

Two Journeys of Hope to the Ends of the Earth

By Eva Guralnick

Last year, a banner bearing the name of the National Brain Tumor Foundation waved on Mt. Everest on behalf of everyone who has ever faced a brain tumor diagnosis. Karen Brooks had made the ascent and planted the banner in honor of her mother, a brain tumor patient. Her journey, and the cycling adventure from Alaska to Argentina made by Mike and John Logsdon, are emblematic of the journeys that patients and families make every day after receiving a brain tumor diagnosis.

Karen Brooks was struggling emotionally during the holidays in December 2005 when she decided to honor her mother Bonnie's battle with a brain tumor. "I resolved then to take on some physical challenge that would allow me to channel all that sadness at her loss and at the same time give me a way to raise

money for brain tumor research," she said. "I was drawn to Everest almost immediately."

One of Karen's college roommates had been an avid climber who had used an expedition to Denali to raise money to fight HIV-AIDS. "I wasn't a climber then," said Karen, "but her commitment and sacrifice—and the huge amount of money she raised—always stuck with me."

Once she made up her mind to use a climb to raise money, Karen found Everest an irresistible way to celebrate the many sacrifices her mother had made for her family. "Everest is the supreme symbol of man's personal struggle to achieve," she said. "I thought such an objective made a fitting way to honor my mom." Karen spent six months training and procuring gear, and completed her climb in November 2006. Her story is told on the NBTF website at www.brainumor.org.

During one of her greatest challenges on the Everest trip, Karen became disoriented due to hypoxia—oxygen starvation caused by the high altitude. It was a moment that brought her eerily closer to her mother's brain tumor symptoms. In her journal on day 11 at 17,600 feet, she wrote of the experience, "My body didn't execute what my brain told it to do. I fumbled with the pack and pulled out my pants, but then just stared at them.

How to put them on? They looked hopelessly complicated."

Karen's condition forced her to retreat down the mountain overnight to recover, and as she descended, her thinking cleared. She wrote later, "I thought about how what I experienced up there was like what Mom dealt with while she struggled with her brain tumor—knowing what she wanted to do but not being able to get her body to cooperate; knowing what she wanted to say, but having it come out all wrong. I had walked a few feet in her shoes, and it made me miss her all the more."

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courtesy Karen Brooks

Karen Brooks unfurls her banner on Mt. Everest.

"Your trip had a profound impact on us in lifting our spirits and knowing there were others out there running the good race."

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Karen raised over \$50,000 for brain tumor research, which will fund a joint National Brain Tumor Foundation and American Association for Cancer Research fellowship for brain tumor investigators in memory of Bonnie Brooks.

“I can’t imagine a more fitting and important tribute for Karen’s mother,” said Rob Tufel, MSW, MPH, NBTF Executive Director. “We’re proud to collaborate with the American Association for Cancer Research on this grant, not only because AACR is a leading cancer organization that reaches thousands of cancer researchers throughout the world but because AACR has agreed to match all the funds that Karen raised.” Thanks to the AACR match, Karen’s climb will have raised more than \$100,000—and the figure continues to grow.

As Karen was making her ascent, two brothers on a similar mission were peddling hard to the finish line. Mike and John Logsdon had been talking for some time about making an epic bicycle trip spanning the length of the Americas. Their mother Jean, who had died of a brain tumor when they were still in their teens, had been an enthusiastic world traveler. A trip of this scope would give them a chance to honor her memory and raise money for the brain tumor cause. Their journey is chronicled on www.spinningsouthward.com.

The Logsdons set for themselves a course from the far northern shores of Prudhoe Bay, Alaska, to Ushuaia, Argentina, the southernmost city in the world. In July 2005, they began pedaling the long road south. It would take them fourteen months to reach their destination.

“Logistically, we came into this with no experience,” said Mike Logsdon. “We had each done some tours, but nothing can prepare you for something on this scale. We basically built this idea from scratch. Even the best planning can’t take into account all the unknowns that you’re going to face on a 16,000-mile road trip. That was daunting, but also confidence-building. We took on these challenges one by one, mile by mile, and we got better at what we were doing

along the way, in terms of both our riding and our brain tumor advocacy.”

The brothers were surprised and gratified by the responses of the people they met on their trip. “We realized the commonalities that we share far outweigh the differences,” Mike said. “It didn’t matter if we were meeting farmers in Oaxaca, Mexico or gauchos in southern Argentina. We went through hundreds of small cities and villages, and it was incredible how people went out of their way to help us, cook us meals, and take us into their homes.”

