Spontaneous Coronary Artery Dissection (SCAD) Research

2018 Progress Report
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To the SCAD Research Inc. Board, Supporters, Volunteers, Funders and Friends:

As members of the Mayo Clinic SCAD research team, we express our sincere gratitude for your participation and support of the ongoing SCAD Research Program at Mayo Clinic in Rochester, Minnesota. You are the inspiration for this ongoing journey to advance the science and improve the care for those with SCAD. This collection of news and SCAD scientific information demonstrates the truly impressive progress that has been made as a result of your critical support. We want to convey our deep appreciation for the support from SCAD Research, Inc. and each patient, survivor, research participant, family member and SCAD supporter who drives and inspires our work.

Mayo Clinic SCAD Research Program Highlights

As of the end of first quarter 2018, the Mayo Clinic “Virtual” Multicenter Spontaneous Coronary Artery Dissection Registry and Mayo Clinic’s Genetic Investigations in Spontaneous Coronary Artery Dissection accomplished the following:

- **Consented almost 950 participants into the Mayo Clinic SCAD Registry**
- **Collected over 1,200 biospecimens** for DNA extraction and evaluation, including more than 760 from those with a history of SCAD and 470 from family members. Under the leadership of Timothy Olson, M.D., and with SRI and Mayo Clinic financial support, analysis of these samples is underway, including:
  - Whole exome sequencing (WES) aimed at discovery of novel gene candidates
  - Genomewide association study (GWAS) aimed at discovery of SCAD-associated genetic variants
- **Engaged many colleagues** from multiple disciplines to advance SCAD knowledge, including emergency medicine, genetics, obstetrics, gynecology, radiology, vascular medicine, psychology, women’s health, internal medicine, neurology, cardiology and cardiac surgery
- **Published more than 35 peer-reviewed manuscripts** and presented over 30 abstracts/presentations/posters at scientific meetings (see Bibliography)
- **Incorporated SCAD practice and research updates** into numerous internal and external continuing medical education sessions so as to teach other medical professionals about the best practices to diagnose, treat and advise SCAD patients
- **Developed online websites, a Mayo Clinic SCAD Facebook page, and other resources for SCAD patients, families and medical professionals** (see Resources)
- **With SRI, support** the online SCAD Angels Facebook group for loved ones who did not survive their SCAD

Mayo Clinic SCAD researchers were major contributors to the 2018 AHA Scientific Statement on SCAD with Sharonne Hayes, M.D., as the chair and Marysia Tweet, M.D., and Rajiv Gulati, M.D., Ph.D., as contributing authors.
Mayo Clinic researchers have obtained and continue to apply for additional funding to further expand and accelerate research on SCAD:

- Dr. Tweet was awarded the highly competitive NIH BIRCWH grant to study SCAD (2017-2019).
- The team applies for internal Mayo Clinic departmental grants to support the costs of the Mayo Clinic SCAD Registry and innovative SCAD projects (Hayes, Gulati, Olson, Tweet).
- The vast majority of work performed by the Mayo Clinic SCAD team physicians such as coronary angiogram review, data review/analysis, grant writing, development of educational materials, and review/writing of manuscripts is conducted during volunteer time.

Support from SCAD Research, Inc. includes:

- $211,675 to Mayo Clinic's SCAD Research Program in 2017
  - $11,675 specifically from SRI Australia
- Grand total of $646,675 since 2011
- Endless encouragement of and inspiration for our work and team

The funding provided by SCAD Research, Inc. has supported the following research activities:

- Study coordinator support to communicate, enroll and manage data collection for all SCAD research activities
- Medical data review and abstraction by specially trained nursing staff
- Novel SCAD genetics research, including:
  - Sample collection, processing and storage
  - DNA whole exome sequencing
  - Genomewide association study lab work and analysis
- Statistical support for data analysis
- Ongoing monitoring for trends and follow-up surveys

With gratitude on behalf of the entire Mayo Clinic SCAD Research Program team members,

Sharonne N. Hayes, MD, FACC, FAHA
Professor of Cardiovascular Medicine, Mayo Clinic College of Medicine
Director, Office of Diversity and Inclusion
Founder, Women's Heart Clinic
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A JOYOUS OCCASION

On October 13, 2017, members of Mayo Clinic’s SCAD Research team were honored to receive additional support from SCAD Research, Inc.

