

Heart Failure and Women

eHealth Initiative Washington, DC October 17, 2017

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.
- PRESULTS 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?

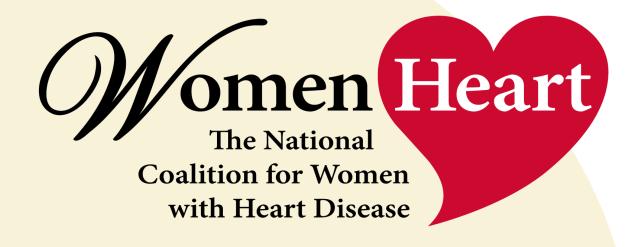
What patient groups need to do

- ♥ 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.



www.womenheart.org





