



# WOMENHEART

THE NATIONAL COALITION FOR  
WOMEN WITH HEART DISEASE

# Annual Report 2021





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# Who is WomenHeart?

WomenHeart is the first and only national patient-centered organization dedicated to serving women living with or at risk of heart disease.

WomenHeart's mission is to improve the lives of women with or at risk of heart disease, while fighting for equity in heart health.

## OUR VALUES

**PATIENT-CENTERED.** WomenHeart is committed to serving the needs of women with diagnosed heart disease.

**EMPOWERMENT.** WomenHeart believes that education, support and training enable women to take charge of their heart health and advocate for other women.

**EQUALITY.** WomenHeart is dedicated to ensuring that women have equal access as men to accurate cardiac diagnostic testing and proper treatment.

**INCLUSIVENESS.** WomenHeart believes that diversity strengthens and enriches every aspect of our organization.

**COLLABORATION.** WomenHeart actively seeks meaningful and productive partnerships with other organizations to educate women about heart disease.

**QUALITY.** WomenHeart is committed to rigorous evaluation and continuous improvement of all aspects of our organization.



# A New Strategic Plan

**2022-2024**



Goal 1: Define and prioritize WomenHeart services to meet the needs of women with heart disease, while aligning with future revenue growth and organizational impact.

- Synchronize WomenHeart's services that leverage core competencies (i.e., patient focus, peer support, advocacy) with funding sources to grow revenue.
- Stabilize the financial health of WomenHeart
- Determine approaches to better serve women affected by health disparities who are most at risk of heart disease
- Develop methods to document organizational impact more effectively, to better inform program development and communicate impact to funders
- Partner with our patient population to provide data that will improve the diagnosis, treatment, and quality of life of women living with heart disease.

Goal 2: Expand WomenHeart's Reach

- Determine methods to acquire new, active participants in WomenHeart's programs.
- Build a robust communications strategy to increase awareness and encourage engagement in WomenHeart programs.
- Invest in and integrate technology more effectively to engage and manage key audiences.



# WomenHeart Looks Back

## Timeline of 2021



January 27th

Convening on Missed and Delayed Diagnosis

Convening Report

#29DaysOfHeart Campaign

February

May 12th

HeartTalks on COVID-19 Vaccine

National Hospital Alliance Virtual Conference

July 13th & 14th

July 21st

Virtual Wenger Awards

\$25,000 Raised

HeartTalks on Heart Disease & Diabetes

August 3rd

September/October

Champion Refresher Course

Champion Town Hall

October 6th

200+ Champions

October 23rd & 24th

Board of Directors In-Person Meeting

HeartTalks on Time for Heart Care

November 9th

December 9th

Approval of Strategic Plan by Board



Dr. Hayes and Wenger Award winner Dr. Brewer celebrating the Virtual Wenger Awards



# WomenHeart Overview

for 2021



Evidence based information and educational materials at [womeneheart.org](http://womeneheart.org) and Youtube channel

HeartTalks - informative webinar series with clinician expertise and patients personal journeys



Champions program that provides peer support in groups

1:1 peer support with a trained Champions through SisterMatch



National Hospital Alliance - support hospitals to better support women living with heart disease

Access to patients and their heart disease stories





# Wenger

## A W A R D S

The annual Wenger Awards are named after Nanette Kass Wenger, MD, a pioneer in women's cardiology. It is the only national event that recognizes the extraordinary contributions of individuals and organizations to women' heart health.

### Excellence in Medical Research

LaPrincess C. Brewer, MD, MPH, FACC, FASPC, FACP - Assistant Professor of Medicine, Mayo Clinic Her primary research focus is addressing cardiovascular health disparities through community-based behavioral interventions for risk factor modification in racial/ethnic minority populations, particularly African-American women. She is currently principal investigator of the FAITH! trial, a cardiovascular health promotion intervention that will be critical to informing evidence-based interventions for preventive care, support and heart health education for Black women across the country.



