ANGIOMA ALLIANCE NEWSLETTER
because brains shouldn't bleed®

Drug Trials Are Here: Our Priorities Together

The turn of the new year also brought the exciting launch of our upgraded Susan Sukalich International Cavernous Angioma Patient Registry (www.angiomaregistry.org). The original patient registry, introduced in 2010, is the largest of its kind, hosting data from over 1,500 registrants. The data we have gathered has helped us learn more about our patient community while propelling research towards improved treatments.

For example, by analyzing patient data we learned that patients are more likely to experience a second hemorrhage within two to three years following an initial bleed. This insight has helped guide the study design of the first clinical trial currently underway for the treatment of these cavernous angiomas. The goal of this trial is to evaluate the effectiveness of the drug atorvastatin on the stabilization of cavernous angiomas that have recently hemorrhaged.

More information about the atorvastatin trial, including eligibility criteria, can be found here angioma.org/pages.aspx?content=586.

We need your help

The number of research projects has grown as a result of the robust patient registry. This is great news, but we are determined to learn even more about cavernous angioma, and this requires the help of our community. Efforts by our team are underway to grow the registry to 2,500 participants by the end of 2019. This goal is so important that we are reaching out to media outlets around the country to help us identify new patients, encourage them to join our registry, and become involved in future research.

If you are curious how you can contribute to Angioma Alliance's efforts, joining the registry is a wonderful way to make an impact. We are also encouraging existing members to update their accounts by spending a few minutes answering new survey questions. Increased participation will enable us to discover more than ever before about the history and behavior of cavernous angioma, as well as how patients are affected.

Benefits to enrolling and how to register

Enrolling will offer you an opportunity to be matched with research studies, clinical trials, and other online surveys developed by researchers working to discover new treatments. Don't worry, no identifiable information will be shared, and you will only be contacted by us if you meet specific criteria. Additionally, you will be able to view summarized data that helps us look for new trends, offering you a unique chance to see how this condition affects our community.

To join the registry, create a profile, then answer two surveys that will take approximately 20 minutes to complete. The first survey collects information about medical history and experience with the condition, and the second asks about additional diagnoses you may have. You will then be invited to participate in shorter periodic progress surveys that will be beneficial for tracking outcomes over time.

New Researcher Portal

With more trials and clinical research protocols on the horizon, we have added a new researcher portal to the site. Researchers can now apply to gain access to de-identified patient data and submit research proposals to be placed within the registry. With permission, the registry will be utilized to connect patients to researchers conducting studies to advance our progress towards effective treatments and a cure. To learn more about current research projects visit: www.angioma.org/pages.aspx?content=375

We are grateful for the generosity of the Be Brave for Life Foundation, and Sara Sukalich and Matt Mingione; their funding has helped make this upgrade possible. To learn more about the patient registry visit www.angiomaregistry.org. You may also contact us at coordinator@angioma.org for questions about your account or to learn more about signing up.

Kristen Dahlem

Upcoming Events

Our communities are revved up and ready for action! We invite you to attend, support, and volunteer to make these events throughout the country a success. For more information on any of these events go to angioma.org/events. We would also like to welcome our two newest Community Alliances, the Texas Community Alliance and the Southern California Community Alliance, both of which already have events planned.

Rare Disease Day Art Auction

February 26-28, online at www.facebook.com/artforangiomaalliance

This online auction features art created by cavernous angioma patients and their family and friends. Tune in to Facebook on February 26; the bidding ends on Rare Disease Day, February 28. Show your support by donating a piece of your artwork and/or bidding on some of these amazing pieces.

Texas Community Alliance Meetup

Saturday, March 9, Dallas/Forth Worth, TX

Join the newly formed Texas Angioma Community Alliance as they gather to connect with others who are affected by cavernous angioma. Dr. Jan-Karl Burkhardt, MD, Assistant Professor of Open Vascular and Endovascular Surgery, Department of Neurosurgery from Baylor College of Medicine will speak. There will also be plenty of time for Q&A and connecting with others. Dinner will be available for a $15 suggested donation. RSVP by 2/22 to txangioma@gmail.com.

Sand Flea Rally Meetup

Saturday, April 27, Cloverdale, OR

Join the Northwest Angioma Community Alliance for a meetup at the Sand Flea Rally held on the sand dunes. This obstacle race for 4x4s & Jeeps is family friendly and free. Many Jeeps are branded with Brains Shouldn't Bleed stickers in support of our mission. This is a great opportunity to connect with others who are affected.

