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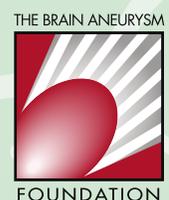
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## Anna Orthwein Chair of Research Established

The Brain Aneurysm Foundation would like to thank The Wodloe Foundation for establishing the Anna Orthwein Chair of Research. Their generous contribution of \$84,000 in Anna's memory will be awarded as two research grants in September 2009 at The Brain Aneurysm Foundation's 3rd Annual Research Grant Symposium in Chicago. Please read the story of Anna written by her mother Jayne Orthwein.

### Anna Orthwein, A Gift for Living

By: Jayne Orthwein

Anna Orthwein was born into this life with every intention to live it to the fullest. She moved through the years with a grace and an appreciation for what life had to offer her in the moment. Happy and contented with who she was, Anna had a self-assuredness that gave her the freedom of mind and heart to pursue those things she loved.

In her early years, Anna found her passion in her love for horses and dedicated so much of her time and energy to loving and caring for her first horse, Bandit. Bandit became Anna's partner in the hard work, determination and fun required to achieve the accomplishments that this team was able to attain. The happiness that Anna found with Bandit was embedded in their shared daily routines. It didn't matter, work or play, both were fine with Anna because the joy was in being with Bandit. Work and play were interwoven and Anna found contentment taking in the moments of the day.

This was a wonderful way to initially experience the concept of hard work and dedication and it was an approach that Anna continued to employ. Seeming to glide through life with an appearance of physical and mental levity, Anna did have a tenacity to pursue a set of goals. A biology major in college, Anna worked hard to achieve academic excellence. She placed on the Dean's List each semester, was a member of several honors and leadership organizations, and as a National Cancer Institute intern at the National Institutes of Health, was a co-author on several publications. Anna enjoyed the study of the biological sciences and felt a great sense of satisfaction from her lab work.

She embraced the educational opportunities available to her and planned to attain a degree in dentistry.

But Anna never allowed her steady focus on future life goals to overwhelm her gift for living. She was imbued fully with the capacity to enjoy life as it unfolded. She savored her time with family and friends and had an endless abundance of energy for fun. She was always ready for a vacation at the beach, a Morton's steak, a productive shopping trip and the excitement of a good horse race. In fact, after attending the 2007 Preakness, Anna began seriously contemplating whether she was too tall to be a jockey.

Yes, Anna traveled through her years with a grace and appreciation for what life had to offer her in the moment, recognizing that the journey was just as important as the destination. On that journey she remained true to herself and looked for that honesty in others. She was vivacious, optimistic, funny, hard-working, a good friend and a wonderful daughter. Anna's life was cut short from a ruptured brain aneurysm on June 4th, 2007, just two months before her 20th birthday.

This tragic loss affects all of us left behind. Society has lost a vibrant, productive young woman who was destined to achieve great things. Those who would have crossed paths with Anna in the future have been denied the opportunity to experience her energy, charm, and witty sense of humor. We who have known her and love her most suffer the emptiness in our lives each day. Even though we no longer get to kiss that smiling mouth and gaze at those beautiful eyes, Anna occupies our consciousness and our dreams, and continues to fill our space and time. Anna remains the center of our universe.



## One Heart

By: Christine Buckley

Over the past few years The Brain Aneurysm Foundation and its supporters have been working hard to open the ears of their legislators on a state level to proclaim September as Brain Aneurysm Awareness Month. At this time, about 10 states have listened and recognized the importance of this designation due to the devastation caused by brain aneurysms.

We were fortunate last year to have Senator Kerry of Massachusetts make a proclamation on the Senate floor regarding the importance of brain aneurysm education, awareness, and research. We are thankful to Senator Kerry for getting the ball rolling to opening the ears of our Congressmen on Capital Hill. Currently I am working with Representative Tiberi of Ohio and Representative McGovern of Massachusetts to make this designation on a national level. There is now a resolution that has been presented on the House floor, House Resolution # 263 to pass this legislation.

So often people tell me they want to help the foundation but they do not have money to give, they do not have enough free time to co-ordinate a local activity, or they do not live close to any events to volunteer or attend. In the past I have asked these people to talk about the foundation or their experience with a brain aneurysm to anyone that they meet. This is the simplest way to raise awareness on a daily and local level and it is something we can all do, and it does make a difference. Now I will ask all of you to take this a step further and become a little more proactive for hopefully a greater net result, the establishment of September as National Brain Aneurysm Awareness Month.

I ask all of you reading this to please write a very short letter to the Member of Congress from your state asking them to support House Resolution 263. This will allow

all of us committed to reducing the incidence of brain aneurysms and making the lives of those affected by a brain aneurysm better, the opportunity to all work as one, no matter where we are. The ultimate goal of declaring September as National Brain Aneurysm Awareness Month will forever connect those affected by a brain aneurysm during this month. It will give everyone a voice to speak more loudly than they may have in the past and it will also open the ears of more people to familiarize them with the need for greater brain aneurysm education and awareness, as well as research funding. For all those who have wanted to help, this is your chance, and you will make an impression to last a lifetime.

