



Angioma Alliance Newsletter

Without You, There Can Be No Cure

IN THIS ISSUE

1. WITHOUT YOU, THERE CAN BE NO CURE
2. 6TH ANNUAL PATHOBIOLOGY OF CCM SCIENTIFIC WORKSHOP
3. NEWS
5. CAVERNOMA ALLIANCE UK UPDATE
6. Q2-3 2010 ANGIOMA ALLIANCE DONORS
8. ABOUT ANGIOMA ALLIANCE

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

We've known for some time that there are just a few things that are needed to find a better treatments, and perhaps even a cure, for cavernous angiomas:

- Better animal models of the illness
- Your willingness to participate in research
- Your willingness to organize public awareness events
- Your financial support to continue this work

Researchers are doing their part to address the first need. At this year's scientific workshop, three labs presented new mouse models. These models are much closer to the human form of the illness than any previous models and will be essential to the initial testing of medications.

The rest is up to you.

This is the time that we all need to challenge ourselves and do what it takes to cure this illness. There will be no cure without everyone's willingness to participate. It seems that very few people with cavernous angioma have actually been diagnosed (see our last newsletter issue for details). If you carry the diagnosis, you can't just wait for a cure. It won't happen without your help. Working together, we can build an army of involved members that will lead to greater awareness, more accurate diagnosis, better research resources, and better treatments.

There are three essential actions you can take:

Sign up for the patient registry. We can't emphasize enough how important this is. Our Chief Scientific Officer Dr. Amy Akers presented the patient registry at the scientific workshop to the entire research community and was met with great enthusiasm. To those already participating, thank you! Please look out for requests to update your profile to address new research questions.

Join our growing group of members who are organizing public events. Because they are public, these events raise awareness and increase the potential for more people to receive an accurate diagnosis. The events also raise badly needed funds for our work. Our new Community Hub (see page 3) is the perfect place to keep up on the news of events planned in your area and to find those members in your area who can bring their talents to your event. Many hands make light work. Email info@angioma.org to offer your time and for step-by-step help in planning.

Donate. Donate your money, your time, and your skills. We need them all to find a cure.

This issue of the newsletter presents a preview of many of the activities that you can build upon as we move into next year. Let's make 2011 a year of involvement. You are an essential part of the community that shares the experience of knowing the impact of cavernous angiomas on human lives. Please do what you can. Without you, there can be no cure.

Connie Lee

Scientific News

6th Annual Pathobiology of CCM Scientific Workshop

The 2010 Pathobiology of CCM Scientific Workshop was held on November 1st and 2nd in Washington, DC. More than 50 scientists, physicians and students traveled from across the United States, Canada, Europe and South America to attend the workshop. This is the only scientific conference focused entirely on the disease biology of Cavernous Angioma. The CCM workshop is also unique in that it combines clinical and basic science audiences, and nearly 30% of the attendees were trainees.

For the 2010 Workshop, Angioma Alliance aimed to focus on facilitating training of the next generation of scientists and clinicians. This effort was realized by providing travel stipend grants to four outstanding trainees (either students or post-doctoral trainees). In addition to attending the workshop, award winners were required to give an oral presentation of their research projects. This year's award winners include:

Nina Gonzales is a 4th year medical student at the University of New Mexico where she is working under Dr. Leslie Morrison to investigate the genetic lineage of the Common Hispanic Mutation. Nina's genealogical research provides evidence to trace this specific genetic mutation back to a founding grandparent who immigrated to New Mexico in the 1500s. The dissemination of this mutation through more than 17 generations of New Mexicans accounts for the high prevalence of Cavernous Angioma in the American Southwest.

Colin Josephson, MD, MSc, is a post-doctoral fellow who works with Dr. Rustam Al-Shahi Salman at the University of Edinburgh, Scotland. Dr. Josephson is currently conducting a population-based study to investigate the risk of epileptic seizure after the diagnosis of a cavernous malformation of the brain.

