

FMD/Dissection Support Group



**University Hospitals
Virtual Meeting
October 19, 2021
6:00-7:30 pm**



University Hospitals
Harrington Heart & Vascular Institute
Cleveland | Ohio

Agenda

Welcome Intros and check-in	Dr. Heather Gornik/All
FMDSA Updates	Pamela Mace, RN
Research headlines/updates	Dr. Heather Gornik
COVID-19 and FMD/SCAD	Dr. Heather Gornik
Ask the ID Specialist	Dr. Keith Armitage, ID Division, Department of Medicine, University Hospitals
Moderated Q and A	All
Adjourn	

Introductions and Check-in, Polls!

Updates from the FMDSA

Pamela Mace, RN

The Fibromuscular Dysplasia Society of America



Pamela Mace, RN
Executive Director
216-834-2410



Cleveland Marathon Races
October 23rd and 24th, 2021

Giving Tuesday
November 30th

Follow the FMDSA Facebook page from 8am-8pm ET on Giving Tuesday. We will be hosting our annual silent auction! Stay tuned for more exciting details.



The world's biggest day of generosity

Giving Tuesday is an important day for FMDSA. We depend on your generosity to help sustain our mission and fund the patient registry. While your financial support is important there are so many ways to be generous on Giving Tuesday.

Join the generosity movement and share your plans with us. Some ideas for generosity are simple such as creating a Giving Tuesday Facebook fundraiser, liking our Facebook page and sharing it, volunteering your skills, being an FMD patient advocate, follow us on Instagram and Twitter, host a FMDSA fundraiser at a local restaurant.



2006 University of Ghent, Belgium



Awareness
got us
here!



Everything we do, we do for you!



Research Headlines

Heather L .Gornik, MD

From the News Headlines- USPSTF

- USPSTF = US Preventive Services Taskforce

Draft Recommendation Statement

Aspirin Use to Prevent Cardiovascular Disease: Preventive Medication

October 12, 2021

Recommendations made by the USPSTF are independent of the U.S. government. They should not be construed as an official position of the Agency for Healthcare Research and Quality or the U.S. Department of Health and Human Services.

This document is available for Public Comments until Nov 08, 2021 11:59 PM EDT



In an effort to maintain a high level of transparency in our methods, we open our Draft Recommendation Statement to a public comment period before we publish the final version.

[Leave a Comment >>](#)



This topic is being updated. Please use the link(s) below to see the latest documents available.

[Update in Progress for Aspirin Use to Prevent Cardiovascular Disease: Preventive Medication](#)

US UPSTF Taskforce NOT for Patients with FMD/SCAD

Recommendation Summary

Population	Recommendation	Grade
Adults ages 40 to 59 years with a 10% or greater 10-year cardiovascular disease (CVD) risk	The decision to initiate low-dose aspirin use for the primary prevention of CVD in adults ages 40 to 59 years who have a 10% or greater 10-year CVD risk should be an individual one. Evidence indicates that the net benefit of aspirin use in this group is small. Persons who are not at increased risk for bleeding and are willing to take low-dose aspirin daily are more likely to benefit.	C
Adults age 60 years or older	The USPSTF recommends against initiating low-dose aspirin use for the primary prevention of CVD in adults age 60 years or older.	D

- This **DOES NOT** apply to patients with cardiovascular disease
- This **DOES NOT** apply to patients with FMD or SCAD who need aspirin to prevent TIA/stroke, recurrent heart attack, embolism
- Please **DO NOT** stop your aspirin or other anti platelet medication
- Please do discuss your concerns with your doctor

From 2019 International FMD Consensus

In the absence of contraindication, antiplatelet therapy (i.e., aspirin 75-100 mg daily) is reasonable for patients with FMD to prevent thrombotic and thromboembolic complications.

