On September 20, 2012 at the Chase Park Plaza in St. Louis, MO, ten grants were awarded at the Sixth Annual Brain Aneurysm Foundation Research Grant Symposium. The evening featured an address by Ralph G. Dacey, Jr., MD, the Henry G. and Edith R. Schwartz Professor and Chairman of Neurological Surgery, as well as the Neurosurgeon-In-Chief of the Barnes-Jewish Hospital and Washington University School of Medicine.

Thanks to our supporters continued dedication to research to improve the lives of those affected by a brain aneurysm tomorrow, the foundation was able to award ten grants totaling $200,000 in 2012!
Nothing Comes From Nothing
By: Christine Buckley

What a wonderful year 2012 was for The Brain Aneurysm Foundation! It was very exciting to surpass the $1,000,000 fundraising goal for the first time ever. I can only hope this wave of enthusiasm and success rolls into 2013, bringing continued progress and new levels of accomplishment.

It is important to realize that all that was accomplished this past year was due to the efforts of many. It was a group effort. Many individuals involved more than 30 people from 11 different states, our monthly webinars are hosted by doctors from various parts of the country and viewed by people worldwide, the continued publication and distribution of our booklets was made possible by corporate contributions, and the commitment of many fundraisers and individual donors to research allowed the foundation to award 10 grants totaling $200,000. Not to mention all the dedicated nurses and doctors who have helped start support groups all over the country and Canada to bring our total to near 70!

The foundation has been fortunate to have the involvement of many prominent physicians as members of the Medical Advisory Board. Their input on a regular basis helps to keep our information up-to-date and accurate. The Medical Advisory Board also promotes the research grant program with a few members involved in scoring the grants. They take part in educational symposiums, speak at events around the country, and provide the foundation as a resource for their patients. The doctors play a vital role in many patients care both pre and post aneurysm treatment.

Then there is YOU… a survivor, a caregiver, a family member or a friend! In one of my favorite musicals, The Sound of Music, it was sung, “nothing comes from nothing, nothing ever could” and this has been so true for the foundation. With your passion, desire to improve the lives of others, and donation of money, time, talent, and goods, The Brain Aneurysm Foundation has become the successful and ever-growing organization that it is today. Almost seven years ago when I began working for the foundation the total amount of funding was barely $100,000. So, the foundation’s success has come from something - slowly, thoughtfully, passionately, strategically, and one task at a time with the help of many. YOU have made a difference. We have worked together. The foundation should be proud of its past, embrace the present, and look to the future brightly because the sky is the limit of what can be done together in our fight against the devastation caused by brain aneurysms.

Here’s to 2013!

Christine

New Medical Advisory Board Members

The Brain Aneurysm Foundation is fortunate to have a Medical Advisory Board composed of neurologists, neurosurgeons, interventional neurologists, as well as rehabilitation specialists from around the world working at many of the world’s most prestigious medical facilities. The doctors provide continued expertise and support to the foundation in a variety of ways and we are grateful for the time contributed and the dedication of our medical experts. In 2012, we expanded our Medical Advisory Board adding sixteen new members to continue to strengthen our visibility and representation throughout the country.

The Brain Aneurysm Foundation is very proud to announce the latest additions to its Medical Advisory Board which include:

FROM THE EXECUTIVE DIRECTOR

New Medical Advisory Board Members

Gavin W. Britz, MD BCH, MPH
Director, Duke Cardiovascular Center
Association Professor, Duke University Medical Center
Division of Neurosurgery, Durham, NC.

E. Sander Connolly Jr., MD, FACS
Bennett S. Stein Professor of Neurological Surgery
Vice Chairman of Neurosurgery Division, Director, Neurological Surgery and Interventional Neuroradiology
University of Cincinnati, Cincinnati, OH

Brian L. Holt, MD, FACS, FAHA, FAANS
William M. Schall Associate Professor of Neurological Surgery
Joint Associate Professor of Radiology and Joint Associate Professor of Neuroscience Program
Director of Neurological Surgery
Director of the ACME-accredited Fellowship in Endovascular Surgical Neurology,
University of Florida, Gainesville, FL

Gavin W. Britz, MD BCH, MPH
Director, Duke Cardiovascular Center
Association Professor, Duke University Medical Center
Division of Neurosurgery, Durham, NC.

