within our reach
ANGIOMA ALLIANCE
What is a cavernous angioma?

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- Is also known as a cavernous malformation or cavernoma
- Is a raspberry-shaped abnormal blood vessel
- Can hemorrhage and cause stroke, seizure, or death
- Is hereditary in 25% of patients and these individuals have multiple lesions

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Angioma Alliance began with a mother, an infant, and a need. When Julia Lee was born, no one knew there were abnormal blood vessels in her brain. At four months old, she was rushed into emergency surgery, dying from a brain hemorrhage. Once a year for four years, Connie Lee surrendered her daughter to a surgeon to save Julia’s life. It became clear Julia’s illness would be a lifelong challenge. Scouring the internet, Connie found nothing. No patient groups, no way to connect with other parents or researchers.

In 2002, to fill the void for all patients and families, Connie Lee, with the help of a group of dedicated experts, started Angioma Alliance. Its mission is to inform, support, and empower individuals affected by cavernous angioma and drive research for a cure.

NEUMAN FAMILY

“Sometimes that’s what gets me through the day, just knowing I am doing all I can.”

Like many boys in their hometown, Jake and Sam love 4-H, hunting, and junior rodeo. Unlike their friends, their future is uncertain.

Liz refuses to stand by and wait for research to catch up. “I knew early on something had to be done. I can’t accept surgery as the only treatment.”

The Neuman’s have worked with their community in Bakersfield, California to raise more than $500,000 over the last ten years.

“Being involved with Angioma Alliance and fundraising will allow me to look my boys in the eyes and say, ‘I tried. I did everything I knew how to do to make this better for you.’ Sometimes that’s what gets me through the day,” Liz says, “just knowing I’m doing all I can.”
As a first step, Angioma Alliance launched a website with disease information and a discussion forum for patients. In less than two years, patients who found each other online were asking to meet in person. By 2012, our annual national meeting had blossomed into 32 regional patient meetings. Our members have found comfort and strength in their Angioma Alliance friendships.

In 2005, scientists asked for a meeting. For ten years, scientists from three continents have gathered in Washington, DC each November. They share their progress and plot a course toward real treatments.

Angioma Alliance brings people together.

ZACH BROWN

“I’ll talk to anyone who’ll listen about cavernous angiomas... I can’t let my son down.”

LIKE MOST ELEVEN-YEAR OLD BOYS, Zach Brown’s entire existence was sports. Football, wrestling, and lacrosse, Zach’s passions, were torn away from him without warning. He suffered two devastating, life-threatening brain hemorrhages within a week from a cavernous angioma in his brainstem.

Once worried he would miss his next game, Zach instead faced learning to walk again. In his breaks from physical therapy, he cheered his old teammates from his wheelchair on the sidelines, wondering if he’d ever be able to join them on the playing field. The bleeding also paralyzed the right side of his face, stealing half his vision, hearing, and smile. The handsome boy received uncomfortable stares wherever he went.

Now thirteen, Zach’s hard work has earned him a partial recovery. However, in addition to the remaining permanent physical challenges, he will never recover the child’s sense of invincibility he once had.

Zach’s parents struggle with the helplessness of knowing they can’t fix this for their son. His cavernous angioma is in a critical location and inoperable. “Every time the phone rings and Zach isn’t home, my heart sinks, afraid it’s someone telling me he’s had another brain hemorrhage.”
CRYSTAL SHAULIS

“The precariousness of my life became too real when I was shown the MRI of my brain…”

CRYSTAL SHAULIS WAS PURSUING a dream: to be the first in her family to graduate from college. But only weeks after finishing her freshman year as an art student, Crystal stumbled into an emergency room. Crippled by a headache, nausea, and numbness along her left side, she found speaking nearly impossible.

After many hours and medical tests, the doctors diagnosed the twenty-five-year-old with a bleeding cavernous angioma in her medulla oblongata, the part of the brain responsible for, among other things, the basic life functions of breathing and heartbeat. They told her surgery wasn’t an option. They told her to go live her life.

