

# Patients Helping Patients



# Lisa M. Tate

*Interim Executive Director, Heart Valve Voice US*



Lisa M. Tate is a long-time health advocate, having held leadership positions for patient organizations, a hospital association, and a medical society. For the past ten years, she has focused on cardiovascular issues. As CEO of WomenHeart, the National Coalition for Heart Disease, she more than tripled the organization's revenue, enabling WomenHeart to reach millions more women. Currently Lisa has her own consulting firm, Health Futures Consulting, Putting Patients at the Center.

# Heart Valve Voice US

Heart Valve Voice US, a patient-led organization, exclusively focuses on improving the diagnosis, treatment and management of heart valve disease by advocating for early detection, meaningful support, and timely access to appropriate treatment for all people affected.

# Heart Valve Voice US

- Raising awareness of the symptoms and severity of heart valve disease within at-risk and underserved populations
- Reducing the toll of heart valve disease by addressing barriers to diagnosis, treatment, and better health
- Advocating for changes to facilitate timely detection, improved recognition and optimal treatment of heart valve disease across the US
- Providing a voice for U.S. heart valve patients to improve access to timely access to appropriate diagnosis and treatment, improving quality of life and overall outcomes





# Susan Strong

*Director of Communications and Patient Engagement, Heart Valve Voice US*



Susan Strong is Director of Communications and Patient Engagement for Heart Valve Voice US. She was the founding President of the Board of Directors and is a passionate advocate for heart valve patients. In addition to her role at Heart Valve Voice US, Strong serves as an American Heart Association Heart Valve Ambassador and is actively involved as a patient stakeholder in clinical research.

# Asking Questions

- To ask questions during the webinar, you can type in questions using the side panel on your screen. Click the question mark bubble icon on the right, and simply type in your question.
- If you're having trouble accessing this feature, you can email any questions you have to [info@heartvalvevoice-us.org](mailto:info@heartvalvevoice-us.org)



# Samuel Thomas

*Director of Research and  
Communications, Rose Li Associates*

# Peer Support

It really *does help* to phone a friend!

June 26, 2019

Heart Valve Voice US Peer Support Webinar

Sam Thomas  
Director, Programs

**RLA**  
ROSE LI & ASSOCIATES



# Many feelings

Scared

Anxious

Worried

Uneasy

Lonely

Sick

Lost

Shocked

# You are NOT alone!

- Heart valve diseases affect more than **11 million Americans**
- More than **700,000** Americans undergo **open heart surgery each year**
  - Including more than 100,000 heart valve surgeries
  - Plus additional 35,000+ transcatheter procedures



Studies  
show that  
peer support  
can...



