



ANGIOMA ALLIANCE NEWSLETTER

because brains shouldn't bleed

The Gut and the Brain

We are entering a new era in the treatment of cavernous angioma: one in which we are beginning to understand that we may each have some control over disease progression, even without medications. In this issue, and for the remainder of 2019, we are focusing on everyday actions our members can take to improve their health outcomes.

We start with an interview with Dr. Mark Kahn, the primary investigator at The University of Pennsylvania, whose group has been at the forefront of research into the impact of the gut microbiome on CCM disease. A research paper exploring the role of the gut lining and of emulsifiers in the diet will soon be published in the journal *Science Translation*. Amy Akers, Angioma Alliance Chief Scientific Officer, interviewed Dr. Kahn about his research on page 2.

In 2017, the Kahn lab published a paper in the journal *Nature* identifying gram-negative gut bacteria as playing a large role in the development of cavernous angioma lesions in mice bred with a CCM mutation. Mice whose guts had no gram-negative bacteria, either because they were raised in a sterile environment or because antibiotics were used to eliminate the bacteria, did not develop lesions. It seems that for lesions to form, gram-negative bacteria must leak from the gut and initiate an inflammatory response. The inflammatory response is likely another necessary hit, in addition to the genetic hit, required for cells to develop into lesions. This finding was revolutionary in our understanding of the disease process.

Since then, the work of the Kahn laboratory has moved in two directions. First, they have been exploring the microbiome of people with cavernous angioma. Our members and patients at the University of New Mexico and University of Chicago participated in a pilot study to gather data on the patient's microbiome composition to see if it is different from the general population's. This work is ongoing, and we hope to hear results in early 2020.

Second, the group has been investigating the gut lining. In order for gram-negative bacteria to create an inflammatory response, they must leave the gut. Our

strong gut lining is intended to prevent this. However, the gut lining can be compromised, and you would expect that mice, and people, with a CCM mutation who have compromised gut linings would have more lesions. That is exactly what was found. This has led to another major understanding about CCM illness, specifically about the difference between CCM3 versus CCM1 and CCM2 mutations.

With a hereditary genetic mutation, every cell in the body has the mutation. So, for example, every cell in the body of a person with a hereditary CCM1 genetic mutation has one mutated copy of the CCM1 gene. However, these genes do not play a role everywhere in the body. We say that they are not expressed everywhere. We are only beginning to understand where the CCM genes are expressed outside of the brain and spinal cord.

The Kahn group found that the CCM3 gene is expressed in the mucous-producing cells of the gut lining. Mice with a CCM3 mutation have impaired gut mucous production and, therefore, have a compromised gut lining and increased leakage from the gut. This is not true for CCM1 or CCM2. We already knew that mice and people with a CCM3 mutation tend to have far more lesions than those with CCM1/CCM2 mutations. The compromised gut lining provides the explanation for this.

The Kahn group also wondered about other ways the gut lining could be compromised, in the absence of a CCM3 mutation. They found previous microbiome research that indicated emulsifiers in the diet (we've included a list in this issue) can impact the gut's mucous layer. They experimented with this in CCM-mutated mice and discovered that feeding CCM1/CCM2 mice a diet high in emulsifiers had the same impact on increasing lesion development as having a CCM3 mutation did. CCM1/CCM2 mice on a high emulsifier diet developed more lesions than those who were not.

To summarize: gram negative bacteria moving from the gut of the CCM-mutated mouse into its system triggers an inflammatory response that leads to the development of cavernous angioma lesions in

the brain. A compromised gut lining makes this more likely to happen, as evidenced by people with CCM3 mutation. Emulsifiers are dietary additives that compromise the gut lining.

In addition to the full interview with Dr. Mark Kahn below, in this issue, you will also find a list of emulsifiers, tips for a CCM-healthy lifestyle as well as a link to a video testimonial, and an invitation to participate in a recipe contest to create a CCM-friendly cookbook. Our National Family Conference in Silver Spring, Maryland on November 8-9 will explore these issues in even more depth, and we hope you can join us.

Dr. Amy Akers: Dr. Mark Kahn is a distinguished professor of medicine and Director of Molecular Cardiology at the Perelman School of Medicine at the University of Pennsylvania. The Kahn lab focuses on researching the biology related to the cardiovascular system, blood vessels, and blood vessel diseases, like cavernous angioma.

Dr. Kahn, last spring your team published a paper linking the gut microbiome to cavernous angioma. For those in our audience who are new, newly diagnosed, or who may have missed this original finding, could you briefly describe how bacteria in the gut are connected to developing brain lesions?

Dr. Mark Kahn: Our studies began in mice. We found that mice that we had genetically engineered to create cavernomas would not create those cavernomas if they were housed in a different mouse facility and had a different set of bacteria in the gut; what we call the microbiome. This led us to understand what initiates disease in the brain, which is signaling downstream of receptors that are activated specifically by bacteria, especially gram-negative bacteria.

Amy: Now, you as part of a larger collaboration, you are working on a new paper that we should be seeing very soon. Tell us about the human studies and how you have taken the next steps to connect with people?

Dr. Kahn: We also had some human data in the paper that was published a couple of years ago that demonstrated that the Toll-like Receptor 4, which binds the gram-negative bacterial cell wall component, was important genetically in regulating

how severe CCM disease could be. Since that time, we've gone in two different directions.

The first is to begin to look at microbiomes in human patients who have symptomatic CCM disease, as well as controls. This is a descriptive study to understand what that biome looks like, and whether it looks different from that of the average individual.

The second study began as an extension of the basic mechanism in the first study. The bacteria in your body, at least the gram-negative bacteria, reside almost exclusively in your colon. And yet, to activate and cause a cavernoma formation in the brain, they have to travel from that spot: they have to get across the gut wall and enter the blood. Of course, the body has a tremendous natural barrier between the billions of bacteria we have in the colon and the blood.

We speculated that the strength of the gut barrier could be important in either preventing or accelerating CCM disease.

Amy: Tell us about emulsifiers. What are they? Why are they relevant to the gut and how do you think they impact cavernous angioma patients?

Dr. Kahn: We began by looking at a number of things that are known to disrupt the gut barrier. Some of them are just experimental agents, like dextran sodium sulfate [used in the lab to induce colitis in mice]. And then we also used genetic techniques to get rid of the mucus that is normally important for the gut barrier. We found that with both those cases in mice, that would accelerate CCM formation.

