



Angioma Alliance Newsletter

Connie Lee Returns as President of Angioma Alliance

Angioma Alliance is pleased to announce that Connie Lee, our founder, has returned full-time to Angioma Alliance to continue building a vibrant community that is dedicated to finding a cure.

In late 2011, I stepped down from leading Angioma Alliance. Together with my daughter, Julia, I toured the country meeting patients and their families, leaving the organization in the very capable hands of Chair, Sara Sukalich, and the Board of Directors.

I had a wonderful adventure and had an opportunity to work directly with CCM3-affected families to develop an action group focusing specifically on the needs of those with this ultra-rare mutation.

In late spring of this year, Sara Sukalich stepped down as Chair; the CCM3 Action group was standing on great footing; and I offered to return as president of Angioma Alliance to focus on working with Dr. Amy Akers, our Chief Scientific Officer, to move us toward clinical drug trials.

I am thrilled to be back at this exciting time. Our membership has been enthusiastically embracing the challenge to push our agenda by advocating our bill with legislators, by raising funds to support our science, and by participating in our DNA/Tissue Bank and patient registry. You

can read more about their efforts throughout this newsletter.

As we move toward our 9th CCM International Scientific Meeting in November, we will be examining our strategy and likely making critical adjustments. We know that genetic testing will become a priority, and we are exploring avenues for increasing the number of our members who are tested.



You can read more about the importance of testing in Dr. Amy Akers' piece in this issue (see page 8). Our vision is large, and we hope you will support our efforts by seeking testing yourself and by helping Angioma Alliance support those who would like testing but have not found it financially feasible.

I am interested in hearing your ideas as we move forward. Why is Angioma Alliance important to you or your family? What are we doing well and where could we improve? We remain a volunteer-driven organization, and I hope you feel comfortable approaching me or one of our Board members about volunteer opportunities. (Cont.)

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Note: In this newsletter, the terms "cavernous angioma," "cavernous malformation," and "CCM" are used interchangeably.

If cavernous angioma patients and their families choose to sit on the sidelines, brain surgery will remain the only treatment. Unlike cancer, heart disease or diabetes patients, there aren't very many of us; every single person has a choice to make. Contact us at info@angioma.org and give us your thoughts.

There was a week in September where I was personally reminded how difficult cavernous angiomas are: my daughter Julia was in the midst of all-too-familiar, anxiety-provoking medical procedures. That was also the week a Kenyan father contacted me about his young son with a brainstem cavernous angioma with the request I hear too often, "Please advise treatment." The unfortunate answer is, "There is no treatment for your child." That was also the week I helped make arrangements for a young Brazilian woman to come to our clinic in Chicago, because she'd had four brain hemorrhages in the last year. She will be evaluated, but there is no treatment for her either. That was the week a beautiful friend in Texas went down with seizures and wound up on a ventilator in ICU. That was the week an adoptive Arizona mother contacted me about her pre-school daughter, who was to have brain surgery the following Monday. Sadly, it was a typical week.

It doesn't have to be this way. We are just a few years away from testing medications for treating cavernous angiomas, to keep them from multiplying and keep them from hemorrhaging. Angioma Alliance is the driving force behind this effort: we move science and we connect patients, notably through the Angioma Alliance Patient Registry (see page 7). One way or another, we provide services to every research lab in the world.

I'm proud of what we've done so far, but there is so much more to do: for the Kenyan dad, for the Brazilian woman, for the Arizona child, for Julia, and for your affected family members. Please help with your time, your contributions, and your passion.

Connie Lee

Legislative Update

In late June, the New Mexico Congressional delegation introduced the Cavernous Angioma Research Resource Act of 2013, calling for the creation of a network of clinical research centers that will be poised to facilitate drug trials when the time comes. With admirable courage, our members got to work, setting up appointments with legislators and their aides to explain the importance of the legislation. We met with the chairs and ranking members of the committees who are considering the bill, as well as a significant number of other legislators. We continue to explore ways to address our needs using legislation, such as incorporating our bill into a larger National Institute of Health bill or attaching language to an appropriations bill in the House. Sen. Tom Udall has included such language already in a Senate bill.

Our Congressional meetings have resulted in high-level meetings with National Institute of Health administrators. NIH controls the grant funding that supports our researchers. In September, member Liz Neuman met with NIH Director Francis Collins to share the impact of cavernous angioma on her family and to explore mechanisms within the Institute for additional research. We have had communication with other members of his staff who are working with us to find ways that the NIH can help expedite clinical drug trials. Our advocacy has opened doors and will continue to bear fruit for some time.