Improve readiness for surgery



Strengthen social networks



Motivate cardiac rehabilitation



Promote stress coping skills

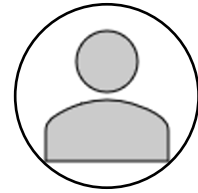


Improve self-care

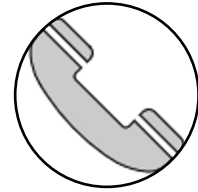


Reduce depression

Something for  
everyone



In Person



Phone



Online



Groups

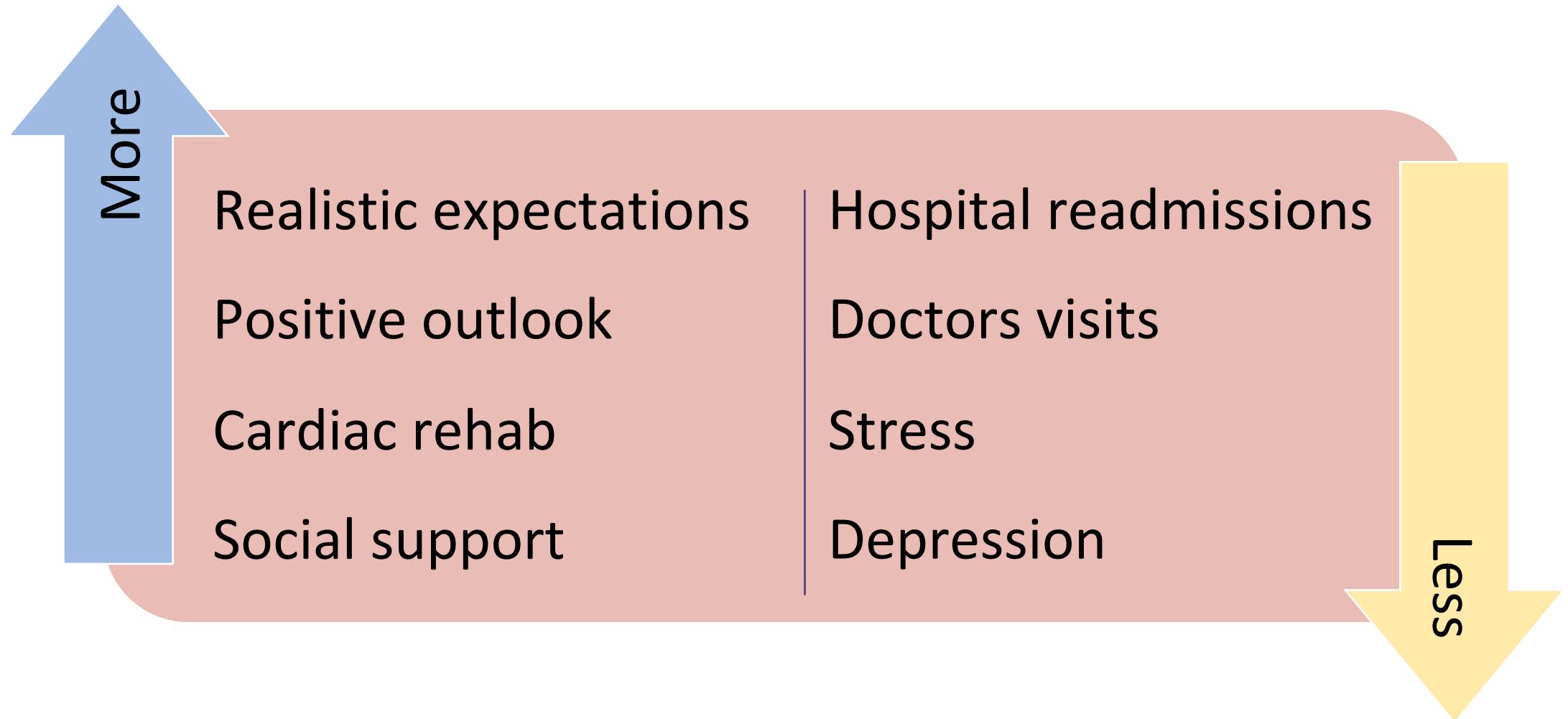


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# Many Benefits

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# Patients enjoy and value peer support

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“It’s nice seeing someone at the foot of your bed that’s been through the same experience. It gives you a kind of hope: If they made it, I can.” – Mended Hearts

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“I just relish the opportunities to interact with other women living with heart disease. I can’t put into words what having support from women who truly understand feels like.” – WomenHeart

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“I just stumbled upon all you ambassadors and it instantly relieved me to know there are others out there with the same issue who could give guidance!” – AHA Heart Valve Ambassadors



