

# A Thinking Ahead

Brain Aneurysm  
Awareness Month pg. 3

The 3rd Annual Research  
Grant Symposium in  
Chicago, IL pg. 5

Team Cindy  
Gathers Speed pg. 8

Runs and Walks  
Abound!!!! pg. 9

Support Group News pg. 13

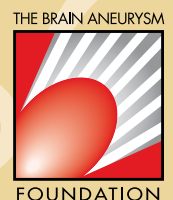
Words From Brain  
Aneurysm Survivors and  
Their Families pg. 16



New BAF Public Service Announcement with  
Keith Lockhart, Peter Gammons, Charlie Austin  
and Amanda Kennedy. See page 3 for the full story.

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## First Public Service Announcement Released

We are excited to announce the release of our first Public Service Announcement (PSA) for brain aneurysm awareness. We were thrilled to have Keith Lockhart, conductor of the Boston Pops, Peter Gammons, baseball sports analyst, Amanda Kennedy, actress and CEO of Sassybax and Charlie Austin, Boston newsman, participate in this effort. It is available in a 30 second spot for both TV and radio.

The PSA was accepted for inclusion by NBC Universal across all their networks and many additional placements were made nationwide.

Please help us increase awareness by getting this aired in your community. To view the PSA, go to the BAF website at [www.bafound.org](http://www.bafound.org).

For copies of the PSA, please contact [office@bafound.org](mailto:office@bafound.org).

## Brain Aneurysm Awareness Month

By Ginny Comstock Tocci

September was Brain Aneurysm Awareness Month nationwide with many states officially making proclamations declaring Brain Aneurysm Awareness Month. Many healthcare facilities and community groups promoted Brain Aneurysm Awareness in their hospitals and communities by providing information and handing out educational information and awareness materials. This year we distributed thousands of magnets listing brain aneurysm symptoms and alerting those experiencing the symptoms to seek medical attention immediately. We appreciate the efforts of all the volunteers who work to make others more aware of the devastating effects of this disease.

Those who have been affected by brain aneurysms- survivors, families, caretakers, friends, entire communities- know first hand the impact a brain aneurysm rupture can have. Some families mourn the loss of a loved one, while others face incredible challenges in recovery for an aneurysm survivor. For the most part, no one really knows what the words "brain aneurysm" mean, until you have to learn them because you or someone you care for is affected by a brain aneurysm.

The Brain Aneurysm Foundation is trying to change that. We work every day to promote more awareness and to foster earlier detection of brain aneurysms which is key for better treatment and recovery. This year we produced a new Public Service Announcement (PSA) with Keith Lockhart, Peter Gammons, and Amanda Kennedy which was broadcast nationwide to bring

more awareness to aneurysms. We also created a new video aimed at early detection of brain aneurysms which was distributed to health professionals at over 4000 hospitals nationwide. The walks and other events across the nation brought more awareness to thousands of people who participated or supported someone who was a participant.

Without your help, none of this would have happened. With your generous donations of time and money, we were able to achieve much this year to bring more

awareness to this often devastating disease. If we can make one more person aware of the symptoms of brain aneurysms and seek medical advice promptly, if we can make one more medical professional consider screening for a brain aneurysm, if we can save one more life, we have all had a tremendous impact together.

**If you are experiencing any of these symptoms, seek medical attention immediately!**

- Sudden Severe Headache (worst headache of your life)
- Stiff Neck
- Nausea/Vomiting
- Blurred/Double Vision
- Change in Mental Status/Awareness
- Seizure
- Sudden Trouble Walking or Dizziness
- Sudden Numbness or Weakness of Face, Arm or Leg
- Pain Above/Behind the Eye
- Drooping Eyelid

The Brain Aneurysm Foundation  
[WWW.BAFOUND.ORG](http://WWW.BAFOUND.ORG)

## I Thank You!

By: Christine Buckley

Recently we sent out our annual Thanksgiving Appeal letter. Enclosed in the letter was a reply card for people to tell us why they are thankful for The Brain Aneurysm Foundation. We thought this would be a good way to engage some people to tell us what things they like about the BAF and what the BAF does and perhaps let others give some constructive criticism. It is nice to know what is done well and what needs improvement, as nothing is perfect.

I started to think to myself, why am I thankful for The Brain Aneurysm Foundation? There are the readily obvious reasons. This BAF is where I work and it provides a job to go to every day which allows me to do things for other people. The BAF is constantly growing and there is so much to be done every day it is never dull or boring. Where this Foundation goes is limitless and I for the moment am a part of the adventure of its destiny. I, unlike many people these days, have a job and better than that, I truly like my job.

But beyond this, I am thankful for the people the BAF has introduced me to and the focus it gives me every day that allows me to realize what is important in life. We all have our daily gripes, things we wish were different, and our own complaints no one wants to hear, I am no different. However, I have not danced with death and neither has anyone in my family due to a brain aneurysm, I have not recovered from brain surgery and neither has anyone in my family, I have not lost my job due to disability from the treatment of a brain aneurysm, I have not had to become a caregiver on a daily basis to a loved one recovering from a brain aneurysm, and I have not lost a loved one to a brain aneurysm. I am thankful I have been spared these realities so many I now call my friends have faced. But, I am even more thankful for the opportunity to have come to know those who have seen death and turned it away, as well as those who have rearranged their entire lives to most lovingly and in the most dignified manner

become a caregiver to their once very independent loved one. And for those that I have met who have suffered a painful loss, yet still manage to give of themselves in an attempt to spare some else a similar loss, I don't know how you do it so well.

The inspiration, strength, and determination I have seen from so many of you and how well you have handled life's curve balls thrown your way, is a gift and life lesson I could not find elsewhere. I spoke at a local support group in October. I can remember when the night came; I was tired, and was thinking I wish I could just go home. The meeting was small, four groups of people. Both survivors and caregivers in each of these groups had all experienced a near loss of a loved one or themselves, some of them were still in the midst of recovering, some were unable to walk without help, but each person in that room was smiling and so very appreciative of the good in their life and life itself. I left that room that evening so very happy I had been invited to attend, and felt that in some strange way the support group was more for me than anyone else.

