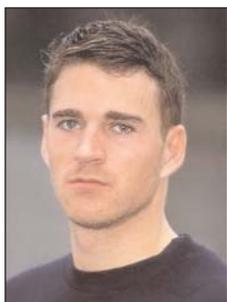


# Heads Up

## Dan Perkins: Winning the Race of a Lifetime



Dan Perkins

At 21 years old, I was in peak physical shape and a student at Dartmouth College with a passion for crew. These young, innocent, and blissfully ignorant

college years flew by until, without warning, I lost feeling in the right side of my body and began to have difficulty speaking and walking. I couldn't make sense of a clock or write my name, and I could speak less and less by the minute. Still, it wasn't until the doctors told me that I had a brain tumor that I began to worry.

A biopsy revealed an aggressive glioblastoma multiforme (GBM) near Broca's Area. The doctors said the tumor was inoperable and that the prognosis was poor. They suggested radiation with an experimental protocol. Fortunately, my parents searched for other opinions, contacting doctors and support groups. We met with a doctor in New York and together agreed that surgery was risky but worthwhile. I didn't care how I ended up post-op; I just didn't want to die.

For many reasons, including a great surgeon and a lot of luck, I came out of the operation virtually cancer-free. I had been incorrectly diagnosed, and my tumor was neither a GBM nor

*Dan Perkins, continued on page 4*

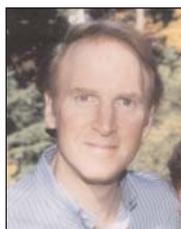
## The Problem of Misdiagnosis

Vigilance is essential for medical professionals

The issue of delayed diagnosis or misdiagnosis of brain tumors is considerable and too significant to be ignored. Patients and family members who contact the Brain Tumor Society often convey stories about how they or their loved ones have been given an incorrect diagnosis or thrust from one doctor to another. Many patients remain undiagnosed until their symptoms present in a more radical way or they are suddenly so ill that they must be hospitalized.

One reason for this is that symptoms of brain tumors are difficult to detect because so many of them are associated with other infirmities. For example, headaches are a very common problem for children and adults, accounting for nearly 20 million visits to health care providers in the United States each year. The vast majority of headaches are due to migraine, stress/tension, sinusitis or other conditions that respond to non-invasive medical care. While recurring headaches understandably raise concern for the possibility of having a brain tumor, tumors are in fact relatively rare. It is estimated that as many as 30-50% of children and young adults have recurring headaches and nearly 5-10% have migraine; however, only about 0.005% of children are diagnosed with a brain tumor each year.

The difficulty, then, is to determine quickly which of the many people with recurring headaches have a brain tumor or another lesion that needs immediate medical attention.



Neal Levitan

Headaches that occur with increasing frequency or intensity, especially at night or upon waking in the morning, should be evaluated by a health care professional. The sudden onset of epileptic seizures, especially if they appear for the first time during adulthood, is another warning sign.

The combination of progressive headaches with other symptoms should prompt thorough evaluation. Even in the absence of headaches, new onset seizures or neurologic signs should raise

*Misdiagnosis, continued on page 3*



Dr. Scott Pomeroy



## Color Me Hope Resource Guide 4th Edition

The updated 4<sup>th</sup> edition of our Resource Guide is a valued asset. It has more information than ever in the Education and Support sections, and it's free. Just call 800.770.8287 or e-mail [info@tbts.org](mailto:info@tbts.org) for your copy.

**HEADS UP** is published six times a year by the Brain Tumor Society, a national non-profit organization committed to finding a cure for brain tumors. The Brain Tumor Society is a founding member of the North American Brain Tumor Coalition. Contact the Brain Tumor Society at 800.770.8287 or [info@tbts.org](mailto:info@tbts.org) or visit our website at [www.tbts.org](http://www.tbts.org).