Together with representatives from SCAD Research, Inc., the recognition event was a joyous occasion to celebrate the program’s accomplishments and future successes through this philanthropic support.
Philanthropic check presentation to Dr. Sharonne Hayes and the Mayo Clinic SCAD team by Jill McComsey and Ellen Robin on behalf of SCAD Research, Inc.
ONLINE WEBSITES AND RESOURCES

**Mayo Clinic SCAD Research Team Contact Information**

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**Mayo Clinic Dedicated SCAD Clinic Appointment Information**

Appointment Coordinator: Amy Cahill  
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**Mayo Clinic SCAD Research Page**

[www.Mayo.edu/Research/SCAD](http://www.Mayo.edu/Research/SCAD)  
Information about Mayo Clinic’s current SCAD research for patients, research participants and health care providers, including links to Mayo Clinic SCAD publications.

**Mayo Clinic SCAD Patient Information Page**

Patient care and health information page discussing SCAD symptoms and causes, diagnosis and treatment, doctors and departments, and care at Mayo Clinic.

**Mayo Clinic SCAD Facebook Page** (Please share and “Like” us)  
[https://www.facebook.com/SCADMayoClinic](https://www.facebook.com/SCADMayoClinic)

**SCAD Survivors**

[https://www.facebook.com/groups/SCADsupport/](https://www.facebook.com/groups/SCADsupport/)  
Closed Facebook group for SCAD survivors: hosted by SCAD survivors, not Mayo Clinic.
SCAD Research, Inc. Web Page
http://www.scadresearch.org

SCAD Research, Inc. Facebook Page
https://www.facebook.com/SCADResearchInc/

SCAD Angels Facebook (For family members of someone who did not survive SCAD)
https://m.facebook.com/groups/135852273695551

Online Community of WomenHeart: The National Coalition for Women with Heart Disease
www.WomenHeart.org
Information and support for women living with heart disease, including an online patient community hosted by Inspire with many SCAD survivor members. Annual education program at Mayo Clinic to train women with heart disease has included many with history of SCAD.
PHYSICAL ACTIVITY AFTER SCAD

Knowing what type and intensity of physical activity in which to participate following SCAD can be a challenge. Health care providers often express uncertainty or are extremely conservative in their recommendations. This is in part because there is insufficient evidence to inform guidelines, there is wide individual variability in needs and capabilities among SCAD survivors, and SCAD has been associated with intense physical exertion. Despite these limitations, it is clear that regular physical activity after SCAD is beneficial. There is evidence that being active leads to improved quality of life and physical and mental health. Based on the consensus published in the 2018 AHA Statement on SCAD (Hayes et al.) and Mayo Clinic experience, the following are some general considerations. It is critical that these recommendations be tailored to each individual since the severity of SCAD, inciting events, associated conditions and subsequent symptoms vary from person to person and affect optimal healthy physical activity. Additionally, as individuals progress and heal after SCAD, those needs change over time.

- All patients should be referred to and urged to participate in cardiac rehabilitation after SCAD.
  Cardiac rehabilitation:
  - Provides an individualized and progressive opportunity to gain confidence in one’s body after SCAD
  - Is associated with improved mental and physical health
  - Can address exercise-induced symptoms and anxiety in a monitored environment that provides immediate feedback
  - Often includes cardiopulmonary stress testing to individualize an exercise program

- Resistance training is important to gain and maintain strength and flexibility as well as to enhance bone health and maintain a healthy weight. While patients often ask for a firm weight-lifting limit, like other post-SCAD recommendations, these must be individualized. After SCAD, individuals should:
  - Use good lifting technique (proper breathing and avoid injury)
  - Use lower resistance and higher repetitions during training sessions
  - Avoid straining and the Valsalva maneuver (bearing down while holding one’s breath) while exercising/lifting objects

- Aerobic training is beneficial. Generally one should aim for 30-40 minutes of moderate-intensity physical activity 5-7 days/week.
  - Start at a lower intensity than before your SCAD and gradually increase while following guidelines from your cardiac rehabilitation team
- Stop or slow down if you are “hitting a wall,” extremely exhausted or feeling uncomfortable

  **Caution:** There are few studies that truly demonstrate harm from specific activities, but in general, it seems prudent to avoid **those activities that often result in extreme exhaustion, impact or conditions.**

