

Fibromuscular Dysplasia & Arterial Dissection Webinar: Q&A Extravaganza | August 11, 2026

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FMD Locations

What is a bruit?

Mace: Bruit is heard when a provider uses a stethoscope to listen over the carotid artery in your neck. Sometimes they'll listen over your stomach, renal, or femoral artery too.

Gornik: Bruits indicate turbulence of blood flow and are nonspecific. You could have a bruit from a plaque blockage, FMD beads, or even if you press too hard with the stethoscope on an artery, sometimes it comes up with the brachials because you're narrowing the artery by pressing on it.

Can renal stenosis be a focal FMD?

Gornik: Yes. Even though it's a minority, as more than 90 percent of patients with FMD have the string of beads, or multifocal type, focal FMD is the most common type in children and young adults and can absolutely cause renal vascular hypertension.

Can there be FMD in the legs? What is iliac beading?

Gornik: The most common site for FMD in the lower extremities is in the external iliac arteries, but it generally doesn't cause symptoms. It can sometimes cause a bruit. Rarely, FMD can cause pain in the legs with walking that improves with rest (called claudication) or a dissection.

What sort of situation merits an intervention for lower extremity FMD?

Gornik: It's very unusual – that was one of the takeaway messages from a lecture given at the 2026 International FMD Think Tank and Symposium – but I have a few patients in my practice who had external iliac artery dissections that caused blockages and lack of blood flow to the legs and had intervention. More rarely, patients with external iliac FMD could have leg pain with walking, with definite limitation of blood flow to the legs on formal vascular lab studies, in which case a balloon procedure might be done.

What's the difference between an iliac dissection and blood pooling/heaviness in the legs?

Gornik: An iliac dissection is an artery dissection or a tear in an artery, which can happen sometimes with FMD. The heaviness and blood pooling sound more like venous disease. When someone has leg symptoms, we evaluate to determine the cause – is it arterial or venous disease? When I hear blood pooling, I think about venous disease, venous congestion, or venous insufficiency. This is separate from FMD. Not all vascular leg problems are in the arteries.

Fibromuscular Dysplasia & Arterial Dissection Webinar: Q&A Extravaganza | August 11, 2026

FMD Progression, Dissections and Aneurysms

What causes a brain aneurysm to grow with FMD, and how can I keep it from growing?

Gornik: We do not know if brain aneurysms and their history differ in people with FMD than without. While data from the North American FMD Registry shows they're present in about 13 percent of patients with multifocal FMD, no one has done a study to show the rupture risk in patients with FMD and if it's different than someone without, so we need more information. But there are two simple things you can do to prevent growth of a brain aneurysm: do not smoke or use tobacco of any type, including vaping, and make sure your blood pressure is well controlled.

I had a vertebral dissection and later diagnosed with FMD. Did the dissection cause FMD?

Gornik: They are likely related. When someone has a dissection in one area, to really say it's due to FMD according to current definitions, you need to see the string of beads in an area that doesn't have a dissection. This is because sometimes when dissections heal up, they look beaded. So, if someone had a vertebral artery dissection, we want to make sure there's beading somewhere else before we say this was due to underlying FMD.

How likely is it to have a dissection if I've been diagnosed with FMD and never had one?

Gornik: Hopefully the North American FMD Registry will look at this in the planned outcomes paper, so I don't have data to quote, but it is uncommon for someone to have a dissection with good FMD care. Most patients will present as having a dissection, then we find FMD. When they get their blood pressure controlled, they lower their rate of another dissection. In my experience, it's very rare for someone who has beads to get a SCAD or a cervical dissection while under care for FMD, though unfortunately it's not impossible.

Is FMD progressive and does it spread?

Gornik: Most clinicians think FMD is not rapidly progressive, and it is unusual for FMD beads to progress significantly over time. There was a talk at the 2026 International FMD Think Tank and Symposium about the need to define progression. Beyond worsening beads, progression might be a new event, like a new dissection or aneurysm. There could be new vascular lesions identified over time, but in my clinical experience, the beads don't significantly progress over time. One of the reasons for head-to-pelvis imaging is to make sure all areas involved with FMD, including aneurysms or dissections, are known and documented. Often when FMD is diagnosed in a new location, it's not that it just cropped up, rather an area was not previously checked.

Do you have information on SCAD recurrence rates?

