

Report on Research Compliance Volume 21, Number 6. May 23, 2024 Executive Order, ARPA-H Projects Offer Hope for Closing Research Gender Gap

By Theresa Defino

Food for thought: “People may not necessarily know that it was not until 1993 that women were required to be included in clinical research that is funded through the NIH.” So recalled Katie Schubert, president and CEO of the Society for Women’s Health Research (SWHR).^[1]

Prior to this, women “didn’t have to be” included, Schubert added. As a result, “everything that we knew, or most of what we knew, [was] really based on information gleaned from research in men and, at that, white men of a certain size, which is not, even today, the average person in the United States.”

The mandate—the result of the NIH Revitalization Act—was “really critical” in fostering a “better understanding of issues that differently or disproportionately or specifically impact women,” Schubert added, “and to get more women included in these clinical trials so that we can fully understand what’s going on with their health.”

Yet, “women continue to be understudied and underrepresented in health research despite meaningful reforms over the past three decades,” according to the description of the talk during which Schubert made her remarks. Hosted by the advocacy group Research!America, the talk also featured Lori Frank, president of Women’s Health Access Matters (WHAM), and Jenny Luray, Research!America’s senior vice president for strategy and public engagement.

15% of NIH Research Focused on Women

Luray pointed out that “it wasn’t until there [was] at least a critical mass of women in Congress that there was any federal attention to women’s health. And then, for example, as women started becoming more equal in numbers in med school, women’s surgeons started focusing on breast cancer, and they had a huge impact on an increased focus and awareness on breast cancer research.”

But there are reasons for hope of bridging the gender gap in research, the speakers said, among them a recent executive order by President Joe Biden and a new initiative announced by the fledgling Advanced Research Projects Agency for Health (ARPA-H).

When it comes to research on women’s health, there are “three legs of the stool” that require attention, Luray noted. Diseases that disproportionately affect women; conditions that impact women differently; and disorders that “impact women because of our physiology and our biology, like endometriosis,” she said. Advocacy organizations need to focus their efforts on all three, as both Frank’s and Schubert’s organizations are doing, Luray said.

Frank explained that WHAM commissioned a series of reports by RAND Corporation to study the “far-reaching” impact of “our limited knowledge about women’s health relative to men’s because of insufficient research addressing women.” Separate reports issued in 2021–2022 address Alzheimer’s disease, rheumatoid arthritis and cardiovascular disease, while *The WHAM Report: The Case to Fund Women’s Health Research* “highlights

findings across all three diseases in one brief report.”^[2]

RAND researchers wanted to “look at the proportion of the NIH extramural funding portfolio that was devoted to women-focused research” to answer the question, “What would the impact be of increasing investment for women’s health research in terms of the whole U.S. economy?” Frank explained. They found that the proportion of NIH-supported research focused on women was 15% or less, which “was our first surprise, to be completely honest,” she said.

“In the case of rheumatoid arthritis” and the “set of disorders included in that that disproportionately affect women, just 7% of that portfolio was focused on women,” she said. “For “coronary artery disease [it was] less than 5%,” Frank said.

This document is only available to subscribers. Please log in or purchase access.

[Purchase Login](#)