The Logsdons also encountered brutal weather, grueling terrain and bears—and were nearly shot by someone who thought they were stealing cattle. “No matter how bad it got, however,” said Mike, “nothing seemed difficult in comparison to what people with brain tumors wake up to face every day, fighting for their lives. It put things in perspective for me.”

The trip also gave Mike and John a chance to grieve the loss of their mother. “When our mother died ten years ago, we didn’t talk about it a lot,” said John. “This was an opportunity to get together and talk about her and attempt to heal our wounds a bit. We were able to change the memories of her battle with brain cancer and make it more than just a tragic event.”

Mike and John estimate that they reached 10 million people with their message during their trip due to the press coverage they received. “We felt that if even one person got the information they needed to get proper treatment for their brain tumor then whatever suffering we experienced on the road was worth it,” said John. “We hope we helped other families when they needed it and made a difference for them.”

Because of Mike and John’s fundraising efforts, NBTF will be able to award a \$75,000 grant to epidemiology researchers. “When we met with the NBTF staff, they immediately wanted to help,” Mike said.



courtesy John and Mike Logsdon

John and Mike Logsdon at the finish point of their journey.

“They stepped up and said ‘We want to support you 100 percent, tell us what you need.’ We were impressed that they have a personal connection with this cause and are so impassioned by it.”

NBTF heard from many brain tumor patients and their families about how moving the Logsdons’ efforts were. “Your biking adventure has been an inspiration for us both—thanks!” wrote one couple in a message to Mike and John. “Your trip had a profound impact on us in lifting our spirits and knowing there were others out there running the good race.” Another wrote, “I wish I’d had the privilege of meeting Mike and John, if just to hug them tight and thank them for helping my husband, who has a brain tumor. You are true warriors on this journey. We are so very proud.”

On behalf of the millions of people inspired by their journeys, thank you Karen, Mike and John.

Attention SEARCH Readers:

The information in this newsletter is subject to change. The reader is advised that information obtained from a physician should be considered more up-to-date and accurate than the information in the newsletter and that this newsletter does not and cannot purport to address facts and circumstances particular to any patient. This is something that can only be done by the patient’s physician. Sponsorship of this newsletter does not imply the National Brain Tumor Foundation’s endorsement or recommendation of any particular form or forms of therapy, regimen or behavior.

Announcements

New!

NBTF Caregiver Trainings in Your Living Room!

Since 2003, NBTF has been conducting family caregiver training workshops around the country in conjunction with treatment centers and hospitals. This spring, we will launch an online version of this program. This six-week educational series is designed for caregivers who cannot attend a workshop in person. Each session will include an educational presentation followed by a facilitated chat and support session for questions and for sharing. This is a free program; however, space is limited and enrollment in the entire series is required. Participants must have a telephone and high-speed internet access.

If you would like more information about this program, please visit www.braintumor.org and click on “What’s New” or call our office at 800.934.2873.

Know How to Read Your MRI? Learn How and More on the NBTF Website!

Did you miss the NBTF fall teleconference series? Check out our website for slides and audio recordings of all presentations! Listen to “Understanding your MRI Report” by Philip Gutin, MD and be sure to download “New Advances in Chemotherapy” by Howard Fine, MD. Our third fall teleconference, “Cancer and the Campus: Finding Support at College When Your Parent Has Cancer” by Heather Servaty-Seib, PhD, is also available in podcast format. To access the teleconference recordings, visit www.braintumor.org and click on “What’s New.”



Every Piece of Mail Can Help the Brain Tumor Cause

The National Brain Tumor Foundation now has a postage stamp! Support NBTF by ordering a few sheets of stamps to brighten up your greeting cards and thank-you notes while spreading information about the brain tumor cause. You can view and order the stamp at

www.zazzle.com/BrainTumor. The colorful image used on the stamp is the same as that on our NBTF pins, and was designed by brain tumor survivor and artist Scott Norris.

New DVD Chronicles the Brain Tumor Experience

Schering-Plough, the maker of Temodar, has partnered with NBTF and The Wellness Community to create a DVD for patients and family members titled “Personal Reflections: Patient Stories of Brain Tumors.” This free DVD covers diagnosis and treatment options, how to find support and cope with having a brain tumor, adjustments to make in your daily life, what to expect in the future, and additional resources that you may find helpful. If you are interested in receiving a copy of this DVD, please call NBTF at 800.934.2873.

clinical trials

For more details on these trials, please visit www.clinicaltrials.gov and enter the trial ID # or call NBTF at 800.934.2873 to request a copy of the study details.

