



Spring 2014

Angioma Alliance Newsletter

Angioma Alliance 2014 Genetic Testing Initiative

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Text RARE to 85944 in March to donate \$10 to Angioma Alliance.

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

Have you had genetic testing for your cavernous angioma? If not, please consider joining our Genetic Testing Initiative. Our goal is to help familial cavernous angioma patients and their families obtain clinical genetic testing. If you have multiple cavernous angioma lesions, and/or a family history of the illness, please consider talking to your doctor about genetic testing.

HOW ANGIOMA ALLIANCE CAN HELP YOU GET TESTING

Enclosed in the center of this newsletter (also available online at http://www.angioma.org/documents/genetic_testing_letter.pdf) is a letter for your doctor from Angioma Alliance's Chief Scientific Officer and our Scientific Advisory Board which explains the importance of genetic testing for familial cavernous angioma patients. Please take the letter to your doctor and ask him/her for genetic testing. The letter also provides instructions for your doctor to order the testing from an accredited laboratory.

WHY GET TESTING?

For yourself...

Familial cavernous angioma is caused by mutations in one of three genes: CCM1, CCM2 or CCM3. These

mutations, typically inherited from one's mother or father, can be detected in a blood or saliva sample that is subjected to sequencing and/or deletion testing.

While all forms of cavernous angioma cause brain lesions that look identical, they can vary greatly among different individuals. Studies have also shown trends in each of the mutation classes. For example, individuals with mutations in the CCM3 gene tend to have an earlier age of onset (often in childhood), higher rates of hemorrhage, and a propensity to develop certain types of brain tumors.

As we continue to learn more about all forms of cavernous angioma, undergoing genetic testing can help to provide your doctors with useful information to guide you in your treatment regimen.

For your family...

Your genetic testing can also benefit your family. Familial cavernous angioma is passed from parent to child with each child having a 50% chance of inheritance from an affected parent. Similarly, you had a 50/50 chance of inheriting the mutation from one of your parents.

By identifying your genetic mutation, your children and extended family members can undergo targeted genetic testing to see whether or not they also carry your family's specific

disease-causing mutation. Targeted genetic testing of a previously identified mutation is a quick and cost-effective way to diagnose family members. Genetic screening of family members can provide them with a definitive diagnosis or with relief, if they don't have the mutation. It can also help avoid unnecessary and costly MRIs or CT scans for family members who have not inherited the disease-causing mutation.

For the Angioma Alliance Community...

Each day, scientific progress draws us closer to a clinical trial and treatment for cavernous angioma. A successful clinical trial will require participation and rapid recruitment from the patient community. In order to be prepared for such trials, we need to have a well-defined group of patient volunteers who are willing to participate.

To keep up to date with the latest research volunteer opportunities, please register with the Susan Sukalich Angioma Alliance International Patient Registry, www.angioma.org/registry. This online registry is a communication tool that links the patient and research communities. Once you have created an account, a portal allows you to upload your genetic testing results so we can identify and contact those individuals who are eligible for any upcoming study. (Angioma Alliance will never share any of your personal information without your permission.)

By joining the Patient Registry and sharing your results, you are helping us to define the cavernous angioma patient community and helping researchers design feasible studies that will be able to quickly recruit participants. Recruitment problems are among the most difficult and cost-prohibitive elements of many clinical trials. Our initiative will both help patients and speed the pace of clinical research.

WHAT IF YOU HAVE A SINGLE LESION AND NO FAMILY HISTORY?

Genetic testing is not recommended for those with single lesions (sporadic CCM) who don't have a family history. Sporadic CCM is not caused by inherited mutations, and testing your blood would not identify a mutation. However, you can still help!

At a cellular level, sporadic CCM lesions look identical to those of any inherited form. Therefore, one can reasonably hypothesize that at a fundamental biological level similar processes are causing all forms of this illness. However, we still need you to join our registry so that we can keep you up to date with new announcements for clinical studies.

