

# Circle of Friends

The Brain Aneurysm Foundation Newsletter

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THE BRAIN ANEURYSM



FOUNDATION

## *Support Groups: A Proven “How To”*

*Robert Kooken, Ph.D.*

*Neuropsychological Services - Lakewood, CO*

A support group for brain aneurysm survivors can serve several critical purposes. First, the group serves as a source of emotional support for survivors, spouses, loved ones, and caregivers. Just knowing that someone else has gone through what you have provides a great deal of comfort. The process of sharing the experience is valuable at every stage of the process.

A support group can also serve as a source of information about how best to cope with and adapt to the changes that accompany a brain aneurysm. One must learn how to become an active participant in the rehabilitation process, because the brain does not improve without practice. The survivor learns that instead of passively waiting for recovery, s/he must seek out and learn new ways to cope with changes in functional abilities. Skills are learned from other survivors, from the group leader(s), and/or guest speakers.

Among other functions, the support group teaches each participant that rehabilitation is a learning process that unfolds over a long period of time. A positive emotional attitude and determined, directed effort are necessary for recovery to be maximized.

It is unusual for a survivor or family members to be educated by medical providers about the process of rehabilitation. In our experience, few of our group participants have received any education about brain functions, how the brain recovers, and/or how the brain learns. An informed caregiver and survivor are more likely to keep a positive attitude and improve than those who know little about the process.

One of the most important objectives of the support group is to teach life skills, both in the form of emotional coping strategies and the acquisition and application of everyday functional skills. The survivor and caregiver live in a new world, one that they have not practiced or prepared for. No one in the newly affected family knows much about how the brain functions, what happens when the brain is damaged, or anything about the process of the illness that has suddenly changed their lives. They simply have no idea what to

expect from the future, and their medical providers often have limited time to teach them what to expect and how to proceed.

In our support group, we feel there is little value in using the group to educate survivors and families about the details of surgical procedures or other technical details. A general discussion of treatment techniques and options from qualified professionals can be very helpful.

It takes time for a therapy group to coalesce into a working unit. The group begins as a collection of strangers. Slowly and over time, group members come to know one another, and to interact in familiar ways. Over time, a core of group members who have learned how to maximize the rehabilitation process forms, and the group incrementally becomes a more and more powerful agent of change for one another and for those who join the group later.

Ideally, group meetings have a theme that is introduced by the group leader. The group leader might spend 15-20 minutes talking about a topic, aided by handouts. If the group takes a definite direction away from the intended theme, allow the process to unfold without interference. In our group, unexpectedly large turnouts may make it necessary to return to an introductory group mode, in which telling one's story and sharing experiences becomes the order of the day.

The rehabilitation process involves the survivor's entire social network, including family, friends, caregivers, and providers of medical service. Support group meetings are just as important, or in many cases, are more important to caregivers and family members than to the survivor.

In the same way the survivor's life has been altered, the caregiver's life is changed by a brain aneurysm. He/she has little or no idea what a brain aneurysm is, how the brain works, or what to expect in the future. The caregiver/family member may become depressed, angry, anxious, or desperate during the rehabilitation process. An emotionally distressed, unprepared caregiver/family member has a difficult time providing a fully support-

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## Forward Progress

*Christine Buckley LeBlanc - Executive Director*

In my first six months as Executive Director there has been quite a bit of activity at The Brain Aneurysm Foundation (BAF). The BAF is growing and taking new turns all of the time. The amount of growth and positive changes are both challenging and exciting.

One area of growth is in our support groups. There are over 20 support groups in 12 states, Canada and Nova Scotia. The support groups are usually led by a medical professional and have the support of a local medical facility. The support groups allow patients and caregivers to come together and share their experiences. The most important elements of these meetings are to give hope and a sense of dignity to the survivor; for the caregivers to know they are a vital part in the long road of recovery for their loved ones; recognition that they too are not alone in the aftermath of a brain aneurysm. I want to thank all the dedicated people who have put these support groups together and keep them running throughout the year. This is an extremely vital part of the mission of the BAF.

Another element that has come as a result of the support groups is the development of chapters of the BAF. Currently about five states are in this process, and our first official signatory is out of the Dallas/Fortworth Texas area. Being a chapter will allow people to act locally on behalf of the BAF in the ways they deem most appropriate for their community. The formation of chapters will allow the BAF to develop a stronger presence nationwide.

Both the increase in support groups and chapters is leading to increased physician involvement in the BAF. Physician participation is of the utmost importance to the BAF for it is the physicians who deal with the patients before, during, and after their aneurysm treatment. The physicians have the ability to be our strongest advocate and they are the ones who can keep the BAF current on new developments of treatment techniques and research activities.