A Pilot Study of Dronabinol for Adult Patients with Primary Gliomas

Sponsored by Duke University and Solvay Pharmaceuticals

Trial ID #: NCT00314808

Contact: Deborah H. Allen, RN, MSN, ARN, BC at 919.681.4719 or allen079@mc.duke.edu

Topotecan in Treating Patients with Refractory or Progressive Primary Malignant Brain Tumors

Sponsored by Herbert Irving Comprehensive Cancer Center and National Cancer Institute

Trial ID #: NCT00324844

Contact: Clinical Trials Office – Herbert Irving Comprehensive Cancer Center at 212.305.8615

Sirolimus in Treating Patients with Glioblastoma Multiforme

Sponsored by National Cancer Institute

Trial ID #: NCT00047073

Contact: Timothy Cloughesy, MD at 310.825.5321, 888.798.0719 or tcloughesy@mednet.ucla.edu

Stress Reduction Program in Patients with Malignant Brain Tumors and Their Family Caregivers

Sponsored by Case Comprehensive Cancer Center and National Cancer Institute

Trial ID #: NCT00376818

Contact: Laura A. Siminoff, PhD at 216.368.0669 or laura.siminoff@case.edu

GP96 Heat Shock Protein-Peptide Complex Vaccine in Treating Patients with Recurrent or Progressive Glioma

Sponsored by National Cancer Institute

Trial ID #: NCT00293423

Contact: Andrew Parsa, MD, PhD at 415.353.2629 or 800.888.8664

Tetra-O-Methyl Nordihydroguaiaretic Acid in Treating Patients with Recurrent High-Grade Glioma

Sponsored by National Cancer Institute

Trial ID #: NCT00404248

Contact: Stuart Grossman, MD at 410.955.8837 or Grossman@jhmi.edu

Boswellia Serrata Combined with a Low-Fat, Vegan Diet or a Standard Diet Alone in Treating Patients Who Have Undergone Surgery and Radiation Therapy for Newly Diagnosed Glioblastoma Multiforme

Sponsored by National Cancer Institute

Trial ID #: NCT00243022

Contact: Mladen Golubic, MD, PhD at 800.862.7798 or golubim@ccf.org

Treatment of Newly Diagnosed Brain Tumors with Chemotherapy and Radiation Using Cells Modified for Chemoprotection and an Experimental Drug to Decrease the Tumor Cell Resistance to Chemotherapy (for ages 5 years - 30 years)

Sponsored by Children’s Hospital Medical Center, Cincinnati

Trial ID #: NCT00272870

Contact: Lars Wagner, MD at 513.636.1849 or Lars.Wagner@cchmc.org
Susan Radtke, RN at 513.636.4961 or Susan.Radtke@cchmc.org

Research Report: Preventing Angiogenesis

By Eva Guralnick

Erwin Van Meir, PhD, of Emory University School of Medicine, Atlanta, Georgia, received the National Brain Tumor Foundation's Glioblastoma Multiforme Research Grant in 2005 for his exciting work in brain tumors. His study, entitled Brain Angiogenesis Inhibitor-1 in Gliomagenesis and Progression, seeks to find a way to stop brain tumors by halting the growth of the blood vessels that support them. We recently spoke with Dr. Van Meir about the results of his research.

What is tumor angiogenesis?

Angiogenesis is the process by which a tumor triggers the growth of its own blood vessels. Tumors do this in order to survive; just like an organ in the body, they need a way to receive oxygen and nutrients and to eliminate waste. Tumors also secrete factors that go into the body's circulatory system to do things such as helping the tumor grow or preventing the immune system from becoming active against the tumor, and they can use the blood vessels to metastasize to other sites.

What is Brain Angiogenesis Inhibitor-1?

There are many factors that can influence angiogenesis. The factor we are studying in my laboratory is a protein called Brain Angiogenesis Inhibitor-1 or BAI-1. This molecule is intriguing because it is almost exclusively found in the brain, as opposed to other factors that have been studied which can be found in any organ. When this protein was discovered, researchers realized that there were certain domains on it that had already been previously studied in another protein called thrombospondin, which is known to inhibit angiogenesis. So researchers tested those areas on BAI-1 and they found that they also could inhibit angiogenesis.

How does BAI-1 work?

The BAI-1 protein is anchored in the membrane of normal brain cells. One piece of the molecule hangs outside the cell surface and another piece connects with the inside. There is less BAI-1 in the cell membrane of brain tumor cells, which suggests that tumors cannot grow well if BAI-1 is nearby.

What did you learn during your NBTF research?

