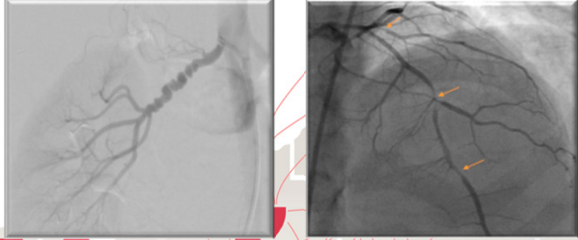



FMD/Arterial Dissection Information and Support Group




**University Hospitals
Virtual Meeting
October 17, 2023
6:00-7:30 pm**

 **University Hospitals**
Harrington Heart & Vascular Institute
Cleveland | Ohio

Tonight's Agenda

Introductions	UH, Atrium Health, FMDSA teams
Check-ins, polling	All
Patient Stories	Multiple
Updates from the FMDSA	Pamela Mace, RN, Executive Director, FMDSA
SCAD and FMD Setting the Stage	Dr. Heather Gornik
SCAD/iSCAD Research Updates	Dr. Esther Kim
Q&A	All
Adjourn	

 **University Hospitals**
Harrington Heart & Vascular Institute

Cleveland | Ohio

We are recording tonight's session to prepare a written transcript of tonight's content. No video will be used and no names will be included in the transcript.

**Welcome
Atrium Health Sanger Heart & Vascular
Institute Colleagues and Patients**



Introductions and Check-in, Polls

Polls

1. Where are you joining us from tonight? If you are joining us from outside the US/Canada, where are you (chat box)?
 2. What brings you to this group? (I am a patient, family member/friend, health care professional)
 3. Do you have FMD?
 4. Have you had a SCAD?
 5. Have you attended the University Hospitals FMD & Arterial Dissection support group before?
 6. Did you attend the Atrium/Sanger SCAD patient conference in April, 2023?
 7. Are you a member of the FMD Society of America (FMDSA)?
- **Put in chat: Name one very fall/autumn thing you have done or plan to do soon

Patient Stories

FMDSA Updates

Pamela Mace, RN




FMDDSA

• FIBROMUSCULAR DYSPLASIA SOCIETY OF AMERICA •

Pamela Mace, RN
Executive Director
FMD Patient
216-834-2410


October 17th, 2023

FMDSA Resources



Download documents

- FMD Brochure
- Emergency Card
- Medication Card
- Letter to Practitioner
- Arterial Map (artery location in the body)
- Dictionary (commonly-used terms)
- Letter to Family and Friends of FMD Patients
- 10 Tips Doctors Should Know About Fibromuscular Dysplasia (FMD)
- What To Do in the First 5 Minutes of Calling 911
- FMD/Dissection Support Group
- Webinar
- FMD and Headache



Regional FMDSA Networks

FMDSA is in the process of organizing **Regional Network Volunteers/ Groups** across the country. If you do not see your City or State listed, please check back soon as we are in the process of adding more groups. Please note these groups are informal and run by volunteers, many who also have FMD.

Resources/Support Groups
www.inspire.com



Fibromuscular Dysplasia Society of America

A support and discussion community for people affected by fibromuscular dysplasia. Share stories about new diagnoses, arterial issues, treatment, and more.

Fibromuscular Dysplasia Society of America Topics ▼

- Newly diagnosed
- Living with fibromuscular dysplasia
- Children with fibromuscular dysplasia
- Dissections
- Stenting
- Aneurysms
- Carotid fibromuscular dysplasia
- Renal fibromuscular dysplasia
- Other arteries affected
- SCAD and FMD
- General
- FMD research
- News and events



2024 FMD Meetings

North American Registry for Fibromuscular Dysplasia

The map displays various participating hospitals across North America, including: Seattle Children's Hospital, Stanford University Medical Center, North Central Heart Institute, University of Colorado, University of Kansas, Vanderbilt University, Emory University, The Ottawa Hospital, University of Michigan, Cleveland Clinic, University of Pennsylvania, University of Virginia, Massachusetts General Hospital, Mount Sinai, Children's Hospital of Philadelphia, Penn State Hershey, Atrium Health, and Miami Baptist. The FMD logo is also present at the bottom left of the map area.

