrepresented in studies of alcohol use and abuse, thus prevention, diagnosis, and treatment methods have been developed largely through studies of men.

Women react differently to treatment and intervention messages than men. The social stigma against women who drink heavily acts as a major barrier to treatment. Other barriers include lack of access to services, transportation, lack of culturally sensitive services for racial and ethnic minorities, responsibility for children, cost, and fear of removal of their children. Studies show that women who receive treatment improve their health, productivity, parenting abilities,

and the health and well-being of their children.²² Researchers are continuing to look at the most effective gender-appropriate methods to prevent and treat alcohol abuse in women.

The NIAAA has identified a broad list of research opportunities concerning women and alcohol. Continued research will help identify patterns of alcohol use and abuse among women, differences in the physiological and social effects of alcohol on women and men, and the prevention and treatment strategies that will be most effective for women.

Congressional Action

During the 107th Congress, the Senate Health, Education, Labor, and Pensions Committee approved a bill (S. 2328) pertaining to safe motherhood that incorporated a number of other women's health provisions, including language that would authorize the Substance Abuse and Mental Health Services Administration to make grants to provide additional prevention and treatment services for mothers and families susceptible to substance abuse.

Report language accompanying the Senate committee-approved FY2003 Labor, Health and Human Services, and Education appropriations bill (S. 2766) encouraged the NIAAA to work collaboratively with other institutes to study the role of gender, ethnicity, socioeconomic status, and other variables in determining the effects of alcohol use and abuse. The committee report also commended NIAAA's efforts to understand the biological mechanisms through which alcohol causes damage to the developing fetus and urges the institute to "aggressively pursue research that will lead to effective strategies for the prevention and treatment of fetal alcohol syndrome."

The report also noted that within the total increase provided for the CDC's work on birth defects, developmental disabilities, disability, and health, \$1.5 million should be used to expand its FAS-related activities, noting that the increase "will allow CDC to expand surveillance activities to document the magnitude of the problem and to develop and implement prevention strategies."

NOTES

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Autoimmune Diseases

Autoimmune diseases encompass more than 80 different chronic diseases whereby the body inexplicably develops antibodies to its own system, which is subsequently attacked by its own immune cells. Roughly 5-8 percent of Americans suffer from an autoimmune disease, and women are disproportionately affected. These diseases traditionally strike women during their working and childbearing years.¹ Examples of autoimmune diseases include rheumatoid arthritis, lupus, multiple sclerosis, scleroderma, Type I diabetes, Graves' disease, and Sjogren's syndrome.

A September 2000 *American Journal of Public Health* study found that autoimmune diseases are the seventh leading cause of death among women aged 1 to 14, the fifth leading cause of death among women aged 15 to 44, and the seventh leading cause of death among women aged 45 to 65.²

Autoimmune diseases are particularly difficult to diagnose because of the vagueness of symptoms. Often women are sent from specialist to specialist, taking years before they are diagnosed. A study by the American Autoimmune Related Diseases Association (AARDA) found that 65 percent of patients were labeled hypochondriacs or chronic complainers by their physicians when they were actually in the early stages of the disease. The emotional, physical, and economic cost for individuals seeking an explanation for their symptoms is significant. According to the AARDA, direct medical costs associated with autoimmune diseases cost roughly \$86 billion per year.³

Research

Research into autoimmune diseases is beginning to produce a wealth of new information about the diseases. While there is no known cause or cure for many of the diseases, researchers are encouraged by research that has discovered antigens, proteins, and antibodies that may be involved in triggering a num-

ber of the diseases.⁴ Research also has demonstrated that fetal cells remain in a woman's body often for decades after she gives birth. In certain instances, the presence of these fetal cells can cause an autoimmune reaction and lead to the development or exacerbation of an autoimmune disease.⁵

Experts also believe that the hormone estrogen plays a role because of the disproportionate number of women afflicted with autoimmune diseases. However, many questions remain, such as why certain diseases, for example, multiple sclerosis and rheumatoid arthritis, become less severe during pregnancy when there are high levels of estrogen in the body, and yet other diseases, such as lupus, become worse.⁶ In fact, a new study by the National Institute of Child Health and Human Development and the National Institute of Arthritis, Musculoskeletal and Skin Disorders (NIAMS) at the National Institutes of Health (NIH) found that a sharp drop in stress hormones after giving birth may predispose some women to develop rheumatoid arthritis or multiple sclerosis.⁷

Additionally, there appears to be a genetic predisposition to autoimmune diseases. While no one gene has been identified, there is evidence that clusters of genes may increase an individual's susceptibility. It is not uncommon for several individuals within a family to have a number of different autoimmune diseases.⁸ Further research is needed on the etiology of autoimmune diseases in an effort to discover a root cause for the diseases.

Researchers at the National Institute of Allergy and Infectious Diseases (NIAID) at the NIH are currently investigating the immune system during disease progression, the influence of genetics, the role of infectious agents, and the effects of therapeutic interventions.⁹ In FY2001, the NIH as a whole spent \$495.1 million on autoimmune disease research.¹⁰

The NIH also supports clinical research and clinical trials through the Autoimmunity Centers of Excellence, a cooperative research program to examine therapies for autoimmune diseases. Additionally, an Immune Tolerance Network was established by the NIAID to test promising treatments in islet transplantation, kidney transplantation, autoimmune diseases, and asthma and allergic diseases. The network consists of over 70 basic scientists and clinical investigators.¹¹

Congressional Action

The 106th Congress enacted legislation (P.L. 106-310) pertaining to children's health that included an autoimmune diseases initiative at the NIH. Under the law, the NIH Director is required to expand, intensify, and coordinate research on autoimmune diseases at the NIH. The law requires the NIH to report to Congress biennially on research, education, and other activities on autoimmune diseases conducted or support by the NIH.

During the 107th Congress, committee report language accompanying the House-passed FY2002 Labor, Health and Human Services, and Education appropriations bill (H.R. 3061) encouraged the NIH to enhance research aimed at improving awareness, diagnosis and treatment for all autoimmune diseases. Additionally, committee report language for the Senate-passed FY2002 Labor, Health and Human Services, and Education spending bill (S. 1536) commended the NIAID for partnering with the National Multiple Sclerosis Society to support gender-based research differences in immune function and immunologic disease.

The Senate committee-approved FY2003 Labor, Health and Human Services, and Education appropriations bill (S. 2766) noted that the committee is awaiting the release of the NIH's Autoimmune Disease Research Plan.

Legislation

Women's Autoimmune Diseases Research and Prevention Act (S. 2234)—Sen. Barbara Boxer (D-CA)

S. 2234 would authorize the Director of the Office of Women's Health at the Department of Health and Human Services to expand, intensify, and coordinate research and related activities with respect to autoimmune diseases in women, including research into the prevalence of autoimmune disease in women, basic research, epidemiological studies, the development of safe, efficient, and cost-effective diagnostic tools, clinical research on new treatments, studies to gain a better understanding of methods of preventing autoimmune diseases, and information and education programs for patients and health care providers.

Women's Autoimmune Disease Research and Prevention Act (H.R. 5104)—Rep. Stephen Lynch (D-MA)

H.R. 5104 would require the NIH to develop outreach materials that target historically underserved groups and would direct the NIH to study the role of environmental factors in causing autoimmune diseases.

Rheumatoid Arthritis

Rheumatoid arthritis (RA) is an autoimmune disease in which the immune system attacks the lining of various joints, causing pain, swelling, and stiffness. RA affects 2.1 million Americans, of whom 1.5 million are women.¹² The Arthritis Foundation estimates that musculoskeletal conditions such as rheumatoid arthritis cost the U.S. economy roughly \$65 billion per year in medical care and indirect expenses, including lost wages.¹³

Researchers are investigating the role that genetic factors play in RA. Scientists have been able to discover that more than one gene is involved in the development of the disease; however, some people who carry these genes do not develop RA while others do.¹⁴ Additionally, the NIAMS has partnered with the Arthritis Foundation to support the North American Rheumatoid Arthritis Consortium.

The consortium will collect medical information and genetic material from 1,000 families in which two or more siblings have RA.¹⁵

Some researchers believe that an incident triggers the onset of RA in people who are genetically predisposed to the disease. As a result, the NIAMS is undertaking research on environmental and genetic factors and RA. In an effort to better understand why women are more affected by RA than men, researchers also are studying male and female hormones, as well as other gender differences.¹⁶ NIAMS also is supporting research to develop biomarkers for RA, as well as new treatments for the disease.¹⁷

Current treatment for RA involves an integrated approach. In addition to prescribing medication, many health care providers also address lifestyle issues, such as diet, exercise, and stress levels. Certain medications are aimed at reducing the inflammation of the joints, while other more powerful disease-modifying antirheumatic drugs are used to slow disease progression.¹⁸ Non-steroidal anti-inflammatory drugs such as ibuprofen and a number of other drugs are commonly used to treat rheumatoid arthritis; however, these medications often have gastrointestinal side effects. Additionally, biological response modifiers are new drugs approved to treat RA, and they can help to reduce inflammation and structural joint damage. Physicians also may prescribe corticosteroids, such as prednisone, to reduce inflammation. Again, these drugs can have side effects, including increased appetite, weight gain, and emotional ups and downs.¹⁹

In an effort to raise awareness about RA, the Centers for Disease Control and Prevention launched the National Arthritis Action Plan in November 1998. The plan was created to serve as a blueprint for health professionals, organizations, academic institutions, communities, and others for the prevention and control of arthritis. In FY2002, Congress appropriated \$13.9 million for continued implementation of the plan.²⁰

Congressional Action

The committee report accompanying the Senate committee-approved FY2003 Labor, Health and Human Services, and Education appropriations bill (S. 2766) included language encouraging the NIAMS to work to identify the extent of gender differences in musculoskeletal disorders and develop a plan for future research.

Multiple Sclerosis

Multiple Sclerosis (MS) is an autoimmune disease in which the immune system attacks nerve tissues of the central nervous system. Symptoms of the disease include difficulty in walking; abnormal sensations, such as numbness or tingling; impaired vision; weakness and fatigue; and equilibrium difficulties. An estimated 300,000 to 350,000 Americans are affected by MS, and it is twice as common in women as in men.²¹

Treatments for MS can include occupational, physical, and speech therapy, in addition to medication aimed at alleviating MS symptoms and preventing relapses.

Like many autoimmune diseases, there is no known cause of, or cure for, MS. However, researchers believe that there are immunologic, environmental, viral, and genetic factors that contribute to disease onset. Certain geographic areas have higher prevalence rates of MS than others, suggesting a possible environmental agent.²² While no MS gene has been identified, studies show that an individual's risk for MS increases if she/he has a first-degree relative, such as a parent or sibling, diagnosed with MS.²³

Scientists have been able to identify the cells that attack myelin, a fatty layer that surrounds nerve fibers.²⁴ Destruction of the myelin causes nerve impulses to be slowed or halted altogether, thereby causing MS symptoms. In November 1999, the *Journal of Neuroscience* reported a study, which isolated cells (oligodendrocyte progenitor cells) in the brain that have the potential to repair myelin that has been destroyed by MS.²⁵

As research into a cause, better treatments, and a cure continues, the NIH has increased the resources devoted to MS research. In 1990, \$40.5 million was allocated for research; in FY2001, the NIH spent \$69.8 million, and is expected to spend \$77.5 million in FY2002 and \$83.9 million in FY2003.²⁶ Furthermore, the Institute of Medicine recently issued a report outlining 18 recommendations for MS research.²⁷

Additionally, in February 2001, the National Multiple Sclerosis Society, in conjunction with the NIAID, announced a \$20 million initiative to fund research on sex-based differences in the immune response.²⁸ As a result of this initiative, six research projects have been funded. These projects will examine how sex hormones influence the behavior of immune cells, how pregnancy changes immune responses, how the sex hormone estrogen protects mice from MS-like symptoms, and how a gene related to immune function is different in men and women.²⁹

Legislation

Multiple Sclerosis Treatment Act of 2001 (H.R. 1758)—Rep. John LaFalce (D-NY)

H.R. 1758 would require Medicare coverage of self-administered beta-interferons or other biologicals and drugs approved by the Food and Drug Administration for the treatment of MS.

Lupus

Lupus is an autoimmune disease in which the immune system attacks organs and tissues. Between one and two million Americans have some form of lupus, and 90 percent of those affected are women.³⁰ African-American women are three times more likely than Caucasian women to develop the disease, and women of Hispanic, Asian, and Native American descent also are more likely to get lupus.³¹

There are several forms of lupus—discoid, systemic, drug-induced, and neonatal. Discoid lupus is limited to the skin only and is characterized by a rash.

Systemic lupus erythematosus (SLE), the most severe form, affects the joints, skin, kidneys, lungs, heart, nervous system, and blood vessels. Drug-induced lupus is most commonly associated with certain drugs used to treat high blood pressure and irregular heart rhythms, and its symptoms are similar to systemic lupus. Neonatal lupus is a very rare form of lupus that can affect the newborn babies of women with SLE. Neonatal lupus is characterized by a skin rash, liver abnormalities, low blood counts, and sometimes a heart defect. Although the disease affects each individual differently, it is characterized by periods of onset and remission. There is no cure for the disease, and it is a lifetime affliction that can be life-threatening.³²

Because lupus is 10-15 times more likely to occur in adult women than in adult men, it is frequently referred to as a woman's disease. The onset of lupus is most likely to occur during a woman's childbearing years. This can limit birth control choices. Women with lupus are discouraged from taking oral contraceptives containing estrogen because estrogen has been linked to increased disease activity. Currently, the NIH is studying the safety and effectiveness of oral contraceptives and menopausal hormone therapy in women with lupus.³³

Although there is no cure for lupus, there are numerous treatments if the disease is detected early. However, side effects from medication, especially on postmenopausal women, can be debilitating. Women treated with corticosteroids—the most common and effective form of treatment—are more likely to develop osteoporosis or cardiovascular disease. The use of corticosteroids also can lead to high blood pressure and high cholesterol. Patients also are treated with nonsteroidal anti-inflammatory drugs and antimalarial drugs.³⁴

The origin of lupus remains largely a mystery. Researchers believe that environmental, genetic, and hormonal factors contribute to the disease. The NIAMS is funding a Specialized Center of Research to study lupus, and it has established several lupus registries to track the prevalence of the disease among

families.³⁵ Researchers are undertaking studies to identify genes that play a role in the development of lupus, as well as genes that may identify an individual's risk for lupus. In addition to genetic susceptibility, researchers are studying environmental triggers, the role of hormones in the development of the lupus, and new treatments for the disease.

Funding for lupus research has increased substantially in the last few years. In FY2001, the NIH spent \$64.6 million for lupus research, roughly an \$18 million increase over FY1999. The NIH is expected to spend \$73.4 million in FY2002 and \$78.9 million in FY2003.³⁶

In September 2002, the Food and Drug Administration approved a new screening test for the diagnosis of SLE. The test detects the presence of a particular protein, which researchers say serves as a biomarker for lupus. Individuals with lupus produce antibodies to this protein, thereby allowing for early diagnosis of the disease.³⁷

Congressional Action

The 106th Congress enacted legislation (P.L. 106-505) to authorize and expand research and services on lupus. The law authorizes an unspecified amount of funding to expand and intensify research on lupus at the NIH. Additionally, the law authorizes an unspecified amount of funding for programs that deliver services to individuals afflicted by lupus and their families.

Additionally, committee report language accompanying the House-passed FY2002 Labor, Health and Human Services, and Education appropriations bill (H.R. 3061) encouraged the NIAMS to enhance research efforts that would increase understanding of the factors associated with the high prevalence of lupus in women and people of color. The report also encouraged research efforts to develop new and innovative treatments that are safer and more effective.

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Breast Cancer

Breast cancer is the most common form of cancer in women and the second leading cause of cancer death in women. There are 2.6 million women living with the disease in the United States today.

- The American Cancer Society estimated that 203,500 new cases of invasive breast cancer and 54,300 cases of in situ breast cancer will be diagnosed in the United States in 2002, with an estimated 39,600 deaths.¹
- While Caucasian women are more likely to develop breast cancer, African-American women are 12 times more likely to die from it. The five-year survival rate for African-American women is 72 percent, compared with 87 percent for Caucasian women.²
- The risk of breast cancer increases significantly with age. Roughly 77 percent of women with breast cancer are over 50, and 84 percent of breast cancer deaths occur in women over 50.³

Background

The public policy response to breast cancer in recent years has been more urgent and energetic than to any other women's health issue. Since 1994, federal efforts have included the National Action Plan on Breast Cancer, a public-private partnership designed to coordinate the research, treatment, and education activities of government and non-governmental organizations. The action plan was developed in response to a National Breast Cancer Coalition petition calling for a comprehensive strategy to end breast cancer. The plan's top priorities include expanding research on breast cancer, enhancing the quality of life for persons with breast cancer, improving survival, and increasing the involvement of diverse partners, such as consumer advocates, in research decisions.⁴

One of the primary goals of the breast cancer advocacy community is to increase the federal investment in breast cancer research. As a result, research funding

has increased more than 600 percent—from less than \$90 million in 1991 to more than \$800 million in 2001.⁵ These figures include programs at both the National Institutes of Health (NIH) and the Department of Defense (DoD).

The National Cancer Institute (NCI) at the NIH is the lead federal agency on breast cancer research. Breast cancer research receives the majority of the funds spent by the NCI on cancers in women. The NCI's work includes basic cancer research, to which approximately half of its breast cancer funds are directed, as well as research on prevention, treatment, and diagnostic technology. The NCI also is funding studies on breast cancer risk factors, including diet and obesity, estrogen replacement therapy, stress, and environmental factors. The NCI is currently funding 37 clinical trials examining treatment, prevention, early diagnosis, detection, and prognosis, and etiology of the disease.⁶ Additionally, the NCI is funding nine Specialized Programs of Research Excellence to research breast cancer.⁷

Several other NIH institutes, including the National Institute of Child Health and Human Development and the National Institute of Environmental Health Sciences, also conduct breast cancer research. Total NIH funding for breast cancer in FY2001 was \$580.9 million, and the NIH estimated that it would spend \$655.2 million in FY2002. Funding for FY2003 is estimated to be \$732.3 million.⁸ Additionally, Congress enacted the Women's Health Reauthorization Act (P.L. 105-340) in 1998. The act reauthorized NIH's breast cancer research program through the year 2003 but did not provide specific dollar amounts for the program.

In addition to the NIH, the Department of the Army administers a peer-reviewed breast cancer research program, which was started in FY1992 with a two-year \$210 million appropriation. In FY2002 and FY2003, the program was funded at \$150 million, a

\$25 million decrease from FY2001, but up from \$135 million in FY1999. In recent years, the well-regarded program has focused on innovative high-risk/high-gain research, training new investigators, and translational research.⁹ Breast cancer advocates believe that the DoD program has fostered a positive competition with the NCI, challenging each institution to be innovative about finding a cure for breast cancer.

In addition to the growth in federal funding for medical research, the 105th Congress voted overwhelmingly in 1997 to establish a special stamp to raise money for breast cancer research when it enacted the Stamp Out Breast Cancer Act (P.L. 105-41). Authorization for that stamp was due to expire on July 29, 2000, but the 106th Congress extended authorization for the stamp through December 31, 2003 under the Semipostal Authorization Act (P.L. 106-253).

Currently, the NIH receives 70 percent of the revenues raised when consumers purchase the alternative first-class stamp, and the DoD receives 30 percent. The 40-cent stamp went on sale to the public in August 1998, and since that time 397.3 million stamps have been sold, raising a total of \$27.6 million for research.¹⁰ In March 2002, the stamp was revalued to 45 cents.¹¹

Genetics

The federal investment in research has resulted in important advances in our understanding of the biology of breast cancer and treatment of the disease. Researchers have discovered over 100 alterations in the inherited BRCA1 and BRCA2 genes, known to cause breast cancer. While the discovery has answered some questions about the biology of breast cancer, there are still questions to be answered, particularly since only 5 to 10 percent of all breast cancers are hereditary. However, scientists believe that BRCA1 and BRCA2 mutations account for 36 to 85 percent of all inherited breast cancer cases.¹² Women who have inherited the BRCA1 mutation have an 80 percent risk of developing breast cancer in their lifetimes.¹³ The NCI estimates that BRCA1 is responsible for 45 percent of breast cancers in families with multiple cases of the disease, and BRCA2 mutations represent 35 percent of breast cancers in such families.¹⁴

An August 2000 study published in the *Journal of the National Cancer Institute* found that European families that have a mutation in the CDKN2A gene have an increased risk for breast cancer.¹⁵ Researchers continue to examine the genetic factors associated with breast cancer.

New Treatments

Additionally, several advancements have been made in the treatment of breast cancer. In early 1998, the NCI and the National Surgical Adjuvant Breast and Bowel Project (NSABP) announced the results of a study documenting the efficacy of tamoxifen in reducing the risk of breast cancer in high-risk women. Although the study demonstrated a 49 percent reduction in breast cancer incidence among trial participants who took the drug, some women experienced potentially life-threatening side effects, including uterine cancer, blood clots, and stroke.¹⁶ For example, the chances of developing uterine cancer were doubled from 1 in 1,000 to 2.3 in 1,000. The Food and Drug Administration (FDA) approved tamoxifen as a treatment to reduce the incidence of breast cancer in October 1998.¹⁷ However, tamoxifen cannot be marketed as a preventive measure due to concerns that women will falsely believe that the drug will offer them a lifetime immunity against breast cancer.¹⁸

Moreover, a Dutch study published in *The Lancet* in September 2000 showed that women who took tamoxifen for two or more years experienced a greater risk of endometrial cancer.¹⁹ More recently, the FDA and the NSABP found that women who took tamoxifen as part of their studies had a slightly increased risk of uterine cancer.²⁰ Researchers will continue to examine the safety and efficacy of long-term tamoxifen use.

The NCI began another study—the Study of Tamoxifen and Raloxifene (STAR)—in 1999. The five-year STAR study is examining whether the drug raloxifene is as effective as tamoxifen in reducing the risk of breast cancer.²¹ After the third year of the trial, almost 12,000 women were enrolled.²² Raloxifene has been approved by the FDA for the prevention of osteoporosis.

In September 1998, the FDA approved herceptin, a drug that can be used to treat women with advanced breast cancer only.²³ The drug targets the HER2 gene, which produces a protein that causes cells to divide, multiply, and grow. Normal cells contain two copies of the HER2 gene, but some women have extra copies of the gene. These extra copies then overproduce the protein—known as HER2 overexpression—leading to a more aggressive form of breast cancer.²⁴ Herceptin targets the HER2 protein by directing the protein to stop growing. Studies show that the drug may help 25 percent of breast cancer patients.²⁵

Most recently, the FDA approved a new device for radiation treatment (brachytherapy) for women who have undergone lumpectomies. According to the FDA, the device is implanted into the breast at the site of the lumpectomy, and a balloon is inflated. A radioactive source is then inserted through a catheter.²⁶

Early Detection

Efforts to develop improved technology for the early detection of breast cancer may further reduce cancer mortality rates in years to come. In April 1999, the FDA approved a hand-held imaging device for use in the diagnosis of breast cancer.²⁷ Clinical studies showed improved diagnostic accuracy for women with ambiguous mammogram results. Additionally, the first digital mammography system (Senographe 2000D) was approved by the FDA in January 2000.²⁸ While the clinical trials that led to its approval did not demonstrate that digital images are better at detecting the disease than traditional film/screen images, digital images offer patients several advantages. These advantages include electronic storage and transfer of the images to facilitate quick evaluation, correction for under- or over-exposed films, and a large range that allows the entire breast to be photographed despite varying breast density.²⁹

Since 1994, the Department of Health and Human Services has worked in collaboration with DoD, the Central Intelligence Agency, and the National Aeronautics and Space Administration (NASA) to adapt missile detection technology for use in identifying breast cancer. The digital mammography system approved in 2000 was a result of this collaboration.

Additionally, the 106th Congress enacted legislation (P.L. 106-391) to reauthorize NASA. The law included a \$2 million earmark for research and early detection systems for breast and ovarian cancer and other women's health issues.

Further Research Needed

Despite recent advances, little is known about how to prevent breast cancer. While the disease's mortality rates have slowly begun to decline, researchers are still unable to explain the steady increase in the incidence of the disease over the past 50 years. The lifetime risk of developing breast cancer has increased over the past two decades from 1 in 20 to 1 in 8 today.³⁰ Further research also is needed to understand disturbing racial, ethnic, and economic differences in breast cancer mortality rates. During the 1980s, mortality rates for African-American women with breast cancer were slightly lower than Caucasian women diagnosed with the disease. However, mortality rates for African-American women were 16 percent higher than Caucasian women in 1990 and 29 percent higher in 1995.³¹ The role of environmental factors is also attracting increased attention in breast cancer research.

Consumer Involvement

The successful role played by consumers in the DoD's breast cancer research program has drawn attention to the importance of involving a broader range of perspectives in the grant review process.

When Congress first appropriated funds for the breast cancer research program in 1992, the DoD asked the Institute of Medicine (IOM) for guidance on how to best use funds to accelerate the pace of research advances. In this report, the IOM recommended the DoD focus on bringing new talent into the field of breast cancer research and on supporting innovative ideas and cross-cutting proposals that could shed light on fundamental questions concerning causation, prevention, detection, diagnosis, and treatment.³² The IOM also helped the DoD create a peer-review process that would be better able to accommodate the goals of the innovative program being developed.

To meet the goal of funding new scientists with new ideas, the IOM recommended that the review panels include a mix of people drawn from a broad pool of reviewers representing different perspectives, expertise, career levels, and disciplines, and that women be strongly represented in the peer-review process, with a special effort made to include women of color.³³

In accordance with the IOM recommendations, the DoD has placed breast cancer advocates as voting members on peer-review panels. Despite initial concerns in the scientific community, there is a general consensus among researchers that the program is working well and that broadening the perspectives represented on study panels has resulted in a better grant-making process.

Legislation

Consumer Involvement in Breast Cancer Research Act (S.261)—Sen. Olympia Snowe (R-ME)

S. 261 would direct the NCI, to the extent practical, to increase the involvement of consumer advocates in breast cancer research decisions. An advocate is defined for purposes of the bill as an individual who is accountable to, represents, and reports back to organizations that represent those affected by breast cancer.

Better Screening Test for Women Act (H.R. 3989)—Rep. Nita Lowey (D-NY)

H.R. 3989 would authorize \$55 million in each of FY2003 through FY2007 for the NCI to support clinical research concerning the early detection and screening of breast cancer. The bill also would authorize \$5 million in each of FY2003 through FY2007 for the NCI to support research and data collection examining the link between early detection of breast cancer and reduced mortality rates.

Breast Cancer Research Stamp Act (S. 1256/H.R. 2725)—Sens. Dianne Feinstein (D-CA) and Kay Bailey Hutchison (R-TX) and Reps. Sue Kelly (R-NY) and Juanita Millender-McDonald (D-CA)

S. 1256/H.R. 2725 would reauthorize the breast cancer research postal stamp through July 29, 2008.

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Cardiovascular Diseases

Cardiovascular diseases are the leading causes of death and disability among American women.

- In 1999, cardiovascular diseases accounted for 42.5 percent of deaths in women.¹
- More than a half million women died from cardiovascular diseases in 1999 and 102,881 women died of stroke in 1999, accounting for 62 percent of all stroke deaths.²
- Thirty-eight percent of women who have heart attacks die within one year compared with 25 percent of men.³
- More than one in five women has some form of cardiovascular disease.⁴
- Between 1979 and 1998, death rates for coronary heart disease for African-American women declined by 26.6 percent, compared to a 40.1 percent decline for Caucasian women.⁵ Death rates for stroke for African-American women were 78.1 compared to 58.7 for Caucasian women.⁶
- In 2001, the cost of cardiovascular disease in the United States was estimated to be \$298.2 billion, and the cost is expected to increase to \$329.2 billion in 2002.⁷

Gender Disparities

Many of the risk factors for heart disease are similar for women and men: smoking, high blood pressure, high cholesterol, obesity, and a sedentary lifestyle. However, some risk factors, such as diabetes, high levels of triglycerides, and low levels of HDL cholesterol appear to increase the risk more for women than for men. In addition, women tend to develop heart attacks later in life than men—on average, 10 years later—and women are twice as likely as men to die after bypass surgery. According to the National Coalition for Women with Heart Disease, while more women than men die of heart disease each year, women receive only 33 percent of angioplasties, stents, and bypass surgeries, 28 percent of inflatable

defibrators, and 36 percent of open heart surgeries.⁸ Furthermore, although stroke is more common in men than in women, more women die from stroke.⁹

Although half of the individuals with cardiovascular diseases are women and nearly half of fatal heart attacks occur in women, cardiovascular diseases have long been perceived as primarily affecting men. A 2001 survey found that only 7 percent of American women believe that heart disease is the greatest health threat to them, and only 34 percent of those surveyed were aware that heart disease is the leading cause of death among American women. Additionally, 38 percent of the women surveyed said that their physician discussed heart disease with them.¹⁰

Studies have shown that doctors are less likely to diagnose heart disease in women than in men with the same symptoms. In fact, a 1999 study published in the *New England Journal of Medicine* concluded that physicians contribute to race and sex disparities in heart disease treatment. Conducted by the Georgetown University Medical Center and funded by the Agency for Healthcare Research and Quality (AHRQ), the study found that the odds of African Americans and women presenting with chest pain being referred for cardiac catheterization were 60 percent less than Caucasians and men. The disparity was most dramatic for African-American women, whose odds of being referred for the procedure were 40 percent less than those of Caucasian men.¹¹

The AHRQ is supporting a several studies examining gender differences in the treatment of heart disease, in particular the role of physicians' decisions in limiting access to certain treatments, racial and/or sex differences in the use of cardiac tests and procedures, and the racial, sex, and income differences in the levels of care provided.¹²

Current Prevention Efforts

Currently, the Centers for Disease Control and Prevention (CDC) is supporting twelve projects in eleven states—Alaska, California, Connecticut, Illinois, Iowa, Massachusetts, Michigan, Nebraska, North Carolina, South Dakota, and Vermont—to screen women for factors that increase their risk for cardiovascular disease. The screening is being conducted through the CDC's WISEWOMAN (Well-Integrated Screening and Evaluation for Women Across the Nation) program, which is operated in conjunction with the National Breast and Cervical Cancer Early Detection Program (NBCCEDP). Women participating in the NBCCEDP are eligible to receive screening and interventions for obesity, sedentary behavior, poor dietary habits, high blood pressure, and high cholesterol. The program has evaluated more than 10,000 low-income and uninsured women aged 50 and older. Roughly 50 to 75 percent of the women screened had either high cholesterol or high blood pressure. The program was funded at \$11.7 million in FY2002.¹³

Most recently, in 2002, the NHLBI launched a women's heart health awareness campaign called *The Heart Truth*. The campaign include women-targeted consumer television, radio, and print public service announcements, consumer materials such as a brochure on heart disease and a *Healthy Heart Handbook for Women*, and speaker's kits for community leaders and others interested in discussing women and heart disease. Additionally, the campaign includes an initiative to encourage health care providers to discuss heart disease with their female patients.¹⁴

The NHLBI also launched the "Act In Time To Heart Attack Signs" campaign, which is aimed at educating Americans about the warning signs of heart attacks and how to respond.¹⁵ Additionally, the CDC received \$35 million in FY2001 to support 22 states in developing cardiovascular health programs.¹⁶

Several medical associations, including the AHA, the American College of Cardiology, the American Medical Women's Association, the American College of Nurse Practitioners, and the American College of Obstetricians and Gynecologists, have joined together

in producing a *Guide to Preventive Cardiology for Women*. Issued in April 1999, the guide recommends that health professionals begin assessing a woman's risk during the preconception period and pregnancy in an effort to establish healthy behaviors that would reduce her risk.¹⁷

Research Initiatives

In FY2001, the NHLBI spent just over \$253 million on research on cardiovascular diseases and women.¹⁸ Despite increased spending on research on cardiovascular diseases and women, women represent only 25 percent of participants in all heart-related research studies.¹⁹

The NHLBI is currently supporting several clinical trials dealing with women and cardiovascular disease, including the Women's Health Initiative (WHI), the Women's Angiographic Vitamin and Estrogen (WAVE) Trial, the Women's Estrogen/Progestin and Lipid Lowering Hormone Artherosclerosis Regression Trial (WELL-HART), and the Estrogen Replacement and Artherosclerosis (ERA) Trial. These trials are slated for completion in 2005 and 2006.²⁰

Evidence that short-term use of estrogen replacement therapy (ERT) and hormone replacement therapy (HRT) in postmenopausal women reduces the risk of heart disease has been mixed and controversial. In 1995, the Postmenopausal Estrogen/Progestin Interventions (PEPI) Trial found that both ERT and HRT increased the level of HDL cholesterol, the "good" cholesterol.²¹ Additionally, the Nurses' Health Study found that ERT and HRT reduced the risk of death from heart disease and stroke. However, results from the Heart and Estrogen/Progestin Replacement Study (HERS), published in August 1998, found that the use of estrogen plus progestin in postmenopausal women with heart disease did not prevent further heart attacks or death from coronary disease.²² Additionally, there are other health risks associated with ERT, such as an increased risk of endometrial or uterine cancer, and an increased risk of blood clots and gall bladder disease.

In April 2000, researchers involved with the HERS trial announced that women who had been taking

estrogen as part of the study were at a slightly higher risk for heart attacks and strokes. However, at that time, officials at the NHLBI cautioned that the results did not address the long-term benefits and risks of HRT and should not influence current medical practice.²³

An August 2000 study published in the *New England Journal of Medicine* found that the use of estrogen alone or estrogen plus progestin did not affect the progression of heart disease in women who already had the disease. The study suggested that “women should not use estrogen replacement with an expectation of cardiovascular benefit.”²⁴

In 2002, the AHA updated its recommendations to state that HRT should not be initiated for the prevention of a second heart attack or death among women with cardiovascular disease.²⁵ Then, in July 2002, the NHLBI halted an estrogen plus progestin study that was being conducted as part of the WHI. Early results from the study showed that women taking estrogen plus progestin were at an increased risk of heart attacks, stroke, blood clots, and breast cancer.²⁶

Further, results from the WAVE trial were published late in 2002, showing that postmenopausal women with heart disease who took hormone therapy and high dose antioxidant vitamins received no benefit, and in fact were at increased risk.²⁷

Congressional Action

During the 107th Congress, the Senate passed a bill (S. 1274) that would establish a national stroke prevention and education campaign, a national stroke registry and clearinghouse, and a grant program for statewide prevention, treatment, and rehabilitation programs. The bill was sponsored by Sens. Edward Kennedy (D-MA) and Bill Frist (R-TN). The measure was not considered by the House.

Additionally, the Senate Health, Education, Labor, and Pensions Committee approved a bill (S. 2328) pertaining to safe motherhood that incorporated a number of other women's health provisions, including the WISEWOMAN Expansion Act of 2001 (S. 208) sponsored by Sen. Bill Frist (R-TN). The Senate did not consider the measure prior to adjournment.

Legislation

WISEWOMAN Expansion Act of 2001 (S. 208/H.R. 633)—Sens. Bill Frist (R-TN) and Tom Harkin (D-IA) and Reps. Rosa DeLauro (D-CT) and Jim Leach (R-IA)

S. 208/H.R. 633 would expand the WISEWOMAN program by authorizing additional preventive services, including screenings for osteoporosis, health education and counseling, and referrals for medical treatment and follow-up services. S. 208 would authorize \$15 million in FY2002, \$20 million in FY2003, and \$25 million in FY2004, while H.R. 633 would authorize \$20 million in FY2002, \$25 million in FY2003, and \$30 million in FY2004. Both bills would limit additional funding for the WISEWOMAN program for a given fiscal year, unless at least \$173.9 million is spent on the National Breast and Cervical Cancer Early Detection Program in that fiscal year.

Stroke Treatment and Ongoing Prevention Act of 2001 (S. 1274/H.R. 3431)—Sens. Edward Kennedy (D-MA) and Bill Frist (R-TN) and Reps. Lois Capps (D-CA) and Charles Pickering (R-MS)

S. 1274/H.R. 3431 would authorize \$40 million in FY2002 for a national stroke prevention and education campaign and would establish a stroke registry and clearinghouse. The bills also would create a grant program for states to establish statewide prevention, treatment, and rehabilitation programs. The program would be authorized at \$50 million in FY2002, \$75 million in each of FY2003 and FY2004, \$100 million in FY2005, and \$125 million in FY2006.

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Cervical Cancer/HPV

Evidence indicates a strong link between human papillomavirus (HPV)—the most common viral sexually transmitted disease (STD) in the United States—and cervical cancer, which the American Cancer Society estimated will be diagnosed in 13,000 women and claim 4,100 lives in 2002.¹ The death rate for African Americans is more than twice the national average. In addition, Hispanics and Native Americans have higher than average death rates from cervical cancer.² A recent study found that while rates for cervical cancer for women as a whole are dropping, the rates remain the highest for Hispanic women over the age of 30.³

HPV refers to more than 100 types of viruses. Several “high-risk” types of HPV have been associated with cervical cancer.⁴ The Centers for Disease Control and Prevention (CDC) estimate that 20 million people are currently infected with HPV, and 50 to 75 percent of sexually active individuals will acquire HPV infection at some point in their lives.⁵ While some types of HPV cause genital warts, often the virus lays dormant and in most women (90 percent) HPV infection becomes undetectable within two years.⁶

HPV infection is the major risk factor for cervical cancer. Most HPV infections, however, do not develop into cancer. A recent study found that 95 percent of teens and young women with low-grade, benign cervical lesions caused by HPV spontaneously cleared the lesions without medical intervention.⁷ In addition, the process of developing cancer from initial exposure to HPV takes at least a decade, which explains why cervical cancer is a disease most often affecting midlife and older women—even though HPV infection is most common in young women.⁸

One study suggests that genes also may play a role in a woman's risk of cervical cancer. According to the study, published in the *International Journal of Cancer*, more than one in four (27 percent) cervical cancers in Swedish women were attributed to genet-

ics. A woman's risk for cervical cancer was highest if her sister had cervical cancer. Additionally, the authors of the study also suggest that genes may make some women more vulnerable to HPV infection.⁹

Other risk factors for cervical cancer include unprotected intercourse at an early age; a large number of sexual partners; infection with other viruses, including HIV; cigarette smoking; and low socioeconomic status.¹⁰ Two new studies have shown that infection with chlamydia and herpes may increase a woman's risk of developing cervical cancer.¹¹ While condoms may provide some protection, HPV can be transmitted by parts of the groin area that are not covered by condoms.¹²

Cervical cancer was once one of the most common causes of cancer death for women. However, between 1955 and 1992, deaths from cervical cancer declined by 74 percent. This shift was due mainly to the use of a simple and readily available screening method, the Pap test, that allows for early detection of cervical cancer.¹³ Diagnosed while it is localized, the disease has a 5-year survival rate of 92 percent.¹⁴

Over the past few years, several new screening techniques have been approved by the Food and Drug Administration (FDA), including improved versions of Pap testing and HPV DNA testing of cervical cells for HPV.¹⁵

As a result of these improvements, the American Cancer Society has issued new guidelines regarding cervical cancer screening. Announced in November 2002, the new guidelines recommend that cervical cancer screening begin about three years after a woman begins having vaginal intercourse, but no later than age 21. Additionally, screening should be done yearly if the physician is using a regular Pap test or every two years if the physician is using a newer liquid-based Pap test. Women 30 years of age and

older who have had three normal test results in a row may be screened every two to three years, unless the woman has certain risk factors that would make her more susceptible. Further, women 70 years of age and older who have had three or more normal test results and no abnormal results in the last 10 years may stop cervical cancer screening. Finally, the recommendations clarify that women who have had a total hysterectomy, including removal of the cervix, for reasons not related to cancer may stop screening.¹⁶

Because most HPV infections do not progress to cancer, treatment in the past has mainly been decided on a wait-and-see basis, with follow-up Pap testing.¹⁷ More recently, controversy has arisen over how to manage women with Pap tests showing mild abnormalities. Many physicians have been referring these women for colposcopic exam and biopsies, while others have adopted the wait-and-see approach. Colposcopic exams not only are expensive, but also create what may be undue stress for the woman, particularly if the results are normal.¹⁸

As a result, the National Cancer Institute (NCI) at the National Institutes of Health conducted a national study, the ASCUS/LSIL Triage Study or ALTS, to determine the best way to address mildly abnormal Pap tests. ASCUS and LSIL are the acronyms for two mild abnormalities detected by Pap tests.¹⁹ The study examined three approaches, including immediate colposcopic exam and biopsy, repeat Pap tests every six months, and HPV DNA testing to determine which abnormalities indicate colposcopy and which would be better followed by repeat Pap testing.