We wanted to examine how BAI-1 works. The large fragment of the protein that hangs outside the tumor cells contains the anti-angiogenesis properties. We hypothesized that it needed to be separated from the rest of the molecule to become active, travel, and stop blood vessels from forming. We looked for fragments of that portion of BAI-1 and found that it breaks in at least two different places. There is one breakage site right outside the cell membrane that generates a fragment that we have now named Vasculostatin-120. During the study funded by NBTF, we showed that Vasculostatin-120 is very

capable of inhibiting the growth of glioblastoma in the brains of mice. We also began studying another site where BAI-1 can be cleaved, and have preliminary evidence that shorter fragments can inhibit vessel formation in culture models. We'd like to continue studying that fragment, which we call Vasculostatin-40, and identify the enzymes that mediate its separation from BAI-1 and how the cleavage event is regulated.



Erwin Van Meir

What makes you hopeful about this as a treatment?

What we've learned can be helpful in different ways. One would be to find the smallest possible fragment of BAI-1 which inhibits angiogenesis—or make a molecule that mimics it—and deliver that to the patient as a drug. That would be wonderful. Also, the brain already makes BAI-1; if we could stimulate the splitting off of Vasculostatin fragments, suddenly you'd have a lot of soluble Vasculostatin in the brain to inhibit angiogenesis. A third way would be to treat patient tumors with Vasculostatin fragments delivered through viral gene therapy.

Has your NBTF grant helped you secure more funding?

Yes. The NBTF grant of \$50,000 allowed us to leverage a \$1.9 million grant from the National Institutes of Health to continue these studies by helping us generate the extra data that strengthened our application. We and the neuro-oncology community at large are very grateful for support we receive from brain tumor foundations such as NBTF. Seed money like that from NBTF helps fund exploratory pilot projects and keeps labs active when research money is tight, as it is now.

Why are you focusing on brain tumors?

It is a long story that brought me from my native Belgium to studies in biology in Switzerland, a post doc in La Jolla, California, and finally to working at Emory in Atlanta. In Switzerland, I studied brain cancer and found it exciting and challenging. The biology is interesting, there is so much to learn, and it's so important for the patients. I made it my career and have never regretted it. It is my hope that our work will lead to better therapies, which are urgently needed.

Ask the Health Professional

By Mary Lovely, RN, PhD

News About Cutting-Edge Brain Tumor Research

Question:

What is the most recent research being done on brain tumors?

Answer:

Each year, scientists, researchers and health professionals from around the world gather at the Society for Neuro-Oncology conference to share information and learn from one another. I attend as your representative. At the last conference, hundreds of abstracts were presented on new findings about immunology, causes, genetics, targeted drug therapy, radiation techniques, innovative drug delivery systems and quality of life.

The National Brain Tumor Foundation is proud to sponsor this meeting each year. Here are some highlights from 2006:

- Treatment with radiation and temozolomide followed by temozolomide has made progress in survival and quality of life for patients with high-grade gliomas. As we learn more about the molecular makeup of tumors, some patients may benefit from other drugs as first-line therapy.
- The combination of Avastin and CPT-11 continues to show promising results for recurrent high-grade gliomas such as GBM and anaplastic astrocytoma. Research is being conducted to evaluate this combination as first-line therapy.
- Testing the brain tumor tissue for its molecular makeup is used for oligodendroglioma tumors. The loss of alleles on chromosomes 1p and 19q has been established as a good prognosis for oligodendroglioma and oligoastrocytoma patients. Other tests for glioma treatment sensitivity and prognosis such as activation of MGMT and EGFRviii are still in the process of development for clinical use.
- A brain tumor survivor's family spoke about the need for more focus on quality of life for survivors, and challenged health care professionals to find ways to decrease symptoms so survivors are not as impaired.

Next year's meeting will bring new research that may promote the cure and alleviate symptoms related to brain tumors.

Mary Lovely, RN, PhD, Medical Information Specialist (made possible with financial support from the Tim & Tom Gullikson Foundation), is available to answer your questions concerning brain tumors. Contact her by visiting the Ask The Health Professional section at www.braintumor.org, or by calling 800.934.2873.

The general medical information provided in this column is not a substitute for your doctor's medical advice. Consult your physician about your individual medical treatment.

RACING AHEAD® Wins Again!

All across the country, brain tumor patients, their friends and families are participating in athletic events of their choosing to raise money for National Brain Tumor Foundation programs. Here are some great success stories.

Rocking 'n Rolling for a Cause in San Jose



Nicole Meise

Jan Meise

Jan Meise completed his first half marathon in just over two hours, but that was only one small reason to be cheering. At the Rock 'n Roll Marathon in San Jose in October 2006, Meise raised \$5,800 in honor of a very close friend to him and his wife Nicole. "Conny Fisher was our maid of honor, she was a best friend, and why she lost her battle against brain cancer, we will never understand," said Meise. "Not only did we lose her, but we watched her small children cope with so much. How do you explain to a child about cancer? Nicole and I want the dollars we raised to help other patients, and to find a way to avoid more of this pain."

