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.