



ANGIOMA ALLIANCE NEWSLETTER

because brains shouldn't bleed

Announcing: Accelerating Cures in 2021

In 2021, in addition to our existing programs, you are helping us to launch a major, critical effort to Accelerate Cures. It has taken researchers and the patient community years to develop all the pieces needed for multiple successful drug trials. Within the next two years, we will have everything in place: a robust and eager patient community, tools such as validated surveys and biomarkers that will measure the efficacy of a medicine, a network of Centers of Excellence to host trials, and a large pipeline of potential treatments. We now need to attract the attention of treatment developers (the pharmaceutical industry and others) in what is a very competitive field among rare diseases. We need to convey the message that we are ready, that a drug trial is feasible, and that developing treatments for CCM would bring a good return on investment

To that end, we plan to launch the Accelerating Cures program this year. At the time of this writing, we are seeking a Director of Industry Relations, a senior-level scientist staff member who will lead this effort by coordinating a critical examination of our current resources and who will engage in outreach to prospective industry partners. The Director of Industry Relations will be familiar with business development in the pharmaceutical sector as well as

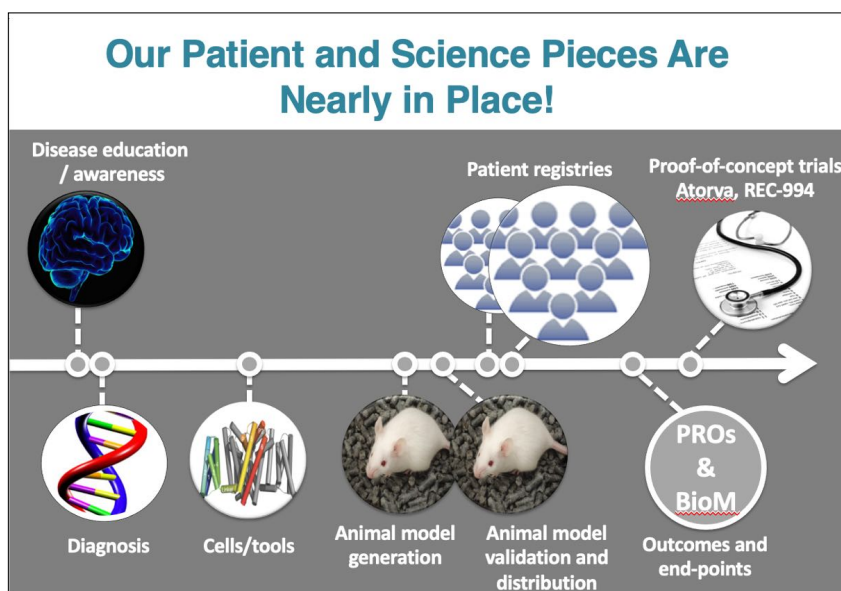
moving potential treatments from academic institutions to commercialization. The Director will assist in the development of clinical trials and, most importantly, will have a mission-driven mindset. We have no doubt the Accelerating Cures program will increase both the number of treatments and the speed of development. Other organizations that have chosen this approach have increased clinical trials dramatically, one even moving from four to 24 trials within three years.

In December, I presented a 25-minute webinar that introduced the program and explained exactly what is needed for a cure and how close we are to reaching this tremendous goal. I encourage you to take a few minutes to hear the good news and share our enthusiasm and hope (youtu.be/iGXQ8C_HXUY).

We are asking for your support to launch this critical initiative. There are two ways to help. First, your participation in our research efforts, through the patient registry and by clinical trial participation, is our path to treatments. Without your participation, there can be no cure; there is no one else who can get us there.

Second, Angioma Alliance will be launching a campaign specifically to raise funds to accelerate cures within our annual fundraising activities. Please look for a national gala in August, one in which you and your friends and family can participate because it will be both virtual and in-person, COVID-permitting, wherever you are. We'll sponsor other outreach events throughout the year. Our goal is to increase our fundraising by \$500,000 to ensure that the program and position can be sustained for three years. One gift at a time, this is achievable. We are excited to come together with you to reach our goal of BETTER TREATMENTS by 2025 and a CURE by 2030. With your support, nothing can stop us.

