Federal Policy Agenda

2019-2020

WOMENHEART
THE NATIONAL COALITION FOR WOMEN WITH HEART DISEASE

About WomenHeart

WomenHeart: The National Coalition for Women with Heart Disease is the leading voice of the nearly 48 million 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 supports, educates, and advocates for millions of women, remaining the only national patient-centered organization dedicated to serving women with heart disease.

Key Facts and Statistics

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

- 1 in 4 women's deaths, of U.S. women, are caused by heart disease.[1]
- 47.8 million women in the United States are living with some form of heart disease, including 7.8 million women living with coronary heart disease. [2]

There are important heart disease health disparities for women.

- Of African-American women over 20 years old, **nearly half** (49%) have heart disease.[3]Despite higher risk of heart disease, African-American women are 10% less likely than Caucasian women to receive aspirin and 27% less likely to receive cholesterol-lowering drugs. [4]
- American Indians/Alaska Natives die from heart disease at younger ages than other racial and ethnic groups in the United States.[5]
- On average, Hispanic women are likely to develop heart disease 10 years earlier than non-Hispanics.[6]

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.[7]
- Heart disease is the leading cause of death of women in pregnancy.[8]
- There is an **upward trend** of young women experiencing heart attacks.[9]

Women are at risk for all types of heart disease, including heart attack, stroke, heart failure, arrhythmia, and heart valve problems.

Heart disease is often linked to other health conditions.

- Women with diabetes are **40%** more likely to develop heart disease.[10]
- Women suffering from depression are two to three times more likely to develop heart disease than women who are not depressed.[11]

Access to care matters.

- One year after the Affordable Care Act went into effect, between 2013 and 2014, the percentage of women with heart disease who were uninsured[12]dropped from 16.7% to 12.4%; and the percentage of women at risk for heart disease who were uninsured dropped from 20.5% to 15.8%.

ACCESS TO COVERAGE AND CARE

WomenHeart supports policies, such as the Affordable Care Act (ACA), that guarantee protections for people with pre-existing conditions and expand access to comprehensive and affordable health insurance coverage. We advocate for policies that promote prevention and address disparities in access to care, including for women of color who experience disparate health care outcomes, such as higher rates of heart disease compared to white women.

High quality, affordable health coverage means women with and at risk of heart disease can access prevention, screening, and treatment services; medical devices and equipment; and medications as prescribed or recommended. 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. Women living with heart disease face a number of barriers, such as cost, which can prevent and/or impact their ability 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.

The Affordable Care Act (ACA) has been instrumental in increasing the number of women living with heart disease who have health insurance. In particular, the ACA's provisions banning health insurance providers from denying coverage to people with pre-existing conditions, including women with heart disease, and the requirement that each ACA plan cover a set of defined essential benefits, including preventive care, has been transformative for many who were previously unable to access coverage. Research conducted one year after the ACA went into effect found that, between 2013 and 2014, the percentage of women with heart disease who were uninsured dropped from 16.7% in 2013 to 12.4% in 2014.[13]

Still, more than one in ten (11%) women between the ages of 19 and 64 remain uninsured.[14]American Indian and Alaska Native adults under 65 years have the highest uninsured rate at 22%, followed by Hispanics at 19%, and Blacks at 11%.[15] 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.[16] It is important that policies advance access to insurance coverage for all people.

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.

Cardiac rehab is an individualized, medically supervised program that facilitates recovery from and reduces future risk after a heart attack or other diagnosis related to heart disease. Cardiac rehab consists of exercise counseling and training, education for heart-healthy living, and counseling to reduce stress.

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.[17] 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.[18] 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.[19]

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.[20]

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 in 2019. 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.

INCREASED REPRESENTATION OF WOMEN IN CLINICAL TRIALS AND MEDICAL RESEARCH

WomenHeart supports measures that break down barriers to participation and oversight of policies that hold researchers accountable for including women and other underrepresented groups in clinical research. We also support basic scientific research that leads to a better understanding of biological sex differences, which could inform treatment of heart disease.

