Helping Women Change the Odds Against Their Number 1 Health Threat

Nancy Brown, BS

Heart disease survivor Paula Rice of New York has straightforward advice for every woman: if you have not seen your doctor lately, schedule an appointment right away. Two years ago, when Paula began to experience nausea and fatigue, heart disease was the last thing on her mind. She discussed her symptoms with family members, friends, and workmates; yet she never told a doctor. She chose to fight through her symptoms, hoping that they would soon pass. Everything changed several days later when she found herself almost completely out of breath while climbing the subway stairs. Soon after, she went into atrial fibrillation and had a cardiac arrest. Today, as a volunteer advocate for the American Heart Association’s Go Red For Women movement, Paula is sharing her story with women across the country, hoping that her example will serve as a reminder of why it is important to make room on the calendar to see a doctor. Stories like Paula’s are a key reason why Go Red For Women is encouraging every woman to schedule a well-woman visit, an annual prevention check-up to discuss your overall health, lifestyle, blood pressure, and cholesterol and to look for signs of heart disease, stroke, and other illnesses. For most women, a well-woman visit has no additional costs because of the Affordable Care Act and is separate from other appointments for specific sicknesses or injuries. However, women should check with their health insurance plan for preventive service coverage before scheduling the visit. A 2013 survey by Go Red For Women found that at least 20% of women had put off preventive services in the past year because of cost concerns. Today, it is likely that many women still are not taking full advantage of benefits like the well-woman visit. Our vision is to create a social norm in the United States, so that by 2020, all women will be making well-woman visits to their doctor to review their overall health, including the key components of ideal cardiovascular health.

