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The SCAD Ladies Stand Up

Stories of Patient Empowerment

SCAD SISTERS

A Special Report from Inspire

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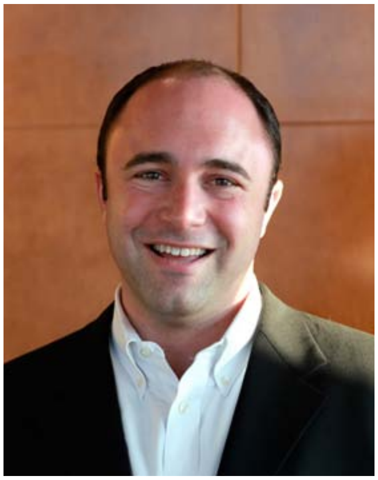

Brian Loew

The "SCAD Ladies" story is an extraordinary one: women with a rare heart disease self-organized online and began studying their disorder. This patient-initiated effort led to physicians at the Mayo Clinic launching new research to learn more about spontaneous coronary artery dissection (SCAD).

It's an extraordinary story, but its underpinnings aren't rare at all.

What Katherine Leon and Laura Haywood-Cory spearheaded, without "official" authorization, speaks to the power of patients sharing stories. Katherine told a story and later, as you'll see in this report, Laura asked for stories. Laura borrowed a line from the singer Beyonce and asked "all the SCAD Ladies to stand up" and describe their SCAD experiences.

In our online patient support communities and others, you see patients reaching out to gather information that they then use in multiple ways—to research further online, to use as background materials in broaching a topic with their physicians, to help explain the disease to loved ones and friends. Lots of patients and caregivers are standing up.

We shared the "SCAD Ladies" story with a member of our Foundation for Sarcoidosis Research Support Community, a sarcoidosis patient who likewise has conducted her own research within her community. "I think that scientifically, I lack a lot of specific information," she told us, "but I hope we can use our online community as a tool. Crazy how our minds never stop wondering how this happened or what I could have done to change or stop it from happening. I'm not sure we will ever have that peace of mind, but that doesn't stop me from trying."

This special report is not intended to delve into the Mayo Clinic SCAD project itself. The Wall Street Journal, Mayo itself, and other media have covered that topic well. Rather, through first-person narratives of patients, this is a closer look at how several members of the WomenHeart Support Community on Inspire banded together and started something special. We also solicited the perspectives of newer members, who found the community through online searching and the publicity from the announcement of the Mayo project. While Katherine and Laura are from the US, SCAD Ladies are from the UK, Canada, New Zealand, Sweden, and elsewhere. As Laura wrote in her essay (see p. 15), "Online tools and social media can help create a patient community that spans countries and oceans, and with that support backing you up, reach out to the people who can research your condition."

Docs "prescribing" social networks

What's encouraging is seeing new members of the WomenHeart Support Community join it in response to the publicity about the Mayo project. One new member, from Knoxville, TN, joined the community after her doctor suggested doing so. "My doctor saw the article in the Wall Street Journal, and then he told me about the website and suggested I might want to check it out," she told us. "He thought it would be good for me to hear other SCAD stories."

I'd like to thank our partner, WomenHeart: The National Coalition for Women with Heart Disease. I'd also like to thank Mary Graper of another of our partners, the Wilson's Disease Association, who wrote the Afterword, (see p. 31), Special thanks to Dr. Sharonne Hayes of the Mayo Clinic, who wrote the Foreword (see p. 5) and to Katherine Leon, Laura Haywood-Cory, and all the women who contributed their first-person stories to this report. They are part of a special online community.

The stories you will read in this report exemplify something we often say at Inspire: "Together, we're better." I know you'll enjoy reading them.

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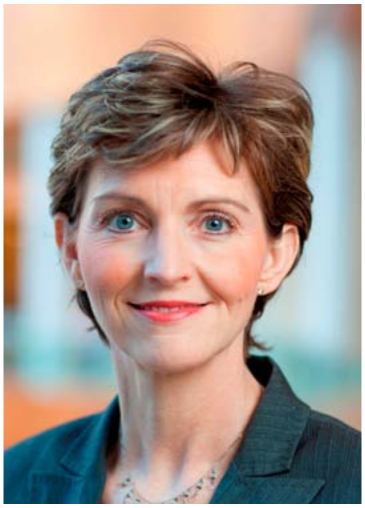
Traditional Research Methods Turned Upside Down: The Untapped Potential of “Patient- Initiated” Research in the Study of Rare Diseases



Sharonne N. Hayes, MD

“Investigator-initiated” research studies, in contrast to “industry-initiated” (and funded) research, are often considered the “gold standard” for the study of medical conditions, with the latter being considered more prone to potential conflict of interest. In investigator-initiated research, a scientist typically identifies a clinical question or problem that needs a solution, develops his or her hypothesis and research methods to solve it, seeks support (financial and regulatory) and proceeds with the study.

A significant factor in the approval, funding and ultimate success of a research study is its “feasibility”. In the case of clinical trials involving patients, successful completion of the study depends heavily on adequate subject recruitment. As a result, studies in which there is a high likelihood of identifying and enrolling sufficient patients to answer the “question” are more likely to receive approval and grant funding.

Conversely, if the work and cost of recruiting subjects is high, or deemed impossible, the research is unlikely to proceed. Identifying and recruiting study participants with rare conditions such as spontaneous coronary artery dissection (SCAD) can be a formidable challenge because no single medical center, even Mayo Clinic, has adequate experience and/or patient volume to even begin to perform meaningful research.

Enter "patient-initiated" research. Still in its infancy, this may prove to be the new "gold standard" for the study of uncommon medical conditions.