If you are interested in visiting your legislative office either locally or in Washington, please let Connie Lee know at clee@angioma.org. She will give you the most up-to-date status of the advocacy efforts and work with you on developing your presentation.



Passing of Libby Davis

We at Angioma Alliance are saddened to report the passing of Libby Davis, friend to many and long-time moderator of the Angioma Alliance Community Forum. Over the years, Libby touched the lives of hundreds of cavernous angioma patients and their families with her compassion, gentle humor, and wisdom. Even during periods when she herself was not well, she was 100% committed to helping newcomers and old timers alike. We will miss her.

News

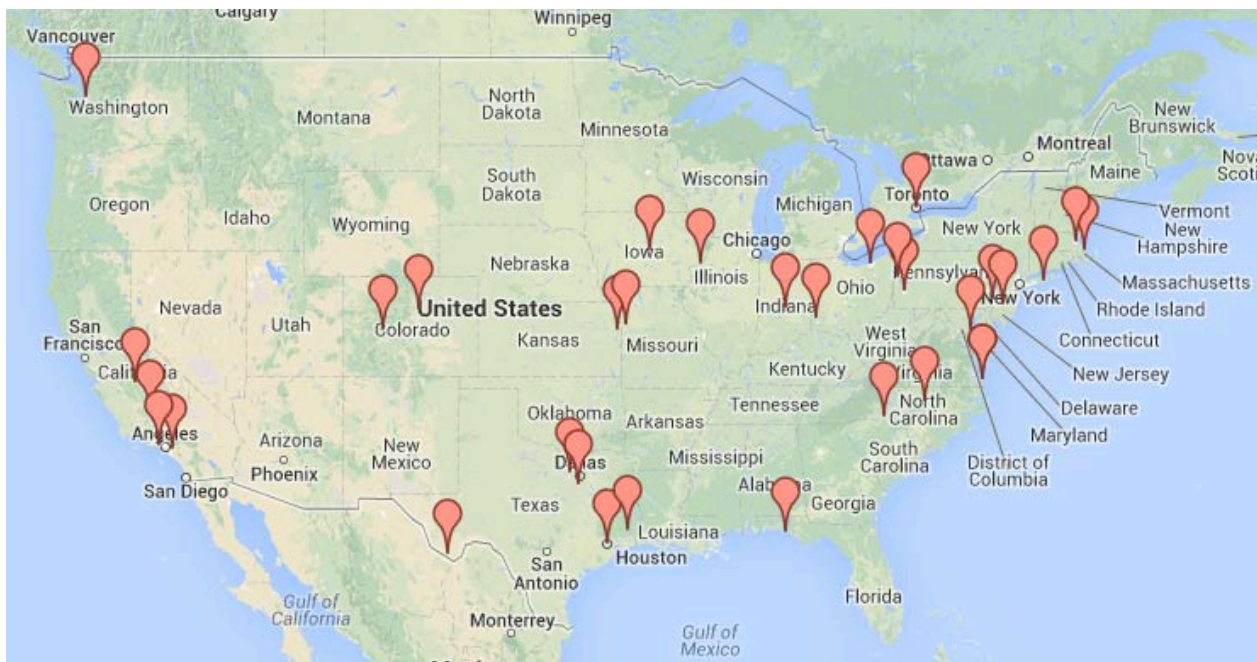
Zach Brown Angioma Alliance Virtual 5k and Anywhere Walk

In early June, Tracy Brown hatched an idea for a fundraiser to support the work of Angioma Alliance. Her 12-year-old son, Zach, has an inoperable brainstem lesion that has hemorrhaged twice, causing facial paralysis on the right side of Zach's face and weakness on the left side of his body. The work of Angioma Alliance is critical to his future. Tracy wanted to organize a charity walk, but hers is a family with two homes. They currently live in Edgewater, Maryland, but their roots are in Indianapolis, Illinois. She also wanted Angioma Alliance members in other parts of the country to participate. The solution, thought Tracy, was to organize a "virtual" 5K. By this, she meant folks would walk, but they could walk in their home towns any time over the weekend of October 5-6.