Know any runners? Ask them to join the FMDSA Team

20% off all races
Discount Code: FMDSA24

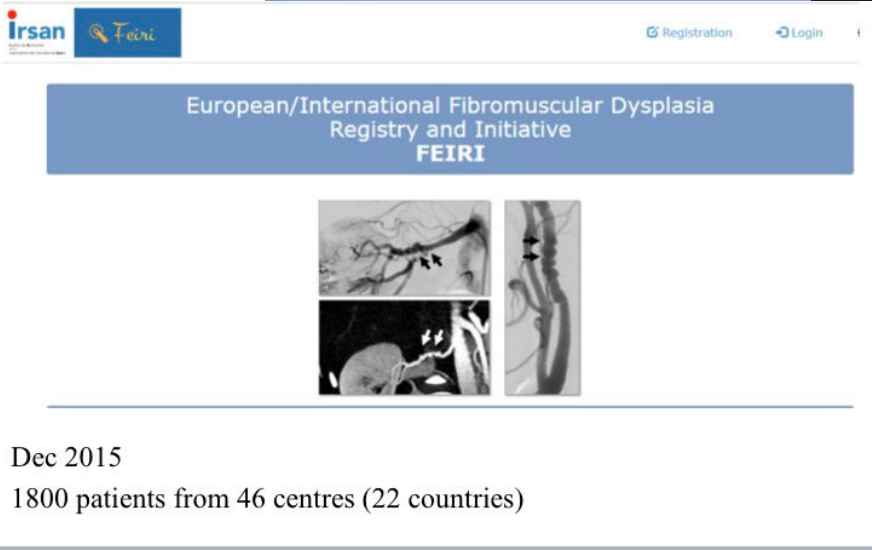
Cleveland Marathon

Full • Half • 10K • 5K



Cleveland Marathon Races
May 18th-19th, 2024

Join our team at the finish line



irsan Feiri Registration Login

**European/International Fibromuscular Dysplasia
Registry and Initiative
FEIRI**

Dec 2015
1800 patients from 46 centres (22 countries)

The UK FMD Study and the FEIRI godmother

International Research

Dr Constantina (Tina) Chrysochou
Consultant Nephrologist
Salford Royal Hospital
19/09/2023

FMD/SCAD SYMPOSIUM 2023



"SAMEN AAN DE SLAG"

FRI, 27 OCT AT 12:45

patientsymposium FMD/
SCAD 2023

☆ Interested

Where we started
2003



2018



International Symposium




**Together
we give.**


Nov 28, 2023

**GIVING
TUESDAY**

**SCAD and FMD –
Setting the Stage**

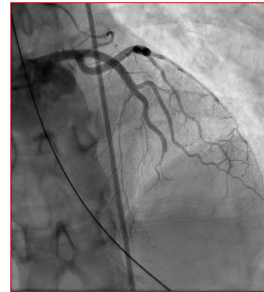
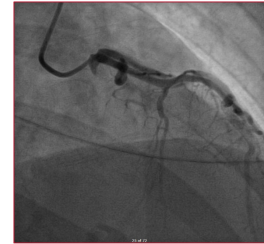
Heather Gornik, MD
John B. Lally Family Master Clinician in
Fibromuscular Dysplasia and Vascular Care



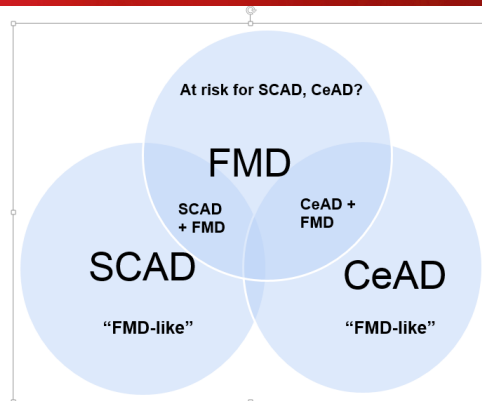
 **University Hospitals**
Harrington Heart & Vascular Institute
Cleveland | Ohio