Connie Lee



COVID Update

If you have tested positive for COVID-19, please consider joining our COVID registry at www.angioma.org/COVID to share your experience. We are working with the University of Chicago and Mayo Clinic to create the only existing anonymous database of COVID outcomes for people with cavernous angioma. This will help us to understand whether our members are more likely to experience hemorrhage or other symptom exacerbation during or after COVID illness and whether their experience of the illness is different from the general population. Please join the registry even if you are an international patient.

Our numbers are small, but we have not yet seen any difference between cavernous angioma patients and the general public in severity of COVID illness in those who have reported. We worry that we may be missing the most seriously ill or those who have passed away. Please be sure to report to us any cavernous angioma COVID patients that you know who may not be able to report on their own.

The Angioma Alliance Scientific Advisory Board consensus statement regarding COVID-19 vaccination is below. We encourage you to become vaccinated as soon as this available to you. Dr. Issam Awad provided more detail and information in a late February webinar available on our YouTube channel (youtu.be/ZeV507lt-k).

Webinar: CCM Genetics and You

Cavernous angioma genetics can be confusing. The illness may be caused by hereditary genetic mutation or can occur spontaneously. Please join us on Thursday, April 22, at 7 pm ET, 4 pm PT, for a webinar with Dr. Connie Lee, Angioma Alliance President/CEO, to learn the basics of CCM genetics and genetic testing. This webinar is intended especially for those who are wondering whether they should be tested. It will include a discussion about the clinical differences between the genetic mutations, the pros and cons of testing, and details of the Angioma Alliance free genetic testing program. Pre-registration is required at bit.ly/CCMGenetics.

Consensus Statement by the Angioma Alliance Scientific Advisory Board about COVID-19 Vaccines

With approval by the U.S. Food and Drug Administration, long-awaited COVID-19 vaccines are now available. Based on exceptional effectiveness data (greater than 90% protection from COVID-19 illness), the durability of benefit after a recommended second dose, and minimal reported side effects in multiple phases of testing of each vaccine, we strongly recommend that the CCM patient community seek vaccination through any one of the approved vaccines, including any recommended follow-up dose.

There is no reason to believe that CCM patients will react any differently to these vaccines than the general population, and no scientific basis to fear the vaccine more than COVID-19, which has taken or interfered with so many lives.

Angioma Alliance Scientific Advisory Board

Dr. Issam Awad

*Chair, Angioma Alliance Scientific Advisory Board,
University of Chicago Neurosurgery*

Dr. Kelly Flemming

Mayo Clinic Rochester Neurology

Dr. Helen Kim

UCSF Anesthesia

Dr. Rustam Al-Shahi Salman

University of Edinburgh Neurology, UK

Dr. Kevin Whitehead

University of Utah Cardiology

Dr. Atif Zafar

St. Michael's Hospital Neurology, Toronto

Dr. Brent Derry

*Hospital for Sick Children Developmental & Stem Cell
Biology Program, Toronto*

Dr. Angeliki Louvi

*Yale University Department of Neurosurgery and
Neurosciences*

Health Equity: Breaking Barriers for Black Health Empowerment



It gives us great pleasure to announce a new member of our team and a new initiative within Angioma Alliance. Jessica Biggs has joined us as our Health Equity Program and Outreach Specialist.

Finding a cure for cavernous angioma is going to need everyone's participation and our goal is to improve care for everyone. Jessica's first job will be to help us find and engage African-American patients through our new Breaking Barriers Initiative (www.angioma.org/care-community/community/breaking-barriers-initiative/). The largest clinical and research databases of cavernous angioma (CCM) patients in the US contain a disproportionately small number of Black patients. We do not understand the reasons for this disparity yet, but we suspect it is the result of a combination of lower diagnosis rates and, possibly, mistrust of medical research efforts. With our new knowledge about interventions like diet and treating sleep apnea, it is more critical than ever that all patients receive timely diagnosis, information, and opportunities to participate in research and clinical trials. Additionally, FDA requires that our clinical drug trials include patients who represent the diversity of the population who eventually may be taking the medicine being tested.

Our plans include fostering a welcoming community among Black patients, working with our Centers of Excellence to train additional medical personnel in high-risk city hospitals, and forming partnerships with larger organizations, like the Epilepsy Foundation, to integrate CCM awareness into their existing outreach efforts. Jessica will also be working with researchers at the University of Virginia and the University of Chicago to better understand the barriers to care and research participation faced by Black patients. Finally, a goal of Breaking Barriers is to create tools that can be used by all of our members, such as a CCM-specific health tracking and emulsifier identification app.