I would be remiss if I did not say I am thankful as well for the physicians, nurses, rehab specialists, and all the medical professionals I have met who treat and care for those affected by brain aneurysms. I have had my eyes opened to a huge world of bright, talented, committed, and caring people who respect their patients, their families, and their circumstances. It is their commitment to excellence that helps set many patients on the path to a better recovery.

So, for all the wonder that The Brain Aneurysm Foundation has brought into my life through the many people I have met, I am forever grateful. Thank you.

Warm Wishes-

*Christine*

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)

## The 3rd Annual Research Grant Symposium in Chicago, IL

On September 17, 2009, The Brain Aneurysm Foundation awarded \$145,000 in research grants at the Union League Club of Chicago for basic scientific research directed at early detection, improved treatment modalities, and technological advances that will ultimately improve outcomes for patients with brain aneurysms.



The Susco family of Virginia, Tom, Nancy, and Tom Jr. at the Research Symposium to present the Timothy Susco Chair of Research Grant

The 2009 Research Grant Symposium was jointly-sponsored by Northwestern University's Feinberg School of Medicine and The Brain Aneurysm Foundation. The event was hosted by Robert Rosenwasser, M.D. FACS, Professor of Radiology and Neurosurgery at Thomas Jefferson University Hospital. Dr. Rosenwasser is the Chairman of the Foundation's Research Grant Committee. The course director for this program was Hunt Batjer, M.D., the Michael J. Marchese Professor of Neurosurgery and Chairman of the Department of Neurological Surgery at Northwestern University's Feinberg School of Medicine and Chairman of the Department of Neurological Surgery at Northwestern Memorial Hospital.

### The guest speakers for the evening were:

- Robert Brown, M.D.- Chair, Neurology Department at Mayo Clinic in Rochester, Minnesota
- Fernando Vinuela, M.D.- Professor of Radiology, Director, Interventional Neuroradiology Division Department of Radiological Sciences, Ronald Reagan UCLA Medical Center in Los Angeles, California

### The 2009 research grant recipients were:

- Brian Hoh, M.D. - \$40,000 Anna Orthwein Chair of Research - "Inflammation and Cerebral Aneurysms: Therapeutic Targets for Modulation and Vascular Repair"- McKnight Brain Institute in Gainesville, Florida
- Gregory Zipfel, M.D., - \$40,000 Anna Orthwein Chair of Research - "Endogenous Protective Mechanisms Against Cerebral Vasospasm" - Washington University in St. Louis, MO
- Byung Hee Han, Ph.D. - \$20,000 Shirley Dudek Demmer Chair of Research - "Matrix Metalloproteinase - 9 in Neurovascular Dysfunction Following Subarachnoid Hemorrhage" - Washington University in St. Louis, Missouri
- Michael Stiefel, M.D. - \$20,000 Timothy Susco Chair of Research - "Characterization of the Relative Roles of Coagulation and Cerebral Vasospasm in Neuronal Injury following SAH" - University of Pennsylvania in Philadelphia, PA
- Tom Schweizer, M.D. - \$15,000 Cynthia Sherwin Chair of Research - "Neurocognitive, Neuroimaging, and Functional Profile of Patients after Aneurismal Subarachnoid Hemorrhage" - St. Michael's Hospital in Toronto, Ontario
- G. Edward Vates, M.D.- \$10,000 The Brain Aneurysm Chair of Research - "Manipulation of Endothelial glycocalyx to improve microcirculation after SAH" - University of Rochester, School of Medicine in Rochester, New York



Dr. Robert Rosenwasser, Dr. Hunt Batjer, Dr. Robert Brown, Dr. Fernando Vinuela

The evening was a great success. Those in attendance included medical professionals, medical companies, survivors, family members and friends. Please continue to keep abreast with brain aneurysm research at [www.bafound.org](http://www.bafound.org).

A special thank you to the University of Illinois Support Group for putting together a wonderful video presentation on the importance of brain aneurysm support groups. This was a wonderful addition to the evening.

# North Shore University Hospital Joins The Brain Aneurysm Foundation for Long Island's First Brain Aneurysm Awareness Walk

By Betty Olt

More than 300 walkers and runners hit Jones Beach's boardwalk to raise funds for research, education and awareness of brain aneurysms. With overcast skies and occasional glimpses of sun, more than 300 spirited individuals recently turned out at Jones Beach to support Long Island's first Brain Aneurysm Awareness Walk, organized by the Harvey Cushing Institutes of Neuroscience Brain Aneurysm Center at North Shore University Hospital (NSUH) in Manhasset and The Brain Aneurysm Foundation.

Supporters included doctors, nurses and staff members of the Brain Aneurysm Center and the North Shore-LIJ Health System; KJOY, of the Long Island Radio Group, as well as brain aneurysm survivors, their families and friends. Participants at the event also paid tribute to

Jessica Lynn Nolan, a senior at CW Post Long Island University, who died earlier this year from a ruptured brain aneurysm. Many of Ms. Nolan's family members, friends and sorority sisters from Delta Phi Epsilon remembered Jessica by wearing her sorority's emblem and T-shirts printed with "We love JNO."



Neurosurgeon David Chalif, MD, co-director of the Brain Aneurysm Center, also recognized Ms. Nolan, saying "That despite heroic efforts to save her life, she fought a war and didn't win." Dr. Chalif said the more than \$45,000 raised from the event will help to increase awareness and research to prevent the tragedy of brain aneurysms.

Dr. Chalif and Avi Setton, MD, co-directors of the Brain Aneurysm Center, honored all the brain aneurysm survivors at the walk, most of whom were patients they had treated at NSUH, as well as family and loved ones who supported them throughout their recovery. Ginny Tocci, Director of Development and Administration at The Brain Aneurysm Foundation, thanked participants and volunteers for their tremendous support.

