



ANGIOMA ALLIANCE NEWSLETTER

because brains shouldn't bleed

We're Dreaming Big

I have spent this summer dreaming, and I've been turning those dreams into conversations, meetings, and, more practically, grant requests. Let me tell you about my dreams, but first, let's review where we are and how we got here.

Angioma Alliance is now 14 years old. In May, 2002, I had a two-year-old daughter who had already had three brain surgeries for hemorrhaging lesions. I was determined that she would grow up knowing other children with cavernous angiomas. She would not feel alone, nor should anyone with a cavernous angioma. Angioma Alliance was born as a vehicle to bring us together, to unite us in mutual support. Now, thousands of people from around the world participate in Facebook groups, receive one-on-one peer support, and attend our conferences. Soon, we will do more.

Then...

In 2002, there was no information on the internet about the illness written in lay language. Medical professionals can help us, but in the end, our brains and spinal cords go home with us and we are responsible for making our own care decisions. It always has been part of the Angioma Alliance mission to provide information so that each of us can make the best possible decision. Now, our website provides the most extensive, accurate lay information available anywhere. We have expert presentation videos on YouTube and an ongoing series of patient conferences in the US as well as those hosted by our sister organizations in Canada and the United Kingdom. By the time you read this, we will have a new 36-page patient booklet heading to the print shop, preparing for national distribution. And, there will be more.

In 2002, the number of patients participating in research could fill an elevator with room to spare. There were no mechanisms to connect patients with labs. We knew we were still far from treatments; at that time researchers had identified only one of three known genes that cause the illness and did not yet understand what function even that one gene performed. Through Angioma Alliance, we offered what only patients could create: an annual international scientific meeting, a DNA and Tissue Bank, a patient registry, a small grants program, free genetic testing, a CCM3 clinic, and collaborations with researchers and drug companies

around the world. Now, we have seven medications in the pipeline. And we will do more.

In 2002, medical care for cavernous angiomas was rife with ignorance. This was somewhat excusable because, just like the dearth of lay information, very little information existed for medical professionals. Only neurosurgeons received formal exposure at medical school. Through Angioma Alliance, we offered financial awards to neurology residents. We sponsored travel awards for young doctors and researchers to attend our scientific meeting. Our Chief Scientific Officer Dr. Amy Akers and Scientific Advisory Board created review articles that could be referenced by curious physicians (the latest came out in the journal *GeneReviews* just before this issue of the newsletter went to press). I knew we'd gotten onto the radar when doctors started over-diagnosing cavernous angioma; misdiagnosing other illnesses as cavernous angioma when they were, indeed, something else. A mistake, yes, but one that showed that doctors were now aware of the illness. Obviously, we can do more.



This many people attended the first Angioma Alliance Scientific Conference in 2005.

...and Now

In 2016, I dream of an organization that continues to support its members as we've done, and also has a program of support specifically for those who no longer have cavernous angioma but who continue to live with the impact of the illness. Ryan Westmoreland, Angioma

Alliance Ambassador and former Red Sox prospect, in a recent speech in Boston, talked about feeling suicidal after his second surgery because of the loss of his career. He told how his brain surgery led to 16 additional surgeries to mitigate his deficits. Life after cavernous angioma does not simply go on as before for many people. They may no longer be in need of a cavernous angioma cure, but they are in need of community. Our post-surgical membership has grown over the years, and I'm deeply grateful for their continuing participation and investment. We are forming a committee to explore ways that Angioma Alliance can serve and support those who may have moved beyond their cavernous angioma but who are still navigating the changes. Contact me if you would like to be part of brainstorming and creating the program.

In 2016, I dream about a network of Clinical Care Centers providing quality treatment to patients around the United States. By our next newsletter, I should have good news about a first Center of Excellence. I should also have a date for the publication of our Clinical Care Consensus Guidelines, written by the Angioma Alliance Scientific Advisory Board and invited experts. The guidelines will be published in a major clinical journal and on the Angioma Alliance website for everyone to share with their doctors. I dream that our Clinical Care Center program will expand to include 20 or more institutions, recognized and trained with the help of a future Angioma Alliance Medical Director.