Vincent R. Patrone, Esq.  
*Chair, Board of Directors*  
Scott L. Pomeroy, M.D., Ph.D.  
*Chair, Medical Advisory Board*  
Darell D. Bigner, M.D., Ph.D.  
*Chair, Scientific Advisory Council*

G. Bonnie Feldman ..... *Founder*  
Mary Catherine Calisto ..... *Vice-Chair*  
Michael R. Corkin ..... *Treasurer*  
Robin Boss Dorman ..... *Secretary*  
Neal P. Levitan, Esq. .... *Executive Director*

Dawn Grenier ..... *Managing Editor*  
JLM Marketing Group, Inc. .... *Printing*

The information herein is based on professional advice and expert opinion and does not constitute therapeutic recommendations. BTS recommends that you discuss all medical questions with your physician. Further, BTS does not endorse products, services or manufacturers, nor does it assume liability for any product or service mentioned.

©2004 Brain Tumor Society. All rights reserved.

## Our Mission

The Brain Tumor Society exists to find a cure for brain tumors. It strives to improve the quality of life of brain tumor patients and their families. It disseminates educational information and provides access to psychosocial support. It raises funds to advance carefully selected scientific research projects, improve clinical care, and find a cure.

## From the Chair of the Board of Directors



Vincent R. Patrone, Esq.  
*Chair, Board of Directors*

As we all know, it is very easy to get caught up in the day-to-day and be preoccupied with small worries. Then, suddenly, a brain tumor is diagnosed for you or a loved one. Life as you know it is forever changed.

As soon as you hear the diagnosis, isolation, confusion and uncertainty set in. A brain tumor? What now? You are confronted with the challenge of making informed decisions but may feel overwhelmed with new information, terminology and disheartening statistics.

One of our goals at the Brain Tumor Society is to empower those affected by a brain tumor. We know that knowledge is power. We offer a wide range of information and services to help patients and their loved ones manage the multiplicity of problems associated with brain tumors, enabling them to make informed decisions about treatment options and recovery plans, and empowering them to regain the sense of control so often lost under these circumstances.

We provide current brain tumor resources, including information on diagnoses and treatment, and is available by phone or email to share this information. In addition, the Society offers access to comprehensive clinical trial listings for brain tumor patients. Our staff can also refer patients, caregivers and family to support groups across the country. For those who cannot attend support groups, we created the Patient/Family Network of volunteers. This network offers support through the sharing of mutual experiences via phone or email conversations. Finding someone else who shares your needs and concerns can address isolation and uncertainty and provide a source of strength and support. This newsletter, our *Color Me Hope Resource Guide*, and our fact sheets and other brochures are valuable resources, and our newly redesigned website, [www.tbts.org](http://www.tbts.org), makes more of this information available anytime and anywhere.

Planning is underway for our fall Symposium (see the center insert for details) that will address research, treatment and management issues. Appropriately, the theme of the conference will be "Information is Power ... Power is Hope." The Brain Tumor Society remains committed to offering assistance to and inspiring hope in all those affected by a brain tumor diagnosis.

Vincent R. Patrone, Esq.

*Misdiagnosis, continued from page 1*

concern for the possibility of a brain lesion. Evaluation should include a thorough history and physical examination, and a CT or MRI scan may be needed as part of the assessment.

Nearly all brain tumors are accompanied by abnormalities detectable by thorough neurological and ophthalmological examination. If an initial examination reveals abnormalities suggestive of a brain lesion, then a CT or MRI scan should be obtained. If the initial examinations are normal and the headaches or other symptoms persist, then follow-up examinations within 1-3 months should be performed to monitor for the appearance of new abnormalities.

The challenge of diagnosis is additionally difficult if the presenting symptoms are non-specific, such as subtle behavioral

changes. Children under 2 years old present a particular challenge, for their symptoms are often irritability, vomiting and/or failure to gain weight, all of which are extremely common.

For all of these symptoms, careful examination and thorough follow-up are essential.

Vigilance for neurologic signs through repeated examinations together with a high level of awareness for the diagnosis and appropriate CT/MRI scanning are essential to avoid delays or misdiagnosis in establishing the existence of a brain tumor.

