



From Errors to Solutions: Building a Research Agenda to Improve Diagnosis of Heart Disease in Women

EXECUTIVE SUMMARY OF THE CONVENING ON MISSED AND DELAYED DIAGNOSIS OF HEART DISEASE IN WOMEN



on Missed and Delayed Diagnosis
of Heart Disease in Women

In 2020, WomenHeart: The National Coalition for Women with Heart Disease and the Society to Improve Diagnosis in Medicine (SIDM) came together with a shared goal of advancing research on how to improve the diagnosis of heart disease in women. With funding from the Patient-Centered Outcomes Research Institute, they formed a Steering Committee to plan a convening of diverse stakeholders and experts designed to develop ideas for patient-centered research focused on solutions.

The Convening on Missed and Delayed Diagnosis of Heart Disease in Women took place virtually on January 27, 2021. The approximately 50 participants included patients, clinicians, hospital personnel, advocates and experts from the Centers for Disease Control and Prevention and the National Institutes of Health. Five *WomenHeart Champions* — women with heart disease who are trained to provide peer support and community education — presented their stories and, along with a handful of additional Champions, participated in panel discussions and small group sessions.

The day-long program began with informational presentations designed to establish context and shared knowledge. Later, small groups engaged in interactive discussions that generated a series of potential research topics.

Background

Heart disease is commonly assumed to be “a man’s disease,” yet it is the leading cause of death for women in the United States, with more than 400,000 deaths each year.¹ That misconception is a blind spot for many — patients, providers, policymakers, researchers and others — and contributes to missed and delayed diagnosis of the disease in women. Furthermore, the risk factors and symptoms of heart disease for women can differ from those for men.² The challenges of diagnosing heart disease 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. Black women in particular experience racial discrimination that can lead to disparities in rates of heart disease and maternal death, often related to missed and delayed diagnosis.³

Prior to the convening, WomenHeart, SIDM and members of the Steering Committee scanned published literature and common sources of information to understand what is already known about the challenge of diagnosing heart disease in women. While substantial work has been done to report information and evidence focused on understanding problems related to disparities in diagnosis and treatment of heart disease in women, little research focuses on how to fix those problems going forward. That awareness informed the purpose of the convening, to identify areas most in need of research and to suggest possible topics for patient-centered research. (Results of the environmental scan are offered as a resource in the appendix of the larger report that resulted from the convening.)

Program Summary

The program began with three *WomenHeart Champions* who shared their experiences of being diagnosed with heart disease. Their stories featured delayed and missed diagnoses caused by a variety of factors, including provider bias, gaps in medical education and training, a lack of appropriate diagnostic testing and more.

Experts gave informational presentations to help all participants understand cardiovascular diseases, including spontaneous coronary artery dissection (SCAD), microvascular disease, heart failure, cardiac amyloidosis and heart valve disease, which have special relevance for women. They also described the interaction of pregnancy and heart disease and how the environment of the emergency department affects the diagnostic process.

An interactive panel discussed social determinants of health as significant factors affecting diagnosis and patient outcomes. In addition to employment and family status, the places where people live, learn, work and play affect health and quality of life. Biological, cultural and environmental

interactions, as well as interpersonal and structural discrimination, contribute to health disparities and can have a profound influence on a patient's journey through the diagnostic process. Presenters talked about empowering women with health information and connecting them to community resources as effective ways to engage them as partners in diagnosis. And at the same time, as one of the *WomenHeart Champions* pointed out, women often need more direct help when they are ill and should not be charged with having to advocate for themselves in order to receive quality care. A proactive, collaborative approach to care — one that includes social workers, community resources and clinicians from different disciplines — can help support and improve outcomes for patients. The health care system and the care provided must be set up to meet women where they are, whether during appointments, visits to the emergency department or when patients return home.

Generation of Research Topics

In the second half of the program, participants met in small groups to brainstorm patient-centered interventions and research questions which, if studied, could lead to improved diagnosis and outcomes of heart disease in women. A list of diagnostic challenges and possible interventions generated by the small groups are presented in detail in the convening report. Reframed as potential research questions, those ideas are intended to provide support for future research in this area of growing interest. A sampling of questions from the report, specifically related to patients, providers and health systems, are offered below.

PATIENTS

- ▶ Are patients who access information or support from other women with heart disease and/or from a patient-centered organization more likely to be accurately diagnosed or better informed about their diagnosis compared to those who do not access peer support?