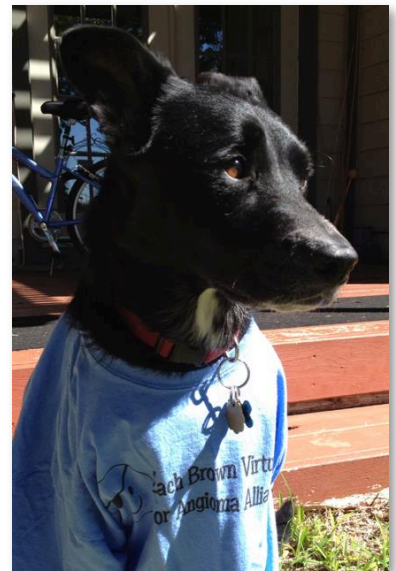
Tracy's idea took off in ways she couldn't imagine. In Edgewater, various groups took up the cause and hosted additional events in the weeks before the walk. The Kelly Charity Golf Tournament, which included several former NFL players, chose Angioma Alliance as their charity. The Anne Arundel Laxtoberfest lacrosse tournament did as well. The Edgewater Chipotle hosted a benefit night and over \$1,700 was

raised; that's a lot of burritos! The St. Barnabas 7th graders in Indianapolis, Zach's old class, walked during school hours to support him; and his current middle school friends sold handmade bracelets at lunch. And, on Sunday morning, October 6, over 200 people came out to walk, enjoy the music of Ashley Forrest, and eat the delicious food provided by All Fired Up. It was a beautiful morning full of smiles and good feelings all around.

One determined mom with an idea inspired people across the country, and even around the world. News of the virtual walk spread and grew. The same weekend, at least thirty-five events, called Angioma Alliance Anywhere Walks, were held in the US, Canada, Italy, Austria and the UK. Our members rallied around the idea of raising awareness locally: in parks, on city streets, or on country roads. Many asked their family and friends to join them and appealed to their social circles for sponsorships. The final totals are not in as of this writing, but it appears that the national Anywhere walks will raise over \$15,000 and the Zach Brown Virtual 5K will raise more than \$20,000. This is destined to become an annual event, and we hope many more people will participate in 2014. Thanks to everyone who walked and sponsored! It was an event to remember.



The Zach Brown virtual 5K took place in 32 locations from sea to shining sea.



CCM3 Action Update

The CCM3 Clinic with Dr. Awad at the University of Chicago is in the final months of its second year, and it has led to tremendous growth in knowledge about the illness. Three papers will be presented at the Angioma Alliance CCM Scientific Meeting by the University of Chicago using data from the clinic. Dr. Awad will also give a talk, "Exceptional Aggressiveness of CCM3 Phenotype." Although the information we're gleaming from the clinic is difficult to hear because of the severe nature of the illness, it is not unexpected based on the experiences of our families. The clinic gives us a way to fight back, to validate our understanding, and to move forward with treatments.

Dr. Amy Akers and Connie Lee are developing a program within Angioma Alliance that will allow us to perform genetic testing on a larger group of individuals in a financially feasible and ethically responsible way. This has become a priority because, in addition to genotyping as many members as possible, we have been charged with finding as many CCM3 patients as we can. We anticipate this will start by identifying individuals who have a combination of multiple cavernous angioma lesions and a benign brain tumor, such as meningioma. This is a combination found frequently in CCM3 but does not seem to appear in the other forms of CCM illness. We'll give you more information on this initiative as it develops.

We have several fundraisers in the works to help us in our work. A poker tournament will be held at the Aviator Casino in Delano, CA, on November 2nd. Several fundraisers are being planned in Indianapolis and in the Pittsburgh area. In 2014, we will again be part of the MadoroM Wine Charity Auction. The Bakersfield group is planning a new fundraiser, called Boots and Ballgowns, on October 11, 2014. We are grateful to everyone who supports our work toward a cure.

Photos, facing page, clockwise from top left: Zach Brown trying on former NFL player Ron Saul's Superbowl ring; the Wilkinson family walked in State College, Iowa, for three affected family members; Romeo, who belongs to Jo Macaluso in Austin, TX.; Kristy Fowler's family and friends in Orange County, CA, wearing eye patches in honor of both Zach Brown and Kristy; Allison and Ken Ruggles in Massachusetts; St. Barnabas Seventh Grade, Indianapolis, Zach Brown's class before he moved to Maryland four years ago.