VASCULAR
MEDICINE

Consensus Document

First International Consensus on the diagnosis and management of fibromuscular dysplasia

Heather L Gornik¹, Alexandre Persu^{2*}, David Adiam^{3,4}, Lucas S Aparicio⁵, Michel Aziz^{1,7,8}, Marion Boulanger⁹, Rosa Maria Bruno¹⁰, Peter de Leeuw¹¹, Natalia Fendrikova-Mahlay¹², James Froehlich¹³, Santhi K Ganesh¹⁴, Bruce H Gray¹⁴, Cathlin Jamison¹⁵, Andrzej Januszewicz¹⁶, Xavier Jeunemaitre^{17,18}, Daniela Kadian-Dodov¹⁹, Esther SH Kim²⁰, Jason C Kovacic¹⁷, Pamela Mace²¹, Alberto Morganti²², Aditya Sharma²³, Andrew M Southerland²⁴, Emmanuel Touzil²⁵, Patricia van der Niepen²⁶, Jiguang Wang²⁶, Ido Weinberg²⁷, Scott Wilson^{28,29}, Jeffrey W Olin^{19*} and Pierre-Francois Plouin^{4,7,8*}, on behalf of the Working Group 'Hypertension and the Kidney' of the European Society of Hypertension (ESH) and the Society for Vascular Medicine (SVM)

Vascular Medicine
2019, Vol. 2(4) 164-189
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SAGE

BRIEF COMMUNICATION

Association of Fibromuscular Dysplasia and Pulsatile Tinnitus: A Report of the US Registry for Fibromuscular Dysplasia

Andrew B. Dicks, MD; Heather L. Gornik, MD; Xiaokui Gu, MA; J. Michael Bacharach, MD; Natalia Fendrikova Mahlay, MD; James B. Froehlich, MD; Kamal Gupta, MD; Bruce H. Gray, DO; Esther S. H. Kim, MD; Redah Mahmood, MD; Aditya M. Sharma, MD; Bryan J. Wells, MD; Jeffrey W. Olin, DO; Ido Weinberg, MD

BACKGROUND: Fibromuscular dysplasia (FMD) is a nonatherosclerotic arterial disease that has a variable presentation including pulsatile tinnitus (PT). The frequency and characteristics of PT in FMD are not well understood. The objective of this study was to evaluate the frequency of PT in FMD and compare characteristics between patients with and without PT.

METHODS AND RESULTS: Data were queried from the US Registry for FMD from 2009 to 2020. The primary outcomes were frequency of PT among the FMD population and prevalence of baseline characteristics, signs/symptoms, and vascular bed involvement in patients with and without PT. Of 2613 patients with FMD who were included in the analysis, 972 (37.2%) reported PT. Univariable analysis and multivariable logistic regression were performed to explore factors associated with PT. Compared with those without PT, patients with PT were more likely to have involvement of the extracranial carotid artery (90.0% versus 78.6%; odds ratio, 1.49; $P=0.005$) and to have higher prevalence of other neurovascular signs/symptoms including headache (82.5% versus 62.7%; odds ratio, 1.82; $P<0.001$), dizziness (44.9% versus 22.9%; odds ratio, 2.01; $P<0.001$), and cervical bruit (37.5% versus 15.8%; odds ratio, 2.73; $P<0.001$) compared with those without PT.

CONCLUSIONS: PT is common among patients with FMD. Patients with FMD who present with PT have higher rates of neurovascular signs/symptoms, cervical bruit, and involvement of the extracranial carotid arteries. The coexistence of the 2 conditions should be recognized, and providers who evaluate patients with PT should be aware of FMD as a potential cause.

Key Words: cerebrovascular dissection ■ fibromuscular dysplasia ■ pulsatile tinnitus ■ vasculopathy

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Key Words: cerebrovascular dissection ■ fibromuscular dysplasia ■ pulsatile tinnitus ■ vasculopathy

- New data from US Registry for FMD
- 37% of patients in the Registry have pulsatile tinnitus (“the swoosh”) as a presenting symptoms of FMD
- Presence of PT associated with carotid/vertebral FMD, headache, neck pain, dizziness, cervical bruit
- Not associated with stroke
- www.whooshers.com

