

ANGIOMA ALLIANCE NEWSLETTER

because brains shouldn't bleed

COVID-19: We are Meeting the Challenge

"CCM hasn't stopped, and neither have we." That's the slogan we used during our June Cavernous Angioma Awareness Month, and it encapsulates what has happened in the months since we began to feel the impact of the virus on our work. I want to share with you how we've been responding, and I think you'll be pleased. In short, we are thriving by finding creative new ways to achieve our mission, and, because of you, we will be stable financially through the end of our fiscal year 2020 and beyond.

COVID-19 Direct Response

As Fred Rogers advised, during times of crisis, look for the helpers. During the COVID-19 pandemic, we are the helpers.

We are providing the latest science-based information about COVID-19 and its possible impact on people with cavernous angioma to our members through webinars, official statements from our Scientific Advisory Board, and by responding to countless direct questions via email and social media.

We have partnered with the Mayo Clinic and the University of Chicago to create a CCM COVID-19 Registry (www.angioma.org/COVID). Our consortium is the only group in the US, and possibly

the world, interviewing and analyzing data for cavernous angioma patients who contract the virus. As we learn more about COVID-19, and particularly about its vascular impact, this information becomes critical. We are looking to see whether those who are infected with COVID-19 experienced increased CCM symptoms and whether their experience of COVID-19 is different from patients who don't have cavernous angioma.

International CCM Scientific Meeting

The greatest impact of the virus has been on our annual International Scientific Meeting. Each November, this meeting brings together the world's researchers, offering them the opportunity to share pre-published data and form collaborations. It is the only meeting of its kind and has served to expedite research by years, and perhaps by a decade or more.

We are moving to a virtual format for the meeting; with a twist. We are pre-recording presentations and making them available to attendees in the two-week period before the meeting. The meeting itself will be comprised entirely of discussion to make optimal use of researchers' time. Zoom fatigue is real, and we have the added challenge of managing time zones: we

include participants from Australia, Asia, North and South America, and Europe. Limiting our meeting to discussion-only format will allow us to turn what is usually 12 hours of plenary into 4-6 hours of Zoom time over 2-3 days.

One benefit of moving to a virtual format is that we will host a much larger number of participants. Typically, because of travel costs and budgetary constraints, labs can send only a few representatives. With a virtual meeting, all lab members can attend.



The Birth of a New Science Series

Our in-person meeting includes a poster session during which trainees may present their work. This year, we are creating a new program: a series of virtual poster sessions, spread throughout the year, to encourage ongoing trainee commitment to CCM research. Three posters will be presented at each session, and senior CCM scientists will be invited to moderate, critique, mentor, and judge. We are excited about this brand-new offering and believe that by keeping science fresh throughout the year, we are offering a valuable service to the field that will continue beyond COVID-19.

We have every intention of hosting an in-person scientific meeting in November 2021 if conditions allow. Virtual meetings, as well-designed as ours may be, are not a substitute for seeing the smiles on colleagues' faces when they spot each other across the room or the intensity when they're swept up in the energy of brilliant minds incubating ideas. Hope is born and fed in our meetings through relationships, and we will be together again as soon as we can.

CCM Research Programs

We are keeping in close contact with academic labs and with pharmaceutical company partners to monitor the impact of the virus on their progress and to assist as we are able.

So far, the impact on laboratory research progress has not been huge. For our basic researchers, if cell lines and animal models are kept alive, research can be picked up where it left off. For those in larger facilities where social distancing is possible, the return has already begun. In smaller facilities, the return will be stepwise and staggered, with each lab optimizing use of their limited space. Even their down time has not been wasted. While they have been out of their labs, researchers have been writing papers and grant applications and having conversations with other labs and with us about future collaborations.

Clinical research also has continued apace. The atorvastatin drug trial paused enrollment for only two months. Plans for Phase II of drug testing for Recursion's medicine REC-994 remain on track. Most other clinical research is conducted over the phone or through medical records and has not skipped a beat,

including the projects in which Angioma Alliance is involved, like development of the CCM-Health Index, a quality of life survey that will be used to measure treatment efficacy, the Angioma Alliance International Patient Registry, and the Brain Vascular Malformations Consortium.