Join the Patient registry today: www.angioma.org/registry. And remember, without you, there can be no cure!

Amy Akers

**Angioma Alliance
Rare Disease Day
Auction**



Thank you to everyone who participated in our first Rare Disease Day online auction. Our auction of exotic travel, rare wines, memorabilia, art and other one-of-a-kind objects and experiences was a success and we look forward to recognizing International Rare Disease Day again next year. In the meantime, a few choice items remain for sale at www.biddingforgood.com/rare/. Grab them before they're gone!

Spread the Word: Text-to-Donate in March!

March is Text-to-Donate month to support Angioma Alliance! Simply text RARE to 85944 and a one-time \$10 donation will be added to your phone bill. We're very excited to be partnering with EveryLife Foundation for Rare Diseases who have provided us this service and who will match every text donation up to \$1000. So, your \$10 donation will become \$20. The EveryLife Foundation selects one rare disease patient advocacy organization a month to support and March 2014 is Angioma Alliance month. All we need is 100 donations to get the full matching grant!



Get further details at <http://www.everylifefoundation.org/support/text-to-donate/> and tell all your friends and family!

Research Update

Association of Cardiovascular Risk Factors with Disease Severity in Cerebral Cavernous Malformation Type 1 Subjects with the Common Hispanic Mutation

A new publication from the Brain Vascular Malformations Consortium (BVMC) research team describes cardiovascular risk factors (age, obesity, gender, etc) that are associated with variability of CCM disease symptoms among patients with the Common Hispanic Mutation. This study used the number of lesions per patient as a primary measurement of disease severity. In this study group, men had more CCM lesions than women and advancing age also correlated with a higher lesion count. Conversely, obesity and a high body mass index were correlated with a lower number of lesions. Diabetes, high cholesterol and smoking do not affect lesion count in this study group. This is an excellent preliminary study; further research of larger and more diverse populations will be useful to confirm the results.

Choquet H, Nelson J, Pawlikowska L, McCulloch C.E, Akers A, Baca B, Khan Y, Hart B, Morrison L, Kim H. Publication date: April 2014. Abstract available at; <http://www.ncbi.nlm.nih.gov/pubmed/24401931>

Dynamic permeability and quantitative susceptibility: related imaging biomarkers in cerebral cavernous malformations.

A recent report from Dr. Awad's research and clinical team at the University of Chicago describes two new imaging techniques: Dynamic contrast-enhanced quantitative perfusion (DCEQP), which measures permeability, and Quantitative Susceptibility Mapping (QSM), which can determine iron content (bleeding). These techniques likely will become useful tools for monitoring and measuring treatment effectiveness in future drug trials for CCM.

Mikati AG, Tan H, Shenkar R, Li L, Zhang L, Guo X, Larsson HB, Shi C, Liu T, Wang Y, Shah A, Edelman RR, Christoforidis G, Awad I. Publication Date: February 2014. <http://www.ncbi.nlm.nih.gov/pubmed/24302484>



"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>.

Long-term seizure outcomes following resection of supratentorial cavernous malformations.

In a review of records from 56 CCM patients who suffered seizures and sought surgery at Harvard and Massachusetts General Hospital, this study team found that 82% of patients experienced post-surgical seizure freedom. In those patients whose seizures were not alleviated by surgery, the presence of multiple lesions was associated with worse post-surgical outcome.

Kwon CS, Sheth SA, Walcott BP, Neal J, Eskandar EN, Ogilvy CS. Publication Date: November 2013. <http://www.ncbi.nlm.nih.gov/pubmed/24075713>

Dylan Mayer Rock & Bowl for Angioma Alliance is Back for 2014

The first ever Dylan Mayer Rock & Bowl for Angioma Alliance in April, 2013, was a great success, raising over \$11,000. The Rock & Bowl will be back on April 12 in Hamilton, OH, (about 30 miles north of Cincinnati).