It stands to reason that the people most highly motivated to support or to even initiate investigations of a rare condition are those personally affected and their close relatives. Our experience with the "SCAD ladies", Katherine Leon and Laura Haywood-Cory and their online "heart sisters", provides an example of successful patient-driven, social networking–enabled research. Our pilot and ongoing studies demonstrate that if a large organized group of patients self-identify and present themselves to researchers as study participants, a major barrier to rare disease research can be eliminated.

Delivering a patient-prioritized research agenda to potential investigators, as was done by the SCAD group, also may serve as an incentive for busy clinician-investigators and help convince them to commit to a new line of research or to this unfamiliar study methodology. Many organized patient advocacy groups have developed research agendas. However, the highly engaged and committed women who prompted the SCAD study, linked only via the Internet, demonstrated levels of sophistication and specificity in their patient-initiated research questions that were on par with those developed by formally organized groups. They had clearly done their research, and as a result, allowed this researcher to more clearly visualize the potential of success.

> Patients with rare diseases therefore increasingly seek answers, medical information and peer support on the Internet.

From a patient's perspective, being diagnosed as having a rare condition is challenging. Frustration regarding their physicians' lack of knowledge about and experience with their specific condition is often compounded by repeated reminders regarding its obscurity. Patients grow tired of hearing how little is known and how "unique" and "unusual" they are (Katherine recalls being told she was a "fluke"), and those with sometimes fatal conditions are often frightened by the seeming "shotgun" or inconsistent

> Perhaps even more gratifying is the explosion of interest in our methods among both colleagues and other patient groups who hope to leverage the "power of the patient" to advance the science for other conditions.

approach to management and the explicit and implicit messages that their health care professionals have "no data" to guide treatment recommendations. Patients with rare diseases therefore increasingly seek answers, medical information, and peer support on the Internet. There, they may form research networks unencumbered by the regulatory limitations placed on physicians, such as HIPPA and IRB rules.

Dr. Brandom, in her accompanying editorial writes, "Authority and responsibility for research into rare medical conditions are devolving from the researchers to the patient-participants. . .In the case of rare conditions, greater commitment of the patients to research appears to be necessary for the advancement of translational science in areas relevant to their own well-being. A positive outcome is that patient-participants and their families will have greater empowerment to advance both the understanding and the potential treatment of their medical conditions."

Key to this patient-initiated project was the fact that members of the social network initiated contact with us. Laura and Katherine later described their efforts as a self-proclaimed "pre-meditated mission" to get their research agenda in front of researchers and that they figured that they "had nothing to lose" by approaching me. They approached the right researcher, which also is important. I had an interest in SCAD as a cardiologist whose practice focuses on women; my passion is working with patients and helping them advocate for better care; and through Mayo, WomenHeart and other organizations, I have spent many years helping women across the country to feel empowered when they walk into their physicians' offices. How could I say no?

My study team has unquestionably benefitted from the organizational and leadership skills and frankly, the courage of Laura and Katherine and the willingness of the other women to share themselves with us. My colleagues and I at Mayo Clinic feel indebted to the "SCAD Ladies" on many levels. As a physician, I see how difficult it can be for patients to live with a disease; it takes work. I also was amazed and inspired by these women who found the energy and time to focus on the possibilities of research for their disease.

Perhaps even more gratifying is the explosion of interest in our methods among both colleagues and other patient groups who hope to leverage the "power of the patient" to advance the science for other conditions. While a more formal multicenter registry and prospective clinical trials will ultimately be necessary to fully understand SCAD, this unique model involving self-organized patients provides an excellent option for a virtual multicenter registry and an option for other patient-investigator partners to consider. Our early findings already have generated new hypotheses that will be the source of future scientific inquiry for this condition. I have every reason to believe this can be successfully translated to study other conditions and have already been contacted by several patient groups.

It is evident that social networking tools can catalyze community action and that the energy and commitment of affected patients can overcome inertia and ignite excitement and commitment to new research. The singular motivation and focus of patients with little-understood conditions, combined with the natural organizing framework in a social networking site, may significantly improve the timeliness and cost-effectiveness of research in these conditions.

We hope that our experience with these empowered and activated women can serve as a model for other patient groups AND scientists and that it will be replicated to study and propel medical advances in other uncommon conditions that may not otherwise be subjects of active investigation by the medical community. More power to the patients!

Sharonne N. Hayes MD, FACC, FAHA, is Associate Professor of Medicine and Cardiovascular Diseases, Founder of the Women's Heart Clinic, and Director of Diversity and Inclusion, at Mayo Clinic, Rochester MN, and is a member of the Board of Directors at WomenHeart: The National Coalition for Women with Heart Disease.

The "furiously angry momma" who spearheaded the online research

Katherine Leon
Alexandria, VA

I had my heart attack from SCAD at age 38 in 2003. It went like this: A call to 911 and an ambulance trip to ER on Wednesday, April 30 (and sent home with advice to check gallbladder and get my childhood asthma under control); driven to ER by husband and admitted by compassionate female physician on Saturday, May 3; and then repeatedly told by doctors, "it's not your heart;" catheterization and emergency double bypass surgery Monday, May 5.

In 2004, I was quite the basket case as the anniversary of my heart attack and surgery approached. My immediate family had been great support the first year, but my extended family to this day "doesn't get it." I wanted my anniversary to represent a life celebration for me. It was a challenge.

Many women experience this. Their world wants them to be "better," whether or not they are. Humans were failing me left and right, so I decided to turn to the Internet. I was determined to prove to the doctors and those belittling my experience that this was a big deal after all. If I could find other people with SCAD, then I could eventually convince someone to research our condition. Who better to keep alive than new mothers? At this point, I had been told that SCAD was only related to pregnancy, labor, and delivery.