  **Consider** avoiding or minimizing the following:

  - Abrupt high-intensity exercise without a warmup period
  - Prolonged high-intensity activities (endurance events)
  - Highly competitive and/or contact sports
  - Activities performed to complete exhaustion (“boot camps” and racing)
  - Activities performed in extreme conditions (hot yoga and extremely hot or cold weather)

- Some experts also suggest avoiding certain activities, particularly if there is evidence of vascular abnormalities such as FMD or dissection in other arteries. These include:

  - Vigorous chiropractic manipulations or direct massage to the neck over the carotid arteries
  - Extreme acceleration/deceleration activities such as intense roller coaster rides or race car driving
The following journal articles were included in the hard copy version. Permission or a subscription may be required to access:

- **Spontaneous Coronary Artery Dissection: Current State of the Science: A Scientific Statement From the American Heart Association.** Circulation.137:2018. http://circ.ahajournals.org/content/early/2018/02/21/CIR.0000000000000564

- **Spontaneous coronary artery dissection in women: What is known and what is yet to be understood.** Tweet MS, Kok SN, Hayes SN. Clinical Cardiology, 41(2):2018. https://onlinelibrary.wiley.com/doi/epdf/10.1002/clc.22909?author_access_token=loTfU8jdwkOp8Fybxk3tk4keas67K9QMdlWULTWMo8N8nQCs5BIEHJ77l3vDRQkY6x0HVj0-aRd114_twoDRsL72zhqpBlcAf7C0r3gdNSCiColbNqy6Rl3Bq-oS474t&

Peer-Reviewed Publications (Authors from Mayo Clinic are bolded)


Book Chapter

Abstracts, Posters, and Presentations at Scientific Meetings


Tweet M, Hayes SN, Rihal C, Gulati R. Percutaneous coronary intervention for acute spontaneous coronary artery dissection is associated with reduced rates of technical success. ACC Controversies in Cardiovascular Disease Fellows in Training Poster Competition (2nd place), Minneapolis, MN, 2013. (Poster, 2nd place)


Chandra, SM, Fenstad ER, Nyguen D, Hayes SN. Déjà Vu All Over Again: Recurrent Spontaneous Coronary Artery Dissection Presenting as Acute Coronary Syndrome, AMA Poster session. Honolulu, HI, November 2012. (Poster)


**Tweet M, Kumar G, Gulati R, Hayes SN.** Spontaneous coronary artery dissection in women. (Poster) 7th Annual Women’s Health Research Conference, September 2010, University of Minnesota, Minneapolis, Minnesota.


**Tweet M, Gulati R, Hayes SN.** Internet networking to propel the research of rare diseases: Our experience with spontaneous coronary artery dissection. (Poster) Awarded second place at the ACC Controversies in Cardiovascular Disease Fellows in Training Poster Competition, May 2011, St. Paul, Minnesota.

**Tweet M, Gulati R, Hayes SN.** Internet networking to propel the research of rare diseases: Our experience with spontaneous coronary artery dissection. (Poster) 8th Annual Women’s Health Research Conference, September 2011, Minneapolis, Minnesota.

**Select Presentations, Videos, and Teaching**

**SCADaddles: 2012-2018** Drs. Hayes, Tweet, Best and Olson have collectively participated in all National (IL) and West Coast (CA) SCADaddles.

Tweet M and Olson T. Healthy women who have heart attacks: Deciphering spontaneous coronary artery dissection. Center for Individualized Medicine, Mayo Clinic, Rochester, MN, March 2018.


Gulati R. To treat or not to treat SCAD. American College of Cardiology Scientific Sessions, Orlando, FL, March 2018.


Hayes SN. Women and heart disease prevention-Should we do anything different? Northwestern University Cardiovascular Symposium, July 2017.


Gulati, R. To Treat or Not to Treat: PCI, CABG, or Conservative Management of SCAD. American College of Cardiology Scientific Sessions, Washington, DC, March 2017.

Hayes SN. Understanding Spontaneous Coronary Artery Dissection (SCAD): What We Know, What We Don't Know, American College of Cardiology Scientific Sessions, Washington, DC, March 2017.


Tweet M. Heart Disease in Women, Alpha Phi Heart Gala, Minneapolis, MN, February 2017.