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Joint Associate Professor of Radiology and Joint Associate Professor of Neuroscience Program
Director of Neurological Surgery
Director of the ACME-accredited Fellowship in Endovascular Surgical Neurology,
University of Florida, Gainesville, FL

Sacheta A. Kamath, MA, MA, BC-NCD, CCC
Cranial Matters
University of Miami. Director of Cerebrovascular Care, Co-Director, Microsurgery Training Center,
University of Miami, Miami, FL

Michael Lawton, MD
Associate Professor of Neurological Surgery
Director of the Comprehensive Neurological Program
UCSF Medical Center, San Francisco, CA

Jacqueline J. Marcus, MD, FRCS (Eng), FRCS(Ed)
Director of Skull Base Surgery
UCSF Medical Center, San Francisco, CA

Michael Lawton, MD
Associate Professor of Neurological Surgery
Director of the Comprehensive Neurological Program
UCSF Medical Center, San Francisco, CA

Jacqueline J. Marcus, MD, FRCS (Eng), FRCS(Ed)
Director of Skull Base Surgery
UCSF Medical Center, San Francisco, CA

Andrew J. Ringer, MD
Neurosurgeon Mayfield Clinic for Brain & Spine
Cincinnati, OH

Joshua Seinfeld, MD
University of Colorado Hospital, Aurora, CO

Adnan H. Siddiqi, MD, PhD
Director of Neurological Surgery
University at Buffalo Neurosurgery, Buffalo, NY

Gary K. Steinberg, MD
Director of Neurological Surgery
Stanford Hospital and Clinics, Stanford, CA

Bennett M Stein Professor of Neurological Surgery
Vice Chairman of Neurosurgery Director, Cerebrovascular Research Laboratory
Bennett M Stein Professor of Neurological Surgery
Columbia University Medical Center and New York Presbyterian Hospital, New York, NY

Andreas D. Asitsos, MD
UCSF Medical Center, San Francisco, CA
The Brain Aneurysm Foundation invites applications for basic scientific research directed at early detection, improved treatment modalities, and technological advances that will ultimately improve outcomes for patients with brain aneurysms, as well as projects that are translational, clinical/outcome-based, early detection, imaging, and SAH/SAH complications-focused. Any project with the potential to advance basic scientific, translational, and clinical brain aneurysm research will be considered. The foundation’s Research Grant Committee is headed by Robert Rosenwasser, MD, FACS, Professor of Radiology and Neurosurgery at Thomas Jefferson University Hospital. He, along with three other members of the Medical Advisory Board, scores all grant applications to determine the grant recipients based on the highest scores.

The Brain Aneurysm Foundation will award the 2013 recipients in September at the Annual Brain Aneurysm Foundation Research Grant Symposium to be held in Seattle, WA in conjunction with Seattle Neuroscience Institute - Swedish Hospital.

$200,000 in Research Grants Awarded continued from page 1

The 2012 research grant recipients are pictured below receiving their awards.

This is the second year The Brain Aneurysm Foundation has organized a Lobby Day on Capitol Hill, which is scheduled for May 21st. The purpose of our visit to Capitol Hill is to raise awareness about the importance of early detection and the need for greater funding for research in order to save lives. We hope to have representation from all over the country to visit with Members of the House of Representatives’ and Senators’ offices from their respective states to discuss brain aneurysm awareness, the importance of early detection and brain aneurysm research funding. On May 22nd, we will be hosting a briefing luncheon at which there will be a few presentations by appointed people, including at least one physician. We hope to have many members of Congress or their staff attend. Are you interested in joining this group? Register at http://bafound.donorpages.com/LobbyDay/

New Medical Educational Initiative

The Brain Aneurysm Foundation developed a medical educational lecture that was delivered at a PRI-MED conference targeting primary care physicians and nurses. The lecture focused on the importance of early detection via proper diagnosis and screening, as well as treatment options. The lecture is CME/CEU accredited.

The first lecture took place at the PRI-MED East Conference held in Boston, MA on November 15-18, 2012. It included primary care professionals from MA, NH, ME, NY, CT, and RI and had a general attendance of 6,000+ medical professionals.

Carlos David, MD, Director, Cerebrovascular and Skull Base Surgery at Lahey Clinic and Assistant Clinical Professor of Neurosurgery, Tufts University School of Medicine and Regional Director of The Brain Aneurysm Foundation Medical Advisory Board, delivered the lecture. It was both well attended and well received by the medical professionals at the conference. The Brain Aneurysm Foundation would like to thank Aesculap, Inc. for providing an educational grant in support of this program.

PLEASE JOIN US - As We Go Back to Capitol Hill to Lobby for Brain Aneurysm Awareness!

The 2012 Annual Report is now available online at http://www.bafound.org/sites/default/files/2012%20BrainAneurysm%20Foundation%20Annual%20Report.pdf. Read all about the wonderful activity in 2012 that made reaching this milestone possible.

We are grateful to all of our supporters, fundraisers, event organizers, corporate sponsors, Medical Advisory Board Members and Board Members for this achievement. Together we are The Brain Aneurysm Foundation.
Rebooting My Brain

I can say from my experience that many definitions I had for myself no longer apply, now that I’ve had brain damage. I used to be much more of a neat freak, always tidying up and avoiding clutter. Now I let things slide a bit and Paul often has to step in. I used to be a master multitasker, able to juggle a full-time, demanding executive role while still making time for performing in plays, writing freelance articles, and having a pretty full social dance card. Now I must balance my time in chunks, leaving room for only one or two networking events per week or committing to only one big volunteer project every six months. I used to be a bit more spontaneous. I once dropped a boyfriend off at the airport and decided when I got there to simply hop the plane with him, buy a new outfit when I got to our destination, and call in sick. Now? Forget it! The thought alone gives me a headache.