In the spring of 2004, I found a woman whose daughter had survived postpartum SCAD in Lubbock, TX. She herself did not want to talk about it, so that effort fizzled. I fired off an email to Dr. Sanjay Gupta that year when John Ritter died, and of course, that went nowhere! I joined WomenHeart, but struggled with its mission statement, which at the time focused on supporting "working women." With my own continuing health problems and surgeries in 2005-2006, I didn't find a single other SCAD survivor until January of 2007 on WomenHeart's "pre-Inspire" message board. Here is my original post:

> *"... I have searched and searched to find others with this experience. My doctors were no help. They say since most women die on the spot or need a heart transplant, there are not many survivors to study (great). Some of the theories they've offered up are that the stress of labor causes the tear, or a congenital defect was there all along.*
>
> *At an appointment last year, my cardiologist assured me that the latest thinking is that it's estrogen related. (I was worried I could have passed the defect to my sons.) You know how your joints and everything loosens up with pregnancy? Well, he said a type of estrogen causes the loosening, and this is what doctors believe causes the arteries to weaken and dissect. He and the surgeon said they've seen this happen in the third trimester, during delivery, or months afterward, like me.*
>
> *I was so glad to see these posts. When I joined WomenHeart two years ago, it was depressing to not find any information. I hope my comments are helpful — and I hope I did this right. I've never done an online post before!"*

Although patient-initiated campaigns can seem daunting, people truly just need to DO something.

So that was the beginning. There weren't that many posts ahead of mine, but they dated to July 2005. The first was from a woman called dirksie, who'd had two SCADs, two weeks apart! I had been told you could never have another; they were so "rare." And, more shocking details: hers wasn't pregnancy related and her treatment was a bucket full of medicine—not bypass surgery.
I had been determined from the start, but this turn of events had me completely hooked. Every discussion thread became data for my research project.

For my "4th anniversary," my husband encouraged me to apply for the WomenHeart Science and Leadership Symposium at Mayo Clinic. I had about 26 SCAD stories at that point; the problem was that many were defunct. When Inspire took over the original WomenHeart board, many posts were given a new date, and I couldn't talk with those individuals who didn't join Inspire. But they were frozen in time in a Word file on my computer, so I still had their stories, including age, general health history, artery affected, treatment, locale, and concerns.

Per Murphy's Law, life got in the way, and although I was accepted to the WomenHeart Symposium, I had a TIA and subsequent surgery so was unable to attend in fall 2007. WomenHeart allowed me to defer, and during 2008, there was a great deal of activity on the message board. A woman in Israel named Odia offered a research opportunity through her cardiologists at a university there. It had never been a matter of ego for me exactly who started the research, so I compiled and sent my "data" to her, and we worked together to generate women who would be willing to email off the board and participate in the research.

Sadly, this was not to be. Odia disappeared from our lives. She left a legacy of women's stories on the WomenHeart online community that is represented in the Mayo research today.
With this development, I was beginning to feel the walls close in. I was lost in the shuffle for the 2008 Symposium, but WomenHeart graciously allowed me to reapply for the Symposium to be held in October 2009.

Worried about Odia, I worked extra hard to ferret out the SCAD survivors on the board. The process is more than just searching for SCAD in the member field. I have always searched for variations of the name in the search engine, and read thread after thread. Sometimes, women will post without identifying SCAD in their profile. Or vice versa, creating a profile, but never posting to a thread. Or they'll call it something a slightly bit different, like LAD dissection. It takes a lot of time, but to me this research has always been as real as the true Mayo studies now underway. As of today, there are 164 self-identified SCAD survivors in the WomenHeart online community. It's a shame they don't all participate, but of course, that's the prerogative and beauty of Internet communication.

My several-year delay in attending Mayo is where the silver lining shone. Laura Haywood-Cory and I now know that we would have never met if I'd gone to the WomenHeart Symposium in 2007. Her SCAD was in April 2009 and she wrote the "All the SCAD Ladies Put Your Hands Up" post on September 23, 2009. It was a very active post, with women telling their stories. As always, talk turned to "something should be done" and "no one ever will because it's so rare."

I tend to save my energy for answering questions and talk of recovery strategies, not the philosophical angst of SCAD. Over the years, I had noticed a pattern of collective misery. So just before the Symposium, I piped up to say, "Hey, I have all of our data from scrolling through the board. There are 68 of us, and I'm going to Mayo to see if I can generate interest in some research." The only person who responded was Laura, saying she would be there as well—another miracle in the universe of SCAD.

Meeting Dr. Hayes was certainly a stroke of good fortune. It was nerve-racking to try to catch her between sessions. On my second attempt, I was able to clearly express what I'd been waiting to say for so many years: SCAD deserved to be researched and I knew survivors who were willing to participate. I'll never forget the look on her face, because I could tell she was going to help.

Another lucky piece was the Mayo institution's interest and commitment to social media, which clearly played a big role in the SCAD study seeing the light of day! As was, of course, the megaphone provided by Inspire. On October 20, 2009, as soon as I got home from Mayo, I posted a message about Dr. Hayes' positive reaction to the idea of SCAD research. I sent her my formal proposal with data on the 22nd. She replied on the 28th. And by November 2, I was getting commitments from women that they would request their records to participate.

> No one wins if you settle into an online pity party. Especially in the case of rare conditions like SCAD, research has to be the "do it" resolution.

I think what strikes me now looking back is that I did what was necessary. Not a very sentimental notion, but truly, I saw the Internet as a tool to get me what I wanted, which was a research study of SCAD. If something is rare, you have to have the bodies to convince researchers it is feasible. The online community was my giant net to cast in the Internet ocean and scoop out information from SCAD survivors all over the world.

