



MAKING WOMEN'S HEALTH MAINSTREAM

A HISTORY



Society for
Women's Health Research

MAKING WOMEN'S HEALTH MAINSTREAM



30 YEARS

THIRTY YEARS AGO, THE HEALTH OF WOMEN WAS AT SERIOUS RISK.

- Women were intentionally excluded from participating in most medical research. Why? Researchers argued that female hormones and potential pregnancies were too difficult to manage in experiments and that using only one sex would reduce variation in study results. They assumed they could simply extrapolate male-only study results to females, setting a dangerous precedent that overlooked fundamental biological differences between women and men.

In 1990, the Society for Women's Health Research (SWHR) was founded by Dr. Florence Haseltine and a group of physicians, researchers, and health advocates to confront this injustice and change the culture of medical research. They succeeded.

- Thanks to the efforts of SWHR and other advocacy groups, women are now routinely included in medical research and scientists are studying how biological sex differences affect the prevention, diagnosis, and treatment of disease. We are overcoming the historical biases that led to women's exclusion and making science and medicine more inclusive.

Since its founding, SWHR has fought to bring attention to research gaps and unmet needs in women's health and to advance its mission to eliminate imbalances in care for women through science, policy, and education.

Moving forward, we will continue to advocate for greater investment in women's health research, champion policies that benefit women's health, and raise awareness about women's unique health needs.

SWHR IS MAKING WOMEN'S HEALTH MAINSTREAM. JOIN US.



1990

SWHR FOUNDED BY
DR. FLORENCE HASELTINE

The Society for Women's Health Research (SWHR) was officially founded by Florence Haseltine, PhD, MD, along with other physicians, medical researchers, and health advocates, to change the culture of medical research and advocate for the inclusion of women in clinical research at a time when they were being actively and intentionally excluded.

1990

■ GAO REPORT REVEALS NIH NOT INCLUDING WOMEN IN RESEARCH
SWHR and the Congressional Caucus for Women's Issues requested that the Government Accountability Office (GAO) examine whether the National Institutes of Health (NIH) was following its 1986 policy that encouraged the inclusion of women in clinical research. The resulting GAO report, "Problems in Implementing Policy on Women in Study Populations," revealed NIH had made little progress on including women.

■ NIH STRENGTHENS POLICY ON THE INCLUSION OF WOMEN IN RESEARCH
Just one month after the release of the GAO report that showed NIH was failing to comply with its policy on including women in clinical research, NIH published an updated policy that required "a clear rationale" for the exclusion of women and minorities in grant applications for clinical research.

■ NIH ESTABLISHES OFFICE OF RESEARCH ON WOMEN'S HEALTH
In addition to strengthening its policy of inclusion, NIH established the Office of Research on Women's Health (ORWH), whose mission is to "strengthen and enhance the prevention, diagnosis, and treatment of illnesses in women and to enhance research related to diseases and conditions that affect women."

1991

■ HHS CREATES OFFICE ON WOMEN'S HEALTH
The Department of Health and Human Services (HHS) established the Office on Women's Health to serve as the focal point for women's health across all HHS offices and agencies. OWH published an Action Plan for Women's Health to identify widely disparate health needs of women that required more attention and scrutiny.

■ DR. BERNADINE HEALY BECOMES NIH'S FIRST FEMALE DIRECTOR
NIH took another step forward for women when President George H.W. Bush appointed Bernadine Healy, MD, as NIH Director. Healy, a cardiologist, went on to establish NIH's \$625 million Women's Health Initiative. This 15-year study enrolled more than 160,000 women to make strides in preventing heart disease, breast and colorectal cancer, and osteoporosis.

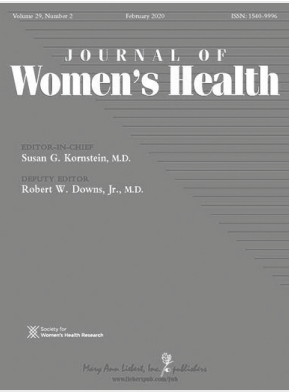
■ SWHR HOLDS FIRST SCIENTIFIC ADVISORY MEETING: 'TOWARDS A WOMEN'S HEALTH RESEARCH AGENDA'
SWHR kicked off a decade of annual Scientific Advisory Meetings (SAMs) with an event to establish priorities for women's health research. The top priorities identified were: (1) cardiovascular disease, (2) cancer, (3) violence against women, and (4) depression/substance abuse. The first SAM also shed light on the need to increase the number of women in STEM leadership positions.



APRIL 1991 • Dr. Bernadine Healy became NIH's first woman director.



In 1992 and 1993, SWHR held a series of meetings on the need for more women in medicine and science careers.



1992

■ JOURNAL OF WOMEN'S HEALTH LAUNCHES

SWHR helped establish the Journal of Women's Health, whose founding editors were SWHR Founder Dr. Florence Haseltine and SWHR Board member Dr. Anne Colston Wentz. The first issue featured a foreword about SWHR and a short commentary by then-NIH Director Dr. Bernadine Healy.