And when confronted with too many decisions all at once, such as trying to book a round-trip flight online when there are dozens of time and cost options, I am literally paralyzed into silence and inaction. Paul has learned to recognize that look, that total “my-internal-system-must-shut-down” look, and he will gently offer to walk me through it one step at a time. I still get overemotional at times, bursting into tears if my husband unexpectedly needs to work late and our dinner plans change, or tearfully hugging a confused Eddie when we randomly walk by the trauma center that attracts some of the very best trauma surgeons when I collapsed and having my husband come home early that day. I work from home alone most of the time, and not in a social office setting. I have a dog to think about when considering taking off at a moment’s notice, I don’t have a corporate structure to lean on that tells me what I need to do and how to prioritize my time. The fact is that I’m getting older, too. Who knows if I would still struggle with the overwhelm, the fatigue, mood swings or the memory lapses—brain injury or not?

In the end, I don’t think the answer really matters. The fact is that I had a brain hemorrhage that almost killed me. If not for a (divine or lucky) set of circumstances, such as being at home when I collapsed and having my husband come home early that day, living a mere five miles from the five-state region’s Level 1 trauma center that attracts some of the very best trauma surgeons from around the country, having access to one of the leading neural rehab programs in the country—if it weren’t for these facts, things may have turned out very differently for me.

I strongly believe that your brain function impacts your personality, but it doesn’t have to define who you are. My cognitive deficits and emotional changes threatened to change my very core, leaving paralyzing fear, sadness and frustration in their wake. But the ability to fight through them, to keep trying to find a way around them, to deal with the tears by trying to find something to laugh at—that’s all a very real part of who I was before the injury. These days, I realize that this desire to keep moving forward, to keep pushing through, is what makes me who I am—pre- or post-brain injury. As a result, the success or failure of the attempt doesn’t really matter.

My hope is twofold. First, that people take brain injury more seriously and understand what its effects can be on those they know and love. And, second, that it doesn’t take a brain aneurysm for people to learn the lessons I learned about slowing down, finding the humor, having more patience and savoring each activity in our 24/7 connected world. Everyday challenges can present a new opportunity to reboot, start over and refrain the conversation with your work, your relationships—and with yourself. It’s not easy and, like me, you won’t be great at it every single day. But again, it’s the attempt that matters the most, not the outcome.

Have You Missed any of the Informative Webinars from The Brain Aneurysm Foundation?

The Brain Aneurysm Foundation has continued the tradition of empowering patients with important information related to the care of their aneurysms. To accomplish this goal, recent Brain Aneurysm Foundation live webinars have used the power of the Internet to create a webinar forum where patients can reach experts to discuss important details of their care, and most importantly, have the ability to ask questions while they are at home, at no cost. Dr. Aaron Cohen-Gadol, an aneurysm surgeon and a member of the BAF Medical Advisory Board, has been moderating these webinars. We continue to receive very positive feedback from our members who attend these webinars from all over the world. The chat function of this webinar platform not only allows the members to interact with the speakers, but also offers a discussion forum for the patients to relate to each other while the live webinar is in progress. Importantly, these webinars are archived and are available for viewing shortly after the presentation of the live webinar on the BAF website. Here are some recently presented topics you can view if you missed them live:

Webinar: “Managing Cognitive, Social and Emotional Challenges After Ruptured or Treated Aneurysms” presented by Sucheta A. Kamath
Webinar: “I’ve Been Diagnosed With A Brain Aneurysm....Now What?” presented by Dr. Robert J. Singer
Webinar: “Management of Vascular Headaches” with Noah Rosen, MD

For these as well as a complete list of archived webinars, go to http://www.bafound.org/webinars.
The Importance of Outreach
by Tamala Jones

For all the Castle TV Show fans out there, you may be surprised to find out that the actor who plays Medical Examiner, Lanie Parish, is real life brain aneurysm survivor Tamala Jones. Recently, she shared her experience with us in hopes of raising brain aneurysm awareness.

Q: When was the first time you heard the term brain aneurysm?
A: The very first time when I heard the term “brain aneurysm” was when I had one.

Q: How old were you when you had a ruptured brain aneurysm?
A: I was 23 years old when my brain aneurysm ruptured.

Q: What happened the day of your rupture?
A: The day it happened, I was working on a network show and it was our last day of shooting for the season. I remember waking up with the worst headache that I’ve ever had. I got out of bed and when I stood up I had no control of my balance. I was stumbling while walking to the bathroom. My head was hurting beyond any pain I have ever felt. I got up from the toilet, looked in the mirror and then I passed out. While I lay on the floor I could hear myself say, “Get up Tamala, get up, get up now!” Maybe the voice I heard was an angel, it sounded familiar – I don’t know, but I got up! I called my boss and told her what happened, but she told me to come to work anyway. “It’s our last day of shooting; you’ll finish work then go to the hospital.”

