



Summer 2008

Angioma Alliance Newsletter

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Congressman Tom Udall Introduces Cavernous Angioma Resolution into U.S. House of Representatives

On May 13, 2008, Congressman Tom Udall of New Mexico introduced House Resolution 1193 calling for increased cavernous angioma awareness, education, and research. Congressman Udall's effort is a direct response to the requests of the Angioma Alliance community. We must try to support him in any way that we can. You can read the text of the resolution and Congressman Udall's statement on page 4 of the newsletter. While his focus in the resolution is the impact of the illness in New Mexico, any action that results will benefit everyone affected by cavernous angiomas. We are very grateful to Congressman Udall for bringing cavernous angiomas to national attention.

We need your help to keep this resolution moving through Congress. It is currently assigned to the House Committee on Energy and Commerce, which is the committee that considers health legislation. The resolution needs the support of other representatives—we need to ask them to sign on as co-sponsors. You can help by phoning and faxing your House representative, sharing how cavernous angiomas have affected you or someone you love, and

asking for their support. You can find a customizable template letter and a phone script from the home page of our website as well as instructions for finding your representative's contact information.

You can also help by thanking Tom Udall for his help. Please fax a note to (202) 226-1331 or call at (202) 225-6190 to express your appreciation. His office has put many hours into drafting this legislation—we need to acknowledge how important their efforts are to us.

Finally, you can fax (202) 225-8671 or call (202) 225-6161 Congressman Joe Baca, the chair of the Congressional Hispanic Caucus (CHC), to stress the importance of the support of the CHC to this legislation.

Even without moving forward, the introduction of this legislation has already born fruit. Joyce Gonzales was interviewed on radio, an article is being written about the illness in the Albuquerque Alibi, and the New York Times has expressed an interest in updating the story about cavernous angioma they published in September.

Connie Lee

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

News

Angioma Alliance Receives Community-Centered Family Health History Grant

Angioma Alliance has received a grant from the Genetic Alliance as part of their Community Centered Family Health History project. With this grant, Connie Lee, medical student Nina Gonzales, scientific advisor Dr. Leslie Morrison, and Angioma Alliance New Mexico coordinator Joyce Gonzales will work together to produce and distribute two new booklets. The first booklet “A Guide to Family Health History” provides information for individuals who are interested in collecting family health history information. The second booklet “A Guide For Understanding Genetics and Health” provides more general information explaining the role of genetics in several common illnesses as well as in cavernous angioma. As a pilot project, the booklets will be distributed along with more specific cavernous angioma brochures at La Familia Health Center and during Cavernous Angioma Awareness Week in Santa Fe, NM, and in the genetics and pediatric neurology departments at the University of New Mexico.

Family Conference 2009

The Angioma Alliance Family Conference 2009 will be held April 3rd through April 5th in the San Francisco Bay area. The conference will feature neurosurgeon Dr. Michael Lawton and neurologist Dr. Wade Smith, both from UCSF. Additional program details will follow, but we are planning a larger number of special break-out sessions than in previous conferences to allow a wider variety of offerings. Some ideas include sessions on alternative treatments for pain, vision therapy, and mindfulness meditation. Please check our website in the coming week for hotel reservation information. We are considering offering childcare for this conference if there is demand—please let us know if you’d like to bring your children along.

DNA/Tissue Bank and Patient Registry: We’re On Our Own Now

The Angioma Alliance DNA/Tissue Bank and Patient Registry has officially become an independent biorepository. We have separated from the Genetic Alliance BioBank both in order to save money and to move our clinical database development along more quickly. Our program has received approval from an institutional review board; we’ve purchased our own freezer and transferred our samples to PreventionGenetics in Marshfield, Wisconsin; and we’ve developed a full-fledged computerized database that we are now testing. Direct enrollment continues to surge, and we continue to transfer samples from the Barrow’s tissue bank. We would love to talk with you if you have an upcoming surgery scheduled or if you had surgery in the last three years at St. Joseph’s in Phoenix.

New Mexico Updates

As reported in the last newsletter, the City of Santa Fe will be hosting a “Cavernous Angioma Awareness Week” later this year. We now have dates in place. Cavernous Angioma Awareness Week 2008 will be October 6-11. We would like to use this time to visit physicians’ offices in the greater Santa Fe area to provide information about cavernous angioma, to raise awareness through local radio and newspaper coverage, and to end the week with a public event. If you are interested in participating in this event (even if you don’t live directly in Santa Fe), please contact Connie Lee at info@AngiomaAlliance.org.

