

**TESTIMONY ON BEHALF OF THE SOCIETY FOR WOMEN'S HEALTH RESEARCH
SUBMITTED BY KATHRYN G. SCHUBERT, PRESIDENT & CEO**

**Prepared for the Subcommittee on
Labor, Health and Human Services, and Education, and Related Agencies**

Chair DeLauro, Ranking Member Cole, members of the Committee, and staff – thank you for giving me the opportunity to testify. My name is Kathryn Schubert, and I am President and CEO of the Society for Women's Health Research. For over 30 years, SWHR has been dedicated to promoting research on biological sex differences in disease and improving women's health through science, policy, and education. While SWHR supports strong funding across all federal public health programming, I want to focus my testimony today on the important work being done at the National Institutes of Health. We specifically urge the Committee to support at least \$46.1 billion for the NIH, including at least \$1.7 billion for the Eunice Kennedy Shriver National Institute of Child Health and Human Development, and \$55.4 million for the Office of Research on Women's Health in fiscal year 2022.

Biological differences between women and men influence disease development, progression, and response to treatment, while social determinants of health — including gender — affect disease risk, health care access, and outcomes. For example, the pandemic has exposed an array of health disparities, including significant sex and gender differences. Men are more likely to develop severe complications from COVID-19 and have a heightened risk of death, while women are more likely to be diagnosed with post-acute sequelae of COVID-19 and report more adverse events following vaccination. Women are disproportionately affected by layoffs and socioeconomic challenges, food insecurity, domestic violence, and mental health concerns related to COVID-19.

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Nevertheless, much of the ongoing COVID-19 research fails to thoroughly investigate the impact of sex and gender. The pandemic has highlighted what we have known to be true for decades: Robust funding for federal institutes and offices that prioritize women's health research is critical to achieve health equity for women.

The National Institutes of Health

The NIH is America's premier medical research agency and the largest source of funding for biomedical and behavioral research in the world. As such, its public health mission is vital to promote the overall health and well-being of Americans by fostering creative discoveries and innovative research, training and supporting researchers to ensure continued scientific progress, and expanding the scientific and medical knowledge base.

Multiple initiatives within the NIH are aimed at improving the health of women. The agency released its Trans-NIH Strategic Plan for Women's Health Research in April 2019, which laid out broad agency goals to complement its more targeted women's health programs. The NIH's emphasis on improving standard research methodologies to better address sex and gender and funding relevant women's health research makes continued strong support of this agency fundamental to supporting women's health.

To sustain and bolster its funding through competitive grants to researchers across the United States and around the world as well as support the work of researchers within the NIH, SWHR requests that Congress provides at least \$46.1 billion for the NIH, a \$3.2 billion increase over current funding, to build upon current efforts and to mitigate the pandemic's impact on ongoing research. Additionally, we encourage the Committee ensure that the NIH studies the race and gender breakdown of the impact of COVID-19 on participation in the workforce, in

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order to ensure current reported gender disparities do not persist post-pandemic. Finally, we urge Congress to support research that studies how sex as a biological variable impacts short and long-term outcomes due to infection with SARS-CoV-2.

The Office of Research on Women's Health

I also want to highlight the important work of the NIH Office of Research on Women's Health. For decades, and as late as into the 1990s, women were treated as small men. Research on diseases and treatments was conducted almost exclusively on male subjects, as researchers avoided the presumed "complications" introduced by including female subjects in their work.

Unfortunately, this approach ignores the impact of sex and gender on human development, disease progression and ultimately on approaches to research as a whole. As the NIH focal point for coordinating women's health research, ORWH ensures women are represented across all NIH research, and works to improve representation of women and women's health issues within federally funded research. ORWH provides critical leadership to programs like the Specialized Centers of Research Excellence, which advances translational research on the role of sex differences in the health of women, and the IMPROVE initiative, which coordinates interdisciplinary research on factors impacting maternal mortality.

For FY 2022, SWHR recommends \$55.4 million in funding for ORWH, an increase on par with the overall NIH budgetary recommendations, in order to allow the office to continue to coordinate and drive the conversation on women's health across the NIH. We also recommend an additional \$3 million be allocated to the Building Interdisciplinary Research Careers in Women's Health program, an initiative that trains investigators to research sex and gender

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influences on health. A diverse workforce can increase research breadth and allow for improved creativity and innovation.

Eunice Kennedy Shriver National Institute of Child Health and Human Development

The *Eunice Kennedy Shriver National Institute of Child Health and Human Development* provides a home for women's health research in areas including reproductive sciences and maternal health. SWHR requests that Congress provides at least \$1.7 billion for the NICHD for FY 2022. I also want to highlight two key areas of need within the NICHD:

Pregnant and Lactating Individuals

Nearly 94% of women take at least one medicine during pregnancy, and 50% take at least one medication during the postpartum period. Yet, pregnant and lactating individuals are excluded from the majority of biomedical research. Consequently, these women and their health care providers do not have access to the information they need to make confident decisions about their health care.

SWHR supports the appropriate inclusion of these populations in clinical research. The federal Task Force on Research Specific to Pregnant Women and Lactating Women, housed within the NICHD, has been crucial to outlining next steps for improving research in pregnant and lactating populations. Based on the Task Force recommendations from August 2020, SWHR requests Congress include report language recommending that NICHD to contract with the National Academies of Medicine to convene a panel with specific legal, ethical, regulatory, and policy experts to develop a framework for addressing legal and liability issues in research specific to pregnant and lactating people.

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Uterine Fibroids

Finally, I want to highlight the need for improved attention to uterine fibroids, one of the most common gynecological conditions nationwide. Approximately 26 million individuals in the U.S. from ages 15 to 50 have fibroids, and 15 million experience symptoms like severe menstrual bleeding, anemia, impaired fertility, and pregnancy complications. Fibroids cost the health care system \$5.9 to \$34.4 billion annually.

Prominent and troubling health disparities exist in fibroids prevalence, onset, and severity. Black women are 2 to 3 times more likely to develop fibroids than white women. Black patients also tend to develop fibroids at earlier ages, develop more and larger tumors, and show increased symptom severity.

Fibroid research remains drastically underfunded compared to disease burden. In 2019, fibroid research received about \$17 million in NIH funding, putting it in the bottom 50 of 292 funded conditions. SWHR asks Congress to urge the NICHD to prioritize funding to expand basic, clinical, and translational research pathophysiology to identify early diagnostic methods and fertility-preserving treatments, and to understand and mitigate the impact of health disparities.

In conclusion, I would like to thank the Chair, Ranking Member, and the Committee for their support for medical and health services research and their commitment to the health of the nation. Thank you in advance for your consideration of this HHS FY2022 funding request and the rationale behind it. If you have questions or would like more information, please do not hesitate to contact me at kathryn@swhr.org.