With my head in so much pain and the discovery that the right side of my body was not working at all, I cried, got in my car and drove to work slowly, with my left foot and hand. When I arrived at work everyone was joking about why my body was numb on one side, not thinking anything was seriously wrong with me. My arm was stuck in a position as if I were offering it to someone. I had 3 scenes to shoot that day and they were throwing coats, purses, anything that would make sense of why my arm was bent like that. I finished my work for the day and went to the hospital. When I got there the doctor was amazed that I was walking, talking or even alive. He told me that I had a brain aneurysm and he needed to run an MRI to see how bad the damage was. After the MRI I was told that I had hemorrhaged and the side of the brain the blood was on is why I was paralyzed, but once the blood dried up I would get the feeling back on the right side of my body.

Q: Did you have any warning signs before your rupture?
A: The warning sign of this happening to me was a headache that I had for two weeks. It felt like a rubber band around my brain and someone was pulling it tighter every day.

Q: Did you have a family history of aneurysms? Did you know about the history before your aneurysm?
A: After speaking with the doctor about what could have caused this I discovered that we have a serious family history of brain aneurysms. This is the first time I’m hearing about this.

Q: A brain aneurysm can be a life-changing event. How has it affected your life?
A: This was definitely a life changing experience for me. I no longer worry about little things; I live everyday like it’s my last. I’m sure about my life. I’m strong and I speak my mind.

Q: You didn’t talk about your aneurysm for many years. Why? And why have you decided to talk about it now?
A: Being raised by very strong women, my grandmother and mother, I was beyond embarrassed that something like this happened to me at such a young age. I didn’t want people to know because I didn’t want to show weakness or vulnerability on any level, especially in such a tough town......Years later after hearing many stories of other young people suffering from brain aneurysms and dying from them, I chose to be more conscious of responsibility and how far it goes. I decided to share my story. I thought if I started to open up and share my experience that I could change my life and learn to be vulnerable, accept it as a strength and maybe save some lives along the way.

Q: What would you tell others today regarding the importance of early detection and knowing the signs and symptoms of a brain aneurysm?
A: If you have a headache and have taken everything to get rid of it and it’s still hurting or getting worse, go get a CAT scan or MRI!!! Don’t wait, go to the doctor and have it checked right away.

Q: If you had known the signs and symptoms of a brain aneurysm prior to your rupture, would you have reacted differently?
A: If I had had this information ahead of time, I definitely would have gone to the doctor a lot sooner.

Q: Why do you feel it is important to raise awareness of brain aneurysms, stress the importance of early detection, and highlight the need for more research funding?
A: It is extremely important to raise awareness about brain aneurysms because a lot people think that it only happens to elderly people but it doesn’t, it even affects babies. Early detection can save thousands of lives. If you know the signs and receive early treatment, it can save your life! People die from brain aneurysms every day. It is imperative that more funds are raised for early detection, research and preventative treatment options.

The Brain Aneurysm Foundation would like to thank Tamala Jones for sharing her personal story to help promote the importance of brain aneurysm awareness, early detection and research funding to save lives. We look forward to having Tamala join us in Washington, D.C., for our Lobby Day on Capitol Hill. She is a great example for other survivors to have the courage to make a difference where you can, locally or globally.

You can see Tamala in character on Castle which airs Monday nights at 10/9 Central on ABC.

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- It’s the FREE, fast, friendly and hassle-free alternative to selling or trading,
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The Brain Aneurysm Foundation
Support Groups Share Highlights and Accomplishments

San Antonio, Texas Chapter by Mickey Urias

The San Antonio Chapter Support Group was founded in 2008 and proudly serves survivors, family members and other care givers. St. Luke’s Baptist Hospital generously provides our meeting venue, complete with refreshments so the group may meet the first Tuesday of every other month in the comfort of their Executive Board Room. This allows us to use A/V equipment at our disposal for any presentation or seminar we want to partake in. The group is also excited to begin bringing in various guest speakers to include physicians and motivational speakers. The San Antonio Chapter continues to embrace new survivors, and easily recognize how we have each come ‘full circle’ in terms of our own progress. Topics for discussion have included everything from overcoming fear to various accomplishments we consider milestones. Factor in fashion, coping skills and dealing with lifestyle changes, the group continues to learn from one another and help make transitions easier for newcomers. We look forward to participating in a fundraising event later this spring: Goodwill’s Partners for Good in an effort to raise funds for The Brain Aneurysm Foundation that has been instrumental in our well-being. Visit our local website at www.bafoundsa.org for more information.

