Fibromuscular Dysplasia “AWARENESS”

Fibromuscular Dysplasia (FMD) is a disease that causes abnormal cell development in the walls of one or more arteries in the body. Areas of narrowing (stenosis) may occur as a result of this abnormal cell development. If enough narrowing causes a decrease in blood flow through the artery, symptoms (hypertension, arterial dissection, stroke) may result. Many patients with FMD do not have symptoms or signs on physical examination; many are diagnosed by accident during routine examination for another problem. Up to 75% of all patients with FMD will have disease in the renal arteries (kidneys) and may present with hypertension. The second most common artery affected is the carotid artery, found in the neck, supplying the brain with blood and patients may experience nonspecific complaints including dizziness, temporary blurring or loss of vision, tinnitus (ringing or buzzing in the ears), vertigo (feeling as if the room was spinning around you), neck pain, bruises (whooshing sound) and/or chronic headaches. FMD can affect the arteries in the abdomen (supplying the liver, spleen and intestines) which may cause abdominal pain after eating and unintended weight loss, and FMD in the extremities may cause limb discomfort with use, cold limbs, weakness, numbness, or skin changes in the fingers and toes due to lack of blood flow. More than one artery may have evidence of FMD in 28% of people with this disease.

The cause of FMD is not known. Just last year FMD was listed on The National Organization of Rare Diseases. It is more common in women, between the ages of 25-50, however, we do see men with the disease. Some forms of the disease have been diagnosed in children and teenagers. It is possible that many factors are involved in the development of FMD. It is difficult to determine how common FMD is in the general population. This is due to several reasons. Individuals with mild disease are often asymptomatic and so the disease may go undetected. FMD commonly presents as a “string of beads” appearance in the affected artery due to changes in the cellular tissue of the artery wall causing narrowing and dilation of the artery. A less common, but more aggressive form of FMD may cause areas of vessel narrowing only without the “string of beads” appearance.

How can FMD be diagnosed?
CT and CTA scans, MRI/MRA, Ultrasound, and Angiogram. Your health care provider will determine what diagnostic options are best for you.

How is FMD treated?
There is no cure for FMD. The kind of treatment used for FMD depends largely upon which arteries are affected and the patient’s symptoms. In some cases an attempt should be made to improve the flow of blood through the vessel. Currently, there is not a set protocol for treating FMD; some patients are placed on an antplatelet agent daily (i.e., aspirin) or a blood thinner, such as Coumadin. All patients who use tobacco should be encouraged to quit. The appropriate treatment will vary with individuals depending on the severity of their disease.

How can I find out more about FMD?
FMDSA (the Fibromuscular Dysplasia Society of America) assists patients, physicians and other healthcare providers in finding the latest information on FMD. We have put together resources and diagnostic information on the disease. FMDSA’s awareness campaigns are the key to FMD now being recognized as a cause of stroke by the American Stroke Association with a feature article in Stroke Connection. The National Stroke Association’s Stroke Smart Magazine featured FMDSA Board Chair and patient, Pamela Mace as their Champion of Hope. FMDSA has been featured on several news and talk shows across the nation and has made the Cover of Cath Lab Digest and RENALIFE Magazine.

FMDSA along with The University of Michigan are working together on an International Patient Registry. The National Institute of Health is currently conducting a research study on FMD. One of the latest articles published states that “FMD is not that uncommon: it is often overlooked or misdiagnosed” With your help, we will continue to promote awareness, educate our health care providers, and fund research to find the cause and a cure for FMD. Visit FMDSA.org or call 1-216-834-2410 for more information and membership information.

Cheryl was diagnosed with advanced FMD during a routine exam for a bladder infection three years ago. Her disease affects both carotid arteries with a carotid aneurysm, both vertebral arteries and her right renal artery. Cheryl’s physician at Shore Memorial Hospital follow her every 6 months with CTA’s and carotid ultrasounds, she takes aspirin as an antplatelet, and monitors her blood pressure daily. Cheryl joined FMDSA shortly after being diagnosed and joined the Board of Directors this year to work with other FMD patients and volunteers, to help spread awareness.

By Cheryl Bailey-FMDSA

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