The New Mexico Medical Society will be including a two-page cavernous angioma fact sheet written by Connie Lee and Dr. Leslie Morrison in their next newsletter. The newsletter is mailed to all 2300 physicians who are part of the Society. Despite having the highest population density of the illness in the world, New Mexico has a shortage of physicians who are familiar with the illness. The newsletter enclosure is a first step toward better statewide cavernous angioma medical education.

Ron Schechter joins Angioma Alliance Board of Directors

We are happy to welcome Ron Schechter to the Angioma Alliance Board of Directors. Ron has been working in finance and information technology for more than 25 years. He is a Certified Public Accountant and received an MBA degree in 2004.



Ron is a CCM patient and in consultations with medical advisors has chosen a “wait and see” approach toward further treatment. Ron has been involved in strategic planning for Angioma Alliance, and has been a volunteer assistant for the Angioma Alliance Scientific

Workshops and Family Conference. Ron has contributed to the Angioma Alliance newsletter and has interests in advocacy and patient and physician education.

Amy Jagemann has stepped down from the Angioma Alliance Board of Directors in order to dedicate more time to her growing family. We would like to thank Amy for her many years of service and look forward to having her continue to contribute through peer support and other special projects.

GINA Signed into Law

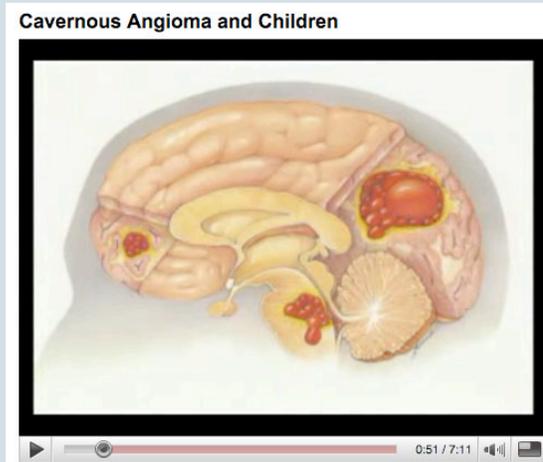
On May 21st, the Genetic Information Non-Discrimination Act was signed into law by President Bush. This legislation makes it illegal for insurance companies and employers to discriminate on the basis of genetic test results. Insurance companies may not deny coverage or increase rates for asymptomatic individuals who discover they have the potential for a genetically based illness based on testing. It also makes it illegal for employers to deny employment based on genetic testing results or to require genetic testing as a condition of employment. The components of the law that apply to insurance companies will go into effect in May, 2009; the components applicable to employment will become effective in November, 2009. Finally, we will be able to be tested or have our loved ones tested for the genetic form of cavernous angioma without fear of future insurance or employment consequences.

We Need a new Laptop!

With the growth of our DNA/Tissue Bank and our in-house volunteer staff, Angioma Alliance is in need of an additional laptop, preferably one with the computing power to run our clinical database (minimum of 2 GB of RAM). If you can donate a new laptop or if you work for a computer manufacturer that has a gift-in-kind program, we would love to hear from you!

Angioma Alliance on YouTube

Angioma Alliance now has its own video on YouTube, MySpace, and Bebo. “Cavernous Angiomas and Children” began running in March and has received nearly 2,000 views. The video provides information about cavernous angiomas and the impact of the illness on children who are affected. You can find the video on YouTube by searching for “angioma” or you can view it from our home page www.AngiomaAlliance.org.



Text of House Resolution 1193

110th CONGRESS
 2d Session
 RES. 1193

Expressing the sense of the House of Representatives that there is a critical need to increase research, awareness, and education about cerebral cavernous malformations.

IN THE HOUSE OF REPRESENTATIVES
 May 13, 2008

Mr. UDALL of New Mexico submitted the following resolution; which was referred to the Committee on Energy and Commerce

RESOLUTION

Expressing the sense of the House of Representatives that there is a critical need to increase research, awareness, and education about cerebral cavernous malformations.