New Brochures Available

With the help of Lynn Abramovic's firm, ProSource Marketing, we have two new brochures. One is directed at new patients, and the second brochure is for awareness and fundraising. These show the real impact of cavernous angioma and educate the public on the work of Angioma Alliance. We encourage members to request these brochures to give to your doctors for distribution to their patients. If you'd like brochures, please request them by emailing info@angioma.org. Please let us know whether you would like the new patient or the public awareness brochure and how many you'd like us to send.

Helping Our Kids Raise Awareness

I have often marveled at the creativity and resources of our kids in their efforts to raise awareness and funds for cavernous angioma research.



In early October, a group of middle school students in Edgewater, MD, made bracelets they sold for 50¢ during lunch. By the end of the day, 189 bracelets had sold and the entire school had been introduced to cavernous angioma facts.

If your kids want to raise awareness, here are some ideas from our members' past events:

- A "Jeans Day" where students with a dress code pay for the privilege of wearing jeans to school
- A flapjack breakfast at a local Applebee's restaurant
- A community bake sale
- Knitting scarves
- A used book sale
- Selling lollipops

Organizing events can help kids feel they are doing something positive, particularly for those who are affected, or their siblings. This allows them to take some control of what can feel like a helpless situation. By courageously sharing their story, our kids can learn how to create their own knowledgeable circle of support at school and in the community. What a great skill for any kid, or any adult, to have.

Connie Lee

New Scientific Advisory Board Members

We are pleased to welcome three new members to the team of physicians and research scientists that make up Angioma Alliance's Scientific Advisory Board. The role of the Board is to work closely with our Chief Scientific Officer, Dr. Amy Akers, to provide advice and expertise and to help guide Angioma Alliance through the next few years as we focus more on research, recruitment and clinical trials.



Dr. Brent Derry, PhD, is a Senior Scientist of Developmental & Stem Cell Biology at the University of Toronto, SickKids Hospital. His research interests primarily focus on using *C. elegans* (worms) as a model for human disease and studying the molecular mechanisms for the normal process of programmed cell death. This line of research has led him to discover a unique function in the worm version of CCM1 and has demonstrated how worms can be a fantastic research tool for learning about the basic biology of a disease system.



Dr. Kelly Flemming, MD, is a neurologist at the Mayo Clinic in Rochester, Minnesota. In addition to her clinical responsibilities, Dr. Flemming runs a research project dedicated to investigating the natural history of CCM illness. Her research aims to better understand the long-term behavior of CCM lesions (risk of bleeding, seizure, etc) and how these activities affect the human condition. This type of research helps to inform both clinical decision making as well as clinical trial design.



Dr. Kevin Whitehead, MD, is an Associate Professor of Cardiology at the University of Utah. His research interests focus on developing and characterizing animal models (mice) for cardiovascular disease. He has worked to investigate the abnormalities of blood vessel development in CCM mice and he was part of the team that first discovered the effects of statin drugs on CCM blood vessels.

New Board Members

Angioma Alliance is pleased to announce the election of two new members to our Board of Directors.



Kristen Lewis is an attorney who lives in Topanga, CA, with her husband and two children. Kristen has already been essential in our legislative efforts, meeting with Rep. Henry Waxman, the ranking Democrat on the House Energy and Commerce Committee, as well as arranging meetings in Washington with other high-level government officials. Kristen's skills make her a well-rounded member of our Board. We look forward to her applying her skills in legislative advocacy, development activities, general awareness, and physician education, with the help of her father, a retired neurologist. She is passionate and driven; you will be hearing more from her.



Tracy Brown is the mastermind behind this year's inaugural Angioma Alliance Anywhere Walk. The walk started as the Zach Brown Virtual 5K for Angioma Alliance, in Annapolis, MD, where the Brown family currently lives. Three separate walks in their previous hometown of Indianapolis included family, friends and former classmates. (You can read more about the event on page 3.) Tracy and her son Zach have made multiple trips to Capitol Hill to visit legislators in support of the Cavernous Angioma Research Resource Act. Tracy plans to use her organizational and fundraising skills to support any Angioma Alliance member who would like to host an event and to continue her advocacy for a cure.

The *Susan Sukalich* Angioma Alliance INTERNATIONAL PATIENT REGISTRY

We are pleased to announce the launch of the Susan Sukalich Angioma Alliance International Patient Registry; this is being reintroduced with its new name as a memorial to one of our members who passed away this year. The Sukalich family has funded the patient registry since its inception, and they would like to ensure its availability as a tool for research.