Mark your calendars for these Fall events:

- Torrington, CT Winetasting, September 27
- Denver, CO Zombie Walk, late September
- Mission, Viejo, CA Walk, September 15
- Malibu, CA Walk, October 13

Kickin' It for a Cure Kickball Tournament

Saturday, May 4, Houston, TX

This event is hosted by the Texas Angioma Community Alliance and Jonathon & Brandy Ott in honor of their son, Kelan, who has cavernous angioma. This family-friendly kickball tournament will take place at Bear Creek Park. The cost to participate is $30/pp or $100/family of four. You can also watch from the sidelines and eat for a $10 donation.

Pig Roast & Toast

Saturday, May 4, Hillsborough, CA

This pig roast and BBQ is hosted by Jodi & Isaac Babbs, whose son, Lukas, has cavernous angioma. Highlights include a roasted pig, chicken sh** bingo, spirits/beer/wine tastings and cowboy/honky tonk music by Jake Neuman, 21, from Bakersfield who has cavernous angioma. $150/ticket.

Brains Shouldn't Bleed® Benefit Concert

Thursday, May 9, Pittsfield, MA

This fundraising and awareness benefit concert at The Garage in Pittsfield, MA, is hosted by Tyler Fairbank, who has cavernous angioma. His band, T-Bone Daddy, will play to celebrate his CCM journey and honor other CCM warriors. Tickets are $25 each.

Cavernous Angioma Game at Great American Ballpark

Sunday, June 16, Cincinnati, OH

Bring your dad/son for this Father's Day game where the Reds play the Rangers. This is the fifth year that Cari & Tony Mayer have held this fundraising and awareness event in honor of their son, Dylan, who has cavernous angioma. Tickets are $20 each.

Mets vs. Yankees Game

Wednesday, July 3, Queens, NY

Join the Tristate Angioma Community Alliance as we raise funds and awareness for those affected at this subway series game. The first 100 tickets sold will have an on-field photo opportunity before the game. Limited tickets available. Prices from $70 for Promenade ticket to $210 for Field Box.

Stephanie Alband

Atorvastatin Clinical Trial Webinar

This update, presented by the Florida Angioma Community Alliance, features Dr. Issam Awad, MD, MSc, FACS, founding Chairman of the Angioma Alliance Scientific Advisory Board and John Harper Seeley Professor of Neurosurgery and director of Neurovascular Surgery at the University of Chicago.

During this live webinar, Dr. Awad will provide updates on the first-ever clinical trial for cavernous angioma hemorrhage which began enrolling in September and will answer questions. You'll also hear from one of the trial participants. Please register to join us!

The webinar will take place on Monday, February 25 at 7 pm EST, 4 pm PST.

Register at https://tinyurl.com/cashtrialupdate.

2019 Shirts Now Available

Get your 2019 Angioma Alliance gear! This year's theme is BRAVE. Shirts are $15 + $5 shipping. Receive free shipping when you buy two shirts or spend $30 on other gear. Enter the code SHIPFORFREE at checkout. There's lots of other gear available including awareness bracelets, swag bags and more!

Help Raise Money on Facebook

You don't have to wait for your birthday. A Facebook fundraiser is a great way to mark any occasion and raise awareness at the same time. Thank you for your help toward a cure!

2018 CCM Scientific Meeting Overview

The 2018 CCM Scientific Meeting held in November continued on a great tradition of success: we had over 100 attendees with representatives from five continents, five drug companies, three advocacy organizations, government officials, and an international consortium of clinicians and scientists.

There were two other landmarks. For the first time, we had more presentations dedicated to CCM clinical research than to animal models of the illness or basic biological building blocks. This allowed us to dedicate an entire meeting day to topics focused on treatments and on understanding the impact of the illness in humans. Also, for the first time, we held a concurrent national patient conference that allowed researchers and patients to meet each other over lunch and attend a joint session. The shared time was appreciated by both groups and may be included again as our budget allows.

A unique feature of this meeting is our focus on unpublished research and lively discussion. With a strong privacy policy in place, our researchers feel comfortable sharing with one another, engaging in discussion and developing new hypotheses and collaborations. These collaborative efforts have led us to where we are today: recruiting for our first clinical trial for hemorrhage, our first Phase I trial for safety, and with a whole host of new drugs and druggable targets.