In 2016, I dream about successful clinical drug trials. We know trials are coming, but we also know that executing a drug trial is very difficult. We will need patients who are committed to testing the medications that may help cure this illness. Depending on the medication and structure of the trial, the number of patients required could be in the thousands, possibly three or more times the number of people currently in our patient registry.

I dream that we are able to engage cavernous angioma patients in research and trials by reaching out in places like New Mexico where we need to be doing so much more. Because of the Common Hispanic Mutation,

a version of the CCM1 mutation that has been passed down in New Mexico since the late 1500s, the state has the largest population of people affected by the illness in the world. They need better services and they need engagement. Angioma Alliance is assisting the University of New Mexico in a number of ways, and we dream about starting our own outreach programs in the state. I wrote four grant proposals over the summer specifically requesting support for our work there.

In 2016, I dream we have a way of quantifying the experience of those affected by cavernous angioma. We want data that can be used to paint our picture in the largest, clearest terms. Crunching numbers from questionnaires may not seem exciting, but it shines light and answers questions that drug companies, investors, and government funders have been asking. How exactly does this illness affect us? What would "better" look like?

I dream that we will have many ways of evaluating whether a medication is effective. To that end, we have been working to find ways to develop a comprehensive tool to measure the quality of life of patients. You may be asked to participate in this work over the next 12-18 months. Please consider giving your time and your expertise to help.

The landscape in which our Angioma Alliance community finds itself in 2016 has been changing at a head-spinning pace, and we are positioning ourselves to keep pushing the pace. Amy Akers and I are learning new languages—those of the FDA, the pharmaceutical industry, and clinical research—and dreaming dreams we couldn't have conceived just three years ago.

We know we're running a marathon; this is a long project, and every step takes us closer to our goal. We are very grateful to have your support, both financial and emotional, as we continue this race to fulfill our mission of informing, supporting, and empowering those affected by cavernous angioma and driving research for better treatments and a cure.

Connie Lee



This was the attendance at the 2015 Scientific Conference.

News

Join Team Angioma Alliance

Angioma Alliance has unveiled our walk t-shirts for 2016, and we encourage you to join us as we walk to raise awareness around the United States or wherever you are. This year's shirt sends a message about the strength of our members and our will to find a cure.



Anyone can join this team to support the work of Angioma Alliance. Many members have organized walks in past years: individual walks, small groups, and large events. To start, simply pick a date and location, invite your friends and family, order some shirts, and walk. Other ways to make your walk count:

- Join one of our regional Facebook groups to find other members in your area who can join you.
- Open a page on the EverydayHero website as part of Angioma Alliance 2016 at give.everydayhero.com/us/team-angioma-alliance-2016. Ask for the support of your family and friends.
- Share your story with local news outlets. Brian Fair (bfair@angioma.org) can help you with this.
- Visit our Anywhere Walk page to download guides with more tips and helpful information at www.angioma.org/pages.aspx?content=406.

Your walk raises awareness and supports the many things we do to support those affected by cavernous angioma and to drive research for a cure. Currently, we are raising funds to:

- Create a Clinical Center of Excellence Recognition program, which includes hiring an Angioma Alliance Medical Director.

- Develop measures that can be used to determine whether new medications have an impact on our members' quality of life.
- Support our annual Scientific Meeting, the only meeting that brings together cavernous angioma researchers from around the world.
- Distribute a new patient booklet, with content that reflects the new Angioma Alliance Clinical Care Consensus Guidelines.
- Organize a series of patient conferences. Read about the upcoming conference in Durham, NC, on the next page of this newsletter.
- Create a patient outreach program in New Mexico, where there is great need and opportunity.
- Continue our existing programs including extensive peer support and education, free genetic testing, a DNA and Tissue bank that supports research, a patient registry, and our active partnerships in upcoming clinical drug trials and other research.

Order your t-shirts now at angioma-alliance.myshopify.com and take the first step. Without you, there can be no cure.