So even though this story has morphed into the "power of the patient," the process started out as one furiously angry momma who wasn't going to take, "Get over it," for an answer one minute longer. What I kept hearing was, "There is no research because there isn't anything to research. You either die, need a heart transplant, or are lucky like you." I was shocked and appalled by the unscientific attitude of these medical professionals. And the hypocrisy—if every other commercial on TV is for erectile dysfunction, it couldn't possibly hurt to sponsor research to keep young mothers alive!

> At that point in my life in 2004, no one would have been able to convince me that the SCAD research project was impossible.

The miracle of Inspire is how our numbers grow. Thanks to Google, each newly diagnosed woman just types a few keystrokes and she is viewing our conversations. That is just amazing. And the closeness that we share is equally astounding. I find myself talking about Laura, Sharon and so many others—my new Kansas City friend, Miss Puerto Rico, and Kathy with the yellow Lab—as if we've just sat around a pot of coffee in my living room. And it isn't a farce. I've found an individual's character can shine through brightly in text. Since we are communicating about real concerns (i.e., issues relating to health and the quality of our lives), the superficiality dissolves immediately. I have noticed that from day one. Online communication allows you to portion out your energy and thoughts to those on your wavelength, whereas in day-to-day life, we often keep up a façade.

My priority has always been the research. And I think it's safe to say Laura's has been to support other survivors. And that is what makes our collaboration work. We can feed off each other's energy, or pick up slack when one is sidelined for a bit. I call our efforts on the WomenHeart community a bit of a good cop/bad cop routine in supporting women while also encouraging them to participate in the study if they are ready, a key consideration.

> Even though this story has morphed into the "power of the patient," the process started out as one furiously angry momma who wasn't going to take, "Get over it," for an answer one minute longer.

Reflecting on what I know now, versus when I began, I'd say that ignorance is bliss and is also the key to success! At that point in my life in 2004, no one would have been able to convince me that the SCAD research project was impossible. Although patient-initiated campaigns can seem daunting, people truly just need to DO something. No one wins if you settle into an online pity party. Especially in the case of rare conditions like SCAD, research has to be the "do it" resolution.

I am very fortunate that I could be the messenger to present all the wisdom and experience of the SCAD ladies to Dr. Hayes. My experience shows that empowered patients need to be "patient patients" as well. While this story looks quick and easy, it was years in the making. Success truly came from determination, creativity, and a lot of good fortune. Each group out there will need to chart its own path and use the tools of social media to create unique, and maybe even better, solutions.

Perhaps in a year, an advance in social media or the research community will make our patient-initiated SCAD study seem like 8-track tape or the Walkman. Who knows? Tweet-search may be the next great development!

Creating a community that spans countries and oceans

Laura Haywood-Cory
Durham, NC

Looking back, I wasn't consciously saying to myself, "Hey, we're using social media to organize a pool of study applicants." I think I was more focused on the day-to-day, getting the word out, supporting the women who came forward and self-identified as SCAD survivors.

I don't know if the studies would have happened if Katherine hadn't taken the opportunity to talk with Dr. Sharonne Hayes from the Mayo Clinic in person at the WomenHeart Science & Leadership Symposium in October 2009. Email and message boards are fantastic tools, but there's something about being able to make your case in person, that makes it harder to be ignored. Emails can be deleted.

So how did it all come together? Here's a timeline of my involvement:

April 2009: I had my heart attack and SCAD, and got home from the hospital on April 6, 2009. Via search engines I found a few messages here from SCAD survivors, and so I joined the WomenHeart online group a few days later.

September 2009: Seeing that there seemed to have been no new information on the research project discussion that an Israeli woman, Odia, had been working on with Katherine, I wrote my "All the SCAD ladies, put your hands up" post, to try and get a ore recent head count. My main thought at the time was to just try and get everyone together in one spot.

I wasn't so much focused on pushing for research, but Katherine Leon was. Katherine jumped into that thread, and that's when we realized that we were both going to be attending the Symposium in Oct. 2009, and Katherine was planning to talk to Dr. Hayes in person. Dr. Hayes tentatively said yes to doing a small pilot study.

Katherine pointed out that there was a group here of dedicated, enthusiastic patients who WANTED to participate in research.

> But being able to talk to each other, even across continents, across oceans, makes us feel less rare and freakish and alone.

Ever since I'd discovered all of the SCAD survivors online, I felt that doctors tell us all how rare this is and how lucky we are to have survived, but in this one spot online, there are a lot of us, and we don't feel particularly rare at all.

Subjectively, "a lot," I should say. I realize that in actual numbers, we're still a pretty small group. But being able to talk to each other, even across continents, across oceans, makes us feel less rare and freakish and alone.

Late 2009: Around this time Katherine got the OK from Dr. Hayes to put the word out about the pilot study. So she, and then I, started posting it here on the board, and we started contacting women via Inspire message--we split them up; Katherine sent messages to the pregnancy-related SCAD ladies, and I sent messages to the idiopathic (no known cause) ones.

And actually, someone complained about it, so we had to stop. It was rather distressing, because the only people we were reaching out to were ones who'd specifically self-identified as SCAD survivors, but some member or members complained that we were acting inappropriately.

It upset me so much that I didn't come back to the site for several months. Then I realized that I was letting one bad apple ruin the bunch, and that I had work to do reaching out to new SCAD survivors--paying back the support that was first given to me when I showed up, new and scared.

> I wasn't consciously saying to myself, 'Hey, we're using social media to organize a pool of study applicants.'

I know that a few SCAD ladies fell through the cracks while I wasn't participating here. They posted their stories and I didn't see or respond to them. But in mid-2010 I came back, and I'm not leaving again. I don't want to miss a chance to offer support to someone, and I'm working on developing a thicker skin.

During the rest of 2010, we were responding to new SCAD patients as they showed up to the online community. Occasionally Dr. Hayes or Dr. Marysia Tweet would email Katherine with an update on the study, and Katherine would email us privately.