Yasir Kahn, MD, is a post-doctoral fellow who works with Dr. Leslie Morrison at the University of New Mexico. Dr. Kahn's presentation discussed his current research that aims to investigate whether clinical symptoms and outcomes are associated with lesion burden (number of angiomas) in familial Cavernous Angioma. By retrospectively reviewing imaging and medical records for 150 patients, Dr. Kahn's research shows that in general, a fewer

number of lesions is correlated with a better clinical outcome.

Dave McDonald is a 3rd year graduate student in Doug Marchuk's lab at Duke University. Dave has been working to develop a new mouse model for Cavernous Angioma that is based on the genetic mechanism for the illness and that can be used to investigate potential drug treatments.

An additional Award was offered to Dr. Luca Goitre from the University of Torino, Italy; however, Dr. Goitre was unable to attend the workshop due to personal reasons. Dr. Goitre planned to present on his work related to reactive oxygen species and the CCM1 gene. (More information about Dr. Goitre's research can be found on our blog.)

The presentations described above were integrated into a scientific agenda containing 25 talks divided among sessions on Human Genetics, Vascular Biology, Molecular Biology, Clinical, and Mouse Models. There was considerable discussion about the function of the CCM1, CCM2 and CCM3 proteins, how they work together to maintain the proper structure of blood vessels, and how this structure is disrupted in cavernous angioma lesions. This year we saw the first mouse model for the CCM3 form of the illness and new, more robust mouse models for both CCM1 and CCM2 have also been created. These mice develop angiomas that are similar to the human condition and have become an essential tool for drug treatment studies that are now currently underway.

Many discussions at this workshop addressed the question of, "are we ready for a clinical trial?" While there has been tremendous progress this past year in the basic science, we are not ready to move to a clinical trial for either statins or Fausadil. The published research for these compounds and their affect on blood vessel structure is very promising; however, more pre-clinical work is needed to demonstrate the effects of these drugs on Cavernous Angioma lesions to determine how the drugs alter lesion development and/or bleeding. The new mouse models are being used as a surrogate for human patients to see how these other potential therapeutics affect the disease outcome. This is where the new animal models become very important. This work is the next step toward establishing a treatment protocol, and is currently being performed in a variety of labs.

Amy Akers

News

The Community Hub is Born

Visit Angioma Alliance at www.angioma.org/community and become part of our new Community Hub. You'll find a new and improved Community Forum, a place to ask questions and talk with others who are affected by cavernous angiomas. But, we haven't lost those years of old posts; you'll also find archives in the Hub.

If you'd like the news more frequently than what you get from this newsletter or if you'd like stories with more depth, as well as much more research news, visit our new blog at www.angiomacommunity.org/blog. Do you prefer your news short and sweet? Subscribe to our Twitter feed. On Facebook, you can "like" our Page and join our Group.

The Community Hub also includes a link to our Peer Support program. This is an established program in which we match newcomers with trained volunteers who provide one-on-one support.

Finally, the Hub is rounded out with our collection of Member Stories from 2003 to the present. If you've spent time reading these stories, you know how enlightening and comforting it is to read about others who have experienced living with cavernous angiomas.

Our community is vibrant, and our website is the heart of what we do. We hope that you will visit often to get up-to-date, ask questions, and share your experiences.

Angioma Alliance Weekend in Dallas

Mark your calendars for March 25 - 27, 2011. These are the dates for the Angioma Alliance weekend we're holding in Irving, TX, near Dallas. Here are the highlights:

Friday, March 25th

Evening: get-together at Savannah Hollis' home

Saturday, March 26th

Morning: Fun Run/Walk at T.W. Richardson Grove Park to benefit Angioma Alliance with lunch at the park. We expect citizens of the greater Dallas area to participate in the event. It would be wonderful to have a good turnout of Angioma Alliance members to raise awareness of the illness.