For details on this resolution please visit: <http://www.thomas.gov/cgi-bin/query/z?c111:H.RES.263>:

To find contact information for your Congressperson in the U.S. House of Representatives, please visit: <https://writerep.house.gov/writerep>

To find contact information for the United States Senator for your state, please visit: [http://www.senate.gov/general/contact\\_information/senators\\_cfm.cfm](http://www.senate.gov/general/contact_information/senators_cfm.cfm)

The Brain Aneurysm Foundation will be 15 years old on August 14, 2009. On this day, I know I will reflect and be thankful for all the foundation has accomplished and I hope you do the same. Remember you are part of the team that has brought the organization to a higher level. "A successful team beats with one heart." – Unknown. I ask all of you to put your hearts together, write to your Congressmen, and let's get September proclaimed as National Brain Aneurysm Awareness Month!

*Christine*



### Announcing New Monthly Pledge Processing Program at The Brain Aneurysm Foundation

For those wishing to pledge to make a monthly donation to The Brain Aneurysm Foundation by credit or debit card, we have established a new program in 2009. To make a pledge, simply fill out the donation information on the back of this newsletter with your monthly pledge amount and credit or debit card information, or for more information go to our website at [www.bafound.org](http://www.bafound.org) or contact [office@bafound.org](mailto:office@bafound.org)

## Pause T-shirts Inspired by Artist's Recovery From Brain Aneurysm

On January 31, 2006, Keith Tamashiro suffered from a brain aneurysm and was taken immediately to the hospital where his chance of survival was expected to be minimal. Beating almost insurmountable odds, Keith was able to survive his aneurysm, but his physical abilities and memory were severely compromised and his world changed overnight. With months of therapy and rehabilitation and the support of family and friends, he was able to return home. However, Keith had to work diligently to regain the ability to speak and walk, and even though he overcame many challenges in his rehabilitation, Keith was unable to return to work.

Today, with continued therapy and medication, Keith's condition has stabilized. He currently experiences trouble with his short-term memory, but is looking to improve his condition so that he can accomplish some key goals he set for himself, including marrying his girlfriend, returning to his company, working on web designing and driving a car again. Throughout his ordeal, Keith keeps a positive attitude and finds encouragement in his loved ones; strength to fight for his life; and the insight to realize the beauty and power of living each day with meaning. He is thankful for every moment he has to simply be alive.

Even though the aneurysm brought a lot of hardship to Keith's life, it did have positive impacts on it, as well. One such impact was that Keith was brought closer in his relationship with his brother Dave. From the inspiration of Keith's experience and the result it had on bringing the brothers closer together, Dave and family friend Mark Hamaguchi formed Pause Clothing. Based on the notion that everyone can benefit when you "pause" and realize the importance of your life and the significance of each moment we live, Dave and Mark are creating a line of graphically designed t-shirts and activewear that will remind us of that idea. They are currently designing art that will be universally uplifting to anyone suffering from roadblocks in their lives. Pause Clothing is donating a portion of its proceeds to The Brain Aneurysm and has already donated \$1000. For more information go to [www.pauselivenow.com](http://www.pauselivenow.com)



## An Opportunity to Participate in Current Brain Aneurysm Research

The Brain Aneurysm Foundation wishes to inform you of the opportunity to participate in an ongoing brain aneurysm study conducted by researchers at the Yale University School of Medicine, including Dr. Murat Gunel, a member of The Brain Aneurysm Foundation's Medical Advisory Board. This research has been continuing for over a decade and the researchers are still in search of subjects for this study on the causes and formation of aneurysms.

The study focuses on identifying genes responsible for the formation and bleeding of brain aneurysms. The recently-completed initial phase of the study, based on over 2,000 patients and 8,000 healthy individuals, successfully identified the first aneurysm susceptibility genes in European and Japanese populations. The results were published in the scientific journal *Nature Genetics* and have been extensively profiled by news media, including CNN and the BBC. The ultimate goal of this project is to extend the results to the American population and subsequently develop new methods of early identification of people afflicted with brain aneurysms which will lead to less-invasive, more-effective treatments for aneurysms.

All study records are confidential and there is no cost to participate. If you are interested, please contact Nikhil Nayak ([nikhil.nayak@yale.edu](mailto:nikhil.nayak@yale.edu) or 800-299-9528) or Andrea Chamberlain, RN ([andrea.chamberlain@yale.edu](mailto:andrea.chamberlain@yale.edu) or 203-737-2096).

The Brain Aneurysm Foundation believes that it is important to inform you of this research as well as the opportunity to participate.

# Twenty Minutes That Changed my Life

By: Judy Lynne Arena

**W**ith the help of family and friends and the gift of a second chance, I remember....

## TWENTY MINUTES

Last Memorial Day weekend I was awakened at eight o'clock with what I thought was a migraine headache. I had gone to bed late the night before, after a wonderful



and joyous day and evening, but this Sunday morning there was something strange about my head and neck. The ache and pain was piercing, something just wasn't right. I tried to ignore it, assuring myself that everything would be alright. I walked quietly to the front door and retrieved the morning paper. I was listening to the sound of the percolating coffee pot and reading the

headlines at the kitchen counter when involuntarily my left hand released its grasp and the papers spewed to the floor. A sharp agonizing pain generated from deep within my skull, my left side became numb as the pounding and throbbing of my head immediately disoriented me and I became extremely nauseous.