Board member Tony Mayer and his wife Cari (also active in the Angioma Alliance) are again hosting the event named for their son Dylan. At the age of 1, Dylan was diagnosed with cavernous angiomas



in his brain. He underwent brain surgery to remove one lesion that was causing seizures, but many more cavernous angiomas remain. All proceeds from Rock and Bowl will go directly to Angioma Alliance for research and funding to help find a treatment for all those affected by this disorder.

If you can attend, please join us on April 12 for bowling and lots of fun. We will also have a DJ, Split the Pot, Silent Auction, Raffles and more. If you cannot attend and would still like to support our event follow the Constant Contact link below to donate and/or purchase a shirt.

Please visit our Facebook page at www.facebook.com/RockAndBowlForAA

To register or donate please visit our Constant Contact page: <http://conta.cc/1bKtNDG>

News

We're Registered! SoKind Registry and our Volunteer Needs

Have you been wondering how you can help Angioma Alliance? We've registered with SoKind Registry, which provides you with free or low-cost ideas: www.sokindregistry.org/registry/2733. You'll find how to help with our Facebook page, donate airline miles, tell your doctor about your need for genetic testing and much more.

If you have a skill you'd like to offer that's not listed, please feel free to fill out a Volunteer Interest Form at www.angioma.org/volunteer, and we'll contact you to match you with the right project.

And we're always looking for new Peer Support Volunteers: individuals who can provide phone or email support to those newly diagnosed. Visit www.angioma.org/peer to find out more. Without you, there can be no cure!

Local Events

Allentown, PA

Kylie and Alexis Buck, the girls who founded Scarves4CCM1 when in middle school, are now in high school, and are organizing another fundraiser. They will be hosting a breakfast at Applebee's on Cedar Crest Boulevard in Allentown, PA, on March 23, from 8-10 am.

Edgewater, MD

Join Zach Brown at Chipotle Night on Solomon's Island Rd, Edgewater, MD. Eat your fill and support Angioma Alliance on April 23, from 5-9 pm.

Hamilton, OH

Dylan Mayer's 2nd Annual Rock and Bowl will take place on April 12, from 6-10 pm at Columbia Bowling Lanes. The event will include bowling, a DJ, and contests including longest drive on the golf simulator. See more about this event on page 3 in this issue.

Greenwood, IN

The first annual Cavernous Cure Movement walk will take place at Greenwood Community High School on May 17, from 12-6 pm. See our CCM3 Action article on page 5 for more information.

Cut-a-thon a Success!

We'd like to thank Robert Andrew, The Salon and Spa in Gambrills, MD, for the successful Cut-a-thon they hosted on February 21. The event raised \$870 toward our work while making the world a better looking place.

What I'm Working On: Director Kristen Lewis

I was elected to the Angioma Alliance Board of Directors in September, 2013. I was diagnosed with CCM1 nearly three years ago after emergency surgery to remove a hemorrhaging lesion from my spinal cord. As a former practicing litigation attorney, it is my sincere hope to benefit the entire cavernous angioma patient community.



Along with Connie Lee and Dr. Amy Akers, I am currently working on our new genetic testing initiative. We have long known that one of our roles as a patient advocacy organization is to provide scientists with patients who are able to participate in clinical drug trials. Patients will only be eligible for future drug trials, however, if they have a clinical diagnosis of their specific mutation. So, we have expanded our mission to include helping patients obtain genetic testing. We have already launched the first phase of this project: providing patients with information for their physicians and insurance companies so those patients who are insured, or have the means, may pursue testing.

We will be unveiling another very exciting component of this project later this year and are busy laying the groundwork. This next phase will be critical but will be very costly; we will need \$30,000 to even get started. We are starting to explore untapped funding streams: corporate donors, family foundations, capable individual donors and other grantmakers. Please think hard about anyone you know who may help connect us to any of these potential funding streams. Increasing our media presence will be vital, so assistance in this area is welcome.

