



Angioma Alliance Newsletter

Get Involved: Start an Action Group!

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

One of the strengths of Angioma Alliance is that it brings together a diverse group of people. Our lives are affected by cavernous angiomas in one way or another but we are all different. We live all over the country and around the world. We are men, women, and children of all different ages and backgrounds. Some of us struggle with headaches, others have had strokes. Some of us have a single angioma, others have many. Some of us have had surgery, others have decided not to, and others are still thinking about options.

Angioma Alliance helps us set aside our differences and work together toward common goals: seeking a cure, finding peer support, answering research questions and helping each other to live full lives. The Board of Directors fully supports this solidarity and believes that we are stronger when we are together with our shared diagnosis of cavernous angiomas. However, we also think that there is a place for creating more specific groups, within Angioma Alliance, for those who have particular concerns and interests. In this way, the organization can meet the needs of all

our members in ways that serve each person best.

At this time, we are excited to see which groups may want to form and become what we call action groups. Groups could focus on a particular problem, such as brainstem lesions, or a specific location, such as New Mexico.

Action groups will focus on a particular problem, such as brainstem lesions, or a location, such as New Mexico.

Our first group will be the CCM3 action group. Individuals with the CCM3 mutation (which can run in families) tend to have an aggressive form of the disease and may have other associated medical problems. Connie Lee, Angioma Alliance

President, will be working within this group to start initiatives that are specific to those with the CCM3 mutation, including the development of a CCM3 clinic.

The Board is interested in hearing your suggestions and needs. Please send me your ideas for other action groups at ssukalich@angioma.org. Angioma Alliance is here to support all of our members' needs; from a single person, to an action group, to the majority. I look forward to hearing from you.

*Sara Sukalich, Chair,
Angioma Alliance Board of Directors*

Navigating Scientific Literature: Trust it or Trash It?

Navigating the scientific literature available on the Internet and in print can be an overwhelming task—there are so many different types of papers and, it is often hard to tell if the published information is trustworthy or not.

The Genetic Alliance (www.geneticalliance.org) recently created a guide to help us determine the quality of a particular piece of literature or website providing health information. This guide is called “Trust it or Trash it?” The original article may be accessed on the web (www.trustortrash.org/TrustorTrash.pdf), and a synopsis is below.

The “Trust it or Trash it?” method encourages readers to think critically about scientific or health literature by asking three questions.

Who said it?

Information that can be trusted should clearly identify the author, and that author should be someone who is experienced and respected in his or her field. Also, you should be able to identify the sources of the information or who paid for the study. In the US, most research is funded by the National Institutes of Health, but funding can also come from private foundations or groups (like Angioma Alliance). However, some funding can come from those interested in specific results, such as pharmaceutical companies; one should be a bit skeptical about such studies.

When did they say it?

In the rapidly changing field of medical and scientific research, it is essential to keep up to date. One should be cautious of information that seems out of date or that conflicts with other previously published information without a supporting explanation.

How did they know?

This question should make the reader think about how the authors came to their conclusions—did the authors study many people, or draw their conclusions from just one or a few? Studies with large numbers of participants are stronger and more trustworthy than those with small numbers.

In addition to variations in quality, there are also several different types of scientific literature. If you

are looking for information on Cavernous Angioma, for example, you will most likely find case reports, as well as research and review articles.

Case reports are typically descriptive reports of a single patient. These reports are an interesting addition to the scientific literature; however, because they are findings representing only a small number of patients, case reports are not intended to immediately influence medical treatment for a particular illness. Instead, case reports provide preliminary evidence for scientists to develop hypotheses and perform larger research studies.

The majority of the scientific literature is made up of research articles. These are reports of original research that have been peer-reviewed prior to publication. Peer-review refers to the process where a paper that is submitted for publication is critiqued by a group of expert researchers. Any questions or suggestions from the peer-review committee must be resolved before the paper is published. The purpose of a peer-review is to ensure research articles are of the highest possible quality and reflect the most current research practices. Research articles may report on basic laboratory science, studies involving people, and clinical trials. Research articles that explain the findings of therapeutic clinical trials and studies with large numbers of participants are the best resources for learning about new treatments and medical care related to a particular illness.

Another type of paper often seen in the scientific literature is a review article. Review articles are not original research reports, but instead provide a comprehensive summary of recent research in a particular field. They examine a number of research reports on a specific subject, and attempt to arrive at broad conclusions based on a variety of results.