Connie Lee, President and CEO

4th Annual Zach Brown 5K

Please join us for the 4th Annual Zach Brown 5K for Angioma Alliance on October 30th, beginning at 9 am. You can join us in person at beautiful Camp Letts in Edgewater, Maryland, or join us in spirit by participating virtually from wherever you are! Follow us on Facebook at Zach Brown Virtual 5K for Angioma Alliance for updated information and registration. All donations go directly to Angioma Alliance. Thank you!



North Carolina Family Conference and Awareness Walk

Join us at Duke University for a morning of updates on the latest cavernous angioma research and treatment presented by Duke University Professor Dr. Douglas Marchuk, Angioma Alliance Chief Scientific Officer Dr. Amy Akers, and Angioma Alliance President and CEO Dr. Connie Lee. After the presentations and discussions, we'll have lunch followed by an awareness stroll in the beautiful Sarah P. Duke Gardens on the campus. Attend the conference, the walk, or both. Register at tinyurl.com/Duke2016Conference.

Where: Duke University Medical Sciences Research Building, 203 Research Drive, Durham, NC

When: Saturday, September 24, 2016 from 9:30 – 2:30

Where to stay: If you are coming from out of town, please book your hotel as soon as possible. We suggest trying the Holiday Inn Express Durham with a free hospital shuttle (to the conference) and free breakfast, microwave, and fridge. Rates are \$127-\$149/night. For a less expensive hotel option, check out the Brookwood Inn, Durham. This hotel offers a free hospital shuttle (the hotel is also in walking distance) and rooms are \$84-\$99/night. Breakfast is not included.

Brain Vascular Malformations Consortium



In collaboration with two other disease foundations (The Sturge Weber Foundation and Cure HHT), Angioma Alliance has partnered with researchers to apply for and receive a Rare Disease Clinical Research Network (RDCRN) Consortium Grant. This unique funding mechanism requires advocacy groups to be partners in research.

The Brain Vascular Malformations Consortium (BVMC) is a study team investigating three rare diseases that cause brain vascular malformations including, Hereditary Hemorrhagic Telangiectasia

(HHT), Sturge-Weber Syndrome (SWS), and Cerebral Cavernous Malformations (CCM).

We are currently recruiting participants for a study called "Brain Vascular Malformation Consortium: Predictors of Clinical Course. Project 1: Modifiers of Disease Severity and Progression in Cerebral Cavernous Malformations (CCM)."

Why Is This Important?

The goal of this study is to investigate the genetic factors that contribute to CCM disease severity and progression. To address this question, researchers are looking specifically at the genetic variations in individuals with CCM1 gene mutations.

In this study, clinical, genetic and environmental information will be collected from people with the CCM1 to look for risk factors affecting CCM disease severity.

Any potential risk factors that are identified may have implications for all forms of CCM, including those with other genetic mutation or the sporadic form of the illness.

How to Participate

1. Join the Angioma Alliance Patient Registry at www.angioma.org/registry – this is the registry run by our foundation. If you enroll in this registry and are eligible for the BVMC study, or another actively enrolling study, we will contact you by email.

2. Contact the Study Scientist: Amy Akers, PhD, Principal Investigator, amy.akers@angioma.org

To learn more about this study, please visit: www.rarediseasesnetwork.org/cms/bvmc/

The Brain Vascular Malformation Consortium (BVMC; U54NS065705) is a part of the National Institutes of Health (NIH) Rare Disease Clinical Research Network (RDCRN), supported through a collaboration between the NIH Office of Rare Diseases Research (ORDR) at the National Center for Advancing Translational Science (NCATS), and the National Institute of Neurological Disorders and Stroke (NINDS).

Sabermetrics Seminar Benefits Angioma Alliance: Ryan Westmoreland Shares His Story

On August 13th in Boston, a gathering of self-proclaimed “baseball nerds” listened to former Red Sox prospect Ryan Westmoreland share his emotional and courageous cavernous angioma story. His words brought tears to their eyes. When he finished, Ryan received a standing ovation.