In 2007 the BAF hopes to, with the help of a special committee of the Medical Advisory Board, award a few grants for research. It is important for the BAF to be supportive and on the forefront of any research activity in the area of brain aneurysm detection, prevention, treatment options, and improved recovery systems.

In early October I was at the Congress of Neurological Surgeons with a few other members of the BAF manning an exhibition booth. This was an excellent opportunity for me to personally meet some people I have been communicating with over the past months, to meet physicians and other medical professionals from all over the world who were interested in learning about the BAF and medical company representatives who deal in some of the cutting edge of brain aneurysm technologies. This gave me the opportunity to learn that people would be grateful to have our educational resources available in other languages and that people would benefit from additional DVD's such as one on recovery and misdiagnosis. It was nice to be so well received both by people who were familiar with us and use our resources as well as those who just met us and were so happy to find that the BAF exists.

The BAF is continually striving to promote brain aneurysm awareness to the point where the term "brain aneurysm" is as commonly understood and easily discussed as the terms "cancer" and "tumor." We are moving in the right direction and with the proper funding, increased physician involvement, the development of chapters across the country, and with your support we will reach this goal in time.

I ask all of you to spread the word about brain aneurysms and the work of the BAF. Participate in our fundraisers in any way you can - attend, donate, volunteer, or pass the invitation on to your family, friends, and co-workers. The BAF needs your support to prosper and serve our mission to our greatest capacity.

Thank you for your support!

Christine Buckley LeBlanc



*BAF at CNS conference in Chicago*



## ***Support Groups: A Proven “How To”***

*Continued from page one*

ive environment for a survivor.

Finally, a brain aneurysm support group can provide information to group participants about health care providers in their areas that can offer specialized rehabilitation evaluation and treatment services. Survivors should be encouraged to seek treatment from neuropsychologists, psychologists, neurologists, neurosurgeons, social workers, speech therapists, and occupational therapists, as their needs indicate. Often, group participants do not understand the services that rehabilitation professionals can offer them.

The modules I have developed are intended to serve as a set of guidelines for the purpose of running a support group for brain aneurysm survivors and their families and loved ones. They are intended to offer concrete, specific recommendations for topics that are useful to discuss with group participants. There are many ways to run a successful, helpful support group, and this is only one of them.

A survivor started our support group in Denver, and I have served as group leader since its inception almost two years ago. I am a clinical psychologist with a practice in neuropsychology and rehabilitation psychology. I have developed these guidelines over the past several years in the process of working with brain aneurysm survivors in a group setting.

I have organized some of the principles we discuss frequently in our group sessions into several modules. Some of the modules address survivor's needs, and others address the needs of caregivers. We feel that caregivers and family members are as important to the rehabilitation process as the survivor, and frequently address their needs.

These modules are a work in progress. They are prepared as vital topics are discussed in our groups that appear to be particularly helpful to the attitude and skills of the group participants. At this stage, there are eight modules, with three dedicated to caregivers and family members, and the others dedicated to the needs of survivors.

Module 1: Caregiver Module: How can I deal with my emotions? - Telling the story

This module is designed as a guide to a session that is dedicated to the caregiver's need to tell the story of his/her experience, and to check with other group members about how they have coped with similar challenges and stresses. The group participant's first experience with the group generally involves sharing his or her story.

Module 2: Caregiver Module: The Learning Process

This module addresses some of the ways a caregiver can maximize the rehabilitation process for the survivor. Suggestions for how to develop a treatment plan, and an example of a program to assist survivors with memory problems is included.

Module 3: The various roles of the caregiver

The caregiver/family member has been thrust into a completely unfamiliar role. This module discusses the various roles a caregiver must fulfill, and leads to a discussion about caregiver skills and needs.

Module 4: Telling the Story

This module also addresses the importance of giving the survivor an opportunity to tell his or her story. This process stimulates group discussion and problem solving, and also serves as an emotional release for the survivor.

Module 5: How long until I'm better?

Many survivors and caregivers are interested in how long it will take to recover from his/her aneurysm. This module addresses some of the principles that govern this process, and helps the participant develop a positive attitude about the slow, gradual nature of improvement.

Module 6: Why am I so tired?

Fatigue is a symptom common to many survivors. Most are distressed by becoming easily fatigued, and may be confused about why they are experiencing it, and how to deal with it. This module addresses the topic, and provides a perspective on the issue.

Module 7: How do I get better?

This module addresses various principles that are important for maximizing the rehabilitation potential of the survivor. The guidelines discussed include the step-wise nature of learning, the up and down nature of the learning process, and the ideal emotional environment for the survivor and caregiver, among others.