Hayes SN. Spontaneous Coronary Artery Dissection: Not Rare, Often Missed, Unique Approach Required, Grand Rounds, Department of Cardiology, Mayo Clinic Arizona, Phoenix, AZ, January 2017.


Tweet M. Multimodality Imaging in Spontaneous Coronary Artery Dissection in the Peripartum Period. North American Society of Cardiovascular Imaging, Baltimore, MD, October 2016,

Gulati R. Spontaneous Coronary Artery Dissection, 27th Annual Oklahoma Heart Update in Cardiology, Tulsa, OK, May 2016.

Gulati R. Alternative Diagnoses in ACS: It's Not All Obstructive Disease, Co-Chair, American College of Cardiology Scientific Sessions, Chicago, IL, April 2016.


Gulati R. SCAD: Emerging From the Shadows, 2016 Cardiology at Cancun, Mexico, February 2016.


Gulati R. Spontaneous Coronary Artery Dissection, St. John Hospital and Medical Center, Cardiology Grand Rounds, Detroit, MI, January 2016.

Hayes SN. Spontaneous Coronary Artery Dissection: Hidden in Plain Sight But Emerging From the Shadows, Mayo Clinic CME Course at American Heart Association Scientific Sessions, Orlando, FL, 2015.


Gulati R. Spontaneous Coronary Artery Disease, Henry Ford Hospital, Division of Cardiology Grand Rounds, Detroit, MI, October 2015.

Tweet M. Spontaneous coronary artery dissection. Minnesota Association of Cardiovascular and Pulmonary Rehabilitation, St. Louis Park, MN, October 2015.


Tweet M. Spontaneous coronary artery dissection, University of Minnesota Fairview Women’s Heart Conference, Minneapolis, MN, February 2015.

Tweet M, Cardiology Minute: Spontaneous Coronary Artery Dissection. Mayo Clinic I-Tunes University, August 2014.


Gulati R. The Natural History of Spontaneous Coronary Dissection: Is This a Systemic Disease? Advances in CV Pathophysiology and Emerging Novel Therapeutic Strategies, Boston, MA, October 2014.

Hayes SN. Spontaneous Coronary Artery Dissection: New Insights and Questions About this Not-So-Rare Condition. Cardiovascular Research Institute, Morehouse Medical College, Atlanta, GA, November 2013.

Hayes SN. Spontaneous Coronary Artery Dissection: New Insights and Questions About this Not-So-Rare Condition. Grand Rounds, Baylor College of Medicine/Texas Heart Institute Houston, Texas, October 2013.
Gulati R. Spontaneous Coronary Artery Dissection, University of Leicester, Leicester, England, August 2013.

Hayes SN. Spontaneous Coronary Artery Dissection. Midwest Cardiovascular Forum - Controversies in Cardiovascular Disease, Minneapolis MN, June 2013.

Hayes SN. Spontaneous Coronary Artery Dissection: To Treat or Not to Treat? ICC CUHK-Mayo Clinic-Asia Cardiovascular Summit, Hong Kong, April 2013.

Hayes SN. Spontaneous Coronary Artery Dissection: New Insights from Mayo Clinic SCAD Practice and Research at Cardiology Grand Rounds, Massachusetts General Hospital, March 2013.

Gulati, R. Spontaneous Coronary Artery Dissection. Mayo Clinic Coronary Artery Disease (CME), Las Vegas, Nevada, November 2012.


Hayes SN, Aase LA, Timimi F. Protecting and promoting participation: The interface of social media, researchers, volunteers and the IRB, 4th Annual Health Care Social Media Summit, October 2012.


Hayes SN. Spontaneous Coronary Artery Dissection: New Insights and New Questions About This Not-So-Rare Condition, Cardiovascular Grand Rounds, Mayo Clinic in Florida, September 2012.


Hayes SN. What’s New in Heart Disease in Women? Leveraging Social Media to Research Rare Conditions, 8th Annual Mayo Clinic Women’s Health Update, Scottsdale, AZ, March 2012.


Select Non-Peer Reviewed Articles, Social Media, News and Blog Coverage


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NPR: Cuda-Kroen G, Patients find each other online to jump-start medical research, May 28, 2012. https://www.npr.org/sections/health-shots/2012/05/28/153706146/patients-find-each-other-online-to-jump-start-medical-research