Something was not only wrong, it was radically wrong. My bodily coordination and my cognitive reasoning were being separated and I seemed like but a spectator to a cruel drama as I just sat on the floor perplexed and in a state of confusion and puzzlement. I knew instinctively that I needed to summon help from my companion Bill, who lay only meters away, but I chose or was unable, for some unexplained reason, to act on my premise. As I reached out my right hand to lift myself by the vanity I became aware that my left arm would not obey its commands.

I lay on the floor and remembered just wanting to die as the pain was becoming so excruciating. I actually thought that I would die, yet I was powerless to call out for help to my partner. I just sat there unable to express my fears into words or sounds. At that moment I looked up and saw a figure in the doorway that was

somewhat obliterated by the light. I was asked "Are you alright?" I somehow was able to utter the words calmly and in a soft yet determined voice "I think I'm going to die-we need an ambulance-you have to call 911". It seemed like an eternity, but I would later learn that it had taken place in the time span of only twenty minutes.

## THE AMBULANCE

My last cognitive thought for the next three days would be my directing the ambulance crew to take me to the nearest hospital. The morning of May 25th was a beautiful spring morning with a bright blue sky and brilliant sun, but I saw none of it as I passed in and out of consciousness throughout the short seven minute ride. Before the doors of the ambulance would open, I had lost all consciousness which I would not fully regain for three more days.

I would learn that we were met by medical personnel at the emergency department where no fewer than seven expertly trained staff members went through individual tasks in what would be a team effort to save my life. The next thirty to forty minutes, as I lay unconscious, were filled with confused phone calls among family and friends, as the people closest to me tried to make sense of the unbelievable rapid chain of events that families experience in an unexplained medical crisis.

## THE CRANIOTOMY

A neurosurgeon soon arrived and within minutes reviewed the CAT scan results with Bill and even his untrained eye had no difficulty seeing the black blot on the contrasted transparency that hung backlit on the wall. The surgeon explained that I had experienced a blood vessel burst deep within my brain, very near the brain stem. Immediate surgery was necessary to minimize the damage, without which I would assuredly die. He pointed to the location of the bleed in proximity to the central nerve stem, and indicated the procedure was very delicate and if he were to touch the brain stem "she will fall into a vegetative state". The procedure was agreed to and a new battery of phone calls to the

(continued on next page)

family resumed. I was being wheeled into surgery as my brain, my very life, was slipping away, moment by moment.

#### **THE INTENSIVE CARE UNIT-(ICU)**

After several hours in surgery the doctor gathered my family, which had now grown to almost a dozen people. He explained to them that I had suffered a hemorrhagic stroke or brain aneurysm and he had performed a craniotomy procedure to drain the area surrounding the hemorrhage of blood that escaped from the ruptured vessel. He indicated that although the procedure had gone extremely well, the next 72 hours would be critical to my survival: a re-bleed, another stroke, infection or clot were all at risk.

It would later be learned, that I was born with a congenital abnormality in my brain referred to as an AVM (Arterial Venous Malformation). It is an irregularity of the meeting of capillaries in the brain where blood is normally transferred between pressurized arteries and the awaiting veins.

#### **THE FIRST THREE DAYS**

Over the next several days, as I lay unconscious, my family marked my progress mostly by what turned out to be involuntary muscle spasms, as I was completely paralyzed from the neck down, due to the bleeding and swelling in my brain. Slowly I would regain mobility on my right side; however the bleed had damaged and impaired movement in my left arm and leg as well as speech and cognitive functions. Despite insurmountable challenges, I had survived my first seventy two hours.

In the first days that I drifted in and out of consciousness, my thoughts were different than before. I was awakened from my three day sleep as the same person that I was before the bleed, only I now had a different brain. My world had changed and it would soon become apparent that my thoughts, emotions and feelings would be affected more than anyone could have anticipated.

#### **THE HURT**

They saved my life but to be honest at the time I had been in such agony that I was disappointed to wake up. I thought that I had gone through all this pain to die and was frustrated to still be alive, to feel the throbbing once more.

Along with the pain from the bleed and the surgery I was in a state of total discomfort and confusion. The tubes and needles were everywhere; I just wanted to be free from this entire burden. All I remember was being too hot, the false sense that everything smelled bad and a terrible taste, accompanied by this awful excruciating pain; and not being able to communicate my discomfort to anyone.

After a few days they removed the breathing tube, my high threshold for pain had vanished and as anxious as I was to have it detached I turned panic stricken. I had become afraid of needles, fearful of even the simplest procedures and I was now super sensitive to noise and light.

#### **THE REHABILITATION**

Physical therapy began almost at once as it is believed that timing is everything in teaching our bodies to respond to our new mind. Once settled in the rehab center, I began a vigorous daily schedule of physical, occupational, speech and cognitive therapies. I would have to relearn the most rudimentary tasks that we all take for granted, such as bathing, dressing, walking, and eating. I even had to relearn the reflexive process of swallowing liquids so as not to drown in my own nourishment. I was unable for the better part of the first month to take juice, coffee or even water without powdered thickeners. All modesty went out the window, but I was taken very good care of by both men and women and of course family and friends helped in anyway they could.