Jessica will eventually be helping us with other DEI initiatives within our organization and our Centers of Excellence, and with outreach in New Mexico. Her work is being funded by a generous grant from the Julian Grace Foundation. You will see her co-facilitating many of our community activities, and we know that she's excited to meet you.

Jessica holds a Master's degree in Public Health and a Bachelor's in Nutrition and Food Science (which is important as we learn more about the impact of the gut microbiome on the illness). She has a long history in the community health and promotion field, working to improve socioeconomic and racial disparities within her local community, and has worked for local school nutrition programs, county organizations, and most recently the RUHS-Black Infant Health program. You can reach Jessica at jessica.biggs@angioma.org.

Adrienne Sheline, Clinical Research Specialist



We welcome Adrienne Sheline to our Angioma Alliance team. Adrienne is the Angioma Alliance team member who can respond to the request, "Tell us about your members" using data, and who can assist

researchers and industry in bringing this information to bear toward their work for better treatments. Adrienne is part of the Angioma Alliance research recruiting team, working to engage members as informed research participants and promoting research participation opportunities.

Adrienne holds a Master's degree in Public Health with a focus on health promotion and education, as well as many years of clinical research experience in pediatric neurosurgery. She has a great interest and passion for neurological research and loves working with both patients and their families. You can reach Adrienne at asheline@angioma.org.

Genetic Testing Program Reopens

Angioma Alliance's free genetic testing program was put on hold in March 2020 at the beginning of the pandemic. We have restarted the program and are accepting applications for genetic testing. To be eligible, you must have multiple cavernous angiomas that are not clustered around a DVA or the result of brain radiation for cancer. If someone in your family has already been tested and you are already diagnosed with cavernous angioma, you are not eligible because your mutation will be the same as your family member's.

As part of the application, you will need the signature of a doctor. This doctor will be the person receiving the genetic testing result; we are not allowed to release the result directly to you. The test is performed using a saliva sample; a kit will be mailed to your home.

If you are interested in testing, please enroll in our International Cavernous Angioma Registry (www.angiomaregistry.org) and let us know.

Our website offers extensive additional information about genetics and genetic testing, and we also have a genetics webinar on our April schedule (see page 2 for details).

Join Our Patient Registry

Even if you are not interested in genetic testing, please enroll in our International Cavernous Angioma Patient Registry (www.angiomaregistry.org). The patient registry is our way of communicating new research results and new research opportunities to you. It is also how we understand our patients' experience and convey this to clinical researchers and to drug companies who are planning trials. Participating in the patient registry is one of the most important ways you can contribute toward a cure.

We are here for each other...

Even in the time of COVID, our Angioma Alliance patient community has been busy organizing and supporting each other.

Our private Facebook group now has 5,500 members who engage in lively, ongoing discussion. We run additional groups for sub-populations including parents, those with brainstem or spinal lesions, or those who have ongoing serious disability as a result of their illness.

On Thursdays, we host a live support group via Zoom. The group is attended by both new members and long-term members who have the opportunity to share and receive feedback while seeing each other. The group is facilitated by Darla Clayton and Lindsay Ramirez, our Community Outreach Specialists. New in 2021, we are hosting a monthly teen and young adult Zoom group. This is a chat and game group; a fun way to meet and get to know each other. The first Thursday of each month, we host CCM101, an educational group for those who are newly diagnosed. Registration for Zoom groups is required. You can find more information on our website and on Facebook.

Finally, our Community Alliances are offering online programming and hope to host in-person gatherings by fall. We welcome two new Community Alliances—the Greater Chicago Angioma Alliance Community and the Greater Kansas City Angioma Alliance Community—who will be moving forward the mission in their local areas.

For more information about Community Alliance and support opportunities, please visit the Care and Community section of our website or email Lindsay Ramirez at lindsay@angioma.org or Darla Clayton at darla@angioma.org.

Our 2021 Theme is Resilient

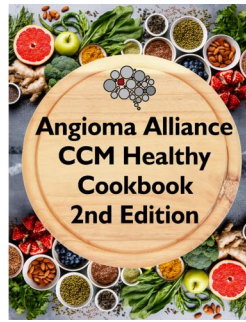
Each year, our Angioma Alliance patient community selects a theme word by popular vote. With the extra challenges of the last year for our families, it seemed natural that our 2021 word would be Resilient. Our members have demonstrated their resilience as they experienced brain surgery alone because of COVID restrictions, as they rehabbed at home on their own rather than with physical therapists, as they were homeschooling while battling medical challenges, and as they offered support to other members who were carrying even heavier burdens, time and again.