While findings from the ALTS study were published in February 2001, analysis of the data will be ongoing. The ALTS study found that HPV testing identified 96.3 percent of the ASCUS abnormalities that needed treatment, indicating that HPV testing is highly sensitive in identifying those lesions that require additional treatment versus lesions that will clear without treatment. Additionally, the study found that HPV testing reduced referrals to colposcopy by about 50 percent.²⁰

As a result of the ALTS study, several new guidelines were issued. First, the system for reporting the results of Pap tests was revised. Under the old system, all results that were abnormal but not clearly precancerous were classified as ASCUS. The 2001 Bethesda System creates a new category, ASC-H, for those abnormalities at higher risk of association with precancer.²¹

Second, the American Society for Colposcopy and Cervical Pathology issued consensus guidelines for the treatment of women with mildly abnormal Pap test results. These guidelines recommend HPV DNA testing for those women with ASCUS Pap results and referral for colposcopic examination for those women with ASC-H results.²²

The NCI is currently working to develop a vaccine for HPV infection and is supporting 17 such studies.²³ In FY1999, the NCI spent \$66.3 million.²⁴ Additionally, results of a recent cervical cancer vaccine study showed promising results. Published in the *New England Journal of Medicine*, the study examined 2,392 young women, half of whom were vaccinated and half of whom were given a placebo, and found that the vaccine was 100 percent effective after 17 to 27 months of follow-up.²⁵

Congressional Action

During the closing moments of the 106th Congress, legislation (P.L. 106-554) was enacted to require sentinel surveillance of HPV by the Centers for Disease Control and Prevention. The law requires the Department of Health and Human Services to study current condom labels to determine if they are medically accurate, specifically with respect to whether condoms are effective or ineffective at protecting against STDs.

A resolution (H. Con. Res. 390) recognizing the importance of cervical health and of detecting cervical cancer in its earliest stages was approved by the House during the 107th Congress. Sponsored by Rep. Juanita Millender-McDonald (D-CA), the resolution also urges health care professionals and facilities to raise public awareness about cervical cancer and the importance of early detection.

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DES

Developed in 1938, a drug called diethylstilbestrol (DES) was prescribed by doctors for nearly three decades to prevent miscarriage and other problems during pregnancy. It is estimated that four million pregnant women in the United States took the drug before it was removed from the market in 1971, exposing five to ten million individuals to the drug.¹

Not only was DES found to be ineffective at preventing miscarriage, it also has been shown to increase health risks for the women who took the drug, as well as for their children. When DES was conclusively linked to clear cell vaginal adenocarcinoma in the daughters of women who had taken the drug, the Food and Drug Administration banned its use in pregnant women in 1971.²

This rare form of vaginal cancer is estimated to occur in 1 out of every 1,000 daughters of women who took DES, and it has an 80 percent survival rate.³ It occurs most often in the late teens and early twenties, although recent research has documented cases in females aged 7-48, with an increase in cases in women aged 40-46. Researchers believe this may demonstrate a possible second peak of incidence.⁴ In addition to vaginal cancer, DES daughters also face greater risks of ectopic pregnancy, premature labor, and infertility.

The effects on DES sons are still unclear, although some DES sons have higher rates of testicular abnormalities. Women who actually took DES have a 30 percent increased risk of breast cancer over women who did not take the drug.⁵

Further research is needed to define long-term health problems from DES exposure, including whether hormone replacement therapy is advisable for DES-exposed women and their daughters, and whether DES could have a genetic impact on the grandchildren of women who took DES.

The National Institute of Environmental Health Sciences (NIEHS) at the National Institutes of Health published a study in 1998 that showed an increase in reproductive tract cancers in third-generation DES-exposed mice. The study, however, did not show signs of infertility in those mice.⁶

More recently, the National Cancer Institute (NCI) published a study that found that women who were exposed to DES in utero were 1.4 times more likely than unexposed women to develop invasive breast cancer.⁷

Detection and Education

Screening procedures can increase the early detection of DES-related health problems and help reduce the impact of DES exposure. Since the drug and similar compounds were marketed under a wide range of names, many women who used DES may not be aware of their exposure. As a result, many women and their now-grown children may not be receiving appropriate health care.

There is an ongoing need for education about the effects of the drug, as well as for improved access to clinical services for the DES population and increased outreach to those who may have been exposed.

National DES Education Program

In 1992, Congress passed legislation mandating the establishment of a national DES research and education campaign. As a direct result, the NCI launched the National DES Education Campaign.

The program's objective is to design, implement, and evaluate expanded health information about DES exposure and to improve early diagnosis and treatment of conditions related to exposure. Grants were awarded in five regions for programs that targeted both the DES-exposed population and health care providers. Six consumer publications were created to

raise public awareness about the issue. Research identifying DES grandchildren for studies of possible effects is now being conducted, as are studies placing DES in the broader context of environmental estrogens, currently receiving increased scrutiny for their possible role as carcinogens.

The campaign, renamed DES Update, is currently carried out by the Centers for Disease Control and Prevention (CDC) and will launch at the end of 2002. Resources and educational materials for the campaign were developed in part by several National Centers of Excellence in Women's Health. The campaign will include a website (www.cdc.gov/DES) for patients and providers.

Congressional Action

The 105th Congress passed legislation—the Women's Health Reauthorization Act (P.L. 105-340)—reauthorizing the DES research and education program through the year 2003.

During the 107th Congress, the House-passed FY2002 Labor, Health and Human Services, and Education appropriations bill (H.R. 3061) included committee report language encouraging the NIEHS to support research on third generation effects of DES exposure, the long-term effects of cancer among DES-exposed daughters and sons, and genetic markers for DES exposure.

The FY2002 Senate-passed Labor, Health and Human Services, and Education appropriations bill (S. 1536) urged the NCI to continue its agreement with the CDC to implement a national DES education campaign.

Additionally, the committee report accompanying the Senate committee-approved FY2003 Labor, Health and Human Services, and Education appropriations bill (S. 2766) also urged the NCI to continue its efforts to implement the education campaign.

NOTES

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Environmental Health

Most human disease is believed to be the product of a complex interaction between genetic and environmental factors. Over the past ten years, the mapping of the human genome has transformed biomedical research and the practice of medicine. However, research on environmental factors has lagged far behind.

Humans are exposed to a multitude of environmental agents from conception to death. From the food we eat, to the synthetic and naturally occurring chemicals in our environment, to physical agents such as sunlight, the impact of the environment on women's health is profound. There is disturbing evidence—both from laboratory experiments and epidemiological surveys—that certain chemicals mimic the biological effects of the female hormone estrogen.

These “environmental estrogens,” like other environmental toxins, tend to accumulate in fat tissues. Because women have a higher percentage of body fat than men, they may build up greater stores of these compounds inside their bodies. In addition, when women's fat reserves are mobilized during pregnancy, lactation, and dieting, they may face secondary exposure to toxins.

Estrogen exposure has been implicated in the development of breast, ovarian, and endometrial cancers, which account for more than one-fifth of cancer deaths in American women.¹ Chemicals that can mimic the effects of estrogen include chlorinated hydrocarbons (such as DDT, PCBs, and dioxin), which are among the most widespread and persistent classes of pesticides.

The 1996 publication of *Our Stolen Future*, co-authored by two environmental scientists and a journalist, raised public concern about the possible human health effects of synthetic chemicals added to

the environment in pesticides, detergents, plastics, and other products. Although the authors acknowledged that the scientific evidence is incomplete, they believed broader public awareness of the effects of environmental toxins on human health is needed. The chemicals they term “endocrine disruptors” may be responsible for the dramatic increase in breast and prostate cancer rates over the past three decades, declining sperm counts, and neurological problems in children exposed in utero.²

A number of federal agencies have jurisdiction over environmental health research and regulation, including the Centers for Disease Control and Prevention (CDC), the Environmental Protection Agency (EPA), the Food and Drug Administration, the National Institute of Environmental Health Sciences (NIEHS) at the National Institutes of Health (NIH), and the Occupational Safety and Health Administration. In 1994, the Public Health Service's Office on Women's Health convened a Federal Interagency Coordinating Committee on Women's Health and the Environment to promote collaboration between the various agencies with responsibility for environmental health issues.

Under the Food Quality Standards Act of 1996 (P.L. 104-170), the EPA was directed to establish a screening program for chemicals that mimic the biological effects of estrogen or other hormones, and report to Congress, within four years of enactment, on the human health effects of those chemicals. Additionally, the Safe Drinking Water Act Amendments of 1996 (P.L. 104-182) required the EPA to establish an estrogenic chemicals screening program. P.L. 104-182 also permitted the EPA to regulate such substances if they are found to pose a threat.

In addition to screening chemicals that may disrupt the endocrine system, the Endocrine Disruption Screening and Testing Advisory Committee at the EPA

recommended that the program expand its efforts to include chemicals that may affect the androgen and thyroid systems in both humans and wildlife.³ Implementation of the Endocrine Disruption Screening Program (EDSP), as required by law, will occur in two phases: the first phase will involve screening chemicals to determine whether they interact with hormone systems, and the second phase will involve a “two-tiered” test to determine the effects of that interaction on hormone systems. The program will focus on providing methods and procedures to detect and characterize endocrine activity of pesticides, commercial chemicals, and environmental contaminants.⁴ The EDSP was established in August 1998, and the EPA is currently in the process of implementing the program. Currently, the EPA is developing the appropriate screening tests that were recommended by the advisory committee. To that end, the EPA established the Endocrine Disruptor Methods Validation Subcommittee.⁵

Also in 1999, the National Academy of Sciences (NAS) completed its report as required by the FY1997 Veterans Affairs and Housing and Urban Development appropriations bill (P.L. 104-204). While the NAS report found that the lack of data on endocrine disruptors led to differences in interpretation of results among researchers, a review of the literature showed that there was evidence of a link between endocrine disruptors and developmental, reproductive, neurological, immunological, and ecological problems within animal and human populations. The report made recommendations for screening and testing endocrine disruptors that are consistent with the goals of the EPA's EDSP.⁶

On the research front, the NIEHS conducts and supports research on a wide range of women's health issues, including the relationship between environmental factors and breast, ovarian, and endometrial cancers. The NIEHS also has been involved in research on the health effects of exposure to diethylstilbestrol (DES), a drug given to approximately five million pregnant women before 1971 in the mistaken belief that it prevented miscarriages.⁷

Additionally, the Institute of Medicine issued a 1998 report, *Gender Differences in Susceptibility to Environmental Factors: A Priority Assessment*. The report was requested by the NIH Office of Research on Women's Health to review the research programs of the NIH, the CDC, and the EPA. In an effort to better coordinate research, the report recommended that an annual interagency workshop be held. The report also recommended additional research on exposure to “environmental estrogens.” Basic research should include studies on environmental contributions and biological causes for gender differences; gender differences in disease outcomes; metabolic and hormonal differences; genetic markers of susceptibility; and translational research, which examines ways in which to apply clinical research to health care practices.⁸

Congressional Action

Committee report language accompanying the Senate-passed FY2002 Labor, Health and Human Services, and Education appropriations bill (S. 1536) urged the NIEHS to establish centers to conduct multi-disciplinary and multi-institution research on environmental factors that may be related to breast cancer.

Additionally, committee report language accompanying the Senate committee-approved FY2003 Labor, Health and Human Services, and Education appropriations bill (S. 2766) encouraged the NIEHS to enhance research on the health effects of exposure to hormone-disrupting chemicals.

Legislation

Women's Health Environmental Research Centers Act of 2000 (H.R. 183/S. 720)—Reps. Louise Slaughter (D-NY) and Sue Kelly (R-NY) and Sen. Mary Landrieu (D-LA)

H.R. 183/S. 720 would authorize \$4 million to establish multidisciplinary research centers regarding women's health and disease prevention at the NIEHS. The centers would be charged with conducting multidisciplinary research on environmental factors that may be related to the development of women's health conditions.

Robin Danielson Act (H.R. 360)—Rep. Carolyn Maloney (D-NY)

H.R. 360 would direct the NIH to conduct research on the presence of dioxin, synthetic fibers, and other additives in tampons to determine what, if any, health risks their presence poses to women. Additionally, the bill would direct the Centers for Disease Control and Prevention to collect and analyze data on toxic shock syndrome.

Breast Cancer and Environmental Research Act of 2001 (H.R. 1723/S. 830)—Reps. Nita Lowey (D-NY) and Sue Myrick (R-NC) and Sens. Lincoln Chafee (R-RI) and Harry Reid (D-NV)

H.R. 1723/S. 830 would establish up to eight Breast Cancer and Environmental Research Centers of Excellence through the NIEHS. The centers would be charged with conducting multidisciplinary research on environmental factors that may be related to the etiology of breast cancer research. The bill would authorize \$30 million each year in FY2002 through FY2007.

Hormone Disruption Research Act of 2002 (H.R. 4709)—Rep. Louise Slaughter (D-NY)

H.R. 4709 would direct the NIEHS to conduct research on hormone disruption and would require the institute to report to the public every two years on the extent to which hormone disruption by chemicals poses a threat to human health and the environment.

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HIV/AIDS Research

HIV/AIDS is a serious health concern for women in the United States and around the world. According to the Centers for Disease Control and Prevention (CDC), an estimated 850,000 to 950,000 Americans are living with HIV and an estimated 40,000 people become infected each year. In 2001, women accounted for 30 percent of new HIV infections.¹

- An estimated 3.1 million people died of AIDS in 2002 and 1.2 million were women.²
- Approximately 45 percent of the 42 million adults and children living with HIV/AIDS worldwide are women, totaling 19.2 million women.³
- The proportion of all reported AIDS cases among adult and adolescent women more than tripled from 7 percent in 1985 to 25 percent in 2001.⁴

U.S. women living with HIV/AIDS are disproportionately African American and Hispanic. In 2000, African Americans and Hispanics accounted for 80 percent of AIDS cases in women, while they accounted for less than 25 percent of all women in the United States.⁵ While HIV/AIDS is now the fifth leading cause of death for all women aged 25-44, it is the third leading cause of death for African-American women.⁶ Additionally, African-American women represented nearly 64 percent of all new AIDS cases in 2001, and Latinas accounted for 17 percent.⁷

Sexual Transmission

Since 1994, heterosexual contact has been the leading source of HIV infection among women, followed by injection drug use. Of new infections among women, it is estimated that 75 percent of women were infected through heterosexual contact and 25 percent through injection drug use.⁸ In 2001, of the AIDS cases reported in women, 41 percent were attributed to heterosexual contact and 39 percent to injection drug use. The source of infection in the remaining cases was listed as blood transfusion (3 percent) and not reported or identified (17 percent).⁹

Other factors associated with an increased risk of HIV infection among women include substance abuse, infection with other sexually transmitted diseases, and domestic violence. The risk of HIV infection is increased not only by sexually transmitted diseases (STDs) like syphilis or genital herpes that cause open sores, but also by gonorrhea and chlamydia—STDs that are often asymptomatic in women and which can go years without detection (see Sexually Transmitted Diseases, p. xx). HIV and a number of other STDs also are more easily transmitted from men to women than from women to men. Individuals with STDs are three to five times more likely to become HIV-infected.¹⁰

Different Manifestation in Women

Because HIV/AIDS first manifested itself in the United States as a disease predominantly affecting Caucasian homosexual men, most research during the beginning of the epidemic was conducted on this population. As a result, the official definition of AIDS for many years did not reflect some of the specific manifestations in women. In response to criticism from women's health advocates, CDC expanded its definition in 1993 to include several conditions that occur frequently in women with HIV infection.

Women with HIV/AIDS experience a number of chronic gynecological conditions that have been linked to HIV infection. These include pelvic inflammatory disease, vaginal yeast infections, genital warts, and a precancerous cervical cell condition associated with human papillomavirus. Although these conditions occur in uninfected women, they are more severe or persistent and more complicated to treat in women with HIV/AIDS. The failure of some health care providers to recognize these chronic conditions as early manifestations of HIV infection may account for later diagnosis and poorer prognosis for some women with HIV/AIDS.¹¹

Currently, researchers are investigating gender differences in HIV/AIDS. Researchers are studying

the unique features of HIV/AIDS in women, including disease progression, complications, and treatments. Several studies have shown that women, upon the initial diagnosis of HIV as well as during the early stages of HIV, have a lower level of the virus in their systems than men. However, women still develop AIDS as swiftly as men, despite lower initial viral loads.¹²

According to the National Institute of Allergy and Infectious Diseases (NIAID) at the National Institutes of Health (NIH), women whose HIV infections are detected early and who receive appropriate treatment survive as long as infected men. While several studies have shown that HIV-infected women have shorter survival times than men, the researchers were unable to identify the reasons for excess mortality among women. Several factors have been posited, including poorer access to health care, lack of social support, domestic violence, and homelessness.¹³

Ongoing Research Efforts

In response to criticism that women were being excluded from HIV/AIDS research and because women were becoming increasingly infected, a number of federal health agencies, including the NIH and the CDC, have initiated studies focusing specifically on women. The Women's Interagency HIV Study (WIHS) was initiated in 1993 to examine the natural history of the disease in women, including conditions specific to women and the role played by substance abuse and sexual behavior. WIHS enrolls both HIV-negative and HIV-positive women, and participants are examined every six months. Since its inception, more than 2,600 women have been enrolled in the study, of which roughly 80 percent are minorities and 60 percent live below the poverty line. In 1998, the NIAID renewed the study for an additional five years after publishing the demographic, socioeconomic, health, and other characteristics of the women enrolled.¹⁴ Furthermore, the study was expanded in 2002 in an effort to evaluate clinical outcomes in the area of highly active antiretroviral therapy. The NIAID launched a campaign to increase recruitment by 60 percent and to increase the number of minority participants.¹⁵

To date, several WIHS studies have been released. One study examined the differences in death rates prior to

and after the introduction of antiretroviral drugs. The study showed a marked decline in mortality among women with AIDS and HIV-infected women after the introduction of the newer therapies (April 1996-March 1999). Another study found that baseline measurements of a blood protein (serum albumin) were strong predictors of three-year survival in HIV-infected women; women with low-to-normal ranges had a higher risk of death compared to women with higher levels.¹⁶

Much of the research on women and HIV/AIDS has been more narrowly focused on pregnant women and the risk that they will infect their newborns. The Women and Infants Transmission Study (WITS) was established in 1989 to determine risk factors for perinatal HIV transmission. Since its inception, 2,336 pregnant women and 1,887 infants have enrolled in the study.¹⁷ To date, the study has shown that AZT use, CD4 counts, duration of membrane rupture, maternal viral load, and injection drug use independently affect the risk of infant infection. Additionally, the study has shown that HIV viral loads predict disease progression in perinatally-infected children.¹⁸

In 1994, the NIAID released a study reporting that women who were treated with AZT during their pregnancies reduced the risk of perinatal transmission to their newborns by as much as two-thirds. As a result, the Public Health Service recommended routinely counseling and voluntarily testing pregnant women and offering AZT to those infected.¹⁹ Overall, the rates of perinatal HIV transmission in the U.S. decreased by 80 percent between 1992 and 2000.²⁰

Further research has shown that giving newborns a single dose of nevirapine no more than 24 hours after birth can protect them from HIV transmission as effectively as AZT and other treatments. The findings have implications for developing countries where a six-week course of AZT costs \$40 compared to 75 cents per dose of nevirapine. The study also showed that nevirapine protected breastfed infants from HIV during the first six weeks of life.²¹

The number of women participating in HIV/AIDS clinical trials, including the AIDS Clinical Trials Group

(ACTG), has drawn criticism from women's health advocates over the years. In 1990, women made up 10 percent of the AIDS cases reported among adolescents and adults and only 7 percent of ACTG participants, half of whom took part in an AZT experiment on preventing perinatal transmission.²² The situation has gradually improved, however. In 1999, women—who accounted for 23 percent of all U.S. AIDS cases—comprised 18 percent of the ACTG.²³ A more recent study found that there was no significant difference by gender in enrollment in clinical trials; however, there were significant racial disparities in enrollment overall.²⁴

In 2001, the National Institute of Child Health and Human Development (NICHD) announced a Women's HIV Pathogenesis Program funded at \$3.5 million per year for five years. Three sites have been funded to conduct research to identify biological factors unique to women.²⁵

Additionally, the NIH Office of AIDS Research issued a plan for HIV-Related research in FY2003, which highlights a number of critical research areas, including vaccines, topical microbicides, and mother-to-child transmission. NIH funding for HIV vaccine research has increased 170 percent between FY1997 and FY2002.²⁶ In 1999, the NIAID formed the HIV Vaccine Trials Network to develop and test preventative HIV vaccines.²⁷

Development of Microbicides

One of the great hopes for women in HIV/AIDS research is the development of a topical microbicide—an agent that would prevent transmission of HIV and other STDs—that could be used by women before intercourse. Presently, there is no effective means of HIV prevention, including abstinence and condoms, that does not depend on the cooperation of a male partner.

Since 1992, Congress has encouraged the NIAID and the NICHD to devote resources to developing topical microbicides. The NIH spent \$47 million on microbicide research in FY2001, and was expected to spend \$55.7 million in FY2002 and \$68.2 million in FY2003.²⁸ Both institutes currently have ongoing

efforts in basic research, product development, and clinical evaluation (including behavioral research). Researchers are pursuing microbicides that could serve as contraceptives, as well as microbicides to protect against STDs only, while still allowing a woman to become pregnant. Scientists are currently pursuing almost 60 different product leads and advocates believe that with sufficient resources a microbicide may be available by 2007.²⁹

In July 2000, researchers announced the results of a study to determine whether nonoxynol-9, a spermicide, would be effective in preventing the transmission of HIV. The study enrolled 1,000 HIV-negative sex workers in Africa. Half of the women received the spermicide, while the other half received a placebo. The study found that women who used nonoxynol-9 became infected with HIV at a 50 percent higher rate than women who used the placebo. Additionally, the more frequently women used the spermicide, the higher their infection risk. As a result of the study, the Food and Drug Administration proposed new warning labels for over-the-counter contraceptives that may contain nonoxynol-9. The warning states that vaginal contraceptives that contain nonoxynol-9 do not protect against HIV and other STDs.³⁰

Congressional Action

Both the House- and Senate-passed FY2002 Labor, Health and Human Services, and Education appropriations bills (H.R. 3061/S. 1536) included committee report language pertaining to microbicides. Both reports encouraged the CDC to expand its microbicide research agenda.

Additionally, both reports urged the NIH to enhance microbicide research and to implement its strategic plan for microbicide research. The committees requested the NIH to submit a report detailing the status of research initiatives and implementation of the strategic plan.

Report language accompanying the Senate committee-approved FY2003 Labor, Health and Human Services, and Education appropriations bill (S. 2766) urged the NIH to continue the implementation of its microbi-

cides research strategic plan and to accelerate and strengthen efforts to coordinate research among the NIH and with other federal agencies.

Legislation

Microbicide Development Act of 2001 (H.R. 2405/S. 1752)—Reps. Connie Morella (R-MD) and Anna Eshoo (D-CA) and Sens. Jon Corzine (D-NJ) and Olympia Snowe (R-ME)

H.R. 2405/S. 1752 would direct the NIH to expand, intensify, and coordinate microbicide research through the development of a microbicide research plan. Under the bills, the NIH would be required to establish a microbicide research program that would include basic research on the initial mechanisms of infection, develop appropriate animal models, develop formulation and delivery approaches, research targeted designs of microbicides, manufacture candidate products for testing in animals and humans, conduct HIV incidence and microbicide feasibility studies, evaluate microbicides in clinical trials, and examine behavioral use, acceptability, and adherence to microbicides. H.R. 2405/S. 1752 would authorize the Office of AIDS Research at the NIH to award grants to establish four multidisciplinary microbicide research centers. The bills would authorize such sums as necessary in each of FY2002 through FY2004. Additionally, H.R. 2405/S. 1752 would authorize such sums as necessary in each of FY2002 through FY2004 for the CDC to expand and coordinate its microbicide activities with the NIH.

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Ovarian Cancer

Although ovarian cancer is a common form of cancer, the lack of a simple diagnostic test makes it particularly deadly. It ranks fifth for cancer-related deaths in women.

- Currently, 52 percent of women who are diagnosed with ovarian cancer will die within five years. Only 26 percent of ovarian cancers are diagnosed in the beginning stages.¹
- The American Cancer Society (ACS) estimated that 23,300 new cases of ovarian cancer will be diagnosed, and 13,900 women will die of the disease in 2002.²
- Ovarian cancer ranks second among gynecologic cancers and causes more deaths than any other gynecologic cancer.³
- African-American women have a 30 percent greater chance of dying from ovarian cancer than do white women.⁴

Risk factors for ovarian cancer include family history of the disease, no childbearing, and age. According to the ACS, roughly 7 percent of ovarian cancer cases result from an inherited genetic defect (BRCA1 or BRCA2), and 90 percent of women who are diagnosed with ovarian cancer do not have any known risk factors.⁵

If ovarian cancer is caught while it is still localized, the 5-year survival rate is 95 percent, but only 26 percent of cases are diagnosed at this stage. Once the cancer has spread and the disease is diagnosed in the late stages, the survival rate falls to 29 percent. Treatment usually consists of surgery combined with chemotherapy.⁶

Improving early detection of ovarian cancer would help reduce deaths from the disease. Transvaginal ultrasound and the CA125 blood test are currently used as diagnostic tools, but not for screening purposes. Additionally, health care providers and patients are

finding that the CA125 blood test produces a high number of false positives and false negatives, leading many to question its accuracy. Some studies have shown that more than half of the participating women with Stage I ovarian cancer had normal CA125 blood levels.⁷

Most recently, researchers have been encouraged by the discovery of a connection between the protein osteopontin and ovarian cancer. In a study published in the *Journal of the American Medical Association*, researchers found that women with ovarian cancer have elevated levels of osteopontin in their blood. Pending further research, investigators are hopeful that an osteopontin screening test combined with other tests will enable doctors to offer ovarian cancer screening and early detection to patients.⁸

Several other protein-based blood tests are being researched for their usefulness in detecting ovarian cancer.⁹ They include a computer program that can detect protein pattern differences between women with ovarian cancer and women without the disease.¹⁰

Another study published in *Cancer* in 2000 found that screening for ovarian cancer using transvaginal ultrasound during routine gynecological examinations greatly improved early diagnosis of ovarian cancer.¹¹ The study screened 183,034 Japanese women over a 10-year period and found 22 primary tumors. According to the study, of the 22 primary tumors detected, 77.3 percent were found during Stage I, the most curable stage.¹²

In addition to improving early detection methods, another study demonstrated the need to educate doctors and women about ovarian cancer. The study examined the medical records of 1,725 U.S. and Canadian women with ovarian cancer and found that many of the women had the symptoms of ovarian cancer. However, only 20 percent of the women were

told they might have ovarian cancer during their first visit to a doctor. Many of the women were diagnosed with a number of other conditions, and 21 percent of the women in the study blamed their doctor for the late diagnosis.¹³

Another recent study found that bloating, nausea, abdominal pain, lower back pain, and lack of energy were much more common and constant, rather than intermittent, in women with ovarian cancer. Many women and doctors dismiss these symptoms because they are so common and could be attributable to a number of conditions.¹⁴

Research funding for ovarian cancer at the NCI has increased substantially over the past several years. Researchers say a sustained effort to identify risk factors, improve early detection, and expand treatment options will be crucial to reducing deaths from this disease. In FY2001, the NIH spent \$90.3 million on ovarian cancer research, with an expected increase to \$104 million in FY2002 and \$118.9 million in FY2003.¹⁵

In October 1999, the NCI announced that it would grant four academic institutions a total of \$5.85 million to research ovarian cancer. The grants are part of Specialized Programs of Research Excellence (SPORE) that support innovative, multidisciplinary research. The four institutions will focus their research on chemoprevention, gene resistance, vaccine development, and prevention and treatment of the disease. Currently, the NCI is supporting 11 ovarian cancer clinical trials and an additional 518 ovarian cancer research projects.¹⁶

In addition to research at the NIH, the Department of Defense also has been conducting research on ovarian cancer since FY1997 when it was appropriated \$7.5 million. The Ovarian Cancer Research Program received \$12 million in FY2001, \$10.2 million in FY2002, and \$10 million in FY2003. Between FY1997 and FY2000, 40 projects have been supported, focusing on better understanding, detection, diagnosis, prevention, and control of ovarian cancer.¹⁷

Congressional Action

During the 107th Congress, the House passed a resolution (H. Con. Res. 385) that expressed the sense of Congress that further research be conducted on screening tests for ovarian cancer. Sponsored by Rep. Steve Israel (D-NY), the resolution called for the Secretary of Health and Human Services to conduct or support research on ovarian cancer screening tests. H. Con. Res. 385 also called on federal health care programs as well as group and individual health plans to cover the tests if the medical screening technique is proven "effective for identifying ovarian cancer."

Additionally, committee report language accompanying the House- and Senate-passed FY2002 Labor, Health and Human Services, and Education spending bills (H.R.3061/S. 1536) urged the NCI to "expedite current research in screening methods to detect, diagnose, and identify staging of ovarian cancer." The reports also encouraged full funding of the four established ovarian cancer SPOREs.

The committee report for the Senate committee-approved FY2003 Labor, Health and Human Services, and Education appropriations bill (S. 2766) urged the NCI to continue funding the ovarian cancer SPOREs.

NOTES

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Treatment of Women Scientists

In recent decades, increasing numbers of women have chosen careers in the sciences. Women have continued to overcome societal attitudes about what interests and activities are “appropriate” for girls and women, a lack of encouragement in the educational system, and institutional indifference in industry, government, and academia. Still, parity has not been achieved:

- Women represented 46 percent of the U.S. workforce but only 24 percent of those employed as scientists and engineers in 1999.¹
- Among science and engineering faculty, 24 percent of women are full professors compared to 51 percent of men. Additionally, 35 percent of full-time employed women science and engineering faculty are tenured, compared to 60 percent of men.²
- In 1997, the average salary of women scientists and engineers was \$47,000—less than the \$58,000 average salary for men—according to the National Science Foundation. The disparity is partly attributed to age; women scientists and engineers are on average younger and less likely to pursue higher-paying fields, such as computer science.³

In the 103rd Congress, several legislative initiatives addressed the status of women scientists at the National Institutes of Health (NIH). A provision of the NIH Revitalization Act of 1993 (P.L. 103-43) instructed the Office of Research on Women's Health to monitor and promote the status of women scientists and physicians at the NIH and NIH-funded institutions, with particular emphasis on increasing the representation of women in senior positions. Additional legislation, introduced as part of the Women's Health Equity Act of 1993, would have required the NIH to establish policies regarding women scientists (including tenure, family leave, and the recruitment of women of color), and to study and address the issue of pay differences between male and female scientists. This legislation was incorporated into the Minority Health

Improvement Act, a bill that died awaiting Senate approval of the conference report in 1994.

Attention by Congress, the General Accounting Office, and the Equal Employment Opportunity Commission to the status of women at the NIH has led to some incremental improvements:

- The representation of women has increased in a variety of positions at the NIH. There were no female scientific directors in 1992; in 1995, 14 percent were women; and in 2002, 17 percent were women. In 1992, 4 percent of lab and branch chiefs were women; in 1995, 10 percent were women; and in 2002, 14 percent were women. In 1992, 13 percent of section chiefs were women; in 1995, 18 percent were women; and in 2002, 19 percent were women.
- Additionally, in 2002, women accounted for 18 percent of tenured scientists and 25 percent of tenure-tracked scientists.⁴

The NIH Office of Research on Women's Health (NIH-ORWH) has undertaken several projects aimed at encouraging women's participation in biomedical science careers. In the fall of 2000, the NIH-ORWH established a Building Interdisciplinary Research Careers in Women's Health (BIRCH) program aimed at providing career development for junior researchers, which provided grants to 12 research institutions. In the fall of 2002, a second round of grants were announced, totaling \$6 million.⁵

The NIH-ORWH also participates in the Professional Opportunities for Women in Research and Education (POWRE) program established by the National Science Foundation in 1997. The program's mission is to encourage the pursuit of careers by women in science and engineering. In FY1999, POWRE provided 159 grants, totaling \$11.5 million.⁶

Congressional Action

Congress also has pursued the advancement of women in science and engineering. In 1998, Congress created a commission (P.L. 105-255) to examine the barriers keeping women, minorities, and the disabled from careers in scientific fields. In July 2000, the commission released its report, which detailed a series of recommendations aimed at advancing the participation of women, minorities, and the disabled in science, engineering, and technology.⁷

The commission recommended that states adopt and implement high-quality education standards in math and science curricula and math and science teachers' qualifications. Additionally, the commission recommended aggressive and focused interventions for women, minorities, and disabled high school students transitioning into post-secondary colleges and community colleges. Another recommendation called for an increase in federal and state financial investments in science, engineering, and technology higher education. In terms of professional life, the commission recommended that all private and public science, engineering, and technology employers be held accountable for the career development and advancement of their women, minority, and disabled employees.⁸

The 107th Congress reauthorized the National Science Foundation. Included in that law (P.L. 107-368) is a provision to give grants to institutions of higher education for programs to increase the number of women, minorities, and people with disabilities in the fields of science, technology, engineering, and mathematics.

Another bill (H.R. 1858) would have encouraged colleges, universities, and the business community to partner with local school systems to improve math and science education, particularly for girls. The bill passed the House but was not considered by the Senate.

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Part Two

Preventive Health Services

Adolescent Pregnancy

After a steady increase in the 1970s and 1980s, the birth rate among U.S. teens aged 15-19 fell 26 percent between 1991 and 2001, according to the National Center for Health Statistics (NCHS).¹

According to the NCHS, the birth rate for African-American teenagers saw the most dramatic decline, falling by 46 percent between 1991 and 2001. Hispanic teenagers continued to have the highest birth rate at 92.5 per 1,000 births.² The NCHS attributes the decline in teen pregnancies over the past decade to a decrease in the proportion of teenagers engaging in sexual activity and an increase in contraceptive use among teenagers, particularly those at high-risk.³ Despite marked improvement, however, unintended pregnancy among teens remains a serious problem.

- Four in 10 young women become pregnant at least once before they reach the age of 20, resulting in nearly one million adolescent pregnancies each year. Eight in 10 of these pregnancies are unintended and 79 percent are to unmarried teens.⁴
- In 2000, one-third of high school students reported that they were currently having sex and nearly one-half reported ever having had sex.⁵
- An estimated 30 percent of teen pregnancies are terminated by abortion and roughly 14 percent end in miscarriage. Teens account for an estimated 20 percent of all abortions in the U.S.⁶
- In 2001, nearly four-fifths of teen births were to unmarried teens, and nearly half of all nonmarital first births occur to teens.⁷

Congressional Action

Congress first attempted to address the problem of teen pregnancy in 1978 with the passage of the Adolescent Health Services and Pregnancy Prevention and Care Act. While the law authorized the development of pregnancy prevention programs, funds were primarily used to provide services to pregnant and parenting teens.

Enacted in 1970 as Title X of the Public Health Service Act, the federal family planning program received \$265 million in FY2002 to fund public and private nonprofit clinics that provide family planning and reproductive health services. In 1978, Congress sought to make contraceptive services more accessible to sexually active adolescents by amending the federal family planning program to require that clinics serve teenagers.

In 1981, a number of health programs, including the Adolescent Pregnancy Prevention and Care Act, were folded into a new Maternal and Child Health Block Grant for states.

Currently, nearly one-third of Title X-funded clinics' clients are teenagers and one-half are women in their twenties. Additionally, many clinics encourage their counselors to spend extra time with teenage clients and maintain education and outreach programs aimed at adolescents. According to the Alan Guttmacher Institute, federally funded family planning clinics have helped to prevent 5.5 million adolescent pregnancies.⁸

By law, Title X clinics must provide confidential services to minors, although they are required to encourage family participation in a minor's decision to seek family planning services. In 1996 and 1997, the House defeated attempts to require parental consent or notification for minors using Title X services. In 1998, during consideration of the FY1999 Labor, Health and Human Services, and Education appropriations bill (P.L. 105-277), the House approved a parental notification requirement, but the language was dropped during a House-Senate conference. Similar amendments were not considered by the 106th or 107th Congresses.

As of 2002, 27 states and the District of Columbia have laws that explicitly grant minors the right to

obtain contraceptives services.⁹ Additionally, 18 states require either one or both parents to consent to a minor's abortion.¹⁰

A recent study published in the *Journal of the American Medical Association* found that 59 percent of adolescent girls surveyed said that they would cease using all sexual health care services, delay testing or treatment for HIV and other STDs, or discontinue use of specific sexual health care services if their parents were informed that they were seeking contraceptives.¹¹

Abstinence Education

In an effort to focus more attention on promoting abstinence, in 1981, Congress created the Adolescent Family Life Act (AFLA). Demonstration projects funded under the AFLA are required to promote abstinence from premarital sexual activity by encouraging strong family values; grantees are prohibited from providing contraceptive services.

In FY2002, the AFLA received \$28.9 million, a \$4.6 million increase over FY2001. The increase was used for programs to prevent second births to teenagers. In addition to the \$50 million mandated under the welfare reform law, community-based abstinence education programs operated through the Maternal and Child Health Bureau received \$40 million in FY2002, a \$20 million increase.

One survey found that abstinence-only sexual education courses were increasing in the United States. The survey found that in 1999, 23 percent of secondary school teachers surveyed taught abstinence-only courses compared with 2 percent in 1988. In contrast, the survey also found that 86 percent of teachers surveyed believed that students who received education on contraceptives would be more likely to use contraceptives when sexually active than students who did not receive contraceptive education.¹²

Currently, 38 states mandate school-based HIV/AIDS and STD education, while 22 states require broader sexuality education. In states with mandates, local

school districts are allowed to discuss contraception but are advised to stress abstinence.¹³

Welfare Reform

The Personal Responsibility and Work Opportunity Reconciliation Act, the welfare reform law (P.L. 104-193) enacted in 1996, has been a vehicle for congressional action on teen pregnancy. One of the stated purposes of the law's Temporary Assistance for Needy Families block grant is to prevent and reduce the incidence of out-of-wedlock pregnancies. Before a state can receive block grant funds, it must submit a written plan outlining how it intends to establish and meet its goal for preventing and reducing out-of-wedlock pregnancies, with special emphasis on teen pregnancies. In addition, the Department of Health and Human Services (HHS) is required to establish national goals for preventing teen pregnancy and to ensure that at least 25 percent of U.S. communities have teen pregnancy prevention programs in place.

In an effort to further motivate states to make teen pregnancy prevention a priority, the welfare law provided a \$20 million "illegitimacy" bonus grant to each of the five states that demonstrate the greatest decrease in out-of-wedlock births and reduce their abortion rate below the 1995 level. Beginning in FY1999, the bonus was granted in each of FY1999 through FY2002.

The welfare measure also imposed new restrictions on block grant assistance for teen parents. States have the option to deny benefits to unwed teen parents under the age of 18. In addition, states are prohibited from using federal grant funds to assist unmarried parents under age 18 who have not completed high school unless they are attending school or an alternative educational or training program. Unmarried teens must live with a parent or in an adult-supervised setting in order to receive federal assistance.

Finally, the welfare law authorized \$50 million a year for five years beginning in FY1998 for abstinence education programs. Administered under the Maternal and Child Health Block Grant, programs eligible to receive abstinence education funds must meet eight

criteria, including the requirement that their exclusive purpose is teaching the social, psychological, and physical gains to be realized by abstaining from sexual activity. States are required to contribute \$3 for every \$4 provided by the federal government.

Although the welfare law was up for reauthorization during the 107th Congress, lawmakers were unable to reach an agreement on a reauthorization package. Rather, authorization and funding for these programs was extended through a number of continuing resolutions. The scope and funding of the abstinence-only education portion of the welfare law remained relatively unchanged in the proposals considered by the House and Senate during the 107th Congress. However, the illegitimacy bonus would have been eliminated under both the House and Senate proposals.

National Teen Pregnancy Campaign

In 1995, President Clinton announced the creation of a private, nonpartisan National Campaign to Prevent Teen Pregnancy with the goal of reducing the teen pregnancy rate by one-third by 2005. One of the first efforts of the National Campaign was to review evaluation data for a wide range of local teen pregnancy prevention initiatives. *No Easy Answers: Research Findings on Programs to Reduce Teen Pregnancy*, released in 1997, concluded that while abstinence-only programs may be appropriate for younger adolescents such as junior high students, no published scientific research existed to demonstrate that such programs have actually delayed the onset of sexual intercourse or reduced sexual activity.¹⁴

Former U.S. Surgeon General David Satcher released a 2001 report on sexual health and responsible sexual behavior. *Surgeon General's Call to Action to Promote Sexual Health and Responsible Sexual Behavior* found that there was not enough scientific evidence to conclude that abstinence-only education programs were effective. The report also found no evidence that providing information about contraception increases adolescent sexual activity.¹⁵

Another report by the National Campaign evaluated a range of teen pregnancy prevention programs and found that comprehensive, long-term programs that included both youth development and reproductive health components substantially reduced teen pregnancy and birth rates over a period of time. Additionally, programs that focused solely on sex and HIV education were successful in reducing the number of sexual partners and increasing contraceptive use.¹⁶

The National Campaign also routinely conducts national surveys to assess the views of adults and teens on preventing teen pregnancy. The most recent survey found that 94 percent of adults and 93 percent of teens believe that teens should be given a strong message from society that they should abstain from sexual activity until they are out of high school. Additionally, 66 percent of adults and 56 percent of teens believe that teens should not be sexually active but if they are they should have access to contraceptives.¹⁷

The 2002 survey also found that 76 percent of adults and 64 percent of teens believe that teens should get more information about both abstinence and contraception, and 66 percent of adults and 72 percent of teens believe that providing information about abstinence and birth control does not send a mixed message.¹⁸

Moreover, 63 percent of teens surveyed said that they wished they had waited longer to become sexually active. Thirty-one percent of teens aged 12 to 14 cited their parents as being the most influential in their decisions about sex, and 69 percent of teens said it would be easier to postpone sexual activity if they had a more open relationship with their parents.¹⁹ Additionally, a Kaiser Family Foundation survey found that only 11 percent of sexually active teens aged 15 to 17 discussed sex with their parents before having sex.²⁰

Legislation

Family Life Education Act (H.R. 3469)—Reps. Barbara Lee (D-CA) and James Greenwood (R-PA)

H.R. 3469 would authorize \$100 million in each of FY2002 through FY2006 for the Department of Health and Human Services to award state grants to conduct family life education programs, including education on both abstinence and contraception for the prevention of teen pregnancy, STDs, and HIV.