Through time and hard work, I continued to improve daily, though my left side was slow to recover. I graduated from a wheel chair to a walker, then to a cane and leg support. This of course was over many weeks of therapy, hard work and my own determination. My friends became active in my therapeutic rehabilitation

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## Great Opportunities To Get Out and Walk For a Great Cause: New Walks Coming Up in Michigan, Indiana, and New York

Get out and get some healthy exercise and meet with other brain aneurysm survivors, remember and honor a loved one, and support brain aneurysm awareness and research at one of the many upcoming walks around the country.

Join over 300 walkers and runners for The 8th Annual Arterial Challenge 5K Road Race and 1.5 Mile Walk For Brain Aneurysm Awareness on May 24th, Marshfield, MA

The 2nd Annual Danielle Bledy Memorial 5K Run/ 1 Mile Fun Walk will take place in Cherry Hill, NJ on May 31st.

Join in for the 1st Health Services Brain Aneurysm Walk in Evansville, IN on Saturday, September 12th, which will take place on the campus of the University of Southern Indiana.

For those of you in Michigan, please come and participate in the The Freddie Harris Memorial Walk/ Fun Run in Belleville, MI on Saturday, September 19th.

Walk along the boardwalk by the seaside on October 2nd at Jones Beach State Park at the 1st Brain Aneurysm Awareness Walk in Wantagh, NY, sponsored by The North Shore\_LIJ Health System Brain Aneurysm Center, Harvey Cushing Institutes of Neuroscience and The Brain Aneurysm Foundation.

Join in once again at The 2nd Annual 5K Run/3K Walk for Brain Aneurysm Awareness and Hope on October 10th in Schertz, TX, just outside of San Antonio.

Come join in as 1,000 runners and walkers celebrate The Second Annual Brain Aneurysm Race for Awareness 8K in Memory of Timothy Susco in Reston, VA on October 17th.

For more information and to register online for any of these great events, please go to [www.bafound.org](http://www.bafound.org)

Interested in starting a walk/run in your area? We can help you too. Please call us at 781-826-5556 or email [office@bafound.org](mailto:office@bafound.org).

## An Event on Ice to Warm the Heart



Jeremy Altman, a 12 year old 7th grader at George White Middle School in Hillsdale, NJ, promoted brain aneurysm awareness while honoring his aunt, a brain aneurysm survivor. Jeremy's ice skating fundraiser

took place on Sunday, March 1, 2009 at the Ice House in Hackensack, NJ with all proceeds going directly to The Brain Aneurysm Foundation.

The concept for the fundraiser, which started out as Jeremy's Bar Mitzvah project, was to raise awareness and funds for brain aneurysm research. Jeremy's Aunt had miraculously recovered from a major brain aneurysm two years ago. Jeremy credits his aunt's doctors and The Brain Aneurysm Foundation for the help and research they provided. When planning the fundraiser, it was natural that Jeremy would turn to skating for inspiration. "Aunt Rozy would appreciate my idea because she is a hockey mom," said Jeremy. He scheduled an event where participants could have fun skating while raising money for The Brain Aneurysm Foundation and raising awareness for the devastating disease.

## Racing In Memory of Mom

**B**radley Paster of Westwood, MA is racing in memory of his mother, Sally Jane Paster, who died suddenly from a brain aneurysm at the young age of 55.

From his webpage, Bradley writes:

When I was growing up, my mother and father were always supportive of my sports endeavors. I remember both of them volunteering and participating in all of the MS bike rides I did in high school, as well as coming to all of my various sporting events in high school and college.

Although it has been 12 years since my mother has passed away from a brain aneurysm, I have always struggled with the best way I could help serve her memory. Since I enjoy doing triathlons, it struck me that doing triathlons in her memory to support The Brain Aneurysm Foundation was the perfect fit. Unfortunately, there is research that suggests that brain

aneurysms are hereditary, so not only am I racing in memory of my mother, but also for myself, my children, my sister and her children.

This summer, I am participating in three sprint-triathlons in my mother's memory:

- Marlborough Triathlon on July 26th, 2009
- Lowell Wild Cat Sprint Triathlon on August 9th, 2009
- Dover-Sherborn Boosters Triathlon on September 20th, 2009

As a husband and a father I want to make sure that I am around to enjoy all that life has to offer with my family and giving back to The Brain Aneurysm Foundation is one way I can help support this life saving research. To support Bradley, please go to his website <http://bafound.donorpages.com/PasterTriathlon/bradpaster> and donate.

## Brain Aneurysm Early Detection Video Hopes to Reduce the Rate of Brain Aneurysm Ruptures

The Brain Aneurysm Foundation is pleased to announce the completion of a new educational video on the importance of the early diagnosis and treatment of brain aneurysms. The video will be distributed nationwide to ER's, Neuro Departments, and EMT/EMS Educators. The concept is for those who are first responders to someone presenting with brain aneurysm symptoms to think "aneurysm" and do the necessary scanning in order to reduce the incidence of ruptures and death. For the medical community, a greater awareness of the signs and symptoms of brain aneurysms will hopefully lead to a brain scan and proper diagnoses before a subarachnoid hemorrhage (SAH) occurs.

The video is accredited through Vanderbilt University School of Medicine for 1.0 AMA PRA Category 1

Credits to ensure more viewing and increased use in educational programs. To obtain CME credits, go to [www.bafound.org](http://www.bafound.org) and click on CME Course.