The group was attending an annual weekend seminar to learn more about their passion but also to support Angioma Alliance and the Jimmy Fund, a Boston cancer charity. Organizers Chuck Korb, himself an Angioma Alliance member, and Dan Brooks decided from the outset that Saberseminar would be both educational and meaningful. This sixth year of the seminar was the first year that they included Angioma Alliance as a chosen charity. Because of their hard work and commitment, and the generosity of their participants, Saberseminar will be donating approximately \$12,500 to Angioma Alliance in 2016. We are very grateful. Please take the time to watch Ryan’s moving presentation at youtu.be/8CM5Nk5pzkE.

Drink Wine and Help Angioma Alliance

The 2nd Annual Wine Tasting to benefit Angioma Alliance will be held on Friday, September 16, from 6:00 to 10:00 p.m. at the Torrington Country Club in Goshen, Connecticut. Experience the scenic views of Litchfield County while enjoying some of the finest wines and mouth-watering appetizers. To complete the evening, listen to the music provided by Brian Mattiello and Anne DeMichiel. Tickets are \$30 if purchased in advance, \$35 at the door. VIP tickets are available for \$50 for admittance to the VIP Room and a sampling of select wines and liquors. For more information, contact Julia DeMichiel at 860-689-3379 or email at julia@bindingsource.com.

A poster for the 2nd Annual Angioma Alliance Wine Tasting. The background is dark with a large, stylized wine glass filled with red wine. The text is in white and gold. The title "2ND ANNUAL ANGIOMA ALLIANCE Wine Tasting" is at the top. Below it, the location "TORRINGTON COUNTRY CLUB 250 TORRINGTON RD, GOSHEN, CT" and the date "FRIDAY, SEPTEMBER 16, 2016 6:00 TO 10:00PM" are listed. Ticket prices are shown: "ADVANCE TICKETS \$30 \$35 AT DOOR" and "VIP TICKETS \$50". There are also mentions of "SAMPLING OF WINES AND BEERS" and "SAMPLING OF EXCLUSIVE WINES AND LIQUORS". At the bottom, it says "TICKETS AVAILABLE AT PONTE'S PACKAGE STORE 1270 EAST MAIN STREET, TORRINGTON, CT 860-482-4762". For questions and ticket information, it lists "JULIA@BINDINGSOURCE.COM • 860-689-3379". Logos for Angioma Alliance, Binding Source, Ponte's Package Store, Minuteman Press, and Trinchero Family Estates are at the bottom.

Find Online Support on Facebook and the Community Forum

Did you know Angioma Alliance has 11 different Facebook discussion groups? Along with our main group, you can find support specific to parents, to those with spinal cord cavernous angiomas, and to caregivers. We offer 7 regional groups, too. While you are on Facebook, search “Angioma Alliance Groups” to see a dropdown listing. The privacy setting on these groups is “Closed” so only members can read posts.

Not on Facebook? Find support online through our Community Forum. Unlike Facebook, it is anonymous but posts are public. The Community Forum can be found at www.angiomacommunity.org/forum. To keep up with the latest news, like our Facebook page at www.fb.com/AngiomaAlliance or follow us on Twitter and Instagram.

Interview: Julia DeMichiel

Connie Lee: I'm here today with Julia DeMichiel who is a member of the Angioma Alliance Board of Directors. I'm going to be talking with her about her experiences with cavernous angioma and about an exciting event that she has going on in September. Julie, can you please tell me a little bit about your and your family's experiences?

Julia DeMichiel: Of course, I'd love to. When I was about ten years old, I had an episode where I had severe, severe headaches. I couldn't get out of bed. It was awful. My mother was terrified. She didn't know what was going on. The headaches seemed to pass after about a week. Then, suddenly I woke up one morning and my right side was very weak. I couldn't walk. We went to the hospital, and I was there for a week or so. They thought I had had a stroke even though I was a young child. But, that seemed to be the end of that episode. I went into physical therapy and recovered pretty well.