*Scott Pomeroy, M.D., Ph.D.  
and Neal P. Levitan, Esq.*

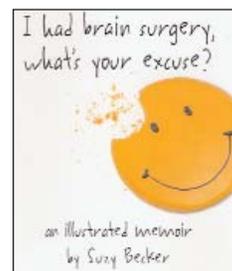
*Dr. Pomeroy teaches neurology at Harvard Medical School and is the Director of Neuro-Oncology at Children's Hospital in Boston. Mr. Levitan is the Executive Director of BTS and a brain tumor survivor.*

#### OTHER SYMPTOMS

- ◆ Behavioral changes
- ◆ Vomiting
- ◆ Deterioration of coordination or gait
- ◆ Weakness of arms or legs
- ◆ Facial weakness
- ◆ Deterioration of vision, especially if associated with double vision

## Have you read...?

Suzy Becker's brain tumor was removed by a great surgeon, but "a thousand neurosurgeons could not have



predicted" what happened next. Suzy, a writer and illustrator, lost many of her language and visual skills after surgery. *I had brain surgery, what's your excuse?* recounts her struggle to recreate herself and regain her creative senses. Her illustrated memoir combines Suzy's narrative with notes, cartoons, and scraps of her writing from the recovery process. Her level-headed but humorous view of the surgery and the unexpected recovery process is likely to reassure patients, and it provides insight to the first-hand experience for the family and friends of any brain tumor patient.

Available through local and online book sellers. Visit [www.workman.com](http://www.workman.com) to learn more about Suzy Becker and her memoir. (ISBN 0-7611-2478-0)

## Heads Up welcomes a new editor



In March, **Dawn Grenier** started at BTS as the Publications Coordinator. As a student at The College of Wooster, she worked on the campus newspaper but then turned to marketing in her post-college work. Dawn joined BTS after she left her previous marketing position in a fit of idealism and struck out to find more meaningful work. She lives within walking distance of the BTS office in Watertown, Massachusetts, and is a member of the board of directors for Watertown Community Housing. This year Dawn is especially glad that spring finally arrived in the Northeast, since she has a red kayak to try out.

*Dawn invites your feedback about Heads Up and our new website. You can reach her at [resources@tbts.org](mailto:resources@tbts.org) or 800.770.TBTS ext 16*

### BTS Notecards

Send a note and support BTS  
Each \$25 box has 12 blank cards  
with unique seasonal photos.



Order online at [www.tbts.org](http://www.tbts.org)  
or call 800.770.TBTS

Dan Perkins, continued from page 1

entirely composed of Grade IV cancer cells. It was thought to be an ependymoma, a common childhood brain tumor.

After I was released from the hospital, some things came back quickly. My speech and strength returned, and my seizures became less frequent. Though I couldn't go out on the water alone to row, I worked out on rowing machines and lifted weights. I focused on my schoolwork and co-founded a support group for students with disabilities. By the spring I had worked back into shape to row on the Dartmouth Varsity.

After I finally graduated in 1999, I moved to Augusta, GA to train for the US National Rowing Team.

Along with a young rowing



star named Ian McGowan, I won the trial for the double scull. Then it hit again: my sculling was fine, but my skull wasn't. I had a grand mal seizure and relapsed.

The tumor had grown back, though it was much smaller. I had another surgery, and this time I had trouble recovering, with seizures and splitting headaches. To add insult to injury, I had to follow up with five weeks of radiation. Besides feeling queasy and losing my hair, it was mostly uncomfortable, but the process took me out of rowing just long enough to make for a difficult return. It was the winter of 2000 when I thought about rowing again, and teams were being hashed out

by the Olympic Coaches. My lack of fitness and mediocre technique kept me off the Olympic team. Instead, I began coaching.

I loved teaching the sport, but as a brain tumor survivor I couldn't let go without proving something to myself. I trained through the summer and made the 2001 team as a spare. I was also accepted to Oxford University for a Master of Education program, a significant reassurance that my recovery was not only physical. I moved to Oxford for classes and trained for the 148<sup>th</sup> Oxford/Cambridge Race. I spent long hours rowing in the cold and rain and short hours catching up on sleep and studying, but in March 2002, in front of more than seven million BBC viewers, it all paid off. We became

only the second crew in the 175 year history of the competition to trail Cambridge for most of the race before taking the lead in the last moments.

The psychological and physical demands of preparing for such a race were similar to fighting a brain tumor. You learn to push yourself when the stakes are high and the opponent's strength is unknown. You think, "I might not win this one, but I'm going to do everything in my power to see if there's a way." That outlook offers a great chance at winning, and – whatever the outcome – you will be remembered and loved for your spirit.