In summary, there is a wealth of scientific and health-related information on the Internet. I would encourage you to read it all with a critical eye and always ask the three “Trust it, or Trash it?” questions to help decide whether the information is useful, and how it can affect you.

Amy Akers

News

Angioma Alliance Patient Registry Making Strides, But it Needs You!

As of this writing, the International Patient Registry has grown to over 325 participants. But we need more of you to sign up! Enrolling takes only 20 minutes, but provides an incredibly valuable resource.

In contrast to the DNA/Tissue Bank, no biological samples are needed; it's open to anyone who has or had a cavernous angioma, and you enter the information yourself. When a researcher who needs participants contacts us, we send out a message to those in the Registry who may be appropriate for their work. The researchers do not know who you are until you contact them.

We also post research participation opportunities on the home page of the Registry. Down the line, the Registry will be the backbone of our facilitation of clinical drug trials. Finally, the Registry gives everyone who registers a snapshot of our community. Responses to questions are combined and displayed in the "Explore" section of the site. Do you want to know the percentage of our Registry participants who report hypothyroidism? It's 7.6% percent. How about the percentage that were diagnosed between the ages of 20 and 30? It's 21%. This isn't the completely unbiased sample that a scientist would want for research, but it provides a starting point for creating hypotheses that researchers can try to test. To sign up for the International Patient Registry, please visit www.angioma.org/registry.

Please take a few minutes to register today. Without you, there can be no cure!

The DNA/Tissue Bank Reaches 200 Participant Milestone

We are pleased to announce that the Angioma Alliance DNA/Tissue Bank has reached 200 enrolled participants and has collected five years of clinical data for 50 of these individuals. Because of the cost of genetic testing, we have been selective in enrollment, limiting initially to those who were able to donate tissue and expanding to those with multiple lesions.

We would like to thank everyone who has been participating, and particularly those who have responded to requests for annual updates year after year. The DNA/Tissue Bank is the only central tissue bank supplying researchers throughout the world. The

clinical data is important to the work of these researchers but is also beginning to be mined for its own sake.

To find out more about the DNA/Tissue Bank and Clinical Database and to enroll, please visit www.angioma.org/dna.

Italian Angioma Alliance

Dr. Francesco Retta, Associate Professor of Cell Biology at the University of Torino in Italy has taken the initiative to create an Italian Angioma Alliance. From Dr. Retta:

"I was able to organize an Italian multidisciplinary research network on CCM disease. Right now, this network comprises five clinical and research centers located in five Italian regions (Piemonte, Lombardia, Toscana, Campania and Puglia). Other groups already have asked to be included.

"In addition, I organized the construction of an Italian web site on the CCM disease, named CCM Italia (www.ccmitalia.unito.it), and containing information about the disease and resources for patients, doctors and researchers.

"Right now, this web site is the only Italian resource for those affected by CCM disease and represents the aims and slogan of CCM Italia: 'Acting locally, cooperating globally.'"

Join the Board of Directors!

The Governance Committee is seeking individuals willing to contribute their time and energy to Angioma Alliance as members of the Board of Directors.

As part of the Board of Directors, you would play an essential role in continuing the success of the Angioma Alliance, helping set strategic goals and overseeing the direction of the organization. Members will serve on committees that best suit their talents and interests.

All are welcome to apply but in particular we are looking for individuals who have expertise in the following areas: finance, fund-raising, grant writing, non-profit development, and web design.

If you are interested, please contact: Kandance Weems Norris, Board Vice Chair, at: kandance@cumbyweems.com

Pathobiology of Cerebral Cavernous Malformations Scientific Workshop

For the first time, the Angioma Alliance Scientific Workshop will be held in Europe. This speaks to the increase in the number of labs in Europe that are conducting cavernous angioma research. There is at least one active research program in nearly every country; many have not been able to participate in past Scientific Workshops because of the expense and amount of time involved in traveling to the meeting in the United States. On November 16-18, we hope that all European labs will be represented at this year's Scientific Workshop in Chantilly, France. Based on early registrations, we know that American labs will continue to be well-represented. Our December newsletter will contain a summary of the important work that is presented.