■ GAO REPORT REVEALS WOMEN ARE UNDERREPRESENTED IN DRUG TRIALS

SWHR asked the GAO to review the inclusion of women in clinical trials used by the Food and Drug Administration (FDA) to evaluate drugs for market approval. The resulting report concluded that women were underrepresented in drug trials and that even when women were included, the data were not analyzed to determine whether their responses to drugs differed from those of men.

■ SWHR HOLDS MEETING SERIES ON WOMEN IN MEDICINE

From October 1992 to February 1993, SWHR held a series of roundtables that collectively served as its second Scientific Advisory Meeting. These meetings focused on the need for more women in academic medicine and health science careers, and resulted in a series of recommendations to advance the prevalence of women in these fields.

1993

NIH REVITALIZATION ACT MANDATES INCLUSION OF WOMEN AND MINORITIES IN RESEARCH

In a historic moment for women's health research, President Bill Clinton signed into law the NIH Revitalization Act, which was written with input from from SWHR. The law mandated that women and minorities be included in all NIH-funded clinical research and that Phase III clinical trials be analyzed for sex differences.

■ FDA RESCINDS GUIDELINE BANNING WOMEN OF CHILDBEARING POTENTIAL FROM RESEARCH

In response to GAO's 1992 report on the inclusion of women in drug trials, FDA rescinded its 1977 guideline that banned all women capable of becoming pregnant from Phase I and Phase II clinical research. FDA released new guidance encouraging the participation of women in Phase I and II studies and requiring their inclusion in Phase III efficacy studies. The new guidelines also required that FDA analyze drug data for sex, racial, and ethnic differences.

■ SWHR FOCUSES ON ENVIRONMENTAL HEALTH

SWHR's third Scientific Advisory Meeting discussed environmental health and produced a report on concerns most important to women, including exposure to pesticides and toxins and environmental health hazards.

1994

■ FDA ESTABLISHES OFFICE OF WOMEN'S HEALTH

A congressional mandate created the FDA Office of Women's Health (OWH). The office's first director, Dr. Ruth Merkatz, noted that the efforts of SWHR staff were “extremely important and lasting, especially to be able to influence members of Congress about the importance of establishing the Office of Women's Health at the FDA.”

■ SWHR PROMOTES HEALTHY BEHAVIOR IN YOUNG WOMEN

SWHR's fourth Scientific Advisory Meeting targeted the unmet health needs of young women ages 18-24. A series of focus groups on college campuses found considerable misinformation about women's health circulating in this age group, so SWHR produced an educational program, “Get Real: Straight Talk About Women's Health,” in collaboration with the U.S. Public Health Service's Office on Women's Health.

1995

■ SWHR HOSTS FIRST SEX DIFFERENCES MEETING

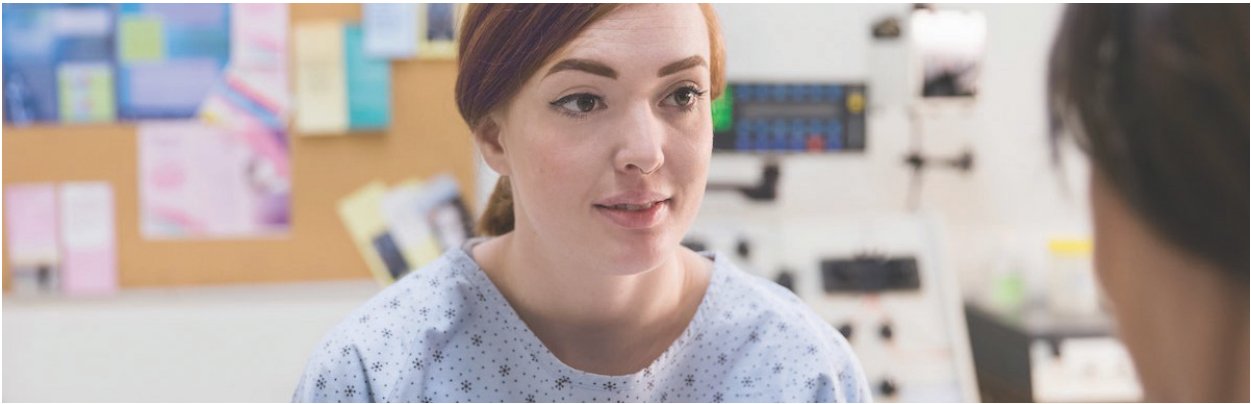
SWHR held its fifth annual Scientific Advisory Meeting on sex differences in neurobiology, language ability after stroke, autoimmunity, and osteoporosis. After the meeting, SWHR published several articles about sex differences in the August issue of the Journal of Women's Health.

■ HILLARY CLINTON SPEAKS AT SWHR AWARDS DINNER

Then-First Lady Hillary Rodham Clinton spoke at SWHR's awards dinner, saying: “We have a very long way to go before we can say with any confidence that women's health has taken its rightful place in the American health care system.” She also thanked SWHR “on behalf of literally millions and millions of American women.”



JUNE 1995 • Hillary Clinton speaks at SWHR awards dinner.



1996

■ SWHR HOLDS MEETING ON GENETICS AND WOMEN'S HEALTH

SWHR held its sixth Scientific Advisory Meeting on the role of sex-based research in human genetics. The meeting focused on the idea that a better understanding of differences in genetics and inheritance between males and females would help improve diagnostics, preventative strategies, and therapies for women and men.

