WOMENHEART: THE NATIONAL COALITION FOR WOMEN WITH HEART DISEASE

FEDERAL POLICY AGENDA 2021–2022

ABOUT WOMENHEART: WomenHeart: The National Coalition for Women with Heart Disease is the leading voice of millions of women in the United States living with and at risk of heart disease. The nonprofit organization was founded in 1999 by three women who survived near-fatal and misdiagnosed heart attacks and subsequently banded together with determination to address gender disparities in health outcomes/ cardiac research and sexism and biases in cardiac diagnosis/care. WomenHeart remains the only national patient-centered organization dedicated exclusively to supporting, educating, and advocating for women with heart disease.

WOMENHEART
THE NATIONAL COALITION FOR WOMEN WITH HEART DISEASE

KEY FACTS AND STATISTICS

Heart disease is the leading killer of women in the United States.

- 1 in 5 women's deaths in the United States are caused by heart disease.[1]
- 60 million women in the United States are living with some form of heart disease, including coronary artery disease, heart failure, stroke and hypertension.[2]
- An estimated 8.8 million women have coronary artery disease, and over 3 million women have heart failure.[3]

Recent data indicate that women's awareness about the threat of heart disease is falling.

- Less than half (44%) of women recognize that heart disease is the leading cause of death of women in the U.S.[4]

There are important heart disease health disparities for women.

- Of African-American women over 20 years old, nearly half (49%) have heart disease. More than 40% of non-Hispanic Black adults have high blood pressure, which is more severe in Blacks than whites, and develops earlier in life.[5]
- American Indians/Alaska Natives die from heart disease at a rate 20-30 percent higher than other racial and ethnic groups in the United States.[6]
- On average, Hispanic women are likely to develop heart disease 10 years earlier than non-Hispanics.[7]

Younger women are not absolutely protected against heart disease.

- Data from the CDC released in 2018 indicate high incidence of heart disease among adults age 35-64.[8]
- Heart disease is the leading cause of death of women in pregnancy.[9]
- There is an upward trend of young women experiencing heart attacks.[10]

Heart disease is often linked to other health conditions.

- Women with diabetes are 40% more likely to develop heart disease.[11]
- Women suffering from depression are two to three times more likely to develop heart disease than women who are not depressed.[12]

COVID-19 Exacerbates Heart Problems

- COVID-19 can cause heart and vascular damage directly.
- Those with heart conditions, including high blood pressure and diabetes, are at increased risk for complications if they become ill with COVID-19.

WomenHeart's mission is to **IMPROVE THE LIVES OF WOMEN** with or at risk for heart disease, while **FIGHTING FOR EQUITY** in heart health.

LISTENING TO WOMEN'S VOICES

In early 2021, WomenHeart conducted a survey of women in the United States living with heart disease to understand their engagement in advocacy and their interest in policies that impact health and women with heart disease. The majority of respondents were White (80%), 65 or older (54%), and were *WomenHeart Champions* (69%).* The results helped inform WomenHeart's policy priorities.

The findings reveal that respondents have a strong interest in "public policy issues that have a specific impact on heart disease." Nearly seven in ten respondents report having engaged in policy advocacy at least once, and three in five would "appreciate the opportunity to express [their] opinion about an issue or to tell [their] heart story to an elected official."

Respondents were presented with a list of policy issues. The top four most common issues of interest were:

- Prevention — education and support to help women
- Missed or delayed diagnosis of heart disease
- Access to cardiac rehab
- Funding for heart disease research

In addition, approximately one-third of participants also expressed interest in diverse representation in clinical trials; disparities in diagnosis, care and treatment for women of color; and health insurance coverage.

* There were 155 survey respondents; 80% were white, 11% African-American, 4% Latina, 2% American Indian, 1% Asian, and 2% prefer not to answer. 8% were age 35-49 years; 38% were age 50-64 years; 44% were age 65-75 years; and 10% were 76 years or older.

FEDERAL POLICY PRIORITIES

ACCESS TO COVERAGE AND CARE

WomenHeart supports policies that expand access to comprehensive and affordable health insurance coverage for all, with guaranteed protections from discrimination. We advocate for policies that promote prevention and address inequities in access to care, including for women of color who experience health disparities such as higher rates of heart disease compared to white women.