The patient registry connects the patient and research communities. To join, create an account and complete the questionnaire at www.angioma.org/registry. Creating your profile allows the Registry Coordinator (Dr. Amy Akers) to notify you about research participation opportunities for which you may be eligible. Your personal information is never shared with researchers; you will be able to contact them if you are interested in joining their study.

Why we need your help

Cavernous angioma research is advancing at a rapid pace; researchers are working hard to understand the natural progression of the disease and biology so we can plan and execute effective and efficient clinical trials. One of the biggest obstacles to successful clinical trials is the challenge of patient recruitment. By having a large registry of patients who are willing to participate, Angioma Alliance will be able to effectively promote, advertise, and quickly complete enrollment in future studies.

Currently Enrolling Studies

- UNM Genetics of Disease Severity Study
- UNM MRI study of Statin Treatment & Permeability

Both UNM studies require participants to be affected by the Common Hispanic Mutation and to travel to New Mexico for a neurological exam and MRI.

- UNC Biology of CCM Protein Study
Requires participants to have a known mutation in CCM1, CCM2 or CCM3 and donate a blood sample.

Completed Studies

- Cavernous Angioma and Ashkenazi Jewish Ancestry Study
Duke University researchers identified a specific genetic mutation in multiple unrelated individuals with Ashkenazi Jewish ancestry.

Exploring the Data

Also, using the Explore section of the website, registry participants are able to view the compiled data to see a snapshot of the registry community. For example, as of the beginning of October, only 16% of participants report having had genetic testing.

To learn more, or to join the Susan Sukalich Angioma Alliance International Patient Registry, please visit www.angioma.org/registry.

Amy Akers



“Like” Dr. Amy Akers’ page on Facebook to stay on top of the latest cavernous angioma science news. You can find her at <https://www.facebook.com/AmyAkersPhD>.

The Orphan Drug Act Is 30 Years Old

This year marks the 30th anniversary of the Orphan Drug Act, which was passed in 1983 to facilitate drug development for rare diseases.

Orphan drugs are those intended to treat a disease with fewer than 200,000 affected individuals in the United States. To obtain orphan designation, drug developers and/or researchers must apply with the Office of Orphan Product Development at the U.S. Food and Drug Administration.

Drug development is extraordinarily expensive: pharmaceutical companies that develop products for rare diseases may not even recover their expenses if the patient population is too small. This financial barrier made rare disease drug research challenging. In the ten years before the passage of this law, fewer than ten drugs were approved to treat rare diseases.

The Orphan Drug Act provides financial benefits to companies who develop orphan drugs. These include tax incentives, market exclusivity (extra patent protection), and development and marketing subsidies. This program has been enormously successful, helping to develop over 400 rare disease therapies since 1983.

CCM Gene Genetic Testing

As we move closer to clinical drug trials, knowing whether your cavernous angiomas (also known as cerebral cavernous malformations or CCM) are the result of a genetic mutation or not will become critical. Here's what you need to know to make informed decisions about genetic testing and to obtain testing.

CCM may be inherited (familial) or acquired sporadically (non-genetic). Individuals with the sporadic form of the disease will have:

- Only one CCM lesion, unless a DVA is present or there is a history of radiation,
- No other affected family members, and
- No inherited genetic mutations in the CCM genes.

The cause of sporadic CCM remains unknown, but it is not believed to be due to inheritable mutations, so genetic testing is unlikely to identify mutations in such people. Those with sporadic CCM are more likely to have a developmental venous anomaly (DVA or venous angioma).

Familial CCM is a hereditary illness that may be passed between generations. Individuals with familial CCM may have:

- Multiple CCM lesions,
- Affected family members, and
- An inherited mutation in CCM1, CCM2, or CCM3 from an affected parent.

Individuals with familial CCM may be the first in their family to have a mutation on one of the CCM genes. Having multiple CCM lesions with no developmental venous anomaly is a compelling sign, even in the absence of other affected family members.

In most cases of familial CCM (as high as 95%), genetic testing of a blood sample will identify a CCM gene mutation. For those families where no mutation is identified, a few different hypotheses are possible:

- There is a mutation in one of the CCM genes that cannot be detected due to technological limitations of standard testing. Or,
- The family carries a mutation in another CCM disease-causing gene not yet identified. Or,
- There are other complex genetic factors that have yet to be identified.

Will genetic test results affect your health insurance?