Several years ago, a paper came out in *Nature* that was very intriguing. It suggested that emulsifiers that are used as preservatives in common foods, such as foods that would have to sit on a shelf for a while, to be eaten at a later time, can also break down the mucus layer that is the gut barrier in the colon. In collaboration with Doug Marchuk's group at Duke University, we put animals on these emulsifiers at more or less the concentration that a person could have on a very high diet of that type of processed food, for several months.

Indeed, we found that first there was a breakdown of the mucus layer in the colon. And, that in association with that breakdown, that CCM disease was worsened in those animals as a result of that dietary change.

We also found that when we looked at the microbiome, the changes that we had caused in the mucus layer had not caused a huge change in the microbiome. Right now, we think that there are a couple of different factors that affect how fast the disease will progress based on conditions in the gut.

One of them is the nature of the bacteria that live down there. How many gram-negative bacteria might you have? How invasive might they be? The other is the nature of the barrier that separates those bacteria from the individual's blood stream and route to the brain endothelial cells [blood vessel cells].

Amy: There is a big focus on this study specifically on CCM3; why is that? And, can you tell us how your findings are relevant to folks with other gene mutations and the sporadic form of the illness?

Dr. Kahn: I am not a clinician for CCM disease, though I am a cardiologist. But, it's been known from the work of many other groups, including Issam Awad's at the University of Chicago, that familial CCM patients that harbor a loss of function mutation in the CCM3 (or PDCD10) gene have a more malignant disease natural history than those that have the more common CCM1 (KRIT1) or CCM2 gene mutations. And, this is a very noticeable clinical difference. CCM3 gene mutation carriers present typically in childhood with hemorrhagic lesions in their brain and stroke. Familial patients with CCM1 or CCM2 disease, they tend to present much later in middle life. The basis of this hasn't been clear.

We and others have done a lot of molecular work to try to understand the complex of CCM proteins and what it does in endothelial cells. We haven't found any more of a requirement for CCM3 than for CCM1 or CCM2. So, in the endothelial cell, we didn't see a difference. And we actually tested that genetically by deleting the three genes just in the endothelial cells. Looking at the difference in the mice and their ability to confer CCM formation, we didn't see a big difference.

We began to speculate that CCM3 might participate in two places: in the endothelial cell where it functions pretty much in the same way as CCM1 and CCM2, *and* maybe also somewhere else where it would have a strong regulatory effect on disease. Since all of our evidence pointed to the gut barrier as a

potential site that would have regulation of the disease, we began to look at CCM3 there.

We also knew that CCM3 is part of a molecular complex, distinct from the one that contains CCM1 and CCM2, that is involved in many other biological functions: the STRIPAK complex. We thought, maybe that complex has another role?

In short, we deleted CCM3 (and CCM1 or CCM2), in the epithelial cells of the gut colon. When we deleted CCM1 or CCM2, we saw no change. Everything was the same in terms of gut barrier. But after deletion of CCM3, there was a severe loss of gut barrier function. This was also true when there was loss of only one of the two gene copies. This is the condition that familial patients have [i.e. one inherited copy of the mutant gene].

It turns out that CCM3 is a double whammy: the mutation in this gene affects disease by altering gut function and brain endothelial function. That's why CCM3 patients have a much more severe disease natural history than do CCM1 or CCM2.

Amy: And why do you think folks should avoid emulsifiers?

Dr. Kahn: I think it is hard to give real clinical advice at this stage. But, in general, emulsifiers are in processed foods that are not particularly good for anyone anyway. If you are eating a high-Twinkie diet, probably no one would think that is a good idea.

I think it would be reasonable to start looking at the emulsifiers in your diet, and if it's high, to start reducing them.

For any individual person, it is going to be hard to know the role any of these variables play. There are going to be other genetic and dietary factors. We are investigating the microbiome in people as well. For now, I think reducing emulsifiers in the diet is a safe thing to do.

Additional information about emulsifiers can be found in the emulsifier list on page 4 and in this article summarizing the research on the impact of emulsifiers on the gut: civileats.com/2015/02/25/how-emulsifiers-are-messing-with-our-guts-and-making-us-fat/

Common Emulsifiers	Where are they hidden?
Acacia (gum Arabic)	Cake decorations, candies, frozen desserts, food dressings and flavorings, jellies, soft drink syrups
Acetic acid esters (ACETEM)	Cakes, shortenings, toppings
Ammonium phosphatide	Used as a replacement for lecithin and mostly found in chocolate
Baker's yeast glycan	Cheese-flavored and sour cream-flavored snack dips, cheese spread, frozen dessert, salad dressings, sour cream
Brominated vegetable oil (BVO)	Mountain Dew
Carboxymethylcellulose, AKA cellulose	Beer, cake icing, candy, cheese, ice cream, jellies, pie filling, salad dressing,
Carrageenan	Chocolate milk, deli meats, ice cream, infant formula, nut and soy milks, popsicles, prepared meals such as frozen burritos and pizza, protein shakes and powders, yogurt
DATEM (Diacetyl tartaric acid esters)	Biscuits, Breads and bread products
Dextrin	Candy, powdered mixes
Guar Gum	Baked goods, baking mixes, breakfast cereals, chees, dairy products, gravies, jams and jellies, milk products, processed vegetables, sauces, soups and soup mixes, syrups
Lactic acid esters (LACTEM)	Cake gel, cake shortening, ice cream, imitation creams
Lecithin (soy and egg)	Naturally found in egg yolks and soybeans. Baked goods, chocolate, ice cream, margarine, mayonnaise
Magnesium stearate	Gum, herbs, spices, supplement tablets, capsules and powders
Mono and diglycerides	Baked goods, breads, cakes and cake mixes, candy, coffee creamer substitute, frozen desserts, gum, ice cream, icing and icing mixes, low calorie spreads, margarine, mayonnaise, nut butters, peanut butter, processed meats, whipped toppings
Phosphates	Baked goods, breakfast cereals, cheese, cured meat, dehydrated potatoes, fast food, powdered foods, ready to eat meals, soda,
Polyglycerol esters (PGE)	Bakery products, cakes, margarine, whipped toppings
Polysorbate 60, 65, 80 (P80)	Baked goods, chewing gum, chocolate flavored syrups, cottage cheese, dill pickles, frozen desserts, gelatin desserts, ice cream, imitation cream, non- alcoholic mixes, powdered soft drinks, protective coating on fruits and vegetables, pudding and pudding mixes, shortening, vitamin and mineral supplements
Propylene glycol esters of fatty acids (PGMS)	Baked goods, cake mixes, cake shortening, candy, creamers, dressings, frosting, frozen meals, ice cream, nuts, pickles, snacks, whipped emulsions
Sodium stearoyl-lactylate (SSL)	Baked goods, cheese and cheese substitutes, dough strengtheners, fillings, icings, imitation milk/cream, pancakes & waffle mixes, puddings, snack dips, sauces/gravies
Sorbitan monostearate	Baked goods, cacao products, cake fillings, cake icing, dessert mixes, frozen desserts, ice cream, milk and cream substitutes
Sucrose Acetate Isobutyrate	Citrus flavored beverages, energy, sport, and electrolyte drinks, malt beverage coolers, premixed cocktails, wine coolers
Sucrose fatty acid ester	Baked goods, baking mixes, beverages with added dairy ingredients, chewing gum, coating applied to fruit, frosting, frozen dairy desserts, whipped milk products
Xanthum Gum	Beverages, gluten free breads, ice creams, non-dairy alternative nut milks, salad dressings

