



Winter 2013

Angioma Alliance Newsletter

The 2012 Angioma Alliance CCM Scientific Meeting

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

With 65 registered attendees, the 8th annual Angioma Alliance CCM Scientific Meeting was the largest professional conference in Angioma Alliance history. Participants from academia, industry, the medical community and government agencies traveled from 31 institutions in nine countries to attend this unique conference.

This year’s meeting included 25 presentations of new, unpublished and/or recently published data from basic and clinical scientists. A wide variety of researchers attended from the fields of proteomics, molecular biology, vascular biology, genetics, neurology, radiology, epidemiology, animal models and neurosurgery.

The majority of international CCM researchers attend this meeting. From 20 researchers attending the first meeting in 2005, attendance at the CCM Scientific Meeting has grown steadily, with 65 researchers at this year’s meeting. This small, but dedicated, group of scientists is committed to attending the CCM Scientific Meeting on an annual basis.

This meeting is a priority for CCM scientists because it has become the site of the first public presentation for many important discoveries: attendance at the meeting often gives researchers

“priority access” to the latest data, even before it is published.

Additionally, the structure of the meeting encourages discussion to facilitate the development of hypotheses for collaborative research endeavors. Over the past eight years, new collaborations, new grant proposals and new project ideas have all been developed from conversations and/or introductions that took place at the CCM Scientific Meetings.

The annual CCM Scientific Meeting is organized by Angioma Alliance, and additional funding is provided by CCM3 Action, PreventionGenetics, and Innolyst. A grant award from the National Institute of Neurological Disorders and Stroke (NINDS) generously provided over \$11,000 of additional financial support for the 2012 meeting. More than half of the NINDS grant was used to sponsor the travel and lodging of young investigators who might otherwise not have been able to attend the meeting.

Much of the data presented at the CCM Scientific Meeting was new and unpublished; therefore we are unable to report specific results from the presentations. However, the following is a summary of the meeting’s highlights.

(Cont.)

Travel stipends were awarded to six trainees who presented original research.

To be considered for this award, the applicant must be a graduate or medical student, postdoctoral fellow, or medical resident and must present original research at the meeting. All applicants submitted abstracts for oral presentations and letters of recommendation from their advisors to be reviewed by the selection committee. For the 2012 meeting, six travel stipend awards were provided for the following trainees:

Hélène Choquet, PhD – Dr. Choquet is a postdoctoral fellow with Dr. Helen Kim at the University of California San Francisco where she is working on the Brain Vascular Malformations Consortium (BVMC) project. This project is a collaboration with Dr. Leslie Morrison at the University of New Mexico and Angioma Alliance. Dr. Choquet presented the initial findings from the BVMC study describing clinical factors associated with the number of lesions in individual CCM patients with the Common Hispanic Mutation. The purpose of this study is to better understand why there is such a wide range of clinical symptoms in CCM patients, even among those in the same family. This genetics of disease severity study is ongoing; for more information or to participate, please visit: angioma.org/registry.

Margaret Horne, MS – Ms. Horne is a graduate student with Dr. Rustam Al-Shahi Salman at the University of Edinburgh in Scotland. She presented her recently published study that compared the

outcomes of CCM patients who underwent brain surgery versus those who chose to follow conservative management by observation. The full text of this study is available online at www.thelancet.com in The Lancet Neurology, Volume 11, Issue 3.

Ryan Li, MD – Dr. Li is a neurosurgical resident who traveled from the West China Hospital of Sichuan University to attend the CCM Meeting. He presented the work completed during his first year of residency with Dr. Issam Awad at the University of Chicago. While at Chicago, Dr. Li was integral to the development of new magnetic resonance imaging techniques. His presentation described preliminary experiments that used MRI to measure iron content (bleeding) in both mouse and human lesions. In future studies, this imaging technique may become a useful tool for measuring effectiveness of drug treatment.

Dave McDonald – Mr. McDonald is a senior graduate student with Dr. Doug Marchuk at Duke University. His work focuses on two themes: developing mouse models for drug studies and investigating the genetic cause of lesion development. The work Mr. McDonald presented at this year's meeting focused on the genetics of sporadic lesions and on developing hypotheses for how these lesions form.

