

ORWH Update

Setting the Research Agenda for the 21st Century

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SINCE SEPTEMBER 1996, THE OFFICE OF RESEARCH ON WOMEN'S HEALTH (ORWH) of the National Institutes of Health (NIH) has convened a series of three regional meetings to update the NIH's scientific agenda on women's health research to meet the challenges of a changing scientific and social world in the 21st century. In convening these meetings, the ORWH has reaffirmed the NIH's commitment to seeking broad representation of individuals from across the spectrum of medical specialties and scientific disciplines. Basic and clinical scientists, health providers, and advocates from across the country have met in Philadelphia, New Orleans, and Santa Fe to provide guidance and recommendations to the ORWH concerning advances in women's health research achieved during the past 6 years, areas in need of further research, strategies to take advantage of opportunities in science, and emerging issues in women's health.

At a public hearing and scientific workshop to take place November 17-19, 1997, in Bethesda, Maryland, participants will have another opportunity to testify about issues of importance to women's health, review the recommendations made at the three regional meetings, discuss issues not previously considered, and provide guidance to an ORWH Task Force charged with developing a comprehensive scientific agenda for research on

women's health for the 21st century. Task Force members are listed in Table 1.

Participants at the three regional meetings reviewed the recommendations published in *Opportunities for Research in Women's Health*, the 1992 report in which the ORWH published the initial agenda formulated as a result of a year-long process that included a public hearing and scientific workshop held in Hunt Valley, Maryland, in September 1991. There, scientists, policy makers, and advocates met to identify salient issues in women's health that should be addressed through biomedical and behavioral research. The resulting coherent and comprehensive agenda expanded the parameters of the medical community's traditional definition of women's health to encompass women's reproductive and nonreproductive health across the life span, from childhood through the later years of life. The agenda contained specific recommendations for basic and clinical research to define normative development in females and to address sex and gender differences in the etiology, progress, and treatment of diseases and conditions common to women and men, as well as to better understand diseases and conditions unique to women. The agenda elucidated the need for research ranging from molecular studies to define biologic and cellular mechanisms, to clinical research involving diverse populations of women, to epidemio-

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TABLE 1. TASK FORCE

Beyond Hunt Valley: Research on Women's Health for the 21st Century
Office of Research on Women's Health
National Institutes of Health

Co-Chairs

Donna Dean, Ph.D. (Division of Research Grants, NIH)^e
Marianne Legato, M.D. (Columbia University)

Karen Antman, M.D. (Columbia Presbyterian Comprehensive Cancer Center)
Mary Berg, Pharm.D. (University of Iowa)^a
Stephanie Bird, Ph.D. (Massachusetts Institute of Technology)^b
George Bryan, M.D. (University of Texas Medical Branch)
Leah Dickstein, M.D. (University of Kentucky)^b
Mary Dufour, M.D., M.P.H. (National Institute on Alcohol Abuse and Alcoholism, NIH)^e
Carola Eisenberg, M.D. (Harvard Medical School)^c
John Estrada, M.D. (Meharry Medical College)^a
Bonita Falkner, M.D. (Allegheny University)
Sheryle Gallant, Ph.D. (University of Kansas)^{a,b}
John Greene, D.M.D., M.P.H. (University of California at San Francisco)^a
Jeane Ann Grisso, M.D., M.Sc. (University of Pennsylvania)
Hazel Harper, D.D.S. (President, National Dental Association)
Joseph Hurd, Jr., M.D. (Lahey Hitchcock Clinic Medical Center)^a
Judith LaRosa, Ph.D., F.A.A.N. (Tulane University)
Angela McBride, Ph.D., R.N., F.A.A.N. (Indiana University School of Nursing)^a
Sherry Mills, M.D., M.P.H. (National Cancer Institute, NIH)^{d,e}
Donnica Moore, M.D. (Sapphire Women's Health Group)^b
Judy Norsigian (Boston Women's Health Collective)
Jane Pearson, Ph.D. (National Institute of Mental Health, NIH)^d
David Robinson, M.D. (National Heart, Lung, and Blood Institute, NIH)
Helen Rodriguez-Trias, M.D. (Western Consortium for Public Health)
Rosalie Sagraves, Pharm.D. (University of Illinois at Chicago)
Gloria Sarto, M.D., Ph.D. (University of New Mexico)^a
Anne Sassaman, Ph.D. (National Institute of Environmental Health Sciences, NIH)^{b,e}
Ora Lee Strickland, Ph.D. (Emory University)
Ramona Tascoe, M.D., M.H.S.A. (Kaiser/National Medical Association)
Darlene Yee, Ed. CHES (San Francisco State University)

Members-at-large: CCRWH^e members, ACRWH members

^aAdvisory Committee on Research on Women's Health (ACRWH) member.

^bWomen in Biomedical Careers.

^cEx officio ACRWH member.

^dResearch.

^eCoordinating Committee on Research on Women's Health.

logic studies to discern trends in morbidity and mortality for women nationwide.