Then, when I was thirty years old and my daughter was 4, I had severe headaches again and I thought, "Oh my goodness. This seems like those headaches that I had when I was a child." I ended up going to Massachusetts General and Brigham and Women's Hospital. They did some testing there. That's when they found out I had cavernous angiomas. At that point, I went through stereotactic radiosurgery, which was new at that time. My doctor felt this could help me tremendously. Well, it didn't really do the trick that they had wanted, but it didn't seem to cause any harm. I'm thankful for that. I wanted to do anything I could. It was on the breaking edge of stereotactic radiosurgery when it was just experimental. I said, "Yes, sign me up for that."

Then, my daughter, when she was in college her freshman year—she had just been there for a couple of weeks—called home and said she didn't know where she was. She had no idea what to call things, where she was, she couldn't explain anything. She couldn't come up with words. We found out she was having a

seizure. It ended up being a grand mal seizure. She went to Providence College, and she went to the hospital there in Providence. They discovered that she also had cavernous angiomas. That's when we did some more testing. It was very devastating for us. Your daughter at college lost . . . they ended up sending the swim team to find her. It was very scary. As time went on, she had no more difficulties with that, which we're very grateful for.

She had a child of her own. When she was born, we found out she had cavernous angiomas as well. She had markings on her body that they thought were bruising at first. When they realized my daughter and I had cavernous angiomas, they realized that's what it was. They did some more testing on her.

Now we know there are four generations of angiomas. My mother has it as well.

CL: What effects do you still have from the cavernous angioma, if any?



JM: I still get very intense headaches. I still have weakness on my right side. I do therapy to try to take care of it. I do walking. I try to keep it as strong as I can. I can't give up. I'm not going to be weak. I'm not going to let it get the better of me. It needs to be fought. I'm not going to

give into it. Really, walking is the hardest part, walking with the limp and the drop foot. I think that's what bothers me the most.

CL: You have an event coming up. Can you tell us a little about what it is, where it is, when it is?

JM: We're having the 2nd annual Cavernous Angioma Wine Tasting. This is held at the Torrington Country Club in Goshen CT. It's a very beautiful, very lovely, setting. They did a wonderful job last year and everyone had a wonderful time. The setting is quite different than most wine tastings we have around this area. It was much more elegant. People were able to schmooze and walk around and greet others. There are tables set up so people can converse and have a good time. We also have entertainment. The people in the

Northwest corner know Brian Mattealo and Anne Gainum DeMichiel. The food at the country club is just awesome and of course the wine. That's why we're there. That's why people are coming; for the wine and also to support this cause and help us find a cure. It's a wonderful time, and I hope people come.

CL: Can you give us a date and a time?

JM: It will be held on September 16th. It's a Friday night. From 6 to 10 o'clock.

CL: Is there anything else you'd like to share, to tell the community, that you think people might want to know?

JM: I think the main thing is "Don't give up." Don't give in to it. Keep fighting. Don't get into depression. I did this for a while, I must confess. Feeling sorry for myself. But, you need to be strong and there's so many things you can do even if you have this disease. For instance, I used to love to bike ride. I found that with my right side being very weak, it was difficult, especially because your rear brakes are controlled with your right hand side. I can't squeeze my right hand very well, so I had my bike altered so my rear brake is now in my left hand. Things like that. Things can be done to accommodate you, to help you live a great life, and I'm very happy now. I keep fighting.

CL: Thank you, Julie. Thanks for taking the time to talk with us. I hope the event in September is a great success.

Free Genetic Testing is Still Available

Do you have multiple cavernous angiomas? If so, do you know whether you have a mutation on one of the CCM genes? Knowing your genetic status is important for treatment planning and for your extended family. Angioma Alliance continues to offer free genetic testing to those in the US and Canada with multiple cavernous angiomas who do not have insurance or another third party payer that will cover the cost. Currently, out-of-pocket CCM genetic testing can cost up to \$2,500.

Learn more about the program on our website at www.angioma.org/testing.

French Foundation Awards €600,000 for CCM Research

Professors Elisabetta Dejana and Elisabeth Tournier-Lasserre were recently awarded the prestigious Lefoulon-Delalande Grand Prize. This annual prize is awarded to a scientist or scientists who has made significant contributions to cardiovascular biology or medicine. The Lefoulon-Delalande foundation was created in honor of the family patriarch who was a distinguished European pharmacist and pioneer of the pharmaceutical industry in the early 1900s. Today, this French nonprofit is committed to facilitating and funding research; this year's award supports CCM research.