I will also be working this year to unite the Los Angeles community with the goal of planning a large-scale local fundraiser. If you would like to contribute time, ideas or connections, please contact me at kristen.lewis@angioma.org.

CCM3 Action

MadoroM Charity Wine Auction

The 2014 MadoroM Charity Wine Auction marked the 10th anniversary of the Bakersfield, California, wine release party, and it was celebrated in style. This event remains our largest annual fundraiser and, over the years, has contributed more than half a million dollars to our organization. This year, Angioma Alliance CCM3 Action development director Liz Neuman presented the Amador family, owners of MadoroM Vineyard, with a scrapbook containing a timeline of Angioma Alliance activities they have supported along with letters of thanks from our staff, advisors, and many of our members. We remain deeply grateful for the support of all the donors in Bakersfield who continue to honor us with their generosity.



Liz and Jake Neuman at the MadoroM wine auction.

Research Award

In January, CCM3 Action awarded its second \$25,000 research grant, the MadoroM Research Award, to Drs. Brent Derry and Ian Scott at the University of Toronto for their work with *C. elegans* (worms) and zebrafish. Their exciting work may lead to medications specific to the more complex CCM3 disease.

We are awaiting the final report from Duke University on the progress of the work completed with last year's Mitchell Asbury Memorial Research Award.

CCM3 Clinic

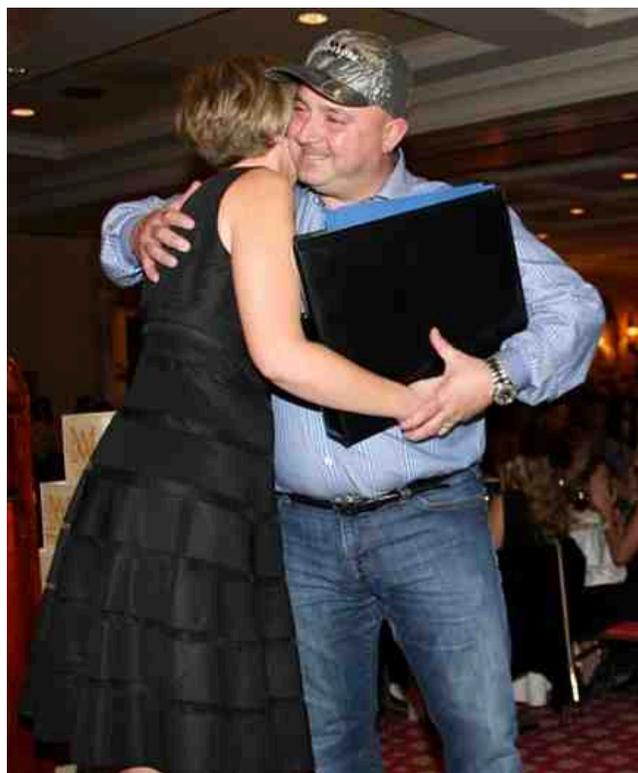
The CCM3 Clinic continues to grow as we identify new families with the CCM3 mutation. Dr. Awad and a group of researchers have written a major paper using

molecular studies, mouse studies, and the findings of the CCM3 Clinic. As of this writing, this paper is in the submission process to academic journals. Once it is published, we will share their results.

From our "CCM3 in Indy" Group

We've been keeping busy here in the Indianapolis area! In November, we started a Facebook page (www.facebook.com/ccm3Indy) to help draw attention to the CCM3 condition and raise community awareness about the Cavernous Cure Movement walk to be held on May 17 at Greenwood Community High School. We're hosting events leading up to the walk, including two Dining for Dollars fundraisers, a Thirty-One holiday bag party, and candle sales. To kick off the New Year, we operated a booth at one of the state's largest trade shows, allowing us to bring awareness of the condition and our mission to thousands of attendees.