Afternoon: Presentations by Dr. Duke Samson, neurosurgeon, and Dr. Jessica Lee, neurologist, from the University of Texas Southwestern, as well as

smaller conversation groups to allow us to get to know each other. This portion of the meeting will be held at the Hyatt Place Dallas/Las Colinas.

Evening: On your own to rest or get out in the vibrant Las Colinas area.

Sunday, March 27th

Morning: Presentations by Angioma Alliance Chief Scientific Officer Dr. Amy Akers and a speaker to be determined as well as a second round of conversation groups. This will again be at Hyatt Place.

If you are planning to attend and have a request for a particular topic to be covered, please let us know.

We will have registration forms online very soon. Registration for the entire weekend with the exception of the Fun Run/Walk will be \$45 per adult. Registration for Fun Run/Walk participants is \$20 and includes a t-shirt and the satisfaction of knowing you are helping Angioma Alliance drive research for a cure. We can help you to find a childcare provider while you are attending any of the conference activities.

We have not reserved a block of rooms at any particular hotel in order to allow the widest range of choices for attendees. That said, at this time, Hyatt Place offers King, Double, and King wheelchair accessible suites with continental breakfast for \$98 a night with internet pre-purchase, or for \$109 with regular purchase. Hyatt Place offers a complimentary Dallas Fort Worth airport shuttle and a complimentary shuttle to anywhere within a 5 mile radius of the hotel, including Savannah Hollis' home for the Friday evening get-together and the Saturday morning Fun Run/Walk. The hotel website is <http://lascolinas.place.hyatt.com>.

What Have We Learned from the DNA & Tissue Bank?

If you have participated in the DNA & Tissue Bank, thank you! You have given a tremendous resource to researchers who are using your DNA, tissue samples and clinical information to make amazing advances in research.

Amy Akers has written an article showing how much has been accomplished through this resource. Visit our blog to read about some of the projects being explored by researchers:

www.angiomacommunity.org/blog/?p=151

Middle School Girls Rule!

One Saturday this summer, Applebee's restaurant in Allentown, Pennsylvania, was open unusually early to host the Scarves4CCM1 Flapjack Fundraiser to benefit Angioma Alliance. What is Scarves4CCM1? It's a group of middle school girls organized by Kylie and Alexis Buck, twins who are affected by cavernous angiomas. The purpose of the group is to raise money for cavernous angioma research. Even before the Flapjack breakfast, the girls had raised \$2,000 by selling scarves that they and their friends had knitted.



The Flapjack Fundraiser was the girls' first venture into an event. They approached their local Applebee's who allowed them to take over the restaurant for two hours, serve flapjack breakfasts, and raffle items donated by local businesses. Applebee's provided a chef and the girls provided everything else. They pounded the pavement in Allentown soliciting businesses for gift certificates and other give-aways. They sold tickets to friends, family, and schoolmates. Over 100 people attended the breakfast and each left with a belly full of flapjacks and a smile. The Scarves4CCM1 Flapjack Fundraiser raised \$2,400 for Angioma Alliance.

Alexis, Kylie and their friends aren't stopping. Since the Flapjack Fundraiser, they've submitted an entry for the Pepsi Refresh project, sold scarves at a Fall Festival (another \$627 raised!), and signed up Angioma Alliance for their local Macy's Shop for a Cure day. We are very grateful for their dedication and for the example they are setting for us all.

Help the Scarves4CCM1 girls help Angioma Alliance. We invite you to buy a scarf (or a dozen) by emailing Samantha Scarf, their mascot, at scarves4ccm1@yahoo.com. The girls offer finger knit styles for \$3 each and hand knit styles for \$10-12 each. It's not too early to start shopping for the holidays!