A shorter version of this video is posted on YouTube to increase overall brain aneurysm awareness.

Many thanks to Bill Demmer for funding the production of the video in memory of his wife Shirley Demmer.

Many thanks as well to Boston Scientific who provided sponsorship through an educational grant for the distribution of the video.

Please help us to save lives and make your medical professionals aware of this CME accredited course by referring them to [www.bafound.org](http://www.bafound.org) to watch the video or to request a hard copy for their facility.

## Adopt an Ironman Athlete!

**Y**ou may not desire to become a triathlete yourself, but wouldn't it be nice to use your network of family, friends, and co-workers to help support a member of TeamCindy in raising awareness and funding for brain aneurysms?

TeamCindy honors the life of Cynthia Lynn Sherwin and promotes widespread public awareness of the dangers of a ruptured brain aneurysm - the sudden and silent killer that took her life and the lives of tens of thousands each year. Cindy was a dedicated athlete, marathoner and triathlete. She was struck down at the young age of 33 while training for her first Ironman competition, Lake Placid 2007. TeamCindy enables and encourages athletes to participate in triathlon events in Cindy's name and to raise awareness and money to continue the fight against this deadly disease through The Brain Aneurysm Foundation.

We have five triathletes participating as part of TeamCindy at the Lake Placid Ironman on July 26, 2009. They are all dedicated so much already with their commitment to participate and train and could really use your help in fundraising to help combat the devastation caused by brain aneurysms.

### FRANK EECKMAN

Frank Eeckman, M.D., PhD will be competing in the Lake Placid Ironman as part of TeamCindy, in honor of Cindy Lynn Sherwin, who lost her life at age 33 while training for her first Ironman event. Frank was touched by Cindy's sad story in The Brain Aneurysm Foundation's newsletter and wanted to compete in the Lake Placid Ironman event in Cindy's memory to to benefit The Brain Aneurysm Foundation and to raise brain aneurysm awareness and funding.



Dr. Frank Eeckman is an analyst and consultant at NeuroInsights helping companies and investors identify and vet opportunities in neurotechnology. He writes indication and company features for Neurotech Insights, the neurotechnology industry newsletter published by NeuroInsights. Dr. Eeckman holds an MD cum laude from the University of Ghent Medical School, Belgium, where he was trained as a neurologist. He also earned a PhD in

Neurophysiology at the University of California Berkeley, where he was a Fulbright Scholar.

Frank would not call himself a natural athlete. He started quite late in his mid 30's. But, it wasn't until 2003 that he decided to start competing for real. Since then he has run in 9 marathons, including the Boston Marathon, and competed in numerous triathlons.

Frank is excited to be competing in the Lake Placid Ironman as part of TeamCindy. To help Frank, visit [TeamCindy.org](http://TeamCindy.org) and click on his name.

### TIM ANDRUS

As a 28 year old husband, father and Ironman, this year I decided to try and give a little back. When I found out The Brain Aneurysm Foundation was trying to utilize the Ironman platform to help raise money for this cause, I couldn't help but find the perfect fit. I too was looking to race again at Ironman Lake Placid and was also trying to find a way I could give back. This seems like a perfect fit to me!

I will start by telling you a little bit about myself. I have a loving and very understanding wife who is an amazing mother to my four children. I have two sets of twins ages 5 and 4, so as one could probably guess, my wife is just about as busy as one could get. Thankfully my career as a utility employee is not quite as demanding as some professions allowing me time to be with my family. When it comes to understanding the time that it takes to train for an Ironman event my wife reminds me every day why I married her.

I have been racing triathlon for 3 years now and have successfully started and finished one Ironman distance event. It happened to be in this fantastic venue last year. I can tell you first hand that it is a grueling event, but as challenging as it is I could only imagine the challenges that exist for those who have had a Brain Aneurysm.

I hope to raise as much money as possible for this cause in order to help us learn more. As we all know research is not inexpensive and certainly is valuable. Every thing we learn about this disease can help us take one step closer to prevention, early detection and



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## Determining the Likelihood of Rupture and Need for Treatment

By: J Mocco, M.D.

Recent research, funded in part by The Brain Aneurysm Foundation, has demonstrated that there just may be a better way to evaluate the likelihood that an aneurysm may rupture. Subarachnoid hemorrhage, which is what happens when a brain aneurysm ruptures, is a devastating disease. However, the treatment of unruptured aneurysms is not without its own significant risk. Therefore, the trick is to identify for treatment those aneurysms that are at a high risk of rupturing, while not risking treatment on those aneurysms that are unlikely to rupture.

Traditionally, the tool used to make this estimation has primarily been the size of the aneurysm. However researchers have now identified that it may not be the absolute size of the aneurysm but rather it is the size of the aneurysm in relationship to the parent vessel from which the aneurysm has grown. This new method of generating a "Size Ratio" to stratify aneurysm risk may have substantial implications on who may or may not benefit from treatment of their aneurysm.