The Genetic Information Non-Discrimination Act of 2008 (GINA) makes it illegal for insurance companies in the United States to use your genetic information to deny you, your family members, or

your unborn children insurance coverage, or to change your insurance rates. Other countries may or may not have similar laws in force.

How can you get genetic testing?

Clinical diagnostic testing must be ordered through your doctor or a genetic counselor. The results are returned to the ordering physician so he or she can report and explain the results to you.

Some research studies, including the Angioma Alliance DNA & Tissue Bank (www.angioma.org/dna), perform genetic testing for research purposes. Research testing is regulated differently than clinical testing, and in many cases precise test results cannot be reported to the study participant. However, by working with the patient's physician, research testing may help expedite and reduce the cost of the genetic testing process.

Why seek genetic testing for familial CCM?

This is a highly personal decision; one could make valid arguments both for and against testing, since genetic testing can yield potentially upsetting results. It is important to consult a compassionate and knowledgeable genetic counselor and/or physician, particularly when diagnosing a family member who shows no symptoms of the illness. If genetic testing discovers a mutation, this may make screening your family more affordable. Rather than going through an MRI, other family members can submit blood, or in some cases simple cheek swabs, and order a rapid, low-priced test to look for the specific mutation that runs in your family.

From a research perspective, knowing one's genetic mutation may prove useful for quickly populating clinical studies. While gene specific therapies are not yet available for CCM, researchers and the patient community are eager to understand whether future drug therapies will work on all genetic forms of the illness and/or sporadic cases. Clinical trials to address this question will require a great deal of help and involvement from the patient community. Also, to be involved in a trial, participants will need to know their genetic mutation status.

Learning more...

For more information about genetic testing, please visit the Angioma Alliance website and consider joining the Susan Sukalich Angioma Alliance International Patient Registry (see page 7) to be notified about studies that need your help.

Amy Akers

International News

Cavernoma Alliance UK

Typically, the months after the June Annual Forum in London are a quiet period for CAUK. Something called "Summer" arrives, and, along with it, seemingly endless months of holidays. (Usually it rains and is generally a miserable experience, but not this summer.) This year, CAUK was inundated with work: new members galore, fundraising events, and preparations for the Big Step (funded by the Big Lottery).

After an exhaustive round of interviews led by our new chair, Professor David C S White, we have appointed two part-time employees. Angela Yeomans will be our locally-based Cavernoma Community Worker, although her responsibility is for the whole of England. Sophie Eldridge, CAUK's part-time Administrator, will handle the day-to-day running of Cavernoma Alliance UK, along with enhanced duties such as increasing membership and keeping records.

Autumn London CaverHubs

Cavernoma Alliance UK are pleased to announce the Autumn London CaverHubs for both adults and young people. For adults, the talk will be given by Mr Raghu Vindlacheruvu, consultant neurosurgeon at Queen's Hospital, Essex. The title of his talk will be "Cerebral cavernoma - do we remove too many?"

Dr. Bhate of Great Ormond Street Hospital will talk in London to parents of children affected by cavernoma. The children will be in an adjoining room with an entertainer.

Parting and Greeting

As this is a time of great change for the board of CAUK, we sadly bid farewell to Frank Gent, who remains an active general member. After four years of dedicated service to the charity, Frank, together with his wife Brana Thorn, our Young Persons' CaverHubs coordinator, has gone into retirement.

We wish Frank well and I am sure he will make his warm and glittering presence felt at our events in years to come. No sooner do we bid farewell to Frank than we say hello to Emily Fletcher, an American living and working in the UK, and a full member of CAUK; she joins our board.

Fundraising

Why bother fundraising for CAUK? They now have a good income, right? Wrong! Our Big Lottery Grant is for the Big Step project only. This project does not include important elements such as the Annual London Forum (which attracted 147 people earlier this year) and CaverFamilies (the residential part of the Young Persons' CaverHubs). The Big Step is an England-only initiative, though CAUK's work covers the entire United Kingdom.

So thank you to the many members and supporters who recognise the importance of our work. These members include Lee Smith, who has been fundraising again. His son, Zane, diagnosed with the extremely rare CCM3, saw Professor Awad in Chicago earlier this year, who recommended a review of Zane once a year. Lee is undertaking major fundraising activities on behalf of CAUK to obtain travel funds to Chicago for 2014. This fundraising included a skydive on 31 August 2013 for two members of the Alliance and 23 of Lee's friends, raising in excess of £6,000.