Cavernoma Alliance UK & Genetic Alliance UK Provide Grants to Workshop

We are very grateful to Cavernoma Alliance UK and Genetic Alliance UK for their sponsorship of a significant portion of this year's Pathobiology of CCM Scientific Workshop. Each organization will be underwriting a half day of our two day event. Our Scientific Workshops provide the only opportunity for researchers to share their work face-to-face; past workshops have led to numerous collaborations that have driven the progress of research. The support of our sister organization Cavernoma Alliance UK and of the leading genetic disease umbrella group in the United Kingdom is invaluable to the success of this event.



Cavernoma Alliance UK Projects

Earlier this summer, CA UK embarked upon the sponsorship of two projects. The first is the writing of a document to help UK clinicians manage patients diagnosed with cerebral cavernous malformations. This project will run under the supervision of Dr Salman in Edinburgh, Scotland. A final report will be written by the Fall and a meeting established in London to review the project's guidelines before they are implemented. The cost of this exercise will be born by Genetic Alliance UK (GAUK) and CA UK.

The second project is the Seventh Annual CCM Scientific Workshop 2011 held later this year in Chantilly, France. In addition to the sponsorship of a portion of the meeting described in the article above, CA UK is also offering a limited number of junior UK researchers hotel accommodation and traveling expenses. In order to make this research project happen, CA UK has established its unique "Adopt a Researcher" program where individuals can support its efforts by donating through <http://www.justgiving.com/adopt-a-researcher>.

Traveling Awareness Bears Are Coming Soon

The Traveling Awareness Bears is an organization that sends out teddy bears to visit children all over the world. The teddy bears each carry a diagnosis and visit a child with the same diagnosis.

The Cavernous Angioma Bears will be Charlie and Charlise. Each bear will have a t-shirt stating its name and diagnosis as well as the Angioma Alliance little red man logo. Darla Clarke-Clayton will serve as the bears' steward, helping them make their journey. Visits from the bears will help children who have cavernous angiomas feel that they are not alone, and will raise awareness in the greater community as news spreads of their arrival.



You can request a visit at: <http://bit.ly/o2sOaM>.

Cavernous Angioma Patient Conference 2011 - Dallas

In late March, Angioma Alliance held its 6th patient conference in Dallas, Texas. Featured speakers included Dr. Duke Samson and Dr. Jessica Lee, neurosurgeon and neurologist at the University of Texas Southwestern, respectively, as well as Dr. Amy Akers and Dr. Connie Lee of Angioma Alliance. Attendees were able to get to know each other well in



Crystal Shaulis & Becky Schnee having fun together at the Patient Conference in Dallas.

conversation groups and during social time. In addition to gaining great information, I know that many friendships were formed that have carried on beyond the conference and that have helped members get through surgeries and other challenges. It is always great when we are able to get together.



A conversation group sharing experiences, gaining knowledge, friendship, and understanding.

We do not have our next general family conference scheduled yet. The New Mexico conference described in the next article is targeted at those with the Common Hispanic Mutation. When we schedule conferences, we typically look for locations that have a patient group that can provide help with organization. We also usually look for a city with a nationally recognized expert neurosurgeon who can present the latest information. If your city qualifies and you'd like to see a conference in your area, please contact us.

Patient Conference in Santa Fe Targets Common Hispanic Mutation

Another successful patient conference was held in Santa Fe in late August. This meeting was sponsored by the University of New Mexico as part of their active outreach program to individuals with the Common Hispanic Mutation.



In addition to holding this meeting, Dr. Leslie Morrison and Beth Baca, of UNM, and Joyce Gonzales, of Angioma Alliance New Mexico, have traveled the state and held multiple meetings in cities such as Taos and Las Vegas, New Mexico, to reach rural areas. A grant from Albuquerque-based La Tierra Sagrada Society has supported their efforts.

The University of New Mexico has partnered with Angioma Alliance and the University of California, San Francisco, on a major research project to track individuals with the Common Hispanic Mutation over 5 years using MRI and whole genome analysis. This is also the location where a short pilot study of the effectiveness of statins in reducing leakiness of cavernous angiomas is being conducted.

In June, 2012, UNM and Angioma Alliance will sponsor another patient conference for those with the Common Hispanic Mutation in New Mexico at a location to be determined. Please check back for more specific information about this conference as plans congeal. This conference will be followed by an executive committee meeting of researchers participating in the research mentioned above as well as others in a consortium of researchers investigating brain vascular malformations.

Creating Awareness & Raising Funds

Since our last newsletter, there have been a number of awareness events and fundraisers for Angioma Alliance. We are very grateful to the organizers and to everyone who participated in spreading the word and helping to keep our work going.