Spring/Summer 2011: Things really started snowballing, when we found out that Dr. Hayes' report on the pilot study had been accepted to the Mayo Clinic Proceedings journal. Not only was the study news coming out, Mayo's public affairs office wanted to do video interviews of Dr. Hayes, Katherine, and me. And to top it off, we were to be interviewed by the Wall Street Journal!

Go where the support is

What I would say to someone else who has a rare disease would be to first, get support online wherever you find it. Go where the support is. And if you have the chance to make your case in person, for research into your condition, grab that chance with both hands.

> We're all holding hands in an unbroken chain of support, one SCAD survivor to another.

Online tools and social media can help create a patient community that spans countries and oceans, and with that support backing you up, reach out to the people who can research your condition. These women, from all corners of the US, the UK, Canada, Sweden, New Zealand, and more--are my friends, as much or more so as anyone I've met in person, and I'm grateful to them all for the tremendous support and understanding they provide.

We're all holding hands in an unbroken chain of support, one SCAD survivor to another.

There will be dark moments, when it seems like everyone's social skills have flown out the door. People will post something without thinking, other people's feelings will get hurt. On days like that, try to remember the work you're doing for the greater good.

And remind people that facial expressions and tone of voice don't convey online, and that if there are multiple ways to interpret someone's words, it's better to give someone the benefit of the doubt. (In other words, it's best to always bear in mind the adage, "Never attribute to malice what can be explained by ignorance.")

There are good days and rough days. On the rough days, savor the triumphs of the good days.

Overcoming aversion to social media, she helps drive research project

Sharon Sutton
New Zealand

My SCAD story began with a heart attack on Dec. 15, 2006. I felt an intense pain in between my shoulder blades, then got incredibly hot all over and felt nauseous. It wasn't until the pain moved through into my center chest, and then down my left arm that I realized that I could be in trouble. I woke my husband and he drove me to the hospital. I was given excellent care at my local hospital, and my cardiologist stated that because I was fit and healthy with no weight issues, great cholesterol and low blood pressure, that he suspected that my confirmed STEMI heart attack had been caused by a rare condition—SCAD in my LAD artery. I was airlifted to a major hospital, and during an angiogram this diagnosis was confirmed, and two drug-eluting stents were placed in my LAD artery.

I was sent home on Day 8 of my hospital stay, having been looked after beautifully medically, but with absolutely no idea of my long-term prognosis, nor of why this had happened.

In the first month or so, although very shocked, my prevailing emotion was that I pleased that I was alive. Then slowly the realization dawned that I could have died—and I had no answers as to why nor what I could do to prevent it happening again, or even if it could happen again. And so the long search for answers began. Why did this happen? What is my long term prognosis? We had two young sons, aged six and eight, one of whom is severely autistic, and I needed to know these answers. So I started trawling the internet for clues, but mostly only found sobering statistics on mortality and little or no information on the causes or long-term prognosis. SCAD has been linked with pregnancy, auto-immune diseases and drug use, but I fell in to none of those categories, and so my condition was termed "idiopathic."

We still had no answers, but there is a huge comfort in knowing that you are not alone.

In March 2009, I was still periodically looking for answers on the Internet. I know that knowledge changes with each passing day, and I kept looking for some kind of breakthrough which would explain my condition and give me the answers I sought. I came across a Web site called "Inspire" which appeared to consist of online conversations between patients—and some had suffered SCAD just like me! I was so excited, but when I realized that I had to sign up to this website I was a bit reluctant. I am old-school and wasn't sure about being part of an online community, and I was worried about privacy issues. But I did sign up, because I was desperate to meet people like me, and I hadn't heard of nor spoken to anyone who had suffered SCAD.

On Inspire I signed up to the WomenHeart group and it was an incredible day when I finally connected online to several people who were walking in my shoes. Words just cannot express it. All of the uncertainty, all of the fear, and all of the questions I could let out and share. We still had no answers, but there is a huge comfort in knowing that you are not alone. Without a shadow of a doubt it was the best thing that ever happened on my journey to emotional recovery.

In May 2009 I noticed through an online conversation that one of the SCAD members, "Laura," was about to have a birthday. I had been reluctant to send any "friend" requests, and up until then had been content to just enter and exit online conversations without going into personal conversations through the messaging system.

Laura's SCAD story really struck a chord with me, as she had only recently suffered her SCAD, and I could tell from her writings that she felt so very much like I had those two years ago. And since I was a bit further down the track in my SCAD recovery, I thought maybe I could help a little, particularly with the emotional impact. I thought I could reassure her that was she was feeling was absolutely normal, and that in time the fear would not dominate her every waking moment. So I took a deep breath and sent her a friend request. When it was accepted that same day, I wished her a happy birthday and told her a little of my story, which was so like hers. And we have been online and offline friends ever since! Laura has often told me that I was the first person to reach out to her online, and I am so glad that I did contact her and ignored my usual reticence at reaching out.

> Maybe I could play a part in getting those answers, both for us and those who would surely follow.

I met Katherine online on Inspire/WomenHeart that same year in the November 2009. Katherine sent me a friend request which I accepted, and then she sent me a note advising of a SCAD study which was about to be conducted at the Mayo Clinic. I was so excited! This was what I had always wanted—answers! And even better, maybe I could play a part in getting those answers, both for us and those who would surely follow. So I sent her back a reply that of course I would take part, and started the long process of obtaining my medical records.

Katherine kept encouraging me via email and the WomenHeart website throughout the process, and the fact that my medical records finally winged their way to the Mayo Clinic is absolutely down to Katherine's patient encouragement and support. We have kept in touch since via the website and via email, and have become firm friends.