List of Common Emulsifiers

Oil and water don't mix; until an emulsifying agent is added.

Emulsifiers made from plant, animal and synthetic sources commonly are added to processed foods such as mayonnaise, ice cream and baked goods to create a smooth texture, prevent separation and extend shelf life. Low-fat spreads, margarine, salad dressings and many other creamy sauces are more examples of foods containing emulsifiers. Emulsifiers are required by law to be included on a food's ingredient list.

On the previous page is a chart listing common emulsifiers found on our shelves. This resource link to the FDA can also be used for looking up a questionable ingredient: bit.ly/FDAResourceList

Kristen Dahlem RN and Cristina Svec RD

Health Tips for CCM

While we still have much to learn about cavernous angioma (CCM), there are many things you can do now to improve your health and functioning both after hemorrhage and after surgery. Here are a few tips we've compiled. There are two themes to remember: moderation and reducing inflammation.

To watch these tips put into action in recovery from brainstem hemorrhage and surgery, please visit our YouTube channel and look for Tyler Fairbank's Road to Recovery video.

Vitamin D: Low levels of Vitamin D have been correlated with a chronic aggressive course of cavernous angioma. Having your Vitamin D level checked and supplement with vitamin D3 to maintain a normal level can help you stay CCM-healthy.

Diet: While taking pro-biotics is strongly discouraged because we don't know whether they may cause harm to those affected by CCM, we suggest keeping your diet free of emulsifiers and preservatives to maintain the mucous lining of your gut, which is the first line of protection.

Sleep: Lack of oxygen during sleep (hypoxia) caused by sleep apnea also can lead to increased inflammation. Research is being conducted to determine whether hypoxia is related to the number of lesions found in those with the hereditary form of the illness.

Help Us Create a CCM-Friendly Cookbook!

This fall, we are soliciting recipe submissions for a cookbook to help our families make good choices. Here's an overview. You can find full details on our website at www.angioma.org/recipe.

We now know that limiting or eliminating emulsifiers is best for those with CCM (see our story on page 1 and the emulsifier list on page 4). However, it is hard to find foods in some categories that are emulsifier-free, such as, store-bought ice cream. We would like to create a cookbook to help with this.

We are accepting submissions of emulsifier-free original recipes with a picture of the prepared dish in the following categories:

- Breakfast
- Comfort food
- 20-minute (or less) main course
- Holiday food
- Desserts
- Easy recipes created by children

We would also appreciate your limiting sucrose in the recipes as we know this feeds gram-negative bacteria in the gut. Stevia is thought to be safer.

The submission deadline is October 1. And, while not required, please also feel free to submit a link to a YouTube video demonstrating preparation of the dish. We will post the recipes for online voting during October. The top 7 popular winners in each category will be included in the cookbook.

Our Community Alliances are planning potluck tasting parties in early November. We will add recipes to the cookbook based on the outcome of the taste tests.

We are also soliciting recipes from professional chefs to include in each category. By the time we're done, we hope to have at least 60 recipes that are emulsifier-free and good for our families.

Finally, we would love cookbook sponsors. This is a wonderful way to show your support of our community and, if you are involved in the food industry, highlight your product or establishment. A sponsorship form is available at www.angioma.org/recipe.

We plan to have a digital version of the cookbook available for purchase before Thanksgiving, just in time for your holiday meal planning.

News

Add Your Experience and Contribute to Clinical Research

This is an exciting time for cavernous angioma research, and in the coming months you will have an opportunity to help us unlock the door to new treatments and a potential cure by sharing your personal experience with the condition. We will be seeking assistance from our community for a very important project, the CCM-Health Index, that will create a scientifically-validated tool to help us understand the health status and quality of life of those affected by CCM. This tool is needed for successful clinical treatment trials.

Angioma Alliance will use the patient registry at www.AngiomaRegistry.org to locate eligible participants for the CCM-Health Index survey project. Ensuring you are a member of the registry would be a great way for you to contribute. During the development of the CCM-Health Index, we will need hundreds of patients to take the survey. If you aren't in the patient registry, we can't include you. Are you in?

In addition to its use for the CCM-Health Index, the registry is a powerful resource for our research community. We have been closely analyzing the data we have so far and linking its members to other research projects for which they qualify. Our researchers are grateful for this resource. You can analyze data, too - the patient registry lets you see compiled data from all respondents who have joined.

Share your experience by participating in the registry and stay in the loop about new and ongoing studies. In 2019, over 900 people updated their profile or became new members, adding their unique stories with cavernous angioma. It takes just a few minutes of your time to register.

We invite you to join by visiting www.AngiomaRegistry.org.

If you have any questions regarding the registry or your account, please contact us at coordinator@angioma.org.

CCM-CARE Bill of 2019 Introduced

On June 27, 2019, Senator Tom Udall, Representative Ben Ray Lujan, and the New Mexico delegation introduced federal legislation called the CCM-CARE Act of 2019. In the Senate, it is known as S.2010 and in the House, it is known as H.R.3573.

We need you to call your legislators to let them know how important this legislation is to you. We particularly need those of you represented by members of the Senate HELP Committee and the House Energy and Commerce Committee to call your legislator's office and ask them to co-sponsor the bill. Our website has lists of these committee members at angioma.org/pages.aspx?content=123.