### Excellence in Medical Innovation

CardioNerds - Amit Goyal MD, & Daniel Ambinder, MD (Co-Founders)  
CardioNerds is a medical education platform that hosts a podcast, mentorship program and more aimed at making cardiology education available to everyone. CardioNerds podcasts cover topics such as cardio-obstetrics and women's cardiovascular health. Their commitment to diverse voices and bringing forward patient experiences will impact the care that women with heart disease receive now and in the future.



### Excellence in Patient Advocacy

The Alliance for Aging Research is dedicated to accelerating the pace of scientific discoveries and their application to improve the experience of aging and health. Its work to advocate for older Americans, to build coalitions and to educate about various types of cardiovascular disease is a benefit to women living with heart disease. The Alliance leads the annual Heart Valve Disease Awareness Day initiative.



### Keynote Address

Janine Austin Clayton, MD  
Director, NIH Office of Research on  
Women's Health





# WomenHeart Programs

WomenHeart's 2021 Champion Refresher Program engaged WomenHeart Champions from every class. Building upon our annual Science & Leadership Symposium, the curriculum - developed by Mayo Clinic faculty and offered virtually - provided updated information on heart disease in women and equipped Champions to provide support, education and advocacy to women with heart disease in an increasingly virtual world.



## HEARTTALKS

HeartTalks are informative webinars that educate women on what they need to know about living with or preventing heart disease. CEO Celina Gorre moderates a panel of experts on a variety of timely topics.







# Champion Success by the Numbers

WomenHeart Champions provided over 2,040 volunteer hours to support and educate women with heart disease. The majority of those hours were spent virtually, given the restrictions on meeting in person.

Our HeartTalks series and other virtual education programs garnered over 5,300 participants and views on YouTube, with thousands more being exposed to the events on social media



380

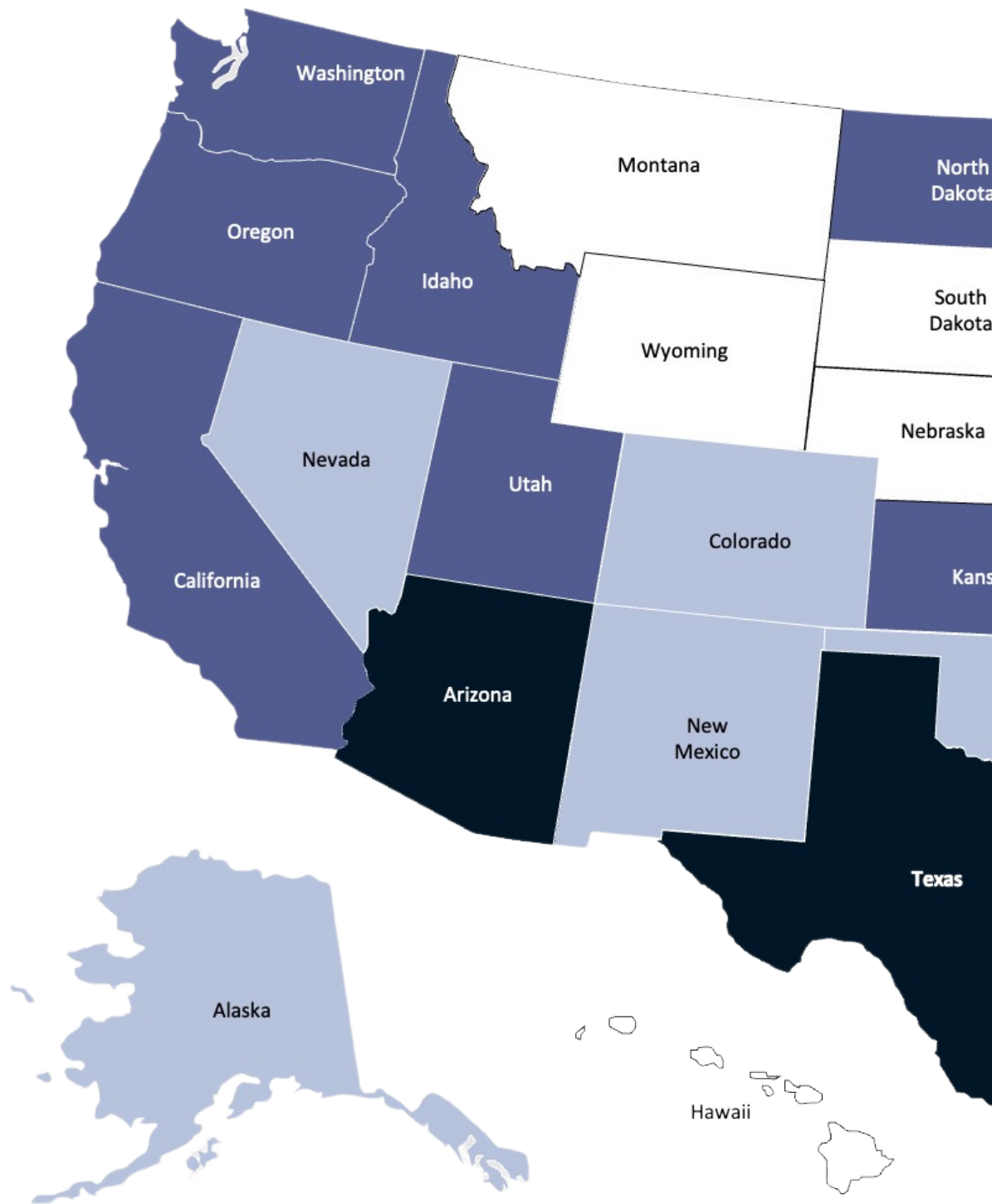
Hosted nearly 380 support network meetings across the country

