

TESTIMONY

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REPRESENTING

THE WOMEN'S HEALTH RESEARCH COALITION

SENATE HEALTH, EDUCATION, LABOR, PENSIONS COMMITTEE

PUBLIC HEALTH SUBCOMMITTEE

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Thank you, Mr. Chairman, for the opportunity to testify before the subcommittee today. I am Dr. Carolyn M. Mazure, Professor of Psychiatry, Associate Dean for Faculty Affairs at the Yale University School of Medicine, Director of the Department of Psychiatry's Women's Behavioral Health Research Division, and Director of Women's Health Research at Yale - a large interdisciplinary women's health research program at Yale.

I am testifying before the subcommittee in my capacity as the Chair of the Women's Health Research Coalition, which was created by the Society for Women's Health Research approximately three years ago. The membership of the Coalition, which stands at nearly 350 persons throughout the country, includes leaders within scientific and medical research, as well as leading voluntary health associations, pharmaceutical and biotechnology companies - all with a commitment to women's health.

I would like to make three points in my remarks today. First, I want to acknowledge the important array of programs and initiatives - within the Department of Health and Human Services - designed to promote the health of women and their families. Second, I would like to note that, despite the progress resulting from these programs, there is much work yet to be done to serve the many populations of women in need of care. And, third, I respectfully submit that a critical element in accomplishing the "work yet to be done" is that Congress support, by statute, the various Offices of Women's Health within the DHHS. These offices provide a base of operations that focus the energy and galvanize the interest within each agency regarding the health of women. Of equal importance, each of these offices is in an ideal position to supply specialized information on women and their health needs.

Mr. Chairman, I wish to thank you and the members of the subcommittee for addressing the issue of women's health and working to identify the initiatives needed to improve the health of women throughout the nation. Improving the health of women is a critically important goal because women comprise over half of the U.S. population, women are largely responsible for the health care decisions in their households, and women comprise the large majority of primary caretakers for their children and their aging parents. Thus, promoting women's health helps women and advances the health of entire families, thereby affecting far more than half the people in this nation.

As you know, the Department of Health and Human Services (DHHS) is committed to monitoring, protecting and improving the health of the nation. Recognizing the importance of women's health as it relates to topics managed by its agencies, the DHHS also has been committed to developing a focus on the health of women. Currently, there are women's health offices and positions within the agencies of the Department of Health and Human Services whose primary responsibility is to promote the health of women and their families. These women's health representatives, whose jobs are specific to the mission of each agency, are dedicated to understanding the unique roles and health concerns of women across the United States, and to initiating and supporting programs that will advance the health of women. They provide a base of operations for focusing the energy and galvanizing the interest within each agency regarding the health of women and, importantly, they bring specialized information on women and their health needs. The programs initiated and supported by women's health staff provide for new and effective medical research studies, prevention strategies,

treatment interventions and, often, make the difference between a productive life and one incapacitated by ill health and disability.

This Subcommittee has a special opportunity to assure that women will receive the health-related attention needed from dedicated representatives by voting for legislation which statutorily assures that women's health offices exist within individual DHHS agencies. Support of the provisions of S. 946 - the Women's Health Office Act of 2001, a bill introduced originally by Senators Snowe, Mikulski and Harkin and since cosponsored by several more of your colleagues, provides a clear demonstration to constituents and colleagues that you are ensuring opportunities to improve the health of women and their families.

Before I discuss the legislation further, I would like to provide a few brief examples of women's health programs that are the outgrowth of the women's health entities within the DHHS agencies under discussion. I believe these illustrations demonstrate the importance of leadership and coordination by women's health offices that is necessary in order to serve the fundamental health needs of women.

Agency for Healthcare Research and Quality

As you know, Mr. Chairman, the Agency for Healthcare Research and Quality (AHRQ) is the government's leader in health services research. It supports and conducts research and disseminates information derived from research that improves access to care and the outcomes, quality, cost, and utilization of health care services. Since the re-organization of the agency, advanced by this committee under your leadership and that of

Senator Frist, AHRQ has distinguished itself as a leading voice in determining what systems of service work best in healthcare.

The AHRQ senior advisor on women's health specifically is dedicated to improving the quality and outcomes of healthcare for women within two broad categories of initiatives. The first category relates to improvement in the quality of life and prevention of functional decline for mid-life and older women. The second relates to improvement in the quality and delivery of care for conditions that are common to women. Concurrently, the publication and dissemination of research findings referable to women's health are a high priority for the senior advisor within AHRQ. The following are but a few examples of the important work of the Senior Advisor and point to the kinds of initiatives that would be enhanced with a secured OWH.