All along the journey

- Before treatment
- During recovery
- Long-term benefits
- Volunteer for others

# Resources

- Heart Valve Voice
- Mended Hearts
- American Heart Association
- WomenHeart







# Katie Bahn

*American Heart Association*

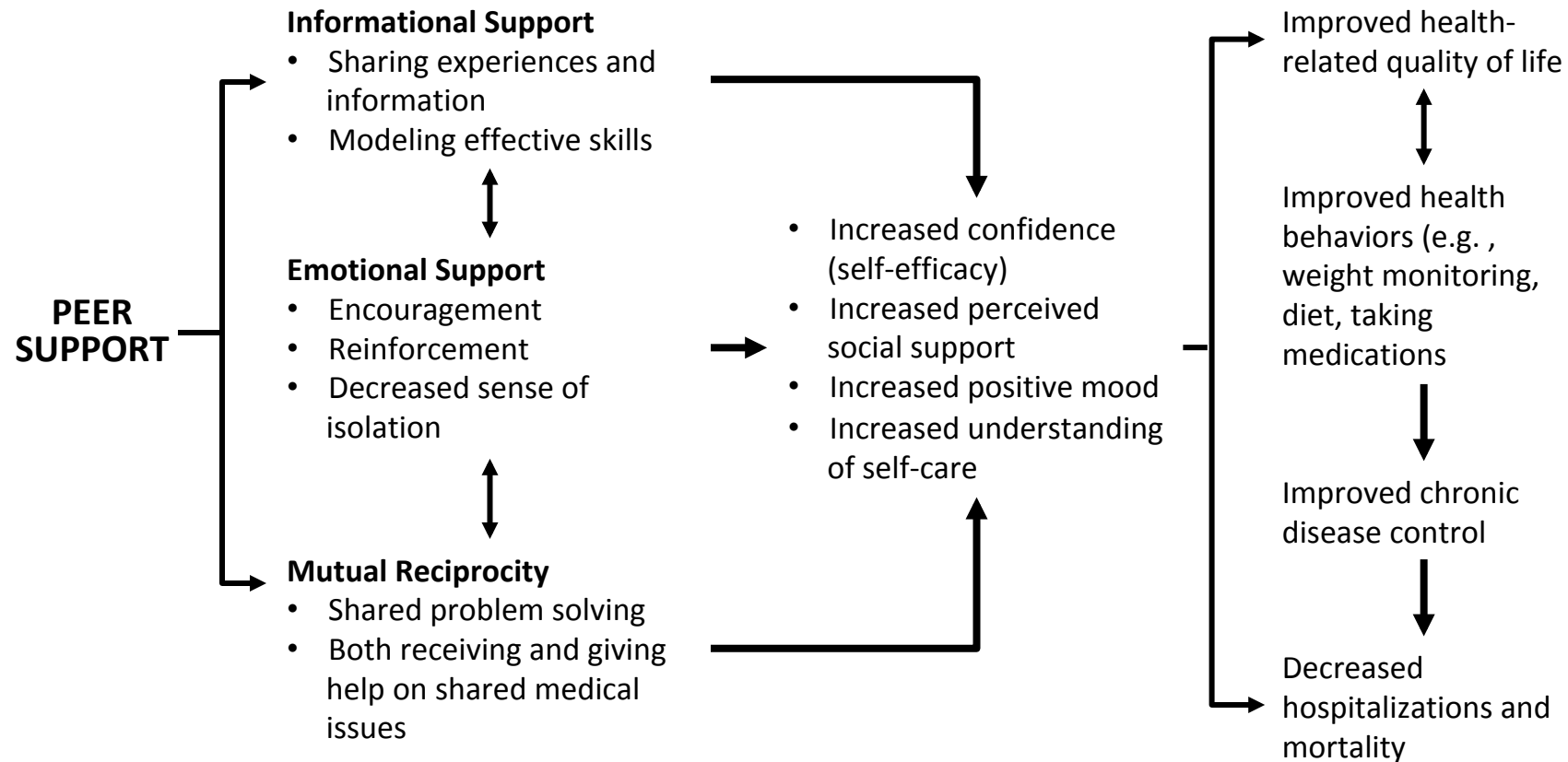


# Support Network | Summer 2019





# HOW PEER SUPPORT CAN IMPROVE CHRONIC DISEASE OUTCOMES



*Building Peer Support Programs to Manage Chronic Disease: Seven Models for Success*



# What we Know About Outcomes & Support

- Patients with cardiovascular disease and stroke can experience poor outcomes, including poor QOL.
- Support of patients with cardiovascular disease and stroke is often associated with improved QOL.
- Support of patients with cardiovascular disease is typically provided 'face-to-face' by loved ones, especially spouses, who often function in the role of being caregivers.
- While loved ones most often provide support, they too, need support, often related to the burden of providing care.





LadyMar38, May 25, 2019 8:19am EST

2 replies 99 views 2 followings

## 2 weeks Post Op

Having open heart surgery was not easy but WE did it!!! The surgeon was able to repair my mitral valve and add support band and now my EF is up from 35% to 45-50%.... Before I was questioning if I should prepare a goodbye for my children just in case...