One brain aneurysm survivor, Erin Lakios, 44, of Mount Sinai, a mother of four, spoke on behalf of all survivors, thanking the doctors and nurses at the Brain Aneurysm Center. "The amount of support I received from the hospital, my family and my community was amazing. I'm grateful for a second chance at life," she said.

NSUH's Brain Aneurysm Center, which is supported by a 16-bed neuro critical care unit, offers state-of-the-art diagnosis and multimodality treatments for incidental or ruptured brain aneurysms. The ICU serves patients throughout Long Island, Queens and other areas.

For more information about the Brain Aneurysm Center, please call Nicole Salant RN, Brain Aneurysm Nurse Coordinator at (516) 562-3815.



## House Resolution 263 is still active and in need of co-sponsors: Please support September as National Brain Aneurysm Awareness Month!

Midway through 2009 Representative Patrick Tiberi of Ohio presented House Resolution 263 on the House floor and it continues to remain active legislation looking for support to establish September as National Brain Aneurysm Awareness Month.

The Brain Aneurysm Foundation asks you to please write a very short letter to your state Congressmen asking them to co-sponsor 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:](http://www.thomas.gov/cgi-bin/query/z?c111:H.RES.263)

**To find the contact to your state representatives please visit:**

<https://writerep.house.gov/writerep/welcome.shtml>

**To find the contact to your state senator please visit:**

[http://www.senate.gov/general/contact\\_information/senators\\_cfm.cfm](http://www.senate.gov/general/contact_information/senators_cfm.cfm)

## New Video Aimed At Early Detection of Brain Aneurysms Distributed To Over 4,000 Hospital Emergency Departments

To help ensure the proper diagnosis of brain aneurysms, The Brain Aneurysm Foundation has developed an educational video entitled *Early Detection of Brain Aneurysms: Life vs. Death*. Designed to educate primary care physicians, emergency room physicians, nurses and emergency medical technicians on the early detection of brain aneurysms, this 20 minute video focuses on recognizing the symptoms related to a brain aneurysm and performing appropriate diagnostic brain imaging to determine if an aneurysm is present. Over 4,000 copies of the DVD were distributed to hospital Emergency Departments across the nation to help promote earlier detection of brain aneurysms and save lives.

*Early Detection of Brain Aneurysms: Life vs. Death* can be viewed for CME credit at [www.bafound.org](http://www.bafound.org) or copies of the DVD can be acquired by calling 888-272-4602 or emailing [office@bafound.org](mailto:office@bafound.org).

## It's A Small World!

The Brain Aneurysm Foundation was pleased to host a reception in Boston on August 31, 2009 to welcome neurosurgery professionals from all around the world who were in the city attending The World Congress of Neurological Surgery. The Foundation took this opportunity to inform the neuro professionals worldwide about the mission of The Brain Aneurysm Foundation and to make them aware of the opportunity to promote the resources of the Foundation in their various countries.

We were pleased to have Carlos David, M.D. of the Lahey Clinic as our guest speaker, as well as the support of Stryker and Microvention. Many physicians were excited to discover The Brain Aneurysm Foundation as a resource for their patients. The convention ran through September 3 and allowed the Foundation to strengthen its voice across the nations.



BAF representatives Dede Buckley, Joy Fischer and Christine Buckley with Dr. Avilla from Columbia

## TeamCindy Gathers Speed

In 2008, Dr. Frank Eckman, a noted scientist and experienced triathlete, read the story of Cindy Sherwin that ran in the Spring 2008 BAF Quarterly. Cindy was struck down and died in April, 2007 from a ruptured brain aneurysm while training for her first Ironman to be held later that year at Lake Placid, NY.

Inspired by her story, Frank decided to run the Ford Tempe Ironman triathlon in Cindy's honor. Cindy's mother, Elaine Schaller, and Christine Buckley, Executive Director of the BAF, traveled to Tempe, AZ to cheer Frank on, and the concept of TeamCindy was born – a means of enabling and encouraging athletes to compete in major sporting events to raise awareness and funding for aneurysm research.

Immediately after the Tempe Ironman, Dr. Eckman and the BAF made contact with the organizers of the Lake Placid Ironman, the largest triathlon in the US and second largest in the world. Like many such events, the Ironman organization offers charitable slots for participants to raise money for worthy causes. The BAF/TeamCindy was granted five slots for athletes to compete in the Lake Placid Ironman scheduled for late July, 2009. Approximately 2500 athletes participate in this highly competitive event. Slots can be difficult to obtain and the charity slots become valuable.



Within weeks, the BAF/TeamCindy website was up and running with an invitation to athletes around the world to fill the five slots and a call for contributors to help the athletes meet their fundraising commitment. It wasn't long before all five slots were filled. Photos and biographies of the athletes are posted on the TeamCindy website at [www.TeamCindy.org](http://www.TeamCindy.org).

The Ironman is the major event of the season in Lake Placid, with the competitors and thousands of supporters in attendance, including a very vocal contingent of BAF/TeamCindy volunteers. The day before the race, the volunteers set up a poster describing TeamCindy and its mission in the middle



**TeamCindy** Left to right: Christine Buckley (BAF Executive Director), Tim Andrus, Frank Eckman, Elaine Schaller (Cindy's mother), Mike Feyko, Angela Vavasori, Loch Macdonald

of the busy downtown area and handed out BAF literature as well as nearly 700 delicious mini-muffins that had been donated by a local merchant and Vitamin Water donated by Glaceau. Hundreds of people crowded the small space, read Cindy's story, took BAF literature and wished the volunteers well in their efforts.

The Lake Placid Ironman Triathlon consists of a two and a half mile swim, a one hundred and twelve mile bike race and a twenty-six mile bike marathon, all beginning at roughly seven in the morning and officially ending at midnight. The winner, a professional triathlete, completed the course in a little over eight hours. All five TeamCindy athletes completed the course in very respectable times, and one, Dr. Loch Macdonald, qualified to compete in the World Ironman Championships in Oahu, HI.