The following is an overview of the meeting proceedings. As each new study is peer-reviewed and published, we will share the details through my Facebook page (facebook.com/AmyAkersPhD), website blog, and Angioma Alliance's newsletters.

New Drug Targets

Basic science continues to charge forward, uncovering new druggable pathways, identifying currently approved drugs that might be repurposed for CCM, and bringing hope for translation from the lab to clinic. Bringing together so many scientists from different backgrounds draws out unique perspectives and leads to exciting discussion. Each model system provides information about the functional biology of the CCM proteins (those that are disrupted and no longer function in the cavernous angioma lesions). Zebrafish models are great for studying vessel biology: baby fish develop in clear eggs and have transparent bodies making them uniquely suited for studies that fluorescently label cells to track the development of vascular systems with advanced microscopy. We also heard from worm and fly research teams. Rapid growth and short generation time are features that make these systems ideal for quickly screening large drug libraries and studying the biology of tube formation.

Several academic labs have developed genetic models for all familial forms of CCM in mice. Mouse studies help us learn about lesion formation and are the model used for drug treatment studies. At the meeting, we heard from two groups who looked closely at the lesion to investigate their cancer-like nature. In recently published work, the team at Duke University used advanced microscopy and a florescent tracking system to show that from the very earliest stage of development, CCM lesions (in the familial form) start with an inherited plus a random (somatic) mutation. In combination, these two mutations completely destroy the function of one of the CCM genes in a brain blood vessel cell. These mutational events change the cell such that it starts to grow like a cancer. As it becomes a mature multi-cavernous large lesion, those mutant cells also recruit non-mutated blood vessel cells into the lesion. How the recruitment occurs remains unknown.

In recent years, there has been a lot of work on the Rho Kinase (ROCK) signaling pathway and how the molecules of that pathway are involved in CCM lesion development. ROCK inhibitors emerged as leading candidates for drug therapy. Atorvastatin (a ROCK inhibitor) is currently in clinical trials for hemorrhage of cavernous angioma (more on that later).

There are many other signaling pathways involved in a complex regulatory network. For the first time, we heard about the new work out of Centenary Institute in Australia showing that a leukemia drug, Ponatinib, is able to prevent lesion formation in CCM mice by disrupting a critical (MEKK3-KLF) signaling pathway. Adding yet another possible drug target to the growing list for CCM, Ponatinib is approved by the FDA as a cancer drug. However, this drug targets more than just MEKK3-KLF and is known to have negative side effects, which make it inappropriate for cavernous angioma treatment. Further studies may determine whether Ponatinib, or perhaps a new generation of this drug, or a new MEKK3-KLF inhibitor might be best suited for human study.

Natural History & Biomarkers – Studies to Prepare for Large Clinical Trials

We use the term natural history to refer to the typical clinical course of an illness over time, when an affected person is left untreated by drugs or surgical intervention. We are beginning to better understand the natural history of cavernous angioma, but one of the major challenges we face is to truly understand the variability between patients, particularly those within families who carry the exact same disease-causing mutation. Major questions include what risk factors or other medical conditions may be associated with future hemorrhage and/or lesion development.

The Brain Vascular Malformations Consortium study is focused on studying variations of familial cavernous angioma. We heard talks and viewed poster presentations from this project team related to studies of spinal lesions, hemorrhagic risk factors, and causes of death. Investigating the microbiome in all patients (sporadic and familial) is another ongoing study related to variation and natural history, for which we discussed preliminary data. Another active area of investigation is on quality of life; the team from the Mayo Clinic was recently recruiting for an online survey-based study to learn about the quality of life for folks with brainstem lesions. The importance of understanding natural history relates to clinical management and also clinical trials. By knowing what outcome to expect over time, one can thoughtfully predict drug effects and design clinical trials that enroll the right number of people to prove a drug's efficacy.

A biomarker is something that is measured either as an indicator of disease course or response to a drug or surgical intervention. Biomarkers can be relevant in the clinic to predict future disease state, or during clinical trials to measure the effect of the drug treatment under study. Previously, Dr. Awad's team at the University of Chicago had identified a series of chemical biomarkers measured from blood plasma that are predictive of future hemorrhage. We heard about the latest findings as his team continues to expand the biomarker set and refine the use of this tool for use in diagnosis. Future FDA qualification can move plasma biomarkers into everyday clinical practice.