Overall, the biggest risks to upcoming research are the possibility of additional lost time if we move back into Phase 1 of COVID restrictions in the United States and, more seriously, the likelihood of budget cuts impacting grant funding and university support. We will stay on top of this and assist our scientific community in every way possible, working to keep CCM research high on the priority list for the limited funds available.

Patient Outreach and Conferences

All of our in-person conferences and meetings for 2020 have been canceled. We have addressed this in numerous ways:

1. We have beefed up our online support. In addition to our numerous Facebook groups, we now host a weekly online support group via Zoom, open to all, with the opportunity for breakout rooms for subgroups, including a monthly CCM-101 breakout for the newly diagnosed. Most of our local Community Alliances also have a monthly support group replacing the in-person meetings they'd previously hosted. Membership in our Facebook groups has been exploding, especially since mid-May when outpatient services re-opened in most areas.

2. Already in the works before COVID, thanks to the support of a generous donor, we launched an updated and upgraded website that includes everything a patient would ever want to know about cavernous angioma. Please check out the improvements at Angioma.org. We hope you like it as much as we do.

3. We have increased the number of webinars we offer. Previously, our webinars were quarterly, but we are now offering these learning opportunities once or twice a month.

4. We have begun work on a very special project, one that will allow our members who have gained expertise in cavernous angioma to receive recognition for their knowledge. We'll share more about this in the months to come.

5. In New Mexico, where we host programming that has been almost entirely conference-based, we have developed unique ways to reach out. Large parts of New Mexico do not have broadband internet access, so moving conferences online is not an option. This summer and fall, we will host our first radio conferences. We'll be broadcasting our information for 90 minutes and answering call-in questions on KDCE, a northern New Mexico station with a large listenership, on KSFR, the Santa Fe NPR affiliate, and KUNM. Following the conferences, we will mail information packets to those who request them. We are also creating an online training module for Community Health Workers to be hosted on the CDC's TRAIN platform.

We have had to put the brakes on some projects. We added the University of Miami/Jackson Health System to our network of CCM Clinical Centers in April, but we are not able to expand our Center of Excellence network further until institutions are able to reduce their focus on COVID and until our travel is safer.

And we have paused our free genetic testing program for budgetary reasons.



Fundraising and Finances

We continue to be good stewards of your gifts and donations, and we remain financially solid. While all of our in-person fundraising events for the year have been canceled, we have been fortunate in many ways:

- Early in the crisis, we were granted \$25,000 in additional funding from the Julian Grace Foundation to support our work in New Mexico.

- We have received a number of unanticipated major donations (\$5,000+), for which we are honored and grateful.

- We were the recipients of a PPP loan that we believe will be entirely forgiven.

- We have cut the second half of our FY2020 budget by 50%. Our fiscal year ends on September 30. We achieved this cut without reducing payroll—our staff is our lifeblood—and while maintaining a robust, responsive program.

- We hosted a multi-faceted virtual event throughout the month of June that raised \$50,000. It included peer-to-peer fundraising through a Move-to-a-Cure challenge, a virtual auction, and a live-streamed finale with patient stories, musical performances, and more. It was so much fun that we're planning another virtual event for this fall. See our CCM Warriors Recognition article on page 4.

Moving Forward

There is no doubt that COVID-19 will impact our 2021 finances. We don't anticipate that we'll be able to host in-person fundraising events again until the summer of 2021 at the earliest. To address this, we'll create a 2021 budget that reflects our anticipated reduced funding.

We may also be asking more of you. I hope you will respond with your heart and with continued confidence in our work to inform, support, and mobilize those affected by cavernous angioma and to drive research for better treatments and a cure.

I am honored and grateful for all of the ways you support us. Please take care and stay safe.

Connie Lee

CCM and COVID-19 Registry

Should you or a loved one with CCM be diagnosed with COVID-19 through testing, please let us know at www.angioma.org/COVID. We are working on a study with Mayo Clinic and the University of Chicago to gather more information about the impact of the virus on our patients. Once you've shared your contact information, we'll reach out to you for more details.