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ARTICLE Check for updates

<https://doi.org/10.1038/s41467-021-26174-2> OPEN

Genetic investigation of fibromuscular dysplasia identifies risk loci and shared genetics with common cardiovascular diseases

Adrien Georges ^{1,32}, Min-Lee Yang^{2,3,32}, Takiy-Eddine Berrandou ^{1,32}, Mark K. Bakker ⁴, Ozan Dikilitas ⁵, Soto Romuald Kiando¹, Lijiang Ma⁶, Benjamin A. Satterfield⁵, Sebanti Sengupta², Mengyao Yu¹, Jean-François Deluze ⁷, Delia Dupré¹, Kristina L. Hunker^{2,3}, Sergiy Kyryachenko¹, Lu Liu¹, Ines Sayoud-Sadeg¹, Laurence Amar^{1,8}, Chad M. Brummett⁹, Dawn M. Coleman¹⁰, Valentina d'Escamard¹¹, Peter de Leeuw ^{12,13}, Natalia Fendrikova-Mahlay¹⁴, Daniella Kadian-Dodov¹⁵, Jun Z. Li ³, Aurélien Lorthioir^{1,8}, Marco Pappacogli^{16,17}, Aleksander Prejbisz¹⁸, Witold Smigielski¹⁹, James C. Stanley¹⁰, Matthew Zawistowski ²⁰, Xiang Zhou ²⁰, Sebastian Zöllner²⁰, FEIRI investigators*, International Stroke Genetics Consortium (ISGC) Intracranial Aneurysm Working Group*, MEGASTROKE*, Philippe Amouyel ²¹, Marc L. De Buyzere²², Stéphanie Debette ²³, Piotr Dobrowolski¹⁸, Wojciech Drygas²⁴, Heather L. Gornik ¹⁴, Jeffrey W. Olin ¹⁵, Jerzy Piwonski²⁴, Ernst R. Rietzschel²², Ynte M. Ruigrok ⁵, Miikka Vikkula ²⁵, Ewa Warchol Celinska ¹⁸, Andrzej Januszewicz¹⁸, Iftikhar J. Kullo ^{5,26}, Michel Azizi^{8,27}, Xavier Jeunemaitre ^{1,28}, Alexandre Persu^{16,29}, Jason C. Kovacic^{15,30,31}, Santhi K. Ganesh ^{2,3,33,33} & Nabila Boutia-Naji ^{1,33,33}

Georges A, Yang M-L, et al.
Nature Communications
Online first 10.15.2021

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FMD Genetics GWAS

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- Multi-site collaboration
- Meta-analysis of 6 studies/sample collections
 - ARCADIA France, ARCADIA Poland, DEFINE FMD – Mt. Sinai, Cleveland Clinic/U Mi FMD Biorepository, Mayo Clinic, European/FEIRI
- 1556 pts. With FMD/7100 control patients
- Identified 4 Loci associated with increased risk of FMD
 - PHACTR1 (CeAD, HTN, migraine)
 - LRP1
 - ATP2B1
 - LIMA1
- These genetic loci require further explanation
- Genetics of FMD complex and genetic testing for FMD or patients with FMD not yet available
- Stay tuned – international FMD genetics community hard at work

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FMD/SCAD and COVID-19

Heather Gornik, MD

FMD and COVID-19: Message from Drs. Olin and Gornik

- *We are unaware of any direct connection between FMD and the likelihood of becoming infected with COVID-19 or having a poor outcome should you become infected.*
- There is an association of COVID-19 and clotting. This has received much attention in the media. Some of these stories have focused on clots forming in different organs of the body including the kidneys and brain.
- The type of clotting seen in the setting of COVID-19 infection generally, involves one of the following:
 - **Deep vein thrombosis (DVT)** – clot in leg or arm veins
 - **Pulmonary Embolism (PE)** – clot breaks loose from legs or arms and is trapped in the lungs. A PE can cause worsening shortness of breath and low oxygen levels.
 - In the sickest patients who are on a ventilator, clots can form in the lung itself and this is referred to as **microthrombosis**.

