

ORWH-SUPPORTED CONFERENCES AND WORKSHOPS FY 03

TITLE: Diabetes Town Meeting **DHHS**
AWARD: \$5000
CONTACT: Frances E. Ashe-Goins

The Diabetes Town Meeting was held in Washington, D.C., May 20, 2003. Major objectives of this meeting include: providing accurate up-to-date health information on diabetes to women, educate women about their risk for diabetes with prevention and management approaches, foster development and support of diabetes control programs for women, showcase national and community resources for women and diabetes, and encourage the establishment of networks for interaction, information and community action on diabetes prevention and treatment.

TITLE: Vulvodynia- Toward Understanding a Pain **NICHD**
Syndrome Workshop
AWARD: \$5000
CONTACT: Marianne Glass Duffy

This workshop was held from April 14- 15, 2003 at the Lister Hill Auditorium at NIH. The aims of this workshop are: To present an overview of the science and epidemiology of vulvodynia, to elucidate the fundamental mechanisms of vulvodynia and related pain syndromes, to stimulate innovative research approaches to vulvodynia, and to develop clinical strategies for the appropriate and evidence- based methods of alleviating vulvar pain.

TITLE: Basic Science- Translational and Clinical Disease in Female **NICHD**
Pelvic Floor Disorders Conference
AWARD: \$5000
CONTACT: Anne M. Weber, MD, MS

This conference was held on November 15-16, 2002 in Bethesda, MD. Major objectives to be discussed included: The review and brief report on current research, the use of different mechanisms depending on specific needs, the terminology and continuing need for standardization, the need for research and training, and to develop a research agenda in female pelvic floor disorders for the next five years.

TITLE: Add Health Users Conference **NICHD**
AWARD: \$5000
CONTACT: Christine Bachrach, Chief, Demographic & Behavioral Science Branch

The Add Health Users Conference was held in Bethesda, Maryland, July 28-29, 2003. These conferences provide an opportunity for investigators using the Add Health data to share research

findings, discuss issues in the analysis of this complex data set, and learn about specialized aspects of the data and its use. This conference consisted of three types of sessions: paper sessions, didactic sessions, and "special" sessions focusing on how to talk to the press for young investigators.

TITLE: Vitamin D and Health in the 21st Century: Bone and Beyond
NICHD
AWARD: \$5000
CONTACT: Daniel Raiten, Ph.D.

This conference was to be held on October 9-10, 2003 in Bethesda, Maryland. Highlights of the agenda include: Demographics and methodology of epidemiology, the current understanding of the role of vitamin D in health and potential mechanisms for Vitamin D related diseases, and developmental, ethnic/ racial considerations in generating recommendations for vitamin D.

TITLE: FASEB Autoimmunity Conference **NIAID**
AWARD: \$5000
CONTACT: Lawrence J. Prograis, Jr., M.D

This conference was held June 28- July 3, 2001 in Saxtons River, Vermont. The goal of this meeting was to help establish and maintain communication between scientists of diverse backgrounds who share common interest in autoimmunity. The conference proved to be highly informative. Much of the data presented was unpublished, thus providing attendees with the most up-to-date knowledge of this fast moving field.

TITLE: Outcome Measures for Sjogren's Syndrome Workshop **NIDCR**
AWARD: \$5000
CONTACT: Kevin Hardwick

The conference covered definitions and identification of Sjogren's Syndrome, outcome measures, quality of life, clinical trials, serial biopsies and focus scores, additional outcome measures that have already been used in clinical trials, and an open forum to discuss individuals' outcome measures that have not already been proposed.

TITLE: American Society for Cell Biology (ASCB) Annual Meeting
AWARD: \$3000
CONTACT: Ms. Elizabeth Marincola

This meeting was held December 14-18, 2002 in San Francisco, California. The Office of Research on Women's Health has supported the 41st annual meeting. These funds supported AV and set-up costs for the Women in Cell Biology and Education Committees Career Discussions and Networking Program. Round Table discussions were lead by women leaders in molecular

biology and other related fields of biomedical research.

TITLE: Fourth International Symposium on Hormonal Carcinogenesis
NCI
AWARD: \$5000
CONTACT: Karen Grotzinger

The upcoming Symposium is to be held June 21 - 25, 2003 in Valencia, Spain. The goal of the Fourth International Symposium is to focus on major developments in the rapidly expanding field of Hormonal Carcinogenesis and Hormonal Cancers. A novel format for these Symposia will be used to integrate different disciplines and approaches in each of the sessions to include basic science, epidemiologic and clinical research. Each session will focus on a specific aspect of a prevalent hormone related cancer. Information gathered from cell-free systems, cell cultures, animal models, and human studies, together will provide important insights to our understanding of hormonal cancer causation, development, and prevention; the primary objective of these Symposia.

TITLE: Women, Tobacco and Cancer: An Agenda for the 21st Century **NCI**
AWARD: \$10,000
CONTACT: Anna T. Levy

This meeting will be held in Houston, Texas, February 3-5, 2003. Major conference goals include: Identify and prioritize research needs to increase understanding of cancer- related biological effects on women's tobacco use and environmental tobacco smoke (ETS) exposure, and develop better interventions to decrease women's and girls' tobacco use exposure. In addition, research areas will highlight the biology of addiction, cancer susceptibility, behavioral aspects of tobacco use, and communications and intervention work.

