



Heart Failure and Women

eHealth Initiative
Washington, DC
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Who we are: WomenHeart: The National Coalition for Women with Heart Disease

- ♥ The only patient-centered organization exclusively serving the 48 million American women living with or at risk of heart disease
- ♥ Founded in 1999 by three women heart attack survivors, concerned about:
 - Misdiagnosis
 - Delays and disparities in care
 - Feelings of fear and isolation
 - Very little information/support



WomenHeart Mission

To improve the health and quality of life of women living with or at risk of heart disease and to advocate for their benefit

- ♥ **Educate** women on the importance of taking charge of their heart health
- ♥ **Support** women living with heart disease and connect them with one another
- ♥ **Advocate** for research funding and policies that meet the needs of women with heart disease
- ♥ **Partner** with hospitals committed to advancing women's heart health nationwide

Heart disease in women – the facts

- ♥ 8 million American women living with heart disease
- ♥ 40 million American women at risk for heart disease
- ♥ Almost every 80 seconds a woman dies of heart disease in the U.S.
- ♥ Heart disease kills more women than breast & lung cancer combined
- ♥ 64% of women who die suddenly of heart disease have NO PREVIOUS SYMPTOMS
- ♥ Cardiovascular disease in American women costs nearly \$126 billion annually (\$94 billion in direct costs, and nearly \$32 billion in indirect costs)

Why heart disease remains the #1 cause of death among women

- ♥ Lack of attention to sex and gender differences
- ♥ Disparities persist across subpopulations of women
- ♥ Heart attacks among women are often misdiagnosed as anxiety, stress, or a minor health issue
- ♥ Women are less likely to receive care according to standard treatment guidelines
- ♥ Critical research questions remain unanswered
- ♥ Women are underrepresented in clinical trials

What do women living with heart disease need to stay healthy?

- ♥ Access to primary care- THIS IS KEY
- ♥ Prompt referrals to specialty care
- ♥ Referral to subspecialty care as needed
- ♥ Coverage for cardiac testing, treatments and devices
- ♥ Access to medications as prescribed
- ♥ Attend and complete cardiac rehabilitation
- ♥ Availability of mental health/counseling
- ♥ Access to peer support

Heart failure in women

- ♥ Women with heart failure face:
 - more shortness of breath
 - lower quality of life
 - more hospitalizations
- ♥ Heart failure is the #1 cause of hospitalization among women and men age 65 and older
- ♥ Only one in four **participants** in heart failure research studies are women
- ♥ Heart failure costs the U.S. \$32 billion a year

WomenHeart Heart Failure Survey

- ♥ WomenHeart conducted a national online survey, two telephone focus groups, and two in-person roundtable discussions to learn how a diagnosis of HF affects women's health and their lives.
- ♥ Results indicated a need for better training for medical students, medical residents, and practicing clinicians on the diagnosis and treatment of HF in women.
- ♥ There is also a need for more sex -specific and multicultural research as well as greater support for women with HF.

Action Steps

- ♥ Increase the rate of physician referrals of women with HF to cardiac rehabilitation, and remove barriers to participation.
- ♥ Increase referrals of women with HF to clinical trials.
- ♥ Improve patient-provider communication.
- ♥ Expand insurance coverage for HF specialty and subspecialty care, medications and devices.
- ♥ Connect patients to support groups and begin new support groups for women with HF.

Support Needs of Minority Women

- ♥ Minority women with CVD indicated interest in attending support groups, particularly with a medical expert facilitator
- ♥ Respondents were most interested in online message boards.
- ♥ Community venues for monthly support group with flexible membership were the most popular choices.
- ♥ Respondents may benefit from referrals to tailored support group types, including online platforms, and to cardiac rehabilitation and clinical trials.

Diagnostic Testing Survey

- ♥ Survey in progress to learn about the experiences women with heart disease have related to diagnostic testing.
- ♥ Diagnosing women with cardiovascular disease (CVD) presents a number of challenges.
- ♥ Presentation of symptoms and timing and accuracy of diagnostic testing can affect outcomes
- ♥ Are women with heart disease are receiving the care, treatment, and information they need to make good decisions about their heart health?

What patient groups need to do

- ♥ Be the patient voice, advocating on behalf of women with heart disease at every opportunity
- ♥ Provide education and support to women with heart disease
- ♥ Encourage implementation of CVD prevention and screening with sex-specific CVD risk factor assessment
- ♥ Advocate for awareness and recognition of cardiovascular risk factors in women, especially during pregnancy.
- ♥ Include a comprehensive reproductive history in women's permanent medical record.
- ♥ Encourage coordination of CVD care among specialists.
- ♥ Promote use of cardiac rehabilitation services and eliminate barriers to participation.

Conclusion

- ♥ Policies advancing the health of women, which include access to affordable, quality care, including prevention, diagnosis, treatment, and rehabilitation must be enacted.
- ♥ Investments must be made in research to improve the heart health of women from traditional biomedical models to social determinants and the environment.
- ♥ Government agencies, researchers, clinicians, patients, women, advocates, and policy makers must commit to implement policies and work together to improve CVD morbidity and mortality rates among women.

Women Heart

The National
Coalition for Women
with Heart Disease

www.womenheart.org