Poker Tournament Helps Angioma Alliance

In early September, Sean Scott and Lucky You Events hosted a poker tournament that raised \$450 for Angioma Alliance. Sean and his wife Tasha are long time Angioma Alliance members.

Sean underwent brainstem surgery to remove a cavernous angioma in December, 2003. Because of his deficits after his surgery, Sean could not do the sports he loved but instead started playing poker. He said, "I think the brain stimulation did wonders for my situation." This led to a new calling for Sean. "Although I will never be 100%—I had to learn to walk and talk again—I am better than many people because of the family that I have and the friends that I play poker with weekly."

"I started Lucky You Events to organize charity poker tournaments earlier in the year. It is a way to give back and help others in the way that I feel poker helped me." Sean would like to make this an annual event and hopes that Angioma Alliance members will come out to support the fundraiser in 2012 and beyond. Sean is also available to assist anyone in California who might want to organize their own charity poker tournament.

3-Year-Old's Family & Friends Raise Hope

In May, the family of 3-year-old Jocelyn Izzi created a Firstgiving page immediately before Jocelyn's third cavernous angioma brain surgery. The family raised nearly \$4,000 to help find a cure for the illness that is so dramatically affecting Jocelyn.

Jocelyn underwent successful brainstem surgery in May and has been steadily recovering at her home in North Carolina.

2nd Annual Angioma Awareness Fun Run

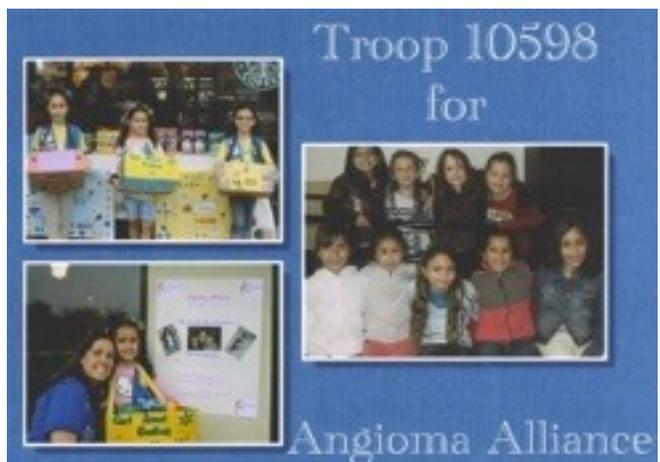
In March, as a lead-in to our patient conference in Dallas, Rachel Hart and Savannah Hollis organized the 2nd annual Angioma Awareness Fun Run. The turnout was wonderful and included many family and friends of conference attendees. The event raised \$4,000 and was enough to cover the cost of the conference itself. A great achievement!



"Parker's Posse," the friends and family of 12-year-old Parker Poole.

Girl Scout Troop Serves Up Cookie Cash

This spring, Girl Scout Daisy Troop 10598 from Pembroke Pines, FL chose to donate \$100 of their hard-earned cookie sale money to Angioma Alliance. Troop leader Bonnie Martis, her daughter Jennie, who is in the troop, and Bonnie's young son are all affected by cavernous angiomas. Each Daisy is now proudly sporting an Angioma Alliance pin on her vest.



High Fashion Silent Auction Very Successful at Jeweler in Durham, NC

In May, our own Chief Scientific Officer, Amy Akers, and Board of Directors Vice Chair, Kandance Weems Norris, worked with the University of North Carolina Chapel Hill to organize a silent auction of high fashion and other wonderful items to benefit Angioma Alliance and the UNC Neurology Department. The event raised nearly \$5,000. It was a lovely evening at Hamilton Hill Jewelers in Durham featuring food, wine, and good company. We would especially like to thank the Junior League of Durham and Orange Counties for their help as volunteers during the event.



The principal organizers L to R: Kandance Weems Norris, Shirley Boychuck whose granddaughter is affected, Amy Akers, and Mary Margaret, Director of Development for UNC Chapel Hill Neurosurgery.



Guests enjoying the high fashion fundraiser which raised nearly \$5,000!

Bridal Shop Donates Portion of Day's Sales

In April, Courtney Calciano hosted a fundraiser at Bella Lucia's Blanche Boutique in Rockaway, NY. The bridal and dress shop donated a percentage of their sales for the day. This turned out to be over \$1,000! Thanks to Courtney and Bella Lucia.