The CCM-CARE Act calls for:

- Support for creation of additional Centers of Excellence that can coordinate drug trials as well as secondary clinical centers that can provide outstanding care;
- Increased funding for research at all levels: basic, translational, and clinical;
- Prioritization of CCM medications at the FDA since, unlike other illnesses, we do not yet have a single pharmacological treatment; and
- Collection and analysis of data on CCM by the Center for Disease Control so that we have a better understanding of how many people are affected by the illness and the ways in which they are affected.

Take Action!

Our website offers scripts for calling your legislators and a one-page summary of the legislation. When you talk to your legislator or their legislative health aide, you can mention why any of the above are important to you and your family. For complete instructions on advocating for this legislation, watch our tutorial video at youtu.be/BD7GGI5b9w4.

Your call can make an enormous difference in the future of care and research for CCM.

Kristen Dahlem, RN

Recent Community Alliance Events

Greater DC Area

The Greater DC Angioma Alliance Community hosted a picnic on June 2. It was a great event with delicious food and lots of wonderful community connection. Connie Lee was able to attend and shared an update on the status of research which was informative for all.

Florida

The Florida Angioma Alliance Community hosted the Atorvastatin Clinical Trial Update with Dr. Awad and his team. It was an excellent and informative webinar, Thank you to Joanna Jimenez for moderating. The Florida Angioma Alliance Community also hosted a Comedy Fundraiser in Miami with all proceeds benefitting Angioma Alliance. It was a fun night out and an opportunity to meet others affected by cavernous angioma.

Michigan

The Michigan Angioma Community Alliance has newly formed and they are working on creating an action plan for their group. The group had a small meetup in June, and they have already reached out to the University of Michigan to see if there is interest in forming a CCM Clinical Center. Michigan currently has an opening for an events committee chair. If you are in the area and thinking about getting involved, now is the perfect time. You can get more information by sending an email to miangioma@gmail.com You can find their Facebook group at [facebook.com/groups/698579807237882/](https://www.facebook.com/groups/698579807237882/).

Tri-State Area

The Tri-State Angioma Alliance Community hosted a wonderful fundraiser event on July 3rd benefitting Angioma Alliance. The subway series Mets vs. Yankees game was great fun for all who attended. Thank you to the members of the Tri-State Angioma Alliance Community!

Also, in the Tri-State area, Alyssa and Brian Ballard hosted an open house fundraiser at A & J Cycles in Hillburn, NY. The event had great music and food and lots of incredible raffles. They raised over \$6000 for the Angioma Alliance. Thank you to the Ballard family for your stellar fundraising efforts.

Upcoming Events

California

Calling all CCM warriors! The 3rd Annual Orange County walk will take place on September 15th at Olympiad park in Mission Viejo, CA. All warriors are asked to come dressed for "Camo for a Cause" and be ready to show off your skills through our kid friendly obstacle course.

Surf's Up! Join us as we raise funds and awareness for those affected by cavernous angioma. The 5th Annual Malibu walk will take place on October 13th at Zuma Beach in Malibu, CA. Our theme this year is Beach Blanket Bingo and we will have lots of refreshments, limbo, bingo, raffle items and more!

Colorado

Superheroes unite! The 2nd Annual Colorado fun run will be held on September 21st, 2019 at Berkley Lake Park in Denver, CO! All superheroes and heroines will be asked to strike their best superhero pose in the fight against cavernous angioma. This family friendly event will feature activities for all ages.

Greater DC Area

The Greater DC Angioma Alliance Community has been preparing for the Family Fun Sports Fundraiser September 21st from 6:30 to 9:30 pm at the Odenton Sports Center in Odenton, MD. The fundraiser will include a pig roast, silent auction and various sport activities. Tickets are only \$25 for adults and \$10 for children 7-17, kids 6 and under are free. To learn more or buy tickets visit: www.crowdrise.com/o/en/campaign/family-fun-sports-night

The Greater DC team is also looking forward to helping out at the patient conference in November and to hosting a webinar by Dr. Min Park from the University of Virginia in September.

New England

For the second year, Bags for Brains will be hosted by Regina Hill in Sharon, MA on October 5, starting at 11am. This event will include a cornhole tournament, cookout and raffles. Go to www.bags4brains.com to register.

Texas

The Texas Angioma Alliance Community Fall Festival is scheduled for October 19, from 1-4pm, to be held in Houston at www.claysrestaurant.com/. They are planning a family fun day of food, activities and games. Consider joining if you are interested in building a community with others in the area. Please email txangioma@gmail.com with any questions. We know it is a big area to cover, but we hope to make it just a little bit smaller with our community group. Here is the Facebook page: facebook.com/groups/248005959426483/

Tri-State Area

The 5th Annual Wine Tasting will be hosted by Julie DeMichiel and Terry Ponte. It will be held at the Torrington Country Club in Torrington, CT on Friday, September 27, 2019 from 06:00 pm to 09:00 pm. This evening will include wine, beer, chocolate, and exclusive liquors (in the VIP room) with music performed by Anne DeMichiel and Brian Mattiello. Email Julia at julia@bindingsource.com for advanced ticket purchase.

New Groups Forming

We have new Community Alliances forming in:

- Arizona: facebook.com/groups/387474621875682/ or lindsay@angioma.org
- Northern California: facebook.com/groups/1093376650852900/ or lindsay@angioma.org
- Chicago area: facebook.com/groups/494790591348797/ or tracy@angioma.org
- New England: darla@angioma.org Sarah Ashe has been a great help over the summer in working to get a community alliance started in New England. Thanks to her efforts, a New England Angioma Community Alliance will soon be joining us.
- Ohio River Valley: facebook.com/groups/939564359718355/ or tracy@angioma.org
- Eastern Pennsylvania: darla@angioma.org An Angioma Alliance community in Eastern Pennsylvania is currently in the works. A group of folks met in July to enjoy lunch and time connecting as a community. Connie Lee was able to join the group and shared an update on the state of the research which was informative and very much appreciated.

Other Recent Events

Saber Seminar

A giant THANK YOU to the Saber Seminar: Sabermetrics, Scouting, and the Science of Baseball, a weekend seminar for the benefit of Angioma Alliance, and to Dan Brooks and Chuck Korb, who are the force behind the event. The seminar took place on August 10 and 11, 2019 in Boston, MA, and raised over \$40,000 for Angioma Alliance. Your continued support and generosity are helping to get us all closer to a cure. We appreciate you. Pictured flanking Chuck Korb are volunteers Wasei Layous and Sarah Ashe.