Abdul Ghani Mikati, MD – Dr. Mikati is a visiting postdoctoral scholar at the University of Chicago working with Dr. Issam Awad. Dr. Mikati's research is focused on investigating brain permeability. His presentation described a novel imaging technique that measures brain permeability (leakiness) and may also be useful as a biomarker (measuring tool) to assess effectiveness in drug studies. Dr. Mikati presented data that was generated from patients visiting the CCM3 Clinic. CCM3 Action generously sponsored his award.

Bilge Yoruk – Ms. Yoruk is a senior graduate student from Canada; she is conducting her PhD research with Dr. Ian Scott at the University of Toronto. Ms. Yoruk uses the zebrafish model system to investigate the role of CCM3 in vascular development and



Connie Lee, Dr. Issam Awad, and Angioma Alliance member Susan Wollersheim.

maintenance of the blood vessel system. She has previously shown that CCM3 works independently from CCM1 or CCM2 and her newest findings describe new molecular roles of the CCM3 protein and its interacting partners.

Structural studies of proteins provide new insight to CCM molecular function.

What are the functions of the CCM proteins? What do they do in the cell and why do they cause CCM lesions when they are mutated (not functioning properly)? To address these questions, a number of groups have taken a structural biology approach to better understand the physical shape of these molecules. Knowing the structure allows researchers to identify new interacting partners, which can give clues to previously unknown functions. We are learning that these molecules have many important roles in the cell. How these different roles affect CCM disease remains unknown. By studying all the functional roles of the CCM proteins, researchers may be able to identify new potential drug targets. This line of research may also lead to better understanding of how treatments will affect sporadic versus familial disease and whether or not treatments will be effective for individuals with different CCM gene mutations.

Mouse models continue to show promising results for therapeutic treatment.

Translating research findings from the laboratory to clinical treatment is a key priority; mouse models are essential to this process. Researchers must demonstrate clinical effectiveness of a drug on mice with CCM before any testing can be done in humans. It has taken many years to refine the CCM mice to be an effective tool for treatment studies. The mice being used currently develop CCM lesions like human patients, and they develop many lesions. Having many lesions is important for treatment studies because it will be easier to see if a treatment is working. For example, if you expect a mouse to develop twenty lesions and it only develops two, you have a good idea that the drug is working to prevent new lesions from

forming. Updated results with the Fasudil treated mice continue to be very promising. In the future, we look forward to learning about how statins and other drugs affect the mice.

Developing strong measuring tools (biomarkers) is critical for effective clinical trials.

As we continue to think about moving laboratory



Brent Derry, PhD, Anne-Claude Gingras, PhD, Issam Awad, MD, Amy Akers and Connie Lee.

findings and mouse studies toward treatments for the human disease, we need to have a good way to measure potential drug effects. In cancer, one can determine that a drug is effective if the tumor stops growing or goes away. With CCM, it is not that simple. We want a drug that stops lesions from developing (particularly in familial cases where multiple lesions are common); we want a drug that stops bleeding from happening; and we want a drug that stops lesions from growing. How can we measure these things? We don't want to just wait for a bleed to know if a drug is effective. New magnetic resonance imaging (MRI) techniques are being developed specifically to address these questions in a non-invasive way. These techniques measure bleeding as well as brain and/or lesion permeability. Likely, these techniques will be very useful tools in clinical practice for monitoring personal health and wellness and also as we look to the future with clinical trials.

Successful clinical trials require strong collaborative relationships and great science.

For the final session of the 2012 meeting, five speakers were invited to participate and lead a group Panel Discussion on clinical trials. We chose to focus the last two hours of the meeting on this topic and use the CCM Meeting as a venue to bring together all of the important stakeholders who are needed for success. Those stakeholders include patient advocates (Angioma Alliance), researchers, clinicians, as well as representatives from the Food and Drug Administration (FDA) and National Institutes of Health (NIH). In this discussion, our panel of experts each spoke for a few minutes on a specific topic, then the discussion was opened up to the entire room to address what we need to do to complete a successful trial.

Issam Awad, MD – Neurosurgeon at the University of Chicago

Dr. Awad led a discussion on the pros and cons of using MRIs to measure drug effectiveness. Possible measurements include: counting lesion number and development of new lesions over time, measuring bleeding and or permeability.