High quality, affordable health coverage means women living with and at risk of heart disease can access prevention, screening, and treatment services; medical devices and equipment; and medications as prescribed or recommended, regardless of their socio-economic status. For women living with heart disease, access to adequate insurance coverage can be the difference between getting appropriate and timely care needed to manage heart disease or relying on emergency rooms, urgent care, and low-cost or free health clinics for care. Addressing social determinants of health means mitigating barriers, such as cost, transportation and caregiving duties among others, which can prevent and/or impact the ability of women living with heart disease to adhere to the recommendations of their health care provider. For those at risk, including women with diabetes or depression, health insurance provides access to critical preventive services, including vaccines.

While the Affordable Care Act (ACA) was instrumental in increasing the number of women living with heart disease who have health insurance over the last decade, more than one in ten (11%) women between the ages of 19 and 64 remain uninsured.[13] American Indian and Alaska Native adults under 65 years have the highest uninsured rate at 22%, followed by Hispanics at 20%, and Blacks at 11%; Asian-Americans have the lowest uninsured rate of any racial or ethnic group at 7%.[14] At the same time, the CDC reported that women between the ages of 35-64 are experiencing high rates of heart attack and other cardiovascular events.[15] It is important that policies advance access to insurance coverage for all people and address the root causes of health inequity.

ADVANCING RESEARCH ON WOMEN'S HEART HEALTH

WomenHeart supports research efforts that lead to better outcomes for women with heart disease, including those that address areas in which women experience disparities or worse outcomes compared to men. We support efforts to address missed and delayed diagnosis of heart disease in women;

basic scientific research that leads to a better understanding of biological sex differences, which could inform treatment of heart disease; and measures that increase the participation of women and other underrepresented groups in clinical research.

The misconception that heart disease is "a man's disease" is a blind spot for the general public, many patients and even health care providers and researchers. At the same time, women tend to experience symptoms and present differently than men with heart disease. The result is women are more likely than men to have a missed or delayed diagnosis for heart disease. Those challenges, combined with bias related to gender, sex, age, race and ethnicity, as well as systemic barriers to high quality care, result in diagnostic error and unequal care for women. Research that creates evidence for patient-centered solutions would help to address this problem.

It is often said that women are not small men, and therefore researchers, clinicians and others must be intentional about studying both the basic sex differences — down to the cellular level, as well as to studying conditions that impact women differently than men, have a disparate impact on women, or impact women almost exclusively. The Offices of Women's Health established within the Department of Health and Human Services and its agencies, including NIH and FDA, are critical to ensuring that these types of investments are made and prioritized, and thus should be supported by policy.

Clinical trials determine the effectiveness and safety of tests and medical treatments. They have been pivotal in the advancement of prevention, diagnosis, and treatment of heart disease. Unfortunately, because women have been historically underrepresented in clinical trials, it means they also have yet to experience the potential full benefits of medical and clinical research. Barriers to participation in clinical trials include fear of experimentation and lack of trust, health related concerns, and challenges with transportation and logistics, among others.[16] In addition, all too often, women are simply not asked to participate. And while participation has increased in recent years, still only about one-third of the participants in cardiovascular clinical trials are women and one study showed that just 31% of cardiovascular clinical studies report the outcomes by sex.[17, 18] We support policies that break down barriers to participation and oversight of policies that hold researchers accountable for including women and other underrepresented groups and reporting out on the findings.

FULL FUNDING FOR HEART AND STROKE RESEARCH

WomenHeart strongly supports sustained and growing funding levels for federal research agencies. We support increased funding for the National Institutes of Health (NIH), including the National Heart, Lung, and Blood Institute (NHLBI), in order to address critical needs related to the ongoing COVID-19 pandemic, including health disparities and long haul COVID syndrome, to sustain current activities and to invest in promising and critically needed scientific research. In addition, we support full funding for the CDC's Heart Disease and Stroke Prevention Division, including WISEWOMAN, a program that provides services to low-income, uninsured, and underinsured women to promote lasting heart-healthy lifestyles;

for Million Hearts, a national initiative to prevent heart disease and stroke; and for the Offices of Women's Health across HHS and its agencies.

Government-funded research through the National Institutes of Health (NIH) and the Centers for Disease Control and Prevention (CDC) is critical to our understanding of how to prevent, diagnose, and treat heart disease, as well as COVID-19 and common co-morbidities to heart disease like diabetes and depression. It is a critical time for making increased investments in heart research. Experts predict the global burden of cardiovascular disease will also grow exponentially over the next few years as the long-term effects of the current COVID-19 pandemic evolve. Increased funding of research would help to sustain current efforts aimed at aggressively advancing the fight against heart disease and stroke, to reduce maternal mortality, to address congenital heart disease, and to decrease the disproportionate burden of heart disease on women of color and those in low-income and/or rural communities.

