Fibromuscular Dysplasia (FMD) Fact Sheet

What is Fibromuscular Dysplasia?
- Fibromuscular dysplasia (also known as FMD) is a medical condition characterized by abnormal cell growth within the arterial wall. FMD is different from other blood vessel disorders that affect the arteries, such as atherosclerosis (blockage of arteries secondary to cholesterol plaque), vasculitis (inflammation of the arteries), and thrombosis (formation of blood clots). FMD can lead to different abnormalities of arteries, such as narrowing, a beaded appearance, or even serious complications such as aneurysms (bulging of the arteries) or dissections (tears of the arteries). FMD is not known to involve the veins or the lymphatic system.

What causes Fibromuscular Dysplasia?
- The cause of FMD is not yet clearly known.
- Likely genetic and environmental factors play a role.
- FMD is much more common in women (Approximately 90% in the US Registry for FMD).

What population does it affect?
- Predominately middle-aged women, but it has presented across the lifespan of men, women and children

What are common signs and symptoms?
- High blood pressure in patients under age 40, or uncontrolled high blood pressure at any age
- Unrelenting headaches (migraine type), neck pain, dizziness, or asymmetry of the pupils
- A pulsatile whooshing or swooshing sound in the ears (pulsatile tinnitus)
- A bruit (abnormal sound when listening with a stethoscope) in the abdomen (abdominal bruit) or neck (cervical bruit); findings suggest there is turbulence of blood flow in the artery;
- Dissection or aneurysm of an artery
- Transient ischemic attack (TIA) or stroke
- Asymptomatic (no symptoms present) FMD can be silent and be detected by testing during a routine physical.
- FMD signs and symptoms vary based on the arteries that are affected making diagnosing complex.
Fibromuscular Dysplasia (FMD) Fact Sheet

What should you do if you suspect Fibromuscular Dysplasia?

- If you suspect FMD contact your primary care provider.
- Print FMD Facts Sheet and Practitioner Letter and take them with you to your appointment.
- If you need further assistance contact FMDSA (www.fmdsa.org).

Are there treatments for Fibromuscular Dysplasia?

- Yes, there are options:
  - Treat high blood pressure with medications or percutaneous transluminal angioplasty of the kidney arteries.
  - Take an antiplatelet agent such as aspirin 81 mg to help prevent stroke.
  - Management of headaches with medications. Some patients find relief with Botox injections to the scalp.
  - Percutaneous transluminal angioplasty (PTA) for severe blockages in any artery if causing symptoms.
  - Vascular coils and/or stents for treatment of aneurysms and in severe cases stents can be used to treat an arterial dissection.
  - Surgery. This is usually reserved for patients with aneurysms that cannot be treated with less invasive techniques.
  - Treatment will vary based on severity, location, and extent of disease.
  - Treatment plans should be discussed in depth with a specialist who is very knowledgeable about FMD.

What is the prognosis for Fibromuscular Dysplasia?

- Currently there is no cure for FMD, but in most patients FMD can be well managed with expert care.
- In rare cases, FMD-related aneurysms can burst and bleed into the brain, causing stroke, permanent nerve damage, or death. Patients with FMD may require an angioplasty or surgical procedure, though many patients can be managed only with medications.
- All patients with FMD should have regular follow-up.
- FMD experts are currently researching the cause, prognosis and outcomes for patients with FMD.

How can you learn more about FMD and how to contact the experts?

- Fibromuscular Dysplasia Society of America (FMDSA) http://www.fmdsa.org/
- FMDSA on line FMD Inspire Support Group
  - www.inspire.com/groups/fibromuscular-dysplasia-society-of-america/
Fibromuscular Dysplasia (FMD) Fact Sheet

- Fibromuscular Dysplasia Patient Registry
  - http://www.fmdsa.org/patient_support/patient_registry
- Cleveland Clinic FMD web Chat with Heather Gornik, MD and Pam Mace, RN
  - http://my.clevelandclinic.org/departments/heart/patient-education/webchats/fmd

The U.S. Registry for FMD Steering Committee:

Jeffrey W. Olin, DO, FACP, FACC
Mount Sinai School of Medicine
New York, NY

Heather L. Gornik, MD
Cleveland Clinic Heart and Vascular Institute
Cleveland, OH

James Froehlich, MD
University of Michigan
Ann Arbor, MI

Pam Mace, RN
FMDSA
Rocky River, OH

Eva Kline-Rogers, NP
University of Michigan
Ann Arbor, MI

The U.S. Registry for FMD Regional Contacts:

Bruce Gray, DO
Greenville Health System
Greenville, SC

Heather L. Gornik, MD
Cleveland Clinic Heart and Vascular Institute
Cleveland, OH

J. Michael Bacharach, MD
North Central Heart
Sioux Falls, SD

Aditya Sharma, MD
University of Virginia Health System,
Charlottesville, VA

Jim Froehlich, MD
University of Michigan
Ann Arbor, MI

Kevin Meyers, MD
Children's Hospital of Philadelphia
Philadelphia, PA

Chris White, MD
Ochsner Health Center
Metairie, LA

John R. Laird, MD
The Vascular Center, University of California,
Davis Sacramento, CA

Jeffrey W. Olin, DO, FACP, FACC
Mount Sinai School of Medicine
New York, NY

Michael R. Jaff, DO
Massachusetts General Hospital,
Boston, MA

Rob McBane, MD
Mayo Clinic
Rochester, MN

Barry Katzen, MD
Miami Baptist Cardiac/Vascular Institute
Miami, FL

Kamal Gupta, MD
University of Kansas
Kansas City, KS

David Slosky, MD
Vanderbilt University
Nashville, TN