The Angioma Alliance Scientific Advisory Board have posted a consensus statement regarding cavernous angioma and COVID that can also be found through this COVID registry page.

Upcoming CCM and COVID Webinar

Dr. Issam Awad, chair of the Angioma Alliance Scientific Advisory Board, will offer a webinar "CCM Updates in the time of COVID-19" on Thursday, August 13, at 4 pm PT, 7 pm ET. You must register to attend at www.angioma.org/webinar-ccm-updates-in-the-covid-19-era-august-13th/. If you have questions for Dr. Awad, send them in advance to Connie Lee at clee@angioma.org. If you are reading this after the date of the webinar, you'll be able to view a recording on our YouTube channel.

Angioma Alliance International Patient Registry

The Angioma Alliance International Cavernous Angioma Patient Registry is used by many researchers to help inform their studies and clinical trials. Your participation has made this a tremendous, one-of-a-kind resource. If you aren't registered, you can do so at www.AngiomaRegistry.org. If you have already registered, thank you! And, please be sure to keep your email address up-to-date and complete any new surveys you receive.

Registry enrollment means you'll be the first learn of new research findings and you'll be notified if there are upcoming studies for which you might qualify. Your information is kept confidential. Enrolling in the patient registry takes only 20 minutes, and it provides the key to a cure.

Angioma Alliance Historical Projects

Angioma Alliance has genealogy projects that seek to trace the founding families of CCM mutations in the United States. This is work that our members have been doing together. If you are affected by one of these mutations, we ask that you reach out to us so that we can connect you to your extended family and help us flesh out the family tree.

Understanding the family tree is important for improving care for several reasons. It will help us:

- find and connect more at-risk families;
- identify geographic areas where we should put more resources into medical provider outreach to improve care; and
- tie the illness to the story of a state, region, or group, which can raise visibility among the public and among legislators who have an influence on research funding.

In the United States, we know of three founder mutations.

CCM1 Common Hispanic Mutation. This mutation has been passed down in families who can trace their ancestry to the original Spanish populations in New Mexico and Northern Mexico. Angioma Alliance has done extensive genealogy in this group, tracing the original mutation to the Baca and Dominguez de Mendoza families of the early 1600s. To connect, contact joyce@angioma.org.

CCM2 Exon 2-10 Deletion. So far, Angioma Alliance has connected families with roots in South Carolina and Missouri in the early 1800s, but we suspect the founders date back much further as there are many families with this mutation who have not been joined to the tree yet. Contact clee@angioma.org.

CCM2 Ashkenazi Mutation. Researchers at Duke University are working with us to understand the origins of this founder mutation. Contact kdahlem@angioma.org.

Genes can mutate in many ways. Many, many families with CCM1 or CCM2 mutations do not fit into one of these founder mutation groups. Your genetic test report will indicate the specific mutation that impacts your family.

Believe: Cavernous Angioma Warrior Recognition!

Tell Us About Your Warrior

Living with cavernous angioma requires the courage and determination of a warrior. This October, we want to hear about the people in your life with cavernous angioma—yourself or your loved ones—and share with the world the challenges your cavernous angioma warrior has met and overcome.

All through the month, we'll feature stories, pictures, and videos:

- on social media,
- in a Cavernous Angioma Warriors section on our website,
- in a live-streamed event on Sunday, October 25.

Help us recognize your cavernous angioma warrior! To participate, create a page with the story you have to tell at give.classy.org/ccmwarrior and include photos and/or video of your hero's victories. We can offer help with writing, if needed.

We will reach out to you as soon as we see your page and ask for your permission to share it. We'll also ask about including your warrior's achievements in our finale. We're excited and inspired, and we're looking forward to recognizing your loved one!

June's Virtual Extravaganza

Because all of our in-person events were canceled for the spring and summer, we needed to get creative. We wanted to promote the health of our members, raise awareness, and celebrate our community. So, June's International Cavernous Angioma Awareness Month became a virtual extravaganza.

We hosted a month-long Move to a Cure challenge in which we asked our members to move, in whatever way is possible for them, for 30-minutes a day. Members created webpages to share with their friends and family who were asked to support their efforts. Congratulations to John Lillibridge for moving the most! Congratulations to Dinah and Evan Winchester (read about their daughter Linnea in this issue), Tania Casaus, and John Lillibridge for raising the most funds through their webpages.