*Dan Perkins coaches rowing at the Massachusetts Institute of Technology and volunteers at BTS, allowing him to see first-hand how the work of BTS helps others cope with brain tumors.*

## ASK THE EXPERT



*"I keep hearing about complementary and alternative medicine? What is this and how can I find out more?"*

It is always important to discuss the possibility of using complementary and alternative medicine (CAM) with your medical team. **Complementary therapies** are used in addition to conventional medicine to control symptoms and improve well-being; examples include aromatherapy, yoga, acupuncture, massage, meditation, nutrition and Reiki. **Alternative therapies** are used instead of conventional medicine to prevent or cure disease; for example, using a special diet to treat cancer instead of surgery, radiation or chemotherapy.

It can be difficult to find objective information about CAM. The National Center for Complementary and Alternative Medicine provides information and supports the training of CAM researchers (888-644-6226; [www.nccam.nih.gov](http://www.nccam.nih.gov)). A number of cancer centers offer **Integrative Medicine**, combining evidence-based complementary and conventional therapies. To locate a CAM provider, ask for a recommendation from your oncologist, primary care physician, support group members, or the American Cancer Society ([cancer.org](http://cancer.org)) or Wellness Community ([www.wellness-community.org](http://www.wellness-community.org)) nearest you. A directory of practitioners is also available at The Alternative Medicine Homepage ([www.pitt.edu/~cbw/altm.html](http://www.pitt.edu/~cbw/altm.html)).

Be wary of websites offering "cures," as they may sell questionable products. Reliable resources include CancerSource ([www.cancersource.com](http://www.cancersource.com)) and the Office of Dietary Supplements (<http://dietary-supplements.info.nih.gov>). Ask the Expert your question via email at [support@tbts.org](mailto:support@tbts.org) or by calling 800.770.TBTS ext 25.

## Tap into the Patient/Family Network

Coping with a brain tumor diagnosis, whether as a patient, long-term survivor, or caregiver, is often an incredibly isolating experience. As is the case with any serious medical illness, friends and family members often mean well but don't know what to say or do. It is not unusual for friends and family members to avoid what they worry will be an uncomfortable situation, which can leave patients and caregivers feeling hurt and abandoned.

Brain tumor support groups are helpful for this very reason. The group not only understands your experience, but also provides a place where you are completely accepted. This sharing of mutual experiences often reduces feelings of isolation and frustration. With that said, not everyone is comfortable with the idea of attending a support group. Maybe you don't think of



yourself as a group person, or perhaps you don't feel well enough to attend a group. Or, as often happens, there may not be a brain tumor support group in your area.

It is important to know that this support can be found in venues other than traditional groups.

A longstanding part of the Brain Tumor Society's support program is our Patient/Family Network. In the Network, volunteers offer support through a sharing of personal experiences via telephone and email conversations. For example, we have matched parents of pediatric patients, patients just starting treatment or facing surgery, family members looking for support, caregivers of both pediatric and adult patients, and long-term survivors.

An informal patient network such as ours often serves as a powerful healing resource. It can help you make sense of your

### Share your story.

The survivors and caregivers featured in Heads Up and on our website are our readers, volunteers and heroes.

If your life has been affected by a brain tumor diagnosis, please email your story and photo to [resources@tbts.org](mailto:resources@tbts.org)

or send to:

BTS - Heads Up  
124 Watertown Street, Suite 3H  
Watertown, MA 02472

*We reserve the right to edit for length and clarity.*

experience, validate your feelings, and provide an opportunity to feel understood at a deeper level. Members of our Network join in order to give and receive vital peer support. We've been told this is an invaluable experience – both for the person seeking support and for the volunteer providing encouragement by sharing his or her experience.

The Brain Tumor Society is committed to improving the quality of life for all those affected by a brain tumor diagnosis. Based on feedback, our Patient Family Network is helping us meet this goal. At this time, we'd like to expand this program by increasing our pool of volunteers. We would appreciate hearing from anyone interested in participating in our Network.

