

# Framework for the Consideration of Chronic Debilitating Conditions in Women

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**NATIONAL  
WOMEN'S  
HEALTH  
NETWORK**

A VOICE FOR WOMEN, A NETWORK FOR CHANGE

# The National Women's Health Network

How do we address women's health issues across their lifespan and where do we spend our advocacy time?

- The National Women's Health Network is a nonprofit based in Washington, D.C. We represent the health interests of women across the life continuum with an intersectional focus on sexual and reproductive health, maternal health and the health and well-being of aging women. We work to improve women's health outcomes through state and federal advocacy, consumer health education, and grassroots technical assistance initiatives.



# The National Women's Health Network

## Our Historical Work On Chronic Conditions:

- The National Women's Health Network has mostly focused on osteoporosis, breast cancer, menopause and HIV/AIDS in our chronic condition work
- Efforts focused on research and more diversity in clinical trials
- Worked on increasing access to care and education for people with chronic conditions by protecting Medicaid, Medicare and the Affordable Care Act (ACA)
- Disseminating reliable consumer health information



# Chronic Condition: Osteoporosis

- 2013 – The NWHN persuaded the FDA to limit the use of bisphosphonates which caused previously rare fractures for women with long-term use of osteoporosis drugs. Our advocacy and education campaign helped women avoid rare fractures and helped healthy women avoid unnecessary use of the drug overall
- 1985 – The NWHN exposed drug company funding and the questionable validity of an osteoporosis public health education campaign



# Chronic Condition: Menopause/HRT

- 2009 – Exposed pharmaceutical manufacturer Wyeth’s funding of CME programs that presented distorted information about the safety and effectiveness of menopause HRT
- 2002 – Proved to be correct on its assessment of HRT. The Women’s Health Initiative showed that HRT does not prevent heart disease, increase energy, prevent memory loss, improve mood or prevent Alzheimer’s disease
- 1994 – Persuaded the NIH to fund the only diverse long-term study of the menopause transition in healthy women. The Study of Women Across the Nation (SWAN) enrolled more than 3000 women representing diverse ethnic groups
- 1994 – Persuaded the U.S. government to launch and fund the largest-ever study on the health of older women, the Women’s Health Initiative
- 1990 – Stopped the FDA from recklessly approving menopause hormone replacement therapy for the prevention of heart disease.



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# Chronic Condition: Breast Cancer

- 1990 – Watched for the safety and efficacy of breast cancer treatments
- 1996 – Distributed consumer health information about the disparities in survival of breast cancer
- 1994 – Disputed a PSA claiming that abortion cause breast cancer
- 1993 – Joined forces with hundreds of groups to push for more breast cancer research
- 1992 – Prompted Congress to investigate the lack of informed consent in trials of breast cancer treatment drug given to healthy women
- 1990 – Successfully petitioned the government to fund the WomenCARE Breast Cancer study
- 1987 – Successfully convinced the NCI to fund the Dietary Modification Trial
- 1986 – Initiated the Breast Cancer Campaign to evaluate and strengthen standards of Care in breast cancer screening clinics



# Chronic Condition: HIV/AIDS

- 2001 – Built support for the development of microbicides so women could protect themselves for STIs and HIV
- 1989 – Distributed AIDS brochure dispelling the myth that women were at low risk of contracting HIV
- 1975 – Inspired direct action at the FDA with our memorial for women who died from the birth control pill



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# NWHN's Other Chronic Condition Work

- 2019 – Instrumental in saving the FDA Office of Women's Health, which provides up to date information on chronic conditions disproportionately affecting women
- 2000's – Worked to pass and then defend the ACA and Medicaid
- 2008 – Successfully advocated for the passage of the HEART for Women Act
- 1992 – Persuaded the FDA to require studies on the safety of breast implants after decades of these implants being on the market





# Chronic Conditions: Future Focus

- More money on federal research dollars focused on women's health conditions
- Chronic conditions effect different populations differently
- Believing women's pain and lived experience
- Creating an environment where women feel heard and where informed consent can be freely given

## Other Chronic Conditions

- Heart disease
- Hypertension
- Diabetes
- Fibroids
- Endometriosis
- Chronic HPV Infection
- Menopause/perimenopause
- Breast Cancer
- Osteoporosis
- Alzheimer's disease



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# SOT: Issue Gaps

- Not enough funding for research into these conditions
- Low reimbursement rates for gynecological procedures, i.e., (procedures to diagnose endometriosis)
- Lack of diversity in clinical trials
- Barriers to care i.e., cost, location and health literacy

# Women's Health Priorities

- Creating environments where informed consent can be fully and freely given
- Bridging the trust and cultural competency gap between researchers/providers and Black and Brown patients
- More research into conditions associated with hard to diagnose chronic pain



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# SDOH: Women's Health

## Implicit Bias

The unconscious attitudes, beliefs, stereotypes, or prejudices that healthcare providers may hold about certain groups based on race, ethnicity, gender, age, SES or other factors.

- Leads to misunderstandings
- Mistrust
- Negative effects on patient care

## Racism

The weathering effects of racism and SDOH have a significant impact on healthcare outcomes, particularly for marginalized and underserved communities.

Studies have found that black and brown patients receive lower quality of care and experience worse health outcomes compared to white patients.

## Poverty

Poverty and Social Determinant of Health are closely linked and poverty can be both cause and a consequence. Poverty can limit access to quality healthcare, healthy goods, safe housing and other resources that are essential.

Individuals may lack financial resources to pay for preventive care or necessary medications leading to chronic conditions and increased risks.

## Environmental

Environmental and social determinants of health play a significant role in shaping health outcomes and health disparities. Environmental determinants can have a direct impact on respiratory illnesses caused by poor air quality or lead poisoning from exposure from lead-based pipes or paint. They also can have indirect impacts on health outcomes such as through their effects on mental health and well-being.



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Thank You

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