[READ MORE](#)



latest reply



AmbassadorDN, May 26, 2019 1:51pm EST

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**I had Mitral valve prolapse and valve repair surgery - the ambassadors on this site are wonderful and can provide some guidance** and I'm by no means an expert but I would think you should definitely see a cardiologist if you're not seeing one already. ...I am 5 months post surgery that has been a very positive experience and while it may seem scary, **the folks on this site and your doctors can provide much-needed support and guidance.**

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**Good luck and stay positive that you can get good support and guidance. Heart Valve Survivor**

# **HOW SUPPORT IMPACTS SURVIVORS AND CAREGIVERS**

# About The Support Network

The Support Network is a far-reaching online community made up of patients, caregivers and families whose lives have been affected by cardiovascular disease and stroke ... people who are seeking to share experiences, offer guidance, and provide support to one another during challenging times.



## Ready for a fresh start? Join and share your story.

Here's what you get when you join the Support Network:

- | Share your story with others
- | Comment on other's stories and give feedback
- | Get answers to your questions from healthcare professionals
- | Speak to others on your own forum
- | Learn about regaining independence

Log In

Email

Password

LOG IN

f

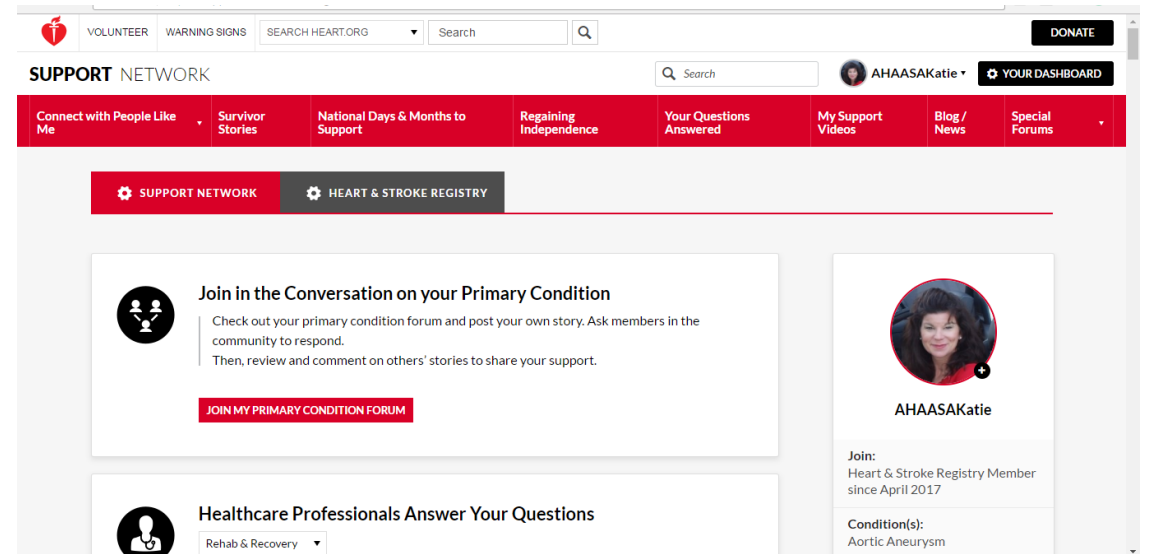
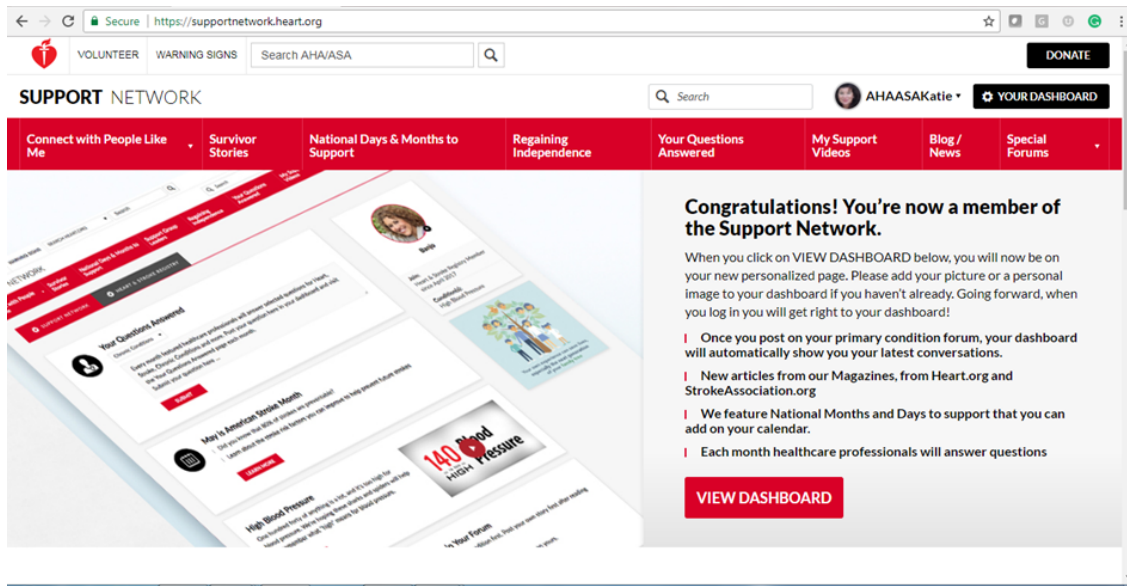
Enroll