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, women have been historically underrepresented in clinical trials. In many cases women with heart disease present with different disease symptoms, respond to different treatments, and have different health outcomes from men,[21] therefore this lack of representation means that women have yet to experience the potential full benefits of medical and clinical research.

Women face various barriers to participation in clinical trials. These include fear of experimentation and lack of trust, health related concerns, and challenges with transportation and logistics, among others.[22] 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.[23] [24]

Fortunately, policies and guidelines have come a long way since 1977, when FDA guidelines essentially banned women of child-bearing age from participating in most clinical research, and there has been increased emphasis on the participation of women and minorities. Most recently, the 21st Century Cures Act, passed in 2016, requires the National Institutes of Health (NIH) to provide an overview of data on study populations in clinical research, specifically regarding the inclusion of women; to implement accountability mechanisms for NIH-funded researchers to ensure women and racial and ethnic minorities are appropriately represented; and to develop and update policies for basic research to assess relevant biological variables, including sex, and how differences between male and females may be studied.

FULL FUNDING FOR HEART AND STROKE RESEARCH

WomenHeart strongly supports sustained and growing funding levels for federal research agencies. We support the recent trend of increased funding for the National Institutes of Health (NIH), including the National Heart, Lung, and Blood Institute (NHLBI), in order to build on the momentum of investments in 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; and Million Hearts, a national initiative to prevent heart disease and stroke.

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 common co-morbidities like diabetes and depression. It is a critical time for making increased investments in heart research. Cardiovascular disease costs are projected to rise to more than $1 trillion annually by 2035.[25] Yet, despite the fact that heart disease caused the deaths of more than 200,000 women and cost women more than $14 billion in hospitalizations in 2016,[26] NIH invests only 4% of its budget on heart research.[27]

PREGNANCY AND HEART DISEASE

WomenHeart supports policies that address heart disease as a threat to maternal health and efforts to educate both health care providers and women who are planning to or have become pregnant about the risk of heart disease. 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. Federal policy is needed to help increase awareness of how to prevent, diagnose, monitor, and treat heart disease before, during, and after pregnancy, particularly among populations most at risk.

Heart disease is the leading cause of death in pregnant women,[28] and heart disease in pregnant women is on the rise.[29] 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.[30] [31] 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.[32]

Pregnant women with or at risk of heart disease need specialized care. It is important that diagnosed and undiagnosed risk factors for heart disease are appropriately screened, monitored, and treated to prevent complications during pregnancy and later in life.[33]

Conclusion

WomenHeart is committed to advancing these policy priorities in the 116th Congress and with the Administration and federal agencies throughout 2019-2020.

Sources

[1] Xu, J.Q., Murphy, S.L., Kochanek, K.D., & Bastian, B.A. (2016) Deaths: Final data for 2013[PDF-7.3M]. National Vital Statistics Report, 64(2). Retrieved from https://www.cdc.gov/dhdsp/data_statistics/fact_sheets/fs_women_heart.htm

[2] Benjamin, E.J., Virani, S.S., Callaway, C.W., et al. (2018). Heart Disease and Stroke Statistics- 2018 Update: A Report from the American Heart Association. Circulation, 137(12). Table 26-2, e261, e487-e488. Doi: 10.1161/CIR.0000000000000558

[3] American Heart Association. Heart Disease in African-American Women. Retrieved January 11, 2019 from https://www.goredforwomen.org/en/about-heart-disease-in-women/facts/heart-disease-in-african-american-women

[4] Jha, A.K., Varosy, P.D., Kanaya, A.M., et al. (2003). Differences in Medical Care and Disease Outcomes among Black and White Women With Heart Disease. Circulation, 108(9), 108:1089-1094.Doi: 10.1161/01.CIR.0000085994.38132.E5