Our community has grown significantly over the past year, and we're looking forward to a time when we can be together again for walks and meetups. If you'd like to get prepared early, or just show your own resilience, you can get an Angioma Alliance Resilient t-shirt in our online store at shopangiomaalliance.bigcartel.com.



While you are shopping for your shirt, don't forget to check out our other offerings, including our patient booklets, wristbands, awareness kits, and more. Please check back frequently for limited time offerings like women's v-neck t-shirts and Angioma Alliance hoodies. Your purchases help to raise awareness and support our work toward a cure.

CCM-Healthy Cookbook 2nd Edition is available



Research has taught us that gut health directly affects CCM disease. Specifically, preservatives and emulsifiers can damage the gut lining, and can create systemic inflammation by allowing gram-negative bacteria to escape the gut. This

inflammation is thought to be a factor in the development of new cavernous angioma lesions in those with the familial form of the illness and in the activity of lesions, including hemorrhage, for everyone with CCM.

Changing your family's diet is hard and can be confusing. To help our members, Angioma Alliance has created a digital book that:

1. Explains the research,
2. Supplies a list of potentially harmful product ingredients to be avoided,
3. Offers a list of some "safe" United States brand name products and alternatives in difficult-to-find categories. For example, did you know that most almond milk brands contain emulsifiers? We found that Malk and Three Trees brands do not. (Angioma Alliance does not receive compensation from any brand.)
4. Provides nearly 100 recipes to get you started. These recipes were submitted both by members and by professional chefs in the following categories: Main Courses in a Hurry, Holiday and Comfort Foods, Breakfasts, and Desserts.

Additionally, we've indicated which recipes are gluten-free, vegetarian, egg-free, dairy-free, and refined sugar-free.

Cooking without preservatives and emulsifiers is one thing you can do to take charge of your CCM illness. We hope our cookbook and reference offers you a jump start on your way to CCM health. You can purchase the digital download in our online store at shopangiomaalliance.bigcartel.com.

Research Update

New Research on Pregnancy and Cavernous Angioma

A new study, published in the journal *Stroke*, investigated whether pregnancy increases hemorrhage risk for women with cavernous malformations (cavernous angioma, cavernoma). Results showed that hemorrhage risk does not appear to increase during pregnancy. Furthermore, the study indicated that vaginal delivery appears safe in women with cavernous malformations if they don't have other significant health issues that warrant caesarian section.

This study, conducted by Mayo Clinic, examined prospectively collected data from 160 women who were part of a larger cavernous malformation registry database. The goal was to assess the influence of pregnancy on the risk of hemorrhage after cavernous malformation diagnosis, during pregnant and non-pregnant states in women of childbearing age.

In total, 365 pregnancies were analyzed among the 160 women followed, all of whom had a brain or spinal cord cavernous malformation. Only 4 of the 160 women experienced a hemorrhage while pregnant. None experienced hemorrhage during delivery. Among the four women who hemorrhaged, all were diagnosed with a cavernous malformation as a result of the hemorrhage during pregnancy, rather than before the pregnancy. Thirty-two of the 160 total women became pregnant after their diagnosis of cavernous malformation and none of these women experienced a hemorrhage during pregnancy.

Similar studies conducted by researchers in the past also found that the incidence rate of hemorrhage occurring while pregnant was very low in women with known cavernous malformation. Furthermore, no cases of hemorrhage during delivery were found in any other published research.

Co-author of this article, Dr. Kelly Flemming, explains the importance of this research: "We have confirmed with this paper what others have published regarding pregnancy and cavernous malformation, which is that the risk of bleeding during pregnancy is not increased. We used a slightly

different methodology than prior investigators by assessing the risk of pregnancy only AFTER the diagnosis of cavernous malformation was made. We are also reassured that vaginal delivery is safe in most patients."

Although more research needs to be done to further examine cases of women that do experience a hemorrhage while pregnant, and formal guidelines need to be developed to manage their care, this research can help women with cavernous malformations, and their doctors, to feel more comfortable and confident while making important family planning decisions.