(continued on next page)



(continued from page 8 "TeamCindy")

The BAF is pleased to report that despite the difficult economic climate, TeamCindy raised \$18,000.

Plans for the 2010 Lake Placid Ironman are underway. The Brain Aneurysm Foundation is happy to announce that TeamCindy was granted ten slots for the coming year. Many of our triathletes have already committed to next year's event, but there are still a few more slots available. In addition, TeamCindy is also developing plans to expand and participate in other athletic events in the US and abroad in the coming years.



Angela on the way to the finish line!

## Runs and Walks Abound!!!!



BAF Founder and supporter Dr. Ogilvy finishing his 8th Arterial Challenge!

May 24, 2009 marked the 8th Annual Arterial Challenge 5K Run and Walk in Marshfield/Humarock Massachusetts. Once again the turnout was wonderful with repeat and new participants. It was a beautiful sunny day as well. For the 8th year, support for the Foundation was tremendous with over 300 participants raising over \$37,000.

But, the most profound impact this event has had is that it has inspired others across the country to hold their own local walks and runs in support of brain aneurysm awareness. This year we had a total of 10 run/walk events, that will hopefully all continue to grow in years to come. This is a great way to get involved and raise awareness of brain aneurysms, as well as to meet others who have shared similar experiences.

To learn how you can start a run or walk in your neighborhood, please contact The Brain Aneurysm Foundation office at 781-826-5556 or [office@bafound.org](mailto:office@bafound.org).

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

This year's event held on Sunday, May 31st, 2009 at Cherry Hill High School East organized by Carol, Wayne, Lisa, Laurie and Mark Bledy. There were over 315 participants, including many supporters from the Brain Aneurysm Survivor Group at Thomas Jefferson University Hospital led by Jill Galvao. A great time was had by all!! Dr. Christopher Festa spoke about pediatric research funding. The run funded \$4,000 in contributions to The Brain Aneurysm Foundation.



(continued on next page)

# Runs and Walks Abound!!!!

## The Daniel Messmer Memorial Walk, Evansville, IN

Deidre Barnes, walk organizer, reports: On Saturday, September 12, 2009, we held our first Daniel Messmer Memorial Walk. We had no idea what to expect and



The Daniel Messmer Memorial Walk at the University of Southern Indiana

were elated when over 200 walkers showed up to support our cause. We are very blessed to have such wonderful family, friends, and brain aneurysm survivors that all made this walk a success, raising over \$7000 for The Brain Aneurysm Foundation.

## The Kimberly Ann Tudor Memorial Walk in Portland, ME

A fundraising memorial walk was held in Portland, Maine on Sunday, September 13, 2009, to raise awareness about brain aneurysms and to help support The Brain Aneurysm Foundation (BAF).



Ginny Tocci, the BAF Director of Development and Administration was on hand at the BAF venue to provide info, handouts, and answer questions. The event was dedicated in memory of Portland, Maine native, Kimberly (Kim) Ann Tudor, at age 32, died suddenly from a brain

aneurysm in late December 2008. Two hundred walkers joined in on the 3.5-mile walk around the beautiful ocean-side Back Cove Boulevard setting, under ideal weather conditions. The walk's seal of approval came as walkers crossed the finish line, when a splendid rainbow appeared right over the course.

Kim loved to run the same Back Cove Boulevard in Portland with her dog, Bella, and participated in many charity run/walks and other fundraising events as well.

The KAT-Walk Committee, made up of Kim's family and friends, wish to thank all those who promoted, participated and donated toward making this inaugural event a great success, raising \$5000 to benefit the BAF. Based upon these results, it is intended to hold this event on a yearly basis. A post-event gathering was held at Portland's 'Bogey's Pub' to toast and celebrate this achievement and share our memories of Kim.



For more information, visit the official walk website at: [www.kat-walk.org](http://www.kat-walk.org), to learn more about Kim, the event, and how to donate to BAF. Donations are welcome at any time. You can make a difference.

Thanks to all for making KAT-Walk 2009 such a success!

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

The 1st Annual Freddie Harris Memorial 2K walk/5K run was held in Belleville, MI on September 19,



2009. There were 167 participants and over \$6,000 was raised for The Brain Aneurysm Foundation. There were several local businesses and a few local families

that donated generously for the raffle as well as food and drinks for all the participants. Brain Aneurysm Foundation Board Member, Bill Demmer was in attendance and spoke to all the walkers and runners before the starting gun went off to raise awareness. Four survivors attended and there were several families walking in memory of their loved one that they had lost to a brain aneurysm.



Walk organizer Melissa Varney

(continued on page 15)

# Dawn Brejcha Memorial Softball Tournament in Escondido, CA

By Beverly Baker

The morning fog was just beginning to lift off the fields, the soft chirp of birds welcoming a new day in San Diego. September 19th – the start of Dawn Brejcha’s 42nd birthday weekend. By the end of the weekend over 400 friends, family members and strangers had gathered together to celebrate the occasion; to raise a beer in her honor and to play her favorite sport, softball. It was exactly the way Dawn would have loved to celebrate her birthday. Unfortunately, she was the one person that didn’t attend. In February 2009, Dawn lost her life, the result of a ruptured brain aneurysm.



Dawn Brejcha

To honor her memory, Brejcha’s friends created The Dawn Brejcha Foundation, a nonprofit organization dedicated to raising awareness of brain aneurysms and funding for much needed research towards early detection, prevention and cure of

this silent killer. The charity softball tournament was the natural choice for a first fund-raising event for the foundation and featured men’s and co-ed slow pitch divisions as well as a coed 3-pitch division. The event also featured a silent auction, raffle, concession stand and craft beer garden brought in part by the generous donations of many local San Diego businesses. BAF Board Member Amanda Kennedy was on hand for the festivities. When the sun set on the 20th, Dawn’s actual birthday, the foundation had raised almost \$14,000 toward their cause.