Module 8: How do I deal with depression?

This module leads to a discussion about how self-talk is critical for maintaining a good mood and a positive attitude, and how some of the attitudes and thoughts that can arise during the rehabilitation process can be harmful and lead to emotional distress. Ways to cope with emotional distress are discussed.

*For more information on how to start a support group please contact The Brain Aneurysm Foundation office at 1888 BRAIN02 or office@bafound.org*



# *The BAF's 1st Annual Golf Tournament*

On August 20, 2006, The Brain Aneurysm Foundation held its first annual golf tournament at the private course Lake of Isles at Foxwoods Resort and Casino. The day was a success all around. The weather was lovely and a great group of survivors, physicians, nurses, family, friends, and medical company representatives came together in support of brain aneurysms.

The golfers took to their carts with their generously packed boxed lunches promptly at 1:00 p.m. and played a delightful 18 rounds of golf. On the way they enjoyed the scenery, had a chance to compete for the longest drive and closest to the pin as well as an opportunity to "beat the pro." The longest drive winners were Suzanne Christiansen and Shawn Parro. The closest to the pin winners were Billy Weiland Jr. and Shawn Golden. After golf the players headed for the clubhouse.

Inside the clubhouse was entertainment by the band *House Arrest* from Boston, a great view of the course, and a delicious buffet meal. People had the opportunity to mingle with one another, meet new friends, and catch up with old ones. There were a great variety of silent auction and raffle items for people to take their chances on and further support The Brain Aneurysm Foundation.

Before the day was over many people went home as winners. The top foursome was Donald Pereira, Kevin Snyder, Norm England, and Gary Langlois; the second place winners were a two-some of Michael Foley and Cynde Childs; and the third place winners were Mark Chisholm, Renato Manansala, Joe Otolo and Jessica Otolo. The biggest winner of all was The Brain Aneurysm Foundation who was able to spread awareness of brain aneurysms and gain more support to better serve its mission.

Thank you again to all who participated and made this day a great success. A special thank you to our Silver Sponsor, Mizuho, for making this day possible. We hope to see you back at Lake of Isles in August 2007.



## *First Annual Fashion Fest Philadelphia, PA*

*Dr. Robert H. Rosenwasser, M.D., F.A.C.S.  
Professor and Chairman of Neurological Surgery*

The Philadelphia Chapter of The Brain Aneurysm Foundation at Thomas Jefferson University recently hosted an event at Siam Lotus Restaurant on Saturday evening, August 26th.

This was a fashion show featuring local designers, with all proceeds going directly to benefit The Brain Aneurysm Foundation. During this event, we spoke about research involving brain aneurysm therapy, including protection against cerebral vasospasm and many of the secondary injuries that occur after an aneurysm ruptures.

The event was very well attended and was covered by local news, both TV, radio and newspaper.

Most of the individuals present knew little about brain aneurysms at the beginning of the event, but clearly had an understanding of the basic healthcare issues associated with this disease process before the night was over.

We thank the local designers and the owner of Siam Lotus Restaurant, Hiran Yii, for providing a venue for what turned out to be a very enjoyable evening promoting brain aneurysm awareness.



*Robert H. Rosenwasser, M.D., F.A.C.S. - Thomas Jefferson University Hospital*



*Rob Guarino of Fox 29, Kristie Bergey, Silver Cho and Hiran Yii*

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## *Brain Aneurysm Awareness Week*

*Kelly Hennessy*

The Brain Aneurysm Foundation (BAF) held its annual Brain Aneurysm Awareness Week September 11 – 15. As part of Awareness Week, several hospitals hosted information tables where volunteers provided information about brain aneurysms and promoted awareness of this disease. We would like to thank all of our volunteers for their time and the hospitals for acknowledging the need to increase awareness about aneurysms. Participating hospitals included:

- South Shore Hospital, Weymouth, MA
- Columbia University Medical Center, New York, NY
- Lahey Clinic, Burlington, MA
- Thomas Jefferson University Hospital, Philadelphia, PA
- Brackenridge Hospital, Austin, TX
- North Shore University Hospital, Manhasset, NY
- Massachusetts General Hospital, Boston, MA
- Skyline Medical Center, Nashville, TN
- Emory University Hospital, Atlanta, GA
- Fallon Clinical Foundation Lifetime Center, Worcester, MA
- Rehabilitation Hospital of the Cape and Islands, East Sandwich, MA

As part of the annual Awareness Week, the BAF held its annual educational symposium. This year’s symposium included highlights of new trends in treating aneurysms, the importance of collaborative care in treating aneurysm patients and new technologies to assist in the rehabilitative process. As in other years, we invited a family member of an aneurysm survivor to speak at the event and this year’s speaker, Carolyn Hennessy, spoke about the needs of caregivers based on her experience. Christopher Ogilvy, M.D. presented data about treatment options for aneurysms including the more recently developed stents and the potential risks and benefits of each treatment option. Owen Samuels, M.D. spoke about the role of the intensive care unit on an aneurysm patient’s recovery process and provided information about a new neurointensive care unit in development at Emory University Hospital. Daniel Parkinson, P.T., M.B.S. provided an update on new technologies designed to help aneurysm patients in their recovery. We would like to thank each of our presenters for their time and participation in this annual event.