I count Katherine and Laura as two of my real friends although we have never met. Maybe it is because having experienced such a life-changing event makes you closer much quicker, because you are sharing feelings from deep inside—fear, worry and grief. I think this cuts through a lot of the usual reserve that we show to people, and gets you to the heart of the person quicker. I feel immensely blessed to have met them.

In Australia's Outback, going online to find her "SCAD sisters"

"Amy"
Warrenton, VA

I came to find the Inspire/WomenHeart community the day after I returned home from the hospital after suffering my SCAD in July 2010. At the time, I was an American who had been living the past three years in Alice Springs, a remote town in central Australia. I was a very fit and healthy 41-year-old mother and wife and couldn't have been more shocked to find out I had a heart attack. I had to be airlifted to the nearest city, Adelaide, which was a three-hour plane flight away, to be evaluated by a cardiologist. I was sent home with no real explanation as to why this happened, because as I was soon to find out—there isn't much known about the condition.

I consider myself to be pretty tech savvy, so I started doing Internet research. This research led me to the thread on Inspire that was basically a roll call of SCAD survivors—(the "All the SCAD ladies—Put your hands up" thread.) NOW I had found what I needed—other women that resembled me! That very day I wrote a WomenHeart journal entry about my SCAD experience, and shortly thereafter, a woman from New Zealand responded to me. She made me feel so much better—and was able to relate to my experience. We have corresponded privately as well and she was able to give me some advice on my early recovery.

Other women on the site have also corresponded with me, giving me the reassurance and support I really needed, that I was missing in Alice Springs. Some of the women had their SCAD around the same time as me, so it was good to be able to compare and discuss what was going on with us. I felt so alone out there when I first joined the community, and was so grateful to have connected with my SCAD sisters.

Now that I have returned to the US, I am thankful that I have a have a super cardiologist, located just minutes away, as well as the continued friendship and support of my SCAD sisters. I feel confident that I can now offer support and advice to those who are searching for it. I am looking forward to participating in the Mayo Clinic studies in the hopes that one day we'll all have some answers.

I feel a deep connection on this community because this event was so life changing and earth shattering and I know that they all feel this way too. I'm sure it's like a group of cancer survivors or other members of other support groups where people feel bound by their sharing of similar experiences.

Getting, and receiving, practical clinical advice

At first when each new person joined the community and shared their story—I would feel so sad and scared for them. I was still dealing with the "loss" of my former self, and I shared their fears. I could say, "Hey I'm here—I'm going through this too. We can go through this together." Now I feel I can give advice and support on a less emotional level. I can answer questions about the recovery process.

I've been able to actually use information from the community. I had some stomach problems when I was first discharged. Another member relayed that she did too and that it was due to the low dose aspirin. Her doctor added another common medication (Omeprazole) to her regime and the problems went away. When my doctor thought I too was having aspirin aversion, he wanted to switch me to Plavix, but I suggested that we try the Omeprazole first. He agreed and I had favorable results. My stomach distress was gone. I am thankful that I was able to avoid the Plavix.

It is really exciting to know that I am contributing to new clinical research. It's the possibility that we'll have answers to the big questions that we all have. Why did this happen? This study is HUGE and unprecedented. I'm proud that the leaders of the group have pushed so hard to get it going.

Days after her SCAD, she finds an online support system

Rachel Willen
Lebanon, NJ

We are in an age of online social networks and even though I have yelled at my 15-year-old, “Get off Facebook, it’s rotting your brain!” while she’s supposed to be doing homework, I feel so grateful to be living and dealing with my spontaneous coronary artery dissection (SCAD) during this era of electronic connectivity. Say what you will about e-friendships and the superficiality of it all, but in the month since my SCAD occurred, I have learned what I know about my condition, felt encouraged, cared for and guided all the way to the Mayo Clinic by the women of this SCAD sisterhood I found online on the WomenHeart Support Community on Inspire.

The day after I came home from the hospital from my SCAD episode and heart attack, I saw an email from my mother-in-law, titled, “Have you seen this?” It was a link to a thread on the online community titled, “Mayo Clinic begins study on SCAD.” My mother-in-law had a close call with artery blockages and now has three stents. She found the WomenHeart support group and follows it religiously for news, friendships and the common ground that I now find is so comforting since my SCAD. Unbelievably, when I when I followed the link she had sent me, there was that article about the Mayo study, just days after my SCAD. It felt like another miracle had occurred in my life, along with other recent “coincidences” that allowed me to survive my SCAD to begin with.

I immediately signed up for the community and joined the SCAD group. I posted my story and a link to my blog that had a more detailed account of what happened and my feelings about it. Within hours, I received a dozen welcome messages and shared stories from other SCAD ladies and it was like connecting with long-lost friends, not strangers. The information was stunning. The comfort I felt in seeing what I had. . .this rare "fluke" as my doctors called it. . .being played out over and over in these women's stories, was immeasurable during those first weeks. The new normal I was trying to get used to, with meds, and strange twinges and fear and anxiety was all there for me to see and read as a common ground amongst my new friends.

I have a Facebook page, and a Twitter account and a LinkedIn account related to my work, and I sort of "live out loud" through my blog (www.foodfixme.com), so I'm not a stranger to using online communities However, I have never really actively belonged to a support group or common interest group online. It has been surprising and heartwarming to be a part of this group. I find myself searching the threads every day to see if there is not only new information and replies to my questions on discussions I've started, but other discussions where I can participate and contribute my experience to help someone else. It's been a wonderful balance of feeling taken care of and having the opportunity to take care of others too.