Gornik: The best data is longitudinal follow-up data from the Canadian SCAD Registry. Their initial series showed a higher rate of recurrence, but the most recent published series with three-year follow-up outcomes had a much lower rate of new SCAD events or cardiovascular mortality (<https://pubmed.ncbi.nlm.nih.gov/36265953/>). It was very reassuring.

Fibromuscular Dysplasia & Arterial Dissection Webinar: Q&A Extravaganza | August 11, 2026

Imaging for FMD

Is it patient-specific whether to have CTA versus MRA?

Gornik: It depends on your anatomy and where you have FMD. It also depends on imaging capabilities and strengths of the institution where you're being followed. Some centers do a lot of research with vascular MRA and can obtain beautiful whole renal artery imaging including branches. For most centers, CTA is the go-to for renal and abdominal arteries. MRA is used a lot for head and neck vessels, but CTA is also used to get the best imaging of beads. While brain arteries cannot be seen with ultrasound, we can see carotid arteries in the neck really well. So, it's a combination of where your disease is, what you have that needs following, and the imaging capabilities where you're being followed.

Is there a specific type of ultrasound machine that should be used for patients with FMD?

Gornik: It's not so much the ultrasound machine, because most modern vascular duplex scanners can image FMD, rather it's the person holding the probe – if they have experience looking for FMD and if they're using a protocol that will optimize for FMD. Vascular ultrasound imaging for FMD is challenging. For example, to identify FMD in the carotids we need to scan really high up in the neck, which is beyond what is usually done for a standard carotid ultrasound. So, it's not the equipment, it's the experience of the person using the equipment and all the optimizations.

How often do you recommend head-to-pelvis scans?

Gornik: According to the International FMD Consensus, at least once to check all your vessels. It doesn't have to be at the same time. You could have a head and neck CTA or MRA when you are first diagnosed, and later you get the chest, abdomen and pelvis. It can be staged. The International FMD Consensus doesn't say if it should be repeated. I will say in my practice, I tend to repeat imaging. If we haven't imaged all the vessels, then five to seven years after the first scan, we image again. But you don't need an annual head-to-pelvis CTA scan. I think as much as there's a risk for under-imaging, I see patients who are over-imaged, who are getting CTAs every six months, and that's not necessary either and carries risk related to radiation exposure and contrast dye.

Fibromuscular Dysplasia & Arterial Dissection Webinar: Q&A Extravaganza | August 11, 2026

Medications and FMD

Are there any medications that patients with FMD should avoid?

Gornik: There's recent data about a class of antibiotics called fluoroquinolones and vascular complications. These medications end in "floxacin" – like ciprofloxacin and levofloxacin among others. A few years ago, the FDA issued a safety announcement advising these medications may increase the risk of aortic dissection or rupture. This is a concern especially for people with conditions highly associated with aortic disease like Marfan and Loeys-Dietz syndromes, but many of us in the FMD field have extended this medication concern to FMD. We also recommend avoiding vasoconstricting medications because they can raise blood pressure. For migraine headaches we move away from the triptans to alternatives such as the newer CGRP receptor blockers or "gepants". This is also relevant for over-the-counter cold relief medications that include decongestants. If you have renal FMD and hypertension and get a cold, don't use pseudoephedrine-type products. Coricidin HBP products may be safer because they offer some relief but don't raise blood pressure.

Should someone who is diagnosed with FMD and has had two SCADs take aspirin?

Gornik: This is individualized, but the International FMD Consensus recommends that patients with FMD be on single antiplatelet therapy, generally with aspirin, mainly to prevent clots from forming in the areas of narrowing, webs or beads.

What should I do if I can't take aspirin and need an antiplatelet?

Gornik: Talk with your doctor about other antiplatelet medications like clopidogrel or other agents.

Is there any contraindication to people with FMD using GLP-1s?

Gornik: GLP-1s have shown to be safe and beneficial for patients with cardiovascular conditions like coronary artery disease, peripheral artery disease and heart failure. While there are no FMD-specific safety concerns that I know of, I'm not aware of GLP-1 studies specifically related to FMD.

Is the birth control pill safe for someone diagnosed with FMD?

Gornik: We don't have definitive data. Years ago, there were conflicting epidemiology studies that reported an association of prior oral contraception pills (OCPs) and developing FMD, but other studies did not show this. Many women take OCPs at some point in their lifetime, so this is a good area for more research. Evaluate the risks, benefits and safest type of birth control based on your medical history, FMD-related and other, with your doctor.