Spontaneous Coronary Artery Dissection (SCAD)

- Important cause of heart attack in young and middle aged women
- Can occur in men too!
- “Tears” in the coronary arteries lead to blockages and lack of blood flow causing myocardial infarction
- Presents with symptoms + abnormal cardiac enzymes (troponin) +/- EKG changes (heart attack)
- ~50% of patients with SCAD have FMD in arteries outside the heart (varies by series)
- Unlike most heart attacks, treatment for most patients with SCAD is generally best with medications not stents/bypass surgery



Overlap of FMD and Artery Dissection



While a significant % of patients with SCAD have FMD, 10% or less of patients with FMD have had SCAD

FMD: Fibromuscular dysplasia
SCAD: Spontaneous coronary artery dissection
CeAD: Cervical artery dissection (carotid/vertebral)

A Reminder...

While a significant percentage of patients who have SCAD are found to have FMD....

The majority of patients diagnosed with FMD who have never had SCAD *never* will

...and perhaps especially true if under good care and with good blood pressure control.



Cleveland, Ohio | 25

Tonight's Special Guest Speaker

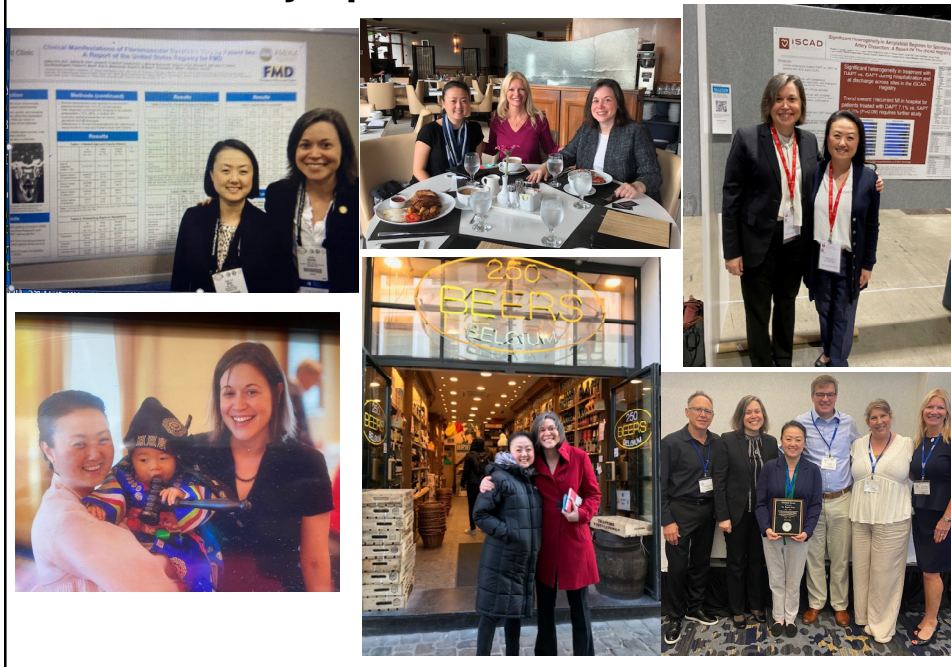
Esther SH Kim, MD
Director, Center for Women's
Cardiovascular health
Atrium Health, Sanger Heart &
Vascular Institute