1997

■ SWHR PUBLISHES BOOK ON WOMEN'S HEALTH RESEARCH AND POLICY

With the goal of making women's health a priority for U.S. researchers and policymakers, SWHR published “Women's Health Research: A Medical and Policy Primer.” The book outlined research and policy agendas aimed at improving women's health research at an institutional level.

■ SWHR EXAMINES HEALTH CARE OUTCOMES FOR WOMEN

SWHR's seventh Scientific Advisory Meeting explored research on health care delivery outcomes. The meeting stressed the importance of understanding when differences in health outcomes between women and men are sex-based (due to biological differences between males and females) and when they are service-based (meaning they differed because women and men receive a different standard of care).

1998

■ SWHR LOOKS AT DISCOVERIES IN GENDER-BASED BIOLOGY

SWHR's eighth Scientific Advisory Meeting examined sex neurology, psychiatry, immunology, and pharmacology. Based on the meeting's findings SWHR published the article “The Sexual Revolution in Science: What Gender-Based Research Is Telling Us” in March 1999 in the Journal of Investigative Medicine.

1999

■ SWHR ESTABLISHES THE WOMEN'S HEALTH RESEARCH COALITION

SWHR brought together a broad spectrum of health researchers, health care providers, and policymakers to promote a women's health agenda by creating the Women's Health Research Coalition. The WHRC's mission was to encourage coordination and funding of women's health research, and its members advocated for SWHR's legislative priorities during an annual Capitol Hill Day.

■ SWHR EXPLORES THE ROLE OF ESTROGEN IN HEART DISEASE

In its ninth Scientific Advisory Meeting, SWHR primarily focused on sex differences in cardiovascular biology and musculoskeletal health. The meeting emphasized the importance of research to learn more about the role of estrogen in protecting premenopausal women from cardiovascular disease.

2000

■ SWHR HOSTS FIRST WOMEN'S HEALTH LEGISLATIVE STRATEGY CONFERENCE

Building on its regular briefings on Capitol Hill, SWHR expanded its policy efforts by bringing together members of the Congressional Caucus on Women's Issues for a series of annual legislative strategy conferences. Attendees discussed advancements in women's health and developed a women's health action plan for the caucus.

■ SWHR HOLDS FIRST SEX AND GENE EXPRESSION CONFERENCE

SWHR began a new annual program called Sex and Gene Expression (SAGE) conferences, which ran through 2006. The initial conference covered molecular and cellular mechanisms that underlie sex differences, and ultimately resulted in publication of the article "Sex, Genes and Women's Health" in Nature Genetics.

■ GAO REPORTS NIH RESEARCH INCLUDES WOMEN, BUT DOESN'T ANALYZE DATA BY SEX

SWHR requested another audit of NIH and the subsequent GAO report stated that while women were included in clinical research appropriate to their proportionate population representation, the resulting data was almost never analyzed for sex differences.

■ SWHR STUDIES DRUG ADDICTION AND PAIN

SWHR concluded its decade-long Scientific Advisory Meeting program with an event on drug addiction and pain in women. The meeting stressed that while drug abuse is typically thought of as a male-dominated disease, it may be equally as prevalent in women but not as easily recognized because of the lack of sex differences research in this area. This meeting led to two publications in the Journal of Women's Health in 2001: "Women and Tobacco Use" and "Women, Men, and Pain."



“The role of the Society for Women’s Health Research was critical because it highlighted the discrepancies and lack of attention to women’s health.”

RITA COLWELL, PhD, former Director, National Science Foundation

2001

■ TWO GAO REPORTS CONCLUDE FDA FAILS TO ANALYZE SEX DIFFERENCES IN DRUG DEVELOPMENT

A GAO audit of FDA records revealed that eight out of the last 10 drugs withdrawn from the market caused adverse effects more often in women than in men. A subsequent GAO report stated that although women were included in drug trials, sex differences were not being considered. The reports suggested that FDA was not sufficiently monitoring research data to analyze how sex affected the drugs' safety or efficacy.

■ SWHR HOLDS CONFERENCE ON SEX DIFFERENCES IN DEVELOPMENT

SWHR's second annual Sex and Gene Expression Conference discussed sex differences during fetal development and later in life, as well as mitochondrial diseases and X-chromosome contributions to sex differences in mammals.

■ SWHR HOSTS SECOND WOMEN'S HEALTH LEGISLATIVE STRATEGY CONFERENCE

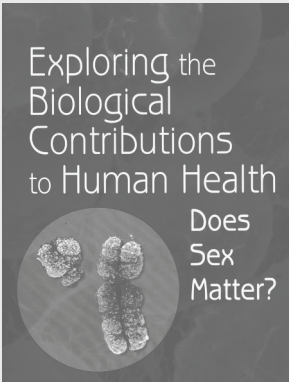
This Capitol Hill event, in collaboration with the Congressional Caucus on Women's Issues, provided an opportunity for members of Congress, their staff, and executive agency leaders to discuss their health policy priorities and craft a women's health action plan.