Family life programs are defined as programs that are age-appropriate and medically accurate, do not teach or promote religion, teach that abstinence is the only sure way to avoid pregnancy and STDs, stress the value of abstinence while not ignoring individuals who are sexually active, provide information about the health benefits and side effects of all contraceptives as a means to prevent pregnancy and reduce the risk of contracting STDs and HIV, encourage family communication about sexuality, teach young people skills to make responsible sexual health decisions, and teach young people how drug and alcohol use can effect responsible decisionmaking.

Preventing Teen Pregnancy Act (H.R. 3581)—Rep. Jane Harman (D-CA)

H.R. 3581 would provide \$20 million in FY2002 for the Department of Health and Human Services to award grants to state and local non-profit coalitions, state, local, and tribal agencies, schools, entities that provide after-school programs, and community and faith-based groups working to prevent teen pregnancy. The Secretary of Health and Human Services would be directed to give priority to those programs targeting communities where teen pregnancy or birth rates are higher than the corresponding state average or where teen pregnancy or birth rates are increasing. Priority also should be given to programs that target underserved or at-risk populations, including young males and immigrant youth, and programs that are coordinated with other programs that serve youth, such as workforce development and after-school programs.

NOTES

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- 8 The Alan Guttmacher Institute (AGI), "Title X: Three Decades of Accomplishment," *The Guttmacher Report on Public Policy* (New York: AGI, 2001).
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- 14 National Campaign, *No Easy Answers: Research Findings on Programs to Reduce Teen Pregnancy* (Washington: National Campaign, 1997).
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- 17 National Campaign, *With One Voice 2002: America's Adults and Teens Sound Off About Teen Pregnancy* (Washington: National Campaign, 2002).
- 18 Ibid.
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Domestic Violence

A 1999 study by the Department of Justice's Bureau of Justice Statistics (BJS) found a 21 percent decline in intimate partner violence against women between 1993 and 1998.¹ Still, female victims of violence are more likely than male victims to identify intimates as offenders. A more recent study found that intimates were the offenders in 21 percent of the overall violence against women, compared to 3 percent of the violence against males.² According to the BJS:

- One million violent crimes were committed against persons by their current or former spouses, boyfriends, or girlfriends.³
- Eighty-five percent of the victims of intimate partner violence were women.⁴
- Women aged 20-24 experienced the highest rates of intimate partner violence.⁵
- While there was an overall decline in domestic violence, African-American women experienced violence at a rate 35 percent higher than Caucasian women, and African-American women were more likely than other women to report abuse to the authorities.⁶
- Approximately 43 percent of female victims of intimate partner violence lived in households with children under the age of 12.⁷

Congressional Action

In 1993, Congress gave new authority to the Centers for Disease Control and Prevention (CDC) to study domestic violence and develop effective strategies for its prevention, including training health care providers to be better able to recognize victims of domestic violence.

Additionally, the 1994 Violence Against Women Act (VAWA) (P.L. 103-22) established a number of programs aimed at combating violence against women. In addition to creating law enforcement grants to encourage arrests, providing judicial and court personnel training in domestic violence, and providing

rape prevention programs, the law established the National Domestic Violence Hotline and expanded support for battered women's shelters.

When VAWA programs were set to expire at the end of FY2000, Congress enacted legislation (P.L. 106-386) to reauthorize all original VAWA programs for five years, as well as to create a number of new VAWA programs. The 107th Congress enacted legislation (P.L. 107-273) to establish a permanent Violence Against Women Office within the Department of Justice. Under the new law, the Director of the Violence Against Women Office is appointed by the President, confirmed by the Senate, and reports to the Attorney General.

Congress also enacted legislation (P.L. 107-311) to reduce domestic violence on military bases by allowing civilian court protective orders to be applied on military bases.

Health Care Providers Response

Several studies suggest that battering may be one of the leading causes of injury to women. The BJS estimates that 37 percent of women treated in hospital emergency rooms were treated for injuries or symptoms associated with physical abuse.⁸ Another 2000 study by the National Institute of Justice and the CDC reported that each year women make 557,929 visits to hospital emergency rooms as a result of injuries sustained from intimate partner violence.⁹ Despite these statistics, another study estimates that 6 in 10 women who were victims of intimate partner violence did not seek treatment for their injuries in 1998.¹⁰

A study published in the *Journal of the American Medical Association* found that while 79 percent of primary care physicians screened for partner abuse when a patient's visit involved physical injuries, only 10 percent of physicians routinely screened during new patient visits, and only 9 percent screened during

periodic checkups. The study also found that patient-related factors were the most common barrier to identifying and referring individuals, with a patient's fear of retaliation by the partner cited as the most common barrier.¹¹

While less than half of physicians cited lack of training, time, and information about local resources as major barriers to identifying and referring victims of intimate partner violence, the study suggested that physicians were not adhering to current screening guidelines and opportunities to identify abused women were being missed.¹²

In 1999, the Family Violence Prevention Fund, in conjunction with the Department of Health and Human Services, issued clinical guidelines on routine screening for domestic violence. The guidelines are supported by the American Medical Association and the American Nurses Association. The guidelines recommend:

- Routine screening for domestic violence for all female patients aged 14 and older in primary care, ob-gyn and family planning, emergency department, inpatient, pediatric, and mental health settings;
- Implementation of culturally competent programs to ensure routine screening of all female patients; and
- Confidential documentation of the screening outcomes.¹³

Discrimination

Unfortunately, until recently many women were forced to pay a stiff penalty for seeking medical assistance by being denied health insurance coverage. A 1995 survey by the Pennsylvania Insurance Commissioner found that one-third of the companies surveyed in that state admitted that they considered domestic violence as a factor in issuing insurance. In an effort to reverse that trend, Congress approved legislation barring group health plans from discriminating against victims of domestic abuse. Passed as part of the Health Insurance Portability and Accountability Act of 1996 (HIPAA) (P.L. 104-191), the law makes it illegal for health insurers to deny coverage on the

basis of medical conditions caused by domestic violence, a history of domestic violence, or current status as a victim of domestic violence.

Legislation

Domestic Violence Identification and Referral Act of 2001 (S. 518)—Sen. Barbara Boxer (D-CA)

S. 518 would provide for the training of health professions students with respect to the identification and referral of victims of domestic violence.

Domestic Violence Screening and Services Act of 2002 (S. 2236)—Sen. Paul Wellstone (D-MN)

S. 2236 would provide coverage for domestic violence screening and treatment, authorize the Secretary of Health and Human Services to make grants to improve the response of health care systems to domestic violence, and train health care providers and federally qualified health centers regarding screening, identification, and treatment for families experiencing domestic violence.

Domestic Violence Screening and Treatment Act of 2002 (H.R. 4032)—Reps. Lois Capps (D-CA) and Steve LaTourette (R-OH)

H.R. 4032 would provide coverage for domestic violence screening and treatment under the Maternal and Child Health Block Grant, Medicaid, and the Federal Employees Health Benefits Program.

NOTES

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- 2 Rennison, "Criminal Victimization 2000: Changes 1999-2000 with Trends 1993-2000," *National Crime Victimization Survey* (Washington: DOJ, 2001), p. 8.
- 3 Rennison, "Intimate Partner Violence and Age of Victim, 1993-99," *National Crime Victimization Survey* (Washington: DOJ, 2001), p. 9.
- 4 Ibid., p. 3.
- 5 Ibid., p. 4.
- 6 Rennison, "Intimate Partner Violence," pp. 1, 6.

Eating Disorders

Eating disorders are long-term, complex illnesses with interacting physical, psychological, and social components. The eating patterns characteristic of these illnesses are often related to the individual's distorted body image and unrealistic societal ideals of thinness. Eating disorders can lead to lifelong psychological and physical problems and are destructive not only to a victim but to family and friends as well. However, the United States does not track epidemiological data on eating disorders, so all statistics are estimates and most research occurring in the field are patient studies.¹

- According to the Harvard Eating Disorders Center, more than 90 percent of those with eating disorders are adolescent women.²
- The National Institute of Mental Health (NIMH) at the National Institutes of Health estimates that 0.5 to 3.7 percent of females suffer from anorexia nervosa in their lifetime, and an estimated 1.1 to 4.2 percent of females suffer from bulimia nervosa in their lifetime.³
- A 1997 survey by the Commonwealth Fund found that one in six girls in grades 5-12 said that she had binged and purged. Fifty-eight percent of girls in grades 9-12 said they had been on a diet and one in three thought she was overweight. Additionally, abused girls were nearly three times as likely to binge and purge as girls who had not been abused.⁴

Eating disorders include anorexia nervosa (characterized by a refusal to maintain a body weight at or above a minimally normal weight, intense fear of gaining weight, feeling "fat," and extreme concern with body weight and shape), bulimia nervosa (characterized by binge eating followed by a form of purging such as self-induced vomiting and/or the misuse of laxatives, diet pills, diuretics, excessive exercise, or fasting), and binge-eating disorder (characterized by repeated episodes of uncontrolled eating).⁵

According to the NIMH, young women with anorexia nervosa are 12 times more likely to die than other women of the same age without the disease. Many individuals suffer for years. In one study, 30 percent of eating disorder victims reported their illness lasting 1 to 5 years, 31 percent reported 6 to 10 years, and 16 percent reported 11 to 15 years. Only about half reported being completely cured.⁶

The physical effects of anorexia include amenorrhea, osteoporosis, hair loss, hypothermia, heart ailments, obstetric complications, and immune system suppression. One study found that anorexics who developed the disorder during their teenage years were at a greater risk of osteoporosis and that 50 percent of the studied anorexics had low bone density.⁷ Additionally, vomiting associated with bulimia can cause damage to tooth enamel, the esophagus, and the salivary glands. The abuse of diuretics and laxatives can lead to chemical imbalances. Eating disorders also are associated with a variety of psychological conditions such as depression, anxiety, and substance abuse.⁸ One study found that almost half of the eating disordered patients studied met the criteria for major depression.⁹

While there is no known cause of eating disorders, certain characteristics have been shown to influence the development of eating disorders, such as low self-esteem, poor family and peer influences, cultural and media influences that emphasize thinness, and clinical depression.

Silence surrounds the issue of eating disorders. Many states and schools devote time and resources to very effective education programs aimed at preventing alcoholism, drug abuse, and HIV/AIDS; however, very few schools and colleges have adequate eating disorder education programs. Prevention programs could help counter the societal causes of eating disorders by educating young people about proper nutrition,

normal body development and growth, and healthy self-esteem.

As a result, in 1998, the Public Health Service's Office on Women's Health established a national media campaign to educate the public about eating disorders. The first phase of the "BodyWise Campaign" developed an eating disorders module aimed at middle-school educators, including teachers, coaches, principals, and school administrators; the second phase targeted health officials. The "BodyWise Campaign" is featured on the National Women's Health Information Center website at www.4woman.org. Additionally, the office is partnering with the National Osteoporosis Foundation and the Centers for Disease Control and Prevention (CDC) to implement the National Bone Health Campaign, the first phase of which targets girls aged 9-18 with information about behaviors that lead to bone loss.

The office also helped launch the Girl Power! campaign, a national public health education campaign for girls aged 9-14. The goal of the campaign is to provide the support and encouragement needed to allow girls to make good health and lifestyle choices. The office also created a Get Real! Video Kit, which is aimed at educating college-age women about important health issues, including eating disorders.¹⁰

Most recently, a new website has been created, www.4girls.gov, to provide information on adolescent girls' health concerns.

Access to Health Care

Eating disorder advocates are calling for increased access to health care by not only calling for mental health parity, but also by urging health insurance companies to include eating disorders among the list of covered mental illnesses. Health plans often place limits on the treatment they will cover for eating disorders or they exclude eating disorders from the list of mental illnesses covered by the plan altogether.¹¹

Under a recent study, one in ten patients received treatment for an eating disorder. Additionally, the study found that the intensity of treatment was less

than what is recommended by clinical guidelines. The study examined a national database of health insurance claims to determine the number of claims for eating disorder treatment and the type and length of treatment received.¹²

Another 1999 survey of leading eating disorders experts in the United States found that 96.7 percent believed that their anorexia patients were put in life-threatening situations because health insurance policies mandated early discharge. Additionally, 18 percent believed that insurance companies indirectly caused at least one of their patients to die, and 100 percent believed that some of their patients suffered relapses as a result of health care coverage limits.¹³

Congressional Action

During the 107th Congress, the Senate Health, Education, Labor, and Pensions Committee approved a bill pertaining to safe motherhood (S. 2328) that incorporated a number of other provisions, including legislation (S. 2249) establishing an eating disorders grant program at the CDC, sponsored by Sen. Hillary Rodham Clinton (D-NY).

Legislation

Eating Disorders Awareness, Prevention, and Education Act of 2001 (H.R. 46)—Rep. Judy Biggert (R-IL)

H.R. 46 would amend the Elementary and Secondary Education Act to allow states and local school districts to use federal education funding for programs aimed at increasing the awareness of eating disorders among parents and students, and to train educators on effective eating disorder prevention and assistance methods. The bill also would require the Departments of Education and Health and Human Services to develop, distribute, and promote public service announcements on eating disorders. H.R. 46 would require the National Center for Education Statistics and the National Center for Health Statistics to conduct a study on the impact eating disorders have on educational advancement and achievement.

Promoting Healthy Eating Behaviors in Youth Act (S. 2249)—Sen. Hillary Rodham Clinton (D-NY)

S. 2249 would establish a grant program through the Centers for Disease Control and Prevention to provide accredited universities, colleges, and nonprofit organizations with funding to develop and test educational curricula and intervention programs to promote healthy eating behaviors in youth. The bill would authorize \$5 million in FY2003, \$5.5 million in FY2004, \$6 million in FY2005, \$6.5 million in FY2006, and \$1 million in FY2007.

NOTES

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- 3 National Institutes of Mental Health (NIMH) at the National Institutes of Health (NIH), *Eating Disorders: Facts About Eating Disorders and the Search for Solutions* (Bethesda: NIH, 2001), pp. 4-5.
- 4 The Commonwealth Fund, *The Commonwealth Fund Survey of the Health of Adolescent Girls* (New York: The Commonwealth Fund, 1997), p. 4.
- 5 National Eating Disorders Coalition, "Eating Disorders Info" <<http://www.nationaleatingdisorders.org>> (12/10/02).
- 6 National Association of Anorexia Nervosa and Associated Disorders (ANAD), "Facts About Eating Disorders" <<http://www.anad.org/facts.htm>> (12/10/02).
- 7 A.E. Becker, et al., "Eating Disorders," *New England Journal of Medicine* 340 (1999): 1092-1098.
- 8 NIMH, *Eating Disorders*.
- 9 A.E. Becker et al., "Eating Disorders."
- 10 Public Health Service's Office on Women's Health, "Girl and Adolescent Health" <<http://www.4woman.gov/owh/girl.htm>> (12/13/02).
- 11 ANAD, "Q&A: Parity Legislation" <<http://www.anad.org/parity.htm>> (12/19/02).
- 12 Striegel-Moore, et al., "One-year Use and Cost of Inpatient and Outpatient Services Among Female and Male Patients with an Eating Disorder: Evidence from a National Database of Health Insurance Claims," *International Journal of Eating Disorders* 27 (2000): 381-389.
- 13 David France, "Anorexics Sentenced to Death," *Glamour Magazine*, Aug. 1999.

Family Planning Informed Consent

The Title X family planning program was created in 1970 to provide voluntary family planning services to low-income individuals. Forty-nine percent of all pregnancies are unplanned, roughly half of which end in abortion.¹

- Eighty-five percent of U.S. counties have at least one publicly funded family planning clinic. About one-quarter of women who obtain family planning services, obtain care at clinics funded in part by Title X.²
- Twenty-four percent of women who use reversible contraceptives obtain them from a family planning clinic or from a private doctor reimbursed by Medicaid. Family planning clinics are an especially important source of care for teenagers, women of color, and low-income women.³

Since its inception, the Title X statute has prohibited the use of federal funds in programs where “abortion is a method of family planning.” Until 1987, that restriction had been interpreted by the Department of Health and Human Services (HHS) only to forbid the performance of abortion with federal funds. The program guidelines required health care providers to offer counseling on all legal options regarding a pregnancy, including abortion, and to refer patients requesting abortions.

Beginning in 1987, HHS sought to prohibit family planning clinics that received federal funds under the Title X program from providing abortion information or referrals to pregnant clients. The HHS regulations were tied up in legal challenges for several years. Finally in 1991, the U.S. Supreme Court voted 5-4 to uphold the policy, ruling that the government could prohibit federally funded clinics from providing patients with information about abortion.

In 1992, the Bush administration formally moved to implement the HHS regulations. On two separate

occasions, Congress voted to overturn the controversial family planning policy. However, the House narrowly failed to override presidential vetoes of the legislation. While one of the vetoed bills simply blocked implementation of the regulations, the other would have put into federal statute the requirement that family planning providers inform pregnant women about all of their options for dealing with an unintended pregnancy, including abortion.

The Clinton administration formally lifted the restrictions in 1993, at which time HHS proposed new regulations on the issue. On July 3, 2000, HHS published its final interpretation of the statutory requirement that no federal funds be used for Title X programs in which “abortion is a method of family planning.” Under the final rule, Title X clinics may provide counseling and referral services for abortions, but the information must be presented in a neutral manner. Additionally, Title X clinics are prohibited from promoting or encouraging abortion as a method of family planning. The rule also clarifies that financial separation of non-Title X abortion activities from Title X activities is sufficient to comply with the law.⁴

Congressional Action

The issue of “gag rules” in government health programs arose in a different context during the 105th Congress. As Congress moved to pass legislation to balance the federal budget, a number of provisions affecting managed care plans that participate in Medicare and Medicaid were considered.

One House-passed provision approved in the Balanced Budget Act (P.L. 105-33) bars managed care plans from restricting the information a health care provider can provide to a patient. The so-called “anti-gag rule” provision also included a “conscience clause,” which allows a health plan to refuse to provide information on a service it finds objectionable on moral or religious grounds. The conference report accompanying

the Balanced Budget Act made clear, however, that states are still obligated to ensure that covered services, such as nondirective counseling and referral for the full range of reproductive health care services, are available through another system or provider.

During the 106th and 107th Congresses, the issue surfaced again during consideration of managed care reform legislation. In each Congress, both the House and Senate passed patients' bills of rights that included "anti-gag rule" provisions that would have prohibited health plans from restricting the information a physician may provide a patient about a patient's illness and/or treatment; however, the legislation stalled in conference during both Congresses.

Most recently, during the 107th Congress, the House passed legislation (H.R. 4691) that would have permitted an array of health care facilities, plans, and organizations to refuse to perform, cover, or pay for abortion services or to provide referrals and information if they object to such services on religious or moral grounds. Current law prohibits federal, state, and local governments from denying funds to health care entities that refuse to undergo abortion training, refuse to provide abortion training, or refuse to provide referrals for abortion training. H.R. 4691 would have expanded current law to health care professionals, hospitals, health maintenance organizations, health insurance plans, and other health care facilities, organizations, and plans. Additionally, the bill would have prohibited federal, state, and local governments from denying funds to any entity that refuses to perform, cover, or pay for abortion services or to provide referrals and information. The legislation was not considered by the Senate.

Legislation

Women's Right to Know Act of 1999 (H.R. 185)— Rep. Louise Slaughter (D-NY)

H.R. 185 would amend the Civil Rights Act of 1964 to prohibit any state or federal government authority from restricting a health professional's right to give, or a woman's right to receive, information about reproductive health options, including family planning, prenatal care, adoption, and abortion services.

NOTES

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- 3 Ibid.
- 4 Department of Health and Human Services, "Provisions of Abortion-Related Services in Family Planning Services Projects," *Federal Register* 65 (July 3, 2000) 128: 41281-41282.

Health Status of Women of Color

The health status of women of color has come under scrutiny because many health indicators for minority women lag behind those of their Caucasian counterparts. Although there is now ample data to demonstrate discrepancies in the health status and outcomes between women of color and Caucasian women, few conclusive reasons for these differences have been established. This knowledge gap has made forging effective programs and policies a frustrating process of trial and error.

Although many generalized pronouncements have been made on the health status of women of color, these generally fail to capture the total picture of this population, made complex by diverse subsets. This diversity manifests itself in different languages, cultures, degrees of acculturation, and histories. These differences may account for some of the difficulty in accurately depicting the health status of this broad spectrum of women.

A 1997 report from the Centers for Disease Control and Prevention (CDC) showed wide disparities in health-risk behaviors, even among members of the same racial and ethnic groups living in different states. The report also found that African Americans and Hispanics engage in more health-risk behaviors and make less use of preventive services.¹

The misclassification of race and ethnicity in data collection also contributes to the disparity. For example, it is not uncommon for some Hispanic, Asian/Pacific, and American Indian/Alaska Native women to be classified as Caucasian on hospital admission records or death certificates.

Another contributing factor is the generally sparse representation of women of color in research studies. This concern has prompted a call for greater outreach to these communities, as well as increased education for health care providers and researchers on the importance of including women of color in studies.

According to the Population Reference Bureau, women of color are more likely than Caucasian women to live in poverty. Of American women currently living below the federal poverty line, 28.5 percent are African American, 28 percent are Hispanic, 24.9 percent are Native American, 13.2 percent are Asian/Pacific Islander, and 9.4 percent are Caucasian.² The negative effect of poverty on health and on accompanying conditions such as housing and violence has been well-documented.

There also may be specific barriers within the health care system that limit the access of women of color to proper services. According to the Public Health Service's Office on Women's Health (PHS-OWH), many health care providers and facilities are not sensitive to the needs and preferences of women of color. The PHS-OWH cites inadequate communication resulting from stereotyping, language barriers, health information provided at an inappropriate literacy level, and a lack of culturally appropriate services and education material.³

Although specific rates of disease vary greatly by race and ethnicity, it is instructive to evaluate a few indicators to understand the depth of the gap between the health status of women of color and that of Caucasian women.

Health Indicators

Life expectancy for most women of color is lower than for Caucasian women. Current estimates of life expectancy for Caucasian women is 79.6 years; for Hispanic women, 77.1 years; for American Indian/Alaska Native women, 74.4 years; and for African-American women, 74.1 years.⁴

Heart disease is the leading killer of women of color, as it is for all women in the United States. African-American women and Hispanics, however, have higher death rates from heart disease than do Caucasian women. The death rate for diseases of the heart for

African-American women is 147 per 100,000, compared to 88 for Caucasian women, 70 for American Indian/Alaska Native women, and 63 each for Hispanic women and Asian-American/Pacific Islanders.⁵ Although family history of heart disease and lifestyle are major risk factors for this disease, the wide gap has not been satisfactorily explained.

Breast cancer provides another example of differences in the health status of women of color as compared to Caucasian women. Although they develop breast cancer less frequently than Caucasian women, African-American and Hispanic women have a higher rate of mortality, due most likely to later diagnosis and treatment.⁶

Screening for early diagnosis continues to be a key factor in breast cancer survival. All groups of women of color are less likely to receive routine mammograms after the age of 40 than are Caucasian women. Fifty-four percent of Asian-American women over the age of 40, 52 percent of African-American women over the age of 40, and 51 percent of Hispanic women over the age of 40 have not had a mammogram within the past two years. Forty-four percent of Caucasian women over the age of 40 have not had a mammogram in the past two years.⁷

A recent statistic may indicate that awareness about breast cancer screening in the African-American community is beginning to have a beneficial impact. From 1990-1998, the death rate from breast cancer among African-American women decreased by 8 percent. This is a dramatic change from 1980-1990, during which time the death rate for African-American women increased by 18 percent. Although this trend is encouraging, it should be noted that from 1990-1998, the death rate for Caucasian women from breast cancer decreased by 20 percent.⁸

Infant mortality rates are frequently viewed by public health specialists as primary indicators of the health of a population as a whole. According to the National Institutes of Health, the infant mortality rate for infants born to African-American women was more than twice as high as those born to Caucasian women at 13.8 deaths per 1,000 live births.⁹ Native

American women followed with a rate of 9.3, while the rate for Caucasian women was 6.0, just below the national average of 7.2.¹⁰ Additionally, infants of mothers who had no prenatal care or began it after the first trimester had an infant mortality rate of 9.4, which was 49 percent higher than the rate for those who began care in the first trimester.¹¹

HIV/AIDS is a pressing health issue for women of color. African-American and Hispanic women constitute 80 percent of women with HIV/AIDS.¹² Asian/Pacific and American Indian/Alaska Native women make up less than 1 percent of the total HIV/AIDS cases among women.¹³ In 1999, HIV/AIDS was the fifth leading cause of death for women aged 25-44. It was the third leading cause of death for African-American women and the fourth leading cause of death for Hispanic women in the same age group.¹⁴

In addition to HIV/AIDS, racial and ethnic minorities are disproportionately affected by other STDs. For some STDs, the reported rate can be as much as 30 times higher for African Americans than for Caucasians. In 2001, African Americans represented 75 percent of all reported gonorrhea cases.¹⁵

Other diseases that are more prevalent among women of color include diabetes, rheumatoid arthritis, and lupus, the latter afflicting African-American women three times more often than Caucasian women.¹⁶

In some instances, women of color may have a lower incidence of illness, but because they are more likely to lack access to adequate health care they are diagnosed at later stages when the health consequences may be more severe. This phenomenon seems to be the case with mental illness. Women of color utilize outpatient services far less often than Caucasian women, yet their rate of inpatient treatment is much higher.¹⁷ Additionally, Hispanic women have the highest lifetime prevalence of depression among all women at a rate of 24 percent.¹⁸ According to the American Psychological Association, women of color are more likely than Caucasian women to share a number of socioeconomic risk factors for depression.¹⁹

It also is important to note violence constitutes a more significant health risk for women of color than for Caucasian women. According to the Bureau of Justice Statistics at the Department of Justice, African-American women experienced a 35 percent higher rate of intimate partner violence than Caucasian women.²⁰ Additionally, 40 percent of African-American women reported coercive contact of a sexual nature before the age of 18.²¹ More research is needed to establish the causes of these troubling discrepancies. Also, increased outreach and education to communities of color regarding prevention and screening may help reduce the gap in health outcomes.

Need for Culturally Competent Providers

Women's health advocates point to a lack of culturally and linguistically competent health care providers as a primary contributor to the poor health status of women of color. According to the American Medical Association (AMA), roughly 12 percent of practicing physicians are African American, Hispanic, Asian American or American Indian/Alaska Native. However, the AMA believes that many minority groups are underreported because the organization has data on only 70 percent of all U.S. physicians. Nearly 25 percent of practicing physicians are female. Of the total number of female physicians, roughly 17 percent represent minority groups; however, the race/ethnicity for 34 percent of female physicians is not known to the AMA.²²

The AMA recently established a cultural competence initiative aimed at establishing cultural competence as the "Fifth Physician Competence." Currently, there are four competence standards to which physicians are held: cognitive knowledge, technical skill, behavior, and managerial competence.²³ A recently published Cultural Competence Compendium provides a list of resources for medical schools, residency program directors, and physicians to assist medical professionals in providing culturally competent health care.²⁴

According to the PHS-OWH, cultural competence—more than gender, race, or ethnicity—is the attribute

that best fosters an environment in which patients of diverse backgrounds will be understood, appropriately diagnosed, and treated.²⁵

Within federal agencies, several programs have been established to specifically address the health of women of color. These include initiatives at the Food and Drug Administration, CDC, National Institutes of Health, Indian Health Service, Health Resources and Services Administration, and the Agency for Healthcare Research and Quality. In addition, the Public Health Service has both an Office on Minority Health and an Office on Women's Health, and the Department of Health and Human Services has implemented a department-wide Initiative to Eliminate Racial and Ethnic Disparities in Health.

Congressional Action

The 107th Congress enacted legislation (P.L. 107-121) to allow Native American women access to state-optional Medicaid coverage for treatment of breast or cervical cancer if they are diagnosed through the national screening program.

Additionally, Congress approved a resolution (H. Con. Res. 388) expressing the sense of Congress that a National Minority Health and Health Disparities Month be established to promote educational efforts on the health problems currently facing minorities and other health disparity populations in the areas of infant mortality, cancer screening, cardiovascular disease, diabetes, HIV/AIDS, and immunizations. The resolution also expressed the sense of Congress that the Secretary of Health and Human Services should develop public service announcements on health promotion and disease prevention. In addition, health care professionals should be provided with information on "factors associated with health care utilization and access, patient attitudes toward health services, and risk and protective behaviors that affect health and illness...so that they may better communicate with all patients, regardless of race or ethnicity, without bias or prejudice."

NOTES

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HIV/AIDS Prevention

As has been the case for the past several years, women are the fastest-growing population group with HIV/AIDS. While treatment advancements have led to a reduction in AIDS deaths in recent years, the growing incidence of HIV infection among women seems to indicate that prevention programs have not effectively reached many young women or women of color.

HIV/AIDS is now the fifth leading cause of death in women aged 25–44, and the third leading cause of death for African-American women in this age group.¹ The proportion of AIDS cases among female adults and adolescents has more than tripled, from 7 percent in 1985 to 25 percent in 2001.²

As of December 2002, women accounted for 30 percent of new HIV infections. African-American and Hispanic women represented 80 percent of AIDS cases in women, while representing less than 25 percent of all women in the United States. In 2000, women aged 13–24 accounted for 47 percent of HIV cases. Given that risk behaviors are most likely to begin during the teenage years, individuals who are diagnosed before age 25 are more likely to represent newer infections, a fact that can be useful in targeting prevention efforts.³

Sexual Transmission

Since 1994, heterosexual contact has been the leading known source of HIV infection among women, followed by injection drug use. Of new infections among women, it is estimated that 75 percent of women were infected through heterosexual contact and 25 percent through injection drug use.⁴ In addition to the direct risk of injection drug use through the sharing of needles, heterosexual transmission also is growing as a result of drug use. Many women are infected through partners who are injection drug users. Thus, effective substance abuse prevention and treatment must be a critical component of HIV/AIDS prevention efforts targeted to women.⁵ In 2001, of the AIDS cases reported

in women, 41 percent were attributed to heterosexual contact and 39 percent to injection drug use. The source of the remaining cases was listed as blood transfusion (3 percent) and not reported or identified (17 percent).⁶

Many women who are newly identified as HIV-infected reported no known risk factor for infection, possibly either indicating a lack of knowledge of their partners' risk factors or that their health care providers did not document the information. According to the CDC, more than two-thirds of AIDS cases in women that are initially reported with no known risk factor are reclassified as infection by heterosexual contact and one-fourth are attributed to injection drug use.⁷

There also is a strong correlation between infection with HIV and other sexually transmitted diseases (STDs). The presence of STDs increases a woman's likelihood of both acquiring and transmitting HIV. Women with STDs are three to five times more likely to become HIV-infected.⁸ The importance of prompt detection and treatment is paramount; all sexually active women should be screened regularly for STDs.

Prevention Messages

In the early 1990s, HIV prevention programs targeted specifically to women tended to focus on relatively narrow groups of women; however, these programs are expanding to meet the needs of all women, particularly minority women.

A substantial effort has targeted pregnant women for HIV counseling and testing. According to the Centers for Disease Control and Prevention (CDC), rates of perinatal HIV transmission decreased by 80 percent between 1991 and 2000.⁹ The CDC attributes the decrease to voluntary counseling and testing of pregnant women, as well as the advent of new anti-AIDS drugs.¹⁰ Annually, an estimated \$67.6 million is spent in the U.S. on perinatal prevention. The CDC estimates

that without these efforts, an additional 656 infants would be born with HIV, costing roughly \$105.6 million in medical care expenses.¹¹

Additionally, in 1999, the Institute of Medicine (IOM) issued a report recommending that the United States adopt a national policy of universal voluntary HIV testing, with patient notification, as a routine component of prenatal care.¹² The recommendations are supported by the American Academy of Pediatrics and the American College of Obstetricians and Gynecologists. However, despite the decline in perinatal transmission, infection rates for women continue to rise. As a result, women's health advocates argue that the best way to prevent HIV infection in infants is to prevent HIV infection in women.

Several studies indicate that STD/HIV prevention programs for women are most effective when they occur at a place where women go for their health and social services, including family planning and women's health clinics, application sites for public assistance and food stamps, and migrant worker camp kitchens. In 1999, the CDC published a compendium of HIV prevention interventions, which detailed effective intervention programs. Recognizing that many women are at risk due to the behavior of their male partner, behavior about which they may or may not have knowledge, many of the programs targeting women focused on risk-reduction skills, such as negotiation, assertiveness, and communication.¹³

Microbicides

Prevention messages that primarily emphasize abstinence, partner reduction, and condom use may fail to recognize that women are not always in control of when, with whom, and on what terms they have sexual relations. Many women's health advocates continue to press for the development of microbicides—a female-controlled method of preventing HIV and other STDs. A woman could use a microbicide without her partner's knowledge to protect herself from HIV, other STDs, and pregnancy. Researchers also are working to develop a microbicide that could protect against HIV, while still allowing women to

become pregnant. Scientists are currently pursuing almost 60 different product leads, and advocates believe that with sufficient resources a microbicide may be available by 2007.¹⁴

Congress has repeatedly encouraged the CDC and the National Institutes of Health to expand their microbicide research portfolios and legislation has been introduced that would authorize increased funding for such research (see HIV/AIDS Research, p. 37).

In July 2000, researchers announced the results of a study to determine whether nonoxynol-9, a spermicide, would be effective in preventing the transmission of HIV. The study enrolled 1,000 HIV-negative sex workers in Africa. Half of the women received the spermicide, while the other half received a placebo. The study found that women who used nonoxynol-9 became infected with HIV at a 50 percent higher rate than women who used the placebo. Additionally, the more frequently women used the spermicide, the higher their infection risk. As a result of the study, the Food and Drug Administration proposed new warning labels for over-the-counter contraceptives that may contain nonoxynol-9. The warning states that vaginal contraceptives that contain nonoxynol-9 do not protect against HIV and other STDs.¹⁵

The CDC has primary responsibility within the federal agencies for HIV education, prevention, surveillance, and population-based research activities. It conducts prevention programs through community-based organizations, schools, and public information campaigns. A relatively small portion of the CDC's HIV prevention budget is specifically targeted to women. In FY2000, 17 percent (\$118 million) of the \$694 million appropriated for HIV prevention was spent on programs targeted to women. In FY2001, \$251 million was spent on programs targeted to women.¹⁶

After passage of the Comprehensive HIV Prevention Act in 1993, the CDC created the HIV Prevention Community Planning Initiative, designed to give local communities input into prevention programs and to

ensure the development of culturally competent programs that best meet the needs of the community. More recently, the 106th Congress reauthorized (P.L. 106-345) the Ryan White CARE Act with language to ensure that populations most affected by HIV/AIDS are represented in the CARE Act's HIV Health Planning Councils.

A 1999 IOM report found that the United States did not have a "comprehensive, effective, and efficient strategy for preventing the spread of HIV." Moreover, the report found that current prevention programs are not effectively reaching women, youth, and racial and ethnic minorities. The report recommends a national prevention goal to avert as many new infections as possible.¹⁷ This would be accomplished through a six-element program, which would include:

- Development of an accurate HIV surveillance system;
- Allocation of prevention resources to prevent as many new infections as possible;
- Direction of prevention activities to HIV-infected individuals;
- Translation of prevention research findings into action;
- Investment in the development of new tools and technologies to expand HIV prevention efforts; and
- Increased efforts to overcome social barriers and to remove policy barriers that impede HIV prevention.¹⁸

In response to the report, the CDC released its "HIV Prevention Strategic Plan Through 2005." The plan highlights five goals for HIV prevention in the United States:

- Reduce the number of new HIV infections per year from an estimated 40,000 to 20,000 by 2005;
- Increase the proportion of HIV-infected people who know they are infected from the current 70 percent to 95 percent by 2005. This would be accomplished through voluntary counseling and testing;
- Increase the proportion of HIV-infected people who are linked to appropriate care and prevention and treatment services from the current 50 percent to 80 percent by 2005;

- Strengthen the capacity nationwide to monitor the epidemic, develop and implement effective HIV prevention interventions, and evaluate prevention programs by 2005; and
- Reduce HIV transmission and improve HIV/AIDS care and support through partnership with resource-constrained countries.¹⁹

Targeted Prevention Services

Because of the connection between heterosexual activity and HIV transmission to women, family planning clinics are a particularly promising site for HIV education and prevention. An estimated 33 million U.S. women are in need of contraceptive services and roughly half of them will receive those services from a publicly funded clinic.²⁰

Family planning clinics routinely provide a broad range of health services, including gynecological and breast examinations, Pap tests, STD and urinary tract infection testing and treatment, pregnancy testing, diabetes and high blood pressure screening, prenatal and well-baby care, and HIV testing. A majority of clinics also provide services to men, including condom distribution, STD testing and treatment, and HIV testing—making these clinics promising sites for educating men about the importance of using condoms to prevent HIV transmission. Additionally, seven out of ten clinics provides outreach and education programs designed to target adolescents.²¹

A number of family planning clinics provide HIV education and testing services, as well as outreach and education programs. Publicly funded family planning clinics account for one in four HIV tests and one in three visits are for other STD services.²² After adjusting for inflation, total public funding for family planning services decreased by 60 percent between 1980 and 1999.²³ Title X received a \$15 million increase in FY2001 and an \$11.1 million increase to \$265 million in FY2002.

NOTES

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International Women's Health

Every year, 515,000 women die from pregnancy-related causes; 98 percent of these deaths occur in developing countries.¹ Over the past decade, congressional action on international women's health has focused primarily on access to family planning services and the practice of female genital mutilation. More recently, action has focused on the global HIV/AIDS epidemic, particularly in Africa. While funding for international family planning programs has proven to be a major point of contention in both the House and Senate, legislation to authorize additional funding for HIV/AIDS education, prevention, and treatment was enacted by the 107th Congress.

HIV/AIDS

The *Journal of the American Medical Association* reports that worldwide, approximately one in every 100 adults aged 15-49 is infected with HIV/AIDS. In 2002, 2 million women worldwide were newly infected with HIV, and 19.2 million women were living with HIV worldwide. There were 3.2 million children under the age of 15 living with HIV.²

High infection rates in young, African women can be attributed to cultural taboos that prevent people from talking about sex, as well as a myth that sexual intercourse with a virgin will cure AIDS. The Joint United Nations Programme on HIV/AIDS (UNAIDS) reports that up to 80 percent of women aged 15-24, living in countries with generalized epidemics in Africa, have been shown to lack sufficient knowledge about HIV/AIDS.³ This lack of knowledge combined with the fact that young women and girls are more biologically prone to infection because the cervix is susceptible to lesions, helps to explain the vast degree of HIV/AIDS prevalence between girls and boys aged 15-19.⁴

HIV/AIDS is the leading cause of death in sub-Saharan Africa, where the rate of the disease accounts for 70 percent of all cases worldwide.⁵ In this region, women

account for 55 percent of adults infected with HIV.⁶ An estimated 800,000 children aged 15 and younger became infected with HIV in 2002.⁷ The World Health Organization reports that most of those cases were transmitted from mother to child.⁸

Life expectancy in Africa has dramatically dropped because of HIV/AIDS. Life expectancy in southern Africa rose from 44 years in the early 1950s to 49 in the early 1990s; however, it is expected to drop to just 45 between 2000 and 2010 because of AIDS.⁹ African economies and infrastructure are not prepared to deal with the vastness of the epidemic. According to UNAIDS, gender inequality is a driving force behind the HIV/AIDS epidemic, and the issue has to be addressed as agencies, governments, and service organizations respond to the problem.¹⁰

Congressional Action

The 107th Congress appropriated \$300 million for a global HIV/AIDS multilateral trust fund in FY2002. One-third of that amount was appropriated through the FY2001 emergency supplemental appropriations bill (P.L. 107-20); one-third through the FY2002 foreign operations appropriations bill (P.L. 107-115); and one-third through the FY2002 Labor, Health and Human Services, Education appropriations bill (P.L. 107-116). The FY2002 foreign operations bill also appropriated \$475 million for global HIV/AIDS initiatives.

Report language accompanying both the House-passed and Senate-passed FY2002 foreign operations appropriations bills (H.R. 4056) urged that the first priority for HIV/AIDS funding should be prevention programs. However, the Senate report noted that funding also should be used for treatment programs. Both reports urged the U.S. Agency for International Development (USAID) to provide at least \$15 million for microbicides research and development, and the

Senate report urged USAID's Women in Development Office to ensure that HIV/AIDS programs take into account the impact of the disease on women and girls.