Cavernous Angioma Night at the Cincinnati Reds

We are thrilled to announce that our June 16th Reds game raised \$7,000 for Angioma Alliance. In addition, we raised awareness to 25,000 people in attendance at the game for a rare disease. This year, thanks to a talented group of Angioma Alliance volunteers, a new awareness video was created and shown during the pre-game on the Jumbotron. You can check out the video on the Angioma Alliance YouTube channel.

Again, we want to thank the Reds, our sponsors, Joe Price, Dr. Vadivelu of Cincinnati Children's, and everyone who attended, donated, and supported our game. We are extremely grateful! For those interested here is the link to our game photos: www.stephenphotoartist.com/p365861689

Caveroma Aliança Brasil

The international effort to provide better choices for our patients continues to grow. On August 12, in Rio de Janeiro, Caveroma Aliança Brasil held its first national scientific, clinical and patient meeting. Attendees were able to share information about the latest CCM research happening in Brazil and about current expertise surrounding clinical care.

Connie Lee presented on the Angioma Alliance Center of Excellence experience, and Dr. Issam Awad presented on the development of biomarkers for the disease as well as on the US atorvastatin trial.

This meeting is a major step forward for the Brazilian patient organization and marks a new visibility for the illness in the country. Caveroma Aliança Brasil had already been instrumental in increasing research funding in the country. Now, they are moving the ball forward in creating collaborations and improving care. Congratulations!

Please also see full coverage of the first planning meeting for a consortium of European patient groups, held in June, in the online version of the newsletter as well as coverage of Cavernoma Alliance UK news. We are organizing around the world to promote community, care, and research.

Angioma Alliance to Meet with FDA

On November 6, a small group of Angioma Alliance members will be participating in an FDA Listening Session specifically about our experiences with CCM. FDA Listening Sessions are:

- Small, informal, non-regulatory, non-public discussions
- About disease experiences, not a specific medical product (drug, biologic, or device)
- Of interest to medical product staff in multiple FDA Centers/programs

Our session will allow members to share their experience of life-altering symptom exacerbation, particularly those that are not been visible on MRI. We have worried that focusing on recent hemorrhage rather than on symptoms for clinical drug trials makes it difficult to enroll sufficient patients to fill trials. We are hoping to share the importance of taking other factors into consideration when deciding on meaningful clinical endpoints for a trial.

If you have a compelling story about an episode of life-altering symptom exacerbation (not headache or seizure) that could be tied to the location of your lesion but was not the result of hemorrhage, please contact Connie Lee at clee@angioma.org. We are collecting examples for the meeting.



Events

National Patient Meeting 2019

Nov 8-9, Silver Spring MD

Please join us for two days of presentations and conversations about cavernous angioma research and treatment. This meeting is happening concurrently with the International Scientific Meeting, and there will be a shared session and other opportunities to interact with the researchers.

Find a full agenda at angioma.org/documents/DCPatientMeeting2019Agenda.pdf.

Highlights include:

- With the researchers, attend a joint keynote presentation by Dr. Issam Awad marking the 15th anniversary of the scientific meeting;
- Hear presentations geared toward patients and their families from leading clinicians and researchers including Dr. Min Park, Dr. Mark Kahn, Diane Darcy, RD, Dr. Kimberly Foley, Dr. Amy Akers, Kristen Dahlem, RN, Tim Considine from Recursion Pharmaceuticals, Dr. Connie Lee, and other speakers to be announced;
- View posters presenting recent, unpublished research findings;
- Have an opportunity to talk with Scientific Meeting attendees over lunch and at breaks;
- Meet other Angioma Alliance members and share stories and tools.

This is a unique opportunity to interact with the research community and to learn about the patient and family role in advancing the search for better treatments. Our International Scientific Meeting attracts every major research laboratory in the world, as well as many leading clinicians.

- Early registration through Oct. 7: \$70 per person.
- Registration from Oct. 8-Nov. 7: \$80 per person.
- On-site registration: \$100 per person.

Unfortunately, we will not be able to offer childcare at this event.

To register, please visit www.bit.ly/angioma2019

Webinar: Neurosurgical Management of Cavernous Angioma and Information About Vitamin D, Monday, September 23, 2019

On September 23rd at 7pm ET/ 4pm PT, Dr. Park, Director of Cerebrovascular and Endovascular Neurosurgery, University of Virginia and Medical Director of the CCM Clinical Center at UVA, will present information about neurosurgical treatment of cavernous angioma. He has also published research on Vitamin D and will share his perspectives on Vitamin D in relation to cerebral cavernous malformations.

Dr. Park trained at UCSD and at the Barrow Neurological Institute under Dr. Robert Spetzler. In addition to his civilian neurosurgery career, Dr. Park has a distinguished service career. From his faculty biography: "From 2009-2013, Dr. Park served as a lieutenant commander and staff neurosurgeon at the Naval Medical Center San Diego. He deployed to Kandahar, Afghanistan in support of Operation Enduring Freedom, where he was the sole neurosurgeon for the southern half of the combat theater and performed over 150 life-saving operations in six months. He has been awarded the Navy and Marine Corps Commendation Medals, Navy Unit Commendation, Afghanistan Campaign Medal, and NATO Medal, among others."

To register for the webinar, visit bit.ly/MinParkWebinar

To read Dr. Park's complete bio, please see his UVA faculty page: uvahealth.com/findadoctor/profile/min-s-park.

To learn more about the UVA CCM Clinical Center, please visit angioma.org/pages.aspx?content=583.

Atorvastatin Clinical Trial

The University of Chicago atorvastatin clinical trial continues to recruit. The trial looks at the effect of atorvastatin on reducing the risk of future bleeds from cavernous angiomas. Dr. Issam Awad has been updating the Angioma Alliance community on the trial through quarterly webinars. In his July webinar, he reported that enrollment is on track and the trial is going well. The next update webinar will be scheduled for October.

To participate, you must be a United States adult, not on statins, with a documented symptomatic hemorrhage in the last year. Additional information about trial enrollment and participation is available on our website and in the trial brochure at www.angioma.org/documents/ATTrialBrochure.pdf.

The atorvastatin trial is a two-year commitment that includes three high quality MRIs at no cost to the participant. A travel stipend is provided for those traveling to Chicago. Participants are free to exit the trial at any time.

