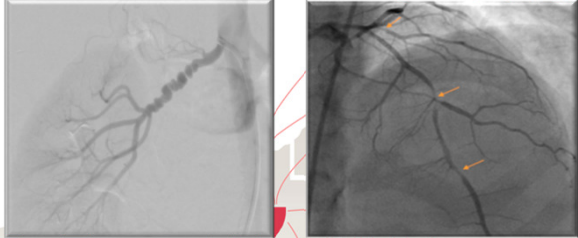



FMD/Arterial Dissection Information and Support Group




**University Hospitals
Virtual Meeting
April 18, 2023
6:00-7:30 pm**

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

Agenda

| | |
|--|--|
| Welcome, Intros, Polling | Dr. Heather Gornik/All |
| Patient Stories | Multiple |
| Updates from the FMDSA | Pamela Mace, RN, Executive Director, FMDSA |
| FMD and IC Aneurysm | Dr. Heather Gornik |
| Brain Aneurysms/ Ask the Neurosurgeon | Dr. Yin Hu |
| 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.

Introductions and Check-in, Polls

Polls

1. Where are you joining us from tonight?
2. If you are joining us from outside the US/Canada, where are you (chat box)?
3. Have you attended the University Hospitals FMD/dissection information/support group before?
4. Do you have FMD?
5. Are you a member of the FMD Society of America (FMDSA)?
6. Do you plan to attend the FMDSA meeting in Cleveland, Ohio next month (Yes, No, Maybe)?
7. Do you have a brain aneurysm? (No, Yes/Being Monitored, Yes/Needed Rx, Never Checked)
8. Put in chat: In 5 words or less, how are you enjoying early spring? What activities have you been up to?

Patient Stories

FMDSA Updates

Pamela Mace, RN



FMDSA

• FIBROMUSCULAR DYSPLASIA SOCIETY OF AMERICA •

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

April 18th, 2023

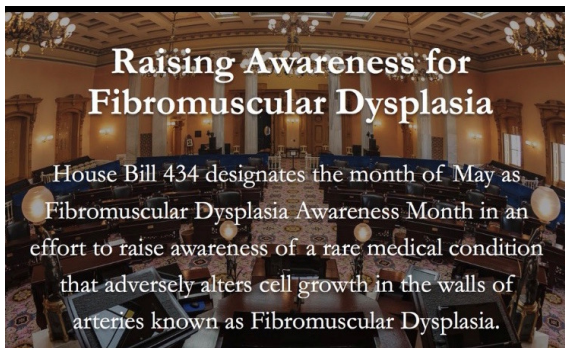
Where we started



May is
FMD
Awareness
Month

Raising Awareness for Fibromuscular Dysplasia

House Bill 434 designates the month of May as Fibromuscular Dysplasia Awareness Month in an effort to raise awareness of a rare medical condition that adversely alters cell growth in the walls of arteries known as Fibromuscular Dysplasia.



Rock and
Roll Hall of
Fame May
1st



Terminal
Tower
Cleveland,
Ohio
May 20th



Mid-
Hudson
Bridge,
New York
May 22nd



Bridge Lights



FMDSA Annual Meeting

Speakers

Dr. Heather Gornik

Dr. Jeffrey Olin

Dr. Esther Kim

Dr. Santhi Ganesh

Dr. Jason Kovacic

Dr. Shazam Hussain

Dr. Deborah Reed

Dr. Alexandre Persu

Eva Kline-Rogers

Topics include

- The Basic's of FMD
- Headache and Treatment Options
- Aneurysm and Dissections
- Renal FMD
- SCAD and the iSCAD Registry
- European Registry Update
- Research Update
- FMD Registry and Outcomes Update



Meet and Greet

Raffle

Entertainment

Opportunity to participate in research



SCAD Patient Symposium Saturday April 22nd




Atrium Health
Sanger Heart & Vascular Institute

- [Sanger SCAD Patient Symposium \(charlotteahc.org\)](https://charlotteahc.org)



VanSCAD2023
May 6-7th

[Vancouver SCAD
Conference 2023
– Spontaneous
Coronary Artery
Dissection \(SCAD\)
\(vanscad.ca\)](#)



Cleveland Marathon Races
May 20th -21st

Join our team at the finish line

Know any runners? Ask them to join the FMDSA Team

20% off all races
Discount Code:FMDSA23



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](#)



Thank you!