■ SWHR KICKS OFF EVENT SERIES ON IOM REPORT FINDINGS

In response to the IOM report, SWHR convened a series of five scientific meetings focused on sex differences research. This first workshop addressed strategies for conducting subgroup analyses to detect sex differences. The meeting resulted in the following publications: "What Women Want: Taking Sex Differences Seriously in Clinical Trials" in Clinical Researcher and "Understanding the Biology of Sex and Gender Differences" in Medscape General Medicine.

■ SWHR ADDRESSES SEX DIFFERENCES IN IMMUNOLOGY AND AUTOIMMUNITY

SWHR discussed sex differences in immunology and autoimmunity for the second meeting in its IOM report series. The meeting resulted in the booklet "Autoimmune Diseases in Women" (a joint project of SWHR and the National Women's Health Resource Center) as well as an article "Molecular and Clinical Evidence of the Role of Estrogen in Lupus" in Trends in Immunology in May 2002.



2001

INSTITUTE OF MEDICINE REPORT CONCLUDES THAT SEX MATTERS FROM 'WOMB TO TOMB'

As a result of SWHR's advocacy efforts, the Institute of Medicine (IOM) published the landmark report "Exploring the Biological Contributions to Human Health: Does Sex Matter?" The report came to the groundbreaking conclusion that sex DOES matter from "womb to tomb" and that "every cell has a sex."

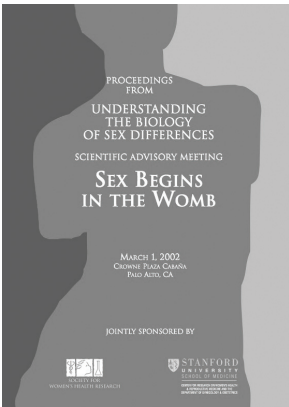
2002

SWHR KICKS OFF
INTERDISCIPLINARY NETWORK
ON SEX, GENDER, DRUGS, AND
THE BRAIN

SWHR established the first of its Interdisciplinary Science Networks — formerly called Interdisciplinary Studies in Sex Differences (ISIS) Networks — to identify knowledge gaps in women’s health and sex differences research and recommend steps to address them. The Brain Network ran from 2002 to 2007 and aimed to develop collaborations for research on sex differences in nervous system function and to translate the results of this research into new and improved therapies.

■ SWHR SCIENTIFIC MEETING
ON HOW ‘SEX BEGINS IN THE WOMB’

SWHR held the third meeting in its IOM report series to discuss the origins of sex differences. Four publications resulted: a) “Early Encounters, Lifetime Effects: Hormones in the Intrauterine Environment,” b) “Sex, Genes and Hormones,” c) “Sex, Cells and Signals in the Developing Brain,” and d) “Strategies and Methods for Research on Sex Differences in Brain and Behavior.”



■ SWHR HOSTS THIRD LEGISLATIVE CONFERENCE
ON WOMEN'S HEALTH

SWHR hosted the third Public Policy Conference on Women’s Health (originally the Women’s Health Legislative Strategy Conference) with a focus on health issues gaining political momentum in Congress. The conference included a breakfast briefing with members of Congress, a congressional committee health staff briefing, and a visit to NIH.

■ SWHR HOLDS THIRD SEX AND GENE EXPRESSION CONFERENCE

At SWHR’s third Sex and Gene Expression Conference, speakers discussed sex differences in development, sex and gene expression in the immune system, steroid hormones, apoptosis, cancer, and more.

■ SWHR RAISES AWARENESS OF SEX
DIFFERENCES IN HEART HEALTH

In partnership with the University of Wisconsin Medical School, SWHR hosted a meeting on sex differences in cardiovascular disease as a part of its series around the 2001 IOM report. Although heart disease is the leading cause of death in women, that fact remained largely unknown to the public and even to some in the medical community. The meeting resulted in publication of “Sex, Hormones and the Cardiovascular System” in Trends in Endocrinology & Metabolism.

■ SWHR TACKLES SEX DIFFERENCES
IN ENVIRONMENTAL EXPOSURES

SWHR’s final event in its series on the 2001 IOM report took place at the National Institute of Environmental Health Sciences to discuss recent advances in environmental health research that explain sex differences in response to environmental exposures. The meeting resulted in the report “Understanding Sex Differences in Environmental Health: A Thought Leaders’ Roundtable” in Environmental Health Perspectives.



2003

■ SWHR KICKS OFF INTERDISCIPLINARY
NETWORK ON METABOLISM

SWHR’s Interdisciplinary Network on Metabolism ran from 2003 to 2009 and advanced the understanding of sex-dependent differences in energy homeostasis and metabolic disorders. SWHR funded three projects investigating sex differences in this topic, and Network members published multiple peer-reviewed articles and presented at two meetings on metabolism.

■ SWHR CONFERENCE LOOKS AT SEX DIFFERENCES IN AGING

At SWHR’s fourth annual Sex and Gene Expression Conference, speakers discussed the future of sex and gene expression research, sex differences in aging, and emerging technologies like somatic cell nuclear transfer.