By communicating so openly and honestly about their experiences, advocates like Paula embody the commitment to education and knowledge sharing that has been a hallmark of the Go Red For Women movement since its inception in 2004. “Science-based, credible, women-focused communication has always been the foundation of Go Red For Women,” says Lori Mosca, MD, Director of Preventive Cardiology at New York-Presbyterian Hospital and the 2015 recipient of the American Heart Association’s Physician of the Year Award. “If we are going to make a difference, we need to speak up. We need to make sure that other women in our lives—our mothers, daughters, sisters, and best friends—understand that heart disease is their number 1 health threat. Nothing is more important than health, and there is no better way to express how much you care about someone than to share information that will help them prevent illness and enjoy a better quality of life.” We created Go Red For Women to counteract a troubling lack of awareness that heart disease affects women and men. The prevalent but false assumption that heart disease was a disease for men was putting women’s lives at risk. Less than a third of women realized that heart disease was by far their leading health threat, and it was time to begin changing their perceptions. The movement began to build momentum almost immediately thanks to the overwhelming support and determination of volunteers who got involved in the first year. Women’s awareness has since risen to ≈55%, an increase made all the more encouraging in light of studies showing that women who are well informed of their risks are more likely to take preventive measures than women with lower awareness levels. Our surveys indicate that 9 of 10 women who join Go Red For Women make at least 1 healthy lifestyle change, such as improving their diet or increasing their physical activity levels. As involvement in the campaign grew, Go Red For Women explored new opportunities to make a difference beyond raising awareness. Subsequent initiatives included the publication of evidence-based treatment guidelines focused specifically on women, the creation of an online risk assessment tool for women, the development of an online risk assessment tool for heart disease, and a scholarship program to support women who are pursuing careers in the health sciences. Through our Get With The Guidelines quality of care program, we began to call attention to treatment disparities in female patients, who are less likely than men to be prescribed medication after a heart attack, less likely to be referred for cardiac rehabilitation, and less likely to receive an implantable cardioverter-defibrillator for the prevention of sudden cardiac death. Currently, >2.5 million women receive care at Get With The Guidelines-registered hospitals for conditions, including atrial fibrillation, heart failure, and stroke. Adherence to Get With The Guidelines’s evidence-based guidelines has been shown to decrease such disparities in women and minority patients. Another primary focus has been the decade-long under-representation of women as subjects in clinical trials and an overwhelming lack of scientific research that specifically targets the causes and symptoms of cardiovascular disease in women. It is clear that cardiovascular disease affects women and men differently. For example, 1 study showed that nearly two thirds of women who
died suddenly of coronary heart disease experienced no previous symptoms versus half of men. Also, researchers have identified sex differences in response to cardiac medications. Drugs that are beneficial for men may even be harmful to women. The drug digoxin, used to treat patients with heart failure, has been associated with an increased risk of death among women but not men, and it is well established that women’s heart attack symptoms are often different from men’s. As with men, women’s most common heart attack symptom is chest pain or discomfort. But women are somewhat more likely than men to experience some of the other common symptoms, particularly shortness of breath, nausea/vomiting, and back or jaw pain. Unfortunately, only 35% of the participants in cardiovascular clinical research studies are women, and just 31% of these studies report the outcomes by sex, making it difficult for researchers and clinicians to draw conclusions about the effects of these illnesses on women. To address these troubling inequities, our advocates strongly support the Research for All Act (H.R. 2101), bipartisan legislation that would help ensure that National Institutes of Health–funded research includes both women and men. The Research for All Act would require the National Institutes of Health to develop guidelines for the inclusion of female subjects in basic research, by authorizing funding for National Institutes of Health’s Special Centers of Research on Sex Differences and by directing the Government Accountability Office to update its reports on the inclusion of women in clinical trials. These long-overdue steps will lead to greater diversity in research and ultimately to better treatments and outcomes for women and men. Another way we are working to advance research in women is by encouraging women to enroll in clinical trials, including the Health eHeart Study based at the University of California, San Francisco. Through handheld devices and other forms of mobile technology, this longitudinal study aims to collect more data about heart health from more people than any research study has done before, with a goal of developing new and more accurate ways to predict, prevent, and treat heart disease. Thus far, Go Red For Women has been the leading enroller of women in the Health eHeart Study. We are also excited about a new era in the history of our national research enterprise that begins this spring with the creation of the Go Red For Women Strategically Focused Women’s Health Research Network. The network, which launches in April, will be based at 5 research centers, each of which will receive about $4 million over the next 4 years to support basic, clinical, and population-based studies to advance the prevention, diagnosis, and treatment of cardiovascular disease in women. Funding will also allow for the training of 3 postdoctoral fellows at each center and will support a multidisciplinary approach, with interaction between centers to provide networking opportunities for trainees and encourage sharing of commonly useful knowledge and methods. “We believe deeply in the network’s potential to advance knowledge and substantially reduce the current gaps in research concerning women’s cardiovascular health,” said Mariell Jessup, MD, Professor of Medicine at the Hospital of the University of Pennsylvania in Philadelphia and a past President of the American Heart Association. “In addition, we know that the network will help produce a cadre of new investigators who will play a critical role in carrying women’s health research forward in the future.” One of the network centers will be designated as the Sarah Ross Soter Center for Women’s Cardiovascular Research, made possible by a donation of $5 million from Sally and Bill Soter of Palm Beach, Florida. Mrs. Soter has faced the effect of heart disease. She was diagnosed with atrial fibrillation 17 years ago and has since undergone 2 ablation procedures. After her diagnosis, she told her doctor that she was determined to conquer heart disease and help other women facing it too. “To be able to fund something that could help women and heart disease is very rewarding,” said Soter. “There is so much we still do not know. It could mean so much for research.” The ultimate goal of Go Red For Women is to save lives. Since 2004, there has been an average annual decrease of ≈2% in women’s deaths from cardiovascular diseases and stroke, representing a total of ≈670000 lives. Every life saved is a powerful symbol of the urgency of the work we do. Despite this progress, we have much more to accomplish. Heart disease continues to be the number 1 killer of women, and stroke remains their fourth leading killer. Meanwhile, the prevalence of these illnesses is growing. More than one third of women have some form of cardiovascular disease, and >90% have at least 1 risk factor for these illnesses. That is far too many women, and it means that organizations like ours have an obligation to do even more. As we move forward, we will be inspired, as always, by the stories of Go Red For Women advocates like Emily Welbourn of Washington. Two years ago, at age 27, Emily had a stroke while running a 3.5-mile race. The stroke was cryptogenic, or of an unknown cause, and resulted in symptoms that included left-side numbness and memory loss. Emily fought bravely through a grueling recovery process, and 11 months later, she completed the Boston Marathon. When we consider the challenges ahead of us, we need only reflect on the powerful example that Emily has set. There are millions of other women like her who have not only recovered but who are thriving today. Yet for each of them, there are many questions that still remain. What caused their illness? Could it have been prevented? Could they have been treated more effectively? Our work is not complete until we have found all the answers.

**Disclosures**

American Heart Association is the owner of Go Red For Women.
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