Shopping Online? Use igive.com

Through the years, Angioma Alliance has raised over \$2,000 through a simple action by our members. When you shop online, first go to www.igive.com, and use their link to get to your store. The first time you visit igive.com, you'll need to select Angioma Alliance as the charity you would like to support. After this, make sure you are logged in and go. Online retailers (including services like Expedia) donate a portion of your purchase to Angioma Alliance. This costs you nothing but an extra moment of your time. Add igive.com to you favorites or even download their toolbar—small purchases add up.

Use Justgive.com or [Firstgiving](http://Firstgiving.com) to Involve Your Circle

Since the last newsletter, the parents of Jocelyn Izzi raised almost \$4,000 for Angioma Alliance by creating a Firstgiving page and sending a request for donations to their social network. Similar pages can be set up using Justgive.com. Creating a page takes less than 30 minutes, yet, as the Izzi family demonstrated, can make a big difference for our work. As the end of the year approaches and giving season is nigh, please consider taking a few minutes to reach out to your family and friends. Likely, they have been looking for a way to help, but didn't know what to do. They can click and donate and know that they are making a difference.

Like Us on Facebook and Support a Facebook Cause

Angioma Alliance has a page on Facebook, at www.facebook.com/AngiomaAlliance/, that we use to transmit information. Go ahead and "like" us—we'll keep you up-to-date. If, like many of us, you spend a good amount of time on Facebook, you can take a few minutes to support us by donating to one of the many Causes that have been created to benefit Angioma Alliance.

After Recovering from a CA Stroke, Triathlete Looks to Undo 'DNF'

On June 3, 2006, Dirk Vlieks, an accomplished triathlete, was 22 miles into the biking portion of a half Ironman race in Hawaii. Out of the water after the 1.2-mile swim, Vlieks pedaled his bike up the Queen K highway. As he raced through the lava fields, he began to feel dizzy. At first he brushed it off, but when the dizziness got worse he knew something was wrong. He got off the bike and lay down by the side of the road.

Race official Jimmy Riccitello, who was coming by on the back of a motorcycle, stopped and called for medical attention. "I think I'm dying," Vlieks told Riccitello. "Tell my wife I love her."

Riccitello told Vlieks to close his eyes and relax. Riccitello's gut told him "it was really bad." As they waited for help, Vlieks became more unresponsive. He remembers nothing of the next six weeks.

Vlieks had suffered a major stroke, and subsequent complications almost killed him. He has spent the past five years relearning how to walk, talk and eat and drink.

And although he still has speech and balance problems and experiences double vision, on Saturday, June 4, the 38-year-old Vlieks returned to the Rohto Ironman 70.3 Hawaii race where he suffered the stroke to complete the 1.2-mile swim, 56-mile bike ride and 13.1-mile run.

"I want to get rid of that DNF," he said, referring to the acronym for Did Not Finish. "As well as finish the story."

At the time of the stroke Dirk and Kelsey, who grew up in Waterford, were living in Northern California, where she worked as a physical therapist and he as a computer consultant. The couple, who moved to Mystic last year, have twin 3-year-old girls.

Qualifies for Ironman

Vlieks was a former college tennis player who hoped to play professionally until a knee injury derailed his career. His rehabilitation program included swimming, cycling and running, so he decided to give triathlons a try.

In 2005 he qualified for the prestigious Ironman World Championships in Hawaii, where he posted a respectable time of 10 hours, 29 minutes.

Coincidentally, he qualified for the race by finishing among the top few competitors in his age group at the then-named Honu Half Ironman, the same race in which he would suffer the stroke a year later.

So the following June, accompanied by Kelsey, Vlieks returned to the Honu race to try to qualify again for the Ironman World Championships.

Kelsey looks for her husband

Kelsey was waiting for Dirk to finish the bike ride. When friends began finishing ahead of him she assumed he had a mechanical problem with his bike.

Shortly after, as she walked by the medical tent, she recognized his legs propped up on a cot. As a physical therapist, Kelsey knew right away that he had a stroke when she saw his flaccid left side.

An emergency room doctor said Vlieks had a large bleed in his brain and would have to be flown to a trauma center on Oahu. At the neurointensive care unit on Oahu, a doctor looked at Vlieks' brain scan. "I don't think your husband is going to survive. Have you talked about his wishes?" the doctor asked Kelsey.