2004

■ SWHR HOLDS FIFTH SEX AND GENE EXPRESSION CONFERENCE

SWHR’s fifth annual Sex and Gene Expression Conference featured speakers on topics including sexual dimorphism in the brain, environmental effects on development, and sex chromosome dosage effects.

2005

■ SWHR CONFERENCE EXPLORES FUTURE
OF SEX AND GENE EXPRESSION RESEARCH

At SWHR’s sixth and final Sex and Gene Expression Conference, speakers presented on sex differences in mental health; molecular, genetic and behavioral basis of drug addiction; chromosome disorders, epigenetics and disease; and sex differences in metabolism and energy homeostasis. Additionally, a workshop helped attendees brainstorm the future of sex and gene expression research.

■ SWHR REPORT REVEALS ONLY 3% OF NIH-FUNDED
RESEARCH ANALYZES SEX DIFFERENCES

SWHR released a report, “National Institutes of Health: Intramural and Extramural Support for Research on Sex Differences,” analyzing NIH’s focus on sex differences in research and found that only 3% of all grants given by NIH take sex differences into consideration. It also noted that the institutes with the largest budgets actually appeared to be doing the least amount of work in sex differences research.



“When it comes to women’s health, being treated like men was and is dangerously wrong.”

JILL B. BECKER, PhD, Chair of SWHR's Brain Network and OSSD founding member

2006

SWHR ESTABLISHES THE ORGANIZATION FOR THE STUDY OF SEX DIFFERENCES

SWHR established the Organization for the Study of Sex Differences (OSSD) to continue scientific collaboration on sex and gender research. Researchers from SWHR's Brain Network were some of the founding members. OSSD was funded and supported by SWHR until 2012, when it became an independent organization.



■ RAISE PROJECT RECOGNIZES WOMEN IN STEM

Directed by SWHR Founder Dr. Florence Haseltine, the RAISE Project tracked awards given by scientific societies and professional organizations to recognize the achievements of women and to demonstrate the underrepresentation of women receiving prestigious awards.

■ SWHR PUBLISHES BOOK TO EDUCATE WOMEN PATIENTS ON SEX DIFFERENCES

SWHR wrote and published a book titled “The Savvy Woman Patient: How and Why Sex Differences Affect Your Health.” The book is designed to be a woman’s guide to her own health — from young adulthood to menopause and beyond.

■ SWHR AND WOMENHEART RELEASE FIRST EDITION OF WOMEN'S HEART HEALTH REPORT

SWHR and WomenHeart published “The 10 Q Report: Advancing Women’s Heart Health Through Improved Research, Diagnosis and Treatment,” which identified the top 10 unanswered research questions related to the diagnosis and treatment of heart disease in women. The groups released an updated report in 2011.

■ SWHR AND MEDTRONIC CREATE PRIZE FOR FEMALE SCIENTISTS

SWHR and the Medtronic Foundation established a prize of \$75,000 to recognize a woman scientist or engineer for her significant contributions to women’s health. Winners: Marisa Bartolomei (2006), Elizabeth Petri Henske (2007), Karyn Frick (2008), Kimberly Kenton (2009), Sabra Klein (2010), Denniz Zolnou (2011), Tracy Bale (2012), and Mia K. Markey (2013).

■ SWHR HOSTS SEX DIFFERENCES WORKSHOP WITH FDA

SWHR and the FDA Office of Women’s Health collaborated to hold a workshop on the FDA Critical Path Initiative to speed the development of new medical products. The event highlighted the importance of recognizing biological differences between men and women in the context of improving or accelerating development of drugs, devices, and biologics.



MAY 2012 • Tracy Bale, PhD, receives the SWHR Medtronic Prize for Scientific Contributions to Women's Health.



APRIL 2013 • Mia K. Markey, PhD, receives the SWHR Medtronic Prize for Scientific Contributions to Women's Health.

2007

■ SWHR KICKS OFF INTERDISCIPLINARY NETWORK ON MUSCULOSKELETAL HEALTH

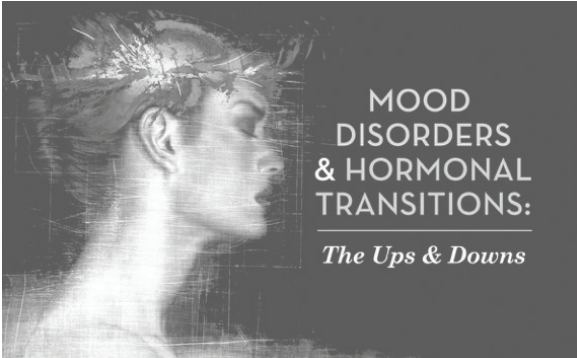
SWHR's Musculoskeletal Health Network focused its efforts on osteoarthritis (OA) of the knee joint because women are more likely than men to experience this condition. The group produced multiple peer-reviewed publications and symposia, and researchers in SWHR-funded pilot projects investigated genetic, physiological, biochemical, and biomechanical sex differences in knee OA.

■ SWHR BRAIN NETWORK MEMBERS PUBLISH BOOK ON SEX DIFFERENCES IN NEUROLOGY

Edited by SWHR Brain Network member Jill B. Becker, PhD, the groundbreaking book “Sex Differences in the Brain: From Genes to Behavior” provides a comprehensive overview of the differences between male and female neurobiology, as well as outlines areas that need further exploration. The book serves as an educational resource for clinicians, scientists, and students.