Chicago Chapter BAF Member has reached her goals! by Janet Sutherland

On October 23, 2006, 38 year-old Maria Micheleotto was in her Lockport, IL home when she was struck with the “worst headache of her life”. She could barely walk and crawled to the phone to get help. By the time she arrived at a local hospital, Maria was paralyzed from the waist down. She sat in the ER waiting room for three long “excruciating” hours while a series of misdiagnoses occurred. Maria was then flown to University of Illinois Hospital & Health Sciences System where neurosurgeon Dr. Amin-Hanjani performed a craniotomy to repair her ruptured brain aneurysm. She later said, “Dr. Hanjani’s staff was fabulous when I was in the hospital. While in the ICU, the nursing care was above great.” Maria was deeply inspired by the care she received at the University of Illinois Hospital and because of this she re-directed her career and recently became a nurse. As a mother of two young children, she has a busy nursing schedule by day, but has found time to volunteer her services to raffle fundraisers to benefit BAF. She later said, “As a new nurse, Maria eases patients’ anxiety as they recover by sharing her own story. Her nursing skills and recovery experience has helped others heal and strive for a healthy life, by providing them with the gift of hope.

Support Group Near You or Get One On The Map

Support groups offer brain aneurysm survivors and their families the opportunity to share life experiences, work through challenges and find new ways to adapt to changes in their life. The goal of support group meetings is to help alleviate fears and concerns through education and group discussions. Survivors realize that they are not alone. Survivors and caregivers share their experiences and show support to those that are in need. The healing of the spirit is just as important as that of the body.

In 2012, the number of support groups continued to grow nationwide. Support groups now exist in 55 locations. Our most recent additions include: Brain Aneurysm Support Group at University of Alabama, Birmingham, AL; Brain Aneurysm Support Group, Buffalo, NY; Aneurysm/AVM Support Group at Capital Health Medical Center, Pennington, NJ; Aneurysm/AVM Support Group at Virtua Voorhees Hospital, Voorhees, NJ; Syracuse Brain Aneurysm Support Group, Syracuse, NY; Brain Aneurysm Support Group, St. Louis, MO; Post Brain Surgery Support Group, Springfield, MO; Brain Aneurysm Support Group, Kansas City, KS; Brain Aneurysm Support Group at Memorial Hermann-Texas Medical Center, Houston, TX; Brain Aneurysm Support Group, Los Angeles, CA and Brain Aneurysm Support Group, Calgary, AB. To find meeting times for a specific group, check online at www.bafound.org/support-2. Don’t see a support group in your area? Contact office@bafound.org if you are interested in starting one.

We also have a very supportive online community at http://www.bafsupport.org/
Thinking Ahead

Events for Awareness and Research

Dr. Reed’s Run
by Abby, Jessa & Paula Reed

David Reed was 57 when he passed away unexpectedly from a brain aneurysm. Our community knew him as a beloved physician, but now we remember him as a husband and father. Five years ago, we lost him. Numbers help to mark the milestones but simply fail in ordinary moments. How many hugs have we missed? How many times have we gone to call him only to remember that he cannot answer? Five years is a completely devastating and inadequate answer. Sometimes, the grief cannot be contained in a number, or even a word.

When David Reed passed away, we did not have a chance to say goodbye. For his brain aneurysm to deny us a chance to say, “I love you” one last time was simply incomprehensible. The Brain Aneurysm Foundation’s support has allowed us to confront our loss. We now face October 15th with a sense of purpose instead of loss. For his friend which motivated him to promise the crowd at the event, “I will support your (Chicago BAF Chapter) efforts and so will the Chicago Bulls 100%!”. Also honored that evening was the U of I Brainstormers team who raised more than $6,000 in their “Relay for Recovery” efforts. Those in attendance included medical professionals from Hinsdale & Resurrection Hospitals who have also partnered with the Chicago BAF chapter in an effort to reach and support every survivor in the Midwest.

It was a Whale of a Time at the 4th Annual Brain Aneurysm Awareness Walk at Jones Beach, NY

On Saturday, September 28, 2013, The Brain Aneurysm Center of the North Shore-LIJ Health System’s Cushing Neuroscience Institute (CNI), along with The Brain Aneurysm Foundation (BAF), hosted Long Island’s 4th Annual Brain Aneurysm Awareness Four-Mile Fun Run/Two-Mile Walk at Jones Beach State Park to promote awareness and education. The event was a great collaborative success and raised $65,000 to support essential research that will directly benefit those affected and help to reduce the incidence of ruptured aneurysms.

Hundredsof walkers, including brain aneurysm survivors and their families and friends, attended the fun-filled event. Another unexpected highlight of the event was a special “creature of the ocean” in attendance - a unique whale sighting off the shoreline while the brain aneurysm walk was in progress. Walk participants stood in awe of the beautiful whale as it spouted water and put on a spectacular show for all. Many doctors, nurses and staff members from CNI’s Brain Aneurysm Center were in attendance to show their support of the many patients they have treated over the years including David Chalf, MD, and Avi Setton, MD, co-directors of CNI’s Brain Aneurysm Center. “One of the goals of this annual event is to increase awareness about the warning signs of a brain aneurysm,” said Dr. Chalf. “The symptoms can include severe headache, nausea, blurred or double vision, stiff neck or neck pain, pain above or behind the eye, and loss of sensation.” This annual event continues to be a great success for everyone involved.