Can I consider hormone therapy if I have FMD?

Gornik: We need more data about hormone safety. Whether or not to take hormones depends on the severity of menopause related symptoms and your personal risk profile. It's not just FMD-related risk, but also breast cancer risk, clotting history, your age, whether you have had a heart attack or stroke – many factors to consider. New formulations of menopausal hormones may be safer than prior formulations, like the transdermal estrogen patches compared to oral. It's a rapidly evolving area. This is an area where discussion with your FMD specialist is important.

Fibromuscular Dysplasia & Arterial Dissection Webinar: Q&A Extravaganza | August 11, 2026

Exercise and Activities with FMD

Is there a guide for patients with FMD on the topic of physical activity and weightlifting?

Gornik: There is a brief document that was published a few years ago by some experts in FMD and coronary artery dissection: <https://pubmed.ncbi.nlm.nih.gov/34097033/>. In general, though, we need more data. Patients hear different things from different physicians mainly because every patient is different. A patient with a few beads in the carotid arteries is very different from one with two brain aneurysms and a prior SCAD. There is a survey on this being conducted by Vanderbilt. If you are interested and want to participate in the Vanderbilt study, visit fmdsa.org to learn more.

Can someone with FMD go to a chiropractor?

Gornik: If you have FMD, especially carotid vertebral FMD, please do not undergo chiropractic neck adjustments. There are alternate modalities chiropractors use to treat pain and other symptoms, so discuss this with them, but I do not recommend neck adjustments.

Are there precautions for hyperextension of the neck if I've had a cervical dissection?

Gornik: I generally tell patients to keep their neck in a neutral position and avoid prolonged hyperextension – if you get your hair shampooed, use a towel to support your neck in the shampoo bowl; if you do yoga, avoid extreme and prolonged poses with hyperextension of the neck.

Is it okay to get a massage if you have FMD?

Gornik: Yes, in general European or Swedish-style massage should be ok, however avoid deep tissue massage, especially on the neck. Of course, you could always ask your doctor specifically.

Is it safe for someone with FMD to use an inversion table?

Mace: Check with your doctor, but for many patients this is not recommended as it may cause dizziness, high blood pressure or other symptoms.

Fibromuscular Dysplasia & Arterial Dissection Webinar: Q&A Extravaganza | August 11, 2026

Coping with FMD

Any suggestions for managing anxiety after getting an FMD diagnosis?

Mace: Dr. Sears is a psychologist who spoke in a previous webinar. He did an awesome presentation on this topic. You can watch the recording on the University Hospitals website: <https://www.uhhospitals.org/services/heart-and-vascular-services/conditions-and-treatments/vascular-disease/conditions-and-treatments/fibromuscular-dysplasia-program/patient-resources>. There's also a paper on Living with Fibromuscular Dysplasia by Dr. Bumpus that summarizes the experiences of a group of patients (<https://pubmed.ncbi.nlm.nih.gov/27758900/>)

Should patients with FMD have a medical alert bracelet?

Mace: If you're on an anticoagulant or you've had a previous dissection, I recommend having a medical alert bracelet, especially when you're going somewhere alone, you're newly diagnosed, or you don't have a family member with you. One thing you can put on it is I-C-E, which stands for *In Case of Emergency*. You don't have to put the person's name, because there's a limited character count, just add a phone number of a loved one who knows your medical history. Add "blood thinner" if you are on one, so it's known there is a risk of a bleed. Note if you have ever had a dissection too, so it's known you may require imaging. In addition, I recommend having a folder of health information at home that you keep on your refrigerator or the counter, so your family members know where it is if they ever have to call 9-1-1. You can also put your emergency information on your mobile device; many first responders look for this now on devices.

FMD and Family Members

How does someone know if FMD is familial or not?

Gornik: The familial element of FMD is complicated and not yet fully understood. In most cases, patients with FMD do not have an affected family member, but there are some families where there's clearly familial FMD. In the North American FMD Registry, less than 10 percent of patients enrolled have a family member with FMD. In the 2019 International FMD Consensus, routine screening of family members of patients with FMD was not recommended, but family members should be evaluated if they have signs or symptoms of FMD.

I have FMD and daughter (age 18) has pulsatile tinnitus – should she be tested for FMD?

