



within our reach
ANGIOMA ALLIANCE



Can be found in one in every 500 people

Is also known as a cavernous malformation or cavernoma

Is a raspberry-shaped abnormal blood vessel

WHAT IS A CAVERNOUS ANGIOMA?

Can hemorrhage and cause stroke, seizure, or death

Can only be treated by brain or spinal surgery

Is hereditary in 25% of patients and these individuals have multiple lesions

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, Julia returned to the operating room to undergo another life-saving operation. It became clear her illness would be a lifelong challenge.

Scouring the internet, her mother Connie Lee found nothing about cerebral cavernous angioma, the rare illness causing Julia's brain hemorrhages. No patient groups, no way to connect with other parents or researchers.

In 2002, to fill the void for all patients and families, Connie, 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 better treatments and a cure.

Building Community

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. Each year since, our regional patient meetings have expanded. Our members have found comfort and strength in their Angioma Alliance friendships.

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 15, 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 lesion is in an inoperable, critical location. “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.”

NEUMAN FAMILY

“SOMETIMES THAT’S WHAT GETS ME THROUGH THE DAY, JUST KNOWING I AM DOING ALL I CAN.”

As the world celebrated on the eve of the millennium, Liz and John Neuman rushed their two-year-old son Jake to the hospital with seizures. Their toddler needed emergency surgery to remove a hemorrhaging cavernous angioma, just one of many discovered in his brain.

Sam, their second son, wasn’t spared the illness. He had cavernous angiomas not only throughout his brain but also in his legs, in addition to a benign brain tumor. Now a teenager, Sam has already survived four brain surgeries and is scheduled for a fifth.

In 2005, the family learned the illness was caused by a mutation on the CCM3 gene, which causes the most aggressive form of the illness. The boys already have over fifty brain lesions each and will continue to develop more each year.

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.”



Driving Research

IN 2005, SCIENTISTS ASKED FOR A MEETING. For twelve years, scientists from five continents have gathered in Washington, DC each November. They share their progress and plot a course toward real treatments. Angioma Alliance invites new partners to the table, most recently pharmaceutical companies who have been inspired to begin developing treatments in collaboration with our academic researchers. Angioma Alliance brings people together.



Angioma Alliance has created solutions and filled resource gaps for research. Early on, we created a DNA and Tissue Bank with a clinical database. We are the major source of cavernous angioma tissue for 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 scientist who is recruiting for a study comes to us first. Most recently, we've opened a clinic for the most rare and severe form of the illness and we provide free genetic testing to eligible members.

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. The doctors told her the best their millions of dollars of technology could do, even if her brain hemorrhaged again, would be to keep her comfortable.

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.



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, the Philippines, and Brazil. We remain the main source of disease information for new patients in the world. We are the face of the patient community for researchers, pharmaceutical companies, legislators, government agencies like the National Institutes of Health and FDA, and the public. We take an active role with special populations, like the thousands of affected New Mexicans who share an inherited form of the illness. Because of its dedicated volunteers, Angioma Alliance remains a lean, internet-based organization with only three key employees. We are good stewards of our donors' generous support.

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, 2016 marked ten 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.”



GALLEGOS FAMILY

“I GUESS WHAT I AM ASKING FOR IS OUR SHOT AT IT BEFORE TIME RUNS OUT.”

Jenae Gallegos came home from her last day of school feeling unwell.

“She had flu-like symptoms,” remembers her father. “She had a cheeseburger for lunch and we thought it had made her sick.”

By the following morning, Jenae wasn’t responsive, and her parents, Tim and Sandra, knew something was very wrong. Three days later, Jenae, their only daughter, passed away in the hospital from a cavernous angioma hemorrhage. She was just nine years old.

A month later, the family learned Jenae’s cavernous angioma was the result of a mutation on the CCM1 gene, a specific mutation carried by tens of thousands of people in New Mexico. Sandra had the mutation which passed on to their daughter and, to the family’s horror, to their then four-year-old son Joel.

Only eight months after Jenae’s passing, Joel 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.

“So many times we feel helpless, like no progress is being made,” Tim says. “Our greatest frustration is that scientists know very little.”

Too late for Jenae, they feel they’re racing to find answers for Sandra, Joel and other suffering families. “I know there are many diseases out there. Many of these have had hundreds of millions of dollars of research done. Most illnesses are hard to crack, but they have had a good shot at doing so,” says Tim. “I guess what I am asking for is our shot at it before time runs out.”

Toward a Cure

ANGIOMA ALLIANCE HAS ALREADY CREATED GUIDELINES USED BY the medical community to standardize care. Our vision leads us to a cure for all cavernous angiomas. Our path is clear. To get there, we must have medications, not surgery. Angioma Alliance is preparing patients and creating a network of Clinical Centers where we can stage drug trials. We are developing ways to accurately assess and measure the effect of medications on a patient’s quality of life. We are working with drug companies and academic researchers to design drug trials that have the best chance of success. Soon, we hope to add a Medical Director to our staff to oversee this work.

We are undertaking big projects that save lives and improve the quality of care for thousands of CCM patients around the world. 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.



ANGIOMA ALLIANCE

because brains shouldn't bleed®

The Vision

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THIS VISION IS WITHIN OUR REACH.

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