Joseph NK, Kumar S, Brown RD, Lanzino G, Flemming KD. Influence of Pregnancy on Hemorrhage Risk in Women With Cerebral and Spinal Cavernous Malformations. *Stroke*. 2021 Jan;52(2):434-441.

Propranolol treatment of CCM animal models reduces the number of lesions and stabilizes leaky vessels; no evidence for an effect on hemorrhage

The beta-blocker propranolol is a safe and effective treatment for high blood pressure and chest pain. In recent years, it has also proved effective for treating infantile hemangioma (a type of birthmark). Anecdotally, several case reports demonstrate regression of particularly aggressive cavernous angiomas by treatment with propranolol.

A two-year clinical trial is currently running in Italy to investigate the effect of propranolol on cavernous angioma patients. However, the mechanism of action and the biology behind how this drug may be impacting the disease course remains unclear.

Two recently published studies offer support for further investigation of propranolol as a potential treatment for cavernous angioma. The following summarizes the research from the Dejana group in Uppsala, Sweden, and the collaborative team from Duke, the University of Chicago, and UCSD.

Both study teams used fish and mouse models. Zebrafish with *Ccm2* gene mutations develop lesions

during embryogenesis. Treatment with propranolol was shown to reduce the number of developing lesions.

Mice with CCM3 gene mutations were studied because they are the most robust models that develop lesions at an early stage of life. Mice were treated either from birth through their mother's milk, or from the time of weaning. Treatment groups ranged from two weeks to three months, with several drug dosages. In all cases, researchers showed a reduction in the number of large lesions that developed with the drug treatment. Notably, the number of multi-cavernous mature lesions was significantly reduced. The number of Stage One dilated vessels was not found to be different between treated and untreated mice. This finding suggests that the drug treatment may slow or stop the progression of lesions rather than blocking their initial development. Notably, the study teams did not observe any effect on bleeding or any lesion shrinkage, but the study design may have limited the ability to see these effects, if they do exist.

Electron microscopy was used to investigate the ultrastructure of the cells within the lesion. Using this technology, the Swedish team showed that propranolol restored vascular stability by tightening cellular junctions and normalizing cellular support structures.

In summary, these findings provide biological support for clinical trials of the beta-blocker propranolol as a treatment for cavernous angioma. Further research focusing on a broader range of doses, dose-escalation, and/or extended treatment periods may help address the unanswered questions related to hemorrhage and the shrinking of existing lesions.

Wenqing Li et al, Propranolol inhibits cavernous vascular malformations by β 1 adrenergic receptor antagonism in animal models. *J Clin Invest*. 2021 Feb 1;131(3):e144893. doi: 10.1172/JCI144893.

Joppe Oldenburg et al, Propranolol Reduces the Development of Lesions and Rescues Barrier Function in Cerebral Cavernous Malformations: A Preclinical Study. *Stroke*. 2021 Feb 23;STROKEAHA120029676. doi: 10.1161/STROKEAHA.120.029676. Online ahead of print.

Cavernous Angioma Patients Found to Have High Prevalence of Allergic Diseases

A leading German research group was interested in determining whether people with cavernous angioma have higher rates of two co-morbidities: cardiovascular disease and allergic disease. They studied 1,352 patients who were seen at a single institution and compared the data they collected on these patients with age- and gender-matched samples from the general population.

The researchers found that cavernous angioma patients do not appear to have higher rates of cardiovascular risk factors. However, the cavernous angioma patient group overall had a much higher rate of allergic disease than the general population. 30% of all cavernous angioma patients had allergic diseases versus 20% of the general population. Within the cavernous angioma group, those with sporadic cavernous angioma had highest rates of allergic disease. 32% of sporadic cavernous angioma patients had allergic disease while 22% of those with familial disease did.

Why is this important? An allergic reaction is an immune response, and there is significant research indicating that immune responses play a role in cavernous angioma disease. The research on the higher prevalence of allergic diseases in people with cavernous angioma provides additional support for the hypothesis that immune response is involved in the development of cavernous angioma lesions.

Philipp Dammann et al, Cerebral cavernous malformations: Prevalence of cardiovascular comorbidities and allergic diseases compared to normal population. *Eur J Neurol*. 2021 Mar 19. doi: 10.1111/ene.14833. Online ahead of print.