Please make plans to join us for our annual symposium in September next year!



# Brainstorm in Columbus, Ohio

Janet Sutherland

Two-hundred members of the medical community as well as brain aneurysm survivors participated in the first brain aneurysm awareness walk in the state of Ohio titled “Brainstorm.”

I had always wanted to lead a walk to support aneurysms ever since I recovered from my ruptured brain aneurysm. On March 22, 2004, I suffered a near fatal ruptured brain aneurysm in my apartment. I had just finished walking my dog, Bogie, when I experienced a massive headache which prompted me to dial 9-1-1. I underwent emergency surgery at Grant Medical Center. My doctor, Dr. Joseph Shehadi, described my condition when I arrived at Grant as “at death’s door.”

I was in a coma for three weeks before awakening in the hospital blind and paralyzed. Doctors described my recovery as “a miracle” but getting well wasn’t enough for me. I eventually made contact with The Brain Aneurysm Foundation. I realized that their support and educational material for survivors and caregivers would help others recover. I believed this brain aneurysm awareness walk would help create awareness and provide support for survivors in my area.

The day of the walk was a clear, sunny, crisp fall Saturday morning at Coffman Park in Dublin, Ohio. Participants signed a memorial banner for those who died from brain aneurysms. To raise additional dollars, there was a silent auction and raffle which added to the excitement of the event. The day of the walk was overwhelming most notably because so many survivors were woman in their thirties!

Neurosurgeons were very visible at the walk and quite passionate about the cause. Dr. Louis Caragine, Director of Endovascular Neurosurgery at Ohio State University Medical Center, and his

staff set up a booth to network with survivors and caregivers. Dr. Caragine is committed to teaching the next generation of neurosurgeons, creating awareness and supporting local survivors.

Former Ohio State University Head Football Coach Earl Bruce gave a pep talk to the crowd. Bruce said the wife of one of his coaches suffered from a brain aneurysm, so the issue hit close to home. He cheered on the crowd as people started walking. The parade of walkers including people pushing strollers and walkers snaked around the park. Dr. Shehadi, who saved my life, joined the walk along with his son Sebastian. The mile and a half journey was a significant one not just for me but for Riverside Hospital ER Director Bob Walsh, a brain aneurysm survivor, also for Bernie Valdez, a stroke and double aneurysm survivor who also lost his father to an aneurysm and for Dr. Ronald Budzik, who treated many of the patients who participated in the event.

Saturday September 9th wasn’t just a Brainstorm Walk Day but it was proclaimed “Brain Aneurysm Awareness Day” by the City of Dublin. We raised nearly \$15,000 for the Brain Aneurysm Foundation. BAF was incredibly supportive providing bracelets and support materials. It was a great day thanks to the Brain Aneurysm Foundation and all of the neurosurgeons and volunteers from Ohio Health and the Ohio State University Medical Center! I was quite proud of such a successful event and planning is underway for another “Brainstorm.” One woman who participated in the walk wore a shirt which I thought appropriately summed up the day; it said “Let Us Not Look Back In Anger Or Forward In Fear But Around Us In Awareness” by James Thurber.



The Brain Aneurysm Foundation

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The Brain Aneurysm Foundation would like to publish your feedback on articles and issues discussed in *Circle of Friends*. Please write to the following address with your questions or concerns:

Circle of Friends Submissions  
c/o The Brain Aneurysm Foundation  
612 East Broadway, South Boston, MA 02127

*The Brain Aneurysm Foundation does not support, endorse, or recommend any method, treatment, or program for persons with a brain aneurysm. We only try to inform you, believing you have the right to know what is available. No endorsement is intended or implied.*

## We Need Your Help!

The BAF would like to give our newsletter a new name that is more closely tied to our cause. We will all still remain a “*Circle of Friends*,” but we want to bring a little more attention to brain aneurysms by a catchy title.

Please send in your suggestions by mail or to [office@bafound.org](mailto:office@bafound.org)

We will choose the top 3 names and put the final vote out to all of you!

The winner will have free admittance for 2 to the fundraiser of their choice in 2007.

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