At the recommendation of the Board of Director’s and with full support of Dawn’s family, The Dawn Brejcha Foundation partnered with the Brain Aneurysm Foundation to establish The Dawn Brejcha Chair of Research. This chair will provide an annual stipend of \$10,000 to be awarded to a deserving project in the area



Al, Lucy and Lisa Brejcha present the championship prizes to tournament winners WTFM.

of brain aneurysm research at The Brain Aneurysm Foundation Research Grant Symposium in September 2010 in Orlando, Florida.

Thanks to all of the sponsors, volunteers, umpires and teams who participated in our inaugural fundraiser. The foundation is actively planning a spring fundraiser and working on next year’s tournament. With continued support of Dawn’s family, friends and the San Diego community, we are excited about our future. For more information about Dawn and The Dawn Brejcha Foundation, please visit <http://www.dawnbrejcha.com>.

## BAF Golf Tournament at Indian Pond

Lots of fun was had by 80 plus golfers who joined us for the 3rd Annual Brain Aneurysm Foundation Golf Tournament. This year the tournament took place at Indian Pond in Kingston, MA. Generous golfers helped us raise over \$32,000 for the BAF.

We are very excited to announce that next year our tournament will be held at the prestigious, scenic Hatherly Golf Club in Scituate, MA on June 21st. This will be a great opportunity to play this private course which offers incredibly spectacular ocean views followed by a wonderful dinner overlooking the Atlantic.



Josh Truitt, President of the BAF Board of Directors with Executive Director Christine Buckley

Survivor Charles Austin, former WBZ newsman, with Dr. In Sup Choi, Interventional Neuroradiologist



## Save the Date—2010

March 25

New York Islanders Brain Aneurysm  
Foundation Night

May 16

First Rosann M. Donato Walk for the Cure,  
Medford, MA

May 30

9th Annual Arterial Challenge 5K Road Race  
& 1.5 Mile Walk, Marshfield, MA

June 21

BAF Golf Tournament at Hatherly Country Club,  
Scituate, MA

## Opportunities to Participate in Current Brain Aneurysm Research

**1) Familial Intracranial Aneurysm (FIA) II Study**

A group of physicians from throughout North America, Australia and New Zealand have formed a collaborative effort to identify genes that may be important in the development of aneurysms in the blood vessels of the brain. This study of affected individuals and families, known as the Familial Intracranial Aneurysm (FIA) study, is sponsored by the National Institutes of Health and has involved over 475 families.

FIA II will involve an additional 200 families plus 1800 subjects with an Intracranial Aneurysm but no family history. These families and individuals will be used to replicate the findings of FIA I. FIA II will take place in North America only.

Participants will be asked to complete a family history questionnaire (if they have a family history) and a medical history questionnaire. They will also have their blood pressure measured and will give a small sample of blood. In addition, medical records will be requested to confirm the diagnosis of intracranial aneurysms. There will be no monetary compensation for participation.

Participation in this project is voluntary and is limited to families with affected siblings or 3 affected family members or individuals with a known intracranial aneurysm. To request additional information or to enroll in this study please contact Laura R. Sauerbeck at University of Cincinnati, at 513-558-1742 or 1-(800) 503-3427. Information about the study can also be obtained via email at [Laura.Sauerbeck@uc.edu](mailto:Laura.Sauerbeck@uc.edu) or through our web site <http://www.FIAStudy.org>.

**2) Yale University Genetic Brain Aneurysm Study**

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).

## Support Group News

**New support groups continue to spring up throughout the country. Recently new groups have formed in many areas. See if there is a NEW support group near you:**

Brigham and Women's Hospital Brain Aneurysm Support Group  
Lowell General Hospital Brain Aneurysm Support Group  
Rochester NY Support Group  
Madison Area Cerebral Aneurysm Support Group  
University of Illinois Medical Center Dept of Neurosurgery Support Group  
Kansas City, MO Brain Aneurysm Support Group  
Twin Cities -The National Brain Aneurysm Center Support Group  
Fort Myers Brain Aneurysm Support Group  
Orlando Brain Aneurysm Support Group  
Deerfield Beach, FL Support Group  
Tampa Bay Area Brain Aneurysm Support Group  
San Antonio Support Group  
Washington Brain Aneurysm Support Group  
Oregon Brain Aneurysm Support Group  
Hoag Memorial Hospital Presbyterian, Newport, CA

Support groups complete the full cycle of patient care that healthcare facilities can provide, from diagnosis, through treatment, to recovery and support. For a full listing of all of our support groups go to [http://www.bafound.org/support/sup\\_grp.php](http://www.bafound.org/support/sup_grp.php).

### **Here is why support groups are so important to survivors:**

*I found the support group here in Colorado and feel that this group is a great resource to survivors and families. They can help begin the healing process and bring a sense of comfort during this trying time. I think that the families need as much support and love as the survivors. This group allows the survivors a place to feel comfortable with people who have had the same experience, able to talk about their feelings, challenges and asking questions without feeling judged.*

*My recovery and quality of life after such a life altering situation continue to improve every day. I hope to become even more involved in the group and I want to help as many as I can in any way that I can.*

Tammy, Colorado

For more information on how to start a brain aneurysm support group in your area, go to [http://www.bafound.org/support/Support\\_Group\\_Manual.pdf](http://www.bafound.org/support/Support_Group_Manual.pdf) or call The Brain Aneurysm Foundation at 781-826-5556 or email [office@bafound.org](mailto:office@bafound.org).

## Rhyme or Reason

In August of 1997

I had a chance to go to Heaven.  
Though I may not be of Heaven's worth,  
I felt I was suffering Hell on Earth.

My head throbbed and "ached so bad"  
I thought that it would drive me mad.  
Six weeks I described that Pain-With-No-End;  
My husband seemed to be my only friend.