Quickly connect with your Facebook account

f CONNECT

OR

✉ EMAIL



# COMMUNITY MEMBER EXPERIENCE



Thank you





# Donnette Smith

*President, Mended Hearts*

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Mended Hearts™



<sup>little</sup>mended hearts

# Mended Hearts

The Largest Peer-to-Peer Cardiovascular Support Network in the World

Donnette Smith, President

# About Mended Hearts

[www.mendedhearts.org](http://www.mendedhearts.org)

1-888-HEART-99

Our mission is “To inspire hope and improve the quality of life of heart patients and their families through on-going peer-to-peer support, education, and advocacy”.

- Mended Hearts has been offering hope and support for 68 years, making more than 200,000 visits every year through the accredited visiting program
- Mended Hearts provides education, support and hope to all types of heart patients and their families
- Mended Hearts and Mended *Little* Hearts has 285 chapters in North America, serving 460+ hospitals





# Our Programs

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**Mended *Little* Hearts** – To meet the needs of patients and families of children born with congenital heart disease. Offering education, support, and advocacy for the “littlest hearts” of all.

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**Accredited Visiting Program** – An accreditation program for volunteers to train them to meet the needs of patients and caregivers as peer supporters. We have over 3,000 accredited visitors.

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**Education Program** – Designed to meet the needs of patients and caregivers with disease specific resources in language that is easy to understand, from medical and patient experts.

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**Advocacy Program** – Empowering patients and caregivers to be their own best advocate and work together to eliminate barriers for patients to access the right care, at the right time.



# Reaching Valve Patients

## Valve Education

- Regional and Chapter Meetings
- Educational Webinars
- Valve GoTo Guide

## Valve Support

- TAVR Visiting Program
- 2400+ Visits with TAVR Patients





# BJ Babcock

*WomenHeart Champion*

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Women Heart's mission is to improve the health and quality of life of women living with or at risk of heart disease, and to advocate for their benefit.

# WomenHeart Champions – Our Core

- ♥ *WomenHeart Champions* are:
  - **“Boots on the ground”** in the fight against heart disease.
  - Women with heart disease trained to share their stories and important messages about heart health to **empower women** to take charge of their heart health.
  - Partners with hospitals, worksites, places of worship, and other local organizations to:
    - Share educational materials
    - Give presentations
    - Conduct special events, or
    - Encourage the media to cover heart health stories.
- ♥ *WomenHeart Champions* also participate in SisterMatch, and HeartScarves programs
- ♥ 900+ *WomenHeart Champions* have been trained as volunteers
- ♥ *WomenHeart Champions* range in age from 23–76 years old



**WOMENHEART**



# WomenHeart Science & Leadership Symposium



- ♥ WomenHeart's flagship program since 2002
- ♥ Heart disease survivors travel to Mayo Clinic in October for a four-day intensive volunteer training program to become *WomenHeart Champions*
- ♥ Attendees learn from leading cardiologists the science of heart disease and how to become WomenHeart Support Network Coordinators or Community Educators
- ♥ Currently 900+ WomenHeart Champions have been trained, with almost 104 Support Networks across the country
- ♥ **2018 Symposium trained 40+ new WomenHeart Champions!**



**WOMENHEART**



*“My cardiologist saved my heart, but WomenHeart saved my life.”*

*WomenHeart Champion*



**WOMENHEART**



**WOMENHEART**

[womenheart.org](http://womenheart.org)



**Thank You!**

# Questions?