■ SWHR ROUNDTABLE ADDRESSES HORMONAL TRANSITIONS AND MOOD DISORDERS

SWHR and the National Institute for Mental Health held a roundtable meeting about the effects of pregnancy and postpartum hormonal transitions on mood disorders in women. The thought leaders in attendance at the meeting published a scientific report on the subject.



2008

■ CONGRESS PASSES GENETIC INFORMATION NON-DISCRIMINATION ACT

The Genetic Information Non-Discrimination Act prohibits discrimination on the basis of genetic information in health insurance and employment. SWHR advocated for the bill because of concerns about the impact of genetic discrimination on the participation of women in clinical trials.

■ SWHR CONVENES EXPERT WORKSHOP TO ADDRESS PTSD IN WOMEN

SWHR hosted a workshop to discuss the state of research and knowledge gaps related to post-traumatic stress disorder in women. The experts in attendance developed a plan for improving diagnosis and treatment of PTSD in female veterans, and SWHR published a summary report after the meeting.

2009

SWHR LAUNCHES INTERDISCIPLINARY NETWORK ON CARDIOVASCULAR DISEASE

SWHR's Cardiovascular Disease Network, which ran from 2009 to 2014, spurred groundbreaking research on sex and gender differences in heart disease and propelled knowledge in this field forward. The Network promoted research that defines sex and gender differences in pathophysiology, health care delivery, and treatment effectiveness to reduce cardiovascular disease burden. The Network members produced dozens of peer-reviewed publications, abstracts, and meeting presentations.



SWHR played a foundational role in establishing the differences in how cardiovascular disease manifests in women and men by bringing together the foremost experts in the field.

2010

■ SWHR ESTABLISHES INTERDISCIPLINARY NETWORK ON EXERCISE AND BREAST CANCER

In collaboration with the Susan G. Komen Foundation, SWHR established the Breast Cancer Network, which ran from 2011 to 2013, to examine how exercise impacts breast cancer risk and recurrence. The Network resulted in a study published in 2019 the journal Clinical Cancer Research that provides some of the first evidence in humans that exercise could directly fight breast cancer.

■ PATIENT PROTECTION AND AFFORDABLE CARE ACT BECOMES LAW

President Barack Obama signed the Patient Protection and Affordable Care Act into law. This bill included the Women's Health Office Act (WHOA), for which SWHR had long advocated. The WHOA was originally introduced in 1994, and finally, 15 years later, SWHR's signature piece of legislation passed, securing the offices of women's health in the NIH, FDA, and many other federal agencies.



■ SWHR LAUNCHES BIOLOGY OF SEX DIFFERENCES JOURNAL

SWHR and the Organization for the Study of Sex Differences (OSSD) founded the peer-reviewed, open-access academic journal Biology of Sex Differences, the official journal of OSSD. Published by BioMed Central and SWHR, Biology of Sex Differences aims to improve understanding of sex differences and foster development of therapeutic and diagnostic tools that are specific for sex differences.



“If we didn’t have the Society for Women’s Health Research, we’d simply have to invent it.”

COLLEEN CONWAY-WELCH, PhD, former Dean, Vanderbilt University Schooling of Nursing

2011

■ SWHR AND WOMENHEART RELEASE
UPDATED REPORT ON WOMEN’S HEART HEALTH

SWHR’s Cardiovascular Disease Network partnered with WomenHeart to update the “10Q Report: Advancing Women’s Heart Health through Improved Research, Diagnosis and Treatment,” which addressed many of the questions that still existed about heart disease and women.

■ SWHR CONFERENCE EXPLORES
CONDITIONS AFFECTING FEMALE VETERANS

This scientific conference highlighted sex differences in conditions that affect female veterans of military combat. The resulting report in the Journal of Women’s Health focuses on post-traumatic stress disorder (PTSD) and depression, urogenital health, musculoskeletal health, and traumatic brain injury.

■ SWHR AND FDA PARTNER ON WOMEN AND
MINORITIES IN CLINICAL TRIALS

SWHR and the FDA Office of Women’s Health collaborated on a two-day conference, “Dialogues on Diversifying Clinical Trials,” and resulting white paper about successful strategies for the recruitment, retention, and subsequent analysis of women and minorities in clinical research.

■ SWHR ROUNDTABLE REVIEWS STATE
OF SEX DIFFERENCES RESEARCH IN ALZHEIMER’S

SWHR hosted a roundtable of experts from academia, medicine, industry, and government to discuss the state of sex and gender differences research in Alzheimer’s disease and identify gaps in need of further study. A summary of the meeting was published in the Journal of Women’s Health. This meeting laid the groundwork for SWHR’s follow-up roundtable in 2015 and its Interdisciplinary Network on Alzheimer’s in 2016.



2012

■ CONGRESS PASSES LAW REQUIRING FDA
TO REPORT ON SEX, RACE, AND ETHNICITY

Less than a year after SWHR and the FDA Office of Women’s Health collaborated for a conference and report about the inclusion of women and minorities in clinical research, Congress passed the Food and Drug Administration Safety and Innovation Act (FDASIA), which requires FDA to provide special reports and accounts of clinical trials by sex, race, and ethnicity.