[5] Oh, S.S., Croft, J.B., Greenlund, K.J., Ayala, C., Zheng, Z.J., Mensah, G.A., & Giles, W.H. Disparities in Premature Deaths from Heart Disease—50 States and the District of Columbia. Centers for Disease Control and Prevention. MMWR2004; 53:121-25. Retrieved from https://www.cdc.gov/mmwr/preview/mmwrhtml/mm5306a2.htm

[6] American Heart Association. Heart Disease in Hispanic Women. Retrieved January 11, 2019 from https://www.goredforwomen.org/en/about-heart-disease-in-women/facts/heart-disease-in-hispanic-women

[7] Heart disease and stroke deaths hitting middle age adults in large numbers. (2018). Centers for Disease Control and Prevention, CDC Newsroom. Retrieved from https://www.cdc.gov/media/releases/2018/p0906-Heart-disease-stroke-deaths.html

[8] Graves, C.R. & Davis, S.F. (2018). Cardiovascular complications in pregnancy. Circulation, 137(12), 1213-1215. Doi: 10.1161/CIRCULATIONAHA.117.031592

[9] Arora, S., Stouffer, G.R., Kucharska-Newton, A., Qamar, A., et al. (2018). Twenty year trends and sex differences in your adults hospitalized with acute myocardial infarction: The ARIC community surveillance study. Circulation. Doi: 10.1161/CIRCULATIONAHA.118.037137

[10] U.S. Department of Health and Human Services, Office on Women's Health. (2018). Diabetes. Retrieved from https://www.womenshealth.gov/a-z-topics/diabetes

[11] National Heart, Lung, and Blood Institute.(2017). Heart disease and depression: A two-way relationship. https://www.nhlbi.nih.gov/news/2017/heart-disease-and-depression-two-way-relationship

[12] http://www.heart.org/idc/groups/heart-public/@wcm/@adv/documents/downloadable/ucm_480864.pdf

[13] Ku, L., Steinmetz, E., Bruen, B., & Bysshe, T. (2016). Effects of the Affordable Care Act on health insurance coverage of Americans at risk of cardiovascular disease. American Heart Association and Milken Institute School of Public Health. Retrieved from http://www.heart.org/idc/groups/heart-public/@wcm/@adv/documents/downloadable/ucm_480864.pdf

[14] Henry J. Kaiser Family Foundation. (2017). Health insurance coverage women 19-64. Retrieved from https://www.kff.org/other/state-indicator/nonelderly-adult-women/?currentTimeframe=0&sortModel=%7B%22colId%22:%22Location%22,%22sort%22:%22asc%22%7D

[15] Henry J. Kaiser Family Foundation. (2017). Uninsured Rates for the Noneldery by Race/Ethnicity. Retrieved from https://www.kff.org/uninsured/state-indicator/rate-by-raceethnicity/?currentTimeframe=0&sortModel=%7B%22colId%22:%22Location%22,%22sort%22:%22asc%22%7D

[16] Heart disease and stroke deaths hitting middle age adults in large numbers. (2018). Centers for Disease Control and Prevention, CDC Newsroom. Retrieved from https://www.cdc.gov/media/releases/2018/p0906-Heart-disease-stroke-deaths.html

[17] Supervía, M., Medina-Inojosa, J.R., Yeung, C., Lopez-Jimenez, F., Squires, R.W., Pérez-Terzic, C.M., Brewer, L.C., Leth, S.E., & Thomas, R.J. (2017). Cardiac rehabilitation for women: A systematic review of barriers and solutions. Mayo Clinic Proceedings, 92(4), 565-577. Doi: 10.1016/j.mayocp.2017.01.002

[18] Li, S., Fonarow, G.C., Mukamal, K., Xu, H., Matsouaka, R.A., Devore, A.D., & Bhatt, D.L. (2018). Sex and racial disparities in cardiac rehabilitation referral at hospital discharge and gaps in long-term mortality. Journal of the American Heart Association. 7(8). Doi: 10.1161/JAHA.117.008088