International Study Chairperson
– iSCAD Registry



Cleveland | Ohio

A Very Special Guest Indeed



Spontaneous Coronary Artery dissection and Updates on SCAD Research

What We Are Learning through the iSCAD Registry

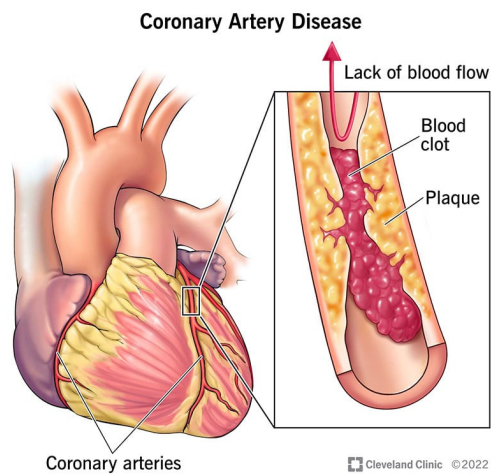
Esther S.H. Kim, MD, MPH

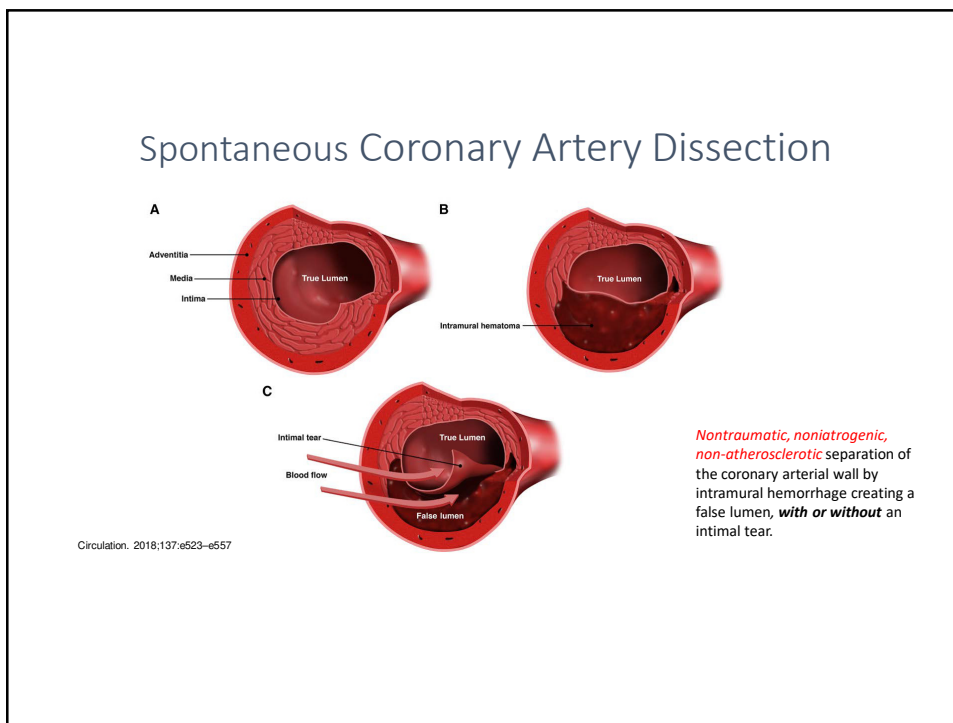
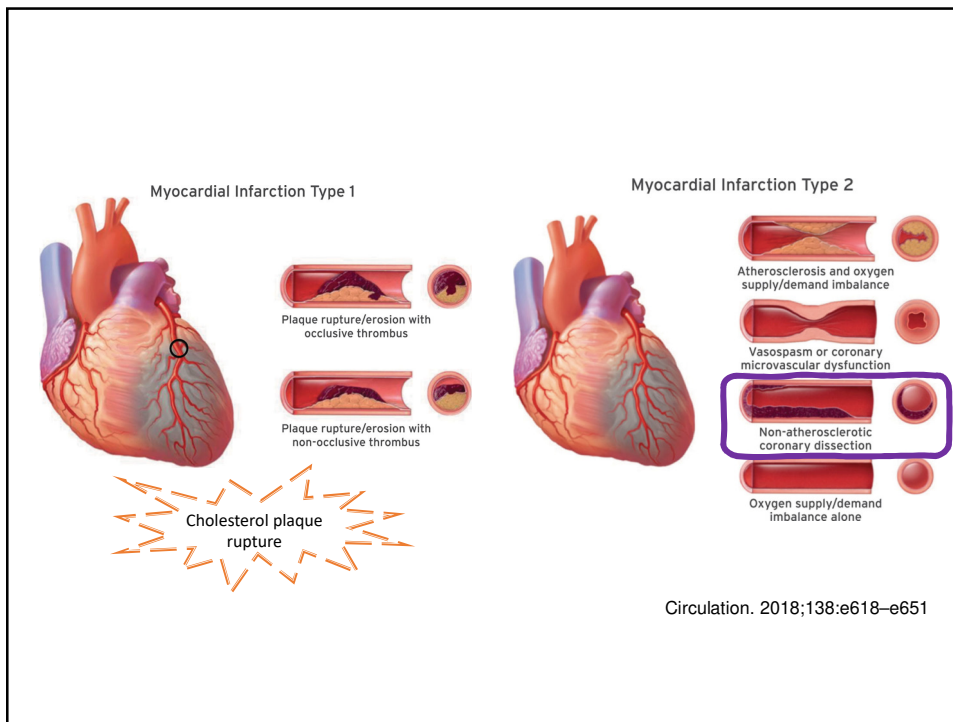
Director, Center for Women's Cardiovascular Health
Atrium Health, Sanger Heart and Vascular Institute