Jamie Roberts – Recruitment Specialist with the NIH National Institute of Neurological Disorders and Stroke

Ms. Roberts discussed how to effectively advertise and enroll a large number of patients in a multi-site study. She shared her unique insight on strategic Internet marketing/advertising and harnessing the power of social media for study recruitment.

Claudia Moy, PhD – Clinical Research Project Manager with the NIH National Institute of Neurological Disorders and Stroke

Dr. Moy described to the group unique funding opportunities that may be available to researchers performing clinical trial work and she discussed how the NIH could help to fund a clinical trial for CCM.

Gumei Liu, MD, PhD – Commissioner's Fellow for the Rare Diseases Program at the Food and Drug Administration



Travel Award Winner Dave McDonald and Mitchell Asbury Award winner Doug Marchuk talking to Dr. Kelly Flemming.

Dr. Liu helped to explain the FDA regulatory process and paperwork needed for a trial, and how Angioma Alliance can help with the application for approval of an investigational new drug.

Importantly, we also discussed feasibility of starting a CCM trial from the science perspective: are we ready to move ahead with Fasudil, should we wait for statin results, would another drug be better? These are all extremely difficult questions to answer. At this time, although the Fasudil research is looking very promising and we are anxious for the statin results, neither drug is ready to move to human treatment studies quite yet. Stronger evidence of effectiveness in mouse models for CCM1, CCM2 and CCM3 is needed; those data are being generated.

Moving Forward

We are moving in a positive direction with all of this great research. Each year we see the science growing at a faster pace. Angioma Alliance has brought together all of the key players, opened new lines of communication and helped to better define the necessary steps needed to move forward. People with CCM should be hopeful that human drug trials will start in the not so distant future. Together, with these scientists, we will find a cure.

Amy Akers

News

Duke University's Dr. Douglas Marchuk Named by CCM3 Action as Recipient of Mitchell Asbury Memorial Award

Award to Fund Testing of Medications in Mice with Mutations on the CCM3 Gene

CCM3 Action has honored Dr. Douglas Marchuk of Duke University with the \$25,000 Mitchell Asbury Memorial Award.

Dr. Marchuk will use the award to support laboratory testing of the drugs Fasudil and Simvastatin (sold under the name Zocor) in mice with a mutation on the CCM3 gene. The proposed research will focus on determining whether these medications can limit the formation of cavernous angiomas or cerebral cavernous malformations, and if use of the drugs can reduce progression and hemorrhage in existing lesions.

Fasudil and Simvastatin have shown promise in animal model studies of CCM1 and CCM2, two other genetic causes of cerebral cavernous malformation development.

"A mutation on the CCM3 gene is often tied to recurrent brain hemorrhage and seizure in both children and adults, and there are no current medication treatment options," stated Dr. Connie Lee, CCM3 Action program coordinator. "Dr. Marchuk's work will determine whether clinical trials employing these medications are warranted. Because results can be immediately translated into human treatment studies, this research is especially exciting for the patient community."

The study should take a bit over a year and, at the end, it will be clear whether either statins or Fasudil will have any role in treating CCM3. This study was not funded by any other source: only CCM1 and CCM2 mice were covered by Dr. Marchuk's existing NIH grant. That means that this work would not have happened any earlier than 2015 without the funding from CCM3 Action.

The Mitchell Asbury Memorial Award was named for an Angioma Alliance member who passed away in 2010, at the age of 53, from complications of CCM3. Mitch Asbury was the husband of long time Angioma Alliance treasurer Karen Asbury. CCM3 Action is

honored to continue his memory with this inaugural grant award.

Dr. Marchuk is a professor and vice chair of the Department of Molecular Genetics and Microbiology at Duke University, and he is director of the Duke University Program in Genetics and Genomics. He has been on the Angioma Alliance Scientific Advisory Board since 2002.

Thank you to everyone who is helping to raise funds for research! This is a great first project to fund and we are hoping it's just the beginning for the CCM3 Action working group.