Patient Experience: The Loden Twins

My identical 16-year-old twins are just like any other teenagers. They love cheerleading, their friends, and spending an absurd amount of time on their hair. Overall, they are great girls. They are juniors in high school and get mostly As and Bs with the occasional C for good measure. We get no trouble from them and, while I'm sure they roll their eyes at me from behind the closed bedroom doors when I remind them to get off the phone and go to sleep, they never talk back.

Freshman year brought about the revelation that they both want to be Lumberjacks and attend NAU in Flagstaff, a 3-hour drive from home. They will room together and know the ins and outs of the in-state scholarship programs to help alleviate at least some of the costs of twins in college. See, I told you they are great kids.

In October of 2020, I got a frantic call from one of my girls that changed the course of our lives forever. Kendall was calling to let me know that Kaydence had a seizure in class, and they called 911. With shaky hands and a lump in my throat, I raced to get Kendall from school and meet the ambulance at the hospital.

After a thorough exam, loads of questions, and a CT, we were transferred to Phoenix Children's Hospital. Several hours, dozens of doctors, and a bunch of tests later, neurosurgeon Dr. David Shafron came in and asked if anyone had explained what was going on. He told me that Kaydence has a rare brain disease called familial CCM and explained what that means.

It seemed she had a bleed in her sensory strip and there was a nearby lesion of a similar size in her motor

strip. Since she is an identical twin, he urged me to have her twin scheduled for an MRI to confirm her presumed diagnosis and make sure she was stable. He wrote down a bunch of information, including the Angioma Alliance website, along with his cell phone number. He told me he would be in touch after he brought her case to conference with his peers.

I spent every free moment online looking for any sign of hope I could find. We all felt completely overwhelmed knowing that surgery was likely. I mean, whose kid has brain surgery? I watched every

video of Dr. Awad's lectures that I could find on YouTube and researched all about Barrow and Dr. Lawton so I could ask for a second opinion, no matter what Phoenix Children's Hospital said.

It's a good thing, too. Because on December 15, 2020, Kaydence went in for her resection at Barrow Neurological Institute with Dr. Lawton, with Dr. Shafron assisting. She had 2 lesions removed right next to each other, measuring just under 2 cm each. She has spent many hours in rehab since, and she makes progress every day. Just

a few days after her surgery we got her genetic results documenting her CCM1 mutation, confirming what we already knew. Her twin obviously has this disease as well.

Able to breathe a small sigh of relief now that Kaydence was out of immediate danger, we got Kendall's scans done on January 14, 2021 late in the afternoon. When I saw the family doctor's number on



my phone the next morning, I knew. I just knew. I could feel it in my bones. We had to do this again.

Our primary care doctor seemed incredibly concerned and was asking all kinds of questions about Kendall. Is she having any one-sided weakness, any slurred speech, any paralysis or tingling? She was asking without asking if my 16-year-old daughter was showing any signs of a stroke. She was not.

Like her twin, she suffered from migraines, even as a young child. Otherwise, she had been healthy, like her twin. Not knowing what to do, I sent the scans over to Dr. Shafron and asked if he thought I should be as alarmed as our primary care doctor thought. I asked him to send the scans and report to Dr. Lawton directly if he thought it was necessary. Otherwise, I would be in touch with his office on Monday. He very honestly told me that he felt the size of two of her lesions were cause for concern. It appeared that one of them was bleeding now and had bled in the past. He sent everything over to Dr. Lawton who tacked a consultation for Kendall onto Kaydence's upcoming post-op follow-up, and we were off to the races.

After a long conversation with Dr. Lawton, an even longer conversation with Dr. Shafron, and advice from some of the most supportive parents I have ever "met" on the Angioma Alliance Parent Facebook page, we opted for surgery based on the size of the largest lesion and the fact that it had bled at least twice by that point.

Kendall watching Kaydence have a seizure at school and seeing the toll it took on her after was enough to give her the insane amount of courage it took for her to

say the words aloud. She wanted to have the surgery and be proactive. She wanted to feel like she had some kind of control over something. I can't say I blame her; for the record, I was leaning that way myself. Her twin was driving a car just two hours prior to her own seizure. The thought of that happening on the road with Kendall was enough for me.

So, on March 4, 2021, we went in for yet another craniotomy. Kendall had her 2.7 cm frontal lobe lesion removed by Dr. Lawton at Barrow. Despite my efforts, we did *not* get a BOGO and I do *not* have VIP parking at the hospital. Kendall was somewhat of a celebrity though. Loads of nurses and doctors commented on "the twins" throughout the ordeal. Some were confused about why "she" was back so soon, not realizing she was one of "the twins."