With regard to the first category of initiatives, the AHRQ women's health advisor has played a key role in responding to concern from Congress, advocacy and policy groups about the need for standards of care for women with cardiovascular disease – the leading cause of death for women in this country. Women are more likely to manifest heart disease when they are older, and symptoms can be different than in men so that they may not be recognized. Women also receive fewer therapies and are more likely to die after a heart attack. After convening an expert steering committee of stakeholders in the health community, AHRQ in collaboration with the National Institutes of Health Office of Research on Women's Health, provided for a review of the knowledge in risk, diagnosis and treatment of cardiovascular disease in women, particularly minority women. Among the outcomes of this collaborative effort will be an evidence-based assessment for health professionals and organizations that want to develop materials for

education of health care providers and patients. This result exemplifies how the efforts of the Senior Advisor complement the larger goals of the agency which, in this case, relate to the agency's commitment to translate research into practice across the United States.

As examples of the second category of initiatives, the AHRQ women's health advisor has been instrumental in the agency's efforts to enhance management of chronic illnesses, improve quality and utilization of maternal health services for minority and other populations of women, create tools for assessing the quality of health care for women, and improve treatment outcomes for victims of domestic violence (including the elderly).

As part of the analytic and communication functions related to determining the unique status of women in our healthcare system, the senior advisor was instrumental in initiating the publication of a new and useable chart-book publication on women's health status, insurance and access to care. She also successfully recommended adding questions to the ongoing Medical Expenditures Panel Survey that soon will provide detailed information on women's health expenditures.

Also of note, working with the Office of Research on Women's Health at the NIH, AHRQ supports training for the next generation of women's health researchers. Nearly half of all programs funded under the Building Interdisciplinary Research Careers in Women's Health (BIRCWH) program involve health services research components. Increasing the numbers and skills of researchers to do this work will lead the way to solutions for a multitude of our nation's health concerns.

Centers for Disease Control and Prevention

The Centers for Disease Control and Prevention (CDC) is committed to promoting health by preventing and controlling disease, injury and disability. The Office of Women's Health within the CDC is dedicated to supporting prevention research programs within and outside the CDC directed toward improving women's health, advocating for public health and policy programs created to enhance women's health, and communicating messages that promote health for women.

As one example of these efforts, the CDC OWH has focused on a serious affliction for Americans – namely, asthma. This is a growing healthcare concern for women since they have higher rates of office visits, hospitalizations, and deaths due to asthma and asthma-related complications. Yet, little is known whether women would benefit from different asthma management strategies than those used for men. The CDC Office of Women's Health is funding work to assess severity, co-occurrence of other diseases and the value of different treatments for men and women with asthma. This will be followed by the development of educational interventions to reduce the severity of asthma in women and evaluate the effectiveness of this intervention. Because chronic diseases, like asthma, can reduce ability to work and perform other necessary daily life activities, results of this work will have direct practical benefit.

Other funded projects supported by the CDC OWH focus on screening for osteoporosis in older women, expanding women's access to tuberculosis treatment, disease prevention for women working in the dry cleaning industry who are at increased risk of cervical cancer related to chemical exposure, enhanced delivery of immunizations

and cancer screening to African-American women enrolled in Medicare, reduction of female adolescent risk behavior, and development of a national public health action plan for diabetes in women.

Food and Drug Administration

The Office of Women's Health in the Food and Drug Administration (FDA) addresses differences between women and men in drug, device, and biologic testing. It ensures that FDA's regulatory and oversight functions remain gender sensitive and responsive, and it provides leadership and an integrated approach across the agency with regard to women's health issues across all organizational components of the FDA. The FDA OWH also forms partnerships with government and non-government entities to promote the FDA's women's health objectives. It does this through cost-effective and scientifically valid initiatives.

Since the office was created, the FDA OWH has funded approximately 100 scientific projects in areas of women's health, including breast and ovarian cancer, HIV transmission in women, cardiovascular disease in women, osteoporosis, the safety of breast implants, estrogen and its effects, and autoimmune diseases. Utilizing a competitive, intramural, peer-review process, OWH has funded the highest caliber scientific projects related to women's health. Projects selected are those that can affect the regulatory process and offer the highest potential yield in new information on women's health in a minimum amount of time.

Currently, the FDA OWH has provided funding to investigate the safety and effectiveness of prescription medication used during pregnancy. This work is designed to understand the metabolism and effectiveness of medications for high blood pressure in pregnant women while also examining whether important dosing information can be ethically and economically obtained from studies conducted in pregnant women. Because medications are not tested in pregnant women prior to the medications coming on the market, this investigation seeks to develop model studies for measuring the drug metabolism for products that are in fact used during pregnancy. For some women with conditions such as high blood pressure, epilepsy, or an autoimmune disease who must continue or begin to take prescription drugs for their medical conditions during pregnancy, results of this work are vital to their health and their potential to have healthy children.