Cycling Ahead Metric Century Races Against Brain Cancer in Georgia

Bruce Radcliff coordinated the Cycling Ahead Metric Century bike race on September 30. "This is the first of many more in Georgia," says Radcliff. "Just a few years ago, my sister was diagnosed with brain cancer. Feelings of fear that I could lose her overwhelmed me. Then my brother was diagnosed with brain cancer also. A dramatic change was required in all of our lives. I now truly believe that each day should be celebrated."

Radcliff has loved bike riding since his twenties, saying it has always been a way to feel focused. Coordinating his own race called on talents he had learned years before, when working on other projects. "The details at times can seem overwhelming, but who knows? CAMC could become an annual event!" said Radcliff.

Los Angeles Marathon: Not Only for Runners!

The Los Angeles Marathon takes place March 4, 2007, and it's not just for runners! Several other events are held in conjunction with the marathon. Want to do a combo of walking and running? Then try the Emerald Nuts 5k Run/Walk. Is cycling your favorite sport? Then the 22-mile Acura Bike Tour should inspire you. Join others who are running, walking and cycling for the brain tumor cause!

For more information on how to organize your own Racing Ahead® event, visit www.braintumor.org and click on Racing Ahead®, email us at racingahead@braintumor.org, or call 800.934.2873.

5th Orange County Angel Adventure® Scores Again!



On October 21, the brain tumor community of Orange County, CA gathered at Huntington Central Park to celebrate yet another Angel Adventure® walk. Many thanks to the 400 registrants who raised \$130,000 for the brain tumor cause. Emcee Maria Hall Brown, Producer and Host at KOCE-TV, returned for the second year and hosted the event with tremendous warmth. This event owes its success to Event Co-Chairs Wendy Fuld and Sue Berman and their dedicated team of committee members. Our heartfelt thanks to all who made this event a success for the 5th year running!

2nd Phoenix Angel Adventure® raises \$115,000!



Despite the prediction of rain, enthusiastic Arizona residents turned out for the 2nd Annual Phoenix Angel Adventure® on October 14 at Eldorado Park. As emcee Jason Barry, CBS 5 News reporter, started the ceremonies, it began to pour. Participants remained in good spirits and a sense of camaraderie prevailed. Thanks to the 433 participants who helped contribute to the day's success. Special appreciation goes out to Co-Chairs Sue Swift and Lanette McLamb-Veres, and the volunteer planning committee for organizing an event with so much heart and dedication.

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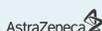


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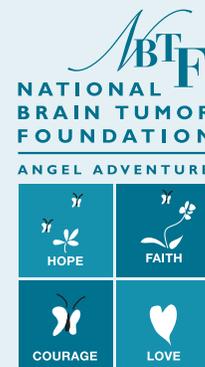
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Thank You Event Sponsors!

Interested in organizing an Angel Adventure® in your community?

NBTF's Angel Adventure® is a fundraising walk and community day that takes place in cities across the country. With support from NBTF, these events are organized by volunteers from the brain tumor community in each city. In 2007, there will be events in San Francisco, Denver, Portland, Washington, DC, San Diego, Phoenix, Orange County, and Dallas-Ft. Worth.

NBTF is actively recruiting new cities for the Angel Adventure® program. If you are interested in organizing an Angel Adventure® in your city, please contact Nealika Caden, Director of Special Events, by email at caden@braintumor.org or call toll-free 800.934.CURE (2873), ext. 108.



JOIN US!
2007 Angel Adventure® Calendar



**We invite you to
come out and
support NBTF's
Angel Adventure®
fundraising
walk and
community day.**

San Francisco, CA
May 5

San Diego, CA
September 29

Denver, CO
May 19*

Phoenix, AZ
October 14

Portland, OR
September 8

Orange County, CA
October 20

New! **Washington, DC**
September 22*

Dallas-Ft. Worth, TX
November 3

* Event date is tentative. Visit www.braintumor.org, click "Angel Adventure® Walk" for confirmed dates.

Go Teams!

Individual and team participants raise 80% of the revenue for our Angel Adventure® program. Join us in the fight against brain tumors by raising money from your family and friends for brain tumor research and patient services. Organize a team of family members, friends and office co-workers! It's fun and rewarding!

Register Online!

Go to www.braintumor.org, click on "Angel Adventure® Walk." You can build your own personal fundraising page and send email messages to your family and friends.