The Senate committee-approved FY2003 foreign operations bill (S. 2779) also urged USAID to provide not less than \$18 million for microbicides research and development.

The House committee-approved FY2003 foreign operations bill (H.R. 5410) urged USAID to focus on three areas: mother-to-child transmission in conjunction with maternal health programs in affected communities, more extensive involvement in treatment programs for people living with HIV/AIDS, and higher funding levels for UNAIDS. The report noted that up to \$100 million should be made available for prevention of mother-to-child transmission and that \$15 million be made available for microbicides research.

International Family Planning

International family planning plays a significant role in stabilizing population growth and safeguarding reproductive health. In addition to contraceptive care, population assistance programs provide quality health care services and public health information.

In 2001, the world's population reached 6.1 billion, with an expected increase of 78 million people each year. The United Nations projects that the world's population could reach between 7.3 billion and 10.7 billion by the mid-21st century.¹¹

- Around the globe, it is estimated that more than 150 million men and women want to space or limit their families but lack access to family planning services.
- Fifty million abortions occur each year and about 20 million are performed illegally or in unsafe conditions, resulting in 78,000 maternal deaths.¹²
- One in every 65 women in developing countries will die from reproductive health-related causes, a rate 33 times higher than the risk to women in developed countries who face a one in 2,125 chance of dying.¹³

The United States began to emerge as an important contributor to international family planning more than three decades ago. In 1967, Congress amended the Foreign Assistance Act to include family planning activities overseas. Most U.S. population assistance is distributed in one of two ways. The first is through the USAID, a federal agency that provides funds to developing countries for economic and humanitarian purposes. A primary USAID goal is protecting the United States against global threats such as destabilizing population growth and environmental degradation. A second channel for U.S. funds is through contributions to the United Nations Population Fund (UNFPA), the largest multilateral family planning organization.

However, for more than a decade congressional debate around international family planning policy has been dominated by the issue of abortion. During the last two decades, Congress has voted to withhold funds from UNFPA because it is active in China, where a one-child population policy promoted coercive abortions. Funding for international family planning was further restricted by the Mexico City policy. Announced by the United States in 1984 at the U.N. International Conference on Population in Mexico City, the restrictions prohibited the United States from giving international family planning funds to private organizations that also provide abortion services. This policy was in place until 1993, when President Clinton reversed the restriction by executive order.

U.S. international family planning received a 35 percent funding cut from \$547 million in FY1995 to \$365 million in FY1996. Although supporters of the family planning program were successful at fending off efforts to restore the Mexico City policy, opponents of the program were able to impose new restrictions, including a 9-month freeze in funding after which time funds were allowed to trickle out over a 15-month period, with no more than 6.67 percent available in any one month.

During the next several years, abortion opponents sought to prohibit funding of organizations that use

their own funds to conduct abortion-related activities. With strong support from the Senate and the White House, the Mexico City policy was dropped in conference in FY1997, FY1998, and FY1999. Although international family planning programs received a modest increase from \$365 million in FY1996 to \$385 million in FY1997, funding restrictions were imposed and the programs remained level-funded through FY1999.

In FY1999, Congress eliminated the U.S. voluntary contribution to UNFPA due to controversy surrounding UNFPA's program in China. In past years, Congress approved the \$25 million contribution but placed restrictions on the money: no funds could be spent in China; U.S. funds had to be kept in a separate account; and the U.S. contribution was reduced dollar-for-dollar by the amount spent in China. In FY2000 and FY2001, Congress reinstated the \$25 million contribution to UNFPA with the funding restrictions; however, U.S. funding was reduced by \$5 million.

With the cooperation of the Clinton administration, Congress enacted a version of the Mexico City policy in FY2000. The restriction was written into both the FY2000 Commerce, Justice, State and Related Agencies appropriations bill (P.L. 106-113) and the FY2000 foreign operations appropriations bill (P.L. 106-113), which were included in an omnibus appropriations measure. Under the restriction, organizations that use their own money to perform abortions abroad or to lobby foreign governments on abortion policy were denied U.S. aid. Lobbying was broadly defined to include "any activity or effort to alter the laws or governmental policies of any country."

The President was allowed to waive the restriction, but by doing so, the total funds available for international family planning were reduced by 3 percent. Upon enactment, the President immediately exercised the waiver, reducing funding from \$385 million to \$372.5 million in FY2000. Additionally, the total funding made available to groups using their own funds to perform abortions abroad or to lobby on abortion policy was capped at \$15 million.

While the FY2001 foreign operations appropriations bill (P.L. 106-429) did not include the restriction, the FY2002 foreign operations appropriations bill (P.L. 107-115) included language that retained the Mexico City policy and allocated \$446 million for international family planning programs. In FY2002, Congress approved \$34 million for UNFPA; however, a 1986 law allows the President to withhold funds from any country or organization if the President certifies that the funds would be used for the performance of coerced abortions and involuntary sterilization. As a result of that provision, FY2002 funds were withheld. The same year, the Senate Foreign Relations Committee approved legislation (S. 367) that would have overturned the Mexico City policy; however, the House did not consider similar legislation.

Legislation

Saving Women's Lives through International Family Planning Act of 2001 (H.R. 361)—Reps. Carolyn Maloney (D-NY) and James Greenwood (R-PA)

H.R. 361 would authorize \$366 million for foreign assistance programs and environment programs dealing with health and population and \$541.6 million for international family planning programs.

United Nations Population Fund (UNFPA) Funding Act of 2001 (H.R. 1117)—Reps. Carolyn Maloney (D-NY) and Mark Kirk (R-IL)

H.R. 1117 would authorize \$35 million for the U.S. voluntary contribution to the UNFPA in FY2002 and \$50 million in FY2003 with certain limitations. The Secretary of State would be required to certify that the UNFPA program in China focuses on improving the delivery of voluntary family planning information and services; is designed in conformity with the International Conference on Population and Development; is implemented only in areas of China where all quotas and targets for the recruitment of program participants have been abolished; is carried out in consultation with UNFPA, is subject to regular, independent monitoring;

continued on next page

Legislation—continued

and suspends operations in areas where the program is found to be in violation of the guidelines. The U.S. contribution would be reduced dollar-for-dollar by any amount the UNFPA spends in China unless the Secretary of State can certify the conditions outlined in the bill.

Saving Women's Lives Act of 2002 (H.R. 3916)—Reps. Carolyn Maloney (D-NY) and James Greenwood (R-PA)

H.R. 3916 would authorize \$34 million for the U.S. voluntary contribution to the UNFPA in FY2002 and \$50 million in FY2003. The bill would prohibit the use of U.S. funds in China, would require the UNFPA to keep U.S. funds in a separate account, would require that the UNFPA not commingle U.S. funds with other funds, and would require that the UNFPA not fund abortions as a method of family planning.

Still Saving Women's Lives Act of 2002 (H.R. 5293)—Reps. Carolyn Maloney (D-NY) and Connie Morella (R-MD)

H.R. 5293 would require that funds appropriated to the UNFPA be released not more than 30 days after they are made available, unless the President certifies that UNFPA performs coercive abortions or involuntary sterilizations.

Female Genital Mutilation

Female genital mutilation (FGM)—sometimes called “female circumcision”—is the cutting of a female's genitals. FGM encompasses practices from the partial removal of the clitoris to infibulation, which involves the removal of all external genitalia and the stitching together of the vulva. It is estimated that between 100 and 140 million women worldwide have undergone some form of FGM and 2 million girls are at risk each year.¹⁴

FGM is usually performed with razor blades, scissors, or other crude tools—often without anesthetics, antiseptics, or antibiotics. Immediate complications of FGM include severe bleeding, shock, and infections (such as tetanus and septicemia) transmitted through the unsterilized instruments used. Long-term effects of

FGM include chronic pelvic infections, infertility, anemia, incontinence, and severe pain during urination, menstruation, sexual intercourse, and childbirth.¹⁵

The age at which FGM is performed varies among different ethnic groups and may be as early as infancy or as late as the time of a woman's first pregnancy. However, it is usually done between the ages of 4 and 10 as part of a coming-of-age ceremony. The reasons cited to justify FGM include purification, personal hygiene, protection of family honor, and prevention of promiscuity. Religion is another reason often given for the practice, but according to the WHO, no religious tradition requires FGM. Girls are taught FGM makes them marriageable, will increase the sexual pleasure of their future husbands, and is required for their acceptance into the community.¹⁶

FGM is most common in a band of 28 countries stretching across Africa, including Egypt, and in several Middle Eastern and Asian countries.¹⁷ As immigration from FGM-practicing countries to the West grows, the practice has been seen in Europe, Canada, Australia, and the United States.

Legislation aimed at criminalizing FGM in the United States became law on September 30, 1996. The criminalization provision was included in the Illegal Immigration Reform and Immigration Responsibility Act of 1996, which became law as part of the FY1997 omnibus appropriations bill (P.L. 104-208). The provision criminalizes FGM in the United States and imposes fines and up to five years' imprisonment for individuals found guilty of performing FGM on girls under the age of 18. The law also directs the Immigration and Naturalization Service (INS) to educate all immigrants who are issued visas on the health hazards of FGM and the legal consequences of performing the procedure in the United States. The Secretary of the Treasury also is required to identify countries that have traditionally practiced FGM and require the U.S. directors of the international financial institutions to actively oppose nonhumanitarian loans to those countries.

In a separate piece of legislation approved in April 1996 (P.L. 104-134), Congress directed the Secretary of Health and Human Services to conduct a study documenting the incidence of FGM in the United States and to engage in outreach and education efforts. Working from 1990 Census data, the Centers for Disease Control and Prevention determined that as of 1990 there were approximately 168,000 women and girls living in the United States who had either undergone the procedure or were at risk. Acknowledging that the study had several limitations, such as the inability to quantify the degree of acculturation, researchers conducting the study said that their numbers probably underrepresented the actual incidence of FGM in the United States.¹⁸

Although FGM was criminalized during the 104th Congress, the United States does not officially consider FGM a form of persecution and therefore it is not considered a sufficient reason to grant asylum. In light of several highly publicized cases involving African women who sought, or are seeking, asylum here rather than be subjected to FGM in their home countries, legislation is pending to include FGM among those forms of persecution for which asylum may be granted.

Congressional Action

The FY2001 foreign operations appropriations bill (P.L. 106-429) required the Secretary of State to determine the prevalence of the practice of FGM and the existence and enforcement of laws prohibiting this practice. Additionally, the Secretary is required to make recommendations on how the United States can work to eliminate FGM. Report language accompanying the bill directed the USAID to allocate \$1.5 million to develop and integrate educational programs aimed at eliminating FGM.

Legislation

Female Genital Mutilation Asylum Protection Act (H.R. 544)—Reps. Carolyn Maloney (D-NY) and Sue Kelly (R-NY)

H.R. 544 would require the Attorney General to issue regulations that set new standards for asylum seekers. The bill would expand the definition of "persecution" in the determination of an alien's eligibility for asylum to include gender-related persecution, such as female genital mutilation.

Global Action and Investments for New Success for Women and Girls Act of 2002 (H.R. 4114)—Reps. Connie Morella (R-MD) and Nita Lowey (D-NY)

H.R. 4114 would authorize increased U.S. assistance to programs aimed at advancing the status of women and girls in low-income countries worldwide. The bill included language urging that funds for programs addressing female genital mutilation be targeted toward certain local nongovernmental organizations.

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Mid-life and Older Women

Today, more than 40 million American women are over age 50.¹ Based on current life expectancies, women spend one-third of their lives in post-reproductive menopausal years. The health concerns of older women are different from those of younger women and older men.

- Breast cancer risk increases with age, with women aged 50 and older accounting for 77 percent of newly diagnosed cases and 84 percent of deaths.²
- One in two women aged 50 and over will have an osteoporosis-related fracture in their lifetimes.³
- Roughly 28 percent of women aged 45-64, and 40 percent of women aged 55-64, have arthritis.⁴
- Ten percent of women aged 45-64 has some form of heart disease; twenty-five percent of women aged 65 and older has heart disease.⁵

Although prevention programs and early detection screenings are available for a number of these health conditions, many women do not take advantage of them or their providers do not routinely offer such screenings. According to a Commonwealth Fund survey, women aged 65 and over receive less preventive care than women aged 45-64. Additionally, two-thirds of women aged 65 and over had a complete physical exam in the past year.⁶

Cost is often cited as a barrier to health care, particularly preventive care, for women of all ages. The effect of income on access to preventive care is of particular concern because so many older women have low incomes. In 2000, 12.2 percent of women aged 65 and over had incomes below the poverty level, compared with 7.5 percent of men the same age. The poverty rate is higher for several groups of elderly women—16.5 percent for widows, 23.1 percent for never-married women, and 20.3 percent for divorced women.⁷

However, even when cost barriers to preventive services are removed, lack of education about the benefits of these services remains a significant hurdle. Many older women believe that preventive services such as mammography and Pap tests are no longer needed. Many physicians stop recommending Pap tests for women over 65 who have a history of normal results, based on the false assumption that older women do not require testing because they are not sexually active. An *Obstetrics & Gynecology* study showed that while 25 percent of invasive cervical cancer occurs in women over 65, only 52 percent of women in this age group received a Pap test in the previous three years, and 25 percent had never received a Pap test.⁸ Further, older women lack knowledge about where to find quality health care facilities in their community or lack transportation to reach facilities outside the community.

Most efforts to increase access to care for poor women have focused on women of reproductive age. Care provided at most women's clinics primarily consists of family planning and prenatal care. As a result, large numbers of post-reproductive-aged women have fallen outside of the health care system.

In recent years, a growing awareness of mid-life and older women's health issues, and the fact that a disproportionate number of breast and cervical cancer deaths occur among low-income older women, has led to some progress. Since 1991, more than 3.5 million cancer screening tests have been provided by the Centers for Disease Control and Prevention (CDC) through the National Breast and Cervical Cancer Early Detection Program (NBCCEDP), which targets free screening services to underserved populations including low-income, minority, and older women.⁹

Additionally, as part of the NBCCEDP, the CDC operates the Well-Integrated Screening and Evaluation for Women Across the Nation (WISEWOMAN)

program to provide screening for cardiovascular diseases, as well as dietary and physical activity interventions for women with abnormal test results. These services are currently provided to eligible low-income and uninsured women aged 40-64. Funded at \$11.7 million in FY2002, the program supports 12 projects in 11 states and has screened more than 12,000 women aged 40-64.¹⁰

Access to screening for conditions such as breast and cervical cancer does not satisfy women's need for comprehensive care. Women of post-reproductive age need access to quality information, prevention, and treatment for conditions ranging from heart disease to osteoporosis. Older women require information on how lifestyle choices can affect a variety of health conditions, as well as access to providers who will respond to their unique health concerns.

In addition, conditions related to menopause can occur for up to ten years, and women whose daily activities are interrupted by these conditions should be informed about hormone replacement therapy (HRT) and other coping strategies. Between two-thirds and three-quarters of Caucasian women experience hot flashes for three to five years before they taper off. Other menopausal symptoms include irregular menstrual bleeding, night sweats, mood swings, depression, sleeplessness, vaginal dryness, and urinary tract infections.¹¹ These symptoms result from a natural decrease in the hormones estrogen and progesterone, which regulate the menstrual cycle. In many cases, doctors prescribe HRT—either as estrogen alone or as estrogen in combination with progesterone—in an effort to ease symptoms by restoring hormones to their premenopausal levels.¹²

Over the years, much controversy has surrounded HRT because conflicting studies have shown that it helps to address some health concerns (such as osteoporosis, menopausal symptoms, and colon cancer) for mid-life and older women while contributing to the development of others (breast cancer and heart disease).

In 1995, the Postmenopausal Estrogen/Progestin Interventions Trial found that both ERT and HRT

increased the level of HDL cholesterol, the “good” cholesterol.¹³ Additionally, the Nurses' Health Study found that ERT and HRT reduced the risk of death from heart disease and stroke. However, results from the Heart and Estrogen/Progestin Replacement Study (HERS), published in August 1998, found that the use of estrogen plus progestin in postmenopausal women with heart disease did not prevent further heart attacks or death from coronary disease.¹⁴ Additionally, there are other health risks associated with ERT, such as an increased risk of endometrial or uterine cancer, and an increased risk of blood clots and gall bladder disease.

In April 2000, researchers involved with the HERS trial announced that women who had been taking estrogen as part of the study were at a slightly higher risk for heart attacks and strokes. However, at that time, officials at the National Heart, Lung, and Blood Institute (NHLBI) at the National Institutes of Health (NIH) cautioned that the results did not address the long-term benefits and risks of HRT and should not influence current medical practice.¹⁵

An August 2000 study published in the *New England Journal of Medicine* found that the use of estrogen alone or estrogen plus progestin did not affect the progression of heart disease in women who already had the disease. The study suggested that “women should not use estrogen replacement with an expectation of cardiovascular benefit.”¹⁶

Other studies have shown a link between HRT and breast cancer risk.¹⁷ One study indicated that HRT combining estrogen and progestin (a synthetic form of progesterone) may increase this risk more than estrogen-only therapy.¹⁸ Another study found that women who used estrogen replacement therapy between the ages of 50 and 60 increased their risk of breast cancer over time by 23 percent. For women who used HRT combining estrogen and progestin for ten years, the risk increased by 67 percent.¹⁹

The most recent controversy came in July 2002, when the NHLBI halted an estrogen plus progestin study that was being conducted as part of the Women's

Health Initiative (WHI). Early results from the study showed that women taking HRT were at an increased risk of heart attacks, stroke, blood clots, and breast cancer.²⁰ The study also showed that there were benefits to HRT, including a reduced risk of hip fractures and colon cancer; however, researchers decided the harmful effects outweighed the benefits and stopped the study. The WHI did not examine the potential benefits of HRT in reducing menopausal symptoms, one of the main reasons many women use HRT.

The WHI consists of several other studies that are ongoing, including a study that is examining the effects of estrogen alone, a study examining the effects of estrogen in preventing Alzheimer's disease, a diet modification study, and an observational study.

The NIH held a menopausal hormone therapy workshop in October 2002 to discuss the study results, ongoing research and data analysis, as well as the prospects for future studies.²¹ Additionally, there are various non-hormonal strategies that are being studied for their effectiveness as alternatives to HRT.

The American College of Obstetricians and Gynecologists has stated that HRT is an "acceptable option for the treatment of menopausal symptoms in certain cases," but recommends that women consult with their physician to determine whether HRT is an appropriate treatment.²²

Congressional Action

During the 107th Congress, the Senate Health, Education, Labor, and Pensions Committee approved a bill pertaining to safe motherhood (S. 2328) that incorporated a number of other provisions, including legislation (S. 208) that would expand the WISEWOMAN program, sponsored by Sens. Bill Frist (R-TN) and Tom Harkin (D-IA).

Report language accompanying the Senate committee-approved FY2003 Labor, Health and Human Services, and Education appropriations bill (S. 2766) urged the NIH to continue its research on possible connections between HRT and stroke in women.

Legislation

WISEWOMAN Expansion Act of 2001 (S. 208/H.R. 633)—Sens. Bill Frist (R-TN) and Tom Harkin (D-IA) and Reps. Rosa DeLauro (D-CT) and Jim Leach (R-IA)

S. 208/H.R. 633 would expand the WISEWOMAN program by authorizing additional preventive services, including screenings for osteoporosis, health education and counseling, and referrals for medical treatment and follow-up services. S. 208 would authorize \$15 million in FY2002, \$20 million in FY2003, and \$25 million in FY2004, while H.R. 633 would authorize \$20 million in FY2002, \$25 million in FY2003, and \$30 million in FY2004. Both bills would limit additional funding for the WISEWOMAN program for a given fiscal year, unless at least \$173.9 million is spent on the National Breast and Cervical Cancer Early Detection Program in that fiscal year.

NOTES

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Osteoporosis

Over the course of a lifetime, bone is constantly being broken down and rebuilt in a process called bone remodeling. Until around age 30, more bone is created than is reabsorbed, and bone mass increases. As people get older, the balance shifts and more bone is broken down than is replaced. This happens to both men and women, but because women have less bone mass to start, the consequences for them tend to be more severe. In addition, the decline in estrogen levels at menopause causes bone to be lost at an accelerated rate, up to 20 percent a year in the five to seven years after menopause.¹

A leading cause of injury and disability among elderly women, osteoporosis is characterized by a thinning of the bones which makes them brittle and prone to fracture.

- An estimated 34 million Americans have low bone mass, which puts them at risk for osteoporosis, and 10 million Americans have osteoporosis.²
- Of those who have osteoporosis, 80 percent (eight million) are women.³
- One in two women aged 50 and over will have an osteoporosis-related fracture in her lifetime.⁴
- By the age of 20, the average woman has attained 98 percent of her skeletal mass.⁵

Osteoporosis causes 1.5 million fractures per year, mostly of the wrist, spine, ribs, and hip. Fractures can result from everyday activities such as bending to pick up a newspaper or lifting a bag of groceries. Spine fractures can lead to a loss of height, curvature of the spine, and chronic back pain. The rate of hip fractures is two to three times greater in women than in men, and a woman's risk of hip fracture is equal to her combined risk of breast, uterine, and ovarian cancer. Caucasian women aged 65 and older have twice as many fractures as African-American women in the same age group.⁶

According to the National Osteoporosis Foundation (NOF), the direct medical costs resulting from osteoporosis totaled \$17 billion in 2001. Without greater preventive efforts, the NOF warns, the cost of osteoporosis will continue to rise.⁷

Osteoporosis is a "silent" disease; most women do not know they are at risk until bone loss is quite advanced and a fracture occurs. Many women also are unaware that osteoporosis is largely preventable and can often be treated through a combination of lifestyle, dietary, and medical approaches. Participating in regular weight-bearing exercises such as walking or jogging, and eating a diet high in calcium and vitamin D (which helps the body absorb calcium) throughout life can help prevent osteoporosis although some bone loss will still occur. In menopausal years, this may not be enough.⁸

New Therapies

Several technologies exist for measuring bone density, which allow doctors to diagnose osteoporosis and determine treatment strategies. If osteoporosis is diagnosed, a number of treatments have been approved by the Food and Drug Administration for both the prevention and treatment of osteoporosis. Such treatments include calcitonin, a naturally occurring hormone that slows bone loss in women five years beyond menopause; estrogen replacement therapy, which has been found to reduce bone loss and increase bone density; alendronate, a drug that has been shown to reduce bone loss and increase bone density in post menopausal women; raloxifene, a Selective Estrogen Receptor Modulator that acts like estrogen in the bones and cardiovascular system but blocks estrogen's effects in the breasts and uterus; and Teriparatide, a recently approved injectable form of parathyroid hormone that has been shown to stimulate new bone formation and increase bone mineral density in postmenopausal women.⁹

Recently, researchers in Arkansas identified a new synthetic estrogen-like compound, Estren, that shows promise in protecting women from osteoporosis in the future. According to a recent article in *Science*, Estren was shown to successfully reverse and even restore bone mass in a study on animal models. The study indicated that Estren protected bone mass as well as estrogen without affecting the reproductive system.¹⁰

Congressional Action

Despite the recent approval of new drugs for the treatment and prevention of osteoporosis, more research is needed to expand the range of treatment options available to patients. Federal funding for osteoporosis research increased from \$60 million in 1991 to roughly \$140 million in 1999.

Congress established the Department of Defense (DoD) Osteoporosis and Related Bone Disease Research Program in 1994 with a \$5 million earmark. The program received \$2.8 million in FY2002. In FY2003, Congress appropriated \$50 million for peer-reviewed medical research, including bone-related diseases, at the DoD. The program is designed to foster innovative research on prevention, early detection and treatment of osteoporosis. In conjunction with the DoD program, a 1998 Institute of Medicine report, *Reducing Stress Fracture in Physically Active Military Women*, found that 10-20 percent of female recruits experienced a stress fracture during basic training compared to 5-10 percent of the male recruits.¹¹

In addition to funding through the National Institutes of Health (NIH) and the DoD, in FY2000, the Veterans Administration (VA) was appropriated \$13 million to research osteoporosis. However, no money was earmarked for osteoporosis research at the VA in FY2001 or in FY2002.

Research directed at developing low-cost screening and treatment options is particularly important. The relatively high cost of bone mass measurement (ranging from \$100 to \$350 depending on the test) may be an obstacle to wider use. In an attempt to provide

greater access to bone mass measurement, Congress mandated Medicare coverage of the test under the Balanced Budget Act of 1997 (P.L. 105-33). Under the law, Medicare is required to cover bone density testing every two years for high-risk women.

Education

The NIH Osteoporosis and Related Bone Diseases National Resource Center was established in 1994 with a grant from the National Institute of Arthritis and Musculoskeletal and Skin Diseases (NIAMS) at the NIH. The resource center was created to provide patients, health professionals, and the public with access to resources and information on metabolic bone diseases. The original four-year grant was renewed in 1998 and extended through 2003. The focus of the resource center is to increase awareness, knowledge, and understanding of prevention, early detection, and treatment of osteoporosis.

In FY1999, Congress earmarked \$3 million through the Public Health Service's Office on Women's Health (PHS-OWH) for a National Bone Health Campaign. The PHS-OWH has partnered with the NOF and the Centers for Disease Control and Prevention to implement the campaign. The first component of the campaign, which was launched early in 2001, features a website that focuses on promoting optimal bone health in adolescent girls.¹² Only 19 percent of girls aged 9-19 meet national guidelines for calcium intake, greatly increasing their risk for osteoporosis later in life.¹³ Additionally, the NIAMS supports an early intervention and prevention project called "Camp Calcium." The goal of the project is determine how much calcium growing girls need in their diets to develop strong bones.¹⁴

In March 2002, the President issued a proclamation declaring the years 2002-2011 as the National Bone and Joint Decade. The proclamation recognizes the importance of promoting healthy bones from childhood to adulthood and calls upon the medical community to pursue much-needed research in observance of this decade.

Recently, the Department of Health and Human Services' Administration on Aging (AoA) awarded \$300,000 in grants to three organizations, the Foundation for Osteoporosis Research and Education, the University of Maine, and the NOF, to develop an osteoporosis awareness campaign aimed at post-menopausal women. These organizations will pursue projects designed to assist the AoA in developing an action plan to educate and raise awareness of osteoporosis among older women.

NOTES

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Reproductive Health

The majority of Americans believe that unplanned pregnancy is a serious problem. When compared with other Western countries, the United States has one of the highest rates of unintended pregnancy. While abortion is one of this country's most divisive political issues, most people also agree that the number of abortions should be reduced.

- Forty-nine percent of all pregnancies in the United States are unplanned.¹ Of the 39 million women at risk of unplanned pregnancy, nine out of ten are using a contraceptive method. Forty-seven percent of unplanned pregnancies occur among the 7 percent of women at risk who do not use contraception.²
- Almost half of all unplanned pregnancies in this country end in abortion. Abortion rates are highest among women under age 25, unmarried women, poor women, and women of color. About 13,000 women have abortions each year as a result of rape or incest.³
- A woman who wants only two children will need to use contraception for at least 20 years of her life.⁴

Congressional Action

Congress cast an unprecedented 139 votes on reproductive rights issues between 1995 and 2002.⁵ Although most votes cast during this period sought to deny the use of government funds to pay for abortion, lawmakers also voted to criminalize a specific method of abortion and, in the House, to deny international family planning funds to organizations that use their own funds for abortion-related services, to prohibit the transportation of a minor across state lines to obtain an abortion, and to make it a federal crime to injure or kill an "unborn child."

The 107th Congress adopted riders to the FY2002 appropriations bills that restricted access to abortion for federal workers and their dependents, women in the military and the Peace Corps, women in federal prison, low-income women in the District of

Columbia, disabled women on Medicare, and low-income women on Medicaid.

In 1997, Congress voted to revise the existing Hyde amendment, which bars the use of federal Medicaid funds to pay for abortions for low-income women. The revised language seeks to make clear that the Hyde restriction also applies to Medicaid recipients who are placed in managed care plans. The 105th Congress also wrote the Hyde amendment into permanent law for the first time as part of a new program to provide health care coverage for uninsured children that was included in the Balanced Budget Act of 1997 (P.L. 105-33).

Since the 104th Congress, lawmakers have voted to outlaw "partial-birth" abortions. The measure was vetoed by President Clinton in 1996 and 1997 because it lacked an exception to protect the health of the woman. Additionally, on June 28, 2000, the U.S. Supreme Court struck down a Nebraska law that was modeled after the bills vetoed by President Clinton.

The 105th Congress successfully implemented contraceptive coverage for federal employees under the Federal Employees Health Benefits Program as part of the FY1999 Treasury, Postal Service, and General Government appropriations bill (P.L. 105-277). The provision has been renewed by the 106th and 107th Congresses in the FY2000, FY2001, and FY2002 Treasury-Postal Service spending bills.

Additionally, Title X, the federal family planning program, received a \$11.1 million increase to \$265 million in FY2002.

Since 1973, more than 1,000 bills dealing with reproductive choice have been introduced in Congress. The trend continued during the 107th Congress. For a listing of selected bills, please see Appendix II.

NOTES

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Sexually Transmitted Diseases

While the rates for some sexually transmitted diseases (STDs) have dramatically declined in recent years, other diseases continue to spread unabated.

- Currently, more than 65 million Americans live with an incurable STD, and an estimated 15 million new STD infections occur each year. Approximately, one-fourth of all new infections occur in teenagers.¹
- A teenage woman with a single exposure to an infected partner has a 1 percent risk of contracting HIV, a 30 percent risk of acquiring genital herpes, and a 50 percent risk of contracting gonorrhea.²
- The highest rates of gonorrhea in women are among adolescents aged 15-19.³
- Women infected with chlamydia or syphilis increase by three- to five-fold their risk of contracting HIV/AIDS.⁴

The long-term effects of STDs fall disproportionately on women and infants. If untreated, 20-40 percent of women infected with chlamydia and 10-40 percent of women infected with gonorrhea will develop pelvic inflammatory disease (PID). Among those women who develop PID, 20 percent will become infertile, 9 percent will have a potentially fatal ectopic pregnancy, and 18 percent will experience chronic pelvic pain.⁵ Women infected with some types of human papillomavirus (HPV) will develop cervical cancer.

Between 40 and 70 percent of pregnant women with active syphilis will give birth to an infected baby.⁶ In a pregnant woman, gonorrhea can result in blindness, joint infection, or a life-threatening blood infection in the baby.⁷ Infants born to women infected with chlamydia may suffer from an eye infection or pneumonia.⁸

In addition, racial and ethnic minorities are disproportionately affected by STDs. For some STDs, the reported rate can be as much as 30 times higher for African Americans than for Caucasians.⁹ In 2000, African

Americans and Hispanics accounted for 80 percent of AIDS cases in women, while they account for less than 25 percent of all women in the United States.¹⁰ Additionally, African Americans represented 75 percent of all reported gonorrhea cases in 2001.¹¹

Syphilis

The incidence of syphilis declined 88 percent from 1990 to 2000 to its lowest level since reporting began in 1941. In 2001, reported syphilis cases increased 2.1 percent. This increase was predominantly seen in men having sex with men; the syphilis rate for women declined from 1.7 cases per 100,000 to 1.4 during the same time period. Syphilis is concentrated primarily in the South, with 20 counties and one city accounting for 50 percent of all primary and secondary syphilis cases in 2001. Syphilis rates for African Americans were 16 times higher than the rate reported for Caucasians but still represented a decline from 1997 when the rate was 44 times higher.¹²

Chlamydia

Since 1994, chlamydial infections have represented the largest proportion of STDs reported to the Centers for Disease Control and Prevention (CDC). In 2001, reported chlamydial infections increased by 10.4 percent, with women disproportionately affected. Chlamydia rates among U.S. women were four times higher than for men, although this number reflects increased efforts to screen women.¹³ Women with chlamydia infections often do not have any noticeable symptoms; chlamydia can cause PID—a major cause of infertility—ectopic pregnancy, and chronic pelvic pain.¹⁴

Gonorrhea

Like chlamydial infection, gonorrhea is a major cause of PID. After a 74 percent reduction in the rate of reported cases of gonorrhea from 1975 to 1997, overall rates increased in 1998 and have remained relatively unchanged. While some of the increase

could be explained by expanded and improved screening, the increase also reflected a higher rate of new infections. Rates were highest in females aged 15-19.¹⁵ Often symptoms will not appear for several months and when they do, they are mild. However, untreated gonorrhea can result in PID, ectopic pregnancy, and inflammation of the joints.¹⁶

Genital Herpes

Over the last two decades, the number of Americans infected with genital herpes has increased 30 percent. Herpes simplex virus (HSV) causes herpes; HSV-type 2 (HSV-2) usually affects the genital area and is more common in women than men. An estimated one out of four women are infected with HSV-2. Women can experience painful genital lesions and increased risk for HIV transmission and infection. If infected during pregnancy, their infants can acquire potentially fatal neonatal infections. As is the case with many STDs, African Americans are disproportionately affected; however, the rate of new infections is increasing most among young Caucasian teens.¹⁷

Prevention and Screening

Because many infections have no noticeable symptoms and because there is such a stigma attached to STDs, most Americans underestimate their risk and often forgo testing.¹⁸ Approximately 70 percent of women with chlamydial infections and 50 percent with gonococcal infections experience no symptoms, and are diagnosed primarily through screening programs. In fact, many STDs can be effectively treated with antibiotics.¹⁹

A 1997 Institute of Medicine report concluded that an effective national STD prevention system does not exist. The report recommended the development of a national STD prevention system, employing four major strategies at the national, state, and local levels: addressing barriers to the adoption of healthy sexual behaviors; developing expanded investment, leadership, and information systems for STD prevention; establishing innovative STD-related services for adolescents and underserved populations; and providing high quality, accessible clinical services for STDs.²⁰ Since the report, a collaborative effort led by the CDC

has been launched to improve national STD prevention and treatment efforts, with a particular focus on eliminating syphilis from the United States.²¹

The geographic concentration and low rate of infection led to the development of the National Plan to Eliminate Syphilis from the United States, announced by former U.S. Surgeon General David Satcher in October 1999. The syphilis elimination plan includes five strategies: strengthened community involvement and partnerships; rapid outbreak response; enhanced surveillance; expanded clinical and laboratory services; and enhanced health promotion.²²

Begun in 1988 as a demonstration project, the CDC's chlamydia screening and prevalence monitoring effort has been steadily expanded. In locations where large screening programs have been in place for a number of years, their effectiveness has been demonstrated clearly. From 1988 to 2001, the screening programs in Pacific Northwest family planning clinics resulted in a decline in chlamydia rates of 59 percent among women aged 15-44.²³ Publicly funded family planning clinics also have become an important resource in STD screening. Sixty-four percent of Title X clinics routinely screen for chlamydia, while 54 percent routinely screen for gonorrhea.²⁴

Despite the effectiveness of such interventions, the program continues on a limited basis in most states. In addition, most men with chlamydia are not diagnosed and treated, since these programs have served only women. However, the expanded availability of a more sensitive urine test is resulting in greater testing rates among men.²⁵

In the late 1970s, a large-scale screening program for gonorrhea in women was implemented, which led to a steady decrease in gonorrhea rates for women and men during the 1980s and early 1990s. However, rates increased in 1998 and have remained steady since.²⁶

The National Institute of Allergy and Infectious Diseases at the National Institutes of Health (NIH) announced in 1999 the development of a behavioral intervention that was effective in reducing new cases

of chlamydia and gonorrhea among African-American and Mexican-American women who were being treated for a STD in San Antonio, Texas. About half the participants received in-depth group counseling to commit to behavior change and to learn the skills necessary to do so, including negotiating safer sex practices. The other women received standard individual counseling, usually for a one-time 15-minute session. The women who were part of the intervention had a 34 percent lower rate of chlamydia or gonorrhea than the control group at six months; a 49 percent lower rate between 6 and 12 months, and a 38 percent lower rate during the entire study.²⁷

While there is no cure for genital herpes, scientists recently announced the development of a vaccine to help prevent the infection in some women. Initial clinical trials found that the vaccine was about 70 percent effective in preventing genital herpes sores in women who had never had either form of the virus; however, there was no clear effect in men. In November 2002, the NIH began enrolling over 7,500 women for a much larger clinical trial to test the efficacy of the vaccine in preventing HSV-1 and HSV-2 in women.²⁸

A heightened effort also has been underway to increase research on the development of gels, foams, creams, or films, known as topical microbicides, that women could apply intravaginally before sex to prevent STD transmission.²⁹ As a woman-controlled method, microbicides would fill a gap in prevention strategies. The NIH funds topical microbicide research; however, many advocates believe the funding should be expanded.³⁰ Legislation (H.R. 2405/S. 1752) has been introduced to expand resources committed to microbicide research (see HIV/AIDS Research, p. 37).

Congressional Action

The FY2002 Labor, Health and Human Services, and Education appropriations bill (P.L. 106-117) included a \$24 million increase to \$1.1 billion for HIV/AIDS, STD, and tuberculosis prevention and control activities at the CDC. The Senate committee report included language recommending increased funding for the

chlamydia screening and syphilis elimination programs. Additionally, the Senate report language urged the CDC to work in collaboration with tribes, urban programs, and the Indian Health Service to develop a more effective strategy for the surveillance of HIV and STDs in American Indian, Alaska Native, and Native Hawaiian populations.

Report language accompanying the Senate committee-approved FY2003 Labor, Health and Human Services appropriations bill (S. 2766) recommended increased funding for the CDC's STD prevention programs, including infertility prevention and syphilis elimination. The increased funds would support expansion of chlamydia screening to reach underserved women.

Report language related to microbicide research was included with both the FY2002 and FY2003 bills (see HIV/AIDS Research, p. 37).

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Smoking

Tobacco use is a public health threat to all Americans, but women may be at greatest risk. Smoking-related illnesses and deaths among women continue to rise. In addition, much tobacco industry marketing has targeted women and, increasingly, girls.

Tobacco use is the leading preventable cause of death among women in the United States, accounting for approximately 178,000 deaths per year.¹ Lung cancer mortality rates for women who smoke are 12 times higher than for women who have never smoked.² More than 22 million adult women smoke.³ According to the National Center for Health Statistics, 21.1 percent of women aged 18 and over smoked cigarettes in 2000.⁴

The linkage between smoking, cardiovascular diseases, and cancer applies to both women and men, but there are other health risks from smoking that are unique to women. These include increased risks of cervical cancer, infertility, and osteoporosis.⁵

Maternal smoking also has been associated with multiple health problems in infants and children, including low birthweight, mental retardation, respiratory problems, and Sudden Infant Death Syndrome. Between 1989 and 2001, smoking during pregnancy declined from 38 to 12 percent of women giving birth. The highest rates of smoking during pregnancy were reported by teens aged 18-19 (19 percent), followed by women aged 20-24.⁶

Most alarming to health experts is the sharp rise in smoking among teenage girls. Currently, 1.5 million adolescent girls smoke cigarettes.⁷ Throughout the 1980s, smoking increased among girls under the age of 18, with the current rate equal to that of boys in the same age group.⁸ The smoking rate is higher among Native American and Caucasian girls and lowest among African-American and Asian-American girls. In 2000, 29.7 percent of high school senior girls reported smoking within the past 30 days.⁹ The

earlier a girl starts smoking, the more heavily she is likely to smoke as an adult.

Socioeconomic factors and educational goals seem to be related to smoking among girls. Smoking prevalence is nearly three times higher for women with 9 to 11 years of education compared to women with 16 or more years of education. Adolescents from low-income homes, particularly those headed by single parents, and whose parents or friends smoke are more likely to begin smoking.¹⁰

Media images publicized by the tobacco industry are thought to have a subtle yet pervasive effect on women's and girls' attitudes toward smoking. Tobacco advertising and promotion have specifically targeted women with appeals to beauty, glamour, independence, defiance, and weight control. This has been true throughout the 20th century and into the 21st century.

As early as 1920, a cigarette company urged women to reach for one of their cigarettes "rather than a sweet" in its advertisements. In the 1960s and 1970s, at a time when women's political power was beginning to grow, tobacco ads featured women suffragists lighting up cigarettes. Currently, many cigarettes specifically geared toward women are marketed under names such as "slim" and "lite."¹¹ Additionally, according to a tobacco company's internal memo, in the early 1990s, a new cigarette was launched and was marketed toward females aged 18-24 who have "no education, watch soap operas and attend tractor pulls." At a subsequent meeting of the Interagency Committee on Smoking and Health chaired by the U.S. Surgeon General, this marketing plan was called a "deliberate focus on young women of low socioeconomic status who are at high risk of pregnancy."¹²

According to a recent study, the tobacco industry has increased its media advertisements in an effort to recruit new customers, mainly teenagers.¹³ In late

1999, Philip Morris launched a new \$40 million “Find Your Voice” advertising campaign aimed specifically at minority women.¹⁴ As a result, the National Coalition FOR Women AGAINST Tobacco launched a counter campaign, “Our Voices are Loud and Clear Without Tobacco.” The campaign designs stickers for individuals to place across cigarette ads in magazines. Individuals can return the magazines to the publisher or to the tobacco company.¹⁵

Policymakers have taken a range of actions to halt the growth in smoking and limit its devastating impact on public health.