The FDA OWH also has coordinated action to develop regulatory policy related to such topics as women as subjects in clinical trials. It has undertaken outreach programs such as “Take Time to Care” that alert women to the importance of the correct use of medicines for themselves and their family members. Millions of Americans have participated in this educational campaign that included dissemination of copies of a brochure entitled “My Medicines” published in English, Spanish and several other languages. An upcoming “Take Time to Care” campaign on diabetes will provide valuable information for women to be aware of the impact of this disease and methods of prevention and management.

Health Resources and Services Administration

The mission of the Health Resources and Services Administration (HRSA) is to assure access to health care that has no disparities for underserved, special needs, and vulnerable populations. HRSA promotes health care infrastructure and systems development, and training for a diverse and culturally competent health professions workforce. The HRSA OWH is the principal advisor for agency activities and policies that address women's health.

As a consequence of lower employment rates among women, lower pay and a greater likelihood to be in a job that does not include health benefits, unequal access to health care is a problem more likely to affect women. In fact, about 15 percent of women under the age of 65 years lack health insurance and many women are underinsured. The HRSA Office of Women's Health plays an important role in assuring the delivery of health care services to medically underserved and underinsured women. It coordinates women's activities across more than 80 HRSA programs, working to ensure that the health needs of these women and girls are addressed across the life span. One indication of the success of the office and, as a result, of the agency is that women of childbearing age who are served in community-based health facilities have higher rates of mammograms and pap smears than comparable women across the nation.

"The Bright Futures for Women's Health & Wellness" program is just one example of a program managed by the HRSA OWH. This program is designed to provide health care information for every woman served, regardless of her education or ethnicity, and for every health care provider within the community health care system so

that every clinical encounter is an opportunity to practice disease prevention and education. This community-wide health promotion program includes materials development and training for community health professionals and families, as well as an evaluation component to refine the program. Another example of a HRSA program, in collaboration with CDC and the states, is “Statewide Partnerships in Women's Health.” The partnerships encourage statewide collaboration in developing the capacity among partner organizations to leverage resources and establish an integrated approach to coordinating health services for underserved women.

In addition, the HRSA OWH, at the request of Congress, has performed detailed assessments of women’s health curricula in medical, dental and nursing schools. It also has developed a model medical school core curriculum on women’s health and strategies for implementation along with summaries of opportunities to improve the dental and nursing curricula. Assuring the nation’s health care providers are educated with the most up-to-date information is another step to assuring this nation’s wellbeing.

Office on Women’s Health in the Office of the Secretary

The Office on Women’s Health in the Office of the Secretary is the focal point and advisory body in DHHS for developing and advancing women’s health research, health services, and public and professional education across the public health service. One crucial component of the Office’s effort is its coordinating function. Just as the Secretary’s Office weaves together the common threads of the entire department so, too, does OWH weave together those common threads related to women’s health services, treatment and research throughout DHHS.

In this role, the Office oversees the Coordinating Committee on Women's Health, comprised of senior level representatives throughout the DHHS, for the purpose of fostering collaboration and coordination in women's health initiatives and activities across the DHHS. The OWH oversees regional women's health coordinators throughout the country assisting with state and community involvement in eliminating health disparities. The Office regularly coordinates DHHS activity on key issues such as domestic violence through the DHHS Steering Committee on Violence Against Women. Still more coordinating and oversight activities include working with representatives from all agencies of the federal government on priority areas in women's health which are regularly updated and outlined on the National Women's Health Information Center web site managed by the DHHS OWH. The Women's Health Information Center offers a single entry point for access to more than 4,000 publications and 1,600 organizations addressing more than 800 health topics.

The DHHS OWH also has been responsible for multiple public information campaigns such as "The Pick Your Path to Health Campaign" which provides comprehensive, culturally-appropriate health information for women of color. Another campaign, in which the OWH partnered with the Society for Women's Health Research, focused on educating young women regarding maintenance of behaviors leading to healthier lives.

The OWH also has funded and supported National Centers of Excellence in Women's Health across the country that provide important models for delivering care to women while offering educational and research opportunities. In this regard, the OWH in the Office of the Secretary, in collaboration with HRSA and the Office of Minority

Health, has been responsible for establishing seven Community Centers of Excellence in Women's Health. These Centers identify, support and replicate promising community-based approaches to women's health services, training, research and outreach in various parts of the country.

Conclusion

Mr. Chairman, women's health has made important strides in the last decade as a consequence of it being increasingly recognized as a national priority. Through the offices and positions for women's health within the DHHS, efforts have been successful in initiating research studies that examine major women's health issues, education campaigns that enhance public awareness of women's health concerns, and clinical services and screening projects that improve women's health. We need to remain vigilant that our recent successes in addressing the health of women are not followed by a decline, because much work remains to be done for many different subgroups and populations of women in need of care.