Whereas cerebral cavernous malformation (CCM), or cavernous angioma, is a devastating blood vessel disease that has enormous consequences for those affected and their families;

Whereas cavernous angiomas are malformations in the brain that cannot be detected easily except through very specific medical imaging scans;

Whereas those with a cavernous angioma should not take blood thinners or aspirin, but are rarely aware that they have the disease;

Whereas in the general population 1 in approximately 200 people has a cavernous angioma and about 1/3 of these affected people become symptomatic at some point in their lives;

Whereas there is a hereditary form of the illness, caused by a mutation or deletion on any one of 3 genes that is characterized by multiple cavernous malformations;

Whereas each child born to parents with the hereditary form of the illness has a 50 percent chance of having cerebral cavernous malformation;

Whereas a specific genetic mutation of cerebral cavernous malformation called the common Hispanic

mutation has been identified, has been traced to the original Spanish settlers of the 1590s, and has now spread down and across at least 17 generations of families;

Whereas the State of New Mexico has the highest population density of this illness in the country, but Hispanic families and those of all other ethnicities throughout the Nation are at risk;

Whereas a person with cavernous malformations may go undiagnosed until sudden death, seizure, or stroke;

Whereas there is a shortage of physicians who are familiar with the illness;

Whereas this shortage makes it difficult for affected individuals to receive timely diagnosis and appropriate care;

Whereas the shortage of physicians who are familiar with the illness has a disproportionate impact on thousands of Hispanics across the Nation; and

Whereas cerebral cavernous malformation has been understudied by the National Institutes of Health and others: Now, therefore, be it

Resolved, That it is the sense of the House of Representatives that there is a critical need to increase research, awareness, and education about cerebral cavernous malformations.



SPEECH OF HON. TOM UDALL
OF NEW MEXICO
IN THE HOUSE OF REPRESENTATIVES
TUESDAY, MAY 13, 2008

Mr. UDALL of New Mexico. Madam Speaker, medical science has made great strides in unlocking the mystery of illnesses that have plagued humanity for centuries. Medical breakthroughs have helped control and eliminate diseases that once threatened the life and health of millions. Yet for all our progress, we still face threats that we do not understand and therefore cannot stop.

One of the lesser known--but no less devastating--diseases is Cerebral Cavernous Malformation, also known as CCM, or Cavernous Angiomas. CCM's are caused by abnormal blood vessels that form clusters, known as angiomas, in the brain or spinal cord. If the angiomas bleed or press up against structures in the central nervous system, they can cause seizures, neurological deficits, hemorrhages, or headaches.

In the general population, 1 in approximately 200 people has a cavernous angioma and about one-third of these affected individuals become symptomatic at some point in their lives. In some Hispanic families, however, the rate of prevalence is significantly higher. It is what is known as an autosomal dominant disease, which means that each child of an affected parent has a 50 percent chance of inheriting it.

And Madam Speaker, tragically, for generations of these Hispanic families, that is exactly what has happened throughout the country, and especially in New Mexico. In New Mexico, this genetic mutation has been traced back to the original Spanish settlers of the 1580's and has now spread down and across at least 17 generations, resulting in what could be tens of thousands of cases of the illness in the state. In fact, New Mexico has the highest population density of this illness in the world.

Unfortunately, and in some cases tragically, many of the carriers of the gene and even the disease are unaware. To make matters worse, New Mexico, and the nation, face a shortage of physicians who are

familiar with this illness. This makes it dangerously difficult to receive timely diagnosis and appropriate care and puts potentially thousands of individuals at risk of a stroke, seizures, or even sudden death.

One New Mexico resident, Joyce Gonzales, was diagnosed with an angioma in her cervical spinal cord and had it surgically removed three years ago. But this success story followed 15 years of pain and misdiagnosis. Tragically, Mrs. Gonzales's 9-year-old second cousin was not as fortunate, recently suffering a cerebral hemorrhagic death caused by CCM.

Madam Speaker, much of the misdiagnosis of CCM, the inexact figures, and lack of knowledge in the medical community is attributable to a lack of research of the disease. NIH funds only eight projects on CCM. This, despite recent indications that staff at the National Institute of Neurological Disorders and Stroke believes CCM to be a "paradigm illness," meaning research findings on CCM could apply to other illnesses that have similar characteristics.

It is clear, Madam Speaker, that more education, awareness, and research is necessary on this disease. That is why I am introducing this resolution today to express the sense of the House of Representatives that there is a critical need to do exactly that; expand education, awareness and research of CCM. This is only a preliminary step in the fight against this disease. I believe a Center of Excellence is needed to provide the highest quality medical and surgical care for families with CCM. An expansion of the existing DNA/Tissue and Clinical Database is also needed. The current database is underfunded, which means that they cannot accept all the samples that are offered. I will be working to establish both of those.