From Drs. Olin and Gornik – COVID-19 and Clotting

- Most of the clotting in COVID-19 occurs in sicker patients who are hospitalized or in the ICU on a ventilator
- Hospitals (including UH) have protocols place for patients admitted to the hospital with COVID-19 infection to assess for risk of clotting and to treat with preventive blood thinning medications as appropriate.
- Clotting in an artery and strokes are much less common in COVID-19. **To our knowledge, this is not associated with FMD/SCAD and we have not seen this in our FMD/SCAD practice.**
- There is a condition called VITT (Vaccine-Induced Immune Thrombotic Thrombocytopenia) which is rare and can cause blood clots after vaccines with low PLT counts
 - There is no known association of FMD/SCAD and VITT

COVID-19 Vaccine: Message from Drs. Gornik and Olin

- We were asked by Pam Mace and the FMDSA to comment on the COVID-19 vaccines and respond to some questions regarding the vaccine FMDSA has received.
- Please know, we have both taken the vaccine and recommend the same for our patients according to the most-recent guidance provided by the Centers for Disease Control and Prevention.
- **To our knowledge, there are no special considerations for taking the COVID-19 vaccine for patients with FMD, but as always, if you have specific questions about your situation, please contact your primary care provider or FMD specialist.**

COVID-19 and SCAD

- **It is unlikely that COVID-19 causes dissections or aneurysms in arteries.** This is not the type of abnormal clotting that occurs in patients.
- Case report of 55 year-old man admitted to the hospital very ill with COVID-19 who developed subsequent SCAD. He had atherosclerotic disease. (June, 2020)
 - I think this is a different process than FMD/primary SCAD
- Case report of a 48 year-old woman with hx of migraines with chest pain and dx of LAD artery SCAD. No symptoms but COVID-19 swab + prior to heart cath. (April, 2020)
 - My take: typical SCAD + incidental dx of asymptomatic COVID-19 infection
- Case report of a 51 year-old woman with history of HTN admitted with COVID-19 infection requiring oxygen, steroids, anti-viral Rx. Developed chest pain, ST-segment elevation hospital day #3 after intense cough. Cath with LAD SCAD treated conservatively.
 - My take: COVID-19 infection, coughing fit induced SCAD

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CASE REPORT WILEY

Spontaneous coronary artery dissection of the left anterior descending artery in a patient with COVID-19 infection

Kris Kumar DO, MSc | Joshua C. Vogt MD | Punag H. Divanji MD | Joseph E. Cigarra MD

DOI: 10.1002/ajd.1380
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IMAGES IN INTERVENTION

Spontaneous Coronary Artery Dissection in a Patient With COVID-19

Pierre Yves Coustaud, MD, PhD^{1,2,3,4}; Bastien Barthelemy, MD, PhD^{1,2,3,4}; Marc Bonnet, MD^{1,2,3,4}; Pierre Lantelme, MD, PhD^{1,2,3,4}

Images in CAD

Coronary Artery Disease 2020, XXX, 000-000

Spontaneous coronary artery dissection in a patient with COVID-19

John Papanikolaou^{1,2}, Abdulrahman Alhathli³, Hossain Patengama⁴, Abdulrahman Bahamny⁵, Sarah A. Alghamdi⁶, Zaid A. Mansour⁷, and Dimitrios Karamantelis⁸, Critical Care Department, King Saud Medical City, Riyadh, Saudi Arabia; ¹Department of Medicine, The Johns Hopkins University Hospital, Baltimore, Maryland, USA; ²Research & Innovation Center, King Saud Medical City, Riyadh, Saudi Arabia and ³Critical Care Department, King Abdulaziz University of Southern California, Los Angeles, California, USA

Correspondence to: John Papanikolaou, PhD, Critical Care Department, King Saud Medical City, PO Box 221505, Riyadh 11515, Saudi Arabia
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A 51-year-old female with a history of hypertension and tobacco use was admitted to our unit due to recent onset of fever, SIRS, cough, and respiratory distress. SARS-CoV-2 infection was confirmed by real-time polymerase chain reaction (RT-PCR) assays performed on