Recent Fun Runs and Houston's Cavernous Angioma Awareness Day

Two 5K Fun Runs were held in September to benefit Angioma Alliance. On a freezing cold September 11th, Brooke Mueller and 100 of her closest friends ran up the trails of Marquardt Park in Ogden, Utah. For their efforts, they were treated to views of the beautiful valley below and the satisfaction of knowing that they were helping the thousands of people with cavernous angiomas. Brooke has become a local celebrity, commenting that a stranger recognized her as the "Angioma Girl" a few days after the race. She is excited about organizing the Fun Run again next year.

September 25, 2010 was proclaimed Cavernous Angioma Awareness Day by the mayor of Houston, Texas, thanks to the efforts of Delia Candelaria, mother of Julien Bruce. Delia organized a 5K Fun Run with a party vibe. A DJ kept the energy going for runners who made it to the finish line. Local businesses provided eats, drinks, and prizes to complete the day.

Thank you to these two wonderful women and all the people who helped them to make these events memorable.



Delia Candelaria, her son Julien Bruce, Rachel Hart, and Savannah Hollis with the Houston Cavernous Angioma Awareness Day Proclamation



Cavernoma Alliance UK Update

Autumn in Britain for Cavernoma Alliance UK is as much about preparation for 2011 as coping with all of 2010's activities, which include an increase in membership of over 40 diagnosed cavernoma patients since my last update.

We have continued with our CaverHubs, which are occasional meetings for our regional members to receive updated information from neurosurgeons, neurologists or geneticists throughout the UK. CA UK has held CaverHubs in Liverpool with a neuropsychologist, Dr Anita Rose; Leeds with Mr Van Hille, consultant neurosurgeon and Dr Jenny Thomson, geneticist; and London with Professor Dr Helmut Bertalanffy (photo below), formerly from the University of Zurich, Switzerland and recently returned to Germany.



London had the best attendance with the Old Boardroom at the National Hospital for Neurology and Neurosurgery, Queen Square, London positively bulging with over 60 members and their partners from all corners of Europe.

CA UK has maintained this CaverHub program with the help of fundraising from half marathons run for us by members. Karen Axtell ran the Royal Parks Half Marathon in October, and Tabitha Bushill, one of our trustees, who raised £4,000 last year shaving her head prior to her awake craniotomy, raised over £1,000 for running the New York Marathon in November, a year on from her operation.

In a previous update, I mentioned how six-year-old Finlay "Fighter" Freeman had recovered successfully from his operations. Due to a number of setbacks, Finlay found himself again in the operating theatre. But Finlay fights on, and here is a picture of

him with Rio Ferdinand from the Manchester United football team, whom he met while appearing on a morning television program.



During the autumn, I represented CA UK at Dr Salman's Scottish Audit of Intracranial Vascular Malformations 10 Year Celebration, which provided me with a wonderful opportunity to interface with 160 other people consisting of patients, surgeons, neurologists and support groups. I also hope to attend a Parliamentary Reception hosted by the Neurological Alliance, together with Frank Gent, one of our trustees.

2011 will see the inaugural introduction of CaverClinics, an outgrowth of the CaverHub program aiming towards stand-alone clinics specializing in cavernomas. These will be free of charge for members, and will be run by Mr Neil Kitchen, for neurosurgery, and Dr Salman, for neurology. An exciting new development will be the Young Persons' CaverHub (YPC) which will include a speaker from the Great Ormond Street Hospital for Children.

Look out for details in the next update about our new board member, our participation in International Brain Awareness Week, Society of British Neurosurgeons, Association of British Neurologists, and, of course, the Fifth Annual International Forum of Cavernoma Alliance UK at the Grange Holborn Hotel, which, I am sure, our American friends will be attending next year on June 4, 2011. Mark your calendars now for this unique event.

Ian Stuart

Angioma Alliance Donors April 1, 2010 through September 30, 2010

In addition to the donors listed below, we would like to thank those who supported us by participating in fundraising events.