In the 5 years since publication of the research agenda, tangible progress has been made in addressing many areas in women's health, including identification of genes responsible for inherited forms of breast and ovarian cancer and advances in the medical community's knowledge of how to prevent perinatal transmission of HIV from mothers to offspring. Nevertheless, many areas still require further investigation, and advances in science now offer investigators fresh opportunities for understanding the complex inter-

play of genetic inheritance, environmental influences, and protoplasm in determining women's health over the life span. Through the three regional meetings, participants reviewed the agenda, acknowledged areas where gaps in knowledge still exist, identified new and emerging areas and topics for study, and developed strategies and recommendations to address existing and future needs for research. They also considered the ways in which research studies should be planned and carried out to best address issues in women's health.

Although each of the regional meetings focused on a unique, overarching theme, partic-

Participants at these meetings were charged with the task of recognizing areas where progress has been made since the Hunt Valley meeting, identifying areas where more investigation is needed, and delineating recommendations for future research priorities. The ORWH also has sought participants' recommendations on how to best implement research through public policy and other mechanisms. Each meeting began with a public hearing at which women's health advocates, investigators, health care providers, and members of the general public with particular expertise in some aspect of women's health provided testimony. Each of the half-day public hearings was followed by 2 days of deliberations by scientific working groups that addressed specific health topics or women's health during specific periods of the life span. From this fruitful exchange of knowledge and views, participants in the working groups have formulated recommendations for research.

At each of the three regional meetings, participants were asked to:

- Identify scientific progress achieved since the establishment of the Office of Research on Women's Health
- Highlight successes in the advances of scientific knowledge about women's health and gender/sex information
- Highlight programs that have advanced women's health research
- Develop strategies for identifying continuing or emerging gaps in knowledge and how to address them
- Generate recommendations for future research priorities and necessary consideration of the biomedical/behavioral research community
- Provide pathways for networking and collaboration among researchers
- Consider effective implementation of research outcomes in public policy and health care of women, with consideration of changing parameters (e.g., advances in biotechnology, managed care)

Participants were directed to bear in mind that all ORWH programs and initiatives should be science driven and to consider how, where, and in what manner the NIH can best ensure

implementation of the results of advances from research. Moreover, in formulating recommendations, participants were reminded that the updated agenda on women's health research must reaffirm the NIH's commitment to an integration of scientific disciplines and medical specialties.

The Allegheny University of the Health Sciences and the University of Pennsylvania School of Medicine hosted the ORWH's first regional meeting, held in Philadelphia in September 1996. At that meeting, participants addressed the life span issues that had served as the framework for the Hunt Valley meeting and the resulting agenda. Priorities identified in 1991 were revisited, and recommendations were made addressing both specific areas of research and research design.

The second meeting, held in New Orleans in June 1997, focused on physiologic, psychologic, and pharmacologic differences between women and men. Participants addressed such topics as the state of knowledge and continuing or emerging gaps in knowledge about women's health across the life span; sex and gender differences and their impact on women's health; new priorities for research on women's health; environmental, genetic, hormonal, nonhormonal, and other factors that influence women's health; and career issues for women scientists and how to overcome barriers to women's participation and advancement in biomedical careers. Speakers in the plenary sessions addressed the role of hormones as contributors to differences in health and health outcomes between women and men, as well as the role of the environment and genetics in health. Attention was also given to the normative development of females, the pharmacokinetic and pharmacodynamic effects of drugs in women and men, and the ways in which behavior can affect health across the life span. Tulane University Medical Center, Xavier University of Louisiana, and Meharry Medical College of Nashville, Tennessee, were cohosts of the meeting.

The third regional meeting, hosted by the University of New Mexico School of Medicine and the University of Iowa School of Pharmacy, was held in Santa Fe in July 1997. The meeting concentrated on identifying differences in di-

verse populations of women and how investigators can best incorporate a sensitivity to cultural and racial differences in their research so as to study and understand diverse populations of women most effectively. The specific objectives of this meeting were to assess differences among populations of women, including those from diverse cultures, minority populations, elderly women, rural or inner city women, those affected by poverty and low socioeconomic status, lesbians, migrant farm women, and women with disabilities. Participants were asked to examine the influence of a number of biologic and social factors on women's health and to recommend research (and public policy) strategies for research that can result in improved health status for women, regardless of race, ethnicity, age, or other population characteristics.

At the Santa Fe meeting, participants addressed factors that contribute to differences in health status and health outcomes among diverse populations of women, including biologic, genetic, cultural and ethnic, psychosocial, and behavioral influences, traditional and alternative health practices, access to health care, and occupational influences on health. In addition, the roles of culture and ethnicity in

health care maintenance and delivery were topics of discussion, and opportunities to include women with disabilities in research studies were enumerated. A working group devoted to exploring career issues of particular relevance to minority women scientists met and made recommendations designed to increase minority women's participation and advancement in biomedical research careers.

The three meetings held to date will culminate in the national meeting, consisting of a public hearing and scientific workshop, in November in Bethesda. At that time, participants will review the results of the regional meetings to develop final recommendations to the ORWH Task Force that has overseen this process and will formulate an updated research agenda. The goal is to formulate recommendations delineating specific topics that can be explored through NIH-supported studies. Recommendations also may address the need for programs on women's health that may be initiated, expanded, or enhanced. The ORWH National Task Force on Research will use these recommendations to develop an agenda that will serve as the foundation for NIH research on women's health for the 21st century.