At the end of the month, as a first for us, we aired a finale full of patients telling their stories and offering musical performances, capping a monthlong silent auction. Our thanks to our patients, silent auction donors, performers, our host Eric Fuchser, and to Recursion Pharmaceuticals who sponsored the event.

We had so much fun that we'd like to do it again!



2020 CCM-Healthy Cookbook

Have you been using the 2019 CCM-Healthy Cookbook? Research out of the University of Pennsylvania has indicated that preservatives and artificial emulsifiers in the diet can negatively impact CCM disease. They can damage the gut lining which allows gram negative bacteria to escape the gut, enter the body, and initiates an inflammatory response. Please visit our website at angioma.org to learn more, and to find a list of commonly used preservatives and emulsifiers to avoid.

We are helping each other stay healthy with tasty recipe ideas that avoid artificial preservatives and emulsifiers. You can find the 2019 CCM-Healthy Cookbook as a digital download in our online store at shopangiomaalliance.bigcartel.com/product/ccm-healthy-cookbook-and-reference-2019

We're planning a new edition for 2020 and need your help to create it. Please send us your CCM-Healthy recipes and any tips you have for emulsifier-free food substitutions. For example, have you found an ice cream or creamy salad dressing that is emulsifier-free?

Our form at www.angioma.org/Recipes2020 allows you to upload recipes with a photo of your creation, providing you an opportunity to bring out your inner food stylist. Please share your favorite meals, and desserts to help keep each other healthy!

More News from the Microbiome

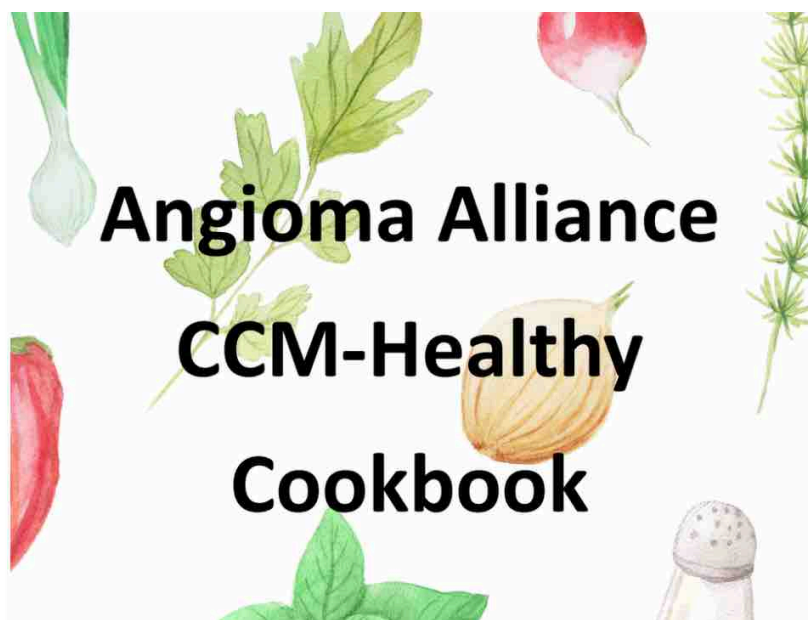
For those of you who participated in the microbiome study by sending in a sample three years ago, thank you! The findings were published in May and offer another step forward in our understanding of how the gut impacts cavernous angioma disease. It appears that the composition of the microbiome of people diagnosed with CCM is different from the general public. We don't know how to fix this yet, but this information is a good starting point.

There are two summaries of the research available. The first is an easier-to-read version in the popular press: newatlas.com/health-wellbeing/hemorrhagic-brain-disease-lesion-microbiome-gut-bacteria-metabolite/

The second is a more detailed account directly from the University of Chicago: www.eurekalert.org/pub_releases/2020-05/uocm-ssp052620.php

The original article is in the prestigious journal Nature Communications: www.nature.com/articles/s41467-020-16436-w

For our members, protecting the gut lining by reducing artificial preservative and emulsifier use is still the best course. Do not begin taking probiotics. Because of the complexity of the microbiome, we don't know which or whether probiotics could be of benefit.