The evidence to support this new algorithm comes from two recently published papers. The first examined a series of patients with aneurysms, some of which had ruptured and some of which had not. The investigators

then used statistical tests to determine which type of measurement Size or Size Ratio (as well as a number of other types of measurements) would be the best predictor of whether an aneurysm had ruptured or not. This data demonstrated that Size Ratio was the statistically better predictor. The second paper attempted to determine why Size Ratio might be so important. In this paper the researchers created virtual aneurysms in a computer and used computational fluid dynamics, a fancy way of saying virtual blood flow, to evaluate how the flow and stress within an aneurysm changes when the Size or Size Ratio changes, even when holding the other constant. The authors discovered that even when Size (and shape) was kept constant, changing just the Size Ratio resulted in drastic changes in the flow and stress within the aneurysm. In fact, higher Size Ratios were consistently associated with flow characteristics and aneurysms stress profiles that have previously been shown to be associated with ruptured aneurysms.

With this developing understanding of what causes aneurysms to have a high risk of rupture, it may turn out that people with aneurysms can better know whether or not they should undergo the risk of treatment.

## All That Jazz!

March 29th at the Fairmont Copley in Boston was all abuzz for The Brain Aneurysm Foundation's 15th Anniversary celebratory jazz brunch honoring founders Dr. Christopher Ogilvy, M.D. and Deidre A. Buckley, N.P. With an overflow crowd in attendance, the founders were humbled by the words that were shared about the impact they have had on the lives of many.

We would like to thank Gail Bickford, Bill Courtney, and Dr. Reese Cosgrove for all taking the time to help The Brain Aneurysm Foundation fete two worthy people for their 15 years of commitment to the Foundation in an effort to help and support those affected by brain aneurysms. Neither Dr. Ogilvy, nor Dede ever anticipated the growth and success that the Foundation has achieved and continues to achieve.



Here's to many more years of continued success!  
Thank you Dr. Ogilvy and Dede for all your hard work and inspiration.

## Save the Date—2009

May 24

8th Annual Arterial Challenge 5K Road Race  
[www.bafound.org](http://www.bafound.org)

May 31

2nd Annual Danielle Bledy Memorial 5K Run/1  
Mile Fun Walk, Cherry Hill, NJ

July 20

4th Annual BAF Golf Tournament at Indian Pond  
Country Club, Kingston, MA

September 17

The 3rd Annual Brain Aneurysm Foundation  
Research Grant Symposium  
The Union League, Chicago, IL

September 19

The Freddie Harris Memorial Walk/Fun Run in  
Belleville, MI

October 3

Brain Aneurysm Awareness Walk, Jones Beach,  
Wantagh, NY

October 10

2nd Annual 5K Run/3K Walk for Brain Aneurysm  
Awareness and Hope outside San Antonio, TX

October 17

Brain Aneurysm Race for Awareness 8K in Memory  
of Timothy Susco, Reston, VA

### Are You A Federal Employee?

The Brain Aneurysm Foundation is now a qualified charity with the Combined Federal Campaign so that Federal civilian, postal and military donors can make pledges to support the foundation. We thank all those who have made pledges for The Brain Aneurysm Foundation, which have already this year resulted in over \$5,000.00 in donations. Our charity identification number is 74342. Thanks to Sheryl Baker of Silverdale, Washington for suggesting we enroll in the program.

### Do You Twitter?

If you are on Twitter, please follow our tweets under BRAINANEURYSMS

## Annual Report 2008

The Brain Aneurysm Foundation's 2008 Annual Report is now available online. Go to [www.bafound.org](http://www.bafound.org) and click on the About Us tab. If you would like to receive a copy, please email [office@bafound.org](mailto:office@bafound.org) or call 781-826-5556.



## Jewelry Designer Donates Sales Proceeds To Benefit The BAF

Chicago Jewelry Designer, **Sarah Radford of Chic Gems Etc.** has teamed up with The Brain Aneurysm Foundation and the Brainstorm Chicago Brain Aneurysm Support Group to broaden support and increase awareness for this condition.

Interested shoppers can visit the website – [www.chicgemsetc.com](http://www.chicgemsetc.com) and receive 10% off any purchase, simply enter the coupon code "baf" at check out. Designer Sarah Radford will be donating 20% of proceeds to the foundation.

Brainstorm Chicago was formed in 2007, specifically to bridge support to survivors and caregivers. The Brainstorm Chicago Brain Aneurysm Support Group was established with the support of The University of Illinois Medical Center at Chicago.

and passed along my triumphs to both family and friends. No one let me rest or escape my scheduled classes. I now see it as a good thing, but at the time I found everything and most everybody to be an intrusion. I wanted to be left alone, however no one would let me be. Good thing - they all had a lot to do with my recovery.

I progressed ahead of schedule at the brain rehab center thanks to the exceptional care and attention I received from a wonderful team of dedicated doctors, therapists and health care workers. I was discharged two weeks earlier than originally planned, to continue my remaining months of therapy as an outpatient.

#### **LUCKY**

The doctors, though amazed, don't tend to speak in spiritual terms. They don't refer to my recovery as a miracle but note how "lucky" I was to survive and recover so well. I was lucky to have gone to a nearby hospital and received a quick diagnosis on a holiday weekend and to be so quickly triaged and that a skilled neurosurgeon was on call. I was lucky that the emergency surgical procedure was accomplished without incident or complications and I was lucky not to be counted in the one in four patients who do not survive an AVM hemorrhage. I was truly a blessed person and I was fortunate to be surrounded and supported by the love and concern of both family and friends.