MadoroM Charity Wine Auction

The 8th Annual MadoroM Charity Wine Auction will be held on February 23 at the Seven Oaks Country Club in Bakersfield, CA. The MadoroM charity auction, hosted by Andy and Marissa Amador, is Angioma Alliance's largest fundraiser and has raised nearly \$500,000 over the years. The magical evening features exclusive auction items like a Rolex watch, a barrel of MadoroM Merlot, a trip to Napa, and lunch in the Congressional Dining Room with House Majority Whip Kevin McCarthy, including airfare. Attendance at the auction is by invitation only. We are extremely grateful for the generosity of the Bakersfield community!

CCM3 Action Opens Etsy Shop

CCM3 Action has opened a shop on the Etsy website to sell donated handmade goods. Our members and their friends and families have donated a wonderful variety of one-of-a-kind items including holiday items, jewelry, scarves and cowls, stuffed animals, baby items and CCM3 Action logo items. All proceeds from sold items benefit the CCM3 Action working group of Angioma Alliance. You can find the shop at www.etsy.com/shop/CCM3Action. Happy shopping!



Shop for a Cure

On the Road with Connie and Julia

Iraan is a west Texas town that Marathon Oil built. Named after Ira and Ann Yates, the ranchers who owned the land in 1926, Iraan sits a little north of Interstate 10, 370 miles west of Dallas, the city where an Iranian would receive expert medical care. Ten years ago, a patient with a cavernous angioma who lived this far off the beaten path would never have known another person with the illness.

Diana Sykes lives in Iraan. Now in her mid-sixties, she has lived there off and on since 1974. Her husband passed away a couple of years ago, and she lives alone. Originally from Kentucky and Tennessee, her accent still reveals her southeastern roots. Diana doesn't own a computer, but her daughter helped her connect with Angioma Alliance. Through the Angioma Alliance peer support program, Diana Sykes was paired with peer support volunteer Diana George in Austin. They spent many hours on the phone together and, over the years, developed a long distance friendship. In a very meaningful meeting, Diana George and her husband Jim visited Diana Sykes in Iraan, and they were finally able to put faces to voices.

In addition to sharing a first name, they share medical history. Both have multiple cavernous angiomas and both have had a brainstem surgery. Since the visit to Iraan, Diana George has been stricken with a hemorrhagic stroke that has taken most of her speech, making her long distance phone friendship with Diana Sykes more complicated although, with Jim George's help, not impossible.

Visiting Diana Sykes in Iraan was one of the highlights of my 2012 trip across the country with my daughter Julia. On Valentine's Day, we drove into town looking for the "house on the corner behind Stripes Market." Iraan's downtown is a checkerboard



Connie and Julia Lee setting out on their road trip.



Diana Sykes, her three dogs, and Julia Lee.

bathed in dirt with just a hint of foliage for shade. GPS doesn't help out there. After a couple of wrong turns, we found ourselves in front of a small brick ranch with a generous yard: Diana's place. We were barely in the front door when Julia heard the barking of three gorgeous, golden dogs that were waiting in the backyard for her to come and play. While Julia got her dog fix, Diana and I talked cavernous angiomas in the kitchenette over red velvet cake. We discussed neurological deficits and research and affected family members back east. Diana is one of the warmest people I've known, and I am certain I would never have had the pleasure of meeting her were it not for the strong network that Angioma Alliance members have developed over the years.

For Julia and me, this encounter and the many others we had on our trip were priceless. For seven months of 2012, we drove around the United States in my Hyundai, sporting a rooftop cargo box full of

camping gear, with the goal of meeting as many Angioma Alliance families as we could. Twenty thousand miles later, we returned home with countless memories and many new friends. We attended 32 get togethers across the US and an Angioma Alliance Canada family conference in Hamilton, Ontario. From Miami to Los Angeles to Seattle to Bangor, we shared, hugged, and laughed with old friends, online friends, and brand new friends.

Julia has always known a few children with cavernous angiomas as a result of my work with Angioma Alliance. After our trip, she can now say that she's met kids face-to-face in 16 different cities around the country. No matter where she ends up, she'll always have a cavernous angioma buddy nearby. She also met adults with severe balance problems, who are unable to walk unassisted, with vision problems, that require a fogged lens, and with speech problems, that make it difficult to communicate. These folks have shown her that it is possible to live a very good life no matter what happens in her future. Julia isn't afraid anymore, and I am deeply grateful to our wonderful Angioma Alliance friends who shared themselves with us.

