Moyamoya Disease

WHAT IS MOYAMOYA DISEASE?
Moyamoya Disease is a progressive narrowing of one or more major blood vessels supplying blood to the brain. This narrowing happens gradually. The brain responds by forming tiny new blood vessels in an attempt to increase the blood supply. These small blood vessels look like a puff of smoke on imaging, giving moyamoya its name—Japanese for ‘puff of smoke’.

WHAT CAUSES THIS?
The cause of moyamoya is unknown in most cases but is associated with genetic diseases such as Down syndrome, sickle cell disease, and neurofibromatosis. Other causes can include cranial radiation and rare genetic mutations, such as RNF213. In North America, the first degree relatives of patients with moyamoya have a 3-4% risk of also having the disease.

Per American Heart Association guidelines, imaging of unaffected family members is generally reserved for identical twins, patients who have more than one relative with documented moyamoya, or relatives with a clinical history suggestive of moyamoya.

WHAT TREATMENTS ARE AVAILABLE?
When a patient has a diagnosis of moyamoya, our team will work with you to decide the best course of action. The goal of treatment is to bring more blood flow to the affected part of the brain and prevent strokes. Our team often prescribes medications such as aspirin to ‘thin your blood’ to decrease the risk of additional strokes. Our neurosurgeon will also work with your family to decide upon the utility of revascularization surgery.

Revascularization surgery is a procedure to help bring more blood vessels to the brain.
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WHAT SHOULD WE EXPECT FOR THE FUTURE?

You will meet with our team every 3-12 months for an assessment and treatment recommendations. Each visit will be tailored to your child’s needs as they may change over time. We will provide the appropriate specialists to help make decisions for your plan of care.

It is particularly important for moyamoya patients to avoid dehydration and head injury.

WHAT OTHER TESTS MAY BE NEEDED?

A MRI of the brain with an MR angiogram of the head and neck is a common imaging test to assess the areas of damage and look for blood vessel abnormalities. Sometimes we will also recommend a conventional angiogram. These procedures are usually completed by radiologists or neurointerventionalists in conjunction with our team.

Your medical team will also consider imaging of the renal arteries that supply the kidney and discuss the usefulness of genetic testing.

In most moyamoya patients (especially those with an Asian ancestry), RNF213 mutation testing is considered to better understand the risk of moyamoya in family members.

WHAT RESOURCES ARE AVAILABLE?

Hemophilia & Thrombosis Center at CU Anschutz Medical Campus

Our clinic specializes in care for pediatric stroke and other related conditions including moyamoya Disease. We work with Children’s Hospital Colorado and have comprehensive, multi-disciplinary services for our patients.

Contact us at the details below or see our website here: medschool.ucdenver.edu/htc

We are located in the CU Medicine Building at the Hemophilia and Thrombosis Center

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