■ SWHR GATHERS EXPERTS ON MENOPAUSAL HORMONE THERAPY

SWHR hosted a roundtable meeting of researchers to analyze evidence on the effects of menopausal hormone therapy, as well as discuss next steps for research. Participants identified gaps in menopause research and published a peer-reviewed article in the Journal of Women’s Health based on discussions at the roundtable.

2013

■ FDA ISSUES REPORT ON DEMOGRAPHIC SUBGROUP DATA

In a report required by the 2012 FDASIA law, FDA examined tools for submission of demographic information, subset analysis, and demographic subgroup participation in clinical trials submitted to the agency. The report mentioned the 2011 joint public workshop hosted by SWHR and the FDA Office of Women’s Health.

■ SWHR EVENT EXPLORES SEX DIFFERENCES IN SLEEP

SWHR’s roundtable meeting explored the role that sex and gender play in sleep, as well as the state of women’s sleep health research. It aimed to identify research challenges facing women with sleep-related problems. The roundtable resulted in a peer-reviewed paper in the Journal of Women’s Health and served as the launching pad for SWHR’s Interdisciplinary Network on Sleep.

“We all know that sex matters. But we’re now finding out just how much sex matters when it comes to medicine and science.”

LESLEY STAHL, CBS News



2014

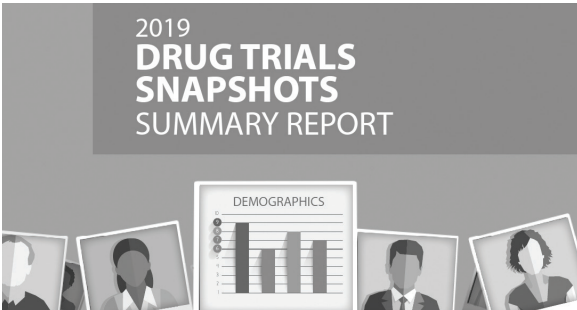
‘60 MINUTES’ REPORTS ON SEX DIFFERENCES

Lesley Stahl of CBS News’ “60 Minutes” reported a story titled “Sex Matters: Drugs Can Affect Sexes Differently” that revealed pharmaceutical companies have almost exclusively tested new drugs on men despite marketing and selling them to women. SWHR provided historical background information, as well as expert contacts, to help CBS develop this story. The report shocked Americans and inspired renewed congressional interest in sex differences.



■ SWHR HOSTS ROUNDTABLE ON WOMEN'S UROLOGIC HEALTH
SWHR convened experts from diverse backgrounds for a meeting on women’s urologic health. The experts reviewed urologic conditions prevalent during key stages of a woman’s life, identified research gaps, and addressed psychosocial and physical challenges to women with urologic conditions. The roundtable resulted in a peer-reviewed report in the Journal of Women’s Health and led to the formation of SWHR’s Interdisciplinary Network on Urological Health in Women.

■ SWHR LAUNCHES INTERDISCIPLINARY NETWORK ON SLEEP
SWHR’s Sleep Network, which ran from 2014 to 2018, featured a diverse group of researchers and health care providers working to bring attention to sleep health issues in women in order to improve diagnosis, treatment, and management of sleep disorders. The network produced a “Women & Sleep Guide,” as well as a handout for patients and clinicians on “Women and Sleep Apnea.”



2015

■ FDA LAUNCHES DRUG TRIALS SNAPSHOTS
The FDA’s Drug Trials Snapshots website provides consumers with valuable information about who participated in clinical trials supporting FDA approval of new drugs. Ensuring transparent clinical trial data has positive implications for women’s health because it allows the public to hold organizations accountable for the appropriate inclusion of women in clinical research.

■ SWHR ESTABLISHES INTERDISCIPLINARY NETWORK ON UROLOGICAL HEALTH IN WOMEN
SWHR’s Urology Network ran from 2015 to 2019 with a goal of raising awareness of the impact of bladder health on women’s well-being across the lifespan. The Network conducted a survey of school nurses revealing that many schools do not have bathroom policies and do not educate students on bladder health. It also published a peer-reviewed paper in Biology of Sex Differences about sex differences in the lower urinary tract.

■ SWHR REPORT IDENTIFIES 10 RELEVANT HEALTH TOPICS FOR WOMEN WITH DIABETES
SWHR released “10 Relevant Health Topics for Women with Diabetes” in collaboration with DiabetesSisters to address women’s unique health concerns associated with diabetes over the lifespan, especially during periods of hormonal fluctuation (puberty, pregnancy, and menopause).



■ SWHR CELEBRATES 25TH ANNIVERSARY AT GALA DINNER
More than 600 guests attended SWHR’s 25th Anniversary Gala to celebrate its achievements for women’s health research. NIH Director Dr. Francis Collins received an award for his development of the NIH policy on inclusion of sex as a biological variable. Rep. Lois Capps (D-CA), Rep. Rosa DeLauro (D-CT), Rep. Nita Lowey (D-NY), and former Secretary of State Hillary Rodham Clinton were also recognized for making women’s health a national priority.