PREGNANCY AND HEART DISEASE

WomenHeart supports policies that address the impact of heart health on maternal health. These include efforts to increase awareness of prevention, diagnosis, monitoring and treatment of heart disease, as well as associated risk factors, before, during and after pregnancy. In addition, because Black women experience disproportionately high rates of both heart disease and of maternal mortality and morbidity, we support policies aimed at reducing those disparities.

Heart disease is the leading cause of death in pregnant women,[19] and heart disease in pregnant women is on the rise.[20] More women with heart disease are becoming pregnant, and one in five women in the United States experiences some type of cardiovascular complication during pregnancy, including gestational diabetes, preeclampsia, eclampsia, or hypertension.[21,22] Further, common obstetric complications can affect women's future heart health. For example, preeclampsia during pregnancy doubles a woman's risk of future heart attacks.[23]

There is tremendous momentum in Congress and across the country to address Black maternal health. For example, the Momnibus Act is federal legislation that addresses racism and other the root causes of disparities in maternal health by, for example, making investments in social determinants of health, improving data collection processes and quality measures, and promoting maternal vaccinations. Such policies would impact not only maternal health, but women's heart health.

SUPPORT DURING HEALTH EMERGENCIES

WomenHeart supports policies that provide financial security and access to needed services that help people make it through a health emergency. These include paid leave policies for medical or caregiving purposes and protection from surprise medical bills, as well as health care services like diagnostic testing and vaccines.

Whether it's a public health crisis or because of an emergency medical situation, people often need support they may not have

otherwise anticipated needing in order to tend to their health. The COVID-19 pandemic brought into immediate focus the need for supportive policies that people will continue to need once we're past the pandemic — because there will always be medical emergencies and the need for people to take care of their health. Policies that allow people — including women with heart disease — to take time off work to heal or to treat a chronic condition without fear of losing a paycheck have tremendous benefit. Similarly, policies that protect people from massive medical bills because they called for an ambulance while having a heart attack or ended up receiving out-of-network care during a medical emergency are critical for patients' financial security.

In addition, the pandemic made clear that in situations like public health emergencies, people may need guaranteed access to tools such as diagnostic testing and vaccines, without any barriers, including cost. Policies should continue to support innovative and effective ways to deliver these basic, life-saving services to all people, particularly those most in need.

EQUITY and ACCESS TO CARDIAC REHABILITATION

WomenHeart supports policies that address barriers and expand access to cardiac rehabilitation. We support increased referrals for women, efforts that promote equal participation, innovative ways to deliver this service to more patients, and policies that make it affordable for all.

While cardiac rehabilitation (rehab) is an incredibly effective treatment, it is under-utilized. Women, especially, are less likely to be referred, to enroll once referred, and to complete a full course of cardiac rehab, compared to men.[24] Research found that women were 12% less likely to be referred than men, and Blacks, Hispanics, and Asian patients were 20%, 36%, and 50% less likely to be referred than white patients.[25] Aside from lack of referral, women experience other barriers to attending regular cardiac rehab sessions, including financial constraints; lack of program availability, transportation, and access; higher levels of psychological stress and depression, which have been shown to decrease participation; and lack of awareness among women about their coronary heart disease risk.[26]

Ensuring that more women are able to participate in cardiac rehab would save lives. These programs are known to reduce heart disease mortality, increase your energy and strength, reduce stress, and decrease hospital readmissions.[27]

In 2018, WomenHeart supported the Improving Access to Cardiac and Pulmonary Rehabilitation Act, which passed as part of the Bipartisan Budget Act of 2018 (P.L. 115–123). This new law allows physician assistants, nurse practitioners, and clinical nurse specialists to supervise cardiac and pulmonary rehabilitation on a day-to-day basis under Medicare. Unfortunately, the bill does not go into effect until 2024. WomenHeart supports legislation allowing this provision to go into effect immediately. In addition, WomenHeart supports allowing qualified non-physician practitioners to order and/or refer patients to cardiac rehab under Medicare, in addition to supervising this care. In many places, these providers are already authorized to refer or prescribe cardiac rehab under state law.

CONCLUSION

WomenHeart is committed to advancing these policy priorities in the 117th Congress and with the Administration and federal agencies throughout 2021–2022.

ENDNOTES

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