- ▶ Do women who self-assess heart rhythm, blood pressure or other biofeedback using wearable devices get diagnosed more quickly/accurately than those who do not?
- ▶ Does access to a social worker for assistance with health insurance or other means of paying for health care lead to more timely diagnosis of heart disease, compared to patients who do not receive assistance from a social worker?

PROVIDERS

- ▶ Do physicians who have been trained in the similarities and differences in how women and men experience heart disease demonstrate greater diagnostic proficiency than physicians who have not received that education?
- ▶ Does incorporating data from a registry that tracks patients' social determinants of health — e.g., employment status — into clinical decision-making lead to fewer missed diagnoses of heart disease?
- ▶ Does a decision support aid with specific sex and gender inputs result in more accurate and timely diagnosis than a traditional aid that is agnostic for sex and gender?

HEALTH SYSTEMS

- ▶ Do women seen in institutions with focused training in ob-gyn residency about the risk for cardiovascular disease experience more timely and accurate diagnosis of heart disease than women seen in institutions without such training?
- ▶ Do women seen in emergency departments using interdisciplinary teams experience fewer diagnostic errors related to heart disease than those seen in emergency departments using solo clinicians?
- ▶ Would training that incorporates blinding of patients for diagnostic exams yield greater awareness and appreciation for gender and racial bias?

These research questions may provide tangible outcomes to improve the diagnostic process for researchers and others interested in leading, funding or otherwise engaging in research. People who participated in the convening benefited from the opportunity to share their knowledge and stories about the challenges women with heart disease face. We expect they will continue to draw on this experience and hope it will influence how they provide medical care and engage with patients; how they work with, teach and mentor new clinicians; where they focus their research; or their efforts to foster greater understanding of the challenges women with heart disease face. For the broader health care community, we hope this report will inspire research and foster solutions that center women's experiences and needs.

Dissemination Strategy

Steering Committee members and several participants are engaged in the dissemination strategy, which includes sending the final report to listservs, research partners and colleagues, associations, industry, patient advocacy groups and more. In addition, WomenHeart and SIDM will collaborate with the Steering Committee and other stakeholders to present findings and share information through news media, conferences and other such events wherever possible. SIDM will also disseminate materials to its Coalition to Improve Diagnosis, which is comprised of over 60 leading healthcare and patient organizations.

Lessons Learned

Patient participation is invaluable. Including patients as members of the Steering Committee — and as speakers and participants during the meeting — helped set the tone and shape the agenda for the convening and influenced the patient-focused research ideas generated throughout the day. Their participation resulted in more diverse panels and participants. Whether during the planning process or the convening itself,

participants often referred back to patient stories to ground the conversation, providing context and guidance for improved diagnosis and outcomes.

Virtual engagement increased participation.

The meeting's virtual format allowed a larger and more diverse number of patients and experts to participate. While participants lost the opportunity to connect and network in ways that only live meetings can offer, the benefit was greater participation and high-quality speakers who might not have otherwise been able to attend. Also, the virtual format did not compromise the small groups' ability to brainstorm and engage in robust and collaborative discussions.

More time is needed to accomplish meeting objectives. The limitation of time is a challenge that is often hard to overcome. The original plan

was for small groups to develop fully formed research questions following the PICOTS framework (population, intervention, comparator, outcome, timeframe and setting). However, given the time constraints, the groups primarily generated ideas for interventions, and not the other components of the framework. Regardless, the informative dialogue and content presented throughout the day — combined with the robust list of interventions and research ideas — provided the necessary platform for the project team to complete a list of more fully-formed research questions.

Appendices

- **Appendix A** Convening Agenda
- **Appendix B** Convening Steering Committee and Attendee List
- **Appendix C** Patient Stories

References

1. Virani SS, Alonso A, Aparicio HJ, et al. Heart disease and stroke statistics—2021 update. A report from the American Heart Association. *Circulation*. 2021;143:e254–e743. doi:10.1161/CIR.0000000000000950
2. Brush JE, Krumholz HM, Greene EJ, Dreyer RP. Sex differences in symptom phenotypes among patients with acute myocardial infarction. *Circulation: Cardiovascular Quality and Outcomes*. 2020;13(2):e005948. doi:10.1161/CIRCOUTCOMES.119.005948
3. Banks AD, Malone RE. Accustomed to enduring: experiences of African-American women seeking care for cardiac symptoms. *Heart Lung*. 2005;34(1):13–21. doi:10.1016/j.jmwh.2008.04.008