Another biomarker type of keen interest for clinical trial, particularly trials of symptomatic hemorrhage, is imaging. Specialized MRI techniques to measure permeability and iron leak (surrogate for hemorrhage) are developed and in use at the University of Chicago for research and the atorvastatin trial. A new study, the CASH (Cavernous Angioma of Symptomatic Hemorrhage) Clinical Trials Readiness Project, brings together six clinical sites (Universities of Chicago, New Mexico, California San Francisco, and Utah, as well as the Mayo Clinic and Barrow Neurological Institute) to validate use of the imaging biomarkers at partnering institutions and to understand better the potential pool of study participants at each site. As the name implies, the purpose of project is preparation of future large-scale multi-center clinical trials.

Clinical Trials

It was exciting to learn about the projects of our clinical research groups. BioAxone BioSciences continues progress with safety and animal studies to prepare for human studies. For the first time, a new chemical entity is being tested for safety as Recursion Pharmaceuticals announced it has moved their drug REC-994 (tempol) to a Phase I trial. Phase I studies are for new drugs, and involve healthy volunteers, not cavernous angioma patients, to determine whether the drug is safe for human use. With positive safety results, REC-994's next step will be Phase II to determine whether the drug is effective in treating CCM patients. Representatives from both BioAxone and Recursion presented at the family conference held jointly with the scientific meeting. Their presentations can be viewed on the Angioma Alliance YouTube channel.

Throughout the course of the meeting, we also heard presentations on two trials for drugs currently approved for use in other indications: atorvastatin and propranolol. In Italy, a multi-center trial is recruiting for

treatment with propranolol, a beta-blocker commonly prescribed to control blood pressure and tremors. The study is designed to investigate the effects of long-term propranolol treatment on clinical symptoms and/or changes to lesion size or number.

Atorvastatin is a cholesterol lowering medication that is being studied at the University of Chicago, with a specific focus on cavernous angioma patients with recent symptomatic hemorrhage. The study is seeking to recruit those who have experienced hemorrhage within the last 12 months. This one-year window is important as the year following a previous hemorrhage is the time when you are most likely to hemorrhage again, and is thus a critical window for potential therapeutic treatment. Enrolling individuals who have recently hemorrhaged allows the trial to be shorter but does not reduce its generalizability to others with CCM.

Cavernous angioma research is active at all levels. It is thrilling to begin our first clinical trials, and also, hopefully, to continue finding new possible ways to treat the illness. In the coming years we expect to have more trials and more clinical studies that need cavernous angioma patient participation. Stay tuned and remember, without you, there can be no cure.

Dr. Amy Akers

UCSD researchers demonstrate the importance of coagulation factors in relation to cavernous angioma hemorrhage

Much of what we know about CCM lesion biology and drug targets comes from studies of diseased tissue: blood vessels, which are made of endothelial cells. Our current thinking is that an inherited CCM gene mutation causes a disruption of neighboring endothelial cell junctions, the places where individual these cells meet, such that the junctions aren't as tight as they should be. This results in lesion blood vessels that are structurally unsound, allowing the possibility of leakage, and endothelial cells that are more active and mobile than typical blood vessel cells.

In a recent study, Dr. Ginsberg's team at the University of California at San Diego identified an increased activity of anticoagulation factors (those that prevent clotting) in response to CCM gene mutation. This finding led them to further investigate coagulation, as it relates to the biology of cavernous angioma.

In the plenary paper published in the journal *Blood*, the study team addressed the question: do increased levels of anticoagulation factors lead to hemorrhage in CCM?

They found two anticoagulation components, thrombomodulin (TM) and endothelial cell protein C receptor (EPCR), that are associated with CCM biology. Both molecules are present at elevated levels in lesion tissue. TM concentration is also at elevated levels in blood plasma of cavernous angioma patients.

In mouse experiments, hemorrhage is associated with higher TM levels (more TM = less coagulation = more hemorrhage). Genetic experiments to decrease TM production and reduce the amount of protein in the blood vessels results in a reduction of hemorrhage in CCM mutant mice. Additionally, CCM3 mutant mice, which would otherwise begin bleeding just nine days after birth, show reduced hemorrhage with an antibody-drug treatment that blocks TM activity.