**1st Dallas-Fort Worth
Angel Adventure® is a Big Success!**



The very first Dallas-Fort Worth Angel Adventure® was an unqualified success! Despite unseasonably cold weather, 400 registrants gathered at Trinity Park to support the brain tumor cause. The event raised \$117,000, making it the most successful first-time Angel Adventure® walk in the history of the program. Megan Henderson of Fox 4 News emceed the event with style and grace. Our heartiest congratulations and thank you to Event Chair Deana Woods and her wonderful team of committee members!

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Thank You Event Sponsors!

Successful fundraisers support NBTF



1. Brain Matters, a DJ/Club Event 2. Brandon Thomas Golf Tournament 3. A Cure in Mind (L to R Matthew Zachary, Linda Kelly Armstrong, Dr. Bernie Siegel, and Rob Tufel)
4. Boot Camp to Beat Brain Cancer 5. 3rd Annual Mimi Avila Fun Run/Walk/Bike

Here are some creative ways people raised hope and funds for NBTF in 2006.

- A Cure in Mind in TX • \$21,400
- Knitting for Brains in CA • \$19,000
- Kiewit Pacific Golf Tournament in CA • \$15,000
- Brandon Thomas Golf Tournament in NV • \$15,000
- Katie Hamill Memorial Tennis Tournament in CA • \$15,000
- Bert Simon Golf Tournament in CA • \$7,000
- Film Premiere of Mind Over Matter: A Spiritual Journey in CA • \$6,000
- 9th Annual Mike Wengerter Memorial Golf Outing in OH • \$4,300
- 3rd Annual David Moorman Memorial Concert: We Came to Play in MO • \$4,000
- Gleason Golf Tournament in CO • \$2,100
- Scooters Scramble in OH • \$2,000
- Oakland Athletics Auction in CA • \$1,500
- 3rd Annual Mimi Avila Memorial Fun Run/Walk/ Bike Ride in CA • \$1,200
- Passion for Paso, A Wine Tasting Event of Paso Robles in CA • \$1,200
- Horseshoe Tournament and Pig Roast in PA • \$1,100
- Annual George Bockos Golf Outing in IL • \$1,100
- Bootcamp 2 Beat Brain Cancer in Memory of Anne Fajgenbaum in NC • \$1,000
- Jester'Z Improv Night in AZ • \$600
- Celebrate and Help Fund a Cure: 1st Anniversary of Columbus Cafe in CA • \$600
- Brain Matters, a DJ/Club event in CO • \$500
- Gangbusters Award Ceremony in CA • \$300

Raising Funds, Raising Hope!

All across the country, NBTF supporters organize a wide variety of fundraising events to support the brain tumor cause. These events have ranged from a chili cook-off to wine-tasting receptions, a hand-knit scarf trunk show to stand-up comedy at a local club, and horseshoe tournaments to golf outings. Our imagination is our only limit! If you are interested in organizing a fundraising event to support the brain tumor cause, please contact Lisa Quarles, Development Manager, Special Events at quarles@braintumor.org or 415.834.9970 ext. 113.

Ask Janet



Janet, six-year survivor

Question: What is a seizure aura, and what “triggers” can cause a seizure?

Fellow brain tumor patients, it's important to educate yourself about seizures.

A seizure aura is a physical sign or feeling that warns you of a coming seizure.

Auras vary among patients. They might be

flashing lights or smells that *only you notice*, a strange taste, tingling, numbness or uncontrolled jerking movements.

Seizure triggers, either external or internal, can cause a seizure. Bright or flashing lights from signs, television and/or computer screens are a trigger for some patients. Ira in New York believes a lot of sunshine triggers his focal seizures. Amie in Colorado suspects her focal seizures are caused by anxiety and fatigue. Another patient's triggers include overexertion, low blood sugar, viral infections, strong smells (especially gasoline and perfumes) and eating raw onions.

Safety first. Take prescribed antiseizure medications as directed to maintain therapeutic levels. Ask if other medications will reduce their effectiveness. Get regular blood testing, especially if you take Dilantin. Avoid stress. Eat and rest properly. Avoid high temperatures from saunas or baths. Also, be cautious with alcohol, caffeine and smoking, which may affect seizure activity.

If you experience auras or new unexplained behaviors, talk to your doctor.

Visit www.epilepsyfoundation.org or www.epilepsy.com for more information.

Question: How do you manage fatigue?

Many patients experience fatigue before, during, and after treatment.

One patient shared these tips that might help with fatigue: “know and respect your limitations, be flexible, and think quality not quantity.” He recommends setting reasonable goals, like accomplishing one task or event per day or week.

Another patient takes timed naps—between 45 minutes to an hour—to combat his fatigue. A third survivor who experienced reduced stamina and attention span was prescribed Ritalin. It helps her during activities requiring concentration.