01.27.21 Agenda

TIME (ET)	TOPIC	SPEAKERS
10:00AM	Welcome	<i>Celina Gorre, CEO WomenHeart</i>
10:10AM	Misdiagnosis of Heart Disease in Women: Stories of Survival	<i>Lyn Behnke Rayette Brown Starr Mirza</i>
10:30AM	Understanding Diagnosis: Mapping Diagnostic Error	<i>Kathy McDonald, PhD</i>
10:45AM	Where do we go from here? Building on the Environmental Scan	<i>Suz Schrandt, JD</i>
11:00AM	PANEL: How Race, Gender and Social Determinants of Health Impact Women's Care and Diagnostic Quality Moderator: Patrice Desvigne-Nickens, MD	Panelists: <i>Daniel Calac, MD Florence Champagne Keith Ferdinand, MD Angela Richard-Eaglin, DNP</i>
Noon	Break	
12:15PM	VIDEO SERIES: A Focus in Specific Conditions and Challenges Heart Failure Heart Valve Disease Microvascular Disease/ SCAD Challenges in the Emergency Room	<i>Eileen Hsich, MD Rachel M. Bond, MD Sharonne Hayes, MD Jenice Baker, MD</i>
1:00PM	Welcome Back A Heart Disease Story	<i>Celina Gorre, CEO WomenHeart Brandie Taylor</i>
1:07PM	Focus on Pregnancy and Heart Disease: Diagnostic Challenges	<i>Afshan B. Hameed, MD</i>
1:30PM	SMALL GROUP WORKING SESSIONS (15 min break between Groups 2 and 3) Group One: Provider education Group Two: Pregnancy-related diagnostic challenges Group Three: Patient-Provider Relationship/Communication Group Four: Overcoming social determinants of health	
3:30PM	Report back and close	
4:00PM	Adjourn	

01.27.21 Attendees

C. Noel Bairey Merz, MD, FACC, FAHA, FESC — Cedars-Sinai Medical Center

Theresa Beckie, PhD — University of South Florida

Biykem Bozkurt, MD, PhD — DeBakey VA Medical Center, Director of Winters Center for Heart Failure Research, Baylor College of Medicine

Rayette Brown — *WomenHeart Champion*

Joe Ann Burgett — *WomenHeart Champion*

Daniel Calac, MD — Chief Medical Officer, Indian Health Council

Justin Choi, MD — Assistant Professor of Medicine, Weill Cornell Medicine

Patrice Desvigne-Nickens, MD — Medical Officer, Heart Failure and Arrhythmias, NHLBI, NIH

Vasken Dilsizian, MD — Professor of Medicine and Radiology; Chief, Division of Nuclear Medicine, University of Maryland School of Medicine

Paul L. Epner, MBA, MEd — CEO, Society to Improve Diagnosis in Medicine

Keith Ferdinand, MD — Tulane University School of Medicine

Amy Friedrich-Karnik, MPP — VP, Advocacy and Communications, WomenHeart

Kecia Gaither, MD, MPH, FACOG — Director, Perinatal Services/ Maternal Fetal Medicine, NYC Health + Hospitals System

JoAnn Gerardo — *WomenHeart Champion*

Celina Gorre, MPH, MPA — CEO, WomenHeart

Martha Gulati, MD, MS, FACC, FAHA, FASPC, FESC — President Elect, American Society for Preventive Cardiology

Afshan Hameed, MD, FACC, FACOG — Professor, Maternal Fetal Medicine & Cardiology, University of California, Irvine

Eileen Handberg, PhD, APRN-BC, FAHA, FACC, FPCNA — Professor Medicine, University of Florida

Ante Harxhi, MD — Medical Director, Johnson and Johnson

Sharonne Hayes, MD, FACC, FAHA — Professor, Cardiovascular Medicine, Mayo Clinic, Rochester MN

Brianna Harris-Henderson, Patient Advocate — Founder/CEO, LetsTalkPPCM

Heidi House, *Executive Assistant to Save The Mommies* — Illinois Representative for Save The Mommies, INC

STEERING COMMITTEE

Jenice Baker, MD, FACEP
Chair of Emergency Medicine,
Chestnut Hill Emergency Department

Lyn Behnke, DNP, FNPBC, CHFN, FAACVPR
WomenHeart Champion

Kathy Berra, RN, NP-NC, FAHA, FAAN, FPCN
Co-Director, The LifeCare Company

Rachel M. Bond, MD, FACC
System Director, Women's Heart Health
Dignity Health, Arizona