"They thought he'd be in a 'locked-in state.' I knew he wouldn't want to live severely disabled," Kelsey said. "But I wasn't ready to give up on him."

The next afternoon he awoke from a coma and began to answer questions by blinking. When doctors removed his breathing tube two days later, he asked "What was my swim time?" He began eating. "We said, 'He's back. It will be OK,'" Kelsey said. The optimism was premature.

A few days later Vlieks developed pneumonia and a fever. Fluid began to build back up in his head and a shunt was put in. Soon he had surgery for deep vein thrombosis, a feeding tube caused him to go into respiratory distress and he underwent a tracheotomy.

On July 9, Vlieks was flown back to California and began his rehabilitation at the facility where Kelsey worked. She said it was good, though, to be back home and working with her colleagues on her husband's recovery.

"I had to start from ground zero for everything," Vlieks said. After six weeks of rehabilitation, Vlieks returned home. He needed constant attention. Friends and relatives helped Kelsey out, especially at night.

Walking, then running

In August the couple found out what had caused the stroke: a collection of abnormal blood vessels in his brain called a cavernous malformation. There was a good chance it could cause another stroke, so Vlieks decided to have surgery the next month.

Since then he has spent countless hours in therapy, which still continues. While he has made great strides, it takes a great deal of work to see even small bits of progress. Because he still has problems with fine motor skills, returning to his computer career has not been possible.

As for his double vision, Vlieks jokes that he's lucky he and Kelsey's twin daughters are not identical. "Then I'd be seeing four of the same one," he cracked.



Riccitello and Hawaii race director Diana Bertsh, who have become good friends with Dirk and Kelsey, said the couple has been an inspiration to them.

"Some people let injuries like this rule their lives. But the grace they have shown in handling this situation has been a model for me," Riccitello said. "It makes you aspire to handle tough things in your life the same way."

When Kelsey went back to work about seven months after the surgery, she said her husband would often walk the three miles home after therapy. That's when he began running to get a little extra exercise.

Despite not being able to go in a straight line and swallowing gallons of pool water at first, Vlieks also relearned how to swim.

He got back on his bike but fell off. The bike didn't get any use until last summer, when he finished the Niantic Bay Triathlon.

Despite his determination to go back and finish the race in Hawaii, Vlieks said his days as a serious triathlete are over. He just hopes to enjoy the training and racing he is able to do now. His focus, he said, is instead on something much more important.

"I want to walk with my girls. Kick the ball with them and ride my bike with them. I want to be a good father to them and a good husband to Kelsey," he said. "I can't do that unless I'm healthy."

Kelsey said she's not worried about her husband.

"I totally trust Dirk. I've been hard on him to get out there on the bike. He's done the swimming and the running. He's strong enough to get through this,"

she said. "And everyone working on the race will be looking out for him that day.

"It's going to be emotional. But I'll put on a good smile most of the time."

Kelsey and Dirk said they are both looking forward to getting back to the race despite what happened there in 2006.

"Hawaii has been a special place for us," Kelsey said. "It could have been much worse. It could have happened to him in the water or during those hundreds of miles on

the bike in the weeks before the race. He was looked after that day.

"So we need to say 'thank you' to this place."

And what will Vlieks do when he passes the 22-mile mark on the bike course?

"I'll just give it a kiss and continue on," he said.

Joe Wojtas

Published in The Day, May 31, 2011

Postscript: on June 2nd, Dirk Vlieks finished his story by completing the Rohto Ironman 70.3 Hawaii in a total time of 6:57:53. A video interview with Dirk and Kelsey Vlieks is available on The Day website at <http://bit.ly/rwgJWY> in the Related Multimedia section.



Cavernoma Alliance UK Update

5th Cavernoma Alliance UK Forum

Sunshine poured through the windows of the Orion Suite, Grange Holborn Hotel, as CA UK held its Fifth International Cavernoma Alliance UK Forum on 4 June 2011. Members came mainly from the UK, but the 84 participants were also from Ireland, Sweden, Spain and America (In the last newsletter, I promised to wear a Stetson. The hat was in attendance although, upon advice, I did not wear it!) All the presentations were recorded by Frank Gent, Trustee, and, thanks to Paul Oldham (the most patient of webmasters) they now appear on the CA UK website at: <http://www.cavernoma.org.uk/opus362.html>

Young Persons' CaverHub (YPC)

As mentioned in the November, 2010 newsletter, CA UK wanted to establish a Young Persons' CaverHub (YPC) in April 2011. Organized by Frank Gent Brana Thorn and myself, CA UK managed to secure funding from the Roald Dahl Marvellous Children's Charity.