Pain, nausea, and stumbling gait-  
I wondered what would be my fate.  
Migraine and sinus were ruled out  
CT and MRI had nothing to tout.

The doctors were baffled or acted aloof  
'Til an angiogram gave them the proof  
That an aneurysm had come to call,  
Looking like medieval mace, a little spiked ball.

They'd now have to carve into my brain:  
Try to save my life; try to end my pain.  
"Why yes," I said, "Go right ahead,  
I might die but I feel already dead."

The operation took all day  
"Touch 'n' go," the doctors say.  
They'd saved my life after quite a fight  
But they couldn't guarantee my sight.

Being blind wasn't the trouble  
It's just that I was seeing double!  
So I wore a patch the pirate way and  
My mood was not exactly gay.

Add poor memory and cracked skull knitting,  
I oftentimes just felt like quitting.  
My husband was always there with a hug;  
Hardware had been fixed;  
Software just needed de-bug.

It had always been my way  
To want things done yesterday.  
Eventually my eyes popped back in place,  
Then I knew I was here by some good grace.

Smell the roses (although I can't);  
Take a deep breath instead of rant.  
I've been granted a bit more time  
Is there a reason? End of rhyme.

Merry Frank, Berkeley, CA, 2005

## Familial Intracranial Aneurysm Study Update

Mario Zuccarello, M.D., University of Cincinnati Medical College

The Familial Intracranial Aneurysm Study (FIA) is one of the largest studies of the genetics of brain aneurysms in the world and has made tremendous contributions to our understanding of why aneurysms form and who develops brain aneurysms.

The primary goal of the FIA study is to identify the gene or genes that lead to the formation and/or rupture of brain aneurysms. The first genome screen was performed in 192 families. There was evidence that 4 (4, 7, 8 and 12) of the 23 pairs of chromosomes in humans may contribute to the formation and/or rupture of cerebral aneurysms. The latest genome screen performed in 333 participating families shows evidence that 2 chromosomal regions (chromosome 4, 7 and 12) contribute to intracranial aneurysms. It was also found that smoking interacts with specific regions of the chromosomes (chromosome 7) with regards to the risk of aneurysm.

In conclusion, it is unlikely that a single gene is responsible for aneurysm formation and/or rupture. Rather, multiple genes and environmental risk factors, i.e. cigarette smoking, contribute to intracranial aneurysms.

Another significant finding resulting from the FIA study is that in the first degree relatives of a person diagnosed with an intracranial aneurysm, it was found that 19.1% of the participants that had undergone a MRA study had a previously diagnosed aneurysm. Those diagnosed were over the age of 30 years, female, or had a history of smoking and/or high blood pressure.

Another very important finding was that the majority of subjects found to have an unruptured aneurysm during the course of the study had small aneurysms (less than 7 mm). The observed annual ruptured rate of these aneurysms was 1.2%. This is approximately 17 times higher than the annual rupture rate previously reported in the International Study of Unruptured Intracranial Aneurysms (ISUIA).

All these findings are very important in the screening of high-risk individuals based on family and medical history and in the management of an intracranial aneurysm in a person with a family history of aneurysms.

## Corporate Sponsors

The Brain Aneurysm Foundation wishes to recognize the following corporate sponsors for their generous contributions:

**Aesculap, Inc.**

**Boston Scientific** *Delivering what's next.™*

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## Are you on Facebook?

### Official Brain Aneurysm Foundation Facebook Cause Site Established

Please join us and become a member of our new official Facebook Cause site at  
<http://apps.facebook.com/causes/302402/61732358?m=69029663>

### **The 3rd Annual Brain Aneurysm Awareness 5K Walk/Run in Powell, OH**

By Jacci Snyder

The 3rd Annual Brain Aneurysm 5K Walk/Run was held in Powell Ohio on September 27th. Despite the rain and cooler temperatures, it went off without a hitch.

I became involved with the foundation because I lost my mother and grandfather to brain aneurysms. My goal is for my event to grow larger and larger every year. If I can save one person from dying from an aneurysm then I will feel as if I have made a difference.

The challenge for me is getting the word out about early screening and prevention, the more knowledge people have regarding symptoms, the more they are apt to seek treatment immediately. I have discovered that this is something that needs to be discussed in the media, hospitals, all of the time, because it is a silent killer. It's frustrating for me because the media discusses and promotes other diseases such as cancer, diabetes, or heart disease and yet, you rarely hear of brain aneurysms and the progress in medical technology. So, I will continue to promote early screening, particularly if you have had a family member who has had a brain aneurysm, talk about brain aneurysms and the Foundation to each and everyone I meet. I look forward to my next event and I will start promoting and spreading the word now.

### **The 1st Annual John Assante Memorial Walk In Boca Raton, FL**

By Geri Assante

My husband, John Assante had just awoken to a typical Saturday morning after laughing at the movies the night before. Everything about this day seemed routine. Within hours John was rushed to the hospital, stricken with a silent predator he didn't know existed. Years before, John's mother was struck down with a sudden, piercing pain of a brain aneurysm. During that time, John was unaware that this disease closely follows the path of heredity. A simple diagnostic test called an MRA, easily ordered from a physician, could have prevented this tragedy. Unfortunately, nobody

told us or John. Seven months ago, we had no idea that John Assante was at risk for a brain aneurysm. If we knew then what we know now, he would be here today.

On September 27, 2009 the Assante Family, with support of friends, Dr. Ali Malek, and St. Mary's Medical Center team, hosted the 1st Annual John Assante Memorial Walk. Our goal was singular in focus, which was to increase awareness around the seriousness of brain aneurysms. With just two short months to organize this event, my daughter Jen and I went about learning how to organize a fundraiser.

What started as a cluster of random ideas turned into a majestic sea of red balloons as over 130 people attended the event supporting my family's personal mission to improve brain aneurysm awareness. The early morning rain and unseasonable gusty winds turned to bright skies and beautiful sunshine. We know John was looking down, probably making a deal with those who control the weather.

