

RAJIV GULATI: Hello. I'm Dr. Rajiv Gulati, from the division of Cardiovascular Diseases at Mayo Clinic in Rochester. I'm delighted to be joined today by Dr. Sharon Hayes, a consultant in the division and founder of the Women's Heart Clinic here at Mayo. Welcome, Sharon.

SHARON It's great to be here.

HAYES:

RAJIV GULATI: You've been interested in the field of spontaneous coronary artery dissection. Perhaps you could tell me and the audience about how your interest in this field began.

SHARON Well, I'll say it has not been a lifelong interest. It actually was only piqued a couple of years ago by a very-- I

HAYES: learned later, strategic-- an encounter with a patient who'd suffered an episode of SCAD, or spontaneous coronary artery dissection, who came to me at a conference and asked what Mayo was doing in terms of research, what I knew about it. And I kind of gave her the standard answer. I was-- it was a rare disease and condition affecting mainly women. And I probably knew more about it than most people because I'm interested in women.

And she sort of stopped me and she said, well I don't think it's that rare. In fact, there are 70 of us on a social media site-- that we have come together-- a social networking site. And we've been talking and we want-- it can't be that rare. We want some research done. And then subsequently handed me a research agenda from the group asking some really sophisticated questions. And I sort of said, how can I not? It was sort of throwing down the gauntlet.

RAJIV GULATI: Absolutely fascinating. This is patient-initiated research enabled by social media.

SHARON Exactly. It's sort of that empowered patient, that electronic patient. The e-patient that we have been hearing

HAYES: more about. Certainly these individuals are engaged patients. And from that, we had to figure out this willing group, who are serving themselves up-- how would we make it work? What I found was among that group-- they were all over the country. They were all over the world. And they were not Mayo patients. So there--it was a very different kind of thing.

And so we set up a virtual registry. We did a little pilot study, which was successful. And then have subsequently been approved to expand that registry to over 200 patients-- men and women-- to look at the history and the demographics and the like, as well as to set up a biobank-- a DNA biobank-- to look for any potential genetic mutations that might point us to an etiology.

RAJIV GULATI: So a 200-patient study seemed like an awful lot. How many patients do we see here at Mayo Clinic with spontaneous coronary artery dissection. Perhaps you can give us a historical perspective.

SHARON Well, we've looked at that. Our research group went back 18 years. And what we found was about 70 patients.

HAYES: So about four or five patients a year we were seeing up until 2010. And now, since one-- I think people are recognizing perhaps it's more common than we thought, as well as the research that's being done-- we're seeing four or five a month within our group.

RAJIV GULATI: So a tenfold increase in numbers of patients with this supposedly rare condition.

SHARON HAYES: Exactly. And I think that it speaks both to rising awareness as well as perhaps that it truly is in-- that it has been there all along and we weren't recognizing and diagnosing it.

RAJIV GULATI: So for the practicing clinician and cardiologist, perhaps you can give us an idea of how this disease may present to them.

SHARON HAYES: Well, I think we all need to have an index of suspicion, particularly for young women having fairly typical heart attack symptoms that aren't in the right demographic. So the average age of the patients with SCAD is about 42. That was reported in other series and it's been confirmed in ours. About 70% are women and of those, about 30% are peripartum. The age range is from late teens to in the 60s, but pretty much in that sort of 30 to 40 range is where most end up. And most of these individuals present with acute coronary syndrome-- myocardial infarction-- either stemi or non-stemi. And most go directly to the cath lab if the index of suspicion is there.

And-- but the treatment afterwards-- because these are individuals who don't have standard cardiovascular risk factors-- statin or no? Beta blocker or no? So those are some of the clinical questions that we're facing as well.

RAJIV GULATI: Very interesting. So the demographic would typically be the young to middle aged female with an unexplained acute coronary syndrome.

SHARON HAYES: Exactly. You know, the more I've observed the patients coming in, I think that it may prove that this might even be the most common cause of acute coronary syndrome in that under 30-35 range. Because these women have no risk factors-- standard risk factors. And I think the big key is getting them prompt care. And then in the outpatient setting-- in the clinic, is trying to sort out what might be the underlying causes since that is very unclear at this point.

RAJIV GULATI: And hence the reason for the research that you were outlining earlier. So maybe you could tell us if you've made any early clinical observations that will change your management or strategies for the future.

SHARON HAYES: Well, many of these are young women who have children. They're very concerned about passing some trait along. So I think a good genetic consultation-- and we're very fortunate here at Mayo to have some real expertise-- and selective genetic testing for collagen vascular diseases and other. Early on in our experience, we noticed some physical exam findings that discuss some extra coronary vascular disease and looked and diagnosed several asymptomatic dissections-- carotid and in other vessels, as well as fibromuscular dysplasia in, actually, quite a few of these individuals-- not all of them. So we now do routine screening of extra coronary vessels and do a really careful vascular examination.

RAJIV GULATI: Very interesting. So in order to move this research forward, clearly, funding is going to be required. Perhaps you could shed some light on some fundraising strategies that you and others have used to help do that?

SHARON HAYES: Well, true to this activated patient group, they've taken the reins themselves and planned a-- started planning last year a virtual walk. So they're all over the world. They decided they'd all do a 5k at the same time together, raising money, maybe organizing a group. Kind of simultaneously, the widower of a woman who died in early 2011 founded a nonprofit to raise funds for research for SCAD. So they are raising money for this nonprofit-- SCADresearchinc.org.

And so a group of them decided they would have a Scad reunion. I think it's an interesting term because they've never met each other in person before. But they're coming to-- a large group are coming together in the Chicago-west Chicago area on May 5th and doing their five OK together. And some of my-- I am going to attend as well as another one of our co-researchers. And we're going to give a little presentation about what we've done so far. So it's kind of that give back to this group who really brought this to our attention.

RAJIV GULATI: Absolutely fascinating. So social media-initiated research, really as a means of propelling investigation into this very rare and potentially life threatening condition.

SHARON Yes. And it has been really gratifying and fascinating and very different than any other research I've been
HAYES: involved in. Because I can tell you that a new woman comes on to one of those sites-- the Facebook site or the women heart site. And they are immediately embraced by the other women and told about Mayo research. So that's-- by all of the other women. So it really has amplified things.

RAJIV GULATI: Wonderful. Well, thank you, Dr. Hayes. And thanks to you for joining us for this really very stimulating discussion. I look forward to seeing you all on May the 5th at the SCAD walk.