Behind CA UK's funding application lies an interesting neurological link. Dahl's son, Theo, suffered brain injury as a baby in a New York traffic accident and, with Dahl and his family returning to the UK, Theo was seen by the Great Ormond Street Hospital. Due to complications with the shunt fitted for his hydrocephalus, Dahl, along with Stanley Wade, a hydraulic engineer, and Kenneth Till, a neurosurgeon, pioneered a shunt. Although it was patented and went into production in 1962, Theo's condition by then had stabilized and the shunt was fortunately never needed by its intended recipient. However, several thousand children did benefit from the shunt's introduction.

Jessica Tournier, a pediatric neurosurgeon from the Great Ormond Street Hospital, National Hospital for Neurology and Neurosurgery, presented information to the parents at the Caverhub. In addition, arents received presentations from two support organizations, Contact a Family, and Genetic Alliance UK. Then both the children and their parents went to lunch at London's Rain Forest Café and visited the London Aquarium. This meeting was so successful that we have another YPC scheduled for 22 October which includes a talk by Mr. Christopher Chandler, consultant pediatric neurosurgeon, from King's College Hospital, London, a visit to the local Pizza

Express and the Science and Victoria & Albert museums.

Other News

For over four years, CA UK occupied my landlady's spare room. But this space was needed again forcing the charity into finding a new home. To rent an office in these financially challenging times was demanding. But with its membership expanding daily, CA UK must continue to exist. And so, at the beginning of September, we moved into an office in Somerleigh Gate, central Dorchester.

CA UK has also developed a new database of its members. As well as reducing paperwork, another advantage the new database is that it is now possible for CA UK to instantly contact all members with our monthly email shots. In addition we can be regionally selective—sending out emails only to those in a particular geographic region—useful for CaverHubs.

Earlier this summer, CA UK embarked upon the sponsorship of a document written to assist UK clinicians manage patients diagnosed with CCM. Under the supervision of Dr Salman in Edinburgh, Scotland, the research costs were born by ourselves and Genetic Alliance UK (GAUK). CA UK hopes that the final paper will be presented by Dr. Salman at the Seventh Annual CCM Scientific Workshop 2011 held this November by Angioma Alliance in Chantilly, France. A day of this workshop will be jointly funded by CA UK and GAUK.

I would like to thank the treasurer of CA UK, Jon Anderson, who is standing down after four years faithful service as a volunteer. An unassuming and generous man, Jon has helped me steer the CA UK ship through rough seas. I shall miss his guidance and advice. Jon releases the treasurer's reigns to our new board member, Tim Millward FCA. I'd also like to welcome Dr. Simon Temple, a long-standing member who takes up the position of trustee on the board.

Partly a result of an excellent training day, I find the Board of Trustees (currently Alison Garwood, Frank Gent, and Ahmed Toma) to be united, very supportive and strong. And with their expertise, I know CA UK will continue to grow.

Ian Stuart

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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- Michel Berg, MD, University of Rochester Medical School
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- Douglas Marchuk, Ph.D., Duke University Medical Center, Dept. of Molecular Genetics and Microbiology
- Leslie Morrison, MD, University of New Mexico Medical School
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How You Can Help

Your contributions will help fund conferences and forums, increase research, and enhance outreach and support efforts. Our pins, car decals and wristbands support the mission and growth of Angioma Alliance. Share these meaningful gifts with your friends and family.

Each donation of \$10 or more will come with a CCM lapel pin as a thank you gift. Our “little red guy” pin is a wonderful way to increase awareness of cerebral cavernous malformation (CCM). Increasing public awareness can go a long way toward increasing research funding and improving quality of life for those with cavernous angioma. Each pin comes with cavernous angioma business-size information cards that can be handed to anyone who might have questions.



Angioma Alliance also offers a wide range of apparel and other items featuring the Angioma Alliance logo. There are t-shirts, sweatshirts, hoodies, mugs, stickers and much more available. You can find these items in our Café Press store. To purchase Angioma Alliance merchandise, go to our web site and click the Store link at the top of the page.

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.

We Need You: Angioma Alliance needs volunteers in many areas. If you have time to give, please visit www.angioma.org/volunteer

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