4,338

Handed out 4,338 Red Bags of Courage, in English and Spanish. Thousands more accessed the materials online, given limited in-person events in 2021.

11,000+

Supported more than 11,000 women virtually at meetings and community events

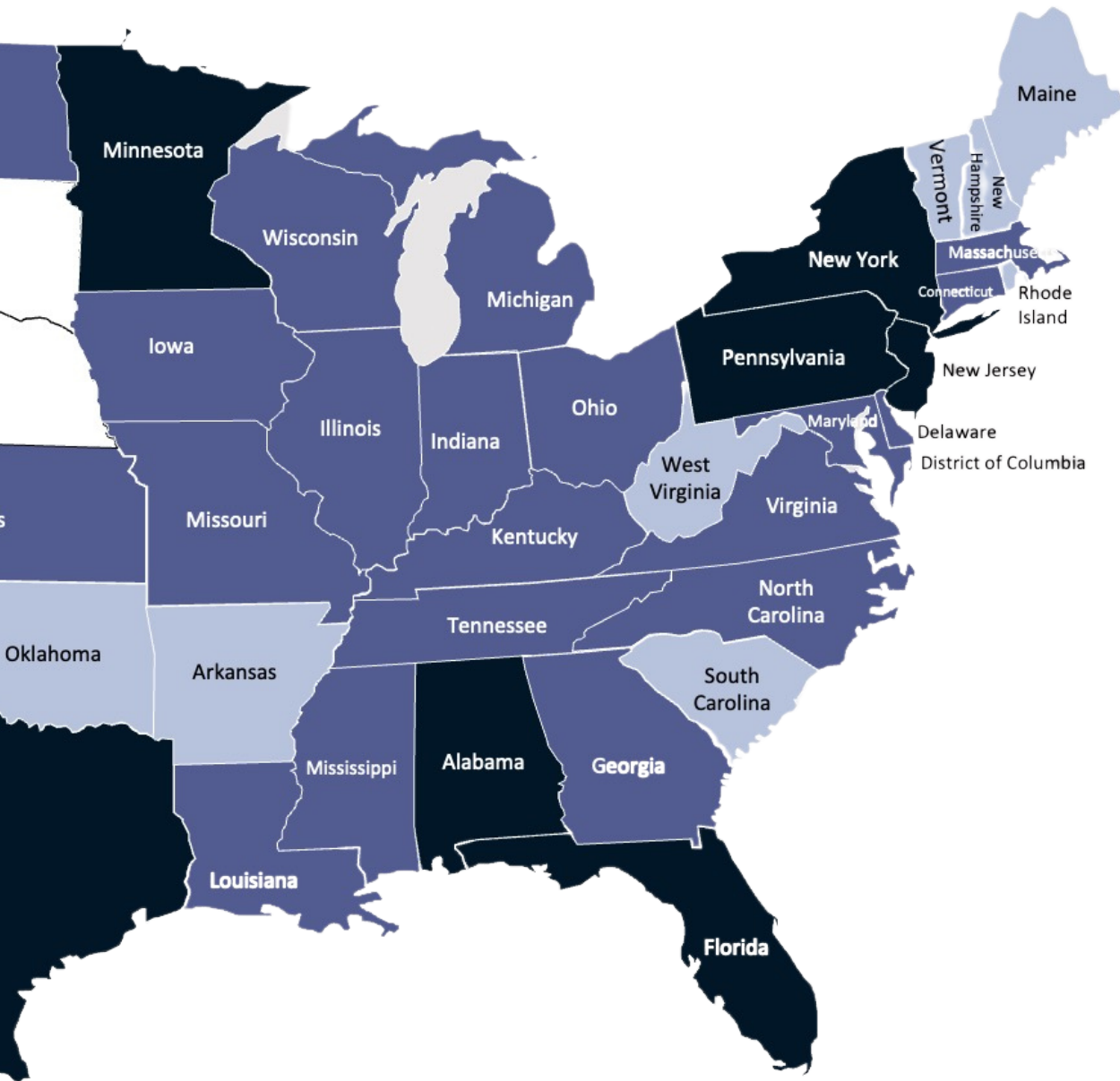


WomenHeart  
Champion

+Support Networks

+NHA Member





WomenHeart  
Champions  
in 45 States



Support Networks  
in 33 States



NHA members in  
8 States



# National Hospital Alliance

WomenHeart's National Hospital Alliance (NHA) is made up of hospitals committed to advancing women's heart health.

Boca Raton Regional Hospital - Christine E Lynn  
Women's Health & Wellness Institute  
Columbia Memorial Hospital  
Chandler Regional Medical Center (Dignity Health)  
Katz Institute for Women's Health  
Lenox Hill Hospital  
Maimonides Medical Center, Heart & Vascular Institute  
Mayo Clinic  
Mercy Gilbert Medical Center (Dignity Health)

Miami Cardiac & Vascular Institute  
Morristown Medical Center  
NYU Langone Hospital - Long Island  
Rochester Regional Health  
Temple Health, Heart & Vascular Institute  
Texas Heart Institute  
University of Alabama Birmingham  
University of Florida Health, Heart & Vascular Hospital

WomenHeart hosted its annual NHA Conference virtually in July. Sessions included a conversation between CEO Celina Gorre and three WomenHeart Champions about the challenges of COVID-19; a discussion on maternal health and heart disease with Dr. Sharonne Hayes, Dr. Rachel Bond and others; and a presentation by Dr. Harmony Reynolds about the decline in women's awareness of heart disease risk.



