

Mayo Clinic finds social media valuable tool to recruit study participants for rare diseases

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Mayo Clinic has identified a new benefit of social media and online networking: a novel way to study rare diseases. Through patient-run websites dedicated to heart conditions and women's heart health, a team of cardiologists led by Sharonne Hayes, M.D., is reaching out to survivors of spontaneous coronary artery dissection, also known as SCAD, a poorly understood heart condition that affects just a few thousand Americans every year.

Study recruitment through social media and online networks could help researchers assemble large and demographically diverse [patient groups](#) more quickly and inexpensively than they can using traditional outreach methods, according to the study, set for publication in the September issue of [Mayo Clinic Proceedings](#).

"Patients with [rare diseases](#) tend to find one another and connect because they are searching for information and support," says co-author Marysia [Tweet](#), M.D. "Studies of rare diseases often are underfunded, and people with these conditions are quite motivated."

SCAD is a traumatic cardiac event that often induces heart attack, but physicians have no clinical studies on which to base treatment plans, says Dr. Hayes, lead author of the study and founder of Mayo's Women's Heart Clinic.

A SCAD survivor inspired the pilot study. The woman approached Dr. Hayes asking how she could spur more research into the unusual

condition. Dr. Hayes' research team then asked the survivor to help recruit participants through an online support community on the website for WomenHeart: The National Coalition for Women with [Heart Disease](http://www.womenheart.org), www.womenheart.org. The SCAD survivor and Dr. Hayes already were affiliated with the site.

"This is a completely different research model than Mayo Clinic is used to," Dr. Hayes says. "Investigators here typically rely on the stores of [patient information](#) from the clinic. This was truly patient-initiated research."

The study landed 18 participants in less than a week, six more than could participate in this pilot of 12 patients. The remaining volunteers are eligible to participate in a new, larger study based on the initial study's success.

The new research seeks patients through conventional and social media outlets and aims to build a virtual registry and DNA biobank of up to 400 SCAD survivors and their relatives. The database will help physicians conduct more detailed analyses of treatment strategies and factors that affect prognosis and better understand the possible genetic basis of some SCAD cases.

Arteries consist of three layers, and during SCAD, the inner layer of one of the coronary arteries tears and can peel away from the middle layer. The resulting flap of tissue can partially or completely block blood flow, leading to a heart attack.

Through its Office of Rare Diseases Research, the National Institutes of Health tracks 6,000 to 7,800 rare diseases such as SCAD that affect fewer than 200,000 Americans. NIH experts can only estimate the number of rare diseases because there's not enough data to know how many patients have them, let alone how to study or treat them.

"Patient leadership in this is huge," says study co-author Lee Aase, director of Mayo Clinic's Center for [Social Media](#). "Designing research protocols to study rare diseases and then recruiting enough patients to participate is extremely difficult for busy physicians, but patients with rare diseases are highly motivated to see research happen."

In an accompanying editorial, Barbara Brandom, M.D., of the department of anesthesiology at the University of Pittsburgh Medical Center, says the SCAD pilot study is a novel way to recruit study participants. "Authority and responsibility for research into rare medical conditions are devolving from the researchers to the patient-participants," Dr. Brandom says.

More information: SCAD patients and their families are invited to participate in the biobank study. More information is available at newsblog.mayoclinic.org/2011/0...dies-at-mayo-clinic/

Provided by Mayo Clinic

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