Staging get-togethers is not easy, and I would like to thank the local contacts who put the energy into finding venues, contacting potential attendees, and even hosting in their own homes. Like Diana Sykes, many of the families we met have been isolated from others with cavernous angiomas, even if they live in



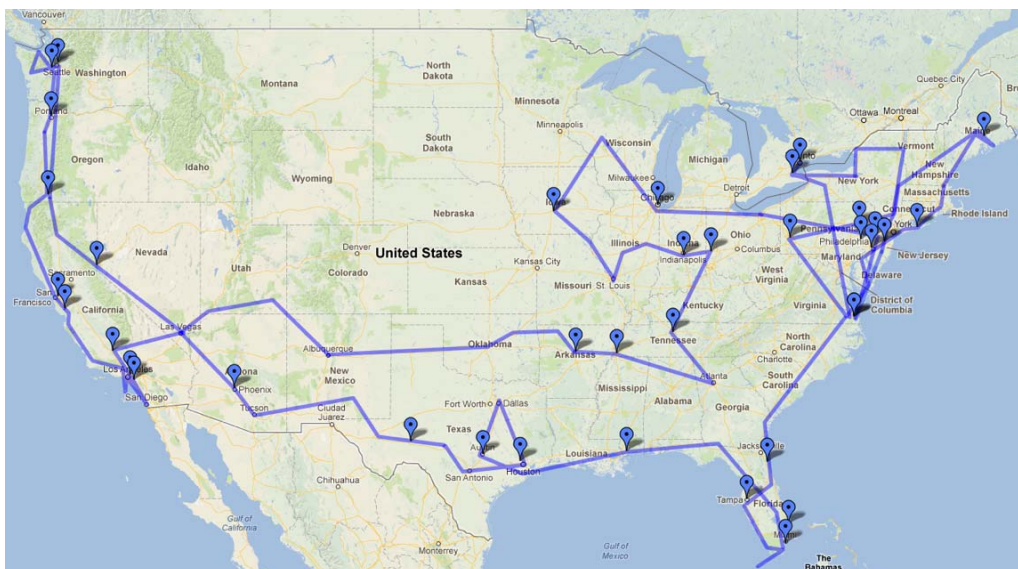
Julia Lee with the Wilkinson family in Des Moines, Iowa.

more populated areas. Our meetings helped folks make local connections that I hope will continue to sustain them long after we've left town.

I would also like to thank the many families that opened their homes to Julia and me while we traveled. Most of you had never met us and yet you gave us beds, meals and hospitality. It was an honor to share your home and get to know you better. I hope we will all meet again.

Because of homesickness that cropped up in April, Julia and I missed our planned visit to the Rocky Mountain States in May. One day, when time and finances allow, I plan to get back on the road. I can't think of a more meaningful way to spend my time than to allow Julia to learn again that she is not alone and to help create a country where this is true for everyone with cavernous angiomas.

Connie Lee



Connie and Julia Lee logged more than 20,000 miles in over 6 months of travel. Each pin marks a get-together with people affected by cavernous angiomas.

Angioma Alliance Zombie 5K Run

The first Angioma Alliance Zombie 5K Run for Research was held on October 20, 2012, in Hamburg, Michigan. Dana Ruff, a 21 year old with first-hand experience with the condition of cavernous angioma, came up with the concept. Dana was diagnosed with a brainstem cavernoma in 2007, and underwent brain surgery to remove the lesion in the spring of 2011. "I wanted to reach out to people in Michigan and let them know that there are other people who have cavernous angiomas and that they are not alone."



Dana was not alone in planning the event either. The unofficial planning committee included her boyfriend Erik Reichenbach, mother Cathy Dustin, and best friend Kaitlyn Wright. Not only was there a great turn out for an inaugural event (around 50 people) and money raised in support of cavernous angioma research (approximately \$2,000), but Dana met several people affected by cavernous angioma the day of the run.

Dana plans to organize subsequent events, one in Michigan and another in California. They have renamed their advocacy efforts "Project A2" (which stands for Angioma Alliance). More details about the 2013 events can be found on their website, www.projectA2.com, on Twitter @A2Project, or on their Facebook page.