Beacons (\$5000+)

The Capital Group Companies
Charitable Foundation
MadoroM Vineyards
Charmean and Robert Neithart
Brad and Liz Peters
James and Theresa Triguciro

Leaders (\$1000-\$4999)

John and Lori Abrams
Andy and Marissa Amador
Alex and Monique Rogers
San Joaquin Bit Service
KS Industries
Luigi's, Bakersfield
Beau Vigne
Brian Blewer
Chad Manning
Terry Maxwell
Teddy Phillips
Steve Roland
Carl and Sue Sciandri
Sara Sukalich and Matt Mingione
Ray Watson
Dan Weiss *in honor of David Jacob Weiss*

Benefactors (\$500-\$999)

Arlington Area Newcomers Club
Karen Asbury and family *in memory of Mitch Asbury*
Meir and Kathy Brown
Mike and Jerri Brown
Goosecross Cellars
Randy and Lisa Harden
Joan and Skinner Hardy
Erin McRoberts *in honor of Glenn Babich*
Alex and Nikki Mejia
Robert O'Connell
Promo Planet
Alicia Kelley Raymond
Kevin and Tuesdy Small
Bill and Irene Thomas

Community Builders (\$250-\$499)

Applebees, Allentown, PA
Jonas and Lisa Batten *in honor of Rebekah Batten*
Kathy Corsi *in memory of Julie Posler*
Antoinette Dansbury and family *in memory of Louis Dansbury*
Fontanella Family Winery
Phil and Ian Fox
Golf Club of Dallas
Joyce and Greg Gonzales
Laura Hebard *in memory of Mitch Asbury*
Douglas and Christina Martin
Rosewood Crescent Hotel
John and Monaco Sacco
Nitza Terranova

Partners (\$100-\$249)

Comeka Anderson
Donna Arnaud
Artesa Vineyards and Winery
Ray and Joyce Asbury *in memory of Mitch Asbury*
Claire and Richard Brooks *in honor of Dr. Dan, Monica and Scout Brooks*
Elizabeth Burt *in memory of Tonya Donahoo*
Carmack's Food Services
Christine Castellano
Chipotle Mexican Grill, Alameda, CA
L. and G. Cooper *in honor of Ronnie Bince*
John and Linda Corsi *in memory of Julie Posler*
Tiffany and Vern Daniel
B.L. Goetz *in honor of Ronnie Bince*
Evelyn Gonzalez
Melodie and David Graber *in honor of Ronnie Bince*
Ruta and Harold Hance
Maureen Heath
Imbibe
Italian American League, Alameda, CA
Jean and John Jacon
Juan's Place, Berkeley, CA
Jamie Kervin
Judy LaDuc
Martha Laham *in honor of Ronnie Bince*
Diane Maldonado *in honor of Ronnie Bince*
Lawrence Marino

Michael and Ramona Marshall *in honor of Ronnie Bince*
Brian Matlock
Microsoft Matching Gifts Program
Nicki and Kenneth Milin
Paul and Bunni Jo Miller
Danny Joe and Ruth Moseley
Janice Nott
Llelanie Orcutt
Elaine Palmer
Luba and Ken Parsons
Mark Peña *in honor of Ronnie Bince*
Stephanie Pignataro
Deborah Porterfield *in honor of Ronnie Bince*
Bridget Rae
Ken and Mary Reeb
John Regan
Renteria Winery
Ron and Amy Schechter *in memory of Mitch Asbury*
Charlotte and Joe Sestito *in honor of Ronnie Bince*
Sandi Souza *in honor of Jake and Sam Neuman*
Robert Studebaker and Mybell Adjunta
Supercuts, Allentown, PA
Nancy Taylor *in memory of Richard Taylor*
Adelle Wood
Mike and Ranae Woods *in honor of Chelsea Woods*

More Ways to Help Angioma Alliance

Donate to Angioma Alliance via iGive.com

Here's an easy and free way to help Angioma Alliance. When you shop online, use www.igive.com. It's simple to register at igive.com and name Angioma Alliance as your preferred charity. The first time you make a purchase using igive.com, Angioma Alliance receives \$5. After this, a percentage of the purchase price goes to Angioma Alliance. Remember to bookmark igive.com as we start moving into holiday seasons. Tell everyone you know!

