

Angioma Alliance  
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**Local Family [WITH CHILD] With Rare Disease Organizing Walk for a Cure**

*The Angioma Alliance walk honoring [HONOREE INFO] will benefit Angioma Alliance’s research for rare blood vessel disease treatments*

For Immediate Release

[CITY/STATE]/[DATE OF NEWS RELEASE] --- [A compelling introduction to your family’s story, for example: Connie and John Lee didn’t know their infant daughter Julia had a rare brain disease until they were handing her to a brain surgeon. When Julia was just four months old, Connie and John noticed their daughter was irritable and cried often. They knew something was wrong when John, bouncing Julia on his knee to soothe her, felt her go limp.

The next morning, Julia was projectile vomiting. She was slipping in and out of consciousness. Julia’s pediatrician urged Connie and John to rush their infant daughter to Norfolk’s Children’s Hospital of the King’s Daughters, where an emergency CT scan revealed a bleeding mass of blood vessels the size of a small orange inside her brain. Surgeons removed the cavernous angioma, but Julia was left partially paralyzed on her right side. Months of rehabilitation followed. Julia, now six, has had three more brain surgeries to remove hemorrhaging cavernous angiomas and her brain has ten more lesions that could hemorrhage at any time.]

Julia is one of about 6000 children [if an adult is affected, use 25,000] in the United States with an active form of this life-changing illness. On October 5th, she and her family will gather friends and supporters to walk 3 miles to raise money for research. Right now, brain surgery is the only treatment for Julia and children like her. The Lee family would like to see medications to prevent brain hemorrhage.

The Lee family walk, which they have named “Julia’s Walk for a Future” will benefit Angioma Alliance, the national patient advocacy and research organization for cerebral cavernous angiomas, also known as cavernous malformations or CCM. The walk will be held at York River County Park on Saturday, October 5th from 2-4 pm. It will include a variety of children’s activities including face-painting, arts and crafts, a bounce house, and games. Walk registration is $20 per adult. The public is invited.

“Julia’s future is uncertain and we want to know we’re doing everything we can to help her,” says Connie. “Julia has cavernous angiomas in places that are life-threatening or will disable her if they hemorrhage. We are running against the clock.”

About Angioma Alliance  
Angioma Alliance is a national patient advocacy and research organization supporting patient and families affected by cerebral cavernous angiomas, also known as cerebral cavernous malformations or CCM. CCM causes the formation of cavernous angiomas - abnormal blood vessels in the brain or spinal cord that resemble mulberries. These can hemorrhage and grow, potentially causing severe neurological deficits, epilepsy, and death. Cavernous angiomas can become active at any age, even in children, and individuals with a hereditary form of the illness can develop over 100 lesions in their brain.

Brain surgery is the only available treatment currently. Angioma Alliance is working with researchers, pharmaceutical companies, and the National Institute of Health to develop medications that can prevent brain hemorrhage and the growth of new lesions. The non-profit organization organizes international scientific meetings, runs a DNA and cavernous angioma tissue bank, has created a patient registry for future drug trials, and has several new initiatives underway to speed the time to treatments.

For more information about cavernous angiomas, visit [http://www.Angioma.org](http://www.angioma.org/).

[IF YOU HAVE A WALK WEBSITE, PLEASE PUT THE PRESS RELEASE ON YOUR SITE AS A WEBPAGE AND AS A PDF FILE. ALSO PROVIDE A LINK TO YOUR WALK OR ANGIOMA ALLIANCE LOGO.]

HTML:

PDF:       
LOGO:

**CONTACT:**

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<http://www.angioma.org> [OR YOUR WALK WEBSITE]

**KEYWORDS:** cavernous malformation, cavernous angioma, charity walk, CCM, medical research, rare disease

**SOURCE:** Angioma Alliance