We have been working hard to secure vendors, entertainment, and activities for our walk so there will be something for everyone to enjoy. Visit our Facebook page to learn about registration events. We hope to see you in May!



Liz Neuman presenting Andy Amador with a scrapbook of Angioma Alliance activities his wine auctions has supported.



520 W. 21st Street, Suite G2-411, Norfolk, VA 23517-1950

www.Angioma.org

info@Angioma.org

Fax: 1-757-623-0616

Dear Physician or Genetic Counselor:

As the Chief Scientific Officer and clinician members of the Angioma Alliance Scientific Advisory Board, we write to endorse the critical importance of pursuing clinical genetic testing for cavernous angioma (cerebral cavernous malformations, CCM, cavernoma) patients who have a **family history** of the illness and/or **multiple cavernous angiomas**. This is an autosomal dominant disease with one of three gene loci and nearly complete clinical penetrance during a patient's lifetime. We ask that you help your patients obtain clinical genetic testing, by referral to one of the laboratories listed below, or by consulting a genetics professional or neurologist for this purpose. Identifying a patient's genotype, which may have immediate clinical implications for the patients and their kindred, is important for clinical monitoring as well as for future research endeavors, as described below.

- CCM follows an autosomal dominant inheritance pattern and therefore can affect many members of a patient's multi-generational family. First degree relatives have a 50% likelihood of sharing the disease, yet clinical screening by MRI is expensive, may require IV contrast or sedation, and may have occasional false negative results. Delay in obtaining a specific diagnosis may result in unnecessary and sometimes risky diagnostic procedures, such as angiograms or unnecessary surgery. Identifying your patients' genetic mutations will enable family screening with greater confidence, and will allow MRI screening to be targeted to other family members at risk. Once the family gene is known, a negative genetic test result for a relative is reassuring not only to that individual, but for all of that individual's descendants and will alleviate the burden and costs of imaging of unaffected relatives and their offspring.
- The different genotypes of CCM are not alike. All patients with familial CCM require monitoring and follow-up care. However, patients with CCM3 gene mutations require additional specialized care and monitoring. These patients are known to have a particularly severe and multi-systemic disease course including early age of symptom onset, high lesion burden, high hemorrhage rates and an association with meningiomas (Riant et. al 2013, PMID: 23801932). A low threshold is appropriate in these cases for aggressive screening of vascular, tumor and other pathologies in association with subtle symptoms.
- Genotypic information will be important for expediting and facilitating recruitment for future clinical trials. Identifying a drug treatment for this illness will dramatically impact the prognosis for CCM patients as well as greatly reduce the lifetime healthcare cost. Genetic information will help to define the patient population for a trial and to determine whether a given drug treatment will be effective in all forms of the illness. Early trials will likely focus on cases with a defined genotype.

Recent publications report that as many as 95% of familial CCM patients will harbor a mutation in *CCM1*, *CCM2* or *CCM3*. Mutations are identified following a tiered approach of standard gene sequencing to be followed with deletion testing, where appropriate. For reference, please see Riant et. al. 2013 (PMID: 23595507) and Schroder et. al, 2013 (PMID: 23722637). A template letter of medical necessity for insurance providers is available at: www.angioma.org/documents/ccmLMN.docx. *Clinical diagnostic genetic testing can be ordered from a variety of for-profit companies including PreventionGenetics, GeneDX, Athena Diagnostics, and ARUP Laboratories.*

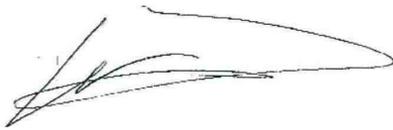
Angioma Alliance is a 501(c)3 non-profit organization. All donations are tax deductible.

Thank you very much for your support and assistance as we strive to increase awareness of the importance of genetic testing for our patients and their families. Please feel free to call Dr. Amy Akers at 757-818-0403 with any questions. She can also be reached via email at amy.akers@angioma.org. Patients, families and health care providers are encouraged to review updated scientific information about this disease, on the Angioma Alliance website at www.angioma.org.