In 1999, the Centers for Disease Control and Prevention (CDC) launched the National Tobacco Control Program. The program spent an estimated \$103 million in FY2001 for comprehensive tobacco control efforts around the country. The CDC recommends four program goals: prevention of tobacco use in adolescents, promotion of cessation among adults and adolescent smokers, elimination of exposure to second-hand smoke, and identification and elimination of health disparities.¹⁶

In FY2001, the National Institutes of Health (NIH) spent \$448.3 million on smoking and health research. The NIH was expected to spend \$503.7 million on smoking research in FY2002.¹⁷

Congressional Action

The Food and Drug Administration (FDA) issued regulations in August 1996 aimed at reducing easy access to tobacco by children. The regulations included requirements of age verification for over-the-counter sales, prohibitions on free sample cigarette distribution, and several restrictions on the format and placement of cigarette advertising that might be seen by children.¹⁸ While Congress appropriated funding to the FDA for this program, in early 2000, the U.S. Supreme Court ruled that the FDA did not have the legal authority to regulate tobacco. Therefore, no money has been appropriated for the FDA program since FY2000.

Legislation

Medicare, Medicaid, and MCH Smoking Cessation Promotion Act (H.R. 1229)—Rep. Diana DeGette (D-CO)

H.R. 1229 would provide for coverage of smoking cessation programs under Medicare, Medicaid, and the Maternal and Child Health Block Grant.

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Veteran Women's Health

Women represent the fastest-growing group of new veterans, a trend that is expected to escalate as the presence of women in the military increases. According to the Department of Veterans Affairs (VA), there are roughly 1.4 million women veterans, making up approximately 5.5 percent of the veteran population. In addition, women currently represent roughly 15 percent of active duty military personnel.¹

With this growth has come increased attention to the unique health care needs of women veterans. The VA has long been criticized for its treatment of women veterans, particularly in its response to their health care needs. In 1982, the General Accounting Office (GAO) reported that VA facilities were not meeting the health care needs of women veterans.² Many women veterans did not even know they were eligible for VA medical services. In addition, the GAO found that many VA medical centers did not provide basic gynecological care like breast exams and Pap tests. The lack of privacy for women veterans also ranked as a major concern, with many hospitals lacking private toilet and bath facilities for women.

A decade later, the GAO conducted a second assessment, concluding that although progress had been made, a number of problems remained. Two problems identified by the GAO in its 1992 report were the sporadic availability of gender-specific cancer screening services for women at VA medical facilities and the failure to adequately monitor in-house mammography programs.³ These findings were particularly troublesome in light of a 1985 VA survey that found that the lifetime prevalence of cancer in women veterans was nearly twice that of the general adult female population, a trend that has held constant over the past decade.⁴

The mental health needs of women veterans also have been long overlooked. In fact, until recently, women were not considered to be at risk for post-traumatic

stress disorder because they were not involved in combat. This misconception has been refuted by several studies of Vietnam-era women, which documented serious mental health problems related to their wartime experiences.⁵ Experts also believe the Persian Gulf War experience may present some unique mental health issues for women. It was the first time in history that women with small children were deployed for wartime service.

Despite the passage of a 1992 law aimed at improving health care services for women veterans, problems in VA medical facilities were still reported. Specifically, women veterans reported a lack of patient privacy, a shortage of gynecologists that caused long waiting lists, a failure to provide routine cancer and osteoporosis screening, undertrained staff who were insensitive and inattentive to women's health needs, and limited outreach to women. In 1993, the VA Inspector General surveyed medical centers to determine how effectively they were meeting the needs of women veterans and to evaluate the scope of gender-specific services. Only one in eight of the health care facilities evaluated by the Inspector General met the VA's definition of comprehensive services for women veterans.⁶ A separate survey of all VA medical facilities found that nearly half of the sites (75 of 166) had no women's health clinic of any type.⁷

More recently, the VA Advisory Committee on Women Veterans issued a 2002 report with 24 recommendations dealing with a range of issues. Specifically, the report recommended:

- the creation or modification of services to provide specifically for the needs of women;
- staffing levels for women veterans coordinators positions;
- permanent removal of eligibility restrictions for sexual trauma counseling;

- the monitoring and analysis of services recently introduced by the VA to ensure that the services meet the demand;
- the development and distribution of guidelines for case management of homeless women veterans;
- an emphasis on the need for research to determine the success of health and benefits programs in meeting the needs of women veterans; and
- the need for research to assess the impact of the increasing number of women in the military.⁸

Congressional Action

Congress attempted to address some of these issues in 1992 with the passage of the Veterans Health Care Act (P.L. 102-585). In response to the increasing number of servicewomen reporting widespread sexual assault and harassment in the military, the bill authorized counseling services for women veterans who were sexually assaulted during active duty. The bill also authorized the VA to provide general reproductive health care, including Pap tests, breast exams, and mammography.

An ambitious effort to provide a broad package of primary and preventive health care services for women veterans died in the final days of the 103rd Congress after House and Senate conferees failed to resolve an abortion dispute. In the end, the only provisions to become law narrowly expanded counseling and treatment services for sexual trauma and required the VA to include women and minorities in clinical research and testing where possible.

During the 104th Congress, however, legislation was passed that required the VA to take three actions to improve the health of women veterans. First, the VA must implement mammography standards consistent with the Mammography Quality Standards Act of 1992 (P.L. 102-539) by accrediting and inspecting VA facilities that perform mammographies. Second, each VA medical facility must be surveyed to identify deficiencies relating to the personal privacy of women patients and to develop plans to correct those deficiencies. Finally, the Center for Women Veterans must assess the use of VA health services by women veterans (including counseling for sexual trauma and men-

tal health services) and identify barriers faced by women veterans seeking health services.

The 105th Congress reauthorized the sexual trauma counseling program through the year 2001 and made several minor changes to the program. The 106th Congress extended authorization for the program through December 31, 2004 (P.L. 106-117). Additionally, the 106th Congress enacted legislation (P.L. 106-413) to make women veterans eligible for a special monthly compensation award for the service-connected loss of one or both breasts, including a loss due to a modified mastectomy.

The 107th Congress clarified that provision when it enacted legislation (P.L. 107-330) stating that women who lost 25 percent or more of tissue from a single breast or both breasts in combination (including loss by mastectomy or partial mastectomy) or have received radiation treatment of breast tissue would qualify for the compensation.

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Women's Health Offices

The first office on women's health was established at the National Institutes of Health (NIH) in 1990. The Public Health Service (PHS) established an Office on Women's Health (OWH) the next year.

Today, each of the agencies that make up the PHS have either established an office on women's health, designated a women's health coordinator, or designated a women's health liaison. In addition to the NIH and the PHS, offices on women's health currently exist within the Centers for Disease Control and Prevention (CDC), the Food and Drug Administration (FDA), the Health Resources and Services Administration (HRSA), and the Substance Abuse and Mental Health Services Administration (SAMHSA). The Agency for Healthcare Research and Quality (AHRQ) has a women's health coordinator. The Indian Health Service and the Health Care Financing Administration have designated women's health liaisons. The only offices established by statute, however, are those at the NIH and SAMHSA.¹

Women's Health Offices

CDC-OWH: The CDC Office of Women's Health works to ensure that women's health needs are reflected in the agency's work. Priority issues include violence and injury, sexually transmitted diseases, including HIV/AIDS, tobacco use, older women's health, reproductive health, and breast and cervical cancer. The office also developed and distributed state-specific information on risk and prevention of cardiovascular diseases, violence against women, and sexually transmitted diseases.² In FY2002, the CDC spent roughly \$825 million on women's health programs and activities.³

FDA-OWH: The FDA Office of Women's Health works to ensure that the FDA is responsive to the needs of women in its regulatory and oversight functions and was funded at \$3 million in FY2002. The Office also "promotes an integrative and interactive approach" to

women's health issues within the FDA and works with partners outside the agency to further its objectives. The Office spearheaded "Women's Health: Take Time to Care," a three-year public awareness campaign about the safe use of medicines; the FDA-OWH and its partners distributed six million copies of the brochure, "My Medicines."⁴ In 2002, the campaign switched its focus to diabetes with the "Take Time to Care About Diabetes" campaign. Most recently, the office established a pregnancy registry website to provide information regarding the effects of medications on women during their pregnancy.⁵

HRSA-OWH: In keeping with its mission to expand primary and preventive health care services to underserved populations, the HRSA Office of Women's Health works to ensure that the health needs of women and girls are addressed across the lifespan. Some of the agency's priorities include the promotion of disease prevention and healthy living through the assistance of the Maternal and Child Health Block Grant; expanded access to primary health care services through its Community Health Centers; an initiative, *Bright Futures for Women's Health and Wellness*, aimed at increasing women's use of preventive services across their lifespan; increased participation of women and minorities in the health professions workforce; and a program, *Statewide Partnerships in Women's Health*, which encourages collaboration to develop coordinated health care services that meet the cultural, linguistic, and gender-specific needs of underserved women. In FY2002, HRSA allocated \$1.5 million for women's health services, health education, and community support.⁶

NIH-ORWH: The NIH Office of Research on Women's Health (ORWH) works both within the NIH and throughout the scientific community to accomplish its mandate to "strengthen, develop, and increase research into diseases, disorders, and conditions that affect women, determine gaps in knowledge about

such conditions and diseases, and establish a research agenda for the NIH for the future directions in women's health research; ensure that women are included as participants in NIH-supported research; and develop opportunities and support for recruitment, retention, reentry, and advancement of women in biomedical careers.”⁷ The office was funded at \$37.33 million in FY2002.⁸

The NIH-ORWH held a series of four meetings across the country in 1997 and 1998 to update the women's health research agenda at the NIH; this effort culminated in a 1999 report, “Agenda for Research on Women's Health for the 21st Century.” In FY2000, the NIH-ORWH established the Building Interdisciplinary Research Careers in Women's Health (BIRCWH) program, which trains researchers studying women's health.⁹ Grants for this program were renewed in 2002. Additionally, in October 2002, the office held a scientific workshop on menopausal hormone therapy.¹⁰

Each year, the office supports a broad range of women's health research projects. In FY2002, the NIH-ORWH supported research on aging, alcohol and substance abuse, cancer, cardiovascular disease, diabetes, endocrinology, eye disease, gastroenterology, genitourinary, HIV/AIDS, immunity/autoimmunity, infectious diseases, menopause, mental health, musculoskeletal systems, neurology, nutrition, obesity/overweight, pain, physical activity, reproductive health, and violence.¹¹

PHS-OWH: Through its collaborations with private organizations and public agencies, the PHS-OWH coordinates women's health initiatives across the federal agencies and within HHS. Some of its partnerships include: the HHS Coordinating Committee on Women's Health, the Collaborative Group on Women and HIV/AIDS, the Federal Interagency Working Group on Women's Health and the Environment, the Minority Women's Health Panel of Experts, the Healthy People 2010 Women's Health Working Group, the Organ and Tissue Donation Initiative, and the Female Genital Cutting Task Force.¹²

The office also sponsors a number of education and outreach initiatives, such as the Pick Your Path to Health Campaign, a cardiovascular education initiative, the National Bone Health Campaign, a lupus awareness project, and the BodyWise Eating Disorder Educational Campaign. The PHS-OWH also created and maintains the National Women's Health Information Center, the gateway to information from the federal government on women's health (1-800-994-woman or www.4woman.gov). A similar website for adolescent girls was recently launched as well (www.4girls.gov).¹³ The office was funded at \$26.82 million in FY2002.

SAMHSA-OWH: SAMHSA's Associate Administrator for Women's Services (AAWS) provides leadership, guidance, and coordination within the agency concerning women's substance abuse and mental health service needs. Additionally, the AAWS provides leadership in developing and implementing the agency's plans regarding women's priorities, including early intervention and treatment for women with addictive and mental health disorders, violence against women, HIV/AIDS and other sexually transmitted diseases, and community-based integrated services for children and families affected by substance abuse and mental illness. In FY2002, SAMHSA allocated \$448 million to its three Centers to conduct women's health programs throughout the agency.¹⁴

Women's Health Coordinator

AHRQ: The Agency's focus on the quality and outcomes of health care services is reflected in the women's health programs priorities. These include development of research examining male-female differences in the aggressiveness of treatment for women with cardiovascular disease, assessing the impact of race and age on access to treatments for breast cancer, and evaluating the costs and effectiveness of health care interventions for victims of domestic violence and sexual assault. AHRQ also reviews new screening technologies for cervical cancer and other preventive care services.¹⁵ AHRQ's women's health program was legislatively established

under the Office of Priority Populations Research when AHRQ was reauthorized in 1999 and was funded at \$345,00 in FY2002.¹⁶

Congressional Action

During the 107th Congress, an attempt was made to provide statutory authorization for all of the federal women's health offices. The House passed legislation (H.R. 1784) that would have provided statutory authority for women's health offices at the CDC, FDA, HRSA, and HHS. The House-passed bill would have authorized AHRQ to designate a women's health coordinator within the Office of Priority Populations.

The Senate Health, Education, Labor, and Pensions Committee included a similar bill (S. 946) in a larger women's health package (S. 2328) that was approved by the committee but never reached the Senate floor.

Legislation

Women's Health Office Act of 2002 (H.R. 1784/S. 946)—Reps. Connie Morella (R-MD) and Carolyn Maloney (D-NY) and Sens. Olympia Snowe (R-ME) and Barbara Mikulski (D-MD)

H.R. 1784/S. 946 would provide statutory authorization for women's health offices at the CDC, FDA, HRSA, AHRQ, and HHS.

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Part Three

Access to Health Care Coverage

Bone Mass Measurement

Osteoporosis, a disease characterized by weak, brittle bones, is a leading cause of injury and disability in older women. Eight million women are afflicted with the disease, which causes 1.5 million fractures annually.¹ The only accurate way to diagnose osteoporosis, predict future risk of fractures, and select the most appropriate treatment is through a bone mineral density (BMD) test or bone mass measurement.

Bone densitometry is often recommended for women at menopause who are trying to decide whether to start hormone replacement therapy because bone density loss is linked to a reduction in estrogen that occurs with menopause. Repeat BMD measurements can help monitor the amount of bone loss or evaluate the effectiveness of treatment over time.²

A variety of techniques for measuring bone density exist, including radiographic absorptiometry (RA), single photon and single x-ray absorptiometry (SPA/SXA), dual photon and dual energy x-ray absorptiometry (DEXA), peripheral dual x-ray absorptiometry (PDXA), quantitative computed tomography (QCT), and ultrasound.³ In addition to BMD tests, health care providers also assess a woman's risk for osteoporosis and fracture, as well as monitor therapy, using biochemical markers, which measure bone formation and resorption.⁴

A high degree of diagnostic accuracy makes DEXA one of the preferred methods of BMD today.⁵ DEXA uses small amounts of radiation (much lower than that of a chest x-ray or CT scan) to measure bone density in the spine, hip, wrist, or heel. The test is quick, painless, and reliable, and can detect even the earliest stages of bone loss.⁶

Bone mass measurement is now covered under Medicare. The Balanced Budget Act of 1997 (P.L. 105-33) included a provision that requires Medicare coverage of bone mass measurement every two years for those women aged 65 and over who are at high risk of developing osteoporosis, including estrogen-deficient women. The law also mandates coverage for individuals being monitored to determine their response to osteoporosis drug therapy.

Recently, the U.S. Preventive Services Task Force recommended that women aged 65 and over be routinely screened for osteoporosis. The task force also recommended that routine screening for high-risk women begin at age 60.⁷

Additionally, under the Balanced Budget Refinement Act of 1999 (P.L. 106-113), Medicare was required to establish a new system to classify and pay for tests performed in an outpatient setting. The final rule, which went into effect on January 1, 2001, classified all BMD tests under "new technology" services and separated them into two categories, central and peripheral bone density tests, which are reimbursed at different rates. For example, a DEXA exam, a more costly test which typically measures central sites such as the hip and the spine, is reimbursed at a rate of \$76.88. A PDXA exam, which is less costly and typically measures peripheral sites such as the wrist, finger, and heel, is reimbursed at a rate of \$25.79. The reimbursement rate only covers the technical portion of the tests, and Medicare patients are responsible for a 20 percent copayment.⁸

Legislation

Osteoporosis Federal Employees Health Benefits Standardization Act of 2001 (S. 263/H.R. 689)—Sens. Olympia Snowe (R-ME) and Robert Torricelli (D-NJ) and Reps. Connie Morella (R-MD) and Ken Bentsen (D-TX)

S. 263/H.R. 689 would prohibit the Federal Employees Health Benefits Program from contracting with a plan that does not include coverage for bone mass measurement.

Medicare Osteoporosis Measurement Act of 2001 (S. 264/ H.R. 595)—Sens. Olympia Snowe (R-ME) and Robert Torricelli (D-NJ) and Reps. Connie Morella (R-MD) and Shelley Berkley (D-NV)

S. 264/H.R. 595 would expand Medicare coverage of bone mass measurement to all individuals at clinical risk of osteoporosis.

Osteoporosis Early Detection and Prevention Act of 2001/Early Detection and Prevention of Osteoporosis and Bone Related Disease Act of 2001 (H.R. 1683/S. 819)—Reps. Carolyn Maloney (D-NY) and Connie Morella (R-MD) and Sens. Robert Torricelli (D-NJ) and Olympia Snowe (R-ME)

H.R. 1683/S. 819 would require group and individual health insurance plans to cover a bone mass measurement test for certain individuals who are at risk of developing osteoporosis.

Improved Access to Osteoporosis Testing Act of 2001 (H.R. 1720/S. 826)—Rep. John Lewis (D-GA) and Sen. Blanche Lincoln (D-AR)

H.R. 1720/S. 826 would eliminate the cost-sharing for bone mass measurement tests under Medicare.

NOTES

- 1 National Osteoporosis Foundation (NOF), "Osteoporosis Facts" <<http://www.nof.org/osteoporosis/stats.htm>> (12/3/02).
- 2 NOF, "Osteoporosis: Bone Mass Measurement" <<http://www.nof.org/osteoporosis/bonemass.htm>> (12/3/02).
- 3 Ibid.
- 4 Christine Simonelli, M.D., "Practical Issues in Bone Mineral Density Testing," *Journal of the American Medical Women's Association* 55 (Summer 2000) 4: 228-233.
- 5 Agency for Healthcare Research and Quality (AHRQ), "Task Force Urges Routine Osteoporosis Screening for Women 65 and Older to Identify Those at Risk for Fracture" (press release, Sept. 16, 2002).
- 6 NOF, "Osteoporosis: Bone Mass Measurement."
- 7 AHRQ, "Task Force Urges Routine Osteoporosis Screening for Women 65 and Older to Identify Those at Risk for Fracture."
- 8 NOF, "Legislative Alert: Action Needed on Final Rule for Ambulatory Payment Classes," May 2000 <<http://www.nof.org/advocacy/legalerts/hcfaalertMay00.htm>> (12/11/02).

Breast and Cervical Cancer Treatment

The National Breast and Cervical Cancer Early Detection Program (NBCCEDP) was created by Congress in 1990 under the Breast and Cervical Cancer Mortality Prevention Act (P.L. 101-354). Administered by the Centers for Disease Control and Prevention (CDC), the program was designed to provide screening for breast and cervical cancer to underinsured and uninsured women.

Since the NBCCEDP's inception, it has served over 1.5 million women, diagnosing over 9,000 breast cancers, 48,170 pre-cancerous lesions, and over 831 cervical cancers. The program is funded at \$192.6 million in FY2002 and reaches roughly 18 percent of the women eligible for screening. Currently, the NBCCEDP operates in all 50 states, 6 territories, the District of Columbia, and 14 American Indian/Alaska Native organizations.¹

Despite the program's success, women's health advocates argued that some women diagnosed under the program were not receiving timely follow-up and treatment. Although states created extensive networks through which women were referred to treatment, these systems were tenuous and frequently disconnected. Treatment was often provided by physicians, hospitals, or managed care organizations on donated time or at a reduced cost.

Congressional Action

In an effort to remedy these problems, the 106th Congress enacted legislation (P.L. 106-354) to provide treatment to women diagnosed under the program. The law gives states the option of providing Medicaid coverage to women diagnosed with breast or cervical cancer under the NBCCEDP. The law provides an enhanced federal match identical to the match provided under the State Children's Health Insurance Program, which ranges from 65 to 83.76 percent, depending upon the state. According to the Department of Health and Human Services, to qualify

for Medicaid coverage under the federal program, women must be under the age of 65, not eligible for Medicaid, and without health coverage. To date, 48 states have been approved to expand their Medicaid eligibility to treat women diagnosed with breast or cervical cancer.²

While states have embraced the new law, budget deficits may force states to cut back Medicaid services and/or eligibility. Most recently, the Texas state legislature approved the state's participation in the federal program and allotted \$1.2 million for the program with the stipulation that the funding would be allocated only if extra money could be found in the state budget. No funding was allocated in the 2002-2003 budget cycle, and Texas is one of 14 states that has been approved for the program but has not implemented it.³

During the 107th Congress, legislation (P.L. 107-121) was enacted to clarify that Indian women who are diagnosed with breast or cervical cancer and are eligible for health care services through the Indian Health Service or a tribal organization be included among the women eligible for expanded Medicaid coverage for their treatment.

NOTES

- 1 Centers for Disease Control and Prevention (CDC), "The National Breast and Cervical Cancer Early Detection Program" (fact sheet, 2002).
- 2 Department of Health and Human Services, "HHS Approves Kentucky Plan to Insure Women with Breast or Cervical Cancer" (press release, Nov. 13, 2002).
- 3 Kaiser Daily Health Policy Report, "Texas Breast and Cervical Cancer Treatment Program Put on Hold Due to Lack of Funds," March 26, 2002.

Clinical Trials

For many years, research on women's health focused primarily on reproductive functions, with information on other health issues affecting women often derived by extrapolation from studies of men. Women have been greatly underrepresented in clinical research, which uses human subjects to translate discoveries in basic science into advances in medicine. Research on coronary heart disease, kidney transplants, alcoholism, tobacco use, and HIV/AIDS, until recently, has been particularly notable for its exclusion of women from clinical trials.

In 1986, the National Institutes of Health (NIH) adopted a policy of encouraging the inclusion of women in clinical trials; however, a 1990 General Accounting Office (GAO) report found that little had been done to implement that policy.¹ That report was requested by Rep. Henry Waxman (D-CA) and the co-chairs of the Congressional Caucus for Women's Issues (CCWI), Reps. Pat Schroeder (D-CO) and Olympia Snowe (R-ME). Additionally, the CCWI introduced the Women's Health Equity Act, which included a provision to establish an Office of Research on Women's Health at the NIH.

As a result, the NIH in September 1990 announced the creation of the NIH Office of Research on Women's Health (NIH-ORWH), which would oversee and coordinate the inclusion of women in clinical trials. In 1993, Congress enacted the NIH Revitalization Act (P.L. 103-43), which established guidelines on the inclusion of women and minorities in clinical trials and established the office in statute.

Ten years after its initial report, the GAO examined the NIH's progress and found that while the NIH had made significant advances in the inclusion of women and minorities in clinical trials, the data from those trials was not being analyzed to reflect sex and gender differences.² The NIH-ORWH responded to the GAO report by creating an NIH-wide Tracking and

Inclusion Committee to specifically oversee the adherence to the 1993 guidelines on the inclusion of women and minorities in clinical trials. NIH guidelines were updated and posted on the NIH website and a new condition of award statement was developed and applied to awards made after October 1, 2000 indicating that analyses must be conducted by sex/gender and/or racial/ethnic groups. The NIH also has conducted a number of training sessions for NIH program and review officials, grants and contract management staff, and current and prospective researchers. In addition, the NIH has been conducting outreach to the scientific community regarding the inclusion of women and minorities in clinical trials.³

In December 2002, the committee released its report detailing data from FY1999 and FY2000. According to the report, more than 95 percent of applications submitted for review met the inclusion requirements. Of those selected for funding, more than 96 percent met the inclusion criteria as submitted.⁴

Another GAO report, issued in July 2001, found that women are sufficiently represented in clinical drug trials; however, the report also found that the Food and Drug Administration needed to improve its oversight of these trials, particularly as it related to the presentation and analysis of data related to sex differences in drug development.⁵

Reimbursement Issues

Broad agreement exists among academic health centers, researchers, and managed care plans that insurers should not be responsible for the research costs of patients enrolled in clinical trials—extra tests, experimental treatment, hospitalization, or outpatient care that patients receive only because they are required by study protocols.⁶ However, the National Center for Research Resources at the NIH and many researchers contend that insurers should pay the normal clinical costs for Category B patients

regardless of the phase of the trial in which they are enrolled, since these costs would be incurred even if the patients were not participating in clinical trials. Category B patients are research participants who have an underlying illness and are hospitalized or are receiving outpatient care for medically necessary reasons—not simply because they are enrolled in a clinical trial.⁷

A 1999 GAO report found that health insurance policies generally exclude coverage for clinical trials, although some exceptions are made on a case-by-case basis. Insurers also reported wide variations in the way they review cases for approved clinical trial coverage.⁸

On June 7, 2000, President Clinton issued an executive memorandum directing the Medicare program to reimburse providers for the cost of routine care associated with participation in clinical trials. The executive memorandum also directs the Medicare program to promote the participation of Medicare beneficiaries in clinical trials. This coverage went into effect on September 19, 2000 and remains in place.⁹

Congressional Action

During the 107th Congress, both the House and Senate passed legislation that would have provided additional protections to patients in managed care plans while allowing those individuals to sue their health plans for denial of coverage. Both bills contained provisions that would have required health plans to cover routine patient costs associated with individuals participating in federally approved clinical trials; however, the legislation languished in a House-Senate conference for over a year.

Legislation

Improved Patient Access to Clinical Studies Act of 2001 (S. 257)—Sen. Olympia Snowe (R-ME)

S. 257 would prohibit health plans from discriminating against enrollees who are participating in clinical research studies. Specifically, plans would be prohibited from denying, limiting, or imposing additional conditions on the coverage of items or services for persons enrolled in approved clinical studies, as long as those items and services would otherwise be covered under the plan.

Access to Cancer Clinical Trials Act of 2001 (H.R. 967)—Reps. Deborah Pryce (R-OH) and Carolyn Maloney (D-NY)

H.R. 967 would require group and individual health plans to provide coverage for individuals participating in approved cancer clinical trials.

NOTES

- 1 General Accounting Office (GAO), *NIH: Problems on Implementing Policy on Women in Study Populations* (Washington: Government Printing Office, 1990).
- 2 GAO, *Women's Health: NIH Has Increased Efforts to Include Women In Research* (Washington: Government Printing Office, 2000).
- 3 National Institutes of Health, "Monitoring Adherence to the NIH Policy on the Inclusion of Women and Minorities as Subjects in Clinical Research: Comprehensive Report" (Fiscal Year 1999 & 2000 Tracking Data) <<http://www4.od.nih.gov/orwh/blue rpt.pdf>> (12/30/02).
- 4 Ibid.
- 5 GAO, *Women's Health: Women Sufficiently Represented in New Drug Testing, but FDA Oversight Needs Improvement* (Washington: Government Printing Office, 2001).
- 6 The Public Health Service, "The Impact of Managed Care on Clinical Research: A Preliminary Investigation," Jan. 1996 <<http://www.ncrr.nih.gov/clinical/crpublic.htm>> (8/10/00).
- 7 National Center for Research Resources at the National Institutes of Health, "NCCR Reporter," May/June 1996.
- 8 GAO, *NIH Clinical Trials: Various Factors Affect Patient Participation* (Washington: Government Printing Office, 1999).
- 9 Centers for Medicare and Medicaid Services, "National Coverage Determinants: Routine Costs in Clinical Trials" <<http://www.cms.gov/ncd>> (12/10/02).

Contraceptive Drugs and Services

Access to contraceptives is a crucial determinant of women's health. Contraceptive use prevents millions of abortions and unplanned births in the United States each year, yet prescription contraceptive devices and services are not routinely covered by most private health plans. This omission places some women at an economic disadvantage and poses health risks for them and their families.

Traditional indemnity (or fee-for-service) health care plans have generally covered medically necessary diagnostic and treatment services but not those services characterized as preventive in nature. These are the health plans least likely to provide contraceptive coverage.

The growth of managed care has expanded coverage of contraceptive services, but the majority of plans still do not cover all of the most commonly used contraceptives. Some types of managed care plans, such as preferred provider organizations (PPOs) and point of service (POS) plans, are considerably less likely to offer contraceptive coverage than are health maintenance organizations (HMOs). According to the Alan Guttmacher Institute:

- Half of all indemnity plans and PPOs, 20 percent of POS networks, and 7 percent of HMOs cover no reversible forms of contraception. However, the majority of indemnity plans and HMOs cover both surgical abortions and sterilization.
- Fifteen percent of indemnity plans and PPOs and less than 40 percent of HMOs or POS networks routinely allow women to choose from the five most commonly used reversible contraceptive methods (oral contraceptives, the IUD, diaphragm, Norplant, and Depo Provera).
- Although 97 percent of indemnity plans cover prescription drugs in general, only 33 percent include oral contraceptives in that coverage. The vast majority of HMOs that cover prescription drugs include coverage of oral contraceptives.¹

Additionally, prior to the enactment of contraceptive coverage under the Federal Employees Health Benefits Program (FEHBP), 81 percent of participating plans did not cover all five methods of reversible contraception, and 10 percent of the plans did not cover any reversible forms of contraception.²

A more recent employer survey by the Kaiser Family Foundation/Hospital Research and Educational Trust found that 42 percent of individuals enrolled in indemnity plans had contraceptive coverage, compared to 76 percent of individuals in PPOs, 80 percent of individuals in POS plans, and 85 percent of individuals in HMOs.³

One important consequence of the lack of contraceptive coverage is that women spend more out-of-pocket for health care services than men. It is estimated that women spend 68 percent more in out-of-pocket health care costs than men.⁴

A 1998 Kaiser Family Foundation study found that three-quarters of Americans support legislation to require contraceptive coverage, with 78 percent of women expressing support for such policies compared to 66 percent of men. Additionally, 73 percent of those surveyed said that they would support contraceptive coverage even if it raises their insurance premiums by \$1 to \$5 per month. Eighty-two percent of those surveyed believe that contraceptive coverage should include all FDA-approved methods.⁵

A 1998 study by the Alan Guttmacher Institute found that the addition of contraceptive coverage to a health plan would cost \$21.40 per year per employee. Of that amount, employers would be responsible for \$17.12 and employees would be responsible for \$4.28. The cost of adding contraceptive coverage would result in an increase of less than 1 percent in employers' costs.⁶

The Washington Business Group on Health estimated that the total costs (direct and indirect) to an employer of not providing contraceptive coverage were 17 percent higher than if the benefit were provided, and the direct costs were 14 percent higher.⁷

In addition to the cost-effective nature of contraceptive coverage, family planning provides a significant health benefit for women as well. By helping women to adequately space their families, contraceptives contribute to healthier pregnancies and births. They also reduce rates of maternal complications, low birthweights, and infant mortality.

As of 2002, 20 states had enacted legislation requiring health insurance plans to cover prescription contraceptives if they also cover other prescription drugs; however, the range of services covered varies.⁸

In December 2000, the Equal Employment Opportunity Commission (EEOC) ruled that it was unlawful for an employer to exclude coverage for prescription contraceptives when it provided coverage for other prescription drugs and services. The EEOC determined that exclusion of such coverage violated Title VII of the Civil Rights Act of 1964, as amended by the Pregnancy Discrimination Act (PDA), which requires equal treatment of women “affected by pregnancy, childbirth, or related medical conditions.” In 1991, the U.S. Supreme Court determined that the PDA prohibits discrimination based on a woman’s ability to get pregnant, as well as the pregnancy itself.⁹ As such, the EEOC determined that the exclusion of contraceptive coverage constituted “prohibited sex discrimination since prescription contraceptives are available only for women.”¹⁰

Congressional Action

After a protracted battle, the 105th Congress enacted legislation to require plans participating in the Federal Employees Health Benefits Program to cover prescription contraceptives if they also cover other prescription drugs. The provision was included in the FY1999 Treasury, Postal Service, and General Government appropriations bill (P.L. 105-277). The 106th Congress renewed the provision during the

FY2000 and FY2001 appropriations process, and the 107th Congress renewed the provision during the FY2002 appropriations process.

Additionally, during the 107th Congress, language was included in the Senate-passed District of Columbia appropriations bill (H. J. Res. 2) allowing the District to enact contraceptive coverage legislation; however, the bill also stated that “it is the intent of Congress that any legislation enacted on such an issue should include a ‘conscience clause’ which provides exceptions for religious beliefs and moral convictions.”

During the first session of the 107th Congress, the Senate Health, Education, Labor, and Pensions Committee held a hearing on contraceptive equity legislation (S. 104).

Legislation

Equity in Prescription Insurance and Contraceptive Coverage Act (S. 104 /H.R. 1111)—Sens. Olympia Snowe (R-ME) and Harry Reid (D-NV) and Reps. James Greenwood (R-PA) and Nita Lowey (D-NY)

S. 104/H.R. 1111 would require health insurance plans that already cover prescription drugs to cover FDA-approved prescription contraceptives and devices. It also would require plans that cover basic health care services to also cover medical and counseling services to promote the effective use of those contraceptives.

NOTES

- 1 Rachel Benson Gold, "The Need for and Cost of Mandating Private Insurance Coverage of Contraceptives," *The Guttmacher Report on Public Policy* 1 (Aug. 1998) 4 <<http://www.guttmacher.org/pubs/journals/gr010405.html>> (1/10/03).
- 2 Marcia Greenberger of the National Women's Law Center (NWLC), testimony before the Senate Health, Education, Labor, and Pensions Committee, Sept. 10, 2001, p. 2.
- 3 The Henry J. Kaiser Family Foundation (KFF) and Health Research and Educational Trust (HRET), *Employer Health Benefits: 2002 Annual Survey* (Menlo Park: KFF and HRET, Sep. 2002), p. 109.
- 4 NWLC, "Contraceptive Coverage: A Multi-Track Approach" (fact sheet, Oct. 2002).
- 5 KFF, *National Survey on Insurance Coverage of Contraceptives* (Menlo Park: KFF, 1998).
- 6 Jacqueline Darroch, "Cost to Employer Health Plans of Covering Contraceptives: Summary, Methodology and Background," June 1998 <http://www.guttmacher.org/pubs/kaiser_0698.html> (1/10/03).
- 7 Rowena Bonoan, M.P.H. and Julianna S. Gonen, Ph.D., "Promoting Healthy Pregnancies: Counseling and Contraception as the First Step," *Family Health In Brief* 3 (Aug. 2000): 6.
- 8 The Alan Guttmacher Institute, "Twenty States Now Require Contraceptive Insurance Coverage," *The Guttmacher Report on Public Policy*, 5 (Aug. 2002) 3: 13.
- 9 Equal Employment Opportunity Commission (EEOC), "Decision on Coverage of Contraception" <<http://www.eeoc.gov/docs/decision-contraception.html>> (1/10/03).
- 10 EEOC, "EEOC Issues Decision on Two Charges Challenging the Denial of Health Insurance Coverage for Prescription Contraceptives" (press release, Dec. 13, 2000).

Family Caregivers/Long-term Care

Family caregivers are those who have primary responsibility for a relative who—due to physical or mental limitations—is dependent upon others for assistance with daily activities. Caregivers assist with tasks such as bathing, grooming, eating, meal preparation, housework, running errands, and administering prescriptions and other medical care. An estimated 52 million Americans are informal caregivers.¹

Most often, caregivers are unpaid family members who provide care on a long-term basis. Caregiving responsibilities disproportionately fall upon women. In fact, 7 out of 10 unpaid caregivers are women.² According to the Older Women's League (OWL), the typical informal caregiver is a married woman who is employed full-time and spends an average of 18 hours per week providing caregiving. Additionally, between 20 and 40 percent of caregivers are deemed members of the “sandwich generation” because they are caring for children under the age of 18 at the same time that they are caring for an elderly relative.³

Many individuals, particularly the elderly, rely on family members because it is determined that they do not require “skilled” care and therefore do not qualify for Medicare home health care benefits. The General Accounting Office found that 60 percent of disabled elderly individuals relied on unpaid caregiving.⁴

Although caregiving is not considered “skilled” care, the responsibilities often can exceed those of a full-time job. OWL estimates that caregivers lose an average of \$550,000 in total wages and \$2,100 in Social Security benefits as a result of their caregiving.⁵ Additionally, family caregivers contribute significantly to the American health care system. A study published in the March/April 1999 issue of *Health Affairs Magazine* found that family caregivers provide \$196 billion in services annually. Comparatively, \$32 billion is spent on private home health providers and \$83 billion is spent on nursing home care.⁶

Many of the personal costs to family caregivers are not quantified. One-third of caregivers consider their health to be fair or poor.⁷ Research has shown an increased likelihood of depression and anxiety among caregivers seeking to balance a variety of responsibilities. Chances for physical injury also are increased. In fact, 44 percent of informal caregivers report physical strain as a result of their caregiving duties. Additionally, as women live an average of seven years longer than men, they often require long-term care themselves. Three-quarters of nursing home residents aged 65 and older are women, and two-thirds of home health care users are women.⁸

Congress has endeavored to provide some assistance for family caregivers. For instance, under the Health Insurance Portability and Accountability Act of 1996 (P.L. 104-191), taxpayers who itemize their deductions can deduct certain expenses related to long-term caregiving if those expenses and other medical costs combined exceed 7.5 percent of the taxpayer's adjusted gross income.⁹

In addition, a caregiver can claim an elderly relative as a dependent and claim a personal exemption if a range of criteria is met. The caregiver and the recipient of care must live in the same home, the caregiver must provide at least 50 percent of the financial support for the relative, and the annual income of the care receiver cannot exceed the personal exemption amount, which is about \$3,000. As many elderly individuals receive Social Security and pension benefits in excess of that amount, few can be claimed as dependents.¹⁰

Congressional Action

The 106th Congress enacted legislation (P.L. 106-265) designed to assist federal and military employees and retirees with the purchase of long-term care insurance. The law allows federal and military employees and retirees to purchase long-term care insurance at

group rates, which usually are significantly lower than the rates for individually-purchased plans. Long-term care insurance policies can be purchased to help cover a range of situations, including private in-home nursing care, family caregivers, and assisted living facilities. The Office of Personnel Management (OPM) is authorized to negotiate with long-term care insurers for benefits, in much the same way that OPM currently negotiates with health insurers on behalf of workers enrolled in the Federal Employees Health Benefits Program.

The 106th Congress also enacted legislation (P.L. 106-501) to reauthorize the Older Americans Act. Included in that bill was a provision to establish the National Family Caregivers Support Program. The National Family Caregivers Support Program received a \$16.5 million increase in FY2002 to \$141.5 million.

Additionally, the Senate Health, Labor, and Pensions Committee approved legislation (S. 2489) designed to provide assistance to family caregivers. Sponsored by Sens. Hillary Rodham Clinton (D-NY) and Olympia Snowe (R-ME), the bill would provide lifespan respite care grants and cooperative agreements to expand and enhance respite services to family caregivers.

Several Senate committees held hearings during the 107th Congress to discuss the challenges facing family caregivers, as well as the National Family Caregivers Support Program.

Legislation

Lifespan Respite Care Act of 2002 (S. 2489/H.R. 5241)—Sens. Hillary Rodham Clinton (D-NY) and Olympia Snowe (R-ME) and Reps. James Langevin (D-RI) and James Greenwood (R-PA)

S. 2489/H.R. 5241 would authorize lifespan respite grants at \$90.5 million in FY2003, \$118 million in FY2004, \$145.5 million in FY2005, \$173 million in FY2006, and \$200 million in FY2007. The grants would be used for the development of lifespan respite care services and the evaluation of those services, respite care worker and volunteer training programs, or training programs for family caregivers to assist family caregivers in making informed decisions about respite care services.

The bills also would authorize \$500,000 in each of FY2003 through FY2007 for the establishment of a National Lifespan Respite Resource Center.

NOTES

- 1 Older Women's League (OWL), *Faces of Caregiving* (Washington: OWL, 2001), p. 2.
- 2 William Scanlon of the General Accounting Office (GAO), testimony before the Senate Finance Committee, March 27, 2001, p. 3.
- 3 OWL, *Faces of Caregiving*, pp. 2-3.
- 4 Scanlon, testimony before the Senate Special Committee on Aging, Sept. 13, 2000, p. 2.
- 5 OWL, *Faces of Caregiving*, p. 3.
- 6 National Alzheimer's Association, "State-by-State Study Shows U.S. Health Care System Benefits from \$196 Billion in Services from Family Caregivers" (press release, March 3, 1999).
- 7 OWL, *Faces of Caregiving*, p. 4.
- 8 Scanlon, testimony before the Senate Finance Committee, March 27, 2001, p. 3.
- 9 AARP, "Long-Term Care," *The Public Policy Agenda 2000* (Washington: AARP, 2000), pp. 7-12.
- 10 Ibid.