Dr. Harmony Reynolds



Dr. Rachel Bond





## Policy & Advocacy

After launching Advocacy Corps in 2020, WomenHeart deepened its engagement with our patient advocates in 2021. We conducted a survey of women living with heart disease to understand their interest in heart health policy and advocacy. Respondents were most interested in:

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

Informed in part by the survey, and building upon our history of federal advocacy, WomenHeart released a Federal Policy Agenda for 2021-2022 with the following policy priorities:

- Access to coverage and care
- Advancing research on women’s heart health
- Full funding for heart and stroke research
- Pregnancy and heart disease
- Support during health emergencies
- Equity and access to cardiac rehabilitation

## Diversity, Equity & Inclusion

WomenHeart was founded on the premise that women experience disparities in heart health. We recognize that Black, Latina, Asian American and Native American women experience a disproportionate burden of morbidity and mortality from heart disease compared to White women. This has always been true, but it was brought into sharper focus by the COVID-19 pandemic.

As our work has evolved, WomenHeart recommitted ourselves to diversity, equity and inclusion. Early in 2021, we released a guide for patient advocates on “The Root Causes of Health Disparities and Heart Disease,” and we trained WomenHeart Champions to engage in policy advocacy with an understanding of the strategies to reduce disparities and improve health outcomes. In November, we hosted a HeartTalks webinar that discussed how to access health care if you are uninsured or under-insured, a key contributor to disparities in health outcomes. Our policy and advocacy work prioritized solutions to the maternal health crisis that particularly impacts Black women and has a strong link to heart disease. With new funding and new partners going forward, we strive to fill critical gaps in support for women and communities that experience heart health disparities.



# CONVENING

on Missed and Delayed Diagnosis of Heart Disease in Women



On January 27, 2021, nearly 50 experts came together virtually to address missed and delayed diagnosis of heart disease in women. The day-long convening was hosted by WomenHeart and the Society to Improve Diagnosis in Medicine (SIDM), and it was funded through a Patient-Centered Outcomes Research Institute (PCORI) Eugene Washington PCORI Engagement Award (EACC-18922).

The meeting brought together women with heart disease, clinicians, hospital personnel, advocates and researchers to develop ideas for patient-centered research focused on solutions. It consisted of context-setting presentations, patient story-telling, and facilitated small group discussions. The final report includes a list of diagnostic challenges and possible interventions reframed as research questions, as well an appendix full of patient stories. The hope is that research on patient-centered solutions will lead to more timely and accurate diagnosis of heart disease in women.

## Context and Background

Heart disease is the number one killer of women, and yet women’s symptoms are often dismissed, they are misdiagnosed, and too often, no one suspects heart disease.

WomenHeart and SIDM teamed up to address this problem. A Steering Committee of professionals and patients developed the convening’s agenda and conducted an environmental scan of existing literature on the topic. Experts shared knowledge about the impact of social determinants of health on women’s diagnostic journey, highlighted the link between pregnancy and heart disease, and shared their expertise about the diagnostic challenges of cardiac conditions that have a particular impact on women.





# WomenHeart Benefits from Cytokinetics

## Communications Grant



To be successful, patient-centered organizations need a team – people who are able to create communication campaigns, develop content and implement a strategy. For WomenHeart, such a team works to ensure that heart healthy messages reach women across the country. Cytokinetics understands this need. Thanks to a grant from the biopharmaceutical company, WomenHeart was able to hire a Communications Fellow for nearly a year to help with just that.

Sybil Masse came to WomenHeart with a Masters in Public Health. Sybil created content for WomenHeart campaigns that featured live interviews on social media with WomenHeart volunteers; that encouraged women to maintain their heart health and return to care after the pandemic caused millions to neglect preventive care and their heart health; and that highlighted the disparate impact of heart disease and diabetes on Black women and Latinas.

In the months that have followed, WomenHeart's following on social media has continued to grow. The team continues to build on the work that Sybil helped advance to empower women with heart health information and to show women who do live with heart disease, it is still possible to thrive.