For more on fatigue, visit “What’s New” at www.braintumor.org.

This column reflects patient experiences and opinions which are not a substitute for your doctor's medical advice.

Next time in Ask Janet: Telling children about a brain tumor diagnosis and/or treatment. Call 800.934.2873 or email questions and/or tips to Ask Janet at nbtf@braintumor.org.

NBTF at the Lance Armstrong Survivorship Summit

In October, Harriet Patterson, MPH, Director of Patient Services at the National Brain Tumor Foundation, joined 800 others from around the country as a part of the first-ever Livestrong Survivorship Summit sponsored by the Lance Armstrong Foundation. Cancer survivors, advocates, and caregivers were selected as delegates to the summit. A strong contingent of brain tumor survivors filled out the crowd.

“This was a unique opportunity to share and work together with those affected by all types of cancer,” said Patterson.

“We talked about the common challenges, such as financial struggles, problems receiving benefits, insurance coverage, difficulty navigating the health system, and coping with symptoms after treatment ends.

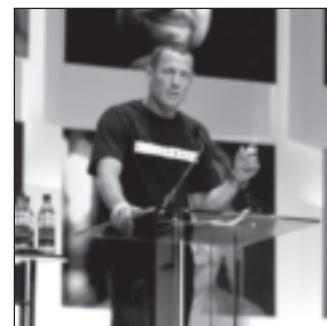
We also started developing solutions and action plans that each delegate can work on in his or her community to make a difference.”

Speakers at the summit read like a who's who of business, healthcare, and politics, including former Senator and Presidential candidate John Kerry,

who talked about his father's fight with prostate cancer and subsequently, his own; Steve Case of AOL/Time Warner who talked about his brother's brain tumor and new approaches to treatment; Former Surgeon General Antonia Novello, MD, MPH, who talked about equality and access to treatment; and several cancer survivors from across the country who have used their passion to make a difference for others.

Lance Armstrong opened and closed the weekend addressing the topics of determination and tenacity. Heads throughout the room nodded as he talked about taking the lessons from his own cycling career and his battle with cancer out into the world to try and make a difference for others.

The National Brain Tumor Foundation has been working with the Lance Armstrong Foundation in a variety of ways. We are a community partner of the Foundation and received a grant from the Foundation to develop programs for Spanish-speaking brain tumor patients. Linda Armstrong Kelly, Lance's mother, also served as keynote speaker at “A Cure in Mind,” an NBTF benefit in San Antonio, Texas. Lance Armstrong continues to be a supporter of the brain tumor community as a survivor and NBTF is proud to be a partner.



Lance Armstrong at the conference

courtesy LAF



caregiver's corner

NBTF Trains Caregivers Across the Country

The National Brain Tumor Foundation has once again wrapped up a successful fall series of Family Caregiver Training programs across the country, with caregivers finding support in Washington, New York, Virginia and Pennsylvania! Are you interested in hosting a Family Caregiver Training at your center? The Caregiver Training program is an eight-hour workshop that can be given over the course of one day or several evenings. The program includes seven one-hour modules that cover medical aspects of brain tumors; neuropsychology; symptom management; lifting, turning and moving somebody safely; how to access social services and resources; legal issues and palliative care. Contact Harriet Patterson, MPH at 800.934.2873 or patterson@braintumor.org to find out how you can get on the map.



Virginia Mason Medical Center in Seattle, Washington, held its first-ever caregiver training and was one of NBTF's largest-attended caregiver trainings to date, thanks to the attendees who braved a harsh storm to be there! Participants enjoyed the opportunity to network with each other, and as one person put it, "It gave me a great opportunity to interact with other families dealing with brain tumors."

The University of Virginia Neuro-Oncology department held a caregiver training on October 20, 2006. This marked the third year in a row that UVA has held the Caregiver Training, which continues to be a resource for the brain tumor community.

Memorial Sloan-Kettering Cancer Center in New York City also held a caregiver training on October 20, 2006. Attendees heard from Dr. Philip Gutin, the Chief of Neurosurgery, and neurosurgeon Dr. Viviane Tabar on the latest treatment options for brain tumors, in addition to the other modules that were presented that day.

Penn State Milton S. Hershey Medical Center in Hershey, Pennsylvania, held their second annual training, with nearly forty people taking part. One family drove seven hours to attend the program. Dr. Elana Farace, PhD, talked to people about the many ways in which a neuropsychologist can help with long-term survivorship issues.



NEW! Can't Make it to a Caregiver Training?

Join us as we launch a special online caregiver training program this spring. See Announcements on page 3 for more details. Registration is limited.