Genetic Discrimination

Medical research is rapidly expanding knowledge about the role of genetics in diseases from cancer to Alzheimer's to heart disease. Researchers continue to discover new genes in the human body and identify how genes are involved in a variety of medical conditions. In fact, in July 2000, researchers announced that they had mapped the entire human genome.¹

With this knowledge comes the possibility of developing more effective treatments, as well as developing genetic tests to identify individuals at risk for certain diseases. These individuals could then participate in early detection screenings, potentially saving both lives and medical costs. However, few practitioners or consumers are adequately informed about the limitations of genetic testing. In the absence of safeguards, some fear that genetic information could be used to deny individuals health and life insurance or employment opportunities.

In the past few years, scientists have identified genes that may predispose individuals to cancers of the colon, breast, and ovary, as well as Huntington's disease, amyotrophic lateral sclerosis, and some forms of Alzheimer's disease. Additionally, scientists have discovered over 100 alterations in the inherited BRCA1 and BRCA2 genes, known to cause breast cancer. This discovery has focused public attention on the role of genetics in breast cancer and raised for the first time the possibility of screening a large segment of the population for a cancer predisposition mutation. Women who have inherited the BRCA1 mutation have a 36 to 85 percent risk of developing breast cancer in their lifetime.²

The possibility of screening women for these mutations, however, also points out the limitations of genetic testing. Only 5 to 10 percent of all breast cancers are hereditary.³ Thus, a negative test result does not guarantee that an individual will not develop cancer. Further, a positive test result for a gene implicated in

a certain medical condition does not guarantee that an individual will develop the disease.

A genetics test does not take into account factors such as exposure to environmental compounds, diet, behavior, and infectious agents that also influence the development and course of a disease. Finally, there are no comprehensive criteria in place to monitor the quality or assess the scientific validity of genetic tests, or to ensure that adequate counseling is provided along with the tests.

Studies have shown that there is a risk of discrimination against those who have a genetic predisposition for a disease. One survey of individuals with a known genetic condition in their family found that 22 percent reported being denied health insurance whether or not they were sick.⁴ Another survey by the American Management Association found that one-fifth of employers take family medical histories of employees and applicants.⁵

Although discrimination on the basis of genetic information may not yet be systemic, as scientists characterize the genetic connections of more diseases and develop screening tests, the potential for genetic discrimination may continue to increase. As of December 2002, 41 states had laws prohibiting health insurance discrimination on the basis of genetic information, and 31 states had laws regarding genetic discrimination in the workplace.⁶ But even in those states, large employers who develop self-funded insurance plans are exempt from such regulations.

Additionally, in 2001, the Equal Employment Opportunity Commission settled its first lawsuit challenging the use of workplace genetic testing under the Americans with Disabilities Act. The lawsuit alleged that the Burlington Northern Santa Fe Railway (BNSF) subjected 36 of its employees to genetic testing without their knowledge or consent, and one worker

was threatened with termination for failing to submit a blood test for genetic testing. Under the settlement, BNSF agreed to pay \$2.2 million to those employees and to refrain from any genetic testing in the future.⁷

Congressional Action

The 104th Congress addressed the issue of genetic discrimination in the Health Insurance Portability and Accountability Act of 1996 (P.L. 104-191). The law prohibits group health plans from using genetic information to deny coverage, but does not protect people who need individual health insurance, such as the self-employed. The law also does not prohibit insurance companies from raising their rates based on genetic tests.

The Balanced Budget Act of 1997 (P.L. 105-33) addressed the effects of genetic discrimination by prohibiting managed care plans participating in Medicare and Medicaid, as well as certain Medigap insurance plans, from discriminating in enrollment or coverage on the basis of genetic information.

Additionally, on February 8, 2000, President Clinton issued an executive order prohibiting federal agencies from using genetic information to discriminate in any hiring or promotion action.⁸

During the 106th and 107th Congresses, legislation to prohibit genetic discrimination was included in the Senate-passed patients' bill of rights (S. 1344/S. 1052), but the bills stalled in a House-Senate conference.

Six congressional hearings on the issue of genetic nondiscrimination were held during the 107th Congress, marking the first time that hearings had been held on the issue since legislation was first introduced.

Legislation

Genetic Nondiscrimination in Health Insurance and Employment Act (S. 318/H.R. 602)—Sen. Tom Daschle (D-SD) and Reps. Louise Slaughter (D-NY) and Connie Morella (R-MD)

S. 318/H.R. 602 would prohibit discrimination in health insurance coverage and employment practices based on genetic information. The bills would prohibit group and individual health plans from denying eligibility or adjusting premiums based on genetic information. The bills refer to "protected genetic discrimination," which is defined as information about an individual's genetic tests, information about genetic tests of family members of the individual, or information about the occurrence of a disease or disorder in family members.

Additionally, employers would be prohibited from discriminating against current or potential employees based on protected genetic information. Employers also would be prohibited from requesting, requiring, collecting, or purchasing protected genetic information unless the tests are required to monitor for exposure to toxic substances in the workplace.

Genetic Information Nondiscrimination in Health Insurance Act of 201 (S. 382)—Sen. Olympia Snowe (R-ME)

S. 382 would prohibit group and individual health insurance plans from using predictive genetic information as a condition of eligibility and to adjust premiums. Under the bill, predictive genetic information is defined as information about an individual's genetic tests, information about genetic tests of family members of the individual, or information about the occurrence of a disease or disorder in family members. The bill does not protect information "derived from physical tests, such as the chemical, blood, or urine analyses of the individual including cholesterol tests, and physical exams of the individual, in order to detect symptoms, clinical signs, or a diagnosis of disease."

Legislation—continued**Genetic Information Nondiscrimination Act of 2002 (S. 1995)—Sen. Olympia Snowe (R-ME)**

S. 1995 would prohibit discrimination in health insurance coverage and employment practices based on genetic information. The health insurance provisions are identical to S. 382. Under S. 1995, employers would be prohibited from discriminating against current or potential employees based on predictive genetic information. Employers also would be prohibited from requesting, requiring, or purchasing genetic information unless the tests are required to monitor for exposure to toxic substances in the workplace, or the employee provides prior, knowing, and voluntary written consent.

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Mammography Screening

Mammography screening is one of the few effective means of breast cancer detection currently available. While government and private educational campaigns have led to steady increases in the use of mammograms, there have been sharp divisions in the scientific community about the age at which screening should begin. A highly publicized debate between the National Cancer Institute (NCI) at the National Institutes of Health (NIH) and the American Cancer Society (ACS) was resolved in March 1997 when the NCI joined the ACS in endorsing regular mammography screenings for women aged 40 and over. Since that time, policymakers have moved quickly to expand public and private insurance coverage for the procedure. However, the debate over screening mammography was renewed in 2001, with the release of a study that questioned its benefits.

During a mammogram, a woman's breast is exposed to a low dose of radiation to create an image of its internal structure. A mammogram can find roughly 85 percent of breast cancer tumors in women over 50.¹ In part because of the density of younger women's breasts, mammograms may miss up to 20 percent of invasive breast cancers in women under the age of 50.² A recent study published in *Radiology* suggested that sonograms may be a useful screening technique for women with dense breasts, although the study needs to be replicated before widespread recommendations can be made.³

Screening mammography—performed when a woman has no symptoms of breast cancer—has been shown to reduce breast cancer mortality rates by up to 30 percent in women aged 50 to 69. Breast cancer deaths rates in all women have declined from 33.3 in 1990 to 27.0 in 1999, a finding cancer researchers attribute to the increase in mammography screening.⁴ According to the National Center for Health Statistics (NCHS), in 2000, 70.3 percent of women aged 40 and over, and

68 percent of women aged 65 and over reported having a mammogram within the past two years.⁵

In 2000, 81 percent of women aged 50-69 reported having had a mammogram within the last two years.⁶ The number of women aged 50 and over who have received at least one mammogram increased from 61 percent in 1994 to 69 percent in 1998. Certain populations are far less likely to be screened, however, including those with low incomes or limited education and those older than 65. According to the NCHS, 55.2 percent of women living below the poverty line reported having a mammogram within the past two years, compared with 72.2 percent of women living at or above the poverty line.⁷

However, according to a 1999 survey by the NCI and the Health Care Financing Administration (HCFA), now called the Centers for Medicare and Medicaid Services, only 57 percent of women aged 65 and older know about recommendations to have a mammogram every one or two years.⁸ This also is the population that is at greatest risk of breast cancer; 77 percent of breast cancers occur in women over 50.⁹

The cost of mammograms and limited access to health care are among the major barriers to regular screening for low-income and older women. A mammogram typically costs \$100 to \$150, with newer technologies costing more.¹⁰ Although coverage under private insurance plans varies widely, most insurers will provide full or partial coverage for an annual screening.

The Balanced Budget Act of 1997 (P.L. 105-33) expanded mammography coverage under Medicare to include annual mammograms—with no deductible—for women aged 40 and older. Under previous law, annual mammograms were covered under Medicare for women aged 50-64. For women under 50 and over 65, the program covered a mammogram every two years. Under current law, Medicare pays 80 per-

cent of the cost of a mammogram for beneficiaries aged 40 and older.¹¹

In addition, many medically underserved women have received free or low-cost mammography screenings through the Centers for Disease Control and Prevention's (CDC) National Breast and Cervical Cancer Early Detection Program. Enacted in 1990, the CDC program now provides support and technical guidance to all 50 states, U.S. territories, and the District of Columbia.¹²

Mammograms for Women in Their 40s

While a broad consensus has existed for many years on the benefits of annual screening for women over 50, the research on whether routine mammography decreases cancer mortality for younger women is less conclusive. As a result, the NCI and the ACS have differed over the years in their recommendations about the age at which women should begin mammography screening.

The NCI first recommended annual mammography for women over 50 in 1977. At that time, however, it stated that the only time a woman between the ages of 40 and 49 merited a mammogram was when she had a personal or family history of breast cancer. In 1983, the ACS came out in support of regular screening for women in their 40s. The NCI followed suit in 1989, in part to eliminate the confusion caused by the conflicting recommendations.¹³

But the debate over mammograms for women under 50 has continued. Although more than half a million women have participated in randomized clinical trials on the value of mammography screening over the past 30 years, researchers argue that these studies have failed to show a clear decrease in mortality rates in women under 50.¹⁴ Researchers also have expressed concern about the fact that women in their 40s who are screened annually have about a 30 percent chance of receiving a "false positive" result.¹⁵

Due to these concerns, the NCI rescinded its guidelines in 1993, rekindling the controversy over the age at

which mammography should begin. Absent conclusive scientific evidence, the NCI said women in their 40s should review the facts with their health care providers and make their own decision.¹⁶

In 1996, following the release of new data showing a 17 percent reduction in breast cancer deaths among women in their 40s who had regular mammograms, the NIH agreed to convene an independent consensus panel to review the research literature and report to the National Cancer Advisory Board, which was preparing to review federal mammography screening guidelines.¹⁷ In late January 1997, the panel issued a draft report which concluded that existing data did not warrant a recommendation that all women in their 40s have regular mammograms.¹⁸

The panel's findings came under immediate attack from other researchers who said the group had overemphasized mammography's risks while paying too little attention to the data that showed benefits.¹⁹ The Senate expressed its disapproval of the panel's recommendations in February 1997, when it voted unanimously (98-0) to strongly urge the National Cancer Advisory Board to consider reissuing its 1993 guidelines recommending mammography for women in their 40s. In March 1997, the Board agreed to recommend again that women in that age range have a mammogram every one to two years, citing the 1995 data.²⁰

On the same day that the NCI adopted its new guidelines, President Clinton announced a series of executive orders on the issue. He instructed HCFA to send a letter to state Medicaid directors encouraging them to cover annual mammography screenings beginning at age 40 and informing them that the federal government would provide matching payments for these services. He also directed the Office of Personnel Management to require all federal employee health plans to provide such coverage.²¹

Adding to the controversy over mammography screening, a recent study by Canadian researchers that examined nearly 40,000 women aged 50-59 found that physical examination of the breasts was equally

as effective at detecting breast cancer as mammograms. Under the study, half the women received physical breast examinations alone, and the other half received both physical examinations and mammograms. After a 13-year period, equal numbers in both groups had died of breast cancer.²²

Additionally, a study published in the *Journal of the National Cancer Institute* found that the cumulative risk of a false-positive mammogram over time varies depending on a woman's risk and factors related to screening technologies. The study reviewed the medical records of 2,227 women aged 40-69 who had at least one screening mammogram. The study found that by the ninth mammogram the risk of a false-positive can be as low as 5 percent for women at low risk for breast cancer and as high as 10 percent for women with a number of known risk factors.²³

Controversy erupted once again in October 2001 when a Danish study published in *Lancet* found that screening mammography was not beneficial at any age. The Cochrane Review reexamined seven large mammography studies, including several prominent Swedish studies, that had asserted a benefit from screening mammography and concluded that many of these studies were flawed.²⁴

Several months later, the U.S. Preventive Services Task Force updated its recommendations, calling for screening mammography, with or without clinical breast examination, every one to two years for women aged 40 and over.²⁵

In a rebuttal to the Cochrane Review, a Swedish team released a new analysis of their studies in March 2002, which also was published in *Lancet*. They concluded that screening mammography reduces the risk of dying from breast cancer by one-fifth and that the benefit is greatest for women aged 55 and over.²⁶

Congressional Action

During the 107th Congress, the Senate Health, Education, Labor, and Pensions Subcommittee on Public Health held a joint hearing with the Senate Appropriations Subcommittee on Labor, Health and Human Services, and Education to examine the recent screening mammography controversy.

A number of legislative proposals aimed at improving women's access to mammography were introduced during the 107th Congress. For a listing, please see Appendix II.

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Mastectomy Hospital Stays

The shift to managed care has created dramatic reductions in the length of hospital stays. Concerns raised by the health and consumer advocacy communities have prompted incremental steps toward regulating coverage in private sector plans. Public outrage over “drive-by deliveries,” in which women were dismissed from hospitals less than 24 hours after giving birth, led to the passage in the 104th Congress of a bill (P.L. 104-204) mandating coverage of a hospital stay for at least 48 hours after delivery. This same legislative strategy is now being applied to the issue of breast cancer surgery, primarily mastectomies.

The trend of decreasing post-mastectomy hospitalization was first brought to national attention by a Connecticut surgeon who clashed with health maintenance organizations (HMOs) in her area regarding covered hospital stays for her patients. These HMOs had adopted guidelines developed in 1995 by an accounting and consulting firm that suggested that mastectomies without complications could be performed on an outpatient basis.¹

While cost containment measures have abbreviated average hospital stays for all surgeries, the length of stays following mastectomies have decreased more rapidly than for other surgeries on the whole. According to a 1997 study of hospitalization by the Connecticut Office of Health Care Access, hospital stays for all surgical procedures in that state dropped by 23 percent over the previous five years. In this same period, stays for mastectomies dropped by more than 42 percent.² The National Center for Health Statistics found that the average length of stay for women aged 45–64 who were diagnosed with breast cancer decreased from 3.6 days in 1995 to 2.1 days in 2000.³ Additionally, the average length of stay in a hospital for any procedure across the United States had decreased from 7.8 days in 1995 to 6.8 days in 2000.⁴

Many women's health advocates argue that reducing hospital stays places undue physical and emotional burdens on women. Following a mastectomy, plastic drains are generally placed in the incision and must be emptied of blood and cleaned every few hours for days after the surgery. Most women need painkillers and antibiotic treatment to prevent infection. Because of pain and weakness, it may be difficult for a woman to manage her own medication schedule and the maintenance of drains immediately following surgery.⁵

Some doctors suggest that the security and comfort of a familiar environment may speed some women's recovery and that shorter stays for mastectomy patients may be advisable under some circumstances. These include an absence of medical complications, thorough patient education about aftercare prior to the procedure, and family or friends who are willing to assist in aftercare.⁶ Proponents of legislation to require minimum hospital stays argue that while it requires insurers to cover a minimum stay, doctors and patients may still decide together if a shorter stay is appropriate in a given situation.

Insurers strongly oppose legislative efforts to create minimum stays, arguing that it is inappropriate for Congress to mandate benefits and levels of coverage. In November 1996, the American Association of Health Plans announced that their members would cover at least a one-night hospital stay for women who undergo mastectomies.⁷

In February 1997, Secretary of Health and Human Services Donna Shalala issued an executive directive to the 350 managed care plans contracting with Medicare. It prohibited them from requiring outpatient surgery, or other limitations on the length of hospital stays, for Medicare beneficiaries undergoing surgery for the treatment of breast cancer.⁸

As of December 2001, 18 states had enacted laws mandating coverage of inpatient mastectomy stays. Half of the states require coverage for a minimum 48-hour stay, and the other half require coverage for a period determined by the physician in consultation with the patient.⁹

Legislation

Breast Cancer Patient Protection Act of 2001 (H.R. 536)—Rep. Rosa DeLauro (D-CT)

H.R. 536 would require insurance companies to provide at least 48 hours of inpatient hospital care following a mastectomy and a minimum of 24 hours following a lymph node dissection for the treatment of breast cancer.

Women's Health and Cancer Rights Act of 2001/Women's Cancer Recovery Act of 2001 (S. 255/H.R. 1485)—Sens. Olympia Snowe (R-ME) and Patty Murray (D-WA) and Rep. Frank LoBiondo (R-NJ)

S. 255/H.R. 1485 would require group and individual health plans to provide inpatient hospital care following a mastectomy, lumpectomy, and lymph node dissection for a period of time to be determined by the physician in consultation with the patient. The bill also would require health plans to cover secondary consultations, whether the consultation is based on a positive or negative test result.

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Mental Health Services

According to a 1999 U.S. Surgeon General's report, an estimated 44 million people in the United States suffer from some form of mental disorder each year, roughly 20 percent of the adult population. The report also estimates that direct medical costs from mental illness totaled \$69 billion in 1996.¹ Fortunately, many of these illnesses can be successfully treated.

Many neurobiological disorders—most notably depression, anxiety disorders (including phobias and panic disorders), and eating disorders—disproportionately affect women. A number of factors associated with neurobiological disorders—particularly depression—include heredity, biochemistry, behavioral responses, high stress work or circumstances, domestic violence, sexual abuse, lower income, and single parenthood. However, experts continue to debate the relative significance of these factors. Further research on individual and social indicators that contribute to depression and other neurobiological disorders is needed.²

Major depression is one of the most prevalent psychiatric disturbances affecting women. Approximately twice as many women (12 percent) as men (7 percent) suffer from depression. Additionally, the National Institute of Mental Health (NIMH) at the National Institutes of Health estimates that 20 percent of women have at least one episode of depression that should be treated.³

Symptoms of major depression include persistent sadness, disruption in sleep patterns, changes in appetite and energy level, loss of interest in daily activities, and impairment of cognitive functions. Major depression can cause severe impairment in social and physical functioning and is a major precipitating factor in suicide. It has been associated with higher medical costs, greater disability, poor self-care and adherence to medical regimens, and increased morbidity and mortality.⁴ According to the American

Psychological Association, depression in women is misdiagnosed 30 to 50 percent of the time.⁵ Noting that more than half of all cases of depression are missed altogether or misdiagnosed by physicians, the U.S. Preventive Services Task Force recently recommended that primary care physicians routinely screen all adult patients for depression.⁶

Depression occurs most frequently in women aged 25-44, with postpartum depression affecting roughly 10 percent of new mothers.⁷ Researchers also are seeing a rise in depression among adolescent women. A 1999 NIMH study of adolescent girls transitioning from high school to early adulthood found that 37 percent of the girls experienced a major depressive episode that had a negative impact on their school performance and their intimate romantic relationships during this time period. Additionally, 47 percent of the girls had experienced depression at some point in their lifetime.⁸

In most cases, a combination of psychotherapy and medication can successfully treat clinical depression in a matter of months. The advent of new medications has brought new hope to long-term sufferers of mental illness. However, approximately 30-35 percent of individuals do not respond to antidepressant drugs. Several alternative treatments, including meditation and relaxation, exercise, acupuncture, and herbals are more frequently being used to treat depression, although more studies are needed to assess their effectiveness.⁹

Research

The NIMH is investigating the causes and treatment of depressive disorders in women, with a specific focus on life stresses. Data from other studies indicate that stressful life experiences may play a role in recurring episodes of depression. Additionally, the NIMH is investigating the role of hormones in depression in women and the mechanisms that contribute to postpartum depression.¹⁰

Congressional Action

Legislation addressing the need for better coverage of mental health services was passed in 1996 under the FY1997 Veterans Affairs, Housing and Urban Development, and Related Agencies appropriations bill (P.L. 104-204). Under the Mental Health Parity Act of 1996, insurers who offer mental health care coverage are required to set similar coverage limits on annual and lifetime coverage for mental and physical illnesses. The law allows employers to purchase plans with different coverage limits for physical and mental disorders if a plan offering similar coverage raises costs by 1 percent or more. Businesses with fewer than 50 employees are exempt from the law's requirement.

A General Accounting Office (GAO) report examined compliance with the Mental Health Parity Act of 1996 and found that 86 percent of health plans were in compliance with the 1996 law. According to the GAO, 14 percent of plans were noncompliant, compared to 55 percent of plans that were noncompliant before the law was enacted. However, of the plans that were compliant, 87 percent limited mental health benefits to a greater extent than medical benefits.¹¹

The Balanced Budget Act of 1997 (P.L. 105-33) included a provision, as part of the State Children's Health Insurance Program, that requires state health plans to expand health coverage and services to include mental health benefits for low-income, uninsured children.

Additionally, in May 1999, President Clinton issued an executive order requiring plans participating in the Federal Employees Health Benefits Program to provide mental health benefits that are equal or comparable to physical health benefits.¹² Plans cannot set limits on the number of inpatient days for mental illness if they do not set similar limits for physical illness. Additionally, the executive order bars higher co-payments for mental health care than for physical health care.

During the first session of the 107th Congress, the Senate Health, Education, Labor, and Pensions Committee approved legislation (S. 543) that would have expanded current law by requiring insurers to provide equitable coverage of mental health illnesses.

That legislation was then included in the Senate-passed version of the FY2002 Labor, Health and Human Services, and Education appropriations bill (S. 2766) but was dropped during conference.

However, during the second session, legislation (P.L. 107-313) was enacted to reauthorize for one year the Mental Health Parity Act of 1996 (P.L. 104-204), which was set to expire on December 31, 2002.

Additionally, several congressional hearings were held to discuss the issue of mental health parity.

Legislation

Mental Health and Substance Abuse Parity Amendments of 2001 (H.R. 162)—Reps. Marge Roukema (R-NJ) and Pete DeFazio (D-CA)

H.R. 162 would prohibit health plans from imposing treatment limitations or financial requirements on the coverage of mental health benefits and on the coverage of substance abuse and chemical dependency benefits if similar benefits or requirements are not imposed on medical and surgical benefits. The bill does not define mental illness.

Mental Health Equitable Treatment Act of 2001 (S. 543/H.R. 4066)—Sens. Pete Domenici (R-NM) and Paul Wellstone (D-MN) and Reps. Marge Roukema (R-NJ) and Patrick Kennedy (D-RI)

S. 543/H.R. 4066 would prohibit health plans from imposing limitations or financial requirements on the coverage of mental health benefits if similar benefits are not imposed on medical and surgical benefits. Under the bill, all categories of mental health conditions listed in the *Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition* would be covered.

Mental Health Parity Enhancement Act of 2001 (H.R. 2992)—Reps. Carolyn Maloney (D-NY) and Benjamin Gilman (R-NY)

H.R. 2992 would clarify that health insurance plans may not impose limitations on the number of visits allowed for mental health, nor may they impose any other limitations on covered mental health benefits.

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Obstetricians-Gynecologists

One result of the dramatic shift toward managed care over the past decade has been the development of the role of the primary care physician as a “gatekeeper” who serves as an entry point into the health care system while playing a variety of other roles in providing for a patient’s care: delivering preventive services, treating common illnesses, and taking primary responsibility for the patient’s general well-being and long-term continuity of care.

According to a 1999 American College of Obstetricians and Gynecologists (ACOG)/Princeton poll, 60 percent of all ob-gyns in managed care plans reported that their patients were either limited or barred from seeing an ob-gyn without prior authorization. Twenty-eight percent of ob-gyns reported that their pregnant patients had to go through a gatekeeper prior to seeing them. Additionally, nearly 75 percent of ob-gyns surveyed reported that their patients had to return to their primary care physician prior to receiving follow-up care.¹

In contrast with other primary care specialists, ob-gyns are the only physicians specifically trained to provide comprehensive primary care for women. Primary care training recently has been expanded in ob-gyn residency programs and must encompass the following: taking comprehensive histories that include medical, nutritional, sexual, family, genetic, and social behavior data; assessing health risks; appropriately screening patients of various ages and under specific circumstances; diagnosing and treating common non-reproductive illnesses affecting women; managing the health care of patients in a continuous manner through all the reproductive and post-reproductive years; knowledge of the behavioral and societal factors that influence health among women of differing socioeconomic and cultural backgrounds; and knowledge of behavioral medicine and psychosocial problems, including domestic violence, sexual assault, and substance abuse.²

Furthermore, women examined by ob-gyns, as compared to other types of primary care physicians, are more likely to receive certain primary care preventive services such as pelvic exams, Pap tests, clinical breast exams, and referrals for mammograms. According to the Kaiser Family Foundation, 81 percent of women whose regular provider is an ob-gyn received a clinical breast exam in 2001, compared to 68 percent of women who saw another type of provider.³ Additionally, of those women who sought care from an ob-gyn, 94 percent received a pelvic exam compared to 35 percent of women who received care from other health care practitioners. Ninety-four percent of women who sought care from an ob-gyn received a Pap smear compared to 33 percent of women who received care from other providers.⁴

In addition, many ob-gyns manage non-reproductive health concerns (such as hypertension, cardiovascular diseases, diabetes, and asthma) for women, including pregnant women.

Direct Access

Surveys consistently show that women consider ob-gyns to be important providers of health care. A 1998 survey found that 82 percent of Americans support direct access to ob-gyns, and 63 percent of Americans would support direct access even if their health insurance costs were to increase as a result.⁵ A 1998 cost analysis found that requiring managed care organizations to allow direct access to ob-gyns would raise an individual’s health insurance premium by only 12 cents a year.⁶ The Congressional Budget Office estimated that direct access to ob-gyns would cost \$1 million in the first year, or 0.1 percent of an individual’s insurance premiums.⁷

Federal and state regulations have adopted several approaches to address this issue. As of 2002, 42 states and the District of Columbia had implemented laws to

require insurers to either allow women direct access or to designate an ob-gyn as their primary care provider.⁸

In response to these actions, the Coalition for Affordable Quality Healthcare, made up of 26 of the nation's largest health care plans, pledged to provide direct access to ob-gyn services, in addition to a number of other services.⁹

Congressional Action

The 107th Congress revisited the issue of direct access during its debate on managed care reform. Both the House- and Senate-passed bills (H.R. 2563/S. 1052) included language that would have required health care plans to provide direct access to a physician specializing in obstetrics or gynecology. However, the legislation stalled in a House-Senate conference committee.

Legislation

Women's Obstetrician and Gynecologist Medical Access Now Act (H.R. 1440)—Rep. Susan Davis (D-CA)

H.R. 1440 would require that group and individual health care plans allow women direct access to the services of obstetrical and gynecological physicians without prior authorization by separate primary care physicians.

Patient Right to Obstetric and Gynecological Care Act of 2001 (H.R. 2314)—Rep. Kay Granger (R-TX)

H.R. 2314 would require that group health insurance plans allow women direct access to obstetrician-gynecologists without prior authorization by separate primary care physicians.

NOTES

- 1 American College of Obstetricians and Gynecologists (ACOG), "Direct Access Fact Sheet" <http://www.acog.org/from_home/departments/dept_notice.cfm?r-ecno=11&bulletin=545> (1/7/03).
- 2 American Medical Association, *Graduate Medical Education Directory, 1999-2000* (Chicago: AMA, 1999), pp. 155-156.
- 3 The Henry J. Kaiser Family Foundation (KFF), "Coverage of Gynecological Care and Contraceptives" (fact sheet, 2000), p. 1.
- 4 KFF, "State Policies on Access to Gynecological Care and Contraception" (fact sheet, 2000), p. 1.
- 5 Ibid., p. 2.
- 6 ACOG, "Direct Access Fact Sheet."
- 7 Ibid.
- 8 Ibid.
- 9 Coalition for Affordable Quality Healthcare, "CAQH At Work" <http://www.caqh.org/whatwedo_improveaccess.html> (1/21/03).

Prescription Drug Coverage for Older Women

Medicare has provided older women and men with health care coverage for more than 37 years; however, when the program was created in 1965, prescription drug coverage was not included. Currently, Medicare covers prescription drugs when they are provided during an inpatient stay at a hospital or nursing facility and when the drugs cannot be self-administered. As a result, Medicare beneficiaries are forced to either seek supplemental coverage for prescription drugs or forgo certain medications. According to a 2000 Kaiser Family Foundation poll, 29 percent of older individuals reported that they did not fill a prescription because of the cost; 25 percent said that they gave up recreational activities/entertainment, household bills, non-essential purchases, and other items to pay for prescription drugs; and 10 percent reported that they gave up basic necessities to pay for their prescriptions.¹ In 1999, 38 percent of Medicare beneficiaries had no prescription drug coverage.²

Women are particularly affected. According to the Older Women's League, women constitute 58 percent of the Medicare population at age 65, and 71 percent of the Medicare population at age 85.³ Minority women constitute 60 percent of all minority Medicare beneficiaries.⁴ Seventeen million women use prescription drugs regularly, and an estimated seven million women served by Medicare lack prescription drug coverage.⁵

Studies show that older women are particularly vulnerable because women live an average of six years longer than men and report more chronic conditions that require prescription drugs than men. A 1999 study found that 70 percent of older women on Medicare reported two or more chronic conditions, compared to 60 percent of older men.⁶ According to AARP, 11 percent of older women reported having one or more severe limitations in activities of daily living, compared to 7 percent of men.⁷

As a result, women pay more in out-of-pocket health care costs than men. In 1999, older women spent \$2,520 in out-of-pocket expenses, while older men paid \$2,320.⁸ Estimates show that women spent an average of \$430 a year in out-of-pocket prescription costs, compared to \$380 a year for men.⁹

Not only are women paying more in out-of-pocket expenses for prescription drugs, but these women also are more likely to be poor. AARP estimates that women constitute three-quarters of poor Medicare beneficiaries, defined as having an income below 200 percent of the poverty line. Seventeen percent of poor Medicare beneficiaries are minority women.¹⁰

A study by the Department of Health and Human Services (HHS) found that seniors without drug coverage not only lack insurance, but do not have access to the discounts and rebates that insured individuals receive.¹¹ The Kaiser Family Foundation found that insured individuals paid an average of \$6 per prescription for generic drugs and \$10 per prescription for brand name drugs. Uninsured individuals paid an average of \$31 per prescription.¹² Additionally, the HHS study found that the percent of Medicare beneficiaries without drug coverage who reported not being able to afford a drug was about five times higher than those with coverage.¹³ In 1996, women who did not have prescription drug coverage used 24 percent fewer prescriptions than women who had coverage.¹⁴ A more recent survey of seniors in eight states found that one-third of seniors with congestive heart failure, diabetes, or hypertension who did not have prescription drug coverage reported skipping doses or not filling their prescriptions due to cost.¹⁵

According to a survey by the Kaiser Family Foundation, 76 percent of Americans support providing prescription drug coverage under Medicare. Sixty-two percent of Americans would support expanding Medicare to provide such coverage directly, while thir-

ty-two percent would support government subsidies for seniors to purchase private health insurance to cover prescription drugs.¹⁶

Congressional Action

The 107th Congress debated prescription drug coverage at length. While Republicans and Democrats agreed on the need for a prescription drug benefit for seniors, there was disagreement about how best to implement the benefit. Disagreements on how much a drug benefit plan should cost and how it should be implemented, through private health plans or through Medicare, divided Members mostly along party lines.

The House passed a Republican-sponsored plan (H.R. 4954) that would have allowed seniors to purchase prescription drug coverage through private insurance plans. The Senate defeated four separate proposals to provide a Medicare prescription drug benefit during debate on a bill (S. 812) to speed the Food and Drug Administration's approval of low-cost generic drugs, leaving the issue to be decided by the 108th Congress.

A number of legislative proposals pertaining to prescription drug coverage for seniors were introduced in the 107th Congress. For a listing, see Appendix II.

NOTES

- 1 The Henry J. Kaiser Family Foundation (KFF), "The Public and Prescription Drugs" (Kaiser Public Opinion Update, 2000), p. 1.
- 2 KFF, "Medicare and Prescription Drugs" (chart pack, June 12, 2002), Figure 2 <<http://www.kff.org/content/2002/6048v1.pdf>> 12/10/03.
- 3 Older Women's League (OWL), *Prescription for Change: Why Women Need a Medicare Drug Benefit* (Washington: OWL, 2000), p. 1.
- 4 Lisa A. Foley and Mary Jo Gibson, "Older Women's Access to Health Care: Potential Impact of Medicare Reform" (Washington: AARP Public Policy Institute, 2000), p. 2.
- 5 OWL, *Prescription for Change*, p. 7.
- 6 KFF, "Women and Medicare" (fact sheet, July 2001).
- 7 Foley and Gibson, "Older Women's Access to Health Care: Potential Impact of Medicare Reform," p. 5.
- 8 Ibid., p. 10.
- 9 OWL, *Prescription for Change*, p. 3.
- 10 Foley and Gibson, "Older Women's Access to Health Care: Potential Impact of Medicare Reform," p. 4.
- 11 Department of Health and Human Services (HHS), *Prescription Drug Coverage, Spending, Utilization, and Prices* (Washington: HHS, April 2000).
- 12 KFF, *Prescription Drug Trends: A Chartbook* (Menlo Park: KFF, 2000), p. 10.
- 13 HHS, *Prescription Drug Coverage, Spending, Utilization, and Prices*.
- 14 OWL, *Prescription for Change*, p. 3.
- 15 KFF, The Commonwealth Fund, and Tufts-New England Medical Center, *Seniors and Prescription Drugs: Findings From a 2001 Survey of Seniors in Eight States* (Menlo Park: KFF, The Commonwealth Fund, and Tufts-New England Medical Center, July 2002).
- 16 KFF, "The Public and Prescription Drugs."

Reconstructive Breast Surgery

The American Cancer Society estimated that 203,500 new cases of breast cancer would be diagnosed in the United States in 2002.¹ Treatment for breast cancer may include two or more of the following: lumpectomy and removal of lymph nodes under the arms, mastectomy and removal of lymph nodes under the arm, radiation, and/or chemotherapy.

- Using data that represents 60 percent of cancer cases, the American College of Surgeons estimates that in 1999, roughly 145,681 women underwent surgery as part of their treatment for breast cancer.²
- According to the American Society of Plastic Surgeons (ASPS) in 2001, 81,729 women underwent reconstructive surgery after a mastectomy.³

For many women with breast cancer, reconstructive surgery is an integral part of the healing process, both physically and mentally. However, the daunting financial burden associated with reconstructive surgery and the possibility that the surgery will not be covered by insurance policies provides further obstacles on the road to recovery.

As of 2001, 38 states had enacted laws mandating insurance coverage for breast reconstruction after a mastectomy.⁴ Despite state efforts to legislate insurance coverage of breast reconstructive surgery, many advocates felt that federal legislation was needed since many women were covered by plans regulated under the Employee Retirement Income Security Act (ERISA), not state law.

Congressional Action

As a result, the 105th Congress enacted the Women's Health and Cancer Rights Act of 1998 (P.L. 105-277). The bill was included in the FY1999 omnibus appropriations measure. The law requires insurance policies to cover reconstructive breast surgery if they cover mastectomies. Reconstructive surgery was defined to include all stages of reconstruction of the breast on

which the mastectomy was performed, surgery and reconstruction of the other breast to produce a symmetrical appearance, and prostheses and treatment for physical complications associated with a mastectomy.

Legislation

Women's Health and Cancer Rights Conforming Amendments of 2001/Breast Reconstruction Implementation Act of 2001 (H.R. 887/S. 331)—Reps. Sue Kelly (R-NY) and James Oberstar (D-MN) and Sen. Joe Biden (D-DE)

H.R. 887/S. 331 would provide technical changes intended to ensure compliance with the Women's Health and Cancer Rights Act of 1998.

NOTES

- 1 American Cancer Society (ACS), "Cancer Facts and Figures 2002" <<http://www.cancer.org/downloads/STT/CancerFacts&Figures2002-TM.pdf>> (11/15/02).
- 2 American College of Surgeons, National Cancer Database, "NCDB Benchmark Reports" <<http://www.facs.org/dept/cancer/ncdb/index.html>> (1/13/03).
- 3 American Society of Plastic Surgeons (ASPS), "2001 National Plastic Surgery Statistics: Cosmetic and Reconstructive Patients" <http://www.plasticsurgery.org/mediactr/2001_expanded_stats/national.pdf> (12/10/02).
- 4 The Henry J. Kaiser Family Foundation, "State Mandated Benefits: Reconstructive Surgery After Mastectomy, 2001" <<http://www.statehealthfacts.kff.org>> (12/10/03).

Appendices

Appendix I: Action on Women's Health Legislation in the 107th Congress

Abortion Restrictions: The FY2002 appropriations bills continued abortion funding restrictions that have been in place for years. Congress voted to restrict the use of federal funds to pay for abortions for military personnel and their dependents, federal employees and their dependents, women in federal prisons, Medicaid recipients, disabled Medicare beneficiaries, low-income women in the District of Columbia, Peace Corps personnel, and Native American women who receive their health care through the Indian Health Service (December 2001).

Abstinence Education: The FY2002 Labor, Health and Human Services, and Education appropriations bill (P.L. 107-116) allocated \$100.16 million for abstinence-only education programs (January 2002). The House defeated an effort to further increase funding for these programs.

Afghan Women and Children: Congress approved legislation (P.L. 107-81) to authorize health care and educational assistance to Afghan women and children refugees (December 2001).

Alzheimer's Disease: The Senate Health, Education, Labor, and Pensions Committee approved a bill (S. 2059) that would have directed the National Institute on Aging at the National Institutes of Health to undertake an Alzheimer's Disease Prevention Initiative (June 2002). The House did not consider a similar bill.

Birth Defects Prevention: The Senate approved a bill (S. 2980) that would have reauthorized the Birth Defects Prevention Act (P.L. 105-168) (October 2002). The House did not consider similar legislation.

Born Alive Infant Protection: Congress approved legislation (P.L. 107-207) to change the definition of an individual under the U.S. criminal code (August 2002).

Breast Cancer Research: Congress approved legislation (P.L. 107-248) to appropriate \$150 million for peer-reviewed breast cancer research at the Department of Defense (DoD) in FY2003. In addition, the legislation provides \$12.8 million for the DoD's Comprehensive Breast Care Project and \$6 million for Peer-Reviewed Breast Cancer Imaging Research (October 2002). Congress approved legislation (P.L. 107-117) to appropriate \$150 million for peer-reviewed breast cancer research at the Department of Defense in FY2002 (January 2002).

Breast Implants: Congress approved two federal studies on breast implants as part of a larger bill pertaining to medical devices (P.L. 107-250) (October 2002).

Breast and Cervical Cancer

Treatment: Congress approved legislation (P.L. 107-121) to allow Native American women access to optional Medicaid treatment for breast or cervical cancer (January 2002).

Breastfeeding: Congress approved legislation (P.L. 107-67) extending current law, which allows women to breastfeed on federal property. The provision was included in the FY2002 Treasury-Postal Service spending bill (November 2001).

Colorectal Screening: The Senate Health, Education, Labor, and Pensions Committee approved a bill (S. 710) that would have required group health plans to cover colorectal cancer screening at regular intervals for beneficiaries aged 50 and over and any beneficiaries who are at high risk (July 2002). The House did not consider a similar bill.

Contraceptive Coverage: Congress approved legislation (P.L. 107-67) to extend current law by requiring health plans participating in the Federal Employees Health Benefits Program to cover prescription contraceptives if they also cover other

prescription drugs. The provision was included in the FY2002 Treasury-Postal Service spending bill (November 2001).

Dating Violence: The Senate approved legislation (S. 410) that would have added dating violence to the list of crimes covered by the Violence Against Women Act (May 2002). The House did not consider similar legislation.

Eating Disorders: The Senate, Health, Education, Labor, and Pensions Committee approved legislation (S. 2249) that would have established a grant program regarding eating disorders as part of a broader women's health package (S. 2328) (September 2002). The House did not consider a similar bill.

Embryo Research Ban: Congress approved the FY2002 Labor, Health and Human Services, and Education appropriations bill (P.L. 107-116) with a restriction prohibiting the use of federal funds for embryo research (January 2002).

Family Caregivers: Congress appropriated \$141.5 million for the newly created National Family Caregivers Support program under the FY2002 Labor, Health and Human Services, and Education appropriations bill (P.L. 107-116) (January 2002).

Global HIV/AIDS Prevention: The Senate approved legislation (S. 2018) that would have authorized funding for global HIV/AIDS prevention, education, and treatment programs (July 2002).

The House approved a similar bill (H.R. 2069) (December 2001). Differences between the bills were not resolved prior to adjournment.

Congress appropriated \$300 million for a global HIV/AIDS multilateral trust fund. One-third of that amount was appropriated through the FY2001 emergency supplemental appropriations bill (P.L. 107-20) (July 2001); one-third through the FY2002 foreign operations appropriations bill (P.L. 107-115); and one-third through the FY2002 Labor, Health and Human Services, and Education appropriations bill (P.L. 107-116) (January 2002).