No Financial Disclosures

- Chair, Scientific Advisory Board SCAD Alliance
- Principle Investigator, iSCAD Registry





How Does
SCAD Relate
to FMD?



SCAD/FMD Relationship

SCAD → FMD 25-86%

FMD → SCAD <10%

→→ SCAD is the presenting sign of FMD
for some patients



JACC 2016;68:176-85

FMD and SCAD Demographics

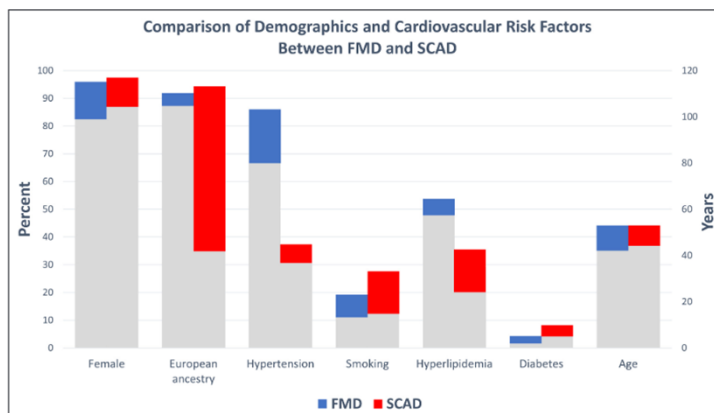
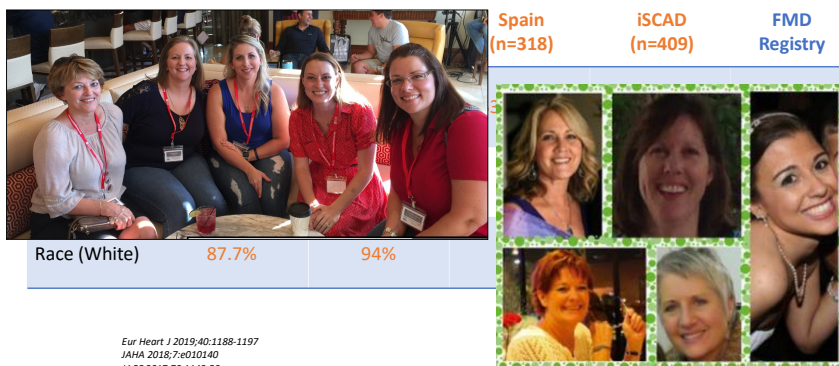


Figure 2. Demographics and cardiovascular risk factors of patients included in studies of fibromuscular dysplasia (FMD)^{1,3,20,24,129} and spontaneous coronary artery dissection (SCAD).^{1,15,23,25} Reported ranges are shown for FMD (blue bars) and SCAD (red bars).

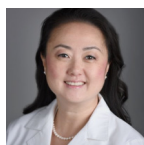
Circulation Research. 2021;128:1958–1972. DOI: 10.1161/CIRCRESAHA.121.318300



Mission

The mission of the International Spontaneous Coronary Artery Dissection (iSCAD) registry is to develop and maintain an independent, quality data repository to advance the pace and breadth of SCAD research around the world, toward the common goals of improving patient diagnosis and outcomes and accelerating scientific discovery.

