Fibromuscular Dysplasia Society of America

The Fibromuscular Dysplasia Society of America (FMDSA) is a not-for-profit patient advocacy organization working towards better diagnosis and treatment of Fibromuscular Dysplasia (FMD). We do this by building awareness of FMD, funding research activities, providing support and educating patients and the healthcare community. FMDSA works to inspire and facilitate collaboration between national and international organizations devoted to FMD and FMD-related research, education, and patient support.

The North American Registry for FMD

In 2007, the Fibromuscular Dysplasia Society of America (FMDSA) decided to begin a registry to better understand the disease and its treatment. The goals of this registry are to identify patient characteristics associated with FMD, potential markers of the disease, and commonly used imaging and treatment modalities, among others. Formerly known as the United States Registry for Fibromuscular Dysplasia, the name change came as a result of the Ottawa Hospital in Ontario becoming a participating registry centre in 2023. To date over 4,400 patients have participated in the registry and there are currently 20 active FMD centers. The registry is solely funded by the FMD patient community. We receive no grants to fund the registry.

What is FMD?

Fibromuscular Dysplasia, commonly called 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).

What causes FMD?

• The cause of FMD is not yet clearly known.
• It is likely that genetic and environmental factors play a role.
• FMD is much more common in women, but men and children are also affected.

What are common signs and symptoms?

- High blood pressure
- Headache, 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)
- Dissection
- Aneurysm

- Transient ischemic attack (TIA) or stroke
- Asymptomatic (no symptoms present) FMD can be silent and detected by testing during a routine physical
- FMD signs and symptoms vary based on the arteries that are affected making diagnosing complex.

What should you do if you suspect Fibromuscular Dysplasia?

- If you suspect FMD contact your primary care provider.
- Print the FMD Fact 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:

- High blood pressure can typically be managed with medications but in some cases percutaneous transluminal angioplasty may be necessary.
- An antiplatelet agent such as aspirin may be prescribed.
- Headaches can typically be managed with medication.
- Vascular coils and/or stents are reserved for the treatment of aneurysms and arterial dissections.
- Surgery may be required to treat aneurysms
- Treatment will vary based on severity, location, and extent of disease.

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

Visit the Fibromuscular Dysplasia Society of America (FMDSA) website at: www.fmdsa.org
26777 Lorain Road, Suite 311, North Olmstead, Ohio 44070 Ph: 216-834-2410

Thank you for supporting our Pampered Chef fundraiser!