Additionally, the FY2002 foreign operations bill appropriated \$475 million for global HIV/AIDS initiatives (January 2002).

Health Care Coverage Resolution: Congress approved a resolution (H. Con. Res. 271/S. Con. Res. 94) expressing the sense of Congress that a National Importance of Health Care Coverage Month be established (May 2002/November 2002).

Human Cloning: The House approved legislation that would have prohibited human cloning (July 2001). During Senate consideration of the FY2002 Labor, Health and Human Services, and Education appropriations bill, an attempt was made to attach legislation that would have banned human cloning. The amendment was not offered when an agreement was reached to consider cloning legislation in February or March 2002 (November 2001). However, the legislation was never considered.

Another attempt was made to attach a six-month moratorium on human cloning to a railroad retirement bill (H.R. 10), but the Senate defeated the amendment (November 2001).

Insurance Coverage for Pregnant Women: The Senate Finance Committee approved legislation (S. 724) that would have allowed states to provide optional coverage under the State Children's Health Insurance Program (SCHIP) to low-income pregnant women (July 2002). The House did not consider similar legislation.

International Family Planning: Congress approved \$446 million for international family planning programs in FY2002. After a protracted debate, Congress also increased funding for the United Nations Population Fund (UNFPA) to \$34 million. Funding for these programs was allocated through the FY2002 foreign operations appropriations bill (P.L. 107-115) (January 2002). As a result of UNFPA's activities in China, President Bush placed a hold on the FY2002 money.

Mammography Quality Standards Act Reauthorization: The House Energy and

Commerce Committee approved legislation (H.R. 4888) that would have reauthorized the Mammography Quality Standards Act (June 2002). Similar legislation was not considered by the Senate.

Maternal and Child Health Block

Grant: Congress appropriated \$731 million for the block grant in the FY2002 Labor, Health and Human Services, and Education appropriations bill (P.L. 107-116) (January 2002).

Medical Devices: Congress approved legislation (P.L. 107-250) aimed at expediting the Food and Drug Administration's approval of medical devices and products (October 2002).

Medical Malpractice: The House approved legislation (H.R. 4600) that would have limited medical malpractice awards (September 2002). The Senate did not consider similar legislation.

Mental Health Parity: Congress approved legislation (H.R. 5716) to extend for one year a law that requires insurers that offer mental health coverage to set similar limits on annual and lifetime coverage for mental and physical illnesses (November 2002).

Mexico City Policy: Congress approved legislation (107-115) retaining the Mexico City policy, which prohibits nongovernmental organizations that use their own funds to perform abortions from receiving U.S. funds. The language was included in the FY2002 foreign operations appropriations bill (January 2002).

Additionally, the Senate Foreign Relations Committee approved legislation that would have overturned the Mexico City policy (August 2001). Similar legislation was not considered by the House.

Microbicides: Congress approved legislation (P.L. 107-115) appropriating funding for microbicides research through the U.S. Agency for International Development. Report language urged the National Institutes of Health to fund microbicide research (January 2002).

National Minority Health and Health

Disparities Month: Congress approved a resolution (H. Con. Res. 388/S. Con. Res. 139) expressing the sense of Congress that a National Minority Health Month be established (May/October 2002).

Nursing Shortage: Congress approved legislation (P.L. 107-205) designed to reduce the nursing shortage (August 2002).

Osteoporosis Research: Congress approved legislation (P.L. 107-248) to appropriate \$50 million for peer-reviewed medical research, including bone-related diseases, at the DoD in FY2003 (October 2002). Congress approved legislation (P.L. 107-117) to appropriate \$2.8 million for osteoporosis research at the Department of Defense in FY2002 (January 2002).

Ovarian Cancer Research: Congress approved legislation (P.L. 107-248) to appropriate \$10 million for ovarian cancer research at the DoD in FY2003 (October 2002). Congress approved legislation (P.L. 107-117) to appropriate \$10.2 million for ovarian cancer research at the Department of Defense in FY2002 (January 2002).

Partial-Birth Abortion Ban: The House passed a bill (H.R. 4965) that would have prohibited "partial-birth abortions" (July 2002). The Senate did not consider similar legislation.

Patients' Bill of Rights: Both the House and Senate approved legislation that would have provided individuals in managed care plans with additional protections, while allowing those individuals to sue their health plans for denial of coverage (June/August 2001). The legislation languished in a House-Senate conference committee.

Periodontal Disease: The Senate Health, Education, Labor, and Pensions Committee approved legislation (S. 2202) that would have increased the awareness of the link between periodontal disease in pregnant women and pre-term, low birthweight babies as part of a broader women's health package (S. 2328) (September 2002).

Prescription Drugs: The Senate defeated four separate proposals to provide a Medicare prescription drug benefit during debate on a bill (S. 812) to speed the Food and Drug Administration's approval of low-cost generic drugs (July 2002).

The House approved a bill (H.R. 4954) that would have provided a Medicare prescription drug benefit (June 2002).

Refusal Clauses: The House approved legislation (H.R. 4691) that would have permitted an array of health care facilities, plans, and organizations to refuse to perform, cover, or pay for abortion services or to provide referrals and information if they objected to such services on religious or moral grounds (September 2002). The Senate did not consider similar legislation.

Respite Care: The Senate, Health, Education, Labor, and Pensions Committee approved legislation (S. 2489) that would have provided lifespan respite care grants and cooperative agreements to expand and enhance respite services to family caregivers (July 2002).

Safe Motherhood: The Senate approved a bill (S. 2328) aimed at promoting safe motherhood (September 2002). Several other women's health-related bills were incorporated into the package, including legislation (S. 946) that would have authorized offices of women's health at the Department of Health and Human Services (HHS), legislation (S. 208) that would have expanded preventive health services for women through the WISEWOMAN program, legislation (S. 2202) that would have increased the awareness of the link between periodontal disease in pregnant women and pre-term, low birthweight babies, and legislation (S. 2249) that would have established a grant program regarding eating disorders. The House did not consider similar legislation.

Sexual Exploitation of Refugees: Congress approved a resolution (H. Con. Res. 349) aimed at improving measures to end the sexual exploitation of refugees (November 2002).

Shaken Baby Awareness: Congress approved a resolution (H. Con. Res. 59/S. Res. 55) expressing the sense of Congress that a National Shaken Baby Syndrome Awareness Week be established (April 2001).

Violence Against Women Office: Congress approved legislation (P.L. 107-273) to establish a permanent Violence Against Women Office within the Department of Justice (November 2002).

WISEWOMAN Program: The Senate Health, Education, Labor, and Pensions Committee approved legislation (S. 208) that would have expanded the preventive health services offered through the WISEWOMAN program as part of a broader women's health bill (S. 2328) (September 2002).

Women Veterans: Congress approved legislation (S. 2237) to extend a number of veterans' benefits, including an extension of a special monthly compensation to women who undergo mastectomies as a result of military service (November 2002).

The House approved legislation that would have authorized funding for the improvement and renovation of Veterans Affairs medical centers. The bill delineated a number of projects that the Secretary of Veterans Affairs should consider a priority, including improving privacy and accommodations for women veterans (March 2001). The Senate did not consider a similar bill.

Women's Health Offices: The House approved legislation (H.R. 1784) that would have provided statutory authority for the federal women's health offices (September 2002). The Senate Health, Education, Labor, and Pensions Committee approved a broader bill (S. 2328) that incorporated the women's health offices provisions; however, the bill was not considered on the floor (September 2002).

Appendix II: Selected Women's Health Bills Introduced in the 108th Congress

Abortion (see Reproductive Health Issues)

Adolescent Health/Pregnancy

S. 74/H.R. 3805-Sen. Jesse Helms (R-NC)/Placed on calendar (1/22/01)-Rep. Melissa Hart (R-PA)/Education and the Workforce (2/27/02)-A bill to prohibit the provision of federal funds to any elementary or secondary schools that distribute or provide emergency postcoital contraception to school children on school premises, or that provide prescriptions for such contraception.

H.R. 476-Rep. Ileana Ros-Lehtinen (R-FL)/Judiciary (2/6/01)-A bill to prohibit taking minors across state lines in circumvention of laws requiring the involvement of parents in abortion decisions.

H.R. 3469-Rep. Barbara Lee (D-CA)/Energy and Commerce (12/12/01)-A bill to provide for the reduction of adolescent pregnancy, HIV rates, and other sexually transmitted diseases, and for other purposes.

H.R. 3581-Rep. Jane Harman (D-CA)/Energy and Commerce (12/20/01)-A bill to authorize the Secretary of Health and Human Services to award on a competitive basis grants to public and private entities to establish or expand teenage pregnancy prevention programs.

H.R. 4585-Rep. Fred Upton (R-MI)/Energy and Commerce (4/24/02)-A bill to extend abstinence education funding under the maternal and child health program through fiscal year 2007.

H. Con. Res. 393/S. Con. Res. 105-Rep. Eva Clayton (D-NC)/Energy and Commerce (5/1/02)-Sen. Joseph Lieberman (D-CT)/Health, Education, Labor, and Pensions (5/2/01)-A concurrent resolution expressing the sense of Congress that the nation should take additional steps to ensure the prevention of teen pregnancy by engaging in measures to educate

teenagers as to why they should stop and think about the negative consequences before engaging in premature sexual activity.

H.R. 4737-Rep. Deborah Pryce (R-OH)/Agriculture, Education and the Workforce, Energy and Commerce, Financial Services, Ways and Means (5/15/02)-A bill to reauthorize and extend the 1996 welfare reform law.

H.R. 4783-Rep. Kevin Brady (R-TX)/Energy and Commerce (5/21/02)-A bill to authorize states under federal health care grant-in-aid programs to require parental consent or notification for purpose of purchase of prescription drugs or devices for minors.

S. 2648-Sen. Tim Hutchinson (R-AR)/Finance (6/19/02)-A bill to reauthorize and extend the 1996 welfare reform law.

Adoption (see Reproductive Health Issues)

Autoimmune Diseases

H.R. 1758-Rep. John LaFalce (D-NY)/Energy and Commerce, Ways and Means (5/8/01)-A bill to provide for coverage under part B of Medicare of certain beta interferons and other biologicals and drugs approved by the Food and Drug Administration for treatment of multiple sclerosis.

S. 2234-Sen. Barbara Boxer (D-CA)/Health, Education, Labor, and Pensions (4/23/02)-A bill to provide for expanding, intensifying, and coordinating activities of the Office on Women's Health in the Department of Health and Human Services with respect to autoimmune diseases in women.

H. Con. Res. 320/S. Con. Res. 126-Rep. Luis Gutierrez (D-IL)/Energy and Commerce (2/7/02)-Sen. Harry Reid (D-NV)/Health, Education, Labor, and Pensions (6/27/02)-A resolution expressing the sense of Congress regarding scleroderma.

H.R. 5104-Rep. Stephen Lynch (D-MA)/Energy and Commerce (7/11/02)-A bill to expand, intensify, and coordinate activities with respect to research on autoimmune diseases in women.

Breast Cancer Research

H.R. 281-Rep. Peter King (R-NY)/Government Reform (1/30/01)-A bill to establish and provide a tax check-off for a Breast and Prostate Cancer Research Fund.

S. 261-Sen. Olympia Snowe (R-ME)/Health, Education, Labor, and Pensions (2/6/01)-A bill to provide, with respect to research on breast cancer, for the increased involvement of advocates in decisionmaking at the National Cancer Institute.

H.R. 1295-Rep. Joe Baca (D-CA)/Energy and Commerce (3/28/01)-A bill to authorize the Secretary of Health and Human Services to make matching grants available to the states in order to encourage the establishment of state license plate programs to provide funds for the treatment of breast cancer, for research on such cancer, and for educational activities regarding such cancer.

H.R. 2317-Rep. Juanita Millender-McDonald (D-CA)/Government Reform, Energy and Commerce, Armed Services (6/26/01)-A bill to make permanent the United States Postal Service's authority to issue a special postage stamp in order to help provide funding for breast cancer research.

S. 1256/ H.R. 2725-Sen. Dianne Feinstein (D-CA)/Governmental Affairs (7/26/01)- Rep. Sue Kelly (R-NY)/Energy and Commerce, Armed Services, Government Reform (8/2/01)-A bill to provide for the reauthorization of the breast cancer research special postage stamp.

H.R. 3186-Rep. Peter King (R-NY)/Energy and Commerce (10/30/01)-A bill to provide for an awareness program and a study of a rare form of breast cancer.

H.R. 3989-Rep. Nita Lowey (D-NY)/Energy and Commerce (3/18/02)-A bill to authorize additional appropriations to the National Institutes of Health for research on the early detection of breast cancer and the reduction of breast cancer mortality rates.

Breast Cancer Access to Treatment

S. 535-Sen. Jeff Bingaman (D-NM)/Indian Affairs (3/14/01)-A bill to clarify that Indian women with breast or cervical cancer who are eligible for health services provided under a medical care program of the Indian Health Service or of a tribal organization are included in the optional Medicaid eligibility category of breast or cervical cancer patients added by the Breast and Cervical Cancer Prevention and Treatment Act of 2000.

S. 1741-Sen. Jeff Bingaman (D-NM)/(11/28/01)-A bill to clarify that Indian women with breast or cervical cancer who receive care through the Indian Health Service or a tribal organization are included in the optional Medicaid eligibility category for breast or cervical cancer patients.

Cardiovascular Diseases

S. 208/H.R. 633-Sen. Bill Frist (R-TN)/Health, Education, Labor, and Pensions (1/23/01)-Rep. Rosa DeLauro (D-CT)/Energy and Commerce (2/14/01)-A bill to reduce health care costs and promote improved health care by providing supplemental grants for additional preventive health services for women under the Centers for Disease Control and Prevention's WISEWOMAN program.

S. 960/ H.R. 2117-Sen. Jeff Bingaman (D-NM)/Finance (5/24/01)- Rep. Fred Upton (R-MI)/Ways and Means (6/7/01)-A bill to expand coverage of medical nutrition therapy services under Medicare for beneficiaries with cardiovascular diseases.

S. 1274/ H.R. 3431-Sen. Edward Kennedy (D-MA)/Health, Education, Labor, and Pensions (7/31/01)- Rep. Lois Capps (D-CA)/Energy and Commerce (12/6/01)-A bill to provide programs for the prevention, treatment, and rehabilitation of stroke.

Clinical Trials

S. 257-Sen. Olympia Snowe (R-ME)/Health, Education, Labor, and Pensions (2/6/01)-A bill to permit individuals to continue health plan coverage of services while participating in approved clinical studies.

H.R. 967-Rep. Deborah Pryce (R-OH)/Education and the Workforce, Energy and Commerce, Ways and Means (3/8/01)-A bill to require group and individual health insurance coverage and group health plans to provide coverage for individuals participating in approved cancer clinical trials.

Domestic Violence

H.R. 21-Rep. Bob Barr (R-GA)/Judiciary (1/3/01)-A bill to provide that the firearms prohibitions applicable by reason of a domestic violence misdemeanor conviction do not apply if the conviction occurred before the prohibitions became law.

H.R. 28/S. 161- Rep. Louise Slaughter (D-NY)/Judiciary (1/3/01)-Sen. Paul Wellstone (D-MN)/Judiciary (1/24/01)-A bill to establish the Violence Against Women Office within the Department of Justice.

S. 410-Sen. Michael Crapo (R-ID)/Judiciary (2/28/01)-A bill to amend the Violence Against Women Act of 2000 by expanding the legal assistance for victims of violence grant program to include assistance for victims of dating violence.

S. 518-Sen. Barbara Boxer (D-CA)/Health, Education, Labor, and Pensions (3/13/01)-A bill to provide for the training of health professions students with respect to the identification and referral of victims of domestic violence.

S. Res. 72-Sen. Arlen Specter (R-PA)/Judiciary (4/24/01)-A resolution designating the month of April as "National Sexual Assault Awareness Month."

S. 1249/H.R. 2670-Sen. Paul Wellstone (D-MN)/Finance, Judiciary (7/24/01)-Rep. Lucille Roybal-Allard (D-CA)/Energy and Commerce, Ways and Means, Education and the Workforce (7/30/01)-A bill

to promote the economic security and safety of victims of domestic and sexual violence.

H.R. 2697-Rep. Robert Andrews (D-NJ)/Judiciary (8/1/01)-A bill to authorize grants to states to fund arrangements between local police departments and public accommodations to have the accommodations serve as emergency domestic violence shelters.

S. 1391-Sen. Charles Schumer (D-NY)/Judiciary (8/2/01)-A bill to establish a grant program for Sexual Assault Forensic Examiners.

H.R. 2874/S. 2055-Rep. Carolyn Maloney (D-NY)/Judiciary (9/10/01)-Sen. Maria Cantwell (D-WA)/Judiciary (3/21/02)-A bill to make grants to train sexual assault nurse examiners, law enforcement personnel, and first responders in the handling of sexual assault cases, to establish minimum standards for forensic evidence collection kits, and to carry out DNA analyses of samples from crime scenes.

S. 1483-Sen. Paul Wellstone (D-MN)/Health, Education, Labor, and Pensions (10/2/01)-A bill to reduce the impact of domestic violence, sexual assault, and stalking on the lives of youth and children and to provide appropriate services for children and youth experiencing or exposed to domestic violence, sexual assault, or stalking.

H.R. 3193-Rep. Judy Biggert (R-IL)/Judiciary (10/31/01)-A bill to expand the legal assistance for victims of violence grant program to include legal assistance for victims of dating violence.

S. 1862-Sen. Richard Durbin (D-IL)/Judiciary (12/20/01)-A bill to provide for grants to assist states and communities in developing a comprehensive approach to helping children five and under who have been exposed to domestic violence or a violent act in the home or community.

H.R. 3595-Rep. Steve Rothman (D-NJ)/Judiciary (12/20/01)-A bill to amend federal crime grant programs relating to domestic violence to encourage states and localities to implement gun confiscation

policies, reform stalking laws, create integrated domestic violence courts, and hire additional personnel for entering protection orders, and for other purposes.

H.R. 3752-Rep. Jan Schakowsky (D-IL)/Financial Services (2/13/02)-A bill to provide housing assistance to domestic violence victims.

H.R. 3828-Rep. Jan Schakowsky (D-IL)/Judiciary, Education and the Workforce, Energy and Commerce, Ways and Means (2/28/02)-A bill to provide additional protections for battered immigrant families.

S. 2002-Sen. Paul Wellstone (D-MN)/Health, Education, Labor, and Pensions (3/8/02)-A bill to ensure that victims of domestic violence get the help they need in a single phone call, and for other purposes.

S. 2009/H.R. 4916-Sen. Richard Durbin (D-IL)/Health, Education, Labor, and Pensions (3/12/02)-Rep. Lois Capps (D-CA)/Energy and Commerce (6/12/02)-A bill to provide services for the prevention of family violence.

H.R. 4032-Rep. Lois Capps (D-CA)/Energy and Commerce, Government Reform (3/20/02)-A bill to provide coverage for domestic violence screening and treatment under the maternal and child health block grant program, Medicaid, and the Federal Employees Health Benefits Program.

H.R. 4091-Rep. Hilda Solis (D-CA)/Judiciary (4/9/02)-A bill to authorize the establishment of domestic violence court systems from amounts available for grants to combat violence against women.

H.R. 4089-Rep. Hilda Solis (D-CA)/Judiciary (4/9/02)-A bill to provide grants for public information campaigns to educate racial and ethnic minorities about domestic violence.

S. 2236-Sen. Paul Wellstone (D-MN)/Health, Education, Labor, and Pensions (4/24/02)-A bill to provide coverage for domestic violence screening and treatment, to authorize the Secretary of Health and Human Services to make grants to improve the

response of health care systems to domestic violence, and to train health care providers and federally qualified health centers regarding screening, identification, and treatment for families experiencing domestic violence.

H.R. 4655-Rep. Carolyn Maloney (D-NY)/Ways and Means (5/2/02)-A bill to ensure that all states address domestic and sexual violence in their Temporary Assistance for Needy Families Program.

S. 2723-Sen. Patrick Leahy (D-VT)/Banking, Housing, and Urban Affairs (7/11/02)-A bill to provide transitional housing assistance for victims of domestic violence.

H.R. 5514-Rep. Carolyn Kilpatrick (D-MI)/Judiciary (10/1/02)-A bill to provide grants to states for establishing sexual assault response team programs, and for other purposes.

H. Con. Res. 501-Rep. Judy Biggert (R-IL)/Government Reform (10/7/02)-A concurrent resolution expressing the sense of Congress that Congress should raise awareness of domestic violence in the nation by supporting the goals and ideals of National Domestic Violence Awareness Month.

H. Res. 584-Rep. Heather Wilson (R-NM)/Judiciary (10/10/02)-A resolution supporting the goals and ideas of a National Sexual Assault Awareness Month.

Eating Disorders

H.R. 46-Rep. Judy Biggert (R-IL)/Education and the Workforce, Energy and Commerce (1/3/01)-A bill to raise awareness of eating disorders and to create educational programs concerning the same.

S. 2249-Sen. Hillary Rodham Clinton (D-NY)/Health, Education, Labor, and Pensions (4/24/02)-A bill to establish a grant program regarding eating disorders, and for other purposes.

S. 2821/H.R. 5412-Sen. Bill Frist (R-TN)/Health, Education, Labor, and Pensions (7/30/02)-Rep. Mary

Bono (R-CA)/Energy and Commerce, Agriculture, Ways and Means (9/91/02)-A bill to provide health services for improved nutrition, increased physical activity, obesity prevention, and for other purposes.

Environmental Health

H.R. 183/S. 720-Rep. Louise Slaughter (D-NY)/Energy and Commerce (1/3/01)-Sen. Mary Landrieu (D-LA)/Health, Education, Labor, and Pensions (4/5/01)-A bill to provide for awards by the National Institute of Environmental Health Sciences to develop and operate multidisciplinary research centers regarding the impact of environmental factors on women's health and disease prevention.

H.R. 360-Rep. Carolyn Maloney (D-NY)/Energy and Commerce (1/31/01)-A bill to establish a program of research regarding the risks posed by the presence of dioxin, synthetic fibers, and other additives in feminine hygiene products, and to establish a program for the collection and analysis of data on toxic shock syndrome.

H.R. 1723/S. 830-Rep. Nita Lowey (D-NY)/Energy and Commerce-Sen. Lincoln Chafee (R-RI)/Health, Education, Labor, and Pensions (5/3/01)-A bill to authorize the Director of the National Institute of Environmental Health Sciences to make grants for the development and operation of research centers regarding environmental factors that may be related to the etiology of breast cancer.

H.R. 4709-Rep. Louise Slaughter (D-NY)/Energy and Commerce, Resources, Science (5/9/02)-A bill to authorize the Director of the National Institute of Environmental Health Sciences to conduct and coordinate a research program on hormone disruption.

Family Caregivers/Long-term Care

H.R. 252-Rep. Benjamin Gilman (R-NY)/Government Reform (1/30/01)-A bill to establish a dependent care assistance program for federal employees.

H. Con. Res. 37-Rep. Christopher Shays (R-CT)/Education and the Workforce, Ways and Means (2/14/01)-A concurrent resolution expressing the sense

of Congress with respect to promoting coverage of individuals under long-term care insurance.

H.R. 831-Rep. Nancy Johnson (R-CT)/Ways and Means (3/1/01)-A bill to allow individuals a deduction for qualified long-term care insurance premiums, use of such insurance under cafeteria plans and flexible spending arrangements, and a credit for individuals with long-term care needs.

S. 464-Sen. Evan Bayh (D-IN)/Finance (3/5/01)-A bill to allow a tax credit for long-term caregivers.

H.R. 1041/S. 2199-Rep. John Peterson (R-PA)/Energy and Commerce (3/22/01)-Sen. Larry Craig (R-ID)/Finance (4/18/02)-A bill to permit additional states to enter into long-term care partnerships under Medicaid in order to promote the use of long-term care insurance.

S. 627-Sen. Charles Grassley (R-IA)/Finance (3/27/01)-A bill to allow individuals a deduction for qualified long-term care insurance premiums, use of such insurance under cafeteria plans and flexible spending arrangements, and a credit for long-term care needs.

H.R. 2575-Rep. John Murtha (D-PA)/Ways and Means (7/19/01)-A bill to provide a credit against income tax for caregivers of individuals with long-term care needs.

H.R. 4002-Rep. Susan Davis (D-CA)/Ways and Means (3/19/02)-A bill to allow individuals a deduction for qualified long-term care insurance premiums, use of such insurance under cafeteria plans and flexible spending arrangements, and a credit for individuals with long-term care needs.

S. 2489/H.R. 5241-Sen. Hillary Rodham Clinton (D-NY)/Health, Education, Labor, and Pensions (5/9/02)-Rep. James Langevin (D-RI)/Energy and Commerce (6/26/02)-A bill to establish a program to assist family caregivers in accessing affordable and high-quality respite care, and for other purposes.

H.R. 4946-Rep. J.D. Hayworth (R-AZ)/Ways and Means (6/17/02)-A bill to provide health care incentives related to long-term care.

S. 2655-Sen. John Rockefeller (D-WV)/Finance (6/20/02)-A bill to improve access to long-term care services under Medicare and Medicaid.

H.R. 5139-Rep. James Oberstar (D-MN)/Energy and Commerce, Ways and Means, Veterans' Affairs (7/16/02)-A bill to provide certain caregivers with access to Medicare benefits, to provide a long-term care tax credit, and to provide for programs within the Departments of Health and Human Services and Veterans Affairs for patients with fatal chronic illnesses.

S. 3179-Sen. Richard Durbin (D-IL)/Health, Education, Labor, and Pensions (11/9/02)-A bill to provide health care coverage for qualified caregivers.

Family Planning (see Reproductive Health Issues)

Family Planning Informed Consent

H.R. 185-Rep. Louise Slaughter (D-NY)/Judiciary (1/3/01)-A bill to prohibit any state or federal government authority from restricting a health professional's right to give, or a woman's right to receive, information about reproductive health options, including family planning, prenatal care, adoption, and abortion services.

Genetic Discrimination

H.R. 602/S. 318-Rep. Louise Slaughter (D-NY)/Education and the Workforce, Energy and Commerce-Sen. Thomas Daschle (D-SD)/Health, Education, Labor, and Pensions (2/13/01)-A bill to prohibit discrimination on the basis of genetic information with respect to health insurance.

S. 382-Sen. Olympia Snowe (R-ME)/Health, Education, Labor, and Pensions (2/15/01)-A bill to prohibit discrimination on the basis of genetic information with respect to health insurance.

S. 1995-Sen. Olympia Snowe (R-ME)/Health, Education, Labor, and Pensions (3/6/02)-A bill to

prohibit discrimination on the basis of genetic information with respect to health insurance and employment.

Health Care Access

H.R. 16-Rep. John Dingell (D-MI)/Energy and Commerce, Ways and Means (1/3/01)-A bill to provide a program of national health insurance.

H.R. 55-Rep. David Dreier (R-CA)/Government Reform, Ways and Means (1/3/01)-A bill to make the Federal Employees Health Benefits Program available to individuals age 55 to 65 who would not otherwise have health insurance.

S. 6-Sen. Thomas Daschle (D-SD)/Health, Education, Labor, and Pensions (1/22/01)-A bill to protect consumers in managed care plans and other health coverage.

S. 24-Sen. Trent Lott (R-MS)/Health, Education, Labor, and Pensions (1/22/01)-A bill to provide improved access to health care, enhance informed individual choice regarding health care services, lower health care costs through the use of appropriate providers, improve the quality of health care, and improve access to long-term care.

H.R. 389-Rep. Anthony Weiner (D-NY)/Education and the Workforce, Energy and Commerce, Government Reform (1/31/01)-A bill to require coverage for the treatment of infertility.

H.R. 567-Rep. Robert Andrews (D-NJ)/Energy and Commerce (2/13/01)-A bill to require Medicaid coverage of disabled children, and individuals who became disabled as children, without regard to income or assets.

H.R. 568-Rep. Robert Andrews (D-NJ)/Education and the Workforce, Energy and Commerce, Government Reform (2/13/01)-A bill to assure equitable treatment of fertility and impotence in health care coverage under group health plans, health insurance coverage, and health plans under the Federal Employees Health Benefits Program.

H.R. 600/ S. 321-Rep. Pete Sessions (R-TX)/Energy and Commerce-Sen. Charles Grassley (R-IA)/Finance (2/13/01)-A bill to provide families of disabled children with the opportunity to purchase coverage under the Medicaid program for such children.

H.R. 792-Rep. Sue Kelly (R-NY)/Energy and Commerce, Ways and Means (2/28/01)-A bill to require that group and individual health insurance coverage and group health plans provide coverage for treatment of a minor child's congenital or developmental deformity or disorder due to trauma, infection, tumor, or disease.

H. J. Res. 29-Rep. Jesse Jackson (D-IL)/Judiciary (3/6/01)-A joint resolution proposing an amendment to the Constitution of the United States regarding the right of citizens of the United States to health care of equal high quality.

H. Res. 87-Rep. Michael Capuano (D-MA)/Energy and Commerce (3/13/01)-A resolution to express the sense of the House that the federal investment in programs that provide health care services to uninsured and low-income individuals in medically underserved areas be increased in order to double access to care over the next 5 years.

S. 554-Sen. Patty Murray (D-WA)/Finance (3/15/01)-A bill to expand Medicare coverage of certain self-injected biologicals.

S. 573/ H.R. 2701-Sen. Dianne Feinstein (D-CA)/Finance (3/20/01)-Rep. Jane Harman (D-CA)/Energy and Commerce (8/1/01)-A bill to allow children enrolled in the State Children's Health Insurance Program to be eligible for benefits under the pediatric vaccine distribution program.

S. 574-Sen. Dianne Feinstein (D-CA)/Finance (3/20/01)-A bill to allow states to provide health benefits coverage for parents of children eligible for child health assistance under the State Children's Health Insurance Program.

S. 575-Sen. Dianne Feinstein (D-CA)/Health, Education, Labor, and Pensions (3/20/01)-A bill to establish standards relating to hospital lengths of stay.

H.R. 1202-Rep. Clay Shaw (R-FL)/Energy and Commerce, Ways and Means (3/22/01)-A bill to provide for coverage of annual screening pap smears and screening pelvic exams under the Medicare Program.

H.R. 1246-Rep. Martin Meehan (D-MA)/Government Reform (3/27/01)-A bill to provide that any health benefits plan under the Federal Employees Health Benefits Program that provides obstetrical benefits shall be required also to provide coverage for the diagnosis and treatment of infertility.

S. 710-Sen. Edward Kennedy (D-MA)/Health, Education, Labor, and Pensions (4/5/01)-A bill to require coverage for colorectal cancer screenings.

H.R. 1798-Rep. Jennifer Dunn (R-WA)/Energy and Commerce, Ways and Means (5/10/01)-A bill to establish procedures for determining payment amounts for new clinical diagnostic laboratory tests for which payment is made under Medicare.

H.R. 1809-Rep. Carolyn Maloney (D-NY)/Education and the Workforce, Government Reform, Ways and Means (5/10/01)-A bill to require that group and individual health plans provide coverage of cancer screening.

S. 868-Sen. Dianne Feinstein (D-CA)/Health, Education, Labor, and Pensions (5/10/01)-A bill to require that group and individual health plans provide coverage of cancer screening.

S. 872-Sen. John McCain (R-AZ)/Placed on the calendar (5/14/01)-A bill to protect consumers in managed care plans and other health coverage.

S. 874-Sen. Robert Torricelli (D-NJ)/Health, Education, Labor, and Pensions (5/15/01)-A bill to require health plans to include infertility benefits.

S. 889-Sen. Bill Frist (R-TN)/Health, Education, Labor, and Pensions (5/15/01)-A bill to protect consumers in managed care plans and in other health coverage.

H.R. 2563-Rep. Greg Ganske (R-IA)/Education and the Workforce, Energy and Commerce, Ways and Means (7/19/01)-A bill to protect consumers in managed care plans and other health coverage.

S. 1244/ H.R. 2630-Sen. Edward Kennedy (D-MA)/ Finance-Rep. John D. Dingell (D-MI)/Energy and Commerce (7/25/01)-A bill to provide for FamilyCare coverage for parents with enrolled children.

H.R. 2627-Rep. John Conyers (D-MI)/Energy and Commerce (7/25/01)-A bill to permit uninsured families and individuals to obtain coverage under Medicaid, to ensure coverage of doctor's visits, prescription drugs, mental health services, long-term care services, and alcohol and drug abuse treatment.

S. 1266-Sen. Hillary Rodham Clinton (D-NY)/Finance (7/27/01)-A bill to expand the provision of child health assistance to children with family incomes up to 300 percent of poverty.

S. 1297-Sen. Richard Durbin (D-IL)/Health, Education, Labor, and Pensions (8/1/01)-A bill to require comprehensive health insurance coverage for childhood immunization.

S. 1390-Sen. Jeff Bingaman (D-NM)/Finance (8/2/01)-A bill to require the Secretary of Health and Human Services to make grants to promote innovative outreach and enrollment efforts under the State Children's Health Insurance Program.

S. Con. Res. 94-Sen. Ron Wyden (D-OR)/Judiciary (1/24/02)-A concurrent resolution expressing the sense of Congress that public awareness and education about the importance of health care coverage is of the utmost priority and that a National Importance of Health Care Coverage Month should be established to promote that awareness and education.

H.R. 3710/ S. 1931-Rep. Benjamin Cardin (D-MD)/Energy and Commerce, Ways and Means (2/8/02)-Sen. Joseph Lieberman (D-CT)/Finance (2/11/02)-A bill to improve patient access to, and utilization of, the colorectal cancer screening benefit under Medicare.

H.R. 3729-Rep. Ted Strickland (D-OH)/Energy and Commerce (2/12/02)-A bill to improve the health benefits coverage of infants and children under Medicaid and the State Children's Health Insurance Program.

H.R. 4000-Rep. Jerry Weller (R-IL)/Energy and Commerce, Ways and Means (3/19/02)-A bill to enhance the access of Medicare beneficiaries who live in medically underserved areas to critical primary and preventive health care benefits, to improve the Medicare Choice program, and for other purposes.

S. 2042-Sen. Susan Collins (R-ME)/Finance (3/21/02)-A bill to expand access to affordable health care and to strengthen the health care safety net and make health care services more available in rural and underserved areas.

S. 2449-Sen. Jeff Bingaman (D-NM)/Finance (5/2/02)-A bill to allow federal payments to be made to states under Medicaid for providing pregnancy-related services or services for the testing or treatment for communicable diseases to aliens who are not lawfully admitted for permanent residence or otherwise permanently residing in the United States, and for other purposes.

H.R. 4959-Rep. Mike Ross (D-AR)/Education and the Workforce, Energy and Commerce (6/18/02)-A bill to require health insurance coverage for certain reconstructive surgery.

S. 2638-Sen. Edward Kennedy (D-MA)/Health, Education, Labor, and Pensions (6/18/02)-A bill to provide health benefits for workers and their families.

S. 2674-Sen. Sam Brownback (R-KS)/Judiciary (6/25/02)-A bill to improve access to health care in medically underserved areas.

S. 2819-Sen. James Jeffords (I-VT)/Finance (7/30/02)-A bill to permit qualifying states to use a portion of their unspent allotments under the State Children's Health Insurance Program to expand health coverage under that program or for expenditures under Medicaid, and for other purposes.

S. 3086-Sen. Blanche Lambert Lincoln (D-AR)/Finance (10/9/02)-A bill to provide coverage under Medicare for diabetes laboratory diagnostic tests and other services to screen for diabetes.

H.R. 5656-Rep. Ken Bentsen (D-TX)/Energy and Commerce (10/16/02)-A bill to permit the use of unexpended allotments under the State Children's Health Insurance Program through fiscal year 2006.

Health Status of Women of Color

H.R. 1218-Rep. Joe Baca (D-CA)/Energy and Commerce (3/27/01)-A bill to provide for an African American Health Initiative under which demonstration projects conduct targeted health campaigns directed at high-risk African American populations.

H. Con. Res. 388/S. Con. Res. 139-Del. Donna Christensen (D-VI)/Energy and Commerce (4/25/01)-Sen. Robert Torricelli (D-NJ)/Judiciary (9/17/02)-A concurrent resolution expressing the sense of the Congress that there should be established a National Minority Health and Health Disparities Month.

H.R. 4937-Rep. John Lewis (D-GA)/Energy and Commerce, Ways and Means (6/13/02)-A bill to allow individuals to designate that a portion or all of their income tax refunds be used jointly by the Office of Minority Health of the Department of Health and Human Services and the Office on Women's Health of such Department to improve the health of minorities and women.

H.R. 5187-Rep. Robert Menendez (D-NJ)/Energy and Commerce (7/23/02)-A bill to authorize the Health Resources and Services Administration and the National Cancer Institute to make grants for model programs to provide to individuals of health disparity populations prevention, early detection, treatment,

and appropriate follow-up care services for cancer and chronic diseases, and to make grants regarding patient navigators to assist individuals of health disparity populations in receiving such services.

S. Con. Res. 139-Sen. Robert Torricelli (D-NJ)/Judiciary (9/17/02)-A concurrent resolution expressing the sense of Congress that there should be established a National Minority Health and Health Disparities Month.

S. 2990/ H.R. 5449-Sen. Jeff Bingaman (D-NM)/Finance (9/23/02)-Rep. Ciro Rodriguez (D-TX)/Energy and Commerce (9/24/02)-A bill to provide for programs and activities to improve the health of Hispanic individuals, and for other purposes.

H.R. 5482-Rep. Diana DeGette (D-CO)/Energy and Commerce (9/26/02)-A bill to prevent and cure diabetes and to promote and improve the care of individuals with diabetes for the reduction of health disparities within racial and ethnic minority groups, including the African-American, Hispanic American, Asian American and Pacific Islander, American Indian, and Alaskan Native communities.

HIV/AIDS

H.R. 684-Rep. Juanita Millender-McDonald (D-CA)/International Relations (2/14/01)-A bill to authorize assistance for mother-to-child HIV/AIDS transmission prevention efforts.

H.R. 2063/ S. 987-Rep. Nancy Pelosi (D-CA)/Energy and Commerce-Sen. Robert Torricelli (D-NJ)/Finance (6/5/01)-A bill to permit states the option to provide Medicaid coverage for low-income individuals infected with HIV.

H.R. 2405/S. 1752-Rep. Connie Morella (R-MD)/Energy and Commerce (6/28/01)-Sen. Jon Corzine (D-NJ)/Health, Education, Labor, and Pensions (11/30/01)-A bill to facilitate the development of microbicides for preventing transmission of HIV and other sexually transmitted diseases.

H.R. 4644-Rep. Gary Ackerman (D-NY)/Energy and Commerce (5/2/02)-A bill to amend the Public Health Service Act with respect to testing pregnant women and newborn infants for infection with the human immunodeficiency virus.

HPV/Cervical Cancer

H. Con. Res. 309-Rep. Juanita Millender-McDonald (D-CA)/Energy and Commerce (1/29/02)-A concurrent resolution recognizing the importance of good cervical health and of detecting cervical cancer during its earliest stages.

International Women's Health

H.R. 361-Rep. Carolyn Maloney (D-NY)/International Relations (1/31/01)-A bill to provide for international family planning funding for the fiscal year 2002.

H.R. 544-Rep. Carolyn Maloney (D-NY)/International Relations (2/8/01)-A bill to require the Attorney General to promulgate regulations relating to gender-related persecution, including female genital mutilation, for use in determining an alien's eligibility for asylum or withholding of removal.

H.R. 755-Rep. Nita Lowey (D-NY)/International Relations (2/27/01)-A bill to prohibit the application of certain restrictive eligibility requirements to foreign nongovernmental organizations with respect to the provision of assistance under part I of the Foreign Assistance Act of 1961.

S. 463-Sen. Dianne Feinstein (D-CA)/Health, Education, Labor, and Pensions (3/6/01)-A bill to provide for increased access to HIV/AIDS-related treatments and services in developing foreign countries.

H.R. 933-Rep. Maxine Waters (D-CA)/International Relations, Ways and Means (3/7/01)-A bill to require certain actions with respect to the availability of HIV/AIDS pharmaceuticals and medical technologies in developing countries, including sub-Saharan African countries.

H. Con. Res. 70-Rep. Tom Sawyer (D-OH)/Energy and Commerce, International Relations (3/19/01)-A con-

current resolution expressing the sense of Congress that the United States should develop, promote, and implement policies to slow global population growth by voluntary means.

S. J. Res. 9-Sen. Barbara Boxer (D-CA)/Foreign Relations (3/20/01)-A joint resolution providing for congressional disapproval of the rule submitted by the United States Agency for International Development relating to the restoration of the Mexico City Policy.

H.R. 1117-Rep. Carolyn Maloney (D-NY)/International Relations (3/20/01)-A bill to provide a United States voluntary contribution to the United Nations Population Fund.

H.R. 1269-Rep. Joseph Crowley (D-NY)/Energy and Commerce (3/28/01)-A bill to improve global health by increasing assistance to developing nations with high levels of infectious disease and premature death, by improving children's and women's health and nutrition, by reducing unintended pregnancies, and by combating the spread of infectious diseases, particularly HIV/AIDS.