Florence Champagne, MSW
WomenHeart Champion

Eileen Hsich, MD
Heart Transplant Medical Director,
Cleveland Clinic

Heather Johnson, MD, MMM, FAHA, FACC
Christine E. Lynn Women's Health &
Wellness Institute, Boca Regional Hospital,
Baptist Health So. Florida

Barry Liden
VP, Patient Engagement, Edwards Lifesciences

Kathryn McDonald, PhD, MM
Bloomberg Distinguished Professor,
Johns Hopkins University

Brandie Taylor
WomenHeart Champion,
lipay Nation of Santa Ysabel

(CONTINUED ON NEXT PAGE)

Attendees (cont'd)

Sue Koob, MPA — CEO, Preventive Cardiovascular Nurses Association

Janice Kwan, MD, MPH — Assistant Professor Medicine, University of Toronto

Starr Mirza — *WomenHeart Champion*

Jeanne Poole, MD, *Professor of Medicine, Division of Cardiology* — University of Washington School of Medicine

Tricia Regan — Filmmaker *Ms Diagnosed*

Angela Richard-Eaglin, DNP, MSN, FNP-BC, CNE, FAANP — Assistant Professor, Duke University School of Nursing

Elena Rios, MD, MSPH, FACP — President & CEO, National Hispanic Medical Association

Stacey Rosen, MD — SVP, Women's Health
Northwell Health / Katz Institute for Women's Health

Haley Stolp, MPH — Centers for Disease Control and Prevention

Suz Schrandt, JD — Senior Patient Engagement Advisor, Society to Improve Diagnosis in Medicine

Glenda Sexauer — *WomenHeart Champion*

Kelly Smith, PhD — Senior Director, MedStar Health Institute for Quality and Safety

Calondra Tibbs, MPH — Special Advisor, WomenHeart

Kaveeta Vasisht, MD, PharmD — Associate Commissioner for Women's Health/Director, Office of Women's Health, FDA

Mary Norine Walsh, MD — Medical Director, Heart Failure and Cardiac Transplantation St. Vincent Heart Center

Nanette Wenger, MD — Emory University School of Medicine

Julie Wright, MSNEd, RN — System Director, Clinical Risk Management, Intermountain Healthcare

Sheryl Zaworski, JD — *WomenHeart Champion*

Stories of Survival: Missed and Delayed Diagnosis of Heart Disease in Women

Our Stories

These stories from *WomenHeart Champions*, women living with heart disease, are just a few examples of the thousands of stories of diagnostic error related to heart disease in women.

WomenHeart, the Society to Improve Diagnosis in Medicine, and the many patients, clinicians, researchers, and other experts are committed to this effort to identify the greatest research needs in heart disease-related diagnostic quality, safety and improved health outcomes and lives of women faced with heart disease. Each of these stories reveals valuable lessons about how we can improve the diagnostic process and we are grateful to the women who were willing to share these personal accounts.

Brandie's Story

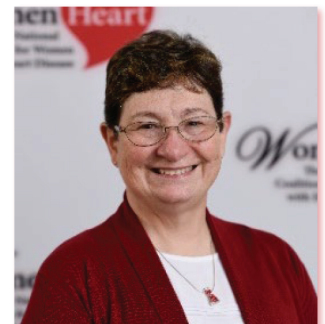


Brandie was diagnosed with cardiomyopathy and congestive heart failure at the age of 32. When she was about eight months into her pregnancy, Brandie began having symptoms of shortness of breath and fatigue, but was initially only prescribed inhalers and sleep medication to address her symptoms at the local Indian Health Clinic. She felt that something was wrong, and it wasn't asthma, so her mother later took her to the nearest hospital, an hour away, where her symptoms were dismissed as pregnancy-related and she was told to deal with it. After continuing to have symptoms she was taken to another hospital where she was immediately placed in the intensive care unit because she was going into heart failure. Brandie believes that because of the delay in diagnosis and appropriate treatment her heart was weakened and led to her need for a heart transplant.

Dianne's Story

Dianne initially presented to her allergist, due to a history of asthma, with symptoms of shortness of breath and fatigue. After a monitored walk, lasting only three minutes because she was out of breath, she was sent back to her primary care doctor for follow-up. She was unable to see her primary care provider the same day, so she made an appointment for the following day. Dianne's primary care provider found a "little anomaly" after doing an EKG, then referred her to a cardiology practice. Dianne got an appointment with the "first available cardiologist" the following day where a next day stress test and echocardiogram was ordered, but her insurance denied the claim. Only after the cardiologist intervened was she able to get her test the following Monday. During her stress test she passed out and was immediately admitted to the hospital and scheduled for a heart catheterization the following day. She coded in the cath lab and underwent open heart surgery for a blocked left anterior descending artery and damage to the mitral and tricuspid valves. The total time between the onset of symptoms and the cath lab was only two weeks, however no one ever communicated the urgency of her situation throughout the process.