Dr. Tournier-Lasserre is an expert in medical genetics who runs a research lab in Paris, France. Several of her many contributions to CCM research include discovery of the CCM3 gene; characterization of the unique features associated with individuals carrying CCM1, CCM2 or CCM3 gene mutations; and her more recent studies in mice to help better understand the physical distribution and function of the CCM proteins.

Dr. Dejana is a distinguished scientist in the field of vascular (blood vessel) biology. Her research team from Milan, Italy, recently identified a unique behavior of the blood vessels that make up CCM lesions. The next step in her research was to identify a possible drug or chemical process that can reverse or block this behavior. This line of investigation led to the finding that the drug Sulindac may be a therapeutic agent for CCM disease. Drs. Dejana and Tournier-Lasserre are currently working together to further investigate Sulindac in mouse models of CCM disease. The work of these two women has significantly impacted the field of CCM research and will be further supported by this generous award.

Research Update

Research Updates and Drug studies

Cerebral Cavernous Malformations Arise From Endothelial Gain of MEKK3-KLF2/4 signalling

In a new study published in the high-profile journal, *Nature*, Dr. Mark Kahn's lab at the University of Pennsylvania identified abnormal genetic activity that occurs very early during the formation of CCM lesions. They showed that when the activity levels are blocked, mice that are genetically modified to develop CCMs do not develop lesions, or develop them at a significantly reduced rate. This finding opens up new molecular targets for drug development that may be able to prevent the formation of new lesions. Interestingly, the disrupted signaling was identified in all types of human CCM lesions (CCM1, CCM2, CCM3 and sporadic), suggesting that a drug targeting the MEKK3 signaling pathway may be able to treat all forms of the illness.

Zhou, et al, *Nature* 04/2016. www.ncbi.nlm.nih.gov/pubmed/27027284

Endothelial Cells Lining Sporadic Cerebral Cavernous Malformations Undergo Endothelial-to-Mesenchymal Transition

Last year, a research team from Milan investigated the behavior of blood vessel cells in CCM lesions. They found that familial (genetic) CCM lesion cells turn on signals that make them more mobile and changeable (endothelial-to-mesenchymal transition, EndMT), features that may contribute to the development of lesions. In this new study, they wanted to know whether sporadic lesions also showed this same behavior. Indeed, this team showed that sporadic CCM lesions also display this unique behavior. These results are important because they can lead to new drug targets (signaling molecules related to EndMT) that may be appropriate for all forms of CCM disease.

Bravi, et al, *Stroke* 03/2016. www.ncbi.nlm.nih.gov/pubmed/26839352

B-Cell Depletion Reduces the Maturation of Cerebral Cavernous Malformations in Murine Models

Recent research has shown a strong inflammatory system response around CCM lesions. This includes accumulation of B-cells (those that produce antibodies). In a new study, Dr. Awad's team at the University of Chicago used CCM3 mice to demonstrate a therapeutic benefit of B-cell depletion therapy. B-cell depletion therapy involves treatment with specific antibodies that targets and removes these cells from the body. This type of therapy has been successful in several cancers and auto-immune conditions. In CCM mice, B-cell depletion therapy has been able to stop the maturation/progression of lesions.

Shi, et al, *J Neuroimmune Pharmacology*. 06/2016. www.ncbi.nlm.nih.gov/pubmed/27086141

Vascular Permeability and Iron Deposition Biomarkers in Longitudinal Follow-Up of Cerebral Cavernous Malformations

In a study of 46 CCM patients, a team from the University of Chicago aimed to demonstrate that specialty MRI techniques [dynamic contrast-enhanced quantitative permeability (DCEQP) and quantitative susceptibility mapping (QSM)] could predict future clinical outcomes. Each participant underwent multiple MRIs; permeability MRI values were correlated with clinical features at each time point. The findings showed that an increase in lesion permeability correlates with lesions that are bleeding and/or growing. Furthermore, in familial cases, the researchers showed that new lesions develop in areas of the brain that have increased levels of permeability. These findings provide supportive evidence for the use of these specialized MRIs as measurement tools in future clinical trials.