Shop at Tom Thumb and Randall's Grocery Stores

Tom Thumb and Randall's grocery stores will donate \$1 to Angioma Alliance for every \$50 you spend on groceries through the end of the year. All you have to do is link your reward/remarkable card to the ID 12518 on the store's website. Easiest way to make a difference!

Supporters (\$1-\$99)

Alameda Theater Cineplex and Cafe
 Linda Antognini
 Eleanor Arnold *in memory of Janet J. Spade*
 George and Barbara Atanasoff *in honor of Ronnie Bince*
 Auteur
 John and Nancy Axt
 Norma Barber *in memory of Janet J. Spade*
 Judith and Woodrow Barnes *in honor of Ronnie Bince*
 Jennifer Beach
 Pamela Bernstein
 Carmen Berrios
 Boopa's Bagels, Fort Worth, TX
 Donovan Blazak *in honor of Ronnie Bince*
 Deborah Brandon
 Burrito Grille, Allentown, PA
 Robert and Ginger Busbee *in memory of Tonya Donahoo*
 Courtney Button
 Theresa and Gary Calibey *in honor of Christine Castellano and Mark Seymour*
 Marsha Cauthen
 Kenneth, Mary Lou and Sandra Cayocca *in honor of Ronnie Bince*
 Frank Chille *in honor of Jeff Jin*
 Barbara Coapman
 Linda Coleman *in honor of Ronnie Bince*
 Chris Crowder
 Katherine Davenport
 Kristen Dehn
 Tamara Delaporte
 Mike and Patti DesRocher *in memory of Louis Dansbury*
 Direct Cleaner and Alteration, Hockley, TX
 Bill and Janice Doan *in memory of Tonya Donahoo*
 Les Dubnick
 Dunkin' Donuts, Allentown, PA
 Cleo Dunn *in honor of Julien Bruce and Delia Candelaria*
 Mr. and Mrs. Jerry Dunn
 Josh Early
 Karen Farler *in honor of Ronnie Bince*
 Judy and Karl Farris *in honor of Donald Adams*
 The Fikes and Dmytryszyn Family *in memory of Louis Dansbury*
 Courtney Flynn
 Pamela French
 Friendly's, Allentown, PA
 Grant Fuller *in honor of Ronnie Bince*
 Yvonne Gabel *in honor of Diane Amundsen*
 Henry and Roberta Gallegos
 Donna Garcia de Quevedo
 Steven and Kimberly Grafuis *in memory of Louis Dansbury*
 Thomas and Joan Graney
 Lester and Marcia Grube

Herbert Hagen
 Joan and Skinner Hardy *in memory of Gary Burwell*
 Erich and Alice Hass
 Thomas Hearity
 Shirley Heller and Edward Zabinsky *in memory of Mitch Asbury*
 Debra Hernandez
 Elizabeth Hish
 Brad and Rebecca Hogue *in honor of Jake and Sam Neuman*
 Savannah Hollis
 David and Ruth Hopkinson
 Hungry Hunter, Bakersfield, CA
 Inside Scoop, Coopersburg, PA
 Matthew Ittycheria
 Sidia Jimenez
 Judy Johnson *in honor of Ronnie Bince*
 Patricia and William Johnson *in honor of Ronnie Bince*
 Jeff Kalbfleisch
 Michael Kahn
 Leslie Kalish *in honor of Ron Schechter*
 Lenin Kamma *in memory of Jenae Gallegos*
 Linda Keaveney *in honor of Ronnie Bince*
 Kick It Poker Club *in memory of Louis Dansbury*
 David and Cathy Kiley *in honor of Ronnie Bince*
 Susan and Curtis Knapp
 James Korth
 Michelle Kuhlman *in memory of Mitch Asbury*
 Mercedes Labindalaua
 Raven Lathrop
 Win and Jo-Ann Latta *in honor of Ronnie Bince*
 Debi Laurin
 Sandra and Stephen Lillegard
 Loard's Ice Cream Parlor, Alameda, CA
 David Mairs
 Andrew Manthei
 Joanne De Jesus Marcajida *in honor of Ronnie Bince*
 Lilly Martin *in memory of Jenae Gallegos*
 Virginia McClenney *in memory of Mitch Asbury*
 Alvin Mente
 Ken and Mary Jane Miera *in honor of our grandchildren*
 Stanley and Leslie Miller
 Lauren and Tim Milligan *in memory of Julie Posler*
 Mexico Lindo, Pleasanton, CA
 Stanley and Leslie Miller
 Lorne Moseley
 Beverly Ollis
 M. and O.R. Ortiz
 Connie Pace
 Brenda Perkins