In the meantime, Joyce Gonzales, Dr. Leslie Morrison of the University of New Mexico, and Connie Lee, the President of the Angioma Alliance, are on the forefront of the fight against CCM. It is my honor to join them in this fight by introducing this resolution today and I urge my colleagues to help raise awareness of this devastating disease. There is too much at stake to ignore it.



Fund-Raising News

A New Way to Help Angioma Alliance

FirstGiving is an organization that provides a simple way for individuals to set up a webpage to raise money for their favorite charity (we hope that we are yours!). FirstGiving allows your friends and family to use credit cards to donate. Simply set up your own page and email the link to your contacts. It can be used several ways:

1. To accept sponsorships or donations for an event. For example, Leslie Baca has set hers up to accept pledges for Brainy Bowling: www.firstgiving.com/labaca. We hope that some of you may want to sponsor a Brainy Bowler or may want to become "virtual" bowlers and set up your own page. Brainy Bowling is happening in Marietta, GA, and in Colorado Springs, CO, on June 21st. Or maybe you'd like to collect sponsorships for running in a race or for engaging in noncompetitive couch sitting—any activity would work!
2. To accept honoraria or memorial donations. For example, if you have a birthday coming up and you'd like folks to donate to Angioma Alliance in lieu of presents, you can set up a page for them to do this.
3. To accept donations for any reason, for almost any length of time—you can choose to keep a general page open for 6 months, 12 months, or 24 months (it's the "use your imagination" choice).
4. If you don't want to set up your own page, you can direct folks to the general Angioma Alliance Firstgiving pages, www.firstgiving.com/AngiomaAlliance, to donate for Brainy Bowling or www.firstgiving.com/AngiomaAlliance2 for general donations. You can also include a widget for our pages on your Myspace page or blog (email info@AngiomaAlliance.org and we will send you the code).

Brainy Bowling

Brainy Bowling, a tournament to benefit Angioma Alliance, is being held at two Brunswick Bowling Centers on June 21st. Angioma Alliance and the Brunswick Center in Marietta, GA, and the center in Colorado Springs, CO, will be offering prizes including bowling balls, family bowling packs, gift certificates to local restaurants/clubs, and Angioma Alliance gear to top scorers, top teams, and top pledge earners. Even if you don't live in these areas, you can participate online by setting up a "virtual bowler" page at FirstGiving.com. You can use Leslie Baca's page www.firstgiving.com/labaca or the Angioma Alliance bowling page www.firstgiving.com/angiomaalliance as a model. You could be one of the top pledge earners without even scoring a single strike! Or, please consider sponsoring a bowler like Leslie or making a donation through the Angioma Alliance FirstGiving page.

We'd like to thank Anjoleen Baca for all the work she has put into creating this event. Thanks to her efforts, we have templates that can be used by anyone who would like to sponsor their own bowling tournament. If you would be interested in putting together an event (and particularly if you are connected with the military, as Anjoleen has lots of tips for getting out the bowlers on base), get in touch with Connie or Anjoleen at info@AngiomaAlliance.org.



Eighth grader **Annie Baldwin** from Rotolo Middle School in Batavia, IL, won first prize in her school for a presentation on cavernous angiomas. The students in her class sold candy at lunch and raised over \$100. Because of Annie's winning presentation, the proceeds were donated to Angioma Alliance. Congratulations and thank you, Annie!

Heather Kurpiewski enlisted her family and friends to sell See's Candy as a fundraiser for Angioma Alliance. Heather told us that we could only imagine what her house smelled like with 24 cases of chocolate in the living room. Amazingly, their sales raised almost \$1000—a sweet result for all of their hard work!

Lisle Cohen continues to run for Angioma Alliance. Lisle has a brainstem cavernous angioma and solicits pledges for each of her races. Her latest race was the Big Sur 21 Miler—an event that winds up the beautiful California coast and features a Yamaha grand piano at Bixby Bridge, Taiko drummers at the foot of Hurricane Point, and belly dancers at the last mile.