I had been a healthy five foot ten 145 pound 52 year old, who neither drank alcohol nor smoked. I lived an active life, worked full time and in the summer liked to sun, sail and snorkel, while in the winter I would ski, hike and snow shoe. I was brought up in a health conscious family, my father was a holistic chiropractor, who insisted we maintain a low sugar, carbohydrate, and sodium diet—the normal culprits of hypertension and stroke. Unfortunately, all these preventative measures can not overcome what we are born with, but they have been acknowledged as playing a big part in my subsequent survival and recovery.

#### **MY PROGNOSIS**

After another CAT scan and several brain angiograms, it has been determined that I am not a good candidate for conventional surgery to remove the remaining malformation due to its precarious location. I still face what will hopefully be a final procedure that will direct a focused beam of radiation on a very small portion of the remaining AVM.

I now am learning to lead my life as an independent, self-reliant woman. With the constructive support and encouragement of family, friends and a dedicated medical staff, I am becoming physically and emotionally stronger each day.

I have relearned to drive my car and again can tend to activities, such as grocery shopping and doctor appointments. I am able to spend time with my new grandson which has meant the world to me and in no small part has hastened my recovery. Watching my grandson learn to speak, feed himself and walk has held a special interest for me. I can see myself in him as he learns and I relearn new tasks and activities.

#### **MY FOCUS AND OUTLOOK**

I now focus less on the past, but live each day as it comes and once again look forward to my future. I don't dwell on what was, but concentrate on what is, and instead of longing for the past I yearn for ten thousand tomorrows.

Prior to my bleed, I worked as a tireless perfectionist trained in several disciplines. I loved my work, my coworkers and patients alike. I enjoyed being a woman and concentrated, was even preoccupied, in looking my best. I now keep my hair short and am pleased with the salt-and-peppered graying that has emerged. Makeup has become a rare activity. I still very much enjoy being a woman, now just a natural woman. I am alive and again looking forward to enjoying life each day, at the highest possible level.

# Celebrating The Brain Aneurysm Foundation's 15th Anniversary

By: Ginny Comstock Tocci

On March 29th, about 150 people gathered in Boston to celebrate The Brain Aneurysm Foundation's 15th Anniversary and to honor two of its founders, Christopher Ogilvy, MD and Deidre Buckley, NP. When the concept of The Brain Aneurysm Foundation was conceived 15 years ago, it would have been impossible to predict how the organization has grown. The Brain Aneurysm Foundation started in Boston, but its impact is felt way beyond Boston, across the nation, throughout the world.

Every day we receive calls from every part of the nation and Canada. Emails come in from all over the world. Aneurysm survivors and their families, who have all been touched in some way by the diagnosis of a brain aneurysm, contact us seeking information and support from The Brain Aneurysm Foundation. In many cases, the outcomes after a brain aneurysm rupture are not always happy, and there are many who have lost loved ones as a result of aneurysm rupture. For those families that have lost a loved one, and for those whose outcomes are a challenge, The Brain Aneurysm Foundation offers information, support and hope as we strive to bring awareness to increase earlier detection of aneurysms and to fund innovative

research directed at early detection, improved treatment modalities, and technological advances that will ultimately improve outcomes for patients with brain aneurysms.

We are grateful for the many people across the nation who feel passionately about The Brain Aneurysm Foundation and have so generously given their donations, time, energy, resources, and intellect. They have worked tirelessly to start support groups, to organize fundraising events and to promote awareness in their communities. All have been touched in some way by the diagnosis of a brain aneurysm and have found The Brain Aneurysm Foundation as a way to connect, share, and make new friends. The size of this of a circle of friends, who have shared, either personally or through a family member or friend, the impact of this life-altering event, keeps growing day by day. From Boston to Honolulu, from Seattle to Cherry Hill, The Brain Aneurysm Foundation continues to grow. So while we celebrate the foundation's 15th Anniversary, we salute everyone across the nation who has been a part of the incredible growth we have experienced.

## Words From Brain Aneurysm Survivors and Their Families

"Thanks for facilitating the connection between brain aneurysm survivor Gabrielle and myself. She and I have become great friends and hope to meet in person one day. I think we have truly helped each other recover from an experience that neither one of us would ever have expected. Thank you for being a source of information and encouragement to me." Sharon

"I had an aneurysm rupture and two strokes about 7 months ago. Just reading through the information on your website makes me feel like someone understands

what I am going through. Thank you for that, it has helped a lot in trying to be better." David

"If it wasn't for your website when I was diagnosed, I would have been so lost. The video had a lot of great info and really helped prepare me for my surgery." Alva

"My father had an aneurysm. I was on your website and we have been really struggling with my dad, but when reading about other people who had also had aneurysms, I was better able to understand why my father was doing the things he was doing. I can't thank you enough." Sharon

## Congrats to Dede!

Congratulations to BAF Founder Deidre A. Buckley, NP for being selected as one of the top 3 nurses in the state of Massachusetts by The Boston Globe's 2009 Salute to Nurses

(continued from page "Adopt an Ironman Athlete!")

effective treatments. The scary part of this disease is the fact that it shows not prejudice as to whom it affects. We are all in this fight together!