■ SWHR HOSTS SECOND ROUNDTABLE ON ALZHEIMER'S DISEASE
SWHR’s second roundtable meeting to discuss sex and gender differences in Alzheimer’s disease covered new advancements in research since the 2011 meeting, as well as explored gender-specific issues in caregiving. The two roundtables led to the creation of SWHR’s Interdisciplinary Network on Alzheimer’s Disease.

■ GAO ISSUES REPORT ON WOMEN'S PARTICIPATION IN NIH RESEARCH
A GAO report concluded that NIH needed to implement better oversight to ensure continued progress on including women in health research. The report examined women’s enrollment in NIH-funded clinical research and NIH’s efforts to monitor this enrollment, as well as reviewed NIH’s efforts to ensure that clinical trials were designed and conducted to analyze potential sex differences.

2016

NIH IMPLEMENTS POLICY ON
SEX AS A BIOLOGICAL VARIABLE

NIH began implementing its new policy (announced in 2014) on consideration of sex as a biological variable in research. The policy now requires grant applicants to account for sex as a biological variable in their research designs, analyses, and reporting in preclinical research. SWHR strongly supported the policy in a white paper titled “New Policies Signal Changing Attitudes on Sex Differences Research: An SWHR Perspective.”

■ SWHR LAUNCHES INTERDISCIPLINARY
NETWORK ON ALZHEIMER'S DISEASE

SWHR's Alzheimer's Disease Network aims to understand and leverage the scientific basis of the roles of sex and gender in Alzheimer's to inform prevention and treatment and provide guidance for research, clinical trials, and policy. The group's major accomplishments include publication of a peer-reviewed paper in Alzheimer's & Dementia: The Journal of the Alzheimer's Association, which garnered significant media attention, including commentaries in STAT and Scientific American.

■ SWHR HOLDS WORKSHOP TO PRODUCE
FEEDBACK FOR FDA ON CLINICAL TRIAL DESIGN

SWHR held a two-day workshop to develop information to share with FDA on achieving meaningful subgroup data in clinical trial design. The workshop focused on understanding the drivers of variability in drug response among different patient populations, improving drug development and approval processes, and refining communication to patients and health care providers about medication response variability.

■ SWHR COHOSTS CONFERENCE
ON SEX DIFFERENCES IN METABOLISM

In partnership with the University of Colorado's Center for Women's Health Research, SWHR hosted the National Conference on Women's Health Research on sex differences in metabolism. Experts gathered to discuss their latest findings in cardiometabolic risk across the lifespan as well as recognize critical next steps to take in order to advance the field of sex differences research.

2017

■ SWHR ROUNDTABLE EXAMINES SEX AND
GENDER DIFFERENCES IN MIGRAINE

SWHR hosted a roundtable discussion and public panel on sex and gender differences in migraine. The meeting aimed to establish next steps to address the gaps in migraine knowledge and resulted in publication of a peer-reviewed paper in the Journal of Women's Health. This work led to the formation of SWHR's Interdisciplinary Network on Migraine.



OCTOBER 2017 • SWHR convenes experts and patients for a public panel on migraine.

2018

■ SWHR CREATES INTERDISCIPLINARY NETWORK ON MIGRAINE

SWHR's Migraine Network provides thought leadership about migraine in the U.S. health care system, with a focus on the disease's disproportionate burden on women. The Network's major accomplishment to date is its Migraine Patient Toolkit, which provides easy-to-understand information about migraine diagnosis and treatment, as well as tips on interacting with health care providers and health insurance companies.

■ SWHR IDENTIFIES GAPS IN
ENDOMETRIOSIS RESEARCH AND CARE

SWHR brought together patients, clinicians, researchers, and other stakeholders for a roundtable discussion and public panel on unmet needs and knowledge gaps in endometriosis. The roundtable set the stage for a congressional briefing identifying policy needs to improve diagnosis, treatment, and access to care for women with endometriosis. Roundtable members also published a peer-reviewed paper in the American Journal of Obstetrics & Gynecology. These events gave rise to SWHR's Interdisciplinary Network on Endometriosis and Fibroids.

2019

■ SWHR ESTABLISHES INTERDISCIPLINARY
NETWORK ON ENDOMETRIOSIS AND FIBROIDS

SWHR's Network on Endometriosis and Fibroids provides thought leadership on how to address the gaps in research, diagnosis, treatment, and care for endometriosis, uterine fibroids, and related conditions. The Network is working on projects to raise awareness about stigma around these conditions and to help patients achieve optimal outcomes in their care.



2020

SWHR CELEBRATES
30 YEARS OF IMPROVING
WOMEN'S HEALTH

SWHR is celebrating its 30th anniversary by honoring decades of work to improve women's health through science, policy, and education. SWHR's annual awards dinner highlights SWHR's historic efforts and future goals for women's health, including our vision of “Making Women's Health Mainstream.”

DEDICATED TO:
Florence Haseltine, MD, PhD & Phyllis Greenberger, MSW



Society for
Women's Health Research

MAKING WOMEN'S HEALTH MAINSTREAM

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