

The Research Agenda Setting Process for Women's Health at the National Institutes of Health

The Office of Research on Women's Health (ORWH), NIH, DHHS was established in September 1990 in response to Congressional and advocacy concerns about the systematic lack of inclusion of women (and minorities) in NIH supported clinical research trials and that medical decisions were being made without the benefit of knowledge derived from research that included these populations. The Office was established in statute at the time of the NIH Revitalization Act of 1993 (Public Law 103-43). Congress codified the Office's mission and included directives that expanded its leadership role in identifying and promoting research on women's health.

Since that time, the Office has been the focal point for guiding the national research effort on women's health issues and is responsible for ensuring that women's health research priorities are integrated into the wider NIH research agenda. The mission of ORWH is:

- 1) advise the NIH Director on matters relating to research on women's health;
- 2) strengthen and enhance research related to diseases, disorders, and conditions that affect women;
- 3) ensure that research conducted and supported by NIH adequately addresses issues regarding women's health;
- 4) ensure that women are appropriately represented in biomedical and behavioral research studies supported by NIH;
- 5) develop opportunities for and supporting recruitment, retention, re-entry, and advancement of women in biomedical careers; and
- 6) support research on women's health issues.

To advance a robust research agenda to guide women's health research at the NIH, ORWH initiated two intensive strategic planning initiatives in 1991 and again in 1998. The earlier strategic planning meetings have been formative in defining the research priorities for women's health research at the NIH. The report that emerged from the first planning effort redefined the parameters of women's health to encompass research to better understand sex and gender differences between women and men in development, health and disease, and to focus on populations of women that have been underrepresented in clinical research in the past. The second report, *Agenda for Research on Women's Health for the 21st Century*, expanded upon the initial scientific agenda for women's health research. More than 1500 scientists, clinicians, public policymakers, advocates and members of the general public met in a series of four regional meetings to address changing public health and scientific needs and opportunities of the 21st century. Their report emphasized the relevance of the full spectrum of research from basic to clinical research and trials, epidemiological and population studies, clinical applications, and health outcomes applied to women's health. As more has been learned about women's health the research agenda was expanded to include additional areas of focus, providing a strategic foundation for ORWH research priorities and programmatic initiatives.

Moving into the Future: New Dimensions and Strategies for Women's Health Research at the National Institutes of Health.

Ten years after the last women's health research agenda was updated, the ORWH has again launched a series of four regional scientific workshops and public hearings to ensure that research on women's health continues to be on the cutting edge of science, and is based upon the most advanced techniques and methodologies. The first of the 2009 regional scientific workshops and public hearings was held March 4-6, 2009 at Washington University, St. Louis. Scientific panels and concurrent workshops addressed a wide range of topics, from the interplay of research and health care to specific research areas, and included:

- Genetics and Microbial Communities (Metagenomics/Microbiome)
- Chronic Pain Syndromes
- Bladder and Pelvic Floor Disorders
- Brain and Psychiatric Disorders
- Infectious Diseases of the Urinary and Reproductive Tracts
- Obesity and Eating Disorders
- Women in Biomedical Careers

The next regional scientific workshop will be held at the University of California, San Francisco, May 27-29, 2009. On the agenda for the San Francisco meeting are the following topics:

- Women's Health and the Environment
- Global Health
- HIV/AIDS and Women
- Stem Cell Research
- Information Technology and Health
- Women in Biomedical Careers

The third scientific workshop will be held at Women and Infants Hospital/Brown University, Providence, Rhode Island, September 21-23, 2009. The wide focus for that meeting will cover lifespan issues, from pre-conception to the frail elderly. A fourth and final regional meeting will be held at Northwestern University, Chicago in October, 2009. The agenda for that meeting is still being planned.

The format of each of the regional scientific workshops is designed to promote an interactive discussion involving leading scientists from across the nation, women's health advocates, public policy experts, healthcare providers and the general public. Individuals representing the full spectrum of academic institutions, professional associations, advocacy organizations, or healthcare facilities interested in biomedical and behavioral research on women's health and sex/gender issues, or individuals wishing to present their personal opinions on these issues are encouraged to provide both written and public testimony at each of the regional meetings.

A final meeting to integrate the findings and recommendations from the four regional meetings, with additional input from the NIH research community, will be held at the NIH in March/April, 2010. The final document will represent the strategic research priorities for women's health research for the coming decade and will be unveiled in September 2010 in time for the 20th anniversary of the ORWH at the NIH.