We must acknowledge that there are many examples of work that has yet to be done.

- We need to understand more about the diseases and conditions that are unique to women such as ovarian and cervical cancer, endometriosis, and post-partum disorders. For example, we need to know why the childbearing years have been shown to be a time of increased vulnerability to psychiatric disorders, and why rates of post-partum depression have been estimated to be as high as 22 percent.

- We also need a better understanding of why certain diseases and conditions have a differential impact on women and men, such as cardiovascular disease and stroke. For example, we need to learn more about why women's risk of heart disease rises with age and why women are more likely than men to have a second heart attack within several years after their first attack. Further, we need to know why women are more likely to die from a stroke, even though women and men are equally likely to have strokes.
- Finally, Mr. Chairman, we need a better understanding of the disorders and conditions that are more common in women such as more common in women such as smoking and substance abuse. In reference to smoking, for example, we know that with the same lifetime exposure to cigarettes, the risk of developing cancer is greater in women than men. Death rates from smoking-related diseases are rising for women and unfortunately, one in four girls under the age of eighteen now smokes.

And it is equally important that the Offices' of Women's Health evaluate ways to provide women with the best treatment and services possible and they need to investigate ways to deliver effectively the type of care that women need. In addition, they need to translate their research findings into practices that focus on preventing disease before it develops and takes a toll on women's health and well-being.

There is a clear need to stabilize representation for women's health within the DHHS in order to maintain current productive efforts, coordinate existing and developing initiatives, and integrate new topics of significance to women's health into each agency.

This can be accomplished by establishing structured offices by statute and, subsequently, assuring future funding commensurate with the mission of each office.

Currently, actual designated representation for women's health varies across agencies. The women's health representatives have varying relationships with their agencies based on a number of factors including the mission and function of the office or position within the agency, the reporting structure for the office or position, whether there is a budget line for the office or position within the agency, and whether the office or position is present by way of statute.

Mr. Chairman, these serious issues require carefully thought-out, comprehensive solutions from a wide-ranging partnership of governmental and non-governmental experts, including state and local officials, nonprofit organizations, universities and private industry. They require an unwavering commitment from the administration and the Congress to look broadly, think deeply, and act smartly. That approach, however, is hampered when offices do not know from year to year - and sometimes from month to month - what they are expected to do, if they will be funded and at what level. For these reasons, it is critical that Congress support by statute the various Offices of Women's Health within the DHHS.

I would respectfully submit to the Subcommittee that one of the most effective and efficient means of addressing women's health needs would be to include provisions that are substantially similar to those in S. 946, the Women's Health Office Act of 2001 bipartisan legislation introduced by Senators Snowe, Mikulski and Harkin, in any comprehensive legislation. These provisions, which would authorize appropriations

through 2006, would enable and enforce a level of security critical for the future of these offices.

Only through strong support from the Congress and the Administration can these offices address the complex and very specialized area that is women's health. It is critically important that dedicated representatives for women's health are "at the table" at the highest levels, and are participants in designing and implementing the agenda for an agency, whether it is the AHRQ, FDA, CDC or HRSA. When each agency has a women's health office by statute, a clear and direct reporting structure, and a budget line for women's health commensurate with its mission, it will be possible to build upon the success of the current women's health offices and positions, and further evaluate the impact and voice of the office within the agency.

Women's health has reached a critical point of awareness in America, and only with continued and dedicated representation will it remain a significant and growing part of our national health agenda for this new century. There is a positive, constructive effort to assure that this message is heard. The various offices, coordinators and advisors on women's health that exist throughout the Department of Health and Human Services personify that voice. On behalf of the Women's Health Research Coalition, I would respectfully request that the Subcommittee include statutory authority for Offices of Women's Health in the Office of the Secretary, ARHQ, FDA, CDC and HRSA in any legislation addressing women's health that it may advance. The presence of women's health offices makes a difference to the health of American women and, thus, will benefit us all.

S. 946 has been endorsed by nearly 50 organizations and, with your permission, I would like to submit for the record, a copy of a letter signed by these groups. Mr. Chairman, thank you for the opportunity to address the Subcommittee this afternoon. I appreciate the difficult task you are undertaking and would be pleased to answer any questions you or any other member of the Subcommittee may have concerning my remarks.

Footnote: Information has been drawn from the Report to Congress on Women's Health Offices, Programs and Activities in the Department of Health and Human Services, Arthur L. Lawrence, Ph.D., Assistant Surgeon General, March 2001; Mazure et al., J Women's Health & Gender-Based Medicine, 10(9), 2001; DHHS web sites.