Leadership



Chair, Steering Committee



Steering Committee



Steering Committee

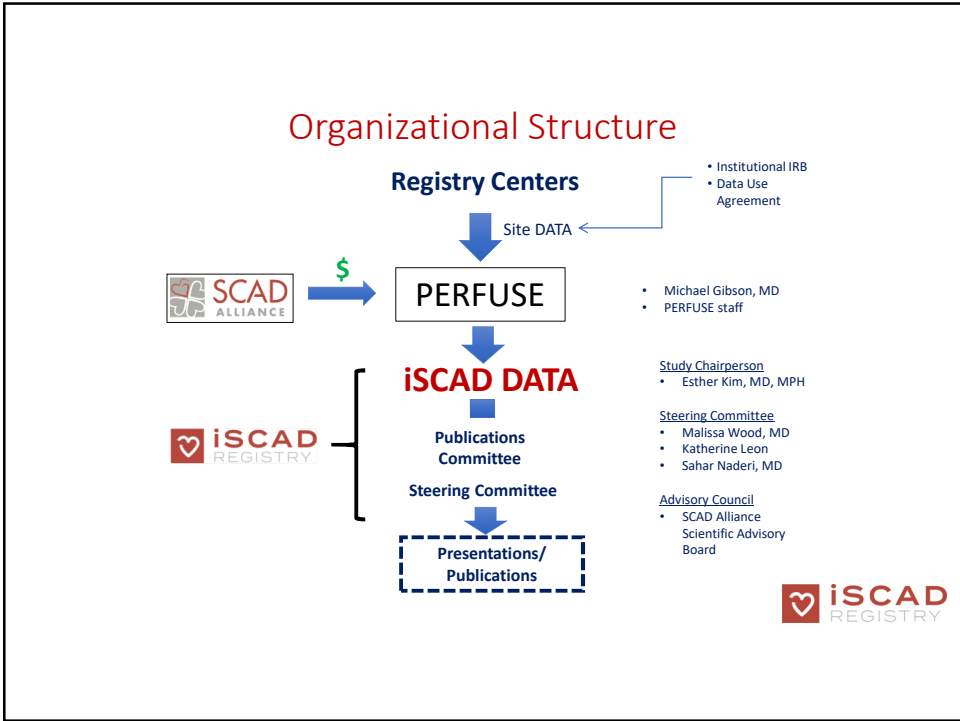


Steering Committee



Director, PERFUSE

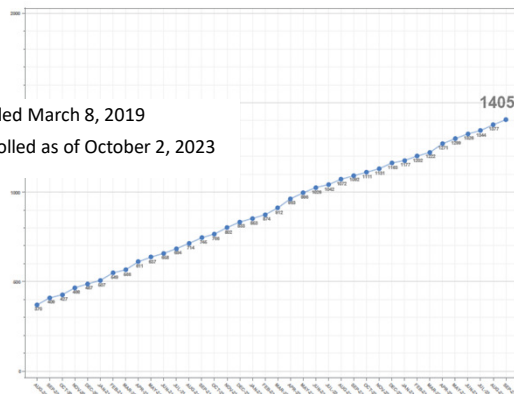




iSCAD Patient Enrollment



01. iSCAD Patient Enrollment by Month (As of 02OCT2023)
N=1405 (+26 from Last Month)



- First patient enrolled March 8, 2019
- 1405 patients enrolled as of October 2, 2023



Planning for the Future

Innovation Incubator

- iSCAD 2.0
 - Maintain relevance
 - Optimize data collection
- Clinical trial
 - What are the important questions
 - How do we fund
- Translational Studies
 - How can we collaborate
 - How can we fund



Join us for the Sanger SCAD Conference in 2024! Date TBA

SCAD ALLIANCE

Atrium Health
Sanger Heart & Vascular Institute

Thank You



Open Q & A

**Please Enter Your Questions into
the “Chat” Box**

Save the Date and Register Now!

Next Meeting: January 16, 2023

“Journal Club”: Updates from the medical literature
on FMD and dissection