FMD/SCAD and Brain Aneurysm

Heather L. Gornik, MD

FMD and Intracranial Aneurysm

- From North American Registry: FMD is associated with intracranial aneurysm
 - 12.9% of patients with IC imaging in US Registry¹
 - 54% of patients found to have IC aneurysm had multiple aneurysms
 - 43% of aneurysms \geq 5 mm
- All patients with FMD should be screened for IC aneurysm
 - Brain to pelvis imaging recommended per International Consensus
- Management of IC aneurysm depends on size, location (posterior vs. anterior circulation), and additional risk factors
 - Family history of rupture, BP control
- Collaboration with neurosurgical and/or neurointerventional colleagues is key
 - Clipping, coiling, Pipeline and other flow diverting stent

Research

JAMA Neurology | Original Investigation
Prevalence of Intracranial Aneurysm in Women With Fibromuscular Dysplasia
A Report From the US Registry for Fibromuscular Dysplasia

Henry D. Lather, MD, Heather L. Gornik, MD, MPH, Jeffrey H. Olin, DO, Gabriel Gu, MD, Steven T. Hersh, BA, Esther S. H. Kim, MD, MPH, Darrela Kurlan Osovin, MD, Aditya Sharma, MBBCh, Bruce Gray, DO, Michael R. Joffe, DO, Yang Wang, MD, DO, Pamela Motta, RN, Eva Kline-Rogers, MD, RN, NP, James S. Forrester, MD, MPH



¹Lather H, et al. JAMA Neurol 2017;74:1081.

SCAD Also Associated with Intracranial Aneurysm

JACC: Cardiovascular Interventions
© 2013 BY THE AMERICAN COLLEGE OF CARDIOLOGY FOUNDATION
PUBLISHED BY ELSEVIER INC.

VOL. 5, NO. 1, 2013
ISSN 1936-8796/13/\$36.00
<http://dx.doi.org/10.1016/j.jcin.2012.08.017>


Spontaneous Coronary Artery Dissection
Prevalence of Predisposing Conditions Including Fibromuscular Dysplasia in a Tertiary Center Cohort

Jaqueline Saw, MD,* Donald Ricci, MD,* Andrew Starovoytov, MD,* Rebecca Fox, MSc,* Christopher E. Baller, MD†
Vancouver, British Columbia, and Toronto, Ontario, Canada

Prevalence of Extracoronary Vascular Abnormalities and Fibromuscular Dysplasia in Patients With Spontaneous Coronary Artery Dissection


Megha Prasad, MD*, Marysia S. Tweet, MD*, Sharonne N. Hayes, MD*, Shuai Leng, MD*, Jackson J. Liang, DO*, Mackram F. Eleid, MD*, Rajiv Gulati, MD, PhD*, and Terri J. Vrtiska, MD**

Mayo Clinic (2015)
~23% of pts. with SCAD had IC aneurysm
Am J Cardiol 2015;115:1672.



iSCAD (2022)
~only 2.5% of pts. With SCAD with IC imaging had aneurysm
Kim ESH, et al. ACC 2022.

Vancouver General (2013)
14% pts. with SCAD + underlying FMD had IC aneurysm
JACC Cardiovasc Interv 2013;6:44.



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Intracranial Aneurysms and Ask the Neurosurgeon

Yin Hu, MD

Fellowship Program Director, Endovascular Neurosurgery, UH Cleveland Medical Center

Division Chief, Neurological Surgery, UH Ahuja Medical Center

Clinical Associate Professor, CWRU School of Medicine

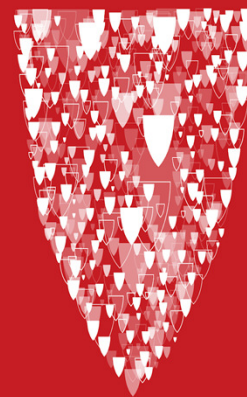




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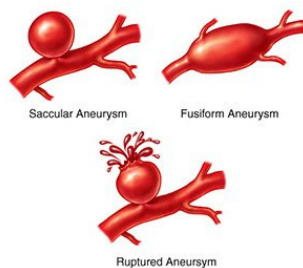
Intracranial Cerebral Aneurysms

Yin C. Hu
Cerebrovascular and Endovascular
Neurosurgery



Demographics

- Cerebral aneurysm
 - A bulge or ballooning on the wall of a brain artery.
 - Caused by a weakness in the artery wall
 - Affects 3-5% of the population
- Majority of the aneurysms do not cause any symptoms
- Most are detected in another test or routine screening
- Common for people to have multiple small aneurysms.



Causes and Factors

Many form spontaneously and do not have a clear cause.

Hispanics and African-Americans are twice as likely to develop a brain aneurysm than Caucasian peers.