Kendall's MRI came back confirming they got every bit of that frontal lobe lesion out. We will monitor her other big one. She is recovering well at home and hopes to be in school soon with her sister.

This is our life now. We are a wait-and-see family. We make

plans to go on trips with the understanding that travel insurance is now a requirement. We watch for updates on clinical trials around the world, and we now use the Angioma Alliance as our go-to charity. Our life is very different than what we thought it would be. Our girls are not out of the woods. They may never be entirely. But because of Angioma Alliance, we have hope. We have hope that one day there will be a cure for our family and so many others who so desperately need one.



Megan Loden

New Mexico's Baca Family Historical Project: Transitions

Cerebral cavernous angioma is more prevalent in descendants of the original Spanish settlers of New Mexico than anywhere else in the world. A specific founder mutation of the CCM1 gene, called the Common Hispanic Mutation, has been passed down through the generations, since the early 1600s. All the families that share this very specific mutation of the CCM1 gene are thought to be related to a single common ancestor. We believe that 30-40,000 patients with the Common Hispanic Mutation live in New Mexico.

In 2006, Angioma Alliance began our work in New Mexico with a patient conference in Santa Fe that attracted more than 100 affected individuals who came together to hear from medical experts and researchers. Our goals were to increase awareness among the public and policymakers, to improve care, and to offer support. However, for many reasons, it was difficult for us to get a foothold in the state.

In 2016, Joyce Gonzales, a New Mexico CCM patient and amateur genealogist, made a striking discovery. She found that all the families she knew could be traced back to a single couple, Cristóbal Baca and Ana Maria Ortiz, who came to New Mexico in the year 1600. With insight

into the founding family, an understanding of the deep significance of historic family ties among Hispanic residents of New Mexico, and generous funding from the Julian Grace Foundation and Global Genes, Angioma Alliance was able to begin an outreach program within New Mexico to explore genealogy and build community. Thus, the Baca Family Historical Project was born, and Nora Chavez, our Community Outreach Specialist, was hired to give it life.

After four years of hard work in New Mexico, we have made enormous strides in raising awareness and increasing diagnosis rates. Now, you would be hard-pressed to find a descendant of the original Spanish settlers in New Mexico who has not heard of "CCM1," as the illness has been dubbed there. Our work included public workshops in which we offered historical and disease information as well as assistance with family trees and genetic testing. We trained more than 1,000 medical providers and worked with the state to increase research and improve care. Finally, we took to the airways, particularly as COVID eliminated in-person events, reaching thousands through TV, radio, and newspaper coverage.

As of December 31st, 2020, our Baca Family Historical Project has officially ended, but the work continues. A New Mexico Angioma Alliance Community has formed to carry forward public outreach efforts and legislative advocacy. As clinical trials and approved treatments become available, the many New Mexican patients will reap the benefits of the success they have had in bringing CCM1 out of the shadows in their state.



Baca Family Historical Project by the Numbers

- Hosted 87 public conferences and workshops with a total of 8,734 attendees
- Trained 1,060 community health workers (*Promotoras*) including CHWs from New Mexico, Texas, and Mexico
- Provided free genetic testing to 290 families
- Featured in 20 newspaper, radio, and television stories
- Increased the number of CCM1 patients seen at the University of New Mexico from 29/year to more than 300/year
- Genealogy database grew from 17,000 to 30,000 ancestors
- Initiated eight in-person meetings and countless calls with the New Mexico Department of Health to improve healthcare around the state

How You Can Help

Volunteer: Share your talent and time in any number of ways including Community Alliances, peer support, events, legislative advocacy, and much more: www.angioma.org/care-community/community/volunteer/.

Donate: Your contributions help fund our research initiatives toward a cure and our patient support programs. To donate, please send a check or money order in the enclosed envelope or visit our website at www.angioma.org to donate with a credit card.

Sponsor: Sponsorships can maintain essential programs or help us expand our support for the patient and research community. Sponsors are acknowledged with logo placement, naming opportunities, or appropriate other recognition. Contact us at info@angioma.org to learn more about these opportunities and valuable benefits for your company.