As I write this I'm sitting in a waiting room at the Mayo Clinic, waiting to have my last test, a CT scan of my carotid arteries and head, before heading home. I've been here three days, on "Planet Mayo," receiving the best care I know I could ever get for my SCAD. This would have never, ever happened if it was not for my connection to the site, and the work that Laura and Katherine did to create this SCAD community and call attention to it with Dr. Sharonne Hayes here at Mayo. What is so important about what Dr. Hayes has given me—more than the most comprehensive care and follow-up plan for my condition—she has given me peace of mind knowing that this team at Mayo is doing all they can to find out why SCAD happens and how it can be prevented. This feeling of being heard and seen and paid attention to is the biggest part of what the online community has given me.

I venture to say that so much of the healing from a heart attack has to do with the emotional and spiritual trauma of it all—the "why me, why now" and the fear of it happening again—a kind of PTSD of the heart. The connection to others, the resource of information, the shared experiences are what have delivered me back on the road to recovering my confident, strong, fearless self.

She joins a “club no one wants to join,” and is happy for it

Minna Ogren
Solleftea, Sweden

Loaded with medicines and good advice I started my new way of life in September 2008, after my SCAD. Being a person who wants to know, I started looking for facts and theories on the Internet. Most of all, I wanted to find other SCAD survivors.

In beginning of June 2011, I stumbled into Inspire.com by pure luck and a whole new world opened up. The mentality and welcoming words of the women on the WomenHeart group made me feel better instantly. To find such emotional support from total strangers is more than I could ever have imagined!

When I posted to the group, the one line in a reply that brought tears to my eyes came from Laura: “Welcome to the club no one wants to join, but we are glad you found us!”

We´ve all been through our individual steps of pain, grief, loss, fear and sense of loneliness. I´d like to add two more steps: happiness and thankfulness. Through my beloved “heart sisters,” I´m in better contact with my emotions than before.

Whenever I feel lost, sad or even really happy, the first thing that comes to mind now is to log on. I read other women´s stories for comfort and education, and share what feels positive to me so that maybe someone else will be encouraged by my story.

Now, when I post to the online community, it feels like somebody sees me as I am when I get replies. I don´t have to put up a façade, and I can express thoughts and ideas that I know my fellow sisters will take the right way. To feel I can be there for somebody, as well as feeling them being there for me, is amazing.

From feeling helpless to feeling hopeful

“Betty”
United Kingdom

Until recently I have regarded myself as a healthy individual despite the fact that for years I have been treated for high blood pressure. To my dismay, in the late summer of 2011, I was admitted into my local hospital suffering from awful chest, neck and left arm pains. I was diagnosed as having had a heart attack. After an angiogram, I was told that I had had a spontaneous coronary arterial dissection in my LAD. I had never heard of this condition before. My experience left me very anxious and frightened as I keep thinking that it could happen again, although my cardiologist was very happy with my angiogram.

When we looked up SCAD on the Internet, we found very little information. This left me feeling helpless and very, very anxious.

When I asked my cardiac care nurse about this condition, she admitted that she was treating me as a “normal heart attack patient,” as she had never had a “dissection patient” before. Luckily, my husband and I came across this online community, where I was able to interact with other women who like myself had experienced a SCAD. I was able to say what I was experiencing and how I was feeling with the other members here in turn helped me realize that what I was experiencing was in fact normal.

Gathering clinical info to share with her docs

These women in the WomenHeart group have given me lots of advice at a time when I was feeling very low and frightened. When I posted to the community, the replies were very quick and that was very reassuring, as it put my mind at ease. It brings me great comfort to read of other people’s experiences.

With regards to using the information I have learned from the community, I do not yet feel that I have had the opportunity to do that as I am still waiting to have a followup appointment with my cardiologist, and to be honest, don't know whether or not I would have the confidence or sufficient medical knowledge to question what he says to me with regards to treatment.

> When we looked up SCAD on the Internet, we found very little information.

I have tried to tell my cardiac nurse things with regards to the type of after pains I have been getting. However, she has admitted she doesn't know much about a SCAD. In her defense, may I say she has been very supportive in other areas of my recuperation.

I am starting to accept what has happened and am determined to take it easy so that I make a full recovery.

So, without the help of these SCAD ladies, I don't think I would be making the very good recovery that I am today. The more research done into this condition the better, so that women who experience a SCAD in the future are not left searching for information, as we all seem to have been doing.

“My Medic Alert bracelet is extremely worn”

Mary Deborah O’Brien
Charlottesville, VA

I had my SCAD at age 51, in 1988. I was thin, active, and heart healthy. Three weeks, two hospitals, and one heart catherization later, I got my SCAD diagnosis.

My episode was so rare that except for Coumadin, the only medical help I received was being told to wear a Medic Alert bracelet. The whole experience has been very lonely, so I was surprised to read the article in the Wall Street Journal in late August 2011 and learn there are other survivors out there. I have never been part of an online support community, and take a dim view of Facebook, etc.

My Medic Alert bracelet is now extremely worn, as I am 74, and, since 1988 I had never found another SCAD survivor. I crave hearing about the SCAD experiences of others and learning about studies.

When I read the Journal article, I was not surprised that it was two women, Laura and Katherine, who organized this online community to get the word out. After John Larson (“Rent”) died alone and John Ritter, the actor, never made it out of the ER, did any men act? Laura and Katherine are typical of how women face things head on, network, and make a difference.

As I read the survivors’ stories in the online community, I sensed they were experiencing the same fears that had bothered me 23 years

> I was alone in a recovery I couldn’t trust because SCAD statistics at the time made me the only person in a boat that had sprung a leak.

ago. I guessed that these nervous survivors might feel hopeful knowing there was a SCAD survivor of many years still standing. "Yes," I said as I read an encouraged reply from a woman in New Zealand, "I was right."

> Now I'm thinking of buying a new bracelet.