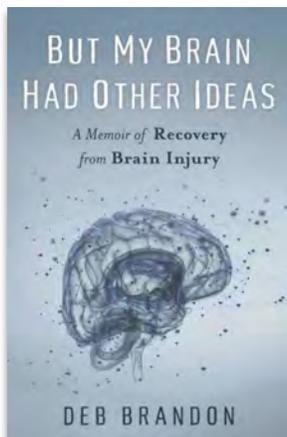
Finding out whether atorvastatin is beneficial in reducing recurrence of symptomatic hemorrhage is of critical importance to our community. Atorvastatin is a well-tolerated, inexpensive medication that has been effective in reducing hemorrhage in mice bred with a CCM mutation. Now, with your help, we can determine whether it can help our families, too.

Awareness Items

Our Angioma Alliance online store is stocked with new awareness items for you. We now have:

- Phone wallets with an integrated screen cleaner in a choice of four messages
- Bracelets in red and black
- Awareness ribbons on special information cards
- Donated copies of Deb Brandon's memoir "But My Brain Had Other Ideas"
- 2019 Brave t-shirts: get them while they last!

Visit our store at shopangiomaalliance.bigcartel.com to see these and more.



Erin Loughran and Her Invisible BFF: Coping with CCM and HOD



I have a rare, inoperable lesion in the pons area of my brainstem called a cavernous angioma. That brainstem hemorrhage actually caused another rare disease called HOD, hypertrophic olivary degeneration, and it has a whole host of other

symptoms. It's also very rare. So, I have lots of things going on in my head.

I actually have not been living with this disease more than 2.5 years. It started when I was 30, and I was just chugging along in my able-bodied self. I had my own car, own job, own house. My job, I loved. I was teaching English to adult immigrants and refugees. Talk about a rewarding, awesome career. It was actually workshop week; I was getting ready to get back to the new school year, but I was experiencing symptoms. After a couple of weeks of a lot of diagnostic testing, that's when my diagnosis came. I've been living with stroke-like symptoms and a plethora of other things since then. I've learned a lot of things along the way.

So first I just want to talk a little bit about things that have helped me cope. That's the biggest thing with disability and chronic illness, is "How do I cope with it?" and "What do I do now?"

I want to say as an aside, I'm not in a good place right now. I'm actually not doing that well with symptom management. I don't have a prognosis. I'm very homebound and have been for the past 3 months. Because of these things, getting through it and going through it, I'm doing the best I can.

One big thing I wanted to share with you is living life in 15-minute increments. It's a lot easier to live life in the present moment, to be mindful, once you have a chronic illness or a disability – or both. Chronic pain definitely makes you live in the moment. So, shout out to all of you out there who are dealing with something like this and living life in 15-minute increments.

When I was first diagnosed, I had a really hard time processing what was happening. I turned to the one thing that helped me in the past, which was journaling. I wasn't able to use my right hand and left hand for writing with ease anymore but typing I could still do. So, I began writing in a journal and started My Invisible BFF [blog]. Slowly, unfortunately, my needs have changed. I have gone from using a laptop to a tablet and now my phone because it's much easier accessibility-wise. But I am still really committed to doing that for my own sense of purpose and for a lot of others, like family members and friends, who appreciate the updates. I think it's a really neat way for you to give them an opportunity to support you in that way.

I started My Invisible BFF. I blog about disability, things that are unique, or not, in my life. I mostly try to be funny but very real about everything I'm experiencing, and I think a lot of other people experience, too. The name My Invisible BFF came to me because I was reading a lot of other blogs and seeing a lot of other people on social media about how they were fighting battles and seemed they were doing these really negative things with their ailments. I decided to change it up a bit and talk about my invisible BFF. It's talking about a group of symptoms that are always there, but it is my invisible BFF because it's always there, it's always with me. Talking about my invisible BFF has been something that, even when I say it, brings me some positive energy, some good vibes.

I use My Invisible BFF for not only good vibes, for chill vibes, but for my story – to share my story with the world and also to educate others on the world of disability. As you know, it's vast, it's very varied, it is fluid. I think not enough people understand that. Both in my writing and in my social media accounts, that is my main goal – keeping it light and also educating people.

Let's talk a little about how to cope with chronic illness, disability, and chronic pain. First, you need to find a community. That could be online. On Facebook, for example, I started a community called My Invisible BFF Sunshine Club. People with chronic illness, disability, chronic pain can come on and share

things like grievances, stuff that has gone well and not so well, try to uplift others, with people of varying conditions. That's been really nice for me and, I think, for other people, too.

One of my "besties" I met over a year-and-a-half ago. My PT went through all the proper HIPAA channels to connect me with one of her other patients who was going through rehabilitation after a bone marrow transplant. I support the hell out of her, and she supports the hell out of me. It's really important to have that community IRL. Or, if you can't find that community in real life, social media is wonderful. Facebook and Instagram. Find your people. Find someone to support you and root for you no matter what you're going through.

If your community that you find IRL or on social media is causing any kind of negativity or pain or you just don't get a good vibe from it, don't worry. It takes time. Don't feel bad about leaving that community to find something else. Don't feel bad about unfollowing people on Instagram. Don't feel bad about finding someplace new.

I want to talk about the way we talk about language to describe our symptoms and what we are going through. For example, I have a daily symptom that is very similar to having a TIA. A TIA is a mini stroke. We call him Taz. Taz is short for Tasmanian Devil that comes on very fast and furious. What I love about Taz is that I can blame a lot of crappy feels on Taz and not on my body. Taz is a symptom that comes. But when it gets annoyed or mad at a certain situation and flares up, I can be like "F--- you, Taz." "Man, Taz is a real B today." And other choice words that you would probably use to describe your symptoms. But I don't say, "Man, I hate my arm. It's numb." Or, "My leg is so heavy I can't even do anything. I can't walk today. What's wrong with me?" I blame all that on Taz and leave it there. It's not to say that my symptoms are any light thing. They're not. They are actually quite serious. But, when you add something that's lighter on top of it, it tends to calm a person down. It tends to raise your vibe a little bit and overall change the vibe of the situation.

Speaking of language, I want to talk about how the word "disability" is not a bad word. There have

been mixed messages in the media about saying "I am a woman with disabilities" versus "I am disabled." For me personally, I don't mind if you use the person-first or the identity-first language, but I do prefer that you refer to me as having a disability or being disabled. Taking the word disability out of the equation is not something I'm interested in, and it's actually a diminishing way to go about it.

Here's a word that I would love for you to eliminate from your vocabulary, please. Handicap. It's a word that's rooted in hurtful and diminishing language toward disabled people. Stop saying it. Stop referring to parking spaces as that. Here's a trick. Every time you want to say the word "handicap," replace it with "accessible." For example: I have an accessible placard. I am parking in accessible parking.