One in 31 million: Linnea's Journey

Our toddler Linnea loves a lot of things, like her "Ducky," her morning "oh-meel," and a favorite barnyard animal, "Mooooo." She shouts "Hi!" to anyone and everything, from Mommy or Dada whenever we enter (and re-enter) a room to the tall London planetree in our backyard. Our neighbor says Linnea is one of the happiest little kids she's ever met.

We appreciate these moments today, because just over six months ago, we thought we were going to lose Linnea. Last fall, we noticed her right arm and leg weren't moving as they should, and she wasn't meeting gross motor milestones. We sought medical help, but we weren't referred to the proper specialists quickly enough. One Saturday morning in November, Linnea began crying inconsolably, vomited, then briefly fell unconscious. We took her to the emergency room where we learned, after several hours and multiple tests, that Linnea was suffering intracranial

pressure because a lesion was bleeding on her brain. Larger in size than a golf ball, this lesion had been oozing blood onto the brain tissue that housed the motor strip for her right side, and it was now pushing her left brain into her right brain. An emergency brain surgery was planned as Linnea became increasingly lethargic, so much so that she didn't move even when an IV needle was inserted into her hand.

During the surgery, we waited in Linnea's pediatric ICU room. Six hours later, our neurosurgeon delivered the news: the lesion had been completely removed, and with intensive physical, occupational and speech therapy, Linnea would be expected to regain almost all of her lost function because of the potent neuroplasticity of her baby brain. We were euphoric.

Since then, however, we've learned that we're not out of the woods at all. After the surgery, Linnea

underwent genetic testing to establish what had caused the bleeding lesion to form in the first place. The testing confirmed what her neurosurgeon suspected: Linnea has a genetic mutation that causes cerebral cavernous malformations (CCM) to form on her brain. CCMs are made up of tiny, tangled capillaries whose vessel walls are weak, making them prone to ooze blood onto brain tissue. This can lead to serious, repeated brain trauma.

The genetic testing also established that Linnea has the rarest form of CCM disease, CCM3, of which there are no more than 250 diagnosed cases in the world. CCM3 is a poorly understood, particularly aggressive version of the disorder that causes earlier and more frequent brain hemorrhages, because CCM3 patients have dozens, if not hundreds of CCMs. Hemorrhages occur most frequently in children with the disorder. We can expect Linnea will have multiple bleeds that will cause functional impairment in her lifetime.

Right now, the only treatment for CCM conditions is to surgically remove lesions



that are causing severe functional impairment, as long as those lesions are accessible. The prospect of Linnea undergoing multiple surgeries, especially after enduring her surgery last fall, is difficult to accept. There is hope, though.

We've recently learned that there are non-surgical treatments in early stages of clinical drug trials, and this is thanks in large part to an organization called Angioma Alliance, a patient advocacy organization that has mobilized research and funding towards finding non-surgical treatments and cures for people who live with CCM3 and other vascular, brain-bleeding disorders. Angioma Alliance is responsible for having elevated the profile of CCM diseases through advocacy and partnerships with the medical and research community.

Because of Angioma Alliance, several Centers of Excellence now exist in hospitals and universities around the country, and every year, experts gather at an international conference to share their latest research on potential treatments and cures, even if their research has not yet been published, to accelerate

the discovery of a cure. Angioma Alliance also funds genetic testing and maintains a patient registry of people with CCM disorders, thus enabling CCM patients to be enrolled in clinical drug trials and other research.

On a personal level, Angioma Alliance has connected us not only to CCM3 medical experts around the country, but to other families around the world who are navigating life with this very rare disorder.

Despite our fear and uncertainty, we are hopeful about Linnea's future. Today, just over six months after her surgery, and after hundreds of hours of therapy from a team of devoted medical professionals, Linnea can now stand up on her own, clapping and shouting "Yay!" She's even taking little steps at a time, and one day soon, we are hopeful that she will walk, and even run.

With your support, we will take steps, however small, towards finding a cure for Linnea's condition.