Taken together, these findings show us that anticoagulation is a component of CCM biology. Targeting this system, either alone, or in combination with therapy for the endothelial cells, may provide a new opportunity for drug development.

Thrombomodulin may also serve as a useful biomarker to predict hemorrhage. Given the association of blood plasma levels of this molecule and hemorrhage, with more research, measuring TM could identify those individuals at greatest risk for future hemorrhage events.

Furthering the Cancer Connection

A team of genetic and cardiovascular disease researchers in Germany recently used CRISPR gene editing technology to develop a cell model that is completely deficient for CCM3 protein. This new model supports other recent findings that CCM lesions have a cancer-like behavior. Like cells of a tumor, these cells, that have a long-term deficiency of CCM3, are able to survive longer and replicate faster than cells with some or full function of CCM3. Furthermore, these cells don't sprout and make branches as blood vessel cells should. Instead, they just replicate themselves over and over, likely contributing to the development of CCM lesions.

The authors of this study propose that this cell model might be useful in the future for testing novel therapeutics aimed specifically at CCM3.

Dr. Amy Akers

News

Brain Awareness Week

March 11-17 marks Brain Awareness Week. During this week, we encourage you to participate in raising public awareness of the progress and benefits of brain research. Every March, Brain Awareness Week unites the efforts of partner organizations worldwide in a celebration of the brain for people of all ages. To learn more about the week, visit www.dana.org. Angioma Alliance will be posting lots of brain information on social media during the BAW: please share!

Barrow Neurological Institute: CCM Center of Excellence

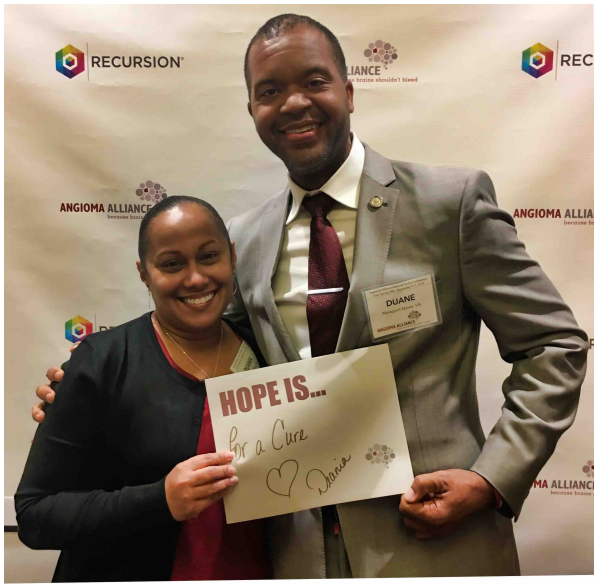
Angioma Alliance will be recognizing the Barrow Neurological Institute in Phoenix, AZ as a CCM Center of Excellence on March 7. The Barrow has a long history of providing expert surgical care to our families, and now has created an interdisciplinary team to provide wrap-around services in neurosurgery, neurology, and genetics. One major benefit is that the Barrow's Second Opinion service will be free to all those who use the special phone number that has been established for Angioma Alliance members. We will post the number on March 7, after the official recognition ceremony. The Barrow has an active CCM research program and we ask that all qualified patients consider enrolling in any studies for which they qualify.

If you plan to be in the Phoenix area on Thursday, March 7, please let us know at clee@angioma.org. We are co-hosting a patient luncheon at the Barrow at noon to celebrate the latest addition to our Center of Excellence program.

National Patient Conference: Save the Date!

Our national patient conference will be held on November 8-9, 2019, in Silver Spring, MD. Again, this year, we will be sharing time with the researchers who attend the Angioma Alliance International Scientific Meeting. This is your opportunity to hear about the latest research directly from the experts and to meet others who are affected. More information will follow on our website, social media, and in the next edition of the newsletter. Please visit our YouTube channel to view videos of last year's presentations.

BARROW
Neurological Institute



We're Growing!

Angioma Alliance is pleased to announce the addition of two new staff members, Tracy Brown and Kristen Dahlem.

Tracy Brown is the new Angioma Alliance Engagement Specialist with primary responsibility for developing Community Alliances, our geographically-constrained volunteer groups that carry out the mission of Angioma Alliance in the groups' areas, and for facilitating the Community Alliances' mission activities. Development Director Stephanie Alband will continue to facilitate the groups' fundraising activities.