Lee Smith skydiving to raise funds for Cavernoma Alliance.

A Date for your Calendar

The International CAUK Forum will be held at the Grange Hotel, London, 14 June 2014. Speakers will Mr Neil Kitchen, consultant neurosurgeon at the National Hospital for Neurology and Neurosurgery, and senior medical adviser to CAUK. The event is free to all participants, and includes lunch and pudding. CAUK very much hopes that our American friends will attend.

Ian Stuart

CCM Italia/AIAC

CCM Italia is promoting and encouraging a large cooperative effort among clinical and basic research centers in Italy, providing a useful framework for coordinated and integrated research approaches. The goal of this effort is to identify the additional factors that may modify the range of severity and other features of CCM disease, and thereby determine the large variability in disease severity.

Medical genetics centers offering genetic diagnosis and counseling to CCM patients and at-risk relatives are already active in many Italian locations. Furthermore, based on growing evidence in cellular and animal models of CCM disease, we have recently launched a multidisciplinary research project aimed at screening potential genetic and environmental risk factors that can modulate the onset and severity of CCM disease. This project, coordinated by the Torino and Siena CCM Italia Units, already involves several clinical and basic research centers across Italy; it will remain open to other teams interested in joining the network at a later stage.

To be successful, the project relies not only on the strong cooperation between researchers but also, and especially, in the active participation of CCM patients and their relatives.



Dr. Brent Derry and his team with Shawn Mulvihill and his son Jaxon: cheque presentation at the Derry Lab, Sick Kids Hospital, Toronto.

Francesco Retta



Professor Francesco Retta and the CCM Italia team.

Angioma Alliance Canada

2013 has been a very active year for the Angioma Alliance Canada. On June 8, the second annual Cavernous Angioma Family Conference was held in Hamilton, Ontario. Attendees learned about the latest developments in scientific research. Neurosurgeon Dr. Chris Wallace and research scientist Dr. Brent Derry presented some new insights into our search for a cure. We presented Dr. Derry with our first financial contribution to research in Canada. A big thank you goes out to Lea Labelle-McKinley, our fundraising director, who made this possible.

Our organization has also laid the groundwork for its own scientific advisory board. We have received confirmation of three highly respected and dedicated individuals: Dr. Derry of Toronto Sick Kids, Dr. Wallace, from Kingston, and R. Loch Macdonald a neurosurgeon from Toronto. We thank these individuals for their support and dedication to our cause of "Working Towards a Cure."

The Angioma Alliance Canada has also expressed its interest in supporting Dr. Jacques P. Tremblay from Montreal as he works toward a new project that will create gene therapies for rare genetic diseases, such as Cavernous Angioma. Although Dr. Tremblay has not confirmed to us that he will target Cavernous Angioma, it is our hope that by providing support, he will consider our disease a viable candidate in his research.

We can proudly look at the future knowing that research into Cavernous Angioma is progressing well on all fronts and that new endeavours are sprouting up everywhere.

Henk van der Wilt

Angioma Alliance Donors May 1, 2013 – August 31, 2013

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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 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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How You Can Help

Your contributions help fund conferences and forums, increase research, and enhance outreach and support efforts. To donate to Angioma Alliance, send a check or money order (using the enclosed envelope) or visit www.angioma.org. You can also donate on line using a credit card with our Paypal connection.

Consider a sponsorship

Sponsorships can maintain essential programs or help us expand the ways that we support the cavernous angioma community. Please contact us at info@angioma.org to discuss these or other sponsorship opportunities.

Travel to Scientific Meeting: \$1,500

Support the vital travel that allows Angioma Alliance to interface with governmental agencies and the scientific community on behalf of those with cavernous angiomas.

DNA/Tissue Bank Research Nurse: \$6,000/year

Support the research nurse who gathers and maintains information for the DNA/Tissue Bank, which allows researchers to obtain material needed for projects that may one day lead to a cure for cavernous angioma.

Patient Registry: \$8,500

Support the ongoing costs of the International Cavernous Angioma Patient Registry, which is an essential way to connect the patient and researcher communities in the shared goal of finding a cure.

Family Conference: \$15,000

Support this important gathering of people with cavernous angiomas and those that care about them for a weekend of networking and education.

Seed grant: \$35,000

Support a young researcher's pilot study that could be leveraged to obtain a \$100,000+ NIH grant.

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