[19] Menezes, A.R., Lavie, C.J., DeSchutter, A. & Milani, R.V. (2014). Gender, race and cardiac rehabilitation in the United States: Is There a Difference in Care?. The American Journal of the Medical Sciences, 348(2), 146-152. Doi: 10.1097/MAJ.0000000000000306

[20] How cardiac rehab can help heal your heart. (2017). Centers for Disease Control and Prevention, CDC Feature. Retrieved from https://www.cdc.gov/features/cardiac-rehabilitation/index.html

[21] Gender matters: Heart disease risk in women. (2017, March 25). Harvard Health Publishing. Retrieved from https://www.health.harvard.edu/heart-health/gender-matters-heart-disease-risk-in-women

[22] Government Accountability Office. (2015). National Institutes of Health: Better oversight needed to help ensure continued progress including women in health research. (GAO Publication No. 16-13). Washington, DC: U.S. Government Printing Office.

[23] Melloni, C., Berger, J.S., Wang, T.Y., Gunes, F., Stebbins, A., Pieper, K.S., Dolor, R.J., Douglas, P.S., Mark, D.B., & Newby, L.K. (2010). Representation of women in randomized clinical trials of cardiovascular disease prevention. Circulation: Cardiovascular Quality and Outcomes, 3(2), 135-142. Doi: 10.1161/CIRCOUTCOMES.110.868307

[24] Scott, P.E., Unger, E.F., Jenkins, M.R., Southworth, M. R., McDowell, T., Geller, R.J., Elahi, M., Temple, R.J., & Woodcock, J. (2018). Participation of women in clinical trials supporting FDA approval of cardiovascular drugs. Journal of the American College of Cardiology, 71 (18), 1960-1969. Doi: 10.1016/j.jacc.2018.02.070

[25] American Heart Association. (2017). Cardiovascular disease: A costly burden for America. Retrieved from http://www.heart.org/idc/groups/heart-public/@wcm/@adv/documents/downloadable/ucm_491543.pdf

[26] New report shows more middle-aged women suffering from heart disease and stroke deaths. (2018). Business Wire. Retrieved from https://www.businesswire.com/news/home/20180906005962/en/New-Report-Shows-Middle-Aged-Women-Suffering-Heart

[27] American Heart Association. (2017). Cardiovascular disease: A costly burden for America. Retrieved from http://www.heart.org/idc/groups/heart-public/@wcm/@adv/documents/downloadable/ucm_491543.pdf

[28] Graves, C.R. & Davis, S.F. (2018). Cardiovascular complications in pregnancy. Circulation, 137(12), 1213-1215. Doi: 10.1161/CIRCULATIONAHA.117.031592

[29] Elkayam, U., Goland, S., Pieper, P.G., & Silverides, C.K. (2016). High-risk cardiac disease in pregnancy. Journal of the American College of Cardiology, 68(4). Doi: 10.1016/j.jacc.2016.05.048

[30] Pregnancy mortality surveillance system. (2018). Centers for Disease Control and Prevention. Retrieved from https://www.cdc.gov/reproductivehealth/maternalinfanthealth/pregnancy-mortality-surveillance-system.htm

[31] 10Q Report: Advancing women's heart health through improved research, diagnosis, and treatment. (2011). WomenHeart and the Society for Women's Health Research. Retrieved from https://swhr.org/portfolio/10q-report-advancing-womens-heart-health-through-improved-research-diagnosis-and-treatment-2011/

[32] Bellamy, L., Casas, J., Hingorani, A. D., & Williams, D. J. (2007). Pre-eclampsia and risk of cardiovascular disease and cancer in later life: systematic review and meta-analysis. BMJ, 335, 974. Doi: 10.1136/bmj.39335.385301.BE

[33] Hall, M. E., George, E. M., & Granger, J. P. (2011). The heart during pregnancy. Rev Esp Cardiol, 64(11), 1045-1050. Doi: 10.1016/j.recesp.2011.07.009