MadoroM Wine Auction Raises Money for Angioma Alliance

As was reported in the last issue of the newsletter, this year's MadoroM wine auction fundraiser raised more than \$35,000 for our work. Below, Andy Amador, organizer and host of the MadoroM wine auction to benefit Angioma Alliance, shares a moment with Dave Manning, an auction attendee and supporter.



International Update



Angioma Alliance UK News

The Forum is Dead. Long live the Forum.

Saturday June 7, 2008, was for many of us UK members the high point of the year. The board and I had spent twelve months lining-up speakers, having meetings, arranging hotel accommodations, having meetings, visiting venues, having meetings, competing for that most unfortunate of things, money, having meetings, ensuring members were informed about the event—the 2nd International Angioma Alliance UK Forum—and having meetings. The only thing it seems we did not have a meeting about was the weather—and there seemed little we could do about that (although I seem to remember hearing something a few years ago on the radio about Paul McCartney and dry ice attempting to change the climate before a concert in Russia).

Finally the weekend that we had been planning for so long arrived. Angioma Alliance UK had asked four speakers to present. And they were all there, bang on time, and, considering their eminence in the field, this in itself was a remarkable achievement. Your own Dr. Connie Lee spoke first on Coping with Cavernoma. Mr Neil Kitchen, consultant neurosurgeon at the National Hospital of Neurology and Neurosurgery, Queen Square, spoke on cavernoma surgery and resisting temptation. From the United States came the keynote speaker Professor Issam Awad updating us on cavernoma research. Mr. Ian Sabin, consultant neurosurgeon, at Barts and the London NHS, spoke on Gamma Knife Surgery and Perfexion, the latest in gamma knife technology for brain lesions. At its height, the Forum attracted 100 people. The afternoon was dedicated to small informal group discussions including a group for carers.

Ian Stuart

Book Review

Your Brain: The Missing Manual

Matthew MacDonald

Pogue Press/O'Reilly, 2008

259 pages—\$24.95

While readers of this newsletter may look at the brain as a potential seat of problems, sometimes it's good to take a step back and look at just what the brain does and how amazing it can be. The brain is certainly complex—after all, it's responsible for thoughts, emotions, perception and movement—but as researchers elucidate more and more how the brain works, it is possible to get a glimpse at its activities. Neuroscience has made great leaps in recent years, especially with the development of MRI (magnetic resonance imaging) and fMRI (function MRI) that allows scientists to map the brain when it's working.

You may be familiar with the Missing Manual series of computer books. These titles provide instruction on software for people with little to medium experience. Using this approach, author Matthew MacDonald sets out to do the same for the brain. Beginning with an overview of basic brain anatomy, he looks at how the "wires" connect and how the rest of the body interacts with the brain. He presents the main areas of the brain, and discusses what they do. He then looks at fuel for the brain: what it takes to keep this organ going, and what one can do to eat well so the brain functions optimally. He completes Part 1 with a discussion of circadian rhythms, sleep and dreams: why we sleep, what happens when we do, and why we dream.

Part 2 looks at five big questions: Perception, Memory, Emotions, Reason and Personality. With a combination of basic neuroscience, pop psychology, and a touch of fun—some word games, riddles and optical illusions—MacDonald gives insights into how

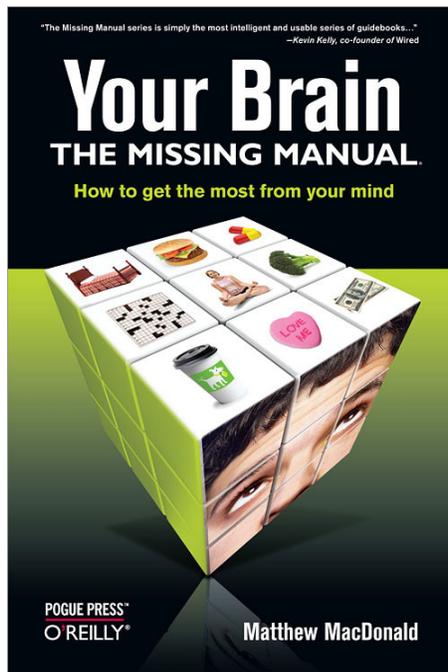
the brain accomplishes all these things. A section called "Techniques for Better Remembering" is especially interesting for those of us who are in the more advanced decades.

Part 3 looks at "other people's brains", and examines two questions: that of the difference between men's and women's brains, and that of brain development. Anyone with children will find some interesting points in this latter section, as you are probably amazed at the way your kids learn so much so quickly.