Several risk factors contribute towards the formation and rupture of aneurysms

- **Hypertension**
- **Older women.**
 - Researchers believe that estrogen helps to prevent aneurysm, so risk increases when estrogen levels drop after menopause.
- **Age.**
 - Aneurysm is more common in people aged 45-65.
- **Family history**
 - 2 or more 1st degree relatives
- **Smoking or high alcohol consumption**
- **Connective Tissue Disorders:** Ehlers-Danos, FMD



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FMD and cerebral aneurysm

- 12.9% in US Registry for FMD
 - Higher percentage of these were in a high-risk location (posterior circulation)
 - Larger size than comparable studies that screened the general population
 - More than ½ with multiple aneurysms.
- Unclear if FMD is an independent rupture risk factors

Prevalence of Intracranial Aneurysm in Women With Fibromuscular Dysplasia. A Report From the US Registry for Fibromuscular Dysplasia. [JAMA Neurol.](#) 2017 Sep; 74(9): 1081-1087.



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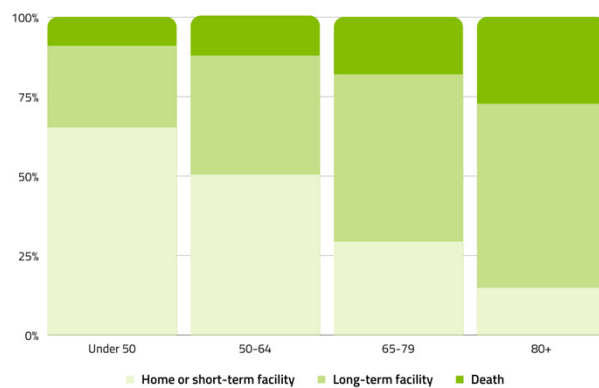
What factors are considered when making a decision about aneurysm treatment?

- Rupture status
- Symptomatic vs asymptomatic
- Family history & genetics
- Associated risk factors: hypertension, smoking, alcohol, drug use
- Size of aneurysm
- Aneurysm location: anterior vs posterior circulation, anterior or posterior communicating segment, extradural vs intradural
- High risk aneurysm characteristics:
 - Change of size or morphology over time
 - New neurologic or cranial nerve symptoms
 - Irregularities and daughter lobes
 - Prior subarachnoid hemorrhage
- Patient's age, functional status, and comorbidities
- Life expectancy
- Anatomy of blood vessels
- Predicted risk of surgical or endovascular treatment



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Ruptured Aneurysm Outcome



W Birnbaek et al. 2013, Age-Related Trends in the Treatment and Outcomes of Ruptured Cerebral Aneurysms: A Study of the Nationwide Inpatient Sample 2001-2009



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Ruptured Aneurysm Outcome

15-20% of patients die before reaching the hospital

A further 20-25% die within 48 hours

The total 30-day mortality rate after SAH can be as high as 50%

~ 30% of survivors become dependent on others due to disability

The most common impairments after hemorrhage include cognitive and neurological impairments in:

- Attention
- Mental flexibility
- Visual working memory
- Verbal fluency
- Response inhibition
- Visual memory

S Dey et al, 2018, *Neurological, neuropsychological, and functional outcome after good grade aneurysmal subarachnoid hemorrhage*. DOI: [10.4103/0028-3886.246243](https://doi.org/10.4103/0028-3886.246243)



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RISK FACTORS REDUCTION

Don't smoke or use recreational drugs.

Avoid heavy alcohol consumption.

- No more than 4 standard drinks per day
- No more than 10 standard drinks in a week.

Eat a healthy diet and exercise.

Control your blood pressure if you have high blood pressure

And Yes, you can fly on an airplane



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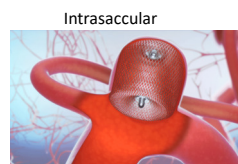
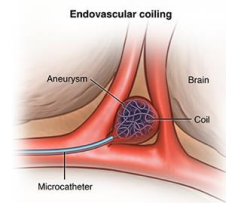
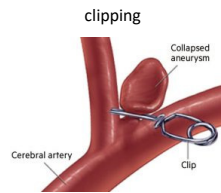
Treatment Options

Observation with serial imaging

Microsurgical Clipping

Endovascular

- Coiling +/- Stenting
- Flow Diverters
- Intracascular Devices




Conclusion

- Higher prevalence of intracranial aneurysm in patients with FMD
- No clear evidence that FMD increases the annual rupture risk of cerebral aneurysm.
- Treatment options are patient specific on a number of factors, including:
 - Aneurysm size
 - Age
 - Co-morbidities
 - Location of the aneurysm

Open Q & A

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

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Harrington Heart & Vascular Institute

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**Save the Date and Register
Now!**

Next Meeting July 18, 2023

Topic: t/b/d

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