Memories Shared in Maine at the 4th Annual Kat-Walk & 1st Annual Karo-5k Event
by David McCausland

On Saturday, September 15, 2012, the KAT-Walk & Karo-5k for Brain Aneurysm Awareness was held in Portland, Maine. The 4th annual KAT-Walk was in honor of Portland native Kimberly A. Tudor, who passed away from an undetected brain aneurysm rupture in December of 2008, at age 32. The 1st annual Karo-5k run was in memory of Scarborough native Karolina A. Kurka, who passed away following a brain aneurysm rupture in July of 2011, at age 27.

Families from Maine, New Hampshire, and as far away as Boston and Baltimore used this event to celebrate their “Amni-Versary” of survival or to remember their loved ones lost to a brain aneurysm. The oceanside Back Cove Boulevard was the perfect backdrop for the event hosting over 450 people that enjoyed a sunny, yet windy day and “shared their tears, remembered with love, and walked and ran to honor”.

In excess of $20,000 was raised to benefit the Brain Aneurysm Foundation, and we are proud these funds will provide critical awareness, education, support and research funding, which will ultimately save lives. On behalf of both Mom’s - Nancy and Mira, LeRay, Heidi, Maryanne, Dianne, and all the other families affected by brain aneurysms that joined us, we thank you for your support and for making this a special day and a huge success. Please visit our website: www.MaineBA.org and follow us on Facebook at: KatWalkKaro5k for more on this and future events.

Did You Know? Vice President Joe Biden, Two Term Vice President, is also a Two-Time Brain Aneurysm Survivor.

V ice President Joe Biden is a very lucky man. First elected into the U.S. Senate from the state of Delaware in 1972, Biden recovered from near-fatal aneurysms in 1988 to continue to serve in the Senate and is now Vice-President of the United States for a second term.

Former Chicago Bulls Basketball Player Promises to Make a Difference for Brain Aneurysm Survivors
by Janet Sutherland

This past fall, the Third Annual Brain Aneurysm Foundation “Survivor In The City” benefit celebrated the Chicago Chapter’s five year anniversary. This event spread awareness, raised funds and garnered a significant advocate when three-time NBA Chicago Bulls All-Star player, Bob Love, addressed survivors, friends and families and brain aneurysm medical professionals from the University of Illinois Hospital & Health Sciences System. Love spoke at the charity event about his friend, former basketball player Bob Boozer, who died suddenly in May, 2012 of a brain aneurysm. Love’s inspirational speech described the tragic loss of his friend which motivated him to promise the crowd at the event, “I will support your (Chicago BAF Chapter) efforts and so will the Chicago Bulls 100%!”. Also honored that evening was the U of I Brainstormers team who raised more than $6,000 in their “Relay for Recovery” efforts. Those in attendance included medical professionals from Hinsdale & Resurrection Hospitals who have also partnered with the Chicago BAF chapter in an effort to reach and support every survivor in the Midwest.

This year, Chicago BAF is creating a cookbook which includes recipes and stories from survivors and those affected by brain aneurysms worldwide. The cookbook will be launched this September at “Survivor In The City” 2013.

As Dr. Reed’s Run has grown over the years, we now share the starting line with others who have lost fathers, other relatives and friends to brain aneurysms. The rhythm of feet striking pavement has become the shared melody of our grief. Feelings that were once reduced to a number are transformed into action as we raise money and awareness with the Brain Aneurysm Foundation in honor of David Reed.

We hope that Dr. Reed’s Run may continue to make strides in connecting individuals living near Pittsburgh, PA, affected by brain aneurysms to a larger community of support through BAF. This year’s event on Saturday, October 12, in Allison Park, PA, will be the first year of official race timing. We are grateful for the generosity of local businesses that have allowed us to grow.
Inspired by Tragedy, Honoring the Life a loved One Lost
by David DeGraw

Being inspired through a tragedy is something that I did not expect. Actually, I didn’t know what to expect when my life partner Kurt Reisinger unexpectedly passed away from a brain aneurysm. I was in shock; I was lost and didn’t know how to get through a day without him. Kurt and I were together for 17 years, and through the good and bad, each day we would communicate somehow. Well now there was silence and the silence continued for a long time. Every day I would think I was dreaming and it would all be back to normal – our daily routines, phone calls or the walk through the front door.

I started the search for the causes of brain aneurysms: what they were and what caused them. Where did this striking painful force come from? I researched what they were and what caused them. Where did I start the search for the causes of brain aneurysms: AHA Brain Aneurysm Awareness had a two day presentation for a long time. Every day I would think I was dreaming and it somehow. Well now there was silence and the silence continued and through the good and bad, each day we would communicate somehow.

Our event was a huge success in many ways: Yes, the money received was beyond our expectations and knowing it helped The Brain Aneurysm Foundation in some way was truly wonderful. But it was also that people got actively involved in bringing awareness to brain aneurysms, and it brought individuals into the salon who talked about their friends, their family and even their own painful experiences with aneurysms. Many to this day were so inspired by me because I took the time, that I wanted to bring awareness to something many people do not talk about, that the team of David Michael Hair Studio and the area’s local Brain Aneurysms Medical Center, which specializes in brain aneurysms, were inspired and wanted to help, learn and spread the love.