Sincerely yours, on behalf of Angioma Alliance,



Amy Akers, PhD
Chief Scientific Officer
Angioma Alliance



Issam Awad MD, MSc, FACS, MA (hon)
Chair, Scientific Advisory Board
University of Chicago



Kelly Flemming, MD
Mayo Clinic



Leslie Morrison, MD
University of New Mexico



Kevin Whitehead, MD
University of Utah

International News

Cavernoma Alliance UK

We have many activities planned for the coming months. On February 26, five of us went to Westminster, London, for the House of Commons Rare Disease Day. We also have events scheduled in the Scottish and Northern Ireland Parliaments.

International Brain Awareness Week is the global campaign to increase public knowledge of the progress and benefits of brain research. CAUK are holding five events with talks on cavernoma by neurosurgeons. in Birmingham, Glasgow, Newcastle, Liverpool and London.

Fundraising has been critical during this period and it has been very successful. The Big Lottery continues to provide us with funds that cover the cost of personnel. But at the same time CAUK is trying to raise sufficient money so that when the Big Lottery grant tapers downwards, the charity will be self-sufficient.

We have been fortunate to receive funding from The Alice Ellen Cooper Dean Charitable Foundation who generously donated £5,000 (approximately \$8,000) which we are using towards this year's International Cavernoma Alliance UK Forum.

Priority Setting Partnerships (PSPs) are run by the James Lind Alliance. Their work is the first step towards a full clinical trial on cavernoma. PSPs cost in the region of £25,000 (\$40,000), and CAUK are trying to raise funds for this. To this end we have been helped by the Hospital Saturday Fund which have provided us with £5,000 (\$8,000); a very good start. We welcome HSF's involvement.

Members have also been helping raise funds. Many of you know Nicola Evans, who has raised over £4,000 (\$6400) by having her head shaved, which is unnecessary for her upcoming operation.



CAUK is busy planning its Eighth International Forum which will be held on 14 June 2014. Presenting this year will be a number of neurosurgeons, a neuroradiologist, and a neurophysiotherapist. In addition, there will be five members' workshops and the AGM. Admission is free, but please reserve your place now as space is very limited. Get more information here: www.cavernoma.org.uk/forum_2014.html. As always, we sincerely hope that you, our American friends, will join us.

Ian Stuart

Angioma Alliance Canada

Our organization promises a busy 2014 for its members and supporters. On Saturday, June 7, we will be holding our 3rd Annual Cavernous Angioma Family Conference in Toronto. One of the lead research members, Dr. Derry, invited us to his brand new research facility: The Peter Gilgan Centre of Research and Learning. Not only do we have a new location to make this conference special, but we are also welcoming Dr. Issam Awad, from Chicago, as keynote speaker. Guests at the conference will also hear from our Scientific Advisory Board, which recently saw the addition of a new member, Dr. Jeffrey Kobayashi, a neurologist from Toronto. The conference this year will have a silent auction and a 50/50 draw to make the day extra special.

In June, International Awareness month for cavernous angioma, we will also hold our first Annual "Anytime... Anywhere Walk, Run or Bike" event. During the week of June 15-22, supporters of Angioma Alliance Canada are encouraged to organize their own local events or to join existing events to walk, run or bike to raise awareness and funds for our organization.

Chris Quinn had a successful Movember Campaign, raising awareness, and raising funds: more than \$500 for our group, just by growing a mustache. Thank you Chris, your efforts have not gone unnoticed.

On February 25, the MPP member for the Welland Riding, Mrs. Cindy Forster, read a statement in the Ontario Legislature highlighting International Rare Disease Day. In her speech, she mentioned how one of her constituents suffers from such a rare disease: Cavernous Angioma. We thank Mrs. Forster for making this important gesture to our community.

On top of all this excellent information we can tease you a little bit: we hope to have a few surprises for our members and supporters for this upcoming fall. More about this in the next newsletter.