Ned and Margaret Perry *in honor of Connie Lee*
 Melanie Pistiolas
 Gary Pleason
 Rockfish Restaurant, Las Colinas, TX
 Linda Rosenbloom
 Mike and Cathy Ruan *in memory of Sonny LoBue*
 Ruby Tuesday, Allentown, PA
 Sal's Pizza, Allentown, PA
 Ron and Amy Schechter *in memory of Julie Posler*
 Bonnie Shive
 The Shoe Box, Allentown, PA
 Shula's Steakhouse, Center Valley, PA
 Carmela Somers
 Patricia and Gene Stallings *in honor of Ronnie Bince*
 Staples, Allentown, PA
 Starbucks, Allentown, PA
 Richard and Teresa Starr
 Susan Stewart
 Monica and Andrew Sullivan
 Brandon and Cristina Svec *in honor of Cristina Svec*
 Bonnie and Gene Termini
 Barbara Tomasian *in memory of Julie Posler*
 Jennifer and William Torres *in honor of Jennifer Torres*
 Brenda Trujillo *in memory of Jenae Gallegos*
 Nina Walsh
 Susan and Kevin Waterloo
 Alice and Robert Watkins *in honor of Ronnie Bince*
 William Weber
 Jim Wilson

Upcoming Events

In the first half of 2011, awareness and fundraising events are being planned in the following areas:

- Bakersfield, CA
- Irving, TX (March 26)
- Durham, NC (May 1)
- Chicago, IL
- Miami area

Dates and specific locations will be posted on our blog as they become available. Please email info@angioma.org if you'd like to be involved in one of these or if you'd like to talk with us about planning your own event.

Who We Are

Angioma Alliance is a non-profit, international, patient-directed health organization created by people affected by cerebral cavernous malformations (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

 866-HEAL-CCM (Toll free)
 757-623-0615
 info@angioma.org
 www.angioma.org

Angioma Alliance Board of Directors

- Connie Lee, Psy.D., President
- Karen Asbury, Treasurer
- Christine Castellano, Secretary
- Kristen Dehn, MS, Director
- Sara Sukalich, MD, Director
- Kandance Weems-Norris, JD, MBA, Director
- Rachel Hart, Director
- Savannah Hollis, Director

Scientific Advisory Board

- Issam Awad, MD, MSc, FACS, University of Chicago Pritzker School of Medicine
- Michel Berg, MD, University of Rochester Medical School
- Jose Biller, MD, Loyola University Chicago Stritch School of Medicine
- Eric Johnson, Ph.D., ACireGeneTics, LLC
- Douglas Marchuk, Ph.D., Duke University Medical Center, Dept. of Molecular Genetics and Microbiology
- Leslie Morrison, MD, University of New Mexico Medical School
- Rustam Al-Shahi Salman, MA, PhD, MRCP, Western General Hospital, Edinburgh, Scotland

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

The Angioma Alliance Newsletter is a quarterly publication of Angioma Alliance

Editor: Kirk McElhearn, kirk@mcelhearn.com