TITLE: Parenthood after Cancer: Today's Options and Tomorrow's Hopes **NCI**
AWARD: \$5000
CONTACT: Anna T. Levy

This conference will be held March 5-7, 2004 at the Hickey Auditorium, University of Texas M.D. Anderson Cancer Center, Houston. The purpose of this conference is to convene the first international meeting on fertility and pregnancy after cancer, and the genetic consequence of cancer treatment on offspring born to cancer survivors. This conference will include advances in fertility preservation, infertility treatment, and the impact of cancer treatment on pregnancy. Also included will be communicating fertility risks and options to cancer patients and their partners, and the psychosocial aspects of choosing nonbiological parenthood among cancer survivors.

TITLE: Computer- based Technology and Caregiving of Older Adults **NIA**

AWARD: \$5000
CONTACT: Dr. Sydney Stahl

The conference was held in the Natcher Center at NIH, October 2-3, 2003. The purpose of this conference was to elevate awareness in the family caregiving community throughout the United States to the rapidly increasing importance of computer-based technology in helping support quality caregiving for older Americans. A Press release follows.



**COMPUTER-BASED TECHNOLOGY AND CAREGIVING FOR OLDER ADULTS
CONFERENCE**
October 2nd and 3rd, 2003

FOR IMMEDIATE RELEASE:

**SPRY Conference Demonstrates How Latest Research,
Newest Technologies are Enhancing Caregiving for Older Americans**

Administration on Aging, NIH Institutes, Veterans Affairs, Agency for Healthcare Quality and Research and Private-Sector Groups Showcase Advances
At Biannual National Gathering

Washington, DC, October 9, 2003 – At the SPRY Foundation’s October 2-3 conference “Computer-Based Technology and Caregiving for Older Adults,” speakers from 40 different government agencies, small and large corporations, and public and non-profit organizations met at the National Institutes of Health to demonstrate that advances in basic research and technological innovation are rapidly converging to transform the care of older adults in the United States so that they can remain independent longer in their own homes and communities. From the opening, televised welcome of Elias Zerhouni, director of the National Institutes of Health, to the closing comments of Karyne Jones Conley, president and CEO of the National Caucus and Center on Black Aged, more than 300 health professionals, researchers, federal and local government officials, and caregiving experts were treated to what one observer called, “A particularly outstanding blend of information about caregiving, from basic research and development to the practical applications of technology that are improving life for many, many older Americans.”

Jonathan B. Perlin, Deputy Undersecretary for Health at the Department of Veterans Affairs, detailed how the VA is using electronic record keeping to achieve patient-centered, coordinated care which is seamless across environments. “Health care is a team sport at the VA,” he declared. “Through our ‘TeleHealth Care’ project, we are combining improved technology with a focus on cooperation up and down the continuum to eliminate the boundaries to excellent health care.”

“It is just like the doctor was there,” Perlin said, noting that the VA’s patients are “older, sicker and poorer” than the national average. “This project is proving that health care can be better,

cheaper and friendlier. We can and must translate this 'just-in-time' care to civilian society," he concluded.

In emphasizing the importance of focusing on the needs of the individual, Suzanne Mintz, president of the National Family Caregivers Association, admonished experts and conference attendees alike to "remember the heart," while Pamela Whitten, assistant professor of telecommunication at Michigan State University, stressed that the "patient-caregiver encounter is paramount."

Talking about the privacy and ethics of older caregiving, Mike Cantor, associate director for clinical affairs at the New England Geriatric Research, Education, and Clinical Center, noted that computer-based caregiving raises all sorts of issues, including ones of access, justice and cost. "Who decides who gets access to all this new information, and what about the 'digital divide' which limits the poor from getting the newest technologies," he asked.

Speaking for the National Hispanic Council on Aging, Elizabeth Bertera urged, "Continue your research but don't lose sight of us Hispanic Americans!" According to her, Hispanic-Americans are widely divergent in education and economics and will comprise 14 percent of the population by 2020. "But 50-percent of us have children 18 years old or younger, and they are computer-savvy—ideal for inter-generational telehealthcare," she noted.

Ron Goetzel, who directs Cornell University's Institute for Health and Productive Studies, pointed out that the economics of caregiving in a rapidly aging society (people 85 and over is the country's fastest-growing cohort) will help to spur tailored communication to improve preventive health care. With less than five percent of the nation's annual \$1.4 trillion health expenditures going for prevention, he said, "There is a business case to be made for investing in better health of the aging and others."

Gary Kreps, chief of the National Cancer Institute's Health Communication and Informatics Research Branch, emphasized that computer technology is a "major strategy" to promote multi-disciplinary collaboration in remote health monitoring and health care coordination. "The challenge," he said, "is to utilize computer technologies to cross the digital divide to promote good health; to provide relevant, persuasive information to help people change their behavior."