H.R. 2069-Rep. Henry Hyde (R-IL)/International Relations (6/6/01)-A bill to authorize assistance to prevent, treat, and monitor HIV/AIDS in sub-Saharan African and other developing countries.

H.R. 2104-Rep. Eddie Bernice Johnson (D-TX)/International Relations (6/7/01)-A bill to authorize the provision of education and related services to law enforcement and military personnel of foreign countries to prevent and control HIV/AIDS and tuberculosis.

S. 1032-Sen. Bill Frist (R-TN)/Foreign Relations (6/13/01)-A bill to authorize expanded assistance to countries seriously affected by HIV/AIDS, malaria, and tuberculosis.

S. 2649-Sen. Edward Kennedy (D-MA)/Health, Education, Labor, and Pensions (6/19/01)-A bill to provide assistance to combat the HIV/AIDS pandemic in developing foreign countries.

S. 1120-Sen. Barbara Boxer (D-CA)/Foreign Relations (6/28/01)-A bill to increase the authorization of appropriations for fiscal year 2002, and to authorize appropriations for fiscal year 2003, to combat HIV and AIDS, and for other purposes.

S. 1230-Sen. Bill Frist (R-TN)/Foreign Relations (7/24/01)-A bill to focus American efforts on HIV/AIDS, tuberculosis, and malaria in developing countries.

S. 1573-Sen. Kay Bailey Hutchison (R-TX)/Foreign Relations (10/25/01)-A bill to authorize the provision of educational and health care assistance to the women and children of Afghanistan.

H. Res. 281-Rep. Louise Slaughter (D-NY)/International Relations (11/7/01)-A resolution commending and urging increased support for organizations led by Afghan women that are providing substantial education, health, and relief services, and for the inclusion of women in any new government established in that nation.

S. 1936-Sen. Richard Durbin (D-IL)/Health, Education, Labor, and Pensions (2/12/02)-A bill to address the international HIV/AIDS pandemic.

H. Con. Res. 344-Rep. Jan Schakowsky (D-IL)/Judiciary, International Relations (3/7/02)-A concurrent resolution supporting the goals of International Women's Day.

H.R. 3916-Rep. Carolyn Maloney (D-NY)/International Relations (3/7/02)-A bill to provide a United States voluntary contribution to the United Nations Population Fund.

S. Res. 223-Sen. Joseph Biden (D-DE)/Foreign Relations (3/8/02)-A resolution designating March 8, 2002, as "International Women's Day."

H. Con. Res. 349-Rep. Juanita Millender-McDonald (D-CA)/International Relations (3/13/02)-A concurrent resolution calling for an end to the sexual exploitation of refugees.

H.R. 3975-Rep. James Leach (R-IA)/Financial Services (3/14/02)-A bill to provide additional funding for the Global Fund to Fight AIDS, Tuberculosis and Malaria through a drawdown fund at the International Monetary Fund between 2004-2006.

H.R. 4114-Rep. Connie Morella (R-MD)/Financial Services, International Relations, Ways and Means (4/9/02)-A bill to increase the United States financial and programmatic contributions to advancing the status of women and girls in low-income countries around the world, and for other purposes.

S. 2525/H.R. 5761-Sen. John Kerry (D-MA)/Foreign Relations (5/15/02)-Rep. Henry Hyde (R-IL)/International Relations (11/19/02)-A bill to increase assistance for foreign countries seriously affected by HIV/AIDS, tuberculosis, and malaria, and for other purposes.

S. 2647-Sen. Olympia Snowe (R-ME)/Foreign Relations (6/19/02)-A bill to require that activities carried out by the United States in Afghanistan relating to governance, reconstruction and development, and refugee relief and assistance will support the basic human rights of women and women's participation and leadership in these areas.

S. 2649-Sen. Edward Kennedy (D-MA)/Health, Education, Labor, and Pensions (6/19/02)-A bill to provide assistance to combat the HIV/AIDS pandemic in developing foreign countries.

H.R. 5293-Rep. Carolyn Maloney (D-NY)/International Relations (7/26/02)-A bill to provide for permanent guidelines for United States voluntary contributions to the United Nations Population Fund.

H.R. 5681-Rep. Joseph Pitts (R-PA)/International Relations (10/16/02)-A bill to provide assistance for the prevention, treatment, and control of HIV/AIDS, tuberculosis, malaria, polio, and other infectious diseases as such diseases affect children in the countries of Central Asia.

Mammography

H.R. 292-Rep. Jerrold Nadler (D-NY)/Education and the Workforce, Energy and Commerce (1/30/01)-A bill to require that group and individual health insurance coverage and group health plans provide coverage for annual screening mammography for women 40 years of age or older if the coverage or plans include coverage for diagnostic mammography.

H.R. 1064-Rep. Robert Andrews (D-NJ)/Education and the Workforce, Energy and Commerce (3/15/01)-A bill to require that group and individual health insurance coverage and group health plans provide coverage for annual screening mammography for any class of covered individuals if the coverage or plans include coverage for diagnostic mammography for such class and to provide for coverage of annual screening mammography under Medicaid.

S. 548-Sen. Arlen Specter (R-PA)/Finance (3/15/01)-A bill to provide enhanced reimbursement for, and expanded capacity to, mammography services under Medicare, and for other purposes.

H.R. 1328-Rep. David Hobson (R-OH)/Energy and Commerce, Ways and Means (3/30/01)-A bill to provide enhanced reimbursement for mammography services under Medicare.

H.R. 1354-Rep. Peter King (R-NY)/Energy and Commerce (4/3/01)-A bill to provide enhanced reimbursement for, and expanded capacity to, mammography services under Medicare.

S. Res. 164-Sen. Joseph Biden (D-DE)/Judiciary (10/1/01)-A resolution designating October 19, 2001, as "National Mammography Day."

S. 2591/H.R. 4888-Sen. Barbara Mikulski (D-MD)/Health, Education, Labor, and Pensions (6/5/02)-Rep. John Dingell (D-MI)/Energy and Commerce (6/6/02)-A bill to reauthorize the Mammography Quality Standards Act, and for other purposes.

S. Res. 326-Sen. Joseph Biden (D-DE)/Judiciary (9/12/02)-A resolution designating October 18, 2002, a "National Mammography Day."

H. Con. Res. 502-Rep. David Vitter (R-LA)/Energy and Commerce (10/7/02)-A concurrent resolution expressing the sense of Congress in support of Breast Cancer Awareness Month, and for other purposes.

H. Con. Res. 513-Rep. Juanita Millender-McDonald (D-CA)/Government Reform (10/17/02)-A concurrent resolution supporting the goals and ideals of National Mammography Day.

Mastectomy and Reconstructive Breast Surgery

H.R. 536-Rep. Rosa DeLauro (D-CT)/Energy and Commerce, Education and the Workforce (2/8/01)-A bill to require that group and individual health insurance coverage and group health plans provide coverage for a minimum hospital stay for mastectomies and lymph node dissections performed for the treatment of breast cancer.

S. 255/H.R. 1485-Sen. Olympia Snowe (R-ME)/Health, Education, Labor, and Pensions (2/6/01)-Rep. Frank LoBiondo (R-NJ)/Education and the Workforce, Ways and Means (4/4/01)-A bill to require that health plans provide coverage for a minimum hospital stay for mastectomies and lymph node dissection for the treatment of breast cancer and coverage for secondary consultation.

S. 331/H.R. 887-Sen. Joseph Biden (D-DE)/Finance (2/14/01)-Rep. Sue Kelly (R-NY)/Ways and Means (3/6/01)-A bill to require group health plans to provide coverage for reconstructive surgery following mastectomy, consistent with the Women's Health and Cancer Rights Act of 1998.

Mental Health

H.R. 75-Rep. Sheila Jackson Lee (D-TX)/Energy and Commerce (1/3/01)-A bill to amend the Public Health Service Act with respect to mental health services for children, adolescents, and their families.

H. Res. 14-Rep. Marge Roukema (R-NJ)/Energy and Commerce (1/3/01)-A resolution expressing the sense of the House with respect to the seriousness of the national problems associated with mental illness and with respect to congressional intent to establish a Mental Health Advisory Committee.

H.R. 162-Rep. Marge Roukema (R-NJ)/Education and the Workforce, Energy and Commerce, Ways and Means (1/3/01)-A bill to prohibit group and individual health plans from imposing treatment limitations or financial requirements on the coverage of mental health benefits and on the coverage of substance abuse and chemical dependency benefits if similar limitations are not imposed on medical and surgical benefits.

S. 543/ H.R. 4066-Sen. Pete Domenici (R-NM)/Health, Education, Labor, and Pensions (3/15/01)- Rep. Marge Roukema (R-NJ)/Education and the Workforce, Energy and Commerce (3/20/02)-A bill to provide for equal coverage of mental health benefits with respect to health insurance coverage unless comparable limitations are imposed on medical and surgical benefits.

S. 690-Sen. Paul Wellstone (D-MN)/Finance (4/4/01)-A bill to expand and improve coverage of mental health services under Medicare.

S. 859-Sen. Craig Thomas (R-WY)/Health, Education, Labor, and Pensions (5/10/01)-A bill to establish a mental health community education program.

H.R. 2805-Rep. Joseph Pitts (R-PA)/Energy and Commerce (8/2/01)-A bill to provide for research on services for individuals with post-abortion depression and psychosis.

S. Con. Res. 71-Sen. Mary Landrieu (D-LA)/Judiciary (9/21/01)-A concurrent resolution designating the week of October 7 through October 13, 2001, as "National Mental Health Awareness Week."

H.R. 2992-Rep. Carolyn Maloney (D-NY)/Energy and Commerce, Ways and Means, Education and the Workforce (10/2/01)-A bill to clarify the application of

the mental health parity provisions to annual and life-time visit or benefit limits, as well as dollar limits.

S. 1535-Sen. Richard Durbin (D-IL)/Health, Education, Labor, and Pensions (10/11/01)-A bill to provide for research on, and services for, individuals with, postpartum depression and psychosis.

S. 1760-Sen. Craig Thomas (R-WY)/Finance (12/4/01)-A bill to provide for the coverage of marriage and family therapist services and mental health counselor services under part B of Medicare.

S. 2203-Sen. John Edwards (D-NC)/Health, Education, Labor, and Pensions (4/18/02)-A bill to provide grants for mental health and substance abuse services for women and children who have been victims of domestic or sexual violence.

S. 2204-Sen. John Edwards (D-NC)/Health, Education, Labor, and Pensions (4/18/02)-A bill to improve treatment for the mental health and substance abuse needs of women with histories of trauma, including domestic and sexual violence.

S. 2393-Sen. Richard Durbin (D-IL)/Health, Education, Labor, and Pensions (4/29/02)-A bill to provide protections for individuals who need mental health services, and for other purposes.

S. 2427-Sen. Jeff Bingaman (D-NM)/Health, Education, Labor, and Pensions (4/30/02)-A bill to require the National Institute of Mental Health and the Human Resources and Services Administration to award grants to prevent and treat depression.

H.R. 5077-Rep. Patrick Kennedy (D-RI)/Energy and Commerce (7/9/02)-A bill to amend the Public Health Service Act with respect to mental health services for elderly individuals.

H.R. 5613-Rep. Rosa DeLauro (D-CT)/Education and the Workforce, Energy and Commerce (10/10/02)-A bill to establish a demonstration project to implement evidence-based preventive-screening methods to detect mental illness and suicidal tendencies in school-age youth at selected facilities.

Mid-Life and Older Women

S. 208/H.R. 633-Sen. Bill Frist (R-TN)/Health, Education, Labor, and Pensions (1/30/01)-Rep. Rosa DeLauro (D-CT)/Energy and Commerce (2/14/01)-A bill to provide supplemental grants for additional preventive health services for women.

S. 982/ H.R. 2058-Sen. Bob Graham (D-FL)/Energy and Commerce, Ways and Means-Rep. Sander Levin (D-MI)/Energy and Commerce, Ways and Means, Rules (6/5/01)-A bill to promote primary and secondary health promotion and disease prevention services and activities among the elderly, and to amend Title XVIII of the Social Security Act to add preventive health benefits.

H.R. 2704-Rep. Sheila Jackson Lee (D-TX)/Energy and Commerce (8/1/01)-A bill to allow states and localities to provide primary and preventive care to all individuals.

H.R. 5204-Rep. Barbara Lee (D-CA)/Education and the Workforce, Energy and Commerce, Government Reform, Veterans Affairs, Ways and Means (7/24/02)-A bill to provide for coverage of hormone replacement therapy and alternative treatments for hormone replacement therapy under Medicare and Medicaid, group health plans and individual health insurance coverage, and other Federal health insurance programs.

Miscellaneous

S. 160-Sen. Barbara Boxer (D-CA)/Health, Education, Labor, and Pensions (1/23/01)-A bill to provide assistance to states to expand and establish drug abuse treatment programs to enable such programs to provide services to individuals who voluntarily seek treatment for drug abuse.

H. Con. Res. 59/S. Res. 55-Rep. Howard McKeon (R-CA)/Government Reform-Sen. Paul Wellstone (D-MN)/Judiciary (3/8/01)-A resolution designating the third week of April as National Shaken Baby Syndrome Awareness Week for the year 2001 and all future years.

H.R. 1215-Rep. James Greenwood (R-PA)/Energy and Commerce, Judiciary (3/27/01)-A bill to ensure confidentiality with respect to medical records and health care-related information, and for other purposes.

S. 1976-Sen. Dianne Feinstein (D-CA)/Health, Education, Labor, and Pensions (2/28/02)-A bill to provide for a comprehensive federal effort relating to treatments for, and the prevention of cancer, and for other purposes.

S. 2139-Sen. Jeff Bingaman (D-NM)/Health, Education, Labor, and Pensions (4/17/02)-A bill to amend the Public Health Service Act to provide grants to promote positive health behaviors in women.

S. 2955-Sen. Sam Brownback (R-KS)/Health, Education, Labor, and Pensions (9/18/02)-A bill to improve data collection and dissemination, treatment, and research relating to cancer, and for other purposes.

H. Con. Res. 474-Rep. Karen McCarthy (D-MO)/Energy and Commerce (9/19/02)-A concurrent resolution expressing the sense of Congress that private health insurance companies should take a proactive role in promoting healthy lifestyles, and for other purposes.

S. 2980-Sen. Christopher Bond (R-MO)/Health, Education, Labor, and Pensions (9/19/02)-A bill to revise and extend the Birth Defects Prevention Act of 1998.

S. 3084-Sen. Bill Frist (R-TN)/Health, Education, Labor, and Pensions (10/9/02)-A bill to provide for the conduct of a study concerning health services research.

H.R. 5659-Rep. Michael Castle (R-DE)/Education and the Workforce, Energy and Commerce (10/16/02)-A bill to establish a comprehensive program for the prevention of obesity.

H.R. 5662-Rep. Jennifer Dunn (R-WA)/Energy and Commerce (10/16/02)-A bill to permit the use of unexpended allotments under the State Children's

Health Insurance Program for an additional fiscal year, and for other purposes.

H.R. 5703-Rep. Lucille Roybal-Allard (D-CA)/Energy and Commerce (10/28/02)-A bill to establish grant programs to provide for education and outreach on newborn screening and coordinated follow-up care once newborn screening has been conducted, and for other purposes.

Nursing

H.R. 2594-Rep. Walter Jones (R-NC)/Energy and Commerce (7/23/01)-A bill to include tertiary-care nurses in the program for the National Health Service Corps.

S. 1281-Sen. Edward Kennedy (D-MA)/Health, Education, Labor, and Pensions (7/31/01)-A bill to reauthorize and strengthen the community health centers program and the National Health Service Corps.

H.R. 3020-Rep. Sue Kelly (R-NY)/Energy and Commerce (10/4/01)-A bill to establish a Nurse Corps and recruitment and retention strategies to address the nursing shortage.

S. 1585-Sen. Joseph Lieberman (D-CT)/Health, Education, Labor, and Pensions (10/30/01)-A bill to establish grant and scholarship programs to enable hospitals to retain and further educate their nursing staffs.

S. 1594-Sen. Hillary Rodham Clinton (D-NY)/Health, Education, Labor, and Pensions (10/30/01)-A bill to provide programs to improve nurse retention, the nursing workplace, and the quality of care.

H.R. 3195-Rep. Joseph Crowley (D-NY)/Energy and Commerce, Ways and Means (10/31/01)-A bill to extend the Medicare Community Nursing Organization demonstration project.

S. 1597-Sen. John Kerry (D-MA)/Health, Education, Labor, and Pensions (10/31/01)-A bill to establish programs to alleviate the nursing profession shortage.

H.R. 3238-Rep. Pete Stark (D-CA)/Energy and Commerce, Ways and Means (11/6/01)-A bill to provide for patient protection by limiting the number of mandatory overtime hours a nurse may be required to work for certain providers of services to which payments are made under Medicare.

H.R. 3487-Rep. Michael Bilirakis (R-FL)/Energy and Commerce (12/13/01)-A bill to amend the Public Health Service Act with respect to health professions programs regarding the field of nursing.

Obstetricians-Gynecologists

H.R. 1440-Rep. Susan Davis (D-CA)/Education and the Workforce, Ways and Means (4/4/01)-A bill to require that group and individual health insurance coverage and group health plans permit enrollees direct access to services of obstetrical and gynecological physician services without a referral.

H.R. 2314-Rep. Kay Granger (R-TX)/Education and the Workforce (6/26/01)-A bill to provide to participants and beneficiaries of group health plans access to obstetric and gynecological care.

Osteoporosis

S. 263/H.R. 689-Sen. Olympia Snowe (R-ME)/Governmental Affairs (2/6/01)-Rep. Connie Morella (R-MD)/Government Reform (2/14/01)-A bill to ensure that coverage of bone mass measurements is provided under the Federal Employees Health Benefits Program.

S. 264/H.R. 595-Sen. Olympia Snowe (R-ME)/Finance (2/6/01)-Rep. Connie Morella (R-MD)/Energy and Commerce, Ways and Means (2/13/01)-A bill to expand coverage of bone mass measurements under part B of Medicare to all individuals at clinical risk for osteoporosis.

H.R. 1683/S. 819-Rep. Carolyn Maloney (D-NY)/Education and the Workforce, Energy and Commerce (5/2/01)-Sen. Robert Torricelli (D-NJ)/Health, Education, Labor, and Pensions (5/3/01)-A bill to require group and individual health plans to provide coverage for qualified individuals for bone mass measurement to prevent fractures associated with

osteoporosis and to help women make informed choices about their reproductive and post-menopausal health care.

H.R. 1720/S. 826-Rep. John Lewis (D-GA)/Energy and Commerce, Ways and Means (5/3/01)-Sen. Blanche Lincoln (D-AR)/Finance (5/3/01)-A bill to eliminate cost-sharing under Medicare for bone mass measurements.

Ovarian Cancer

H.R. 326-Rep. Patsy Mink (D-HI)/Energy and Commerce (1/31/01)-A bill to provide for programs regarding ovarian cancer.

S. Res. 163-Sen. Mary Landrieu (D-LA)/Judiciary (9/21/01)-A resolution designating the week of September 23 through September 29, 2001, as "National Ovarian Cancer Awareness Week."

H.R. 3910-Rep. Steve Israel (D-NY)/Energy and Commerce, Ways and Means (3/7/02)-A bill to provide for coverage under Medicare of certain tests to screen for ovarian cancer upon certification by the Director of the National Institutes of Health that such tests are effective.

H. Con. Res. 385/S. Con. Res. 138-Rep. Steve Israel (D-NY)/Energy and Commerce (4/23/02)-Sen. Harry Reid (D-NV)/Health, Education, Labor, and Pensions (9/9/02)-A concurrent resolution expressing the sense of Congress that the Secretary of Health and Human Services should conduct or support research on certain tests to screen for ovarian cancer, and federal health care programs and group and individual health plans should cover the tests if demonstrated to be effective, and for other purposes.

H.R. 5068-Rep. Patsy Mink (D-HI)/Energy and Commerce (7/8/02)-A bill to expand the current provision of medical assistance to certain uninsured women who have been screened and found to have breast or cervical cancer to also cover ovarian and uterine cancer.

Prescription Drug Coverage

H.R. 758-Rep. Carolyn Maloney (D-NY)/Energy and Commerce, Ways and Means (2/27/01)-A bill to provide for substantial reductions in the price of prescription drugs for Medicare beneficiaries and for women diagnosed with breast cancer.

H.R. 803-Rep. Pete Stark (D-CA)/Ways and Means, Energy and Commerce (2/28/01)-A bill to make Medicare more competitive and efficient, to extend the solvency of Medicare, to provide for a prescription drug benefit under Medicare, to improve quality of care, to make Medicare supplemental insurance (Medigap) more affordable, and for other purposes.

H.R. 1641-Rep. Edolphus Towns (D-NY)/Energy and Commerce (4/26/01)-A bill to require states that provide Medicaid prescription drug coverage to cover drugs medically necessary to treat obesity.

H.R. 1624-Rep. Deborah Pryce (R-OH)/Energy and Commerce, Ways and Means (4/26/01)-A bill to provide for coverage under Medicare of all oral anticancer drugs.

S. 1135-Sen. Bob Graham (D-FL)/Finance (6/28/01)-A bill to provide comprehensive reform of Medicare, including the provision of coverage of outpatient prescription drugs under such program.

S. 1185-Sen. Ron Wyden (D-OR)/Finance (7/17/01)-A bill to ensure access for Medicare beneficiaries to prescription drug coverage through a SPICE drug benefit program.

S. 1239-Sen. Chuck Hagel (R-NE)/Finance (7/24/01)-A bill to provide Medicare beneficiaries with a drug discount card that ensures access to affordable outpatient prescription drugs.

H.R. 2632-Rep. Mark Foley (R-FL)/Energy and Commerce, Ways and Means (7/24/01)-A bill to provide Medicare beneficiaries with a drug discount card that ensures access to affordable outpatient prescription drugs.

S. 126-Sen. Bob Smith (R-NH)/Finance (7/27/01)-A bill to establish a voluntary Medicare prescription drug plan under which eligible Medicare beneficiaries may elect to receive coverage under the Rx Option for outpatient prescription drugs.

H.R. 3626-Rep. Jo Ann Emerson (R-MO)/Energy and Commerce, Ways and Means (1/24/02)-A bill to provide for an outpatient prescription drug benefit under Medicare.

H. Con. Res. 328-Rep. Carolyn Kilpatrick (D-MI)/Energy and Commerce, Ways and Means (2/13/02)-A concurrent resolution expressing the sense of Congress with respect to coverage of outpatient prescription drugs under Medicare and with respect to providing for appropriate new budget authority for such coverage.

H.R. 3913-Rep. Nita Lowey (D-NY)/Energy and Commerce, Education and the Workforce, Ways and Means (3/7/02)-A bill to require equitable treatment in health care coverage of prescription drugs under group health plans, health insurance coverage, Medicare and Medicaid managed care arrangements, Medigap insurance coverage, and health plans under the Federal Employees Health Benefits Program.

S. 2677-Sen. John Rockefeller (D-WV)/Finance (6/5/02)-A bill to improve consumer access to prescription drugs, and for other purposes.

S. 2625-Sen. Bob Graham (D-FL)/Finance (6/14/02)-A bill to provide coverage of outpatient prescription drugs under Medicare.

H.R. 4954-Rep. Nancy Johnson (R-CT)/Energy and Commerce, Ways and Means (6/18/02)-A bill to provide for a voluntary program for prescription drug coverage under Medicare, to modernize and reform payments and the regulatory structure of Medicare, and for other purposes.

H.R. 5019-Rep. Charles Rangel (D-NY)/Energy and Commerce, Ways and Means (6/26/02)-A bill to provide for a voluntary Medicare prescription drug

benefit, to provide greater access to affordable pharmaceuticals, to revise and improve payments to providers of services under Medicare, and for other purposes.

S. 2729-Sen. Chuck Grassley (R-IA)/Finance (7/15/02)-A bill to provide for a Medicare voluntary prescription drug delivery program, to modernize Medicare, and for other purposes.

S. 2736-Sen. Chuck Hagel (R-NE)/Finance (7/16/02)-A bill to provide Medicare beneficiaries with a drug discount card that ensures access to affordable outpatient prescription drugs.

S. 2747-Sen. Robert Torricelli (D-NJ)/Finance (7/16/02)-A bill to provide for substantial reductions in the price of prescription drugs for Medicare beneficiaries and for women diagnosed with breast cancer.

Reproductive Health Issues

H.R. 78-Rep. Jo Ann Emerson (R-MO)/Judiciary (1/3/01)-A bill proposing an amendment to the Constitution of the United States with respect to the right to life.

S. 104/H.R. 1111-Sen. Olympia Snowe (R-ME)/Health, Education, Labor, and Pensions (1/22/01)-Rep. James Greenwood (R-PA)/Education and the Workforce, Energy and Commerce (3/20/01)-A bill to require equitable coverage of prescription contraceptive drugs and devices, and contraceptive services under health plans.

S. 75-Sen. Jesse Helms (R-NC)/Placed on Calendar (1/22/01)-A bill to protect the lives of unborn human beings.

S. 76-Sen. Jesse Helms (R-NC)/Placed on Calendar (1/22/01)-A bill to make it a violation of a right secured by the Constitution and laws of the United States to perform an abortion with the knowledge that the abortion is being performed solely because of the gender of the fetus.

H.R. 285-Rep. Carolyn Maloney (D-NY)/Ways and Means, Education and the Workforce, Energy and Commerce (1/30/01)-A bill to protect breastfeeding by new mothers, provide for a performance standard for breast pumps, and to provide tax incentives to encourage breastfeeding.

S. 256-Sen. Olympia Snowe (R-ME)/Health, Education, Labor, and Pensions (2/6/01)-A bill to amend the Civil Rights Act of 1964 to protect breastfeeding by new mothers.

H.R. 482/S. 251-Rep. David Vitter (R-LA)/Energy and Commerce-Sen. Tim Hutchinson (R-AR)/Health, Education, Labor, and Pensions (2/6/01)-A bill to require the Food and Drug Administration to establish restrictions regarding the qualifications of physicians to prescribe the abortion drug commonly known as RU-486.

H. J. Res. 10-Rep. Jo Ann Emerson (R-MO)/Judiciary (2/7/01)-A joint resolution proposing an amendment to the Constitution of the United States with respect to the right to life.

H.R. 503-Rep. Lindsey Graham (R-SC)/Judiciary, Armed Services (2/7/01)-A bill to protect unborn children from assault and murder, and for other purposes.

H. J. Res. 20-Rep. James Oberstar (D-MN)/Judiciary (2/14/01)-A joint resolution proposing an amendment to the Constitution of the United States with respect to the right to life.

H. J. Res. 32-Rep. Jesse Jackson (D-IL)/Judiciary (3/6/01)-A joint resolution proposing an amendment to the Constitution of the United States relating to equality of rights and reproductive rights.

S. 480-Sen. Mike DeWine (R-OH)/Judiciary (3/7/01)-A bill to protect unborn victims of violence.

H.R. 1346-Rep. Barney Frank (D-MA)/Judiciary (4/3/01)-A bill to eliminate the prohibitions on the transmission of abortion-related material.

H.R. 1350-Rep. Loretta Sanchez (D-CA)/Armed Services (4/3/01)-A bill to restore freedom of choice to women in the uniformed services serving outside the United States.

S. 724-Sen. Christopher Bond (R-MO)/Finance (4/6/01)-A bill to provide for coverage of pregnancy-related assistance for targeted low-income pregnant women.

H.R. 1672/S. 2122-Rep. Stephanie Tubbs Jones (D-OH)/Energy and Commerce (5/2/01)-Sen. Jean Carnahan (D-MO)/Health, Education, Labor, and Pensions (4/15/02)-A bill to provide for an increase in funding for research on uterine fibroids through the National Institutes of Health, and to provide for a program to provide information and education to the public on such fibroids.

H.R. 2175/S. 1050-Rep. Steve Chabot (R-OH)/Judiciary-Sen. Rick Santorum (R-PA)/Judiciary (6/14/01)-A bill to protect infants who are born alive.

H. Con. Res. 165-Rep. Juanita Millender-McDonald (D-CA)/Energy and Commerce (6/19/01)-A concurrent resolution expressing the sense of the Congress that continual research and education into the cause and cure for fibroid tumors be addressed.

H.R. 2610-Rep. Nita M. Lowey (D-NY)/Energy and Commerce (7/24/01)-A bill to provide for coverage of pregnancy-related assistance for targeted low-income pregnant women.

H.R. 2702-Rep. Steny Hoyer (D-MD)/Energy and Commerce, Judiciary (8/1/01)-A bill to prohibit certain abortions.

H.R. 2763/S. 2271-Rep. Duncan Hunter (R-CA)/Judiciary (8/2/01)-Sen. Bob Smith (R-NH)/Health, Education, Labor, and Pensions (4/25/02)-A bill to protect the right to life of each born and pre-born human person in existence at fertilization.

S. 1373-Sen. Bob Smith (R-NH)/Judiciary (8/2/01)-A bill to protect the right to life of each born and pre-born human person in existence at fertilization.

S. 1343/H.R. 2777-Sen. Lincoln Chafee (R-RI)/Finance-Rep. Nita M. Lowey (D-NY)/Energy and Commerce (8/2/01)-A bill to provide states with options for providing family planning services and supplies to individuals eligible for medical assistance under Medicaid.

H.R. 2866-Rep. Loretta Sanchez (D-CA)/Armed Services (9/6/01)-A bill to restore freedom of choice to women in the uniformed services serving outside the United States.

H.R. 2875-Rep. Ron Paul (R-TX)/Judiciary (9/10/01)-A bill to provide that the inferior courts of the United States do not have jurisdiction to hear abortion-related cases.

H.R. 3006-Rep. Jo Ann Davis (R-VA)/Energy and Commerce (10/3/01)-A bill to require assurances that certain family planning service projects and programs will provide pamphlets containing the contact information for adoption centers.

H. Res. 254-Rep. Richard Armey (R-TX)/Government Reform (10/4/01)-A resolution supporting the goals of Pregnancy and Infant Loss Remembrance Day.

H.R. 3243-Rep. Chet Edwards (D-TX)/Energy and Commerce (11/7/01)-A bill to prohibit late-term abortions.

H. Res. 302-Rep. Bob Schaffer (R-CO)/Energy and Commerce (12/5/01)-A resolution expressing the sense of the House of Representatives with respect to crisis pregnancy centers.

H. Con. Res. 285-Rep. Louise Slaughter (D-NY)/Judiciary (12/6/01)-A concurrent resolution condemning the more than 500 anthrax threats sent to reproductive health centers and abortion providers since October 14, 2001.

H. Con. Res. 291-Rep. Howard McKeon (R-CA)/Energy and Commerce (12/18/01)-A concurrent resolution expressing the sense of the Congress with respect to endometriosis.

H.R. 3686/S. 1984-Rep. Cliff Stearns (R-FL)/Energy and Commerce (2/5/02)-Sen. Jim Bunning (R-KY)/Health, Education, Labor, and Pensions (3/4/02)-A bill to authorize the Secretary of Health and Human Services to make grants to nonprofit tax-exempt organizations for the purchase of ultrasound equipment to provide free examinations to pregnant women needing such services.

H. Res. 346-Rep. Ileana Ros-Lehtinen (R-FL)/Energy and Commerce (2/8/02)-A resolution expressing the sense of the House regarding prenatal care for women and children.

H.R. 3887/S. 1990-Rep. Louise Slaughter (D-NY)/Energy and Commerce-Sen. Patty Murray (D-WA)/Health, Education, Labor, and Pensions (3/6/02)-A bill to establish a public education and awareness program relating to emergency contraception.

S. 2008/H.R. 4691-Sen. Judd Gregg (R-NH)/Health, Education, Labor, and Pensions (3/12/02)-Rep. Michael Bilirakis (R-FL)/Energy and Commerce (5/9/02)-A bill to allow physicians and health care entities to opt out of performing or providing coverage for abortions if they object on religious or moral grounds.

H.R. 4113-Rep. Connie Morella (R-MD)/Energy and Commerce, Ways and Means (4/9/02)-A bill to provide for the provision by hospitals of emergency contraceptives to women who are survivors of sexual assault.

H. Con. Res. 380-Rep. Cynthia McKinney (D-GA)/Energy and Commerce (4/17/02)-A concurrent resolution expressing the sense of the Congress regarding women with bleeding disorders.

S. 2202-Sen. John Edwards (D-NC)/Health, Education, Labor, and Pensions (4/18/02)-A bill to increase professional and public awareness of the link between periodontal disease in pregnant women and pre-term, low-birth weight babies and the maternal transmission of dental caries.

H.R. 4602/S. 2328-Rep. John Dingell (D-MI)/Energy and Commerce-Sen. Tom Harkin (D-IA)/Health, Education, Labor, and Pensions (4/25/02)-A bill to reduce the rate of maternal morbidity and mortality, to eliminate racial and ethnic disparities in maternal health outcomes, to reduce pre-term labor, to examine the impact of pregnancy on the short-and long-term health of women, to expand knowledge about the safety and dosing of drugs to treat pregnant women with chronic conditions and women who become sick during pregnancy, to expand public health prevention, education and outreach, and to develop improved and more accurate data collection related to maternal morbidity and mortality.

H.R. 4965-Rep. Steve Chabot (R-OH)/Judiciary (6/19/02)-A bill to prohibit the procedure commonly known as partial-birth abortion.

S. 2923-Sen. Robert Torricelli (D-NJ)/Health, Education, Labor, and Pensions (9/11/02)-A bill to provide for the development and operation of centers to conduct research with respect to infertility prevention, and for other purposes.

Research

H. Con. Res. 17-Rep. Carolyn Maloney (D-NY)/Energy and Commerce (1/30/01)-A concurrent resolution expressing the sense of the Congress supporting federal funding of pluripotent stem cell research.

H.R. 744/ S. 393-Rep. Jennifer Dunn (R-WA)/Ways and Means-Sen. Bill Frist (R-TN)/Finance (2/27/01)-A bill to encourage charitable contributions to public charities for use in medical research.

H. Res. 72-Rep. George Gekas (R-PA)/Energy and Commerce (2/28/01)-A resolution to express the sense of the House that the federal investment in biomedical research should be increased by \$3.4 billion in fiscal year 2002.

H.R. 1144-Rep. Eliot Engel (D-NY)/Energy and Commerce (3/21/01)-A bill to authorize increased federal spending on research for cancer, Alzheimer's disease, and asthma by \$2 billion for FY2002.

H.R. 1260-Rep. Brian Kerns (R-IN)/Judiciary (3/28/01)-A bill to prohibit the cloning of humans.

H.R. 1372-Rep. Cliff Stearns (R-FL)/Energy and Commerce (4/3/01)-A bill to prohibit the use of federal funds to conduct or support research on the cloning of humans, and to express the sense of Congress that other countries should establish substantially equivalent restrictions.

S. 704-Sen. Ben Nighthorse Campbell (R-CO)/Health, Education, Labor, and Pensions (4/4/01)-A bill to prohibit the cloning of humans.

S. 723-Sen. Arlen Specter (R-PA)/Health, Education, Labor, and Pensions (4/5/01)-A bill to provide for human embryonic stem cell generation and research.

S. 2076-Sen. Byron Dorgan (D-ND)/Judiciary (4/9/02)-A bill to prohibit the cloning of humans.

H.R. 1608-Rep. Vernon Ehlers (R-MI)/Judiciary (4/26/01)-A bill to prohibit human cloning.

H.R. 1644/S. 790-Rep. Dave Weldon (R-FL)/Energy and Commerce, Judiciary-Sen. Sam Brownback (R-KS)/Judiciary (4/26/01)-A bill to prohibit human cloning.

H.R. 1672-Rep. Stephanie Tubbs Jones (D-OH)/Energy and Commerce (5/2/01)-A bill to provide for an increase in funding for research on uterine fibroids through the National Institutes of Health and to provide for a program to provide information and education to the public on such fibroids.

H.R. 1961/ S. 961-Rep. Roy Blunt (R-MO)/Energy and Commerce (5/23/01)-Sen. Barbara Boxer (D-CA)/Health, Education, Labor, and Pensions (5/28/01)-A bill to promote research to identify and evaluate the health effects of breast implants; to ensure that women receive accurate information about such implants and to encourage the Food and Drug Administration to thoroughly review the implant manufacturers' standing with the agency.

H.R. 2059-Rep. Jim McDermott (D-WA)/Energy and Commerce (6/5/01)-A bill to provide for human embryonic stem cell generation and research.

H.R. 2096-Rep. Christopher Smith (R-NJ)/Energy and Commerce (6/7/01)-A bill to provide for a National Stem Cell Donor Bank regarding human stem cells, and for the conduct and support of research using such cells.

H.R. 2172-Rep. James Greenwood (R-PA)/Energy and Commerce (6/14/01)-A bill to prohibit human cloning.

H.R. 2505/S. 1899-Rep. Dave Weldon (R-FL)/Judiciary (7/16/01)-Sen. Sam Brownback (R-KS)/Judiciary (1/28/02)-A bill to prohibit human cloning.

H.R. 2598-Rep. Lucille Roybal-Allard (D-CA)/Energy and Commerce (7/23/01)-A bill to provide for increased funding for the Centers for Disease Control and Prevention to carry out activities that would increase the number of medically underserved, at-risk adults and adolescents who are immunized against vaccine-preventable diseases.

H.R. 2608-Rep. James Greenwood (R-PA)/Energy and Commerce (7/24/01)-A bill to prohibit the cloning of humans.

H.R. 2747-Rep. Diana DeGette (D-CO)/Energy and Commerce (8/2/01)-A bill to require implementation of the National Institutes of Health Guidelines for Research using Human Pluripotent Stem Cells.

H.R. 2783-Rep. Carolyn Maloney (D-NY)/Energy and Commerce (8/2/01)-A bill to provide for research on whether drugs approved for human use affect women differently than men.

S. 1439-Sen. John Ensign (R-NV)/Health, Education, Labor, and Pensions (8/2/01)-A bill to provide for a National Stem Cell Donor Bank regarding qualifying human stem cells.

H.R. 2838-Rep. Juanita Millender-McDonald (D-CA)/Energy and Commerce (9/5/01)-A bill to require

the Director of the National Institutes of Health to conduct or support research using certain human pluripotent stem cells.

S. 1758-Sen. Dianne Feinstein (D-CA)/Judiciary (12/3/01)-A bill to prohibit human cloning while preserving important areas of medical research, including stem cell research.

H.R. 3495-Rep. Ron Paul (R-TX)/Energy and Commerce (12/13/01)-A bill to prohibit federal payments to any individual, business, institution, or organization that engages in human cloning.

S. 1893-Sen. Tom Harkin (D-IA)/Health, Education, Labor, and Pensions (1/24/02)-A bill to ban human cloning while protecting stem cell research.

S. 1976-Sen. Dianne Feinstein (D-CA)/Health, Education, Labor, and Pensions (2/28/02)-A bill to provide for a comprehensive federal effort relating to treatments for, and the prevention of, cancer.

H.R. 4011-Rep. Carolyn Maloney (D-NY)/Energy and Commerce (3/20/02)-A bill to establish the Stem Cell Research Board to conduct research on the effects of the President's August 9, 2001 stem cell research directive.

S. 2439-Sen. Arlen Specter (R-PA)/Judiciary (5/1/02)-A bill to prohibit human cloning while preserving important areas of medical research, including stem cell research.

H.R. 4963-Rep. Steny Hoyer (D-MD)/Energy and Commerce (6/19/02)-A bill to provide for the expansion and coordination of activities of the National Institutes of Health and the Centers for Disease Control and Prevention with respect to research and programs on cancer survivorship, and for other purposes.

Smoking

H.R. 1229/S. 622-Rep. Diana DeGette (D-CO)/Veterans Affairs, Ways and Means-Sen. Richard Durbin (D-IL)/Finance (3/27/01)-A bill to promote smoking

cessation programs under Medicare, Medicaid, and the maternal and child health program.

H. Con. Res. 122-Rep. Jim Nussle (R-IA)/Energy and Commerce (5/2/01)-A concurrent resolution encouraging a combination of state legislative efforts and strong health education programs and activities to discourage smoking in children and adolescents.

H.R. 3676/S. 854-Rep. Diana DeGette (D-CA)/Veterans Affairs, Ways and Means (2/5/02)-Sen. Richard Durbin (D-IL)/Finance (5/9/01)-A bill to promote cessation of tobacco use under Medicare, Medicaid, and the Maternal and Child Health Block Grant.

Veteran Women's Health

S. 2205-Sen. John Rockefeller (D-WV)/Veterans Affairs (4/18/02)-A bill to clarify the entitlement to disability compensation of women veterans who have service-connected mastectomies, to provide permanent authority for counseling and treatment for sexual trauma, and for other purposes.

Women's Health Offices

H.R. 1784/S. 946-Rep. Connie Morella (R-MD)/Energy and Commerce (5/9/01)- Sen. Olympia Snowe (R-ME)/Health, Education, Labor, and Pensions (5/24/01)-A bill to establish an Office on Women's Health within the Department of Health and Human Services, and for other purposes.



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