Today I still try to embrace life and continue to be inspired by others. At the same time, I hope I can be an inspiration to others who may need an ear or some guidance; on how to get through the unexpected and how to keep our loved ones alive in our hearts in some way, every day. I am thankful I was inspired.

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Featured Brain Aneurysm Awareness Ambassador Dave McCausland

Giving Brain Aneurysm Awareness A Personal Presence at Maine EMS Conference

Maine Brain Aneurysm Awareness had a two day presentation booth at the 32nd annual Emergency Medical Services Conference held in Rockland, Maine. This event is organized by Atlantic Partners EMS and was attended by over 500 EMTs and Emergency Room personnel from all over the state of Maine. Dave McCausland manned the booth and had the opportunity to talk with first responders and EMTs about the signs and symptoms of brain aneurysms and the critical importance of emergency transport to the hospital. Brochures, symptom magnets and the BAF’s DVD entitled: “Early Detection of Brain Aneurysm: Life vs. Death” were given out. In turn, this 20-minute video will be viewed by many EMS crews throughout the state as part of their ongoing training.

Dave shared: It was gratifying to hear most EMT’s were aware of brain aneurysms as part of their training on “Stroke” and it was encouraging to hear that recent changes to statewide protocols should result with more patients complaining of sudden acute headache - “the worst headache of their life” - being transported to the hospital.

As a personal observation, it was amazing how many folks I talked to at the conference had a personal connection to brain aneurysms. Well over 1 out of 7 talked about family members (or very close friends) having suffered a ruptured aneurysm. Hearing this kind of prevalence of aneurysms continues to reinforce our need and desire to help get the word out - BRAIN ANEURYSM AWARENESS SAVES LIVES!

Thank you, Dave, for your personal commitment to the importance of Brain Aneurysm Awareness. If you are interested in doing something similar within your own community, email us at office@bafound.org.

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Upcoming Events

**MondA, June 15, 2013**
Aces Against Aneurysms, Mandeville, LA

**FridA, June 19, 2013**
Border States 7th Annual Charity Golf Tournament, Phoenix, AZ

**SundA, June 23, 2013**
3rd Annual Wilson Walk, Wilmington, DE

**SatA, June 29, 2013**
Brejicha Memorial Softball Tournament, Escondido, CA

**SundA, June 30, 2013**
A Walk in The Park, Boston, MA

**SatA, July 6, 2013**
1st Annual Brain Aneurysm Awareness Walk, in Loving Memory of Lissa Anne Been, Arnold, MD

**SundA, July 7, 2013**
The 12th Annual Aneurysmal Challenge, Hummerton, MA

**TuesD, July 23, 2013**
Lobby Day on Capitol Hill, Washington, D.C.

**SundA, July 28, 2013**
5K Walk/Run for Brain Aneurysm Awareness, Braham, MN

**SundA, July 28, 2013**
Walk for Brain Aneurysm Research and Awareness, Brooklyn, NY

**ThursD, July 11, 2013**
BAF Night at The Boston Pops, Boston, MA

**SatA, July 13, 2013**
The 12th Annual Arterial Challenge, Fort Royal, VA

**ThursD, July 18, 2013**
A Walk in The Park, Boston, MA

**SatA, July 20, 2013**
3rd Annual Step for Hope 5k Run/Walk, Carol Stream, IL

**SundA, September 8, 2013**
A Sharp Race Toward Brain Aneurysm Awareness, West Omaha, NE

**ThursD, September 12, 2013**
7th Annual Brain Aneurysm Foundation Research Brain Symposium, Seattle, WA

**SatA, September 21, 2013**
Executive K, Benson, VA

**SaturD, September 21, 2013**
Pink Angel Walk: Love Won’t Fade Away Hagerstown, MD

**SatA, September 28, 2013**
Long Island’s 5th Annual Brain Aneurysm Awareness Walk, Jones Beach, Wantagh, NY

**SatA, October 12, 2013**
Dr. Reid’s Run, Allison Park, PA
Bonnie’s Story  continued from page 11

of months to get a bit settled, let it all sink in and hear other opinions.
Different doctors had different opinions. While they agreed that clipping would be better than endovascular treatment, they strongly disagreed about the risks of rupture – placing my lifetime risk of rupture at 5% instead of 50%, with the risks of the surgery being around 20%. Another doctor at another hospital also recommended monitoring, not surgery. We were more confused than ever.

Slowly things began to calm down. My doctor at Hopkins, who diagnosed my vomiting as Vomiting Syndrome from Abdominal Migraines, gave me the information I needed to get the vomiting under control. I worked out regularly to try to stay healthy, but worried about rupturing my aneurysm. I worried every time I carried a heavy bag of groceries or lifted my daughter. Knowing you have an aneurysm is insidious. I struggled to think that this knowledge of how fleeting life is should be making me a better person, but instead was just making me stressed and sad.