2007 Caregiver Training Workshops

NBTF will be hosting more trainings for caregivers in 2007. These free workshops for family caregivers are offered in conjunction with hospitals across the country, and provide detailed information and referrals to resources that brain tumor patients and their families need.

February 24 Houston, TX • Methodist Hospital

March 10 Birmingham, AL • University of Alabama at Birmingham

March 31 Tampa, FL • Moffitt Cancer Center

survivor's story

Preparing Mind and Body for the Fight

By Michael Moyles

I was playing city league basketball in St. Louis when I dove for a loose ball at the same time as another guy. We collided and I was knocked out cold. Fortunately, I'm on active duty with the Air Force, which has a policy that if you lose consciousness you have to have a CT scan to rule out any brain damage. The scan showed that I had no trauma from the accident—but I did have a lesion the size of a golf ball behind my right eye on the optic nerve. I'd had no symptoms at all.

I spent nearly a year with various doctors trying to figure out what it was. I was told it might be an arachnoid cyst or something benign I'd had since birth, but it wasn't until I actually got to a specialist that it was identified as a brain tumor. It was growing and had to come out. After my surgery in May of 2001, I learned that it was a grade 2/3 oligoastrocytoma. It took me nearly twelve weeks to recover from the weakness after surgery and function normally, but I did, with no neurological deficits.

My wife Angela and I settled into a routine of regular MRIs—at first every three months, then eventually only once per year. We got a false sense of security from having

each MRI come back clear. We knew that over 90 percent of people with oligoastrocytomas have a recurrence within four to six years, and we hoped I'd be in that lucky 10 percent. It was a real emotional blow when it came back in four years, and this time

the tumor was larger and more aggressive. We had been through so much already and thought we'd beaten it.

I had my second surgery in May 2005, followed by chemo. This time I recovered much more quickly and was out of the hospital the next day, although I did have trouble with my vision for a few weeks and had to retrain my right eye to work again in concert with my left.

As I was waiting to leave the hospital after that second surgery, I heard Lance Armstrong's announcement that he would be riding his seventh and last Tour de France to benefit his foundation, which raises money for cancer research. Most people don't know that Armstrong has had lung and brain cancer as well as testicular cancer, and had surgery to remove brain tumors. My whole life I'd been athletic and I wanted to do something to give back to people who had helped me during my ordeal. I decided

**It was like NBTF
was beside me
through everything.**



courtesy Michael Moyles

Michael Moyles running the United States Marine Corps Marathon in Washington, DC.

right there in the hospital that I would run a marathon and ask people to make pledges.

I'd never run a marathon—the most I'd run was a 5k race with friends. But I ran my first marathon six months after my surgery, between rounds four and five of my chemo, and raised over \$7,000 for NBTF. While training, I'd get up at 5:30 in the morning, take my chemo pills, go out and run 15 miles or so—and yes, sometimes I'd throw up before I got home. I'm hooked on marathons now and run them to support other cancer research organizations as well. I keep myself in shape while giving back to others.

I picked NBTF as the beneficiary of my first marathon because they were the most helpful of all the organizations I worked with. There was no question for which they didn't have an answer, and all their services were free. They kick-started my educational process. They sent me a big box of books and pamphlets on brain tumors, and I used the website to join discussion forums and hook up with other survivors who told me about their experiences with surgery and chemo. It was like NBTF was beside me through everything, providing people to talk to and recommendations for doctors and treatment centers.

The best advice I could give someone who's been diagnosed with a brain tumor is prepare both your mind and body for the fight. Prepare your mind with knowledge: you need to learn everything you can about your condition to combat the anxiety, fear and apprehension that comes with such a life-changing event as a brain tumor. The more you know, the less likely it is that anything can catch you by surprise. The second part is: prepare yourself physically to fight this illness. If your body has other things to worry about—if you're not in shape, not sleeping or eating well, or are overstressed—that takes away from its ability to fight this disease it's dealing with. Fitness to me is key. It puts my body and my mind in the best possible condition to fight cancer.

SAVE THE DATE!

Caregiver Training Comes to Your Home

Can't get to a family caregiver training workshop? This spring, NBTF is launching a free online version of our caregiver program. Each session will include an educational presentation, a facilitated chat, and a support session for questions and for sharing. See page 3 for details.

Angel Adventure® Fundraising Walk and Community Day

San Francisco, CA
May 5, 2007

Portland, OR
September 8, 2007

Denver, CO
May 19, 2007

Washington, DC
September 22, 2007

Caregiver Program Dates

February 24, 2007 • Houston, TX • Methodist Hospital

March 10, 2007 • Birmingham, AL
University of Alabama at Birmingham

March 31, 2007 • Tampa, FL • Moffitt Cancer Center

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