Girard R, et. al., *J Neurosurgery*. 08/2016. www.ncbi.nlm.nih.gov/pubmed/27494817

Amy Akers, Chief Scientific Officer

Up-to-Date Information for Medical Professionals

Are you looking for accurate, up-to-date information about familial cavernous angioma to share with your doctor? Our Chief Scientific Officer Dr. Amy Akers and our Scientific Advisory Board Member Dr. Leslie Morrison have just updated a web page that helps explain the illness to medical professionals. Visit www.ncbi.nlm.nih.gov/books/NBK1293/ and print the page for your next appointment.

Think Planned Giving to Angioma Alliance is too Complicated? It's Easy with an IRA.

Last year Congress passed a law that is good news for taxpayers over the age of 70½. This law made permanent the exclusion from income of up to \$100,000 per person, per year, for Individual Retirement Account (IRA) distributions giving directly to charities. And, if you are 59½ or older, you can fund your contributions from your IRA with no early withdrawal penalty.

Planned giving is a way of supporting a nonprofit that lets donors make larger gifts than they could from their income alone. The best-known planned gift is a bequest: a donor including a nonprofit as a beneficiary in their estate.

Other types of planned gifts—gift annuities, unitrusts, and life insurance—offer immediate or deferred income and tax benefits to the donor. You can help Angioma Alliance with any of these gifts. The IRA charitable distribution is one these types of gifts that offers great benefits to the donor. It's the easiest to enact and can be used to make annual donations up to 5 years in the future.

The IRA donation is useful to seniors who are retired and on a lower/fixed income yet wish to continue making donations. Unless they are in the top tax bracket, donors receive tax benefits using their IRA because:

- Gifts count towards an individual's required annual distribution requirements,
- Charitable contributions are limited to 50% of adjusted gross income (AGI) each year,
- Since the charitable contribution from an IRA distribution is both excluded from income and is a deduction, making a gift through an IRA causes a donor's AGI to be lowered, and
- Lowering your AGI is more valuable than taking an outright charitable deduction.

Dozens of tax calculations are based on an individual's AGI. The lower the AGI, the less a person is penalized and taxed. For example, some benefits of lowering AGI are:

- Medical expenses for seniors are limited to 10% over the gross AGI, and
- The tax on net investment income only applies as AGI goes above a set threshold.

If you have a child, grandchild, or other family member impacted by CCM, and would like to reduce your tax burden, while helping Angioma Alliance's progress, consider using an IRA as an alternative method of giving. It's easy, reduces expenses and taxes, and allows you more freedom to leave a legacy to the organization in the later part of your life.

Have Your Company Featured at the 12th Annual CCM Scientific Meeting

On November 10-11, 2016, leaders in the world's research, scientific, and medical communities will meet in Washington D.C. for Angioma Alliance's 12th Annual CCM Scientific Meeting. New and unpublished research is presented at the meeting, which includes a panel discussion, keynote speaker, and poster session.

We offer benefits at the Scientific Meeting for companies wishing to be a part of our mission to inform, support, and empower individuals affected by cavernous angioma and drive research for a cure. If you are with a company that could benefit from networking with an elite group of scientists, consider a Corporate Donation. From \$10,000 - \$1,000, any level has benefits. Companies in the medical, pharmaceutical, and technology fields can benefit from being at our Scientific Meeting.

All levels offer base benefits such as a vendor table at the event, meeting attendance offering networking opportunities, and logo recognition in our newsletter and at the event. Other benefits vary by level, including more signage, verbal acknowledgement, and inclusion in public relations materials. Our current corporate donors include DSG, Inc., BioAxone, and PreventionGenetics.

To receive a full corporate benefit menu and/or learn more about using your IRA to make a legacy gift contact Brian Fair at (206) 446-8051 or bfair@angioma.org.