Gornik: While pulsatile tinnitus is common among patients with FMD, there are other things that can cause pulsatile tinnitus, so pulsatile tinnitus does not necessarily mean someone has FMD. Beyond carotid FMD, there can be other types of narrowing like tortuous arteries or anomalies of the veins that drain the head and neck. Your daughter should discuss this with her doctor and maybe see an ENT physician. She should mention that mom has FMD but know there may be other causes and presentation of FMD at age 18 is very unusual. In general, pulsatile tinnitus that persists should be evaluated for vascular causes, including FMD and other conditions.

Fibromuscular Dysplasia & Arterial Dissection Webinar: Q&A Extravaganza | August 11, 2026

North American FMD Registry and Other Research

What should patients expect from being followed in the North American FMD Registry? If I joined the registry a long time ago but haven't received any updates, should I reach out?

Gornik: Unlike some registries where patients get surveys and are asked to complete tasks, all the work in the North American FMD Registry is performed by clinicians and researchers at the centers. Here at University Hospitals, when a patient is seen in clinic and consents to participate in the registry, we complete a form with patient information and then add updates after follow-up visits. Some centers do a chart review periodically to note if the patient has been hospitalized or had any scans. In general, the North American FMD Registry doesn't directly communicate with patients.

Mace: Watch for publications because that's where all the data is analyzed and shared. The FMD Society of America posts registry updates and we provide updates in this forum as well. Having close to 6,000 patients participating in the registry is pretty amazing; the data collected contributes to all the published information. In 2027, we hope to see a lot of information coming out from the registry.

How can I join the FMD Registry?

Mace: You must physically be seen as a patient at one of the centers participating in the registry. To find a participating center, visit the FMD Society of America website (fmdsa.org) or email us and we can help identify the center closest to you. Also, it was noted in the chat that more centers are needed throughout the U.S, and we understand that. One of the biggest obstacles is the lack of funding. While a center may have physicians with expertise in treating patients with FMD, the center may not have funding to support participation in the registry.

Fibromuscular Dysplasia & Arterial Dissection Webinar: Q&A Extravaganza | August 11, 2026

Managing FMD with Other Health Conditions

I have FMD, have had a SCAD, and am also diagnosed with osteoporosis. What should I do to maintain my strength and keep my bones healthy?

Gornik: I recommend seeing a specialist in bone health – an endocrinologist, rheumatologist, or internist who focuses in this area. While somewhat separate from FMD, this is still relevant as most patients with FMD are women, and women are at risk for osteoporosis and osteopenia. Resistance training is important for bone health – the American Heart Association recommends two sessions a week; just avoid heavy lifting and focus on light to moderate resistance and reps.

Can neck arthritis impact neck arteries or cause artery injury, and are there tests that should be done for this?

Gornik: Neck pain is complicated in patients with FMD. Our team here at University Hospitals did a project on this topic. We presented at an FMD Society of America conference that neck pain is common in patients with FMD. We have patients with FMD who also have cervical spine disease (arthritis) and some with scoliosis of the spine. Previous National Institutes of Health (NIH) research also showed some arthritis in patients with FMD, so it's possible that patients with FMD may have manifestations such as arthritis, but it's not a vascular manifestation of FMD. Neck pain is tricky with FMD because sometimes it's hard to distinguish the neck pain of a dissection from neck pain of arthritis or other musculoskeletal issues, but I don't think arthritis or neck issues cause FMD.

Any connection between CSF leak and FMD?

Gornik: Not to my knowledge. I've had a few patients who've had dissections, strokes or aneurysms, and had neurosurgery and CSF leak complications, but I don't know of a connection to just FMD and CSF leak. I've not seen anything regarding that in the literature either.

Is there a known connection between hypermobility and FMD?

Gornik: We published a study when I worked at Cleveland Clinic with then medical student Dr. Sarah O'Connor (<https://pubmed.ncbi.nlm.nih.gov/26156071>). We performed Beighton hypermobility scores on patients with FMD, and they were surprisingly not hypermobile. There was also a NIH study many years ago that studied patients who had hypermobility. While not known to be associated, of course could be studied more down the road. Patients can also have hypermobility or hypermobile Ehlers-Danlos as separate problems.

Is there any connection between lupus anticoagulant antibody and FMD?

Gornik: There's no known connection. We don't think of FMD as being a clotting disorder.

Is May Thurner associated with FMD?

Gornik: May Thurner is a venous condition where the veins, usually to the left leg, are compressed by surrounding arteries, and that is totally separate from FMD which is an artery disorder.