When asked if she had any advice for those contemplating organizing an awareness and/or fundraising event, she responded, "DO IT!! It's

overwhelming and scary at first, but after the first one, you get the hang of the process and it becomes easier... (we can) bring this rare illness into the spotlight. You have nothing to lose and everything to gain by putting on a fundraising or awareness event."

Texas Fun Run: March 23, 2013

Rachel Hart and Savannah Hollis will be hosting the 4th annual Angioma Awareness Fun Run in Irving, Texas on March 23, 2013, at 9am. There will be a 1-mile family fun run and a 5k race. If you would like to participate or make a donation please visit www.runningforareasondallas.com. As always, great prizes will be offered and yummy food will be served. This event is the perfect opportunity for those affected to meet, share stories and offer support. See you there!

Please contact Rachel Hart at rhart@angioma.org or Savannah Hollis at shollis@angioma.org with questions.

Volunteers Wanted!

Do you have fund development skills? The Angioma Alliance Board is seeking individuals with a background in fund development with experience in any combination of the following activities:

- Actively seeking and identifying potential individual and corporate donors.
- Assisting with prospect research, writing and preparation of grant proposals, and with donor solicitations.
- Maintaining involvement with United Way campaigns, and other similar workplace giving programs.
- Supporting media relations activities by preparing press releases, providing support for press events, and engaging in other activities to expose the media and the public to nonprofits.
- Helping develop and prepare effective social marketing and engagement tools.
- Representing nonprofits at public events to raise visibility in the community.
- Assisting with development and distribution of print and other marketing and promotional materials.

If you have any of these skills and would like to make a substantial contribution to the Angioma Alliance, please email Kandance Weems Norris at kandance@cumbyweems.com.



Participants in the Zombie Run.



News from Angioma Alliance Canada

With 2013 just beginning, the Angioma Alliance Canada has made great strides to make the organization stronger and better equipped in its mandate to be "Working Towards a Cure!"

Let me start by thanking some people that made an enormous effort to promote our organization and spread awareness for our cause. An incredible show by Rafaela Carrasco, Carmen Romero and Ilse Gudiño and others was performed on October 20, 2012, at the 6th Toronto International Flamenco Festival. We thank Lionel Félix and Carmen Romero for allowing us to be present at the event and to raise some funds for us, and Shawn Mulvihill and his wife for attending the event and taking care of the booth.

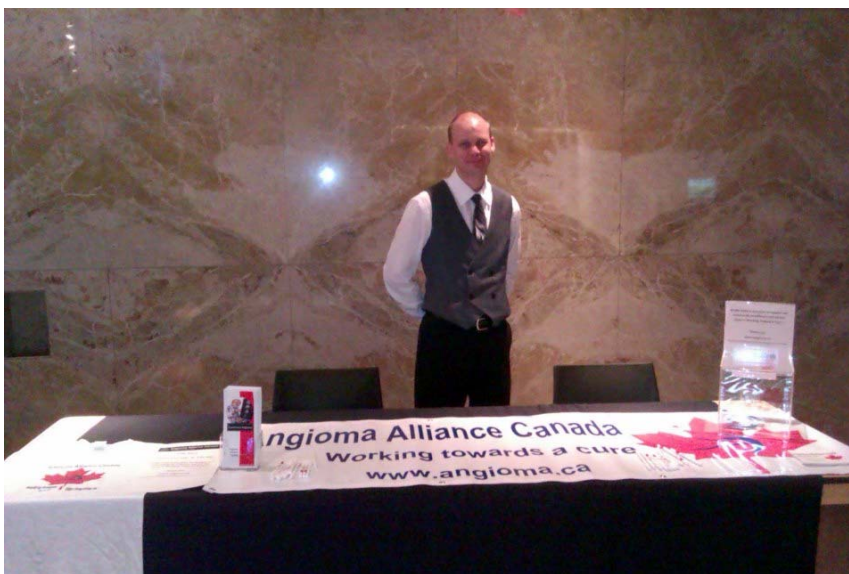
We welcome Lea Labelle-McKinley to our board of directors as our new fundraising director. Lea was already a significant contributor last year when she raised \$1,000 for our organization with her "Bounce to Bounce back" activities. She has already lined up another great event called "Bright Night." Visit our Facebook page to learn more about this initiative. In its recent dealings with the Canada Revenue Agency (CRA), the Angioma Alliance Canada has learned that, with a few minor adjustments to its constitution, it will be able to receive its charitable status. The Board of Directors have acknowledged these changes and have set the wheels in motion to get this document out in the next few weeks. Angioma Alliance Canada will be able to do better fundraising once this charitable status has been received, and besides the planned "Bright Night" there are several other plans in the works to make this a productive year.

