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Contact: Lisa Clough

202.464.8734

lclough@womenheart.org

**WomenHeart Champion Credited with Initiation of First Time Research
into Rare Heart Condition**

***Katherine Leon sought answers through WomenHeart community for rare occurrence of
spontaneous coronary artery dissection***

August 30, 2011 (Washington, DC) – Being a *WomenHeart Champion* took on a whole new meaning recently when Katherine Leon of Alexandria, VA, was credited with being the force behind the first effort for researchers to look more closely at what causes spontaneous coronary artery dissection (SCAD), a rare heart condition in which the coronary artery tears, causing blood to flow between the layers and develops the potential for life-threatening blockages to the heart. SCAD is more common in women and not uncommonly occurs around childbirth.

“After my SCAD in 2003, I couldn’t get answers from my doctors for why this happened. I was 38 years old and healthy – why did this happen, what caused it? It was very frustrating. There was no research to turn to for an explanation,” said Leon.

So, she set out to get answers, for herself and others, primarily women, who experience this rare event – and she started with WomenHeart’s social media networking.

“I joined the WomenHeart online community in 2005 and discovered other women who had experienced SCAD,” she said. “We all had our theories for why SCAD happens, and we shared our experiences. They were remarkably similar.”

Then in 2009, as she prepared to attend the WomenHeart Science & Leadership Symposium at Mayo Clinic, she knew this was her chance to generate a research study of SCAD. WomenHeart hosts this program annually to train 60 patient volunteers from around the country as *WomenHeart Champions*, community educators who return to their communities to inform other women about the risks and prevention of heart disease.

Just prior to the Symposium in October 2009, Katherine also met Laura Haywood-Cory through the WomenHeart online support forum, another SCAD survivor who was to attend the symposium in Rochester, Together they bonded over what would become a mission to find answers.

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“We met Dr. Sharonne Hayes, medical director of the Symposium, and I knew I would not leave Rochester until she had agreed to research SCAD. This was Mayo Clinic – where better to ask?” said Leon. -

“WomenHeart brought these women together and WomenHeart brought them to Mayo Clinic. Katherine gave me insight into this international pool of women SCAD survivors who desperately needed answers. I realized that by working together, we might just find some. I couldn’t *not* do this study,” said Hayes, founder of the Mayo Clinic Women’s Heart Clinic and member of the WomenHeart Board.

The first step was a feasibility study in 2010 funded by Mayo Clinic, that showed that women participating in the WomenHeart online patient support community could be recruited to participate in research and that investigators could successfully access and analyze their SCAD medical records. The enthusiastic response by patients suggested that broader recruitment through social networks could be successful.

Now, just a year later, Hayes is preparing to recruit up to 400 men and women with SCAD to two research studies to help better understand this rare condition and guide future research. One study will build a database of 200 SCAD patients to help identify risk factors and ultimately provide patients with better information about their prognosis and treatment options. The other involves developing a bio-bank of DNA samples from up to 200 SCAD patients and up to 400 of their close family members, which will be analyzed for patterns of genetic mutations that might point to causes of SCAD and help families and patients assess future risk, she said.

“We hope this information will help us better understand, treat and prevent this serious heart condition and set the stage for more accurate genetic risk assessment, multi-center participation, and ultimately, prospective treatment trials,” Hayes expressed.

“This is just one example of the power of a community of patients and the impact they can have on improving the health of women,” said Lisa M. Tate, CEO, WomenHeart, the National Coalition for Women Heart Disease. “Whether it is advocating for their own health care, promoting public policies that benefit patients, pushing for inclusion of more women in clinical trials, or in this case, initiating specific research, our goal is to empower patients to take charge of their heart health and help other women do the same.”

As for Leon, she is in awe of what has transpired. “Someone finally paid attention, thanks to Dr. Hayes and WomenHeart, and support for this research growing,” she said, “it’s encouraging that we might really end up helping people, and hopefully saving lives.”

If you are a SCAD survivor and are interested in applying to be accepted to Dr. Hayes’ study, access the preliminary information at <http://newsblog.mayoclinic.org/2011/08/17/scad-spontaneous-coronary-artery-dissection-studies-at-mayo-clinic/>



Protocol entails diagnosis confirmation and angiographic review to determine eligibility prior to enrollment in either of the studies, so the documents at this link are mainly for this purpose (getting permission to release medical records).

Women with SCAD can access the documents from this link or can request them to be emailed or mailed via the MayoSCAD@mayo.edu email address.

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WomenHeart: The National Coalition for Women with Heart Disease is the nation's only patient centered organization serving the 42 million American women living with or at risk for heart disease – the leading cause of death in women. WomenHeart is solely devoted to advancing women's heart health through advocacy, community education, and the nation's only patient support network for women living with heart disease. WomenHeart is both a coalition and a community of thousands of members nationwide, including women heart patients and their families, physicians, and health advocates, all committed to helping women live longer, healthier lives. To receive a free on line heart health action kit or to donate visit www.womenheart.org/kit.