After some opening remarks regarding the facts around brain aneurysms, we were off to make a difference, and what a difference we made. An amazing start, but make no mistake, only just a start. With every start, there must be a finish. That end point is simply an increased understanding to this preventable condition. We, as a family, might not see the finish line today, but we will get there. As John always said, "Never bet against the Assantes."

We are already beginning to take the steps for the 2nd Annual John Assante Walk to raise brain aneurysm awareness. We know that each step, figuratively and literally, brings us closer to saving others from this under-recognized condition. Raising awareness will forever be our family's mission and how we will always honor John. That is how he would have wanted it and it is what he would have done himself.



John Assante, Jr., Dr. Ali Malek, Geri Assante and Jen Assante

### GINA PAYNE, LOUISIANA

I was diagnosed with a Cerebral Aneurysm in April 2008. I went to the doctor with an ailment and he recommended a CT scan be performed to see what was going on. I remember the day I was diagnosed. I had no symptoms so you can imagine my shock and fright.

So many things were running through my head. How was I going to live with this thing in my head knowing there was no guarantee a rupture would not occur? How did it get there? And as always, why me??????

Well, I believe everything happens for a reason and soon it would become clear what mine was. All my questions suddenly had answers to them. How was I going to live with this? Day by day, how else? How did it get there? Soon after I was diagnosed, I found out that you are at risk if you have a family history of aneurysms. Years ago, my late Aunt suffered from a ruptured aneurysm that left her with many disabilities. I had forgotten how she had gotten that way until a family member reminded me. How could the doctors know I was at risk if they didn't know my family history?

While every medical history form I have completed over the years asked about numerous diseases and conditions, brain aneurysms were never mentioned.

And why me? To educate, to make people aware of their family history, to let people know that brain aneurysms can be a genetic disorder.

I'm one of the lucky ones. My aneurysm was found on accident, not after rupture. I'm not going to lie. It did take a little getting used to and always will be a concern. I just want people to be aware, to know when they need to be tested and that they need to know their family history!

Please tell your family physician if you have a family history of brain aneurysms even if it isn't on the medical history form.

My aneurysm is small so it is recommended that we watch it right now with repeat CT angiograms every six months rather than surgery. Be like me, one of the lucky ones who has been given the chance to watch it!

### ANNA, SPAIN

Hi! I'm a Catalonian girl, I'm recovering from a aneurysm bleed. They put a titanium clip in me and I'm luckily alive and with everything okay. Last week I was astonished because I was and am very tired and I am thankful for this website because now I know its an okay thing and I have to get a bit used to it. Thanks a lot for all the information I've been able to read and learn. Lot of kisses from Catalonia (Spain).

### ERIN

I came to this site in October of 2008, shortly after my mother suffered a subarachnoid hemorrhage, a brain aneurysm rupture. My mother was 55 years old and a very active person.

The city is one hour away and we rushed up there. Little did we know that 2 months later, we would still be driving one hour to the hospital.

She had surgery that night to clip the aneurysm. Her surgeon said that she had a devastating rupture and that time will tell. She also had major heart troubles after as well.

She spent 6 weeks in ICU with hardly any movement at all. Her one side would twitch. Eventually her eyes would open and she would stare at nothing. It seemed that her brain had been so damaged that there was no hope.

After the worst 6 weeks of my life she was transferred upstairs after learning to breathe without the tube. She would have a minute that she would look at you like she knew you and then others when she would stare into space crossed.

Then her brain started to heal. We were only 2 weeks out of the ICU and she was sitting in a chair. She still seemed like she was on another planet, but she was sitting up. Then they moved her back to our small town hospital and she was doing more and more every day. She was eating solid foods and drinking.



In mid December she went in to rehab program where she stayed until Jan 20. On December 24 they let her come home for the weekend. After what she had been through, she never missed Christmas.

Physically she is fine. She is strong and walks around everywhere. What it did affect was her speech and personality. She has an awful time coming up with the right words. Her personality is much different. She is not the same person, but she is with us and we can handle the change.

I read a lot after she had the bleed. People had spoken of the personality change. It is hard to understand at the start, but it really is true.

One year later, she is doing pretty well. She can stay at home by herself, warm up food, cut her lawn. She can't drive yet, but we're hoping soon.

I haven't noticed any depression, but we're watching for it. She has a lot of trouble thinking of the subject of a sentence. She won't go to a store by herself because she could never be able to tell the clerk what she would want. But we're hoping that will become better one day.

We've come a long way since the nurse in our small town hospital telling us that she probably won't make it and a nurse in ICU telling me that she probably would never wake up.

When I started reading stories shortly after mom got sick, the ones with the bad endings really got to me. It was upsetting and it really took a lot out of me. It's hard not knowing the future and listening to the worse possible scenarios. I hope you all enjoy a story with a happy ending.

### EARLY DETECTION IS KEY!

"I am Firefighter/EMT with the Northville Township Fire Department. Over the last few months we have trained with your DVD Early Detection of Brain Aneurysms: Life vs. Death and found it to be very beneficial to our department. We would greatly appreciate a few extra copies to share this information to others in our field."

### SUSAN, ONTARIO

I am writing on behalf of my husband, Chris. Chris is a senior Captain with Air Canada. On December 16th after arriving home from Tokyo, he suffered a major headache followed by nausea and vomiting. I took him to our local hospital where a CT scan with contrast was done. It came back normal. The headache continued and 2 days later a MRI was done. It came back normal.

On December 29, 2006 Chris, at the age of 55, suffered a ruptured aneurysm in the frontal lobe resulting in a massive bleed. When he presented at the hospital, he was in a very deep coma, a Glasgow Coma Score of 3. The admitting resident told me Chris' condition was extremely grave and IF he survived the night he would have lasting physical and mental disabilities. When our son asked if Chris would ever fly again the doctor informed us "He won't drive again."