Just to review. Use positive language for yourself, your symptoms, and your disability. Find your people. Make sure that they're cool and that they align with your values. But make sure you are finding community either IRL or online. Finally, don't be afraid to live life in 15-minute increments. It's not what society tells us, but it will help if you check in with yourself as often as possible, especially for those who are dealing with chronic illness, chronic pain, or disability.

Visit Erin's blog, My Invisible BFF, at www.myinvisiblebff.com where you will find the video version of this article, and follow her on Facebook at facebook.com/myinvisiblebff/.

Join Erin's Hypertrophic Ovary Degeneration Facebook group at facebook.com/groups/1690605697672046/.

Learn more about hypertrophic ovary degeneration (HOD) which is often caused by a brainstem cavernous angioma surgery or bleed, on page 14 of this newsletter and on our website at angioma.org/pages.aspx?content=612.

This article is the transcript of vlog originally created by Erin Loughran for Body Positive Yoga (www.bodypositiveyoga.com).

Hypertrophic Olivary Degeneration (HOD)

Hypertrophic olivary degeneration (HOD) is a disease that can be a complication of a brainstem or cerebellar hemorrhage or surgery (including radiosurgery). In some case series, half of the patients with HOD have developed it as a result of a brainstem cavernous angioma hemorrhage or surgery. Overall, however, it is rare, even among our patients.

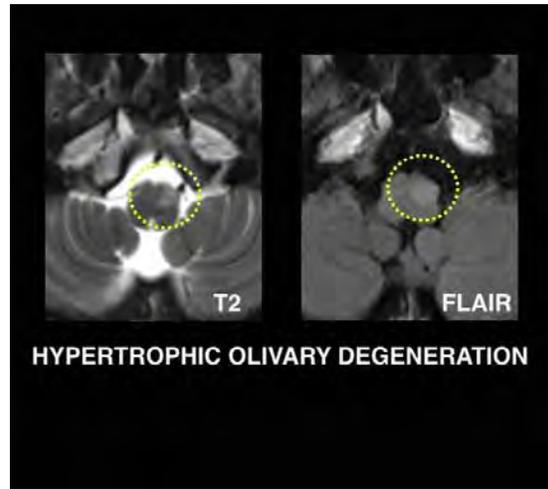
In HOD, a portion of the brainstem called the inferior olivary nucleus initially enlarges. The inferior olivary nucleus is part of the olivary body, an olive-shaped structure on either side of the brainstem. The olivary body assists in cerebellar motor learning and functioning. When the inferior olivary nucleus enlarges, it irritates a motor pathway called the dentate-rebro-olivary pathway (or Guillain-Mollaret triangle). Over time, the olivary nucleus stops enlarging and instead atrophies, but the symptoms persist.

The hallmark symptom of HOD is a rhythmic tremor of the palate and/or other structures in the throat. The palatal tremor may be accompanied by oscillating nystagmus in which the pupil of the eye involuntarily moves in circles. HOD can also include ataxia, clicking tinnitus, and tremor in other parts of the body. These are in addition to any deficits caused by the original hemorrhage or surgery; HOD symptoms typically emerge later.

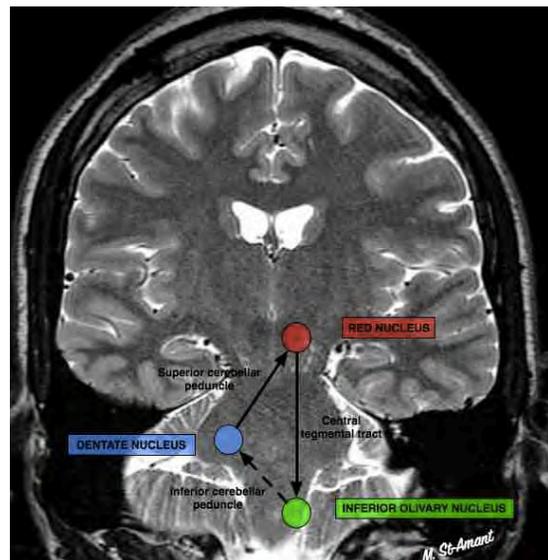
There is no direct treatment for HOD, but medications may help manage symptoms for some people. The most commonly used are gabapentin and memantine to reduce the amplitude and speed of the oscillations of the pupil. Palatal tremor has been treated with trihexyphenidyl with some success.

To learn more, visit www.ncbi.nlm.nih.gov/pmc/articles/PMC5490180/pdf/fneur-08-00302.pdf

For support, please join Erin Loughran's Hypertrophic Olivary Degeneration (HOD) Patient and Family Facebook group at www.facebook.com/groups/1690605697672046/.



MRI of olivary degeneration credit: Case courtesy of Dr Bruno Di Muzio, Radiopaedia.org, rID: 38438.



MRI Image of Guillain Mollaret triangle credit: Case courtesy of Dr Maxime St-Amant, Radiopaedia.org, rID: 34774.

International News

European CCM Network

In conjunction with the Cavernoma Alliance International Forum, European patient advocacy group leaders met for the very first time on June 7, 2019, at De Vere Horsley Estate/United Kingdom to talk about the creation of a European Network in order to be able to work together more efficiently towards our common goal: to stop cavernous angiomas from bleeding.

The participants represented the following official patient organizations: Cavernoma Alliance UK, Association sur les Cavernomes Cérébraux (ACC), France, Asociación Española de Cavernomas (AECCM), Spain, Cavernöst Angiom Sverige (CASE), Sweden as well as the newly forming associations: Cavernoma Ireland and Kavernøs Angiom Norge (KAN), Norway. The official patient organizations from Germany (Federal Association of Congenital Vascular Malformation) and Italy (Associazione Nazionale Angioma Cavernoso Cerebrale - ANACC ONLUS) sent in their materials and slides to be included. We are grateful that two researchers, Petra Magnusson (Uppsala University, Sweden) and Maria Grazia Lampugnani (IFOM, Milan, Italy) as well as Connie Sawartka Lee (Founder & CEO, Angioma Alliance) were able to join this meeting and advise us with their valuable expertise and knowledge.

To get to know each other, each association presented slides about their ongoing work and subsequently, the most important points for the creation of a European CCM network were discussed.

We addressed major goals and values that are crucial for our collaboration and decided to work closely with Eurordis, the umbrella organization for rare disease patient organizations in Europe. Currently, we are running a survey to decide on one of these 6 names for the network:

- European Federation for Cerebral Cavernous Angioma
- European Cavernoma Federation
- Cavernoma United Europe
- European Cavernoma Alliance
- Cavernoma Alliance Europe
- Europe Cavernoma Alliance

Once we have decided on a name and formulated our mission statement, we are looking forward to working more closely with researchers and clinicians.