# Corporate Advisory Council



Cytokinetics

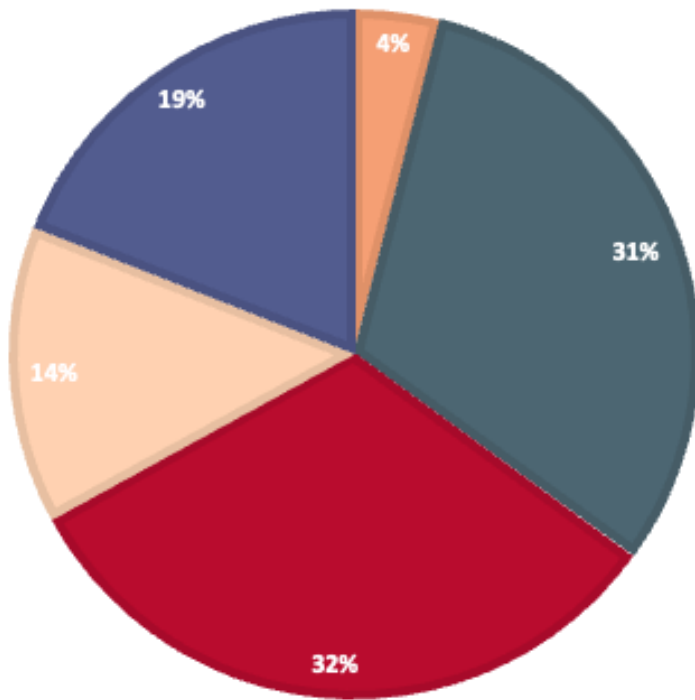




# Financial Information

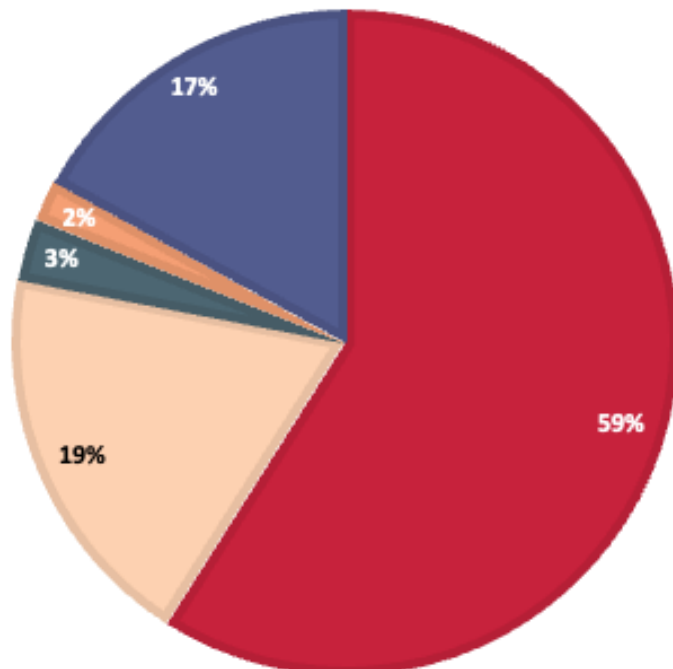


## Expenses



- Public Policy
- Patient Support
- Community Education & Outreach
- Fundraising
- Administrative

## Revenue



- Contributions & Grants
- Corporate Advisory Council
- National Hospital Alliance
- In-Kind
- Other (including: Paycheck Protection Program)



# Board of Directors



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\*WomenHeart Champion



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Susan Wood  
PhD



# WomenHeart Staff



Celina Gorre, MPH, MPA  
CEO



Amy Friedrich-Karnik, MPP  
Vice President,  
Advocacy & Communication



Evan Riggs  
Senior Manager, Development



Morgan Chandler\*  
Senior Manager, Programs &  
Hospital Partnerships



Stephanie Silva  
Operations Manager



Calondra Tibbs, MPH  
Special Advisor



Erin Milone  
Consultant

\*Until Aug. 2021

# Thank you to our generous supporters

## \$5,000+

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