My emotional healing certainly would have been improved years ago by connecting with other survivors. I was alone in a recovery I couldn't trust because SCAD statistics at the time made me the only person in a boat that had sprung a leak.

As for my worn bracelet, when I had my experience so long ago, "spontaneous dissection of a coronary artery" was the only name for it and that is what is engraved on my bracelet. Now I am thinking of buying a new bracelet and just having them engrave "SCAD." How cool is that?

Knowledge is Power, and there is Power in Numbers

Mary Graper

In 1997, I was a typical wife and mom raising a daughter and two sons, busy with all the usual activities that are required to manage a family of five (and three dogs), and running a business with my husband. Though I was educated as an elementary school teacher, I always had an interest in medicine and had spent most of my young adulthood substantially involved in managing my parents' many health problems. Looking back, I'm not really sure how I managed all of that while raising a young family of my own and traveling back and forth to Arizona every time another health crisis occurred with them.

I learned a lot about the medical system during that time and how a sick person really needs someone else around to look out for them. In those days, there was no Internet to look for information, so I spent a lot of time in hospital medical libraries searching through medical literature, tracking down doctors to ask about results and what was next, and just generally making a nuisance of myself with the hospital staff to make sure everything was being done correctly. During that period I recall saying to my own physician, "You know, there really ought to be some job like being a patient advocate, not someone who is medically trained, but just someone who knows how to work on behalf of a patient's best interests." "Yes," she agreed, "That would be a good idea and perfect for someone like you."

Six years had gone by since both of my parents passed and there we were in 1997, just a regular family. I was feeling relieved that those "sick" years were behind me. Feeling particularly blessed, I remarked to my husband one evening while preparing dinner, "You know, we are so lucky that we and our children are all healthy." That was in September. Little did I know then that the "sick" days would be upon us again, very soon.

November 1997 through July 1998 was probably the longest, most tumultuous period of my life to date. I was now a woman who had two children diagnosed with Wilson disease, and a husband diagnosed with colon cancer. Colon cancer was something most people were aware of. It was talked about in the news and most, if not all, doctors knew how to diagnose and treat it or at least refer patients to a specialist who did. There were local cancer support groups for patients and families BUT, here was this thing called Wilson disease; what in the world was that?

> This is not just a story about what they were able to accomplish, but also about the power of patient groups and of social networking.

Again, I put on my researcher hat. Thankfully, there was some Internet access by then and I was able to find and become involved in the Wilson Disease Association (WDA) and its online discussion group. When you are affected by a rare disease, you are essentially an orphan and you feel very alone. When there are less than 200,000 persons in the United States with a particular disease, you can't exactly walk down the street and talk with someone else who has it too. We were fortunate to find a local doctor who made the diagnosis but that was—and still is—very unusual. Most rare disease patients search for years and visit many doctors before they are properly diagnosed.

SCAD Lades show power of patient groups

An example of this struggle is the story about the SCAD Ladies. Their experience illustrates that because no single physician had much exposure to SCAD patients, the disorder was not given the attention it deserved by the medical community. Through Ms. Leon's efforts it turned out there were more women who had experienced SCAD than any one physician knew about. I was thrilled to read how these women used social media to band together, fought to be noticed by the medical community, and succeeded. This is not just a story about what they were able to accomplish, but also about the power of patient groups and of social networking.

Most rare disease patients search for years and visit many doctors before they are properly diagnosed.

Thankfully, now in the 21st century, there are patient advocacy organizations for nearly every rare disease. We, as leaders and members of these organizations, are able to utilize social media and online communities such as Inspire, Facebook, our own websites, and other such tools to encourage an interactive dialogue and empower patients and their families.

Together we are able to gain insight and data about rare disease manifestations that may not yet have been brought to the attention of the medical community. Knowledge is power, and there is power in numbers. Together, from near and far, we are united as one. We are no longer alone.

Mary Graper is president of the Wilson Disease Association. Graper has over 25 years experience as a volunteer leader, and is recognized for her creativity, organizational and leadership skills. She holds a B.S. degree in Education from the University of Wisconsin-Milwaukee. Two of her three children are Wilson's patients. Mary joined the WDA Board of Directors in 2000. The WDA's online community is at www.inspire.com/groups/wilson-disease-association.

SCAD Online Resource Page

WomenHeart Support Community on Inspire http://www.inspire.com/groups/womenheart

WomenHeart: The National Coalition for Women with Heart Disease http://www.womenheart.org

Mayo Clinic study Web site, with links to the application forms http://dev.newsblog.mayoclinic.org/2011/08/17/scad-spontaneous-coronary-artery-dissection-studies-at-mayo-clinic/

Mayo Clinic videos detailing the research project
http://www.youtube.com/watch?v=uNnjLOF3x_Q&feature=share
http://www.youtube.com/watch?v=4WcFYsucy1w&feature=relmfu

The "All the SCAD ladies, put your hands up" post
http://www.inspire.com/groups/womenheart/discussion/all-the-scad-ladies-put -your-hands-up/

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SCAD Research Foundation
http://scadresearch.org/index.html

Carolyn Thomas' "Heart Sisters" blog about the post on the SCAD research project
http://myheartsisters.org/2011/09/06/scad-mayo-research

About Inspire

Inspire℠ together we're better℠

Princeton, N.J.-based Inspire creates safe, moderated online communities, organized by medical condition, for patients to share information and to support one another.

Inspire builds and manages these communities in partnership with more than 75 national patient advocacy and support organizations. For more information, go to www.Inspire.com, or email team@inspire.com. Follow Inspire on Twitter at www.twitter.com/teaminspire, and on Facebook at www.facebook.com/Inspiredotcom.

The "SCAD Sisters" logo on the cover is courtesy of Teri Thom of Canada, a SCAD survivor who is a member of the WomenHeart Support Community on Inspire.