After reviewing her medical records, Dianne realized that her doctor had recorded test results that were warning signs and risk factors for heart disease, such as high blood pressure, high LDL and low HDL, obesity, and pre-diabetes, however she was not told of the danger. She "did not know to ask for copies of [her] test results and trusted [her] doctor to advise her of risk factors."



Stories of Survival: Missed and Delayed Diagnosis of Heart Disease in Women (cont'd)

Florence's Story

Unemployed and uninsured, Florence went to the emergency room for nearly a year experiencing symptoms of chest and upper body discomfort, shortness of breath, fatigue, backache, and pain radiating down her arm. She was finally referred to a cardiologist, after she saw her primary care doctor, but she had to borrow the funds to pay for the visit. Florence found out that an essential test, a cardiac catheterization, was never done for her because she was uninsured. Her cardiologist assured her he would “find a way for [her] to get the proper test” and sent her to a colleague for the cardiac catheterization, where they found that her left anterior descending artery was 99.9% blocked and rushed her to the operating room to save her life. Florence's diagnosis delay was not only impacted by her lack of insurance, but also because no provider believed there was a problem. She also believes that her race and gender played a role in delayed diagnosis. In addition to Florence's diagnosis delay, she was unable to get the follow-up care and therapy, such as cardiac rehab, that was necessary for her recovery. She then “had to try to recover, breathe, walk, and regain strength to improve and reduce [further heart disease risk] all on her own.”



Glenda's Story



Glenda went to her obstetrician/gynecologist because she was experiencing shortness of breath, nausea, fatigue, weight gain and a “gurgle” in her chest and thought she was going through menopause. But after her symptoms didn't improve, she saw a different doctor and was evaluated for thyroid issues. Later, she went to the doctor thinking it might be pneumonia. By the time she got to her last doctor, because the “pneumonia” wasn't clearing up, she was sent to the emergency room and diagnosed with congestive heart failure. Four days later she went into cardiac arrest. Each time she interacted with a health care provider she was treated exclusively for the symptoms she presented, and there was no follow-up by providers.

After her husband insisted she continue to seek care, she mentioned to a doctor that she had gained weight and he ordered an EKG, which helped lead to the correct diagnosis. She believes that doctors and patients share responsibility in the diagnostic process. She admits that she may have misled her providers by only giving them the information specifically asked or that she thought was important.

Gwen's Story

In 1988, at age 32, Gwen was diagnosed with heart disease. She knew she had a family history of sudden cardiac death and had experienced some chest discomfort and shortness of breath. When she finally went to the emergency room while experiencing severe premature ventricular contractions and dizziness, she was treated for a non-existing heart attack and referred to a cardiologist. She got the right diagnosis of hypertrophic cardiomyopathy once she got to the cardiologist. But for years after, she felt there was limited information about her condition, particularly among emergency room, EMT and general nurse professionals. She was initially told that she would “have a shortened life expectancy” with no further information on what that meant nor provided any support for the emotional impact the diagnosis had on her life. In many cases, she's had to educate providers about her condition, what it felt like and how foods, drugs and treatments can trigger adverse reactions.



Stories of Survival: Missed and Delayed Diagnosis of Heart Disease in Women (cont'd)

JoAnn G's Story



At age 55, JoAnn presented with symptoms of chest and upper body discomfort, shortness of breath and fatigue. She finally got the right diagnosis when her current cardiologist listened to her and thoughtfully reviewed all her test results. Prior to that, JoAnn felt other doctors made a lot of assumptions before thoroughly reviewing all the test results. She has been diagnosed with angina, aortic aneurism, broken heart syndrome, heart attack and spontaneous coronary artery dissection. The lesson in her diagnosis journey was that “it is very important to choose your words carefully when describing your symptoms.”

Joe Ann B's Story

Joe Ann was first diagnosed with heart disease at the age of 52 years. She went to an urgent care walk-in clinic with symptoms of chest and upper body discomfort, shortness of breath, nausea, jaw and neck pain, backache, and a persistent dry cough, and she was told that she had anxiety and acid indigestion. The provider even remarked that her medical record should note that she is “morbidly obese,” which was the cause of her symptoms. Worse yet, her general practitioner agreed.