Tracy brings to the position previous experience in education, event planning, fundraising, and social media, as well as a passionate, personal commitment to our work. She is the mother of Zach Brown, a young man with a brainstem cavernous angioma. Tracy is the founder of the Zach Brown 5K, which recently celebrated its 6th run. This event inspired many other members of our community to host their own awareness and fundraising walks over the years. Tracy has served on the Angioma Alliance Board and has been the event co-chair of the Greater DC Community Alliance. You can reach her at tracy@angioma.org.

Kristen Dahlem is the new Angioma Alliance Clinical Research Specialist, the Angioma Alliance team member who will be able to assist researchers and industry in providing information about our members to help them work toward better treatments. The Clinical Research Specialist will also be part of the Angioma Alliance research recruiting team, working to engage members as informed research participants and promoting research participation opportunities. Kristen is a registered nurse with many years in medical data management and is a functional medicine certified health coach. She is a co-author of the Angioma Alliance Clinical Care Consensus Guidelines and has served as a member of the Angioma Alliance Board, our science committee, and as chair of the Tri-State Community Alliance. Kristen was diagnosed with cavernous angioma as a young adult. You can reach Kristen at kdahlem@angioma.org.

Please welcome Tracy and Kristen as they help us to achieve our mission of informing, supporting, and mobilizing those affected by cavernous angioma and driving research for a cure.

Angioma Alliance Thanks Its Major Donors

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New Mexico News

Since January 2017, Angioma Alliance has led a special outreach project in New Mexico called the Baca Family Historical Project. The mission of the project is to connect those at-risk for the Common Hispanic Mutation, a heredity cause of cavernous angioma, through shared genealogy and to educate the medical professionals who care for our families.

The Common Hispanic Mutation is a specific mutation of the CCM1 gene that has been passed down through 14+ generations of the original Hispanic New Mexican founding families. We've hosted public conferences around the state in which we share the history of the original Hispanic settlers, facilitate family tree workshops, and offer genetic testing. We've also introduced hundreds of medical professionals to the impact of the illness in the state and shared information they need to provide better care.

We have been very successful in bringing new families to treatment. As an example, the University of New Mexico's Neurology Department now sees just as many patients with the Common Hispanic Mutation as they do stroke patients. Nowhere else in the world could this be true.

Joyce Gonzales, our staff genealogist, has worked to create a family tree of the illness that helps us know where to focus our efforts, and she has pinpointed what we believe is the founding couple: Cristobal Baca II and his wife Ana Morena de Lara, who date to the mid-1600s. Joyce has just completed work on an article entitled A Tale of the Three Cristobals (angioma.org/pages.aspx?content=594) that shares the story of this prominent family. For most of us, CCM is confined to our small family or to ourselves. In New Mexico, CCM is part of history.

New CCM legislation introduced in New Mexico

We're grateful to Representative Miguel Garcia who has introduced House Joint Memorial 7 into the New Mexico state legislature to support improved care and research for CCM. The full text of the Memorial can be found at nmlegis.gov/Sessions/19%20Regular/memorials/house/HJM007.html. Essentially, the legislation requests increased medical provider education, better tracking of the illness, and exploration of the possibility of Medicaid reimbursement for Common Hispanic Mutation genetic testing. With the testimony of our New Mexico members and lead physicians at hearings, we are hopeful that this legislation will be passed.

Upcoming New Mexico Events

Details and registration information can be found at bacafamily.org.

March 8: Support Group Meeting, El Paso.

March 9: Baca Family Historical Project conference, open to the public. El Paso Main Library.

April 13: University of New Mexico CCM Family Conference.

April 14: Baca Family Historical Project conference, open to the public. Santa Fe.

The CCM2 Common Deletion: A Possible Founder Mutation

While we've focused for years on the mutation that is prevalent among descendants of the original Hispanic settlers in the American Southwest, there is a possible second founder mutation among descendants of northern Europeans in the Southeastern United States that may lead us to just as many affected families. This mutation is known as the CCM2 Exon 2-10 Deletion or the CCM2 Common Deletion.