Our Mission and Goals

It is our mission to inform, support, and mobilize those affected by cavernous angioma and drive research for better treatments and a cure. We do this by developing and executing strategic, creative, high-return interventions as a model for rare diseases:

1) **Facilitate and participate in cavernous angioma research to achieve a complete understanding of the disease** and facilitate clinical drug trials and other treatment improvements. We do this through our Accelerating Cures program, Scientific Meetings, patient registry and biobank, genetic testing program, research collaborations, and outreach to special populations.

2) **Provide disease and resource information** to educate and improve the lives of people affected by cavernous angioma, caregivers, health professionals, researchers, policymakers, the media, and the general public. We achieve this through our website, publications, webinars, conferences, and media appearances.

3) **Foster and promote a caring community to provide support.** We offer live and online support opportunities and broad international outreach.

4) **Get people involved in advocacy and active participation toward a cure.** Involvement can include activities like research participation, Community Alliances, our upcoming Patient-Expert Certification, legislative advocacy, and public events.

5) **Build and sustain a broad base of funding sources to support our mission and goals.** We count on you!



**ANGIOMA
ALLIANCE**

About Angioma Alliance

Angioma Alliance is a non-profit, international, patient-directed health organization created by people affected by cerebral cavernous angiomas (also known as cavernous malformations or CCM). Our mission is to inform, support, and empower individuals affected by cavernous angioma and drive research for treatments and a cure. We are monitored closely in our educational efforts by a Scientific Advisory Board comprised of leading cerebrovascular neurosurgeons, neurogeneticists, and neurologists.

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A copy of the latest financial report, registration filed by this organization and a description of our programs and activities may be obtained by contacting us at: Angioma Alliance, 520 W 21st St STE G2-411, Norfolk, VA 23517, info@angioma.org. If you are a resident of one of the following states, you may obtain financial information directly from the state agency.

- Florida – A COPY OF THE OFFICIAL REGISTRATION AND FINANCIAL INFORMATION MAY BE OBTAINED FROM THE DIVISION OF CONSUMER SERVICES BY CALLING TOLL-FREE, WITHIN THE STATES, 800-435-7352 (800-HELP-FLA) OR BY VISITING www.800helpfla.com. REGISTRATION DOES NOT IMPLY ENDORSEMENT, APPROVAL OR RECOMMENDATION BY THE STATE. Florida Registration CH20096
- Georgia – A full and fair description of our programs and our financial statement summary is available upon request at our office and email indicated above.
- Colorado – Colorado residents may obtain copies of registration and financial documents from the office of the Secretary of State, 303-894-2860, www.sos.state.co.us/ Reg. No. 20063003635.
- Maryland – For the cost of copies and postage, from the Office of the Secretary of State, State House, Annapolis, MD 21401.
- Michigan – MICS # 35000
- New Jersey – INFORMATION FILED WITH THE ATTORNEY GENERAL CONCERNING THIS CHARITABLE SOLICITATION AND THE PERCENTAGE OF CONTRIBUTIONS RECEIVED BY THE CHARITY DURING THE LAST REPORTING PERIOD THAT WERE DEDICATED TO THE CHARITABLE PURPOSE MAY BE OBTAINED FOR THE ATTORNEY GENERAL OF THE STATE OF NEW JERSEY BY CALLING 973-504-6215 AND IS AVAILABLE ON THE INTERNET AT: <http://www.state.nj.us/lps/ca/charfrm.htm>. REGISTRATION WITH THE ATTORNEY GENERAL DOES NOT IMPLY ENDORSEMENT.
- New York – Upon Request, Attorney General Charities Bureau, 102 Broadway, New York, NY 10271
- North Carolina – Financial information about this organization and a copy of its license are available for the State Solicitation Licensing Branch at 919-807-2214. This is not an endorsement by the state.
- Pennsylvania – The official registration and financial information of Angioma Alliance may be obtained from the Pennsylvania Department of State by calling toll-free within Pennsylvania 800-732-0999. Registration does not imply endorsement.
- Virginia – State Division of Consumer Affairs, Department of Agriculture and Consumer Services, PO Box 1163, Richmond, VA 23218.
- Washington – Secretary of State at 800-332-4483 or <http://www.sos.wa.gov/charities/>. REGISTRATION WITH A STATE AGENCY DOES NOT CONSTITUTE OR IMPLY ENDORSEMENT, APPROVAL OR RECOMMENDATION BY THAT STATE.