It wasn't until a friend intervened after her symptoms had significantly progressed that she went to his cardiologist and was diagnosed with heart disease. She believes that because her doctors didn't believe that women could have heart disease and judged her by her appearance, she wasn't taken seriously. She says that “every time [she] asked [her] doctors about a specific symptom they minimized it and misdiagnosed it.” And even when she did get to a cardiologist, when she asked questions, she was told “you're a smart woman. You will figure it out.” She believes her life was saved when she attended the WomenHeart Science and Leadership Symposium – other women listened to her and the doctors at the Symposium provided suggestions to improve her treatment.



Judy's Story



Judy was diagnosed with congenital heart disease and heart valve problems at the age of 10 years. She got a diagnosis when she went to the emergency room after seeking treatment for being hit in the forehead with a bat. She had surgeries at a young age to fix defects in her heart and later received a bovine heart valve in 2006. She was actually one of the first children to survive surgeries to repair her interventricular septal defect in the late 1950's. Her accidental and early diagnosis allowed her to get the right treatment and ensure her health.

Lyn's Story

At the age of 50, Lyn began having a “funny feeling in her neck, [that she] couldn't get rid of.” She was referred for a stress test and was later diagnosed with congestive heart failure, coronary artery disease and peripheral arterial disease. After bypass surgery she developed blockage in the right coronary. It was also thought that she had a bad left internal mammary artery (LIMA) graft. While trying to fix the blockages, her artery was ruptured and she went into cardiac arrest and had a subsequent balloon pump. Her cardiologist overlooked previous films that could have compared the blockages and LIMA to determine the right course of treatment. Lyn felt that when entering care, she was only seen as an overweight, Native American woman, not as someone who is a nurse practitioner who participated in cardiac rehab daily.



Stories of Survival: Missed and Delayed Diagnosis of Heart Disease in Women (cont'd)

Rayette's Story

At 34 years old, Rayette was told that she didn't have heart disease, that it was all in her head. She kept going back to her doctors for a whole month with symptoms of chest and upper body discomfort, shortness of breath, nausea/vomiting, fatigue and other symptoms – being very persistent – until finally learning she had heart disease. She was diagnosed with angina, atrial fibrillation, coronary artery disease and small vessel disease. At each ER visit prior to getting her correct diagnosis, her EKG and blood tests would come up “normal,” and she was told it was a virus, she was having anxiety, and she was even given a pregnancy test because of the nausea and fatigue. She felt that doctors had been too quick to diagnose and attempt treatment of the simple symptoms, not getting to the cardiac issues soon enough. She has had to be an advocate for herself and never gave up on getting the right diagnosis.



Sheryl's Story



Over the course of four years of “normal” results on cardiac diagnostic tests, despite ongoing chest discomfort and jaw pain, Sheryl was diagnosed with panic attacks and potential dental issues. While her cardiologist suspected microvascular disease, they simply prescribed a “heart healthy” diet and lifestyle changes and talked her out of getting certain diagnostic tests, warning her that they were expensive and complicated. After a severe instance of her ongoing symptoms, Sheryl took charge of her health and scheduled an appointment at the Mayo Clinic where an angiogram finally confirmed her diagnosis of microvascular disease.

After diagnosis, Sheryl was then provided with several treatment options that had never been suggested by the network cardiologist and invited to participate in a Mayo Clinic research study. In this study, Sheryl's own stem cells were harvested and placed in her left anterior descending artery (LAD) with the hope of improving the endothelial tissue function in her heart. As a result, her chest and jaw pain symptoms have been greatly reduced. Sheryl thinks that “even well-meaning primary care physicians and cardiologists may not be educated on the finer aspects of how heart disease presents in women” and the combination of lack of awareness, medical research, dissemination of findings, and gender bias contributed to the delay in her diagnosis.

Starr's Story

After years of various symptoms, such as discomfort in her upper body, shortness of breath, episodes of pre-syncope, and visual impairments, it took going into cardiac arrest at 23 years old to “prove” that Starr was sick. Throughout her teen and young adult years, doctors told Starr she had anorexia, bulimia, was suffering from panic attacks, and that she was a hypochondriac. Because she was so young, she was never given a cardiac examination. She attributes her delayed diagnosis to the fact that she was a young female and had little or no health insurance. She has since been diagnosed with prolonged Q-T syndrome, arrhythmia-induced cardiomyopathy which led to congestive heart failure, and multi-valvular dysfunction.