The Angioma Alliance Canada is also working on the details for this year's 2nd Annual Family Conference, again to be held in Hamilton, Ontario. The date has not been finalized, but we hope to secure one in the near future. The board of directors hopes to plan this event in June, to coincide with the "International Cavernous Angioma Awareness

Month." Visit our web site in the next few months to learn more.

So, with the pending charitable status, the lineup of great fundraising ideas, the 2nd Annual Family conference just 5 months away, the Angioma Alliance Canada is definitely moving forward.

Henk van der Wilt



Shawn Mulvihill, chair of the Angioma Alliance Canada, attending the booth at the 6th Toronto International Flamenco festival.

The International Cavernous Angioma Patient Registry turns 3!

March 2013 marks the third anniversary of our Patient Registry. In 2012, over 250 new participants joined the registry, for a current total of 625 participants!

The registry provides a valuable resource to connect the research and patient communities. When a researcher needs participants for a study, Angioma Alliance can help with recruitment by sending out a message to potentially appropriate people. We do not give out your personal information; instead, we provide you with study details and tell you how to participate if you choose to do so. Also, we post study opportunities on the home page of the Registry. In the future, the Registry will be the backbone of our facilitation of clinical drug trials.

Enrollment is open to anyone who has or had a cavernous angioma and who may be willing to participate in research. It takes about 20 minutes to complete the questionnaire about your medical history; this helps us determine which studies you might be eligible for. Questions include: How many lesions do you have? When/how were you diagnosed? What symptoms do you experience?

To sign up for the International Cavernous Angioma Patient Registry, visit www.angioma.org/registry. Please take a few minutes to register today!



Cavernoma Alliance UK Update

Win or lose, this period at the end of January 2013 marks a turning point in the history of Cavernoma Alliance UK (CA UK). Thanks to our fundraisers, FA1MUK, and the Board of Trustees, CA UK has developed a robust bid to help move us forward from a small charity to one that can serve the entire cavernoma community: the growing demands of its membership and the increased need for CaverHubs around the UK and now the Irish Republic, too. Should our proposal be read by someone who chooses another worthy charity's application, CA UK's experienced fundraisers will use this solid approach for other grant applications.

As anticipated in last Summer's Angioma Alliance newsletter, CA UK's CaverWagon trundled to three conferences in September: the British Society of Human Genetics, the 1st World AVM Congress in Edinburgh, Scotland (which held a symposium on cavernoma), and the Society of British Neurosurgeons in Yorkshire.



Dr. Rustam Al-Shahi Salman (1st from left); Mr. Neil Kitchen, consultant neurosurgeon, (3rd from left) medical advisers to CA UK, discuss a potential UK patient trial for cavernomas.

Thanks to funding from the Foyle Foundation, CA UK managed to restart its CaverHub programme, holding two meetings last autumn. Mr. Kitchen's talk, called *It's Time for a Trial*, available on our website, <http://www.cavernoma.org.uk/opus574.html>. And in October 2012, the Yorkshire CaverHub assembled to listen to Mr. Deniz, consultant neurosurgeon, Leeds General Infirmary, speak on cavernoma. In Spring

2013, CA UK presents four local meetings: a CaverHub in Dublin, Ireland, and regional meetings in London, Manchester and Glasgow during International Brain Awareness Week (11-17 March 2013), organized by the Dana Alliance in New York.

During the autumn, CA UK received its second grant from Roald Dahl's Marvellous Children's Charity. The Board decided to offer the first residential trip, for young people with cavernoma and their carers, to a camp in a coastal town in Lincolnshire. Details of this visit will appear in the next issue.