Angioma Alliance has been bringing together families who share this mutation in a closed Facebook group for several years. We now have over 20 families who were previously unknown to each other but who likely share a common ancestor. The group has been working hard, using genealogical databases, to find connections. In December, two of the families were able to identify shared relatives who lived in South Carolina and Mississippi in the early 1800s. With diligence, and perhaps with funding for the assistance of a professional genealogist who can dedicate time to the project, we are hoping to link all the families.

Finding the common ancestor is important for several reasons. First, it allows us to pinpoint undiagnosed, but at-risk, families based on genealogy, getting them to care sooner. Second, it provides us with geographic targets for outreach to medical professionals. Finally, having a historical connection - a story - can help us to raise visibility with the public and with legislators who direct research funding.

Connie Lee

Paola Tapia-Limon's Story

I've resisted writing my story because it made me feel that by typing it, it had to be true. But ignoring I have familial CCM for years has brought me anxiety instead of peace: a fear that any headache, eye twitch, or dizziness could mean a bleed. And when I did have one recently, like the girl who cried wolf, it took my family and me some time to figure out what was happening. So, all the worrying in the world didn't prepare me, or protect me, from what I'm living now.

I was first diagnosed in 2004 when I had a massive bleed in an already massive CM in my cerebellum. I could barely stand without the world spinning and needing to run to the bathroom to throw up. I was a senior in high school, and I was terrified about what my hair would look like for prom if I had it removed. I had surgery and bounced back immediately. In two weeks, I was celebrating at my cousin's wedding, then prom, and then three months later, I moved across the country for college. I was so desperate to put the past behind me and move on with my life that I never took the time to process what had happened to me and to think of what I needed to do to co-exist with this mutation.

More than 12 years later, I'm happily married to a sweet and caring man, thinking of having kids, and have recently scored a dream job: a highly competitive writers' assistant position on a new Netflix show, a stepping stone in the road to becoming a TV writer. I pitched for one of our characters to have CCM disorder and we're using it.

I've been doing lots of research and I'm so frustrated to find out that very little is still known about it. I had my last bleed in one cavernous angioma that grew for 5 years in the CP angle of my cerebellum, giving me double vision, nystagmus, ear fullness, and slight hearing loss. I can either wait and see or take it out. My husband and I have decided to wait as my symptoms have been getting better; but waiting is such a hard thing to do for a control freak like me.

I was told by my neurosurgeons that there's not much to do while I wait for my next MRI in 6 months, but I disagree. I've discovered Angioma Alliance, which inspires me every time I read what people have endured and how they keep fighting. I'm devouring all the literature I can about the mind-body connection, and how meditation can help promote self-healing. I'm watching comedy, doing therapy and calling my friends and family as often as I need to (I've cried to all of them more than once). I find that hearing "no matter what you have to do, you're going to be okay, and I will be there for you," is enough to lift my spirits. And finally, when I meditate or do yoga, I imagine myself covered in light and love, and then I see my cavernous angioma shrinking until it disappears.

Now, I don't know what this all will do. I don't know if I will have to have surgery, but I choose to have faith that it will all be okay. I embrace myself, CCM and all, but that is not all that I am. I am a fighter. I will conquer this disorder and my anxiety, so I'm channeling my Apache ancestors and will keep fighting.

How You Can Help

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.

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. Sponsorships are available for the following:

Scientific Meeting - $35,000 to $1,000

Our scientific meeting offers a variety of opportunities to support and reach the research community, including travel awards and sponsored speakers, breaks, and meals.

Newsletter - $10,000 to $5,000/year

This newsletter reaches thousands of patients and donors both in print and online. It is the only patient-directed source of information for the cavernous angioma community. If you would like to reach this community and support our efforts, please contact us.

Website - $10,000 to $1,000/year

Our website has a global reach, and is always in the top three search results for cavernous angioma. It is the first place newly diagnosed patients look for information and support. In addition to being a patient resource, the website provides information to medical support staff, researchers and the general public.

Events - Range of opportunities

Angioma Alliance members host multiple events throughout the year, from Cavernous Angioma Awareness Night at major league sporting events to smaller Fun Runs and tournaments. Sponsorship opportunities are always available with varying levels of public exposure depending on the event.

DNA/Tissue Bank and Genetic Testing - $20,000/year

The DNA and Tissue Bank is the major source of cavernous angioma biological samples for labs around the world, and we have provided the raw materials for several major published studies.

Contact Stephanie Alband at salband@angioma.org to learn more about these opportunities and valuable benefits for your company.

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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