I had a scan every six months to monitor the aneurysm; the doctors said it looked unchanged and it was fine to continue to monitor it. Almost two years passed since my diagnosis. And then a random meeting changed my life. After working out one day, I overheard a lady in the locker room talking about her recent aneurysm clipping. She graciously agreed to discuss it with me. It turned out hers was in the exact same location and a similar size. It was only several months post op and she was right away and took care of it with two clips. I remember very little from the days following the surgery. Within a couple of days I was coming back to my old self. On the sixth day I returned home with 46 staples in my head. What relief – the aneurysm was gone! I cannot say enough about the team at Hopkins. The doctors, nurses and staff were skilled, attentive, caring and kind. They saved my life.

Dr. Tamargo said the deterioration was further along than he had thought even; the wall of the aneurysm was so thin he could see the blood swirling beneath it. Thanks to Dr. Tamargo’s skill I have no permanent side effects. My vision is fine. I was extremely sensitive to sound initially and fatigued very easily for a while. When fatigued it could be difficult to process information and I also found a lot of stimuli at once would overwhelm and exhaust me.

Looking back on it five months later, it feels surreal. The temporary side effects are largely gone – I still occasionally get more tired than normal and if I’m very fatigued I feel like my brain slows down. But that will continue to diminish. I’m alive with the future looking bright. I am incredibly lucky and will be forever grateful for Dr. Tamargo, the BAF support group, my abdominal migraines and the chance meeting with a stranger at the gym.
Accidentally discovered brain aneurysms are now being found with greater frequency because of the availability of non-invasive brain vascular imaging studies such as magnetic or computed tomography imaging (MRA and CTA). Many of these patients are being managed conservatively with repeat scans. Younger patients, however, are faced with a relatively greater future risk of aneurysm progression or rupture. Current medical management options, which consist of smoking cessation and blood pressure control, are frustratingly limited. Conservative management for an unruptured cerebral aneurysm entails a future risk of aneurysm growth and rupture. A study using magnetic resonance angiography on nearly 200 patients with brain aneurysms followed over four years found that 10% demonstrated growth in size. (Burns, Huston et al. 2009) A Finnish study followed 142 patients with 181 cerebral aneurysms for an average of 19.7 years and found that 33 patients developed aneurysm rupture, yielding an annual incidence of 1.3%, and therefore a 30.3% overall risk of bleeding at 30 years from diagnosis. (Juvela, Porras et al. 2008)

Even among patients who have undergone prior aneurysm treatment, there still remains the original predisposition that may allow for additional aneurysm formation or discovery of previously missed aneurysms. McKissock reported that 12% of patients thought to have a single aneurysm were found to have multiple at autopsy. (McKissock, Richardson et al. 1964) False negative catheter cerebral angiograms occur in up to 5% of cases and have been described to be secondary to temporary clot within the aneurysm, alterations in blood flow around the aneurysm, observer errors and technical factors. (Forster, Steiner et al. 1978)

Unlike all other causes of stroke, rupture of brain aneurysms occurs more often in women (2:1), peaking in the 4th to 6th decades. In the International Subarachnoid Aneurysm Trial (ISAT) (Molyneux, et al. 2005) which looked at over 2000 patients with ruptured brain aneurysms, 70% of patients were women. Interestingly, the median age of rupture was 52, which also happens to be the median age of menopause in North America. The loss of estrogen at menopause has been demonstrated to contribute to the progression of cerebral aneurysm. (Ding, Toll et al. 2012) Stabilization of the substantial physiologic drop in endogenous estradiol levels that occurs at menopause has been proposed as a potential therapeutic target to mitigate cerebral aneurysm progression. (Chen, Ouyang et al. 2011)

A prominent subgroup of all aneurysm patients therefore particularly at risk for future aneurysm growth or rupture is younger women. Several serum markers, including those responsible for vascular integrity, inflammation, vascular breakdown and atherosclerosis has been shown to have strong or significant associations between animals and/or humans and cerebral aneurysms. Our study aims to determine if hormone replacement therapy, given during peri-menopause may help to prevent the progression of brain aneurysms. Specifically, we will perform a parallel design, prospective randomized placebo-control pilot study in peri-menopausal women to assess the effect of low dose estradiol therapy on a panel of serum markers, which in aggregate may be considered surrogate markers for cerebral aneurysm progression. Our secondary endpoints will include an evaluation of any changes in brain vascular imaging, as well as tests of validity for our chosen panel of serum surrogate biomarkers for cerebral aneurysms.

References*

*Please see www.bafound.org for complete list of reference citations.
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I/we want to help The Brain Aneurysm Foundation continue to provide critical awareness, education, support and research funding to reduce the incidence of brain aneurysms. I/we want to help support the continued publication of The Brain Aneurysm Foundation newsletter *Thinking Ahead*.

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