Rushmoor School, Bedford, are the organisers of a group of intrepid canoeists called Paddle for Good, who are conducting a non stop relay from Wales to the Wash. (www.paddleforgood.co.uk) This massive undertaking is to be in support of our charity and the British Lung Foundation. Although this fundraising event is not held until later this year, local member Belinda Crompton and her husband went to the inaugural event on 5th December 2012.

Following on from Lee Smith's outstanding fundraising event in June 2012, Scott Legg also took to the skies to jump out of a plane, raising about £2,000 in sponsorship on behalf of his wife, Georgina, diagnosed with a brainstem cavernoma.

Lee Smith raised over £7,000 to allow his four year old son, Zane, diagnosed with 17 brain lesions, to travel to Dr. Awad's clinic in Chicago. This money raised will cover the costs of the investigations and the balance Lee Smith has kindly donated to help others in CA UK.

Emily Fletcher (member) and Ian Stuart (Founder Member and Co-ordinator) are participating in England's Rare Disease Day in the Houses of Parliament on 27 February, and Godsall (Scottish Representative and Member) in the Scottish Parliament.

CA UK is going to Harrogate, Yorkshire, for the 4th annual meeting of the British Neurovascular Group of Neurosurgeons. Organized by the Society of British

Neurosurgeons, this meeting is dedicated to AVMs, subarachnoid haemorrhages and cavernoma.

Plans for the 7th Cavernoma Alliance UK International Forum on 15 June 2013, Grange Holborn Hotel, are well advanced. With three speakers, six member workshops and a discussion with Sacha Bonsor, author of Dipped Into Oblivion (who had a

brainstem cavernoma removed by Dr. Robert Spetzler at the Barrow in Phoenix, AZ). CA UK extends a very warm welcome to all; especially our American friends.

The charity's next board meeting is in April, when we will either be celebrating or commiserating as the decision on our Big Lottery funding is due at this time.

Ian Stuart

News from CCM Italia/AIAC

Since the inception of CCM Italia/AIAC in March 2012, the awareness and understanding of CCM disease in Italy has increased exponentially in the general population as well as among doctors and researchers. To achieve this goal, we were lucky to take advantage of great support from the Interstructure Centre of Computer Services (CISI) of the Torino University, and the Telethon Foundation, a non-profit organization focused on genetic diseases.

CISI provided enthusiastic assistance in the development and establishment of the interconnected CCM Italia (www.ccmitalia.unito.it) and AIAC (www.ccmitalia.unito.it/aiac) websites. These have been very effective in fostering the expansion of the CCM Italia multidisciplinary research network focused on the CCM disease, as well as in providing useful information and support to CCM patients and family members. The Telethon has also strongly promoted and advocated both CCM Italia and AIAC initiatives through press releases and invitations to speak at important national conferences and television broadcasts. In addition, we took advantage of the expertise and kind support provided by our international partner organizations, including Angioma Alliance, Cavernoma Alliance UK and Angioma Alliance Canada.

Thanks to the initiatives of CCM Italia and AIAC, many Italian CCM families have had the opportunity to get to know each other and create a community, as well as to interact with people providing information and support; they are no longer alone. Moreover, patients have had the chance to be routed to distinct clinical reference centers specialized in diagnosis and treatment of the CCM disease, where they have benefited from the availability of expert clinicians. In particular, I would like to mention Dr. Marco

Fontanella, Director of the Neurosurgery Department at the Brescia University Hospital.

One of our future goals is the establishment of a CCM Italia/AIAC Scientific Committee and the organization of national workshops. These will be aimed at sharing knowledge and information and to draw up collaborative agreements among clinicians and researchers with complementary expertise and interests related to the diverse aspects of the CCM disease.

Recently, the patient-dedicated AIAC organization has elected its new President, Massimo Chiesa, a CCM patient highly motivated in pursuing and achieving AIAC's objectives. You can find a synthesis of his story on the AIAC website (<http://bit.ly/120QwHo>), and in the picture below you can see him enjoying an amazing parachute jump from 4,000 meters. Doing this, he seems to want to send a message: you can smile and live a wonderful life, in spite of everything!

We welcome the new President and wish him continued success in his life and mission!

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.

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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.

The Angioma Alliance Newsletter is a quarterly publication of Angioma Alliance
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