The book has a good index, so you can look up parts of the brain or functions, but it lacks a reading list for those who want to learn more. It mentions a few web sites and books in the text, but it generally doesn't give you suggestions to expand on specific areas. (There are a couple dozen links on the book's page at <http://missingmanuals.com>.)

While this book avoids the bigger questions, such as consciousness, brain injuries and their consequences, and neurological diseases and conditions, its attractive presentation—with four-color illustrations, including several of the brain itself that help you localize different parts of the organ—makes this an entertaining read. No matter how much your brain intrigues you, you'll find interesting information here. The book not only explains, but also includes tips to help you keep your brain working best: what to eat, how to improve your memory, and tips on creative thinking. As this book is written for everyone, you don't need to know anything about your

brain to understand it, and you'll certainly come away from it with more knowledge about your most vital organ.



Research

Nitric oxide synthase and NMDA receptor expressions in cavernoma tissues with epileptogenesis

Researchers in Japan investigated a possible link between a certain neurotransmitter system and the stimulation of seizures, one of the potentially dangerous symptoms in CA. When CAs bleed, iron deposits can form in the surrounding tissues. This hemosiderin can cause detrimental side effects, but a direct link has not been discovered between these deposits and an increase in seizures. Some surgeries have tried to remove affected tissues surrounding a CA that has bled, but without clear positive results. This study instead looked at how these deposits might affect neurotransmitters and calcium levels in the area. If the iron deposits affect a certain neurotransmitter system—called NMDA receptors—they could stimulate the production of nitric oxide. (Nitric oxide is a free radical, a destructive chemical that can damage tissue.) While preliminary results suggest this is the case, there are many changes in tissue surrounding CA and it is not clear what causes more symptoms, and what is caused by symptoms. Very small sample groups also make the study tentative. All in all, this is promising because once factors causing seizures are identified, researchers may be closer to controlling symptoms.

ACTA NEUROLOGICA SCANDINAVICA, Kamida, T, Takeda, Y, Fujiki, M, Abe, T, Abe, E, & Kobayashi, H (2007). Nitric oxide synthase and NMDA receptor. 116, 368-373.

A 10-year experience in pediatric spontaneous cerebral hemorrhage: which children with headache need more than a clinical examination?

Researchers at the Neurosurgery Department at the Centre Hospitalier Universitaire Vaudois in Lausanne, Switzerland, analyzed cases of hemorrhagic stroke in children over ten years in two university hospitals. These strokes were caused by arteriovenous malformations, aneurysms or cavernous angiomas. One of the big problems in identifying whether children have strokes is knowing when to

order further tests after conducting a clinical examination. The usual indicator of strokes in children is headache, a symptom which is very common. However, this research indicates that only about 77% of children who suffered strokes experienced headaches, but all of them had other, more subtle symptoms. These symptoms include the loss of half the vision in both eyes (hemianopsia), incoordination of movement, like undershooting or overshooting the mark when moving hands, arms, legs or eyes (dysmetria), double vision (diplopia), and weakness on one side. Any kind of neurological symptom should be an indication for emergency imaging investigation according to this research. In addition, severe, unusual and intense headaches are a warning sign and should lead to imaging work-ups as well. While these findings are not exactly new, continued research into spotting signs of strokes in children is promising.

de Ribaupierre, S, Rilliet, B, Cotting, J, & Regli, L (2008 Feb 9). A 10-year experience in paediatric spontaneous cerebral hemorrhage: which children with headache need more than a clinical examination? Swiss Med Wkly, 138(5-6), 59-69.

Brain Magnetic Resonance Imaging Scans for Asymptomatic Patients: Role in Medical Screening

This article examines whether or not MRIs—magnetic resonance imaging scans—should be used on healthy people as a screening tool. Such a tool is useful if it finds something that can be treated—it is less helpful if it finds an anomaly that either causes no symptoms or has no treatment. In addition, a screening tool is not useful if it finds something that *might* be wrong but really isn't; these are called false positives. This can lead to patients being diagnosed with a disease when really they don't have any problems, or requiring expensive follow-up procedures to rule out serious problems.

The authors of this article make the point that, while such screening may lead to the discovery of problems (in one recent study of 2,000 people, seven were found to have cavernous angiomas, all of which

caused no symptoms), the net gain is not worth the cost and complications. In addition, since MRI screening is often done only by the well-off (most insurance does not cover screening when no symptoms are present), this only offers such techniques to those who can afford it.