Please help me in my efforts. To help Tim, visit [TeamCindy.org](http://TeamCindy.org) and click on his name.

### **R. LOCH MACDONALD, M.D., PH.D.**

Often people want to help and are not quite sure how, so adopting a triathlete may be a good way to get started! My goal is to raise \$3000.00

R. Loch Macdonald, M.D., Ph.D. is the Division Head of Neurosurgery at St. Michael's Hospital, Keenan

Endowed Chair and Professor of Surgery in the Division of Surgery at the University of Toronto, Toronto, Ontario, Canada. He has dedicated his professional life to the treatment of patients with brain aneurysms and blood vessel diseases. In his spare time, he exercises to for enjoyment and to stay fit and strong for his patients.



He studies cerebral vasospasm which is a complication of aneurysm rupture and that takes the lives of some patients who survive the initial rupture of their aneurysm. He has published hundreds of scientific articles on aneurysms and vasospasm, had millions of dollars in funding for research on aneurysms and vasospasm and is working to bring new treatments to patients with ruptured aneurysms through his company, Edge Therapeutics.

He has been a runner since high school and has run about 15 marathons, including qualifying for and finishing the 100th Boston Marathon in 1996. He was the Illinois masters champion at the Chicago marathon in 2001. He started competing in triathlons in 1998 and has done 3 Ironman events, including qualifying for and completing the Ironman World Championships in Hawaii in 2004. His goals at Lake Placid are to raise money for brain aneurysm research and qualify for Hawaii again.

Dr. Macdonald has been married to Sheilah for over 20 years. They have 3 fantastic kids. His family is the strength that gets him through the long days in the operating room, the laboratory and those weekends in the pool, on the bicycle and running path.

To help Loch, visit [TeamCindy.org](http://TeamCindy.org) and click on his name.

### **MIKE FEYKO AND ANGELA VAVASORI**

I am a Canadian golf professional living in Baltimore, MD with my wife Angela. We are racing together to raise money for [TeamCindy.org](http://TeamCindy.org) via Lake Placid Ironman 2009. This will be my 6th Ironman to date and Angela's 1st.

I served in the Canadian Armed Forces for 10 years. My military career was cut short in November 1997 when performing a parachuting training exercise in Edmonton, Canada. My parachute collapsed and I fell from 75 feet onto the frozen tundra. Miraculously I survived the accident but not unscathed. I broke 9 bones below my waist among a multitude of other injuries. At the time doctors didn't know my prognosis for walking let alone running or hockey – the two sports I have been passionate about and competing in my entire life. I was dismissed from the military on disability and spent the next 3 months in a wheel chair and 8 months on crutches. The doctors told me I would never run or be able to play hockey again. I started swimming for rehabilitation. Then I started aqua jogging. I decided I needed something to challenge myself so I set my sights on something bigger than anything I had done both pre and post accident. One day I saw a flyer at the pool for a sprint triathlon and knew that was my next step. Seven and a half years later I crossed the line at Ironman Canada. Since then I have completed Ironman Canada every year and last year I finished Ironman Coeur d'Alene as well. I was blessed to survive my accident and have found a new passion for exercise and physical endurance. I will never have the same abilities as I did before my accident but I have defied the odds and not only can run again but I can complete an Ironman.

After reading Cindy's story I was compelled to race in her honour and for the benefit of [Teamcindy.org](http://Teamcindy.org). My wife is a competitive triathlete and turns 33 this year. She has wanted to venture into the Ironman distance and after reading Cindy's story decided to race for the charity as well. We are humbled to be able to raise money for a wonderful charity and together have the opportunity to try to complete something as awe inspiring as an Ironman.

To help Mike and Angela, visit [TeamCindy.org](http://TeamCindy.org) and click on their names.



# DONATE

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**.

## Please check donation level

- Supporter, up to \$49
- Circle of Friends, \$50 – \$99
- Silver Circle, \$100 – \$249
- Golden Circle, \$250 – \$499
- Platinum Circle, \$500 – \$999
- Diamond Circle, \$1,000 – \$4,999
- Board of Directors Circle, \$5,000 – \$9,999
- Research Circle, \$10,000 or greater

## Gift Instructions

### Donate by check

Check enclosed for \$ \_\_\_\_\_

(Please make your check payable to The Brain Aneurysm Foundation and mail to: The Brain Aneurysm Foundation, 269 Hanover Street, Building 3, Hanover, MA 02339)

### Donate by credit card

\* Charge my/our **one time** gift of \$ \_\_\_\_\_

Donate **Monthly Pledge** by credit card

\* Charge my/our **monthly** gift of \$ \_\_\_\_\_

### Credit Card Information

Name: \_\_\_\_\_

Type:  Visa  Mastercard  Discover  AMEX

Card Number: \_\_\_\_\_

Expiration Date: \_\_\_\_\_

Your Name: \_\_\_\_\_

Address: \_\_\_\_\_

City: \_\_\_\_\_ State: \_\_\_\_\_ Zip: \_\_\_\_\_

Phone: ( ) \_\_\_\_\_

Email: \_\_\_\_\_

If you prefer to donate online, please go to [www.bafound.org](http://www.bafound.org) or to give credit card information by telephone, please call (781) 826-5556. Your gift of any amount will be deeply appreciated and most helpful. Thanks for your support.

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