Dinah and Evan Winchester

Check Out Our New Website

With the support of a generous donor, Angioma Alliance has a newly updated, upgraded website that provides the information you need to make decisions about your care. Please visit the site at www.Angioma.org to see our new sections on Lifestyle Management, Angioma Alliance Historical Projects, and more!

Events

4th Annual Orange County 5k Walk/Run

Date & time: September 19, from 8-11 am PT

Where: Florence Joyner Olympiad Park, 22760 Olympiad Rd, Mission Viejo, CA 92692

Register/donate: give.classy.org/OCwalk

Join us Saturday, September 19, for a stroll around the lake. Our event will not look the same as usual, but we will continue to raise awareness and support during these uncertain times. We are asking teams of up to 10 people to sign up for a time to start their walk and arrive at least 15 minutes prior to their start time.

www.signupgenius.com/go/10C0D4DAEAD22A2F5CE9-4thannual

T-shirts will be available for individuals who raise or donate \$35 or more. We are aiming for a \$1,000 goal per team with a total fundraising goal of \$10,000 for the event. We look forward to seeing you there!

All proceeds go directly to Angioma Alliance to support our research efforts, DNA/Tissue Bank, scientific meeting, patient support, and much more.



UNITED WE WALK:
TOGETHER WE BELIEVE

Successive Strolls for Support



New Community Alliances Forming!

Our Community Alliances organize grassroots support, education, fundraising, advocacy, and awareness initiatives locally to support the Angioma Alliance mission. Four or more families come together in an area - a metropolitan area, a state, or a region - to work on joint initiatives toward a cure.

This is a growing program and we're pleased to announce the addition of the New Mexico Angioma Alliance Community. The New Mexico group plans to work with the Angioma Alliance CCM Center of Excellence at the University of New Mexico on an annual patient conference, offer public outreach at health fairs and cultural events, and advocate for state funding for services for affected and at-risk families. Contact them at NMAngioma@gmail.com to be involved.

There are several other areas in which we are close to forming Community Alliances. Please reach out if you live in one of these areas and would like to be a part:

- Northern California, Arizona, or Kansas, please write Lindsay Ramirez at lindsay@angioma.org.
- New England, Eastern Pennsylvania/South Jersey/Delaware, or the greater Memphis area, contact Darla Clayton at darla@angioma.org.

We already have Community Alliances in many areas. To find your local group and find out about scheduled events, please visit www.angioma.org/care-community/community/local-community-alliances/ and select your state. Even in the time of social distancing, our Community Alliances are active with online activities and outreach. Please join us!

As part of International Cavernous Angioma Awareness Month, we introduced our members to the twenty-one cavernous angioma patient organizations that now exist around the world. Below is a major research partnership announcement and other news from CAUK. To find contact information for the other international organizations, please visit our website at www.angioma.org/international/international-organizations/.

Cavernoma Alliance UK News: August 2020

Research Project

After several years preparative work, a consortium led by Professor Rustam Al-Shahi Salman has been awarded a major grant from the UK National Institute for Health Research (NIHR) for a pilot trial to address the effectiveness of active treatment (with neurosurgery or stereotactic radiosurgery) versus conservative management in people with symptomatic brain cavernoma. This pilot will determine whether we can recruit the necessary number of patients for a full trial involving other European countries.

This is a three-year programme with a consortium of clinicians and others and with CAUK as the patient organisation to provide the requisite public and patient involvement. In addition to the importance of the programme itself, a major knock-on benefit is the collaboration entailed between over 100 senior clinicians from across the UK and the Republic of Ireland. This will raise the profile of the treatment of cavernoma within all major hospitals in the British Isles and also the visibility of CAUK and our complementary support for those diagnosed with cavernoma and their families.

COVID-19

Whatever the success or otherwise in the UK's dealing with the COVID-19, the impact on the support that we offer our members has been large, since much of this was face-to-face.