Cavernoma Alliance UK News: September 2019

This is the end of our first year with Helen Evans as our first Chief Executive. During the year we have had 420 new members, at least 208 from the UK with symptomatic cavernoma. The literature indicates that about 160 people are diagnosed each year in the UK so even allowing that this number is low, the majority of people diagnosed find us and join.

We have been successful in taking further the top research priority identified in our Priority Setting Partnership published in 2016. Professor Rustam Al-Shahi Salman with a team of 13 clinicians and CAUK as the patient voice have passed Stage 1 of a two-stage application for about £1 million to run a pilot Randomised Controlled Trial to address the question, "How effective is treatment (with neurosurgery or stereotactic radiosurgery) versus conservative management in people with symptomatic brain cavernoma?" A proper evidence base for the optimal treatment of cavernoma will benefit all those diagnosed with cavernoma worldwide and will continue to do so even when good drug regimes are available.

The support that we provide for individuals now has a support line with our staff on rota that responds to phone calls almost immediately from 9-5 Monday-Friday, with email and online messenger rapidly too, and with call backs outside office hours. This runs at about 550 enquiries per year, each phone call lasting about 20 minutes. Our quarterly magazine now has a professional look, and our 11 CaverBuddy support is very well received.

For the community, we have organised our 12 regional CaverCentres more formally, with two volunteers running each with two meetings a year. We have one CaverCentre in each of Wales, Scotland and Northern Ireland. This year we have also held three meetings with talks from clinicians in different parts of the UK

Our Annual Forum in June was voted by many the best ever, and not only because Connie Lee was kind enough to come and keep us up to date with the very exciting scientific developments in in the US. We had two keynote talks plus four seminars of which people chose two and a repeat of our afternoon of nine PODs

which we started last year. In these a leader for a topic (e.g. Teenagers with cavernoma, Post-op, Spinal Cavernoma, Carers) is available in a room and those present wander round and take part however they like. It sounds horrific, but it is incredibly successful.

On the day before the Forum, Jana Bergholtz from CASE (Sweden) and Helen Evans hosted an inaugural meeting of patient organisations from European countries and voted to launch a European CCM Network whose name is still to be determined.

Our CaverFamilies, with its grant-funded programme of seven residential events this year for children, young persons and parents, goes from strength to strength. One of these events was held alongside the Forum (we had an actual castle for the weekend) so the parents came to the Forum on one day. We have a team of two therapists at each CF event, one for parents and one for children.

This was the first year of our Essay Prize, awarded for an essay by a young scientist or clinician, and won by a newly-qualified clinician Yvonne Zuurbier and final year medical student Lottie Hickman. Their essay was published in Lancet Neurology earlier this month.

Helen Evans and David White



Connie Lee, Yvonne Zuurbier, Helmut Bertalanffy, and Ian Stuart.

09.15.2019 3RD ANNUAL
 HOSTED BY THE SOUTHERN CALIFORNIA ANGIOMA COMMUNITY ALLIANCE

ORANGE COUNTY

RUN & 5K

CAMO FOR A CAUSE

FLO JO PARK, 22760 OLYMPIAD RD., MISSION VIEJO

CROWDRISE.COM/OCANGIOMAWALK2019

5K 1 MI

RAISE/DONATE \$35 TO RECEIVE A FREE BRAVE SHIRT

9AM REGISTRATION/10 AM WALK

FAMILY FRIENDLY ACTIVITIES, RAFFLE REFRESHMENTS, AUCTION & MORE!

ALL PROCEEDS BENEFIT ANGIOMA ALLIANCE, A 501C3 ORGANIZATION DEDICATED TO INFORMING, SUPPORTING & EMPOWERING INDIVIDUALS AFFECTED BY CAVERNOUS ANGIOMA AND DRIVING RESEARCH FOR BETTER TREATMENTS & A CURE. ANGIOMA.ORG

? CONTACT LINDA AT LINDA.FUCHSER@GMAIL.COM OR 949.275.6560

ANGIOMA ALLIANCE
GREATER DC COMMUNITY ALLIANCE

Greater DC Community Alliance and Odenton Sports Center Present:

Family Fun Sports Night and Pig Roast!

September 21st, 6:30pm – 9:30pm

There will be a 50/50 raffle and a Silent Auction

Sports, Food, Music, Auction, Fun!
 Menu: Roast Pork, hamburgers, hot dogs, salads, etc.

\$25 Adult (18+); \$10 Ages 17-7; Age 6 or younger FREE!
 All proceeds to benefit Angioma Alliance

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<https://www.odentonssc.com> <http://angioma.org>

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CALLING ALL SUPERHEROES!
2ND ANNUAL

ANGIOMA ALLIANCE WALK
 family friendly activities, raffle, refreshments & more!

Registration 8 AM
 Walk begins at 9 AM

Raise/donate \$35 receive a t-shirt

Largest team kicks off the walk
 Top fundraiser is superhero of the walk

SAT. 9/21/19, BERKLEY LAKE PARK, 4601 W. 46TH AVE, DENVER, CO 80212

Proceeds benefit Angioma Alliance, a 501c3 organization whose mission is to inform, support, and empower individuals affected by cavernous angioma and drive research for better treatments and a cure. angioma.org

?s contact Darlene Garcia at coangiomaalliance@gmail.com

CROWDRISE.COM/COLORADOSUPERHEROWALK2019

Surf's Up!
 Benefiting Angioma Alliance
 Presented by the Southern California Community Alliance
 5th Annual

MALIBU BEACH BLANKET BINGO WALK

October 13, 2019
 Zuma Beach,
 30050 PCH, Malibu

9am registration/10 am walk
 Refreshments, raffle, limbo, bingo & more!
crowdrise.com/malibuangiomaawalk2019

Join us as we raise funds and awareness for those affected by cavernous angioma. All proceeds benefit the mission of Angioma Alliance.

?s: Judy, 310-488-9644, judithamanda@gmail.com
 or Kristen, 310.770.3687, kcrentz@aol.com

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 Lindsay Ramirez at lindsay@angioma.org to learn more about these opportunities and valuable benefits for your company.



**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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www.facebook.com/AngiomaAlliance
info@angioma.org
Twitter: @AngiomaAlliance

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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.