Discussing the changing roles for caregivers, Kathleen Kelly, Family Caregiving Alliance, noted that although as much as 80 percent of long-term care is provided by families, few states know very little about the needs of older spousal caregivers, for example, and what they require in the way of help. "We need to identify them in order to help them," she concluded.

Adam Darkins, the new director of the VA's care coordination initiative, cautioned that in the quest for better health care, "We need to match the technology with existing needs. Our goal is an individualized, fully integrated national system of support which works for people."

Eric Dishman, who manages Intel Corporation's Proactive Health Research unit, talked about the "ties that blind" the current caregiving system and the "lack of visibility of who is doing the

work.” He reported that for private sector companies like Intel, “aging is the locus of the focus” for involvement in health care.

Gail Hunt, executive director of the National Alliance for Caregiving, noted that some caregivers are reluctant to adopt technology because there is “relatively little evidence about the benefits from technology, let alone what it will cost and who is to pay.” “The three top needs for caregivers are information, training and support,” she observed, “and clearly technology can have a positive impact in each of these areas.”

Speaking for the AARP, the nation’s largest membership organization of older adults, John Rother, director of policy and strategy, said that to assure better health care, there need to national health care infrastructure standards, a funding mechanism to pay for the transition to the new system and greater patient involvement in the system. As did all the conference presenters, Rother declared that the needs of both patients and caregivers must be better understood and incorporated into the design and development of new systems.

Carolyn Clancy, director of the Agency for Healthcare Research and Quality, who is concerned with errors in health care, which are especially acute among the chronically ill, older adult, said that computer technology can produce better, more coordinated patient records. “This leads to greater accountability and more involvement of the patient and the family in both health care monitoring and decision making,” she said.

In closing the conference, Dr. Russell E. Morgan, Jr., president of SPRY, noted, “With the Baby Boom generation fast-approaching retirement, the next Great American Dream is to live healthy and independent lives well into old age in their own homes and communities. As we have learned from this conference, the convergence of technological innovation, cutting-edge research and human compassion is beginning to make this dream come true.”

A scientific overview of “Computer-Based Technology and Caregiving for Older Adults” is to be published jointly by the Gerontology Society of America and SPRY in the January 2004 issue of *Public Policy and Aging*. SPRY also will develop a consumer guide to the topic and, with the VA, will produce a training video based on the conference.

SPRY (Setting Priorities for Retirement Years) Foundation is an independent, non-profit 501(c)(3) research and education organization that helps people prepare for successful aging. SPRY emphasizes planning and prevention-oriented strategies in four key areas: health and wellness, mental health, financial security, and life engagement.

TITLE: National Meeting on Treatment Options for LCIS and DCIS
AWARD: NA
CONTACT: Diana Zuckerman, Ph.D.

The conference was held on September 22, 2003 at the National Institutes of Health. The purpose of this working conference was to bring together a dozen of the foremost experts on DCIS and LCIS, to determine what consensus there is about treatment recommendations, and what information could be provided to patients in booklet form.

TITLE: Workshop on Phenotyping Obesity for Human Genetic Studies **NIDDK**
AWARD: \$5000
CONTACT: Robert Karp, Ph.D.

It is widely accepted that identification of genes predisposing to obesity in humans would lead to great advances in understanding of the physiology of obesity, and provide leads for the development of interventions to prevent and treat this increasingly prevalent disorder. It appears that gene identification will require larger-scale studies, which classify individuals into phenotypically homogeneous groups at a greater level of physiological detail than previous studies have attempted. The purpose of this Workshop will be to consider a wide range of anatomical, physiological, behavioral, and developmental phenotypes relevant to obesity and its major medical consequences, and to recommend a comprehensive set of biologically informative, cost-effective measurements to be incorporated into the design of a large-scale genetic study of obesity.

TITLE: Environmental Factors in Autoimmune Disease **NIEHS**
AWARD: \$5000
CONTACT: J. Patrick Mastin, Ph.D.

The purpose of this workshop was to explore the role that exposures to environmental agents play in the development and exacerbation of autoimmune diseases. The goals were to get input from the environmental health science and autoimmune research communities on the most appropriate and productive directions for research.

TITLE: A Multicultural Caribbean United Against HIV/AIDS **OAR**
AWARD: \$200,000
CONTACT: Jack Whitescarver, Ph.D.

This is a unique forum and opportunity to disseminate information to those critically impacted by HIV/AIDS, many of whom are women. The conference goals are:

- To enhance the Caribbean's regional efforts to work collectively towards preventing the spread of HIV and mitigation of HIV/AIDS' impact on the health, social, and economic status of the region.
- To improve regional responses to HIV/AIDS through the application of knowledge, research, learning, collaboration, and best practices within the Caribbean region.
- To develop the regional research capacity through the promotion of a Caribbean research agenda on HIV/AIDS and the dissemination of the latest HIV/AIDS research information.

TITLE: Health Issues and Concerns of Women of Color
AWARD: NA
CONTACT: Celia Maxwell, M.D. - Howard University

This conference addressed A Call to Action IV: HIV, STDs and Women: Still a Challenge. Issues addressed included STDs, HIV, Pregnancy, Complimentary and Alternative Medicine, and the Importance of Mental Wellness.