Emgren ZY, et al. COVID-19 and SCAD 9 pts; 6 men

Table 1. Clinical characteristics of patients with COVID-19 related SCAD

No	Authors	Published date	Origin (country)	Age, sex	Cardiovascular history	Symptoms	Predisposing factors	Timing according to COVID-19 infection	Concomitant COVID-19 complications	COVID-19 severity	Diagnosis	Vessel	Treatment	Outcome
1	Cannata et al ¹	December 18, 2020	Great Britain	45 years, female	None	Anomia, Hypoglossia, Chest pain	Unreported	8 weeks	None	Mild	STEMI	LAD	Conservative, Dual antiplatelet, Beta blocker, ACE inhibitor	Survived
2	Aparisi et al ²	December 21, 2020	Spain	40 years, male	None	Fever, Cough	Unreported	7 days after ECMO	Cardiogenic shock, Severe respiratory distress syndrome, Cardiac thrombus	Severe, Lung infiltration	Non-STEMI	LAD	Conservative	Survived
3	Kumar et al ³	May 7, 2020	USA	48 years, female	Hyperlipidemia	Chest pain	Unreported	COVID test was obtained after SCAD	Polymorphic ventricular tachycardia	Mild	STEMI	LAD	Conservative, Dual antiplatelet, Beta blocker, Amiodarone	Survived
4	Courand et al ⁴	November 12, 2020	France	55 years, male	Peripheral arterial disease	Cough, Febrile, Dyspnea, Chest pain	Unreported	48 hours after test result	None	Moderate, Crazy pavy pattern in the lung	Non-STEMI	RCA	ASA, Statin, Beta blocker	Survived
5	Albero and Senesi ⁵	May 12, 2020	Italy	70 years, male	Smoker, Hypertension, Diabetes	Chest pain, Fever	Unreported	COVID-19 test (+) 1 day after coronary angiography	None	Mild	Non-STEMI	LAD	PCI, Clopidogrel, ASA, Atorvastatin, Metformin, Pantoprazole	Survived
6	Fernandez Gasso et al ⁶	May 7, 2020	Spain	39 years, male	None	Fever, Cough, Myalgia, Chest pain, Dyspnea	Autoimmune diseases were ruled out	Approximately 18 days	None	Severe, Intubation because of respiratory failure	STEMI	LAD, CX	Conservative, Dual antiplatelet treatment	Survived
7	Papanikolaou et al ⁷	December 28, 2020	Saudi Arabia	51 years, female	Hypertension, Smoker	Fever, Cough, Dyspnea	Unreported	3 days	None	Mild	Non-STEMI	LAD	Conservative, Dual antiplatelet, Anticoagulation, Statin	Survived
8	Kiseev et al ⁸	November 27, 2020	Russia	35 years, male	Obesity, Smoker	Weakness, Fever, Nasal congestion, Anomia, Dry cough, Chest congestion	Autoimmune diseases were ruled out	Approximately 18 days	None	Mild	STEMI	RI, RCA	PCI -RI, Conservative -RCA, Dual antiplatelet anticoagulation	Survived
9	Yapin Emren et al (present case)	June 1, 2021	Turkey	50 years, male	None	Cough, Fever, Chest pain (later)	None	7 days	None	Mild	STEMI	RCA	PCI, Dual antiplatelet, Atorvastatin, Metoprolol	Survived

CX: drainflex; ECMO: extra-corporeal membrane oxygenator; LAD: left anterior descending; RCA: right coronary artery; RI: ramus intermedius; SCAD: spontaneous coronary artery dissection; STEMI: ST elevation myocardial infarction; Non-STEMI: non-ST segment elevation myocardial infarction.

Ask the Infectious Disease Expert Anything About COVID-19 and Vaccines

Dr. Keith Armitage
**Professor of Medicine (Infectious
Disease)**
Vice Chairman, Education
Internal Medicine Residency
Program Director
University Hospitals



Save the Date

Next date is January 18, 2021

Topic: t/b/d