As with most other organisations, our response has been to hold virtual meetings, and we have done this with gusto. We have get-togethers of various kinds on Zoom: one or two a week, including people talking about their experiences, a Book Club, a weekly session

for CaverMums (from families with children with cavernoma; I'm not sure what happened to the CaverDads), a sequence of cavernoma science webinars, and coffee-morning chats. We work with a team of two therapists (one child specialist, one for adults) who are continuing their one-to-one therapy online, and who do an eight-week therapy course for small groups. We have an annual forum (similar to the Angioma Alliance patients' conference); Professor Awad gave us an inspiring talk, updating us on the science progress. (www.youtube.com/watch?v=W5RswaiEFsU).

Fundraising

About 40% of CAUK's income comes from our members, and with our gratitude this has been maintained during the pandemic. The ways members raise money is eclectic and wonderful. I hope all those who have contributed so magnificently will forgive me for mentioning bit.ly/OllieWalk

Staff Changes

We are very sad to have to report that Liz Morgan, our CEO, is leaving us at the end of August. Liz has created a very strong team while she has been with us and we have just promoted Joanne Noakes to the number two position with responsibility for much of what we do. I am taking over for the time it takes us to appoint someone else, and focusing on our interactions with our clinicians, our research, and international relations and looking forward to our continuing relationship with Angioma Alliance who give us such strong support.

European Cavernoma Alliance

The pandemic has slowed progress with ECA, but Jana Bergholtz has kept the Facebook site active. Please see their page at www.facebook.com/EuropeanCavernomaAlliance.

David White



Angioma Alliance Supporters January - June 2020

Platinum Circle (\$25,000+)

Anonymous
Julian Grace Foundation
The Neihart Family Foundation

Gold Circle (\$10,000 - \$24,999)

Capital Group Companies
Kristen Dehn *in honor of Connie Lee*
Daniel Engle

Beacon (\$5,000 - \$9,999)

Lee Rashkind *in memory of friend Marsh B Garafola*
Recursion Pharmaceuticals

Leader (\$1000-\$4999)

Carlos Arbelo *in honor of Tania Casaus*
Asofsky Family Foundation
Eleanor Brewer
Amy Crowe *in honor of Dinah Lord*
Brian and Vikki Fairbank *in honor of Tyler Fairbank*
Allen Harris
Johnnie Krewald
Owen and Barb Lewis
Sandra Lord *in honor of Linnea*
Kevin McCarthy for Congress
Joseph and Katherine O'Donnell *in honor of Tyler Fairbank*
Lisa Wixson

Benefactor (\$500 - \$999)

Danielle Annich-Thomas
Rona and Neil Ashe
Rachel Borrass
Susan Bradley
Karen Buck
James Crowley and Carolyn Stimpson
DelBusso Charitable Fund
Diversified Group
Elaine Gemmell
Brooks Goodison
John and Jean Griffey
Indianapolis Auto Trade Association
William Jensen
S.C. Lord

Heidi and Steve MacAlpine
Jose Maria Garcia Margro
Leslie Morgan *in honor of Callie and Westley Northern*
PreventionGenetics, LLC
Schubiner-Leigh Family 2011 Fund *in honor of Luke Babbs*
Walter Smith *with thanksgiving and prayers for my friend John, and in memory of my sister Meg*
Tito's Handmade Vodka
Karen and Len Weber *in honor of Samantha Weber*
Andrea Winchester
Suzanne Wittebort
Rob Yates

Partner (\$250 - \$499)

Dean Allara
Kristin Balden
Paul Arthur Berkman
Carlos Casaus *in honor of Tania*
Sean Conroy
Christian Fitterer
Denise Freeman
Joseph Govan
Janelle Grimes
John and Chichi Guy *in memory of Lindsay Labaree*
Khristine and Gordy Holterman
In Motion
Sandra and Joel Leff
Lon Levin
Darren and Linne Lisse
Danielle Manning
Douglas and Christina Martin
Laury Miller
Pamela Pernal
Diana and Vassily Rodionov
Thomas Rossby
Penelope Schmitz *in honor of Cameron Schmitz*
John Shea
Daniel Sinclair
Patty Steinhardt
Immaculada and Doug Walker *in honor of Tania Casaus*

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 info@angioma.org to learn more about these opportunities and valuable benefits for your company.

About Angioma Alliance



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

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because brains shouldn't bleed® is a registered trademark of Angioma Alliance.

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.