Crystal tried to get on with her life, but couldn’t. She needed physical assistance in the one class she was able to attend. She could have given up, dropped out. But as the months passed, she worked hard to become more independent and to resume a full course load.

Crystal tries not to dwell on the what-ifs. Instead, she celebrates her graduation and ponders graduate school, exhibitions, and life in far away New York City.

Despite her dreams, not a day goes by that she doesn’t think about the cavernous angioma, and how at any moment it could change, or take, her life. “The precariousness of my life became too real, almost tangible,” says Crystal, “when I was shown the MRI of my brain and the cavernous angioma inside it.”

driving research

Angioma Alliance has created solutions and filled gaps for researchers. Early on, we created a DNA and Tissue Bank with a clinical database. We are the major source of cavernous angioma tissue for research labs around the world. We also created an online patient registry. This allows any patient to tell us about their interest in research participation. Through this unique connection to patients, we save researchers tens of thousands of dollars and months of effort every year. Any researcher who is recruiting for a study will come to us first.

Most recently, we are collaborators on major research projects, and we’ve opened a clinic for the most rare and severe form of the illness.
ALLISON RUGGLES

“I’m not going to pretend my recovery hasn’t been challenging. But I haven’t missed any of my daughters’ birthdays…”

AS A NURSE, WIFE, AND MOTHER OF three young girls, Allison Ruggles had the perfect life. In 2004, a trip to a neurologist for back pain resulted in a terrifying diagnosis of brain cancer. When an MRI instead revealed a cavernous angioma, Allison was relieved. She couldn’t know then what the lesion would do to her and her family.

Initially, her doctors recommended a “wait and see” approach. But, over time, the repeated bleeding of her cavernous angioma made intervention inevitable. Her surgery was considered a success. Doctors completely removed her lesion, and hemorrhaging was no longer a worry.

However, instead of returning to her old life, Allison woke from surgery permanently disabled. Her legs would no longer obey the command to walk. Her hands could no longer write or button. Her face was sunken with facial paralysis, leaving her unable to kiss her husband, smile at her children, or close her eyes to sleep. Instead of caring for her family, her family was caring for her.

April 4, 2014 marked seven years since Allison’s lesion was removed. She has endured five eye surgeries and facial reanimation surgery. Yet, Allison knows the alternative to surgery might have been worse.

“I’m not going to pretend my recovery hasn’t been challenging. But I haven’t missed any of my daughters’ birthdays or graduations. For that, I’m very grateful.”

Allison reaches out to those who are newly diagnosed or struggling.

“I know not long ago my surgery was considered too complicated. I also know there are others out there who are not as blessed. I continue on for those who can’t.”

around the world

Angioma Alliance has a global reach. We have trained peer supporters who provide comfort to new patients and their families around the world. We have been the inspiration and mentors for sister organizations in the United Kingdom, Canada, Italy, and Brazil. We remain the main source of disease information for new patients. We are the face of the patient community for researchers, legislators, and government agencies. Because of its dedicated volunteers, Angioma Alliance remains a lean, internet-based organization with only two key employees. We are good stewards of the funding our members provide.
Moving forward, our vision leads us to a cure for all cavernous angiomas. Our path has become clear. To get there, we need medications, not surgery.

Angioma Alliance can help by preparing patients for clinical drug trials and by creating a network of clinical treatment centers. To prepare patients, Angioma Alliance is raising funds for bulk genetic testing. Patients must have testing to participate in clinical trials. To create clinical centers, we begin by developing guidelines for care. We will reach out to university hospitals to assemble multi-disciplinary teams who embrace these standards. These centers will make it easy to coordinate drug trials.

“Toward a cure”

Only eight months after Jenae’s passing, he showed the same disturbing symptoms as Jenae. He was found to have a bleed in the right frontal lobe and eventually underwent brain surgery. For the Gallegos family, a cure can’t come soon enough.

“I guess what I am asking for is our shot at it before time runs out.”
the vision

We are undertaking big projects with priceless long-term benefits. We look forward to a world where no child lives in fear of brain hemorrhage and its crippling effects, where no adult is disabled by seizure or paralysis. This vision is within our reach.

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