Brian Fair, Director of Resource Development

dsgedc⁺

PREVENTION GENETICS
DISEASE PREVENTION THROUGH GENETIC TESTING

BIOAXONE
BIOSCIENCES INC

International News

CAVERNOMA ALLIANCE UK

CAUK held its Tenth Anniversary Forum in June, with a celebratory supper on Friday 10th and the Forum itself the following day with 132 participants. There were three lectures: two from our patrons, Neil Kitchen and Rustam Al-Shahi Salman, who reviewed recent progress in the treatment of cavernoma, and the third from a clinical psychologist, Dr Daniel O'Hara. In addition, we held workshops, including one on Mindfulness Based Approaches and another on Reframing, or how to see the world from a different perspective. These workshops were intended to provide relief to those coping with the stress of a cavernoma.

An issue raised by a number of members has been the Forum's location, in London. In a survey, roughly half those responding wanted this to be held in the north of England. So next year, we are breaking with tradition and holding the Forum in York, a city in the north with its centre enclosed by an old wall of Roman origin.

This year has seen a massive increase in our membership. Published figures suggest that one out of every 400,000 people, or about 160 people, are diagnosed with cavernoma in the UK each year. Our membership is now increasing by more than this figure annually.

Thanks to a grant from Morrison's, a chain of UK grocery stores, Angela Yeomans, CAUK's community

development coordinator, held our first Brighton CaverCentre. Whenever CAUK has a preponderance of members in a geographical area we establish a CaverCentre, a local meeting initially organised by our office in Dorchester but with the aim of the Centre eventually being self-sustaining. According to the wishes of the local cavernoma community, speakers can be invited. On this occasion, Angela had arranged for Mansoor Foroughi, a consultant neurosurgeon to speak to the group. CaverCentres are run independently in both Liverpool and Leeds, in the north-west and north of England and soon a CaverCentre is to be piloted in the north-eastern city of Norwich.

CaverFamilies, a group of parents and children who are directly or indirectly affected by cavernoma, held their annual Residential Weekend in July, this time camping in a Tipi and Yurt farm in the country. Ten families with a total of 24 children, 14 with cavernoma, took part. Arranged by Angela and helped throughout the weekend by an eager group of volunteers, it was action-packed from the word go, though the parents had a session on relaxation with a qualified Counsellor/Psychotherapist. It was a wonder they managed to relax with so many children in the vicinity.

The CaverFamilies residential weekends have been so successful that members without children have asked if we could arrange a similar event for them – somewhere relaxing where they can talk in a more informal setting than the fast and furious Forum. So next year we are holding an informal CaverDay in York the Sunday after the Forum.

Ian Stuart and David White



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.

Angioma Alliance
520 W 21st Street, Suite G2-411
Norfolk, Virginia 23517
Fax: 757-623-0616
info@angioma.org
www.angioma.org
www.facebook.com/AngiomaAlliance
Twitter: @AngiomaAlliance

Angioma Alliance Board of Directors

- Connie Lee, President & CEO
- Karen Asbury, Treasurer
- Tracy Brown, Director
- Julia DeMichiel, Director
- Tim Gallegos, Director
- Kristen Lewis, Director
- Tony Mayer, Director
- Liz Neuman, Director
- Myrna Sarowitz, Director

Scientific Advisory Board

- Issam Awad, MD, MSc, FACS, University of Chicago Pritzker School of Medicine
- Brent Derry, Ph.D., The Hospital for Sick Children, University of Toronto
- Kelly Flemming, MD, Mayo Clinic, Rochester, MN
- Helen Kim, PhD, University of California, San Francisco
- Douglas Marchuk, Ph.D., Duke University Medical Center
- Leslie Morrison, MD, University of New Mexico Medical School
- Rustam Al-Shahi Salman, MA, PhD, MRCP, Western General Hospital, Edinburgh, Scotland
- Kevin Whitehead, MD, University of Utah

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 and Tissue Bank - \$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 Brian Fair at bfair@angioma.org or (206) 446-8051 to learn more about these opportunities and valuable benefits for your company.