Angioma Alliance Recognizes the University of Miami as an Overall Center of Excellence for Cavernous Malformations

The Angioma Alliance has selected the University of Miami/Jackson Health System as a cavernous malformation (CM) Overall Center of Excellence, one of just a handful of such facilities in the country and the only institution in Florida to have earned this distinction. The new designation gives UM clinicians better access to research collaborators and other resources to improve CM treatment.

(At right) Robert Starke, M.D. The
University of Miami has become a destination for many people needing CM treatment.

“This recognition from the Angioma Alliance will increase awareness about cavernous malformations and improve our ability to treat patients and conduct research,” said Robert Starke, M.D., professor of neurological surgery and neuroradiology at the University of Miami Miller School of Medicine, co-director of endovascular neurosurgery at UM/Jackson Memorial Hospital, and director of neurovascular research.

CMs are clusters of dilated blood vessels, located mostly in the brain or spinal cord, that can bleed, cause seizures, and generate other debilitating neurological issues. While there are known genetic precursors, researchers don’t fully understand what causes them. In addition, there are no medical treatments. CMs are either followed radiographically or removed with surgery.

Clinicians approach CMs cautiously, only recommending surgery if the malformation’s risks are greater than neurosurgery. Sometimes, CMs are on the brain surface and can be removed relatively easily. In other cases, neurosurgeons must take elaborate precautions to correct the issue while ensuring patient safety.

“Certain malformations, in deep locations, can be difficult to access,” said Dr. Starke. “The brain has sulci, which are like clefts. We can open these using microsurgery and place a small tube down them, allowing us to operate in deep areas, a technique we pioneered at the University of Miami. We have the
largest series of patients reported who were treated with that approach.”

**UM a Destination for Challenging Procedure**

This delicate technique has benefitted many patients, some of whom had CMs in their primary motor cortex, a brain region once considered inoperable. Dr. Starke said that one child with CMs in his motor center suffered from repeated hemorrhages and seizures. Since surgery, he has gone on to become a top student and adept skier.

Another patient, referred by neurosurgeons outside of Florida for repeated hemorrhages, had a malformation close to motor and speech centers. The surgical team combined the minimally invasive technique with intraoperative stimulation to ensure they weren’t causing any neurological damage, and that patient is now back at work.

Because these procedures are so challenging, the University of Miami has become a destination for many people needing CM treatment.

“Sometimes doctors don’t have much experience in this specialty area, which can be quite daunting,” said Starke. “They may see only a few CM patients a year or every couple of years. Our center sees about one of these patients a week, so we have a lot of experience helping them.”

**Interdisciplinary Team**

Starke is joined by an interdisciplinary team of specialists, including assistant professor and cerebrovascular neurologist Negar Asdaghi, M.D.; assistant professor of clinical neurology and epileptologist Kamil Netyniecki, M.D.; assistant professor
of clinical genetics Willa Thorson, M.D.; and associate professor and neuroradiologist Rita Ghose Bhatia, M.D.

For Dr. Starke, his team, and other Angioma Alliance clinical centers, there are many questions to answer. What are the precise genetic causes? What role do environmental inputs, like the microbiome, play in this condition? Why do some people have malformations but never experience symptoms?

“This will band us together to advance the research,” said Dr. Starke. “We want to develop medical therapies that will reduce cavernous malformations and prevent bleeding. We need better imaging studies to identify CMs that could cause problems, and improved surgical techniques. And we need to study the genetic alterations to figure out why some people develop malformations in the first place.”

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