Henk van der Wilt

Caregiver Resource

Caregivers can find helpful tools and resources online at the Caregiver Action Network. There's even a specific section for caregivers of individuals with rare disease at <http://www.rarecaregivers.org/>.

Angioma Alliance Brazil Has Formed

I first heard of an illness called cavernoma in 1993. My daughter, Taiga Lopes, by then seven years old, woke up with a headache, double vision and dizziness. We could see an obvious strabismus. Scans showed that she had a large area of bleeding in her brainstem, along with many other cavernous angiomas.

Over the years, we have lived with the experience of waiting for appointments, seeing doctors, and searching for the neurologists and neurosurgeons that could give us the right advice. We experienced erroneous prescriptions and genetic tests, unprepared doctors, the use of unnecessary drugs, and a whole litany of misinformation.

In 2008, I discovered Angioma Alliance. Since then, some doors have opened, and I have had the assistance of Connie Lee and doctors dedicated to cerebral cavernous malformation. Around that time, at the suggestion of Connie Lee, I contacted Dr. Jorge Marcondes, a cavernoma researcher from the Federal University of Rio de Janeiro, who put me in touch with Dr. Issam Awad.

We now know that Taiga has CCM3 mutation, the most rare and aggressive form of the illness, which led us to an appointment with Dr. Awad.



I am extremely grateful to Angioma Alliance for all it did and keeps doing for those whose lives are affected by CCM. It is a lifelong disease, and having a family member with CCM affects the whole familial structure.

I have been eager to learn more as well as to help others who are looking for information and support here in Brazil. I decided to create an Angioma Alliance-like organization in Brazil. It is called ABACC: the initials translate to Association of Brazilian Alliance of Support of Cerebral Cavernoma.

Certification by the Ministry of Justice will be necessary for the national registration of the ABACC and, as soon as it is achieved, we will begin our mission: to offer support to research for the development of treatments for cavernous angioma, and to produce informative materials on Cerebral Cavernous Malformation and make them available to the public.

Selva Chaves de Sousa

CCM Italia

CCM disease has been officially recognized as a rare disease by the health care institutions of some Italian regions, currently Piemonte and Valle d'Aosta, but this will be extended to other regions in the future. This achievement, due to the efforts of CCM Italia, represents an important aid for patients. CCM patients resident in these regions will be exempt from health care costs for diagnosis and treatment of the disease.

Patients who have received this exemption are entitled to health care benefits included in the Essential Levels of Assistance (LEA) which are considered appropriate and effective for CCM disease treatment and follow-up care. This allows patients to visit doctors, receive further diagnostic examinations, including genetic tests, as well as take tests and examinations for monitoring the evolution of the disease. If there is the suspicion that the rare disease is of genetic origin, the exemption is extended to genetic investigations of the patient's family members. Each Region can provide further services free of charge, including exemption from payment of class C drugs (which are usually paid entirely by patients).

For more information, including the *presidia* dealing with CCM disease, please visit the Associazione Italiana Angiomi Cavernosi (AIAC) website (www.ccmitalia.unito.it/aiac/).

CCM Italia has contributed to the seventh international Rare Disease Day with a conference held on February 26 at the Torino University in order to raise awareness of CCM disease and its impact on patient life.



We dedicated this conference to Zach Brown, the handsome boy that we hope to soon meet in Torino.

Saverio Francesco Retta

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.

Angioma Alliance
520 W 21st Street, Suite G2-411
Norfolk, Virginia 23517
Phone: 571-306-2873
Fax: 757-623-0616
info@angioma.org
www.angioma.org

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- Leslie Morrison, MD, University of New Mexico Medical School
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- Kevin Whitehead, MD, University of Utah

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.

The Angioma Alliance Newsletter is a quarterly publication of Angioma Alliance

Editor: Kirk McElhearn, kirk@mcelhearn.com