Nineteen hours after his arrival, the nurses were able to get a response from Chris when they asked him to squeeze his hand. At that point, the neurosurgeon scheduled surgery to clip the aneurysm. Thirty-two hours after he was admitted, the surgery began. He was kept in a medically induced coma for a couple of days following the surgery. When he came to, he was still on a ventilator. He had no idea of who he was or who any of us were. He didn't know the date, or his own name.

He was in ICU for 3 weeks and then a week in a step-down unit. From there he came home. He was weak and frail, had lost over 40 pounds, very confused, and extremely fatigued. His improvement was rapid in the first few months and then continued steadily. We had wonderful specialists helping us every step of the way and Chris worked hard.

This year after extensive neurological and psychiatric testing, Chris was approved to go back to work!! Flying airplanes!! He started training on the Boeing 777 in August and last Friday, September 25th I watched in awe as he donned his captain's uniform for his first flight back!! We have dubbed him Captain Fantastic, and he is certainly a walking miracle.

# Vascular Smooth Muscle Differential Gene Expression in a Non-Human Primate Model of Subarachnoid Hemorrhage

By: Douglas Cook, M.D., University of Toronto, Division of Neurosurgery

Vasospasm following aneurysmal subarachnoid hemorrhage is responsible for delayed neurological deficits in many patients who have suffered a ruptured aneurysm. Many therapies to decrease vasospasm following subarachnoid hemorrhage have been developed and tested but few have had a major impact on clinical outcomes, making vasospasm one of the biggest obstacles in treating patients with subarachnoid hemorrhage. One promising therapy is nicardipine, a drug that works by decreasing calcium flow into the muscle cells of blood vessel walls to ultimately decrease vessel constriction. It is a therapy originally developed to treat high blood pressure, but now used to treat vasospasm by implanting slow release drug pellets around affected brain blood vessels at the time of surgery. While the direct effect on blood vessel constriction is one possible mechanism for this drug, some researchers have suggested that there may be other mechanisms of action that might improve outcomes after vasospasm. As a part of the process to evaluate the effectiveness of this therapy in vasospasm, Dr. R. Loch MacDonald (St. Michael's Hospital, University of Toronto) implanted the drug or placebo in non-human primates undergoing an experimental model of subarachnoid hemorrhage. We were able to utilize tissues isolated from these experiments to conduct the current project.

To begin to unravel the mechanisms by which the drug exerts its effects, we sampled smooth muscle cells from brain vessels of animals treated with nicardipine and those treated with a placebo pellet. To explore potential mechanisms of action, we compared gene expression in

the smooth muscle cells from each group using whole genome microarrays, a technology that allows us to measure gene transcription levels in a tissue sample for all genes encoded in the genome of the non-human primate. We then used bioinformatics techniques, statistical methods for large datasets, to sort the genes into clusters that we then explored for genes of interest.

We observed that nicardipine treated animals had less vasospasm as detected by angiogram and CT scan, suggesting that the drug had an effect on the vessels. We also observed after sorting the genes detected in the microarray experiment that there was a cluster of the five most significantly changed genes that related to smooth muscle cell proliferation. Cell proliferation related genes were decreased in the nicardipine treated animals when compared to placebo treated controls. This result suggests that nicardipine may exert its effects, at least in part, by decreasing the growth of smooth muscle cells in brain vessels after subarachnoid hemorrhage. Smooth muscle cell overgrowth is a known cause of small vessel stenosis and occlusion following subarachnoid hemorrhage but not a known target for nicardipine therapy. This observation has led us to further validate our results and will be the subject of future hypothesis based research.

We are grateful to The Brain Aneurysm Foundation for funding this work and look forward to utilizing the data generated in this project to direct our efforts in developing new treatments for vasospasm in future work.

## Hair-Cut-A-Thon in Cherry Hill, NJ

October 25

There were over fifty appointments for haircuts at Julian Hair & Color Studio in Cherry Hill, NJ as part of D's Dawgs fundraising efforts. Get pampered and raise funds for a good cause at the same time!



# How To Host A Non-Event, Or How To Not Do Lunch

By Cheryl Lynn Horsey, Ph.D.

Dear Friend,

I wish to thank you for your support during my convalescence as I sought to regain some semblance of “normalcy” in my life. I look at every day as a gift and choose not to let a minute go by that I take for granted.

Having suffered two brain aneurysms, I can't tell you how important early detection and awareness is to survival. Having gone through over a year of recovery I am now at the point where I want to help others understand the symptoms and increase awareness about an illness that affects about 25,000 people per year.

Once I became strong enough, I sought out information to help me understand just what happened to me. I found the Brain Aneurysm Foundation (BAF) to be a great resource.

That is why I am asking you to join me in supporting the BAF by participating in my “Non-event.” That's

right – I am suggesting that we not do lunch, but rather you make a donation by paying the cost for a takeout lunch, dine in lunch, brunch, or mileage to a Center City restaurant.

You can make a check payable to **The Brain Aneurysm Foundation** and return the check to me in the self addressed stamped envelope and I will compile all the donations and mail to BAF. Let's face it – we could all forfeit another lunch for a good cause. So let's Not Do Lunch! My goal is to raise at least \$1,000.00 for this worthy organization. Please consider joining me and the Brain Aneurysm Foundation as we raise awareness and support research in this area. By the way, September is National Brain Aneurysm Awareness month.

Very truly yours,

Cheryl Lynn Horsey, Ph.D.

## Here is how it works:

**Donate to the option that you would most likely choose if you were to go out for lunch.**

Take out Lunch for two:	\$20.00	_____
Mileage to Center City Restaurant @ \$ .55/mile (40 miles)	\$22.00	_____
Liquid Lunch for two:	\$32.00	_____
Dine In Lunch for two:	\$40.00	_____
Brunch for two:	\$50.00	_____
Prix Fixe (Le Bec Fin)	\$100.00	_____

Congratulations to Cheryl who raised over \$2,500 with this creative fundraising idea. Your next lunch is on us!

# 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 \$ \_\_\_\_\_

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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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