The article concludes: “Valuable screening programs must either address a highly prevalent disease or be applied to high-risk individuals, and must accurately uncover a treatable disease.”

Komotar, R. J., Starke, R. M. & Connolly, E. S. Brain Magnetic Resonance Imaging Scans for Asymptomatic Patients: Role in Medical Screening. Red Orbit: Health. Retrieved May 14, 2008, from http://www.redorbit.com/news/health/1368856/brain_magnetic_resonance_imaging_scans_for_asymptomatic_patients_role_in/

Surgery Indicated for Treatment of Brainstem Cavernous Malformations in Children Despite Higher Morbidity Rates

At an Annual Meeting of the American Association of Neurological Surgeons, the Chief Neurosurgical Resident of St. Joseph's Hospital and Medical Center in Phoenix, Arizona, Dr. Gregory P. Lekovic, discussed a review of twenty-seven children who had surgery for cavernous angiomas of the brainstem. The follow up statistics were worse than for adults: one child died and one had to have another surgery; four patients had new permanent deficits or increased deficits. Five other patients got worse before they got better. Despite these problems, the authors concluded that surgery was indicated for children with brainstem angiomas that could be reached, because the children who came through the surgery without problems did very well.

Nierengarten, M. B. Surgery Indicated for Treatment of Brainstem Cavernous Malformations in Children Despite Higher Morbidity Rates: Presented at AANS. PeerView Media Bar. Retrieved May 14, 2008, from <http://www.docguide.com/news/content.nsf/news/852571020057CCF6852574400068BF2A>

Donate Your Car to Help Angioma Alliance

Can't find a buyer for your SUV? Has your old car finally given up the ghost? Have you totaled your car and need to get rid of it? You can now donate your car, road-worthy or not, to benefit Angioma Alliance. For those of you with cars that can not be driven, if you live within 40 miles of one of the cities below, Angioma Alliance can make arrangements to have your vehicle towed at no cost to you, and you can receive a tax deduction for a charitable donation. If your car is operating, you can either have your car towed or drive your car to a location in one of the cities below to donate it. For those in the United States, IRS publication 4303: A Donor's Guide to Vehicle Donations (<http://www.irs.ustreas.gov/pub/irs-pdf/p4303.pdf>) provides detailed information about the tax implications of donating your vehicle. Please call us if you are considering donating your car and we can discuss details with you.

In Arizona: Chandler

In California: Fairfield, Fresno, Merced, Modesto, Moss Landing, Newark, Oakland, Rancho Cordova, Redding, Richmond, Rocklin, Sacramento, San Jose, Stockton, and Windsor

In Florida: Tallahassee and Panama City

In Illinois: Summit and Wadsworth

In Indiana: Hammond

In Missouri: Kansas City and St. Louis

In Nevada: Sparks and Carson City

In Ohio: Columbus

In Texas: Dallas and Fort Worth

In Utah: Salt Lake City

In Virginia: Virginia Beach

In Canada: Edmonton, Calgary, and Kelowna

Angioma Alliance Donors—First Quarter 2008

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In memory of Marsha Garofalo

Eugene and Mary Grady

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Shayna Dunn

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In memory of Barbara Hebard

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In honor of Allison Ruggles

Barry McAloney

In honor of Sara and Susan Sukalich

Judy and Barry Randall

In honor of Kandance Weems-Norris

Dorothy Cumby and David Virgil

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 and support individuals affected by CCM while facilitating improved diagnosis and management of the illness through education and research. We are monitored closely in our educational efforts by a Scientific Advisory Board comprised of leading cerebrovascular neurosurgeons, neurogeneticists, and neurologists.

Angioma Alliance
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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 thank you gift. Our “little red guy” pin is a wonderful way to increase awareness of cerebral cavernous malformation (CCM), our little known illness. 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 has its own magnetic car ribbon! These unique ribbons are the larger 3 1/2” x 8” size and are available for \$5 each, including shipping. Educate while you travel!

To donate or order Angioma Alliance merchandise, send a check or money order (using the enclosed envelope) or visit www.angiomaalliance.org and purchase all of your Angioma Alliance gear in one fast, easy transaction! You can donate and purchase using a credit card with our Paypal connection.

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