## LINKS to a Cure 2004 is coming in June

The seventh annual golf classic, LINKS to a Cure, will be held on June 14 at the oceanside Kittansett Golf Club in Marion, MA. After the tournament, players enjoy dinner and live and silent auctions to benefit the Brain Tumor Society. The tournament is almost full already! To play or become a sponsor, visit the Get Involved section of our website or contact Event Coordinator Barbara Goodman at [events@tbts.org](mailto:events@tbts.org) or by phone at 866.933.9997 ext 12.



Photo © Pierre Chiha

*To become a volunteer for our Network, or to arrange for phone or email contact with one of our volunteers, please contact Sarah Duggan at 800.770.8287, ext 25, or [support@tbts.org](mailto:support@tbts.org)*

## DEVELOPMENT

Thanks to the generosity of donors like you, the Brain Tumor Society is able to offer support, education, and hope to those affected by brain tumors. We receive no government funding. We rely on individual donors, along with corporate and foundation gifts. Only with your support can the Society continue to fund vital research, assist patients and families, and educate families and healthcare professionals about brain tumors. Last year, 84% of each dollar raised went directly to our programs of research, education and support.

## BTS Sustaining Partners Annual Fund debuts

We are pleased to announce that donors can now join a group of special supporters who choose to make an annual gift to the Society. By joining the BTS Sustaining Partners Annual Fund, you receive exclusive member recognition to honor your yearlong commitment. Contributions may be made all at once or charged monthly or quarterly to a major credit card. All BTS Sustaining Partners will have the option to be acknowledged in the *Brain Tumor Society Annual Report* and *Heads Up* newsletter.



### BTS Sustaining Partner

*Annual gift \$1,200 to \$2,399*

Members will receive a personalized certificate of appreciation and a set of handsome BTS note cards.

### BTS Sustaining Bronze Partner

*Annual gift \$2,400 to \$4,799*

In addition to the benefits previously mentioned, BTS Bronze Partners will receive an enamel "gray ribbon" pin, which may be worn to show your commitment to and support of the Society's mission.

### BTS Sustaining Silver Partner

*Annual gift \$4,800 to \$9,999*

In addition to the benefits previously mentioned, Silver Partners will receive special invitations to Society events.

### BTS Sustaining Gold Partner

*Annual gift \$10,000 or more*

In addition to the benefits previously mentioned, Gold Partners will be invited to exclusive Gold Partner Society events.

More information and ideas are available on our redesigned website. The *Get Involved* section includes an overview of the BTS Sustaining Partners Fund, as well as suggestions for other ways to donate, such as:

- ♦ Matching gifts or a workplace campaign are ways to get your employer involved.
- ♦ Planned giving or the donation of securities can put your assets to work for BTS in years to come.
- ♦ In-kind donations help to keep overhead costs low and allow our events and office to function more efficiently.

## RECOGNIZE AN OCCASION

Tribute gifts are a thoughtful and warm way to honor someone. It is like giving two gifts: one to the Brain Tumor Society and another gift of care and affection to the person you honor with your donation. Consider honoring a birthday, anniversary or other milestone by making a gift in the celebrant's honor to the Brain Tumor Society. For your own special occasion, you might direct friends and loved ones to donate to BTS in lieu of a gift to you. When we send an acknowledgment of your gift, we also send one to the person to whom you are paying tribute to let them know of your thoughtfulness. Of course, all donation information is always strictly confidential between the Brain Tumor Society and you, the donor.

## GIFTS IN MEMORY OF...

You may choose to donate funds in memory of someone who has passed. If you are experiencing a recent loss or recognizing the anniversary of a loved one, consider requesting that those around you make a donation in his or her memory. This keeps memories alive while giving the gift of hope to someone else.

Upon request, we will be pleased to provide you with additional information or materials for memorial donations.

## SSBTR's Third Annual Walkathon

Students Supporting Brain Tumor Research hosted their third annual walkathon on March 6 to raise funds for the Brain Tumor Society and Barrows Neurological Institute's research program. Thousands of people gathered to walk and bid at the silent auction, raising nearly \$80,000. This student-run event was founded by Pinnacle High School's student government in 2002, after three students died of brain tumors.

The event has grown to include schools throughout Maricopa County, Arizona. Community leaders, parents, and celebrities have joined the teens' efforts to raise funds for brain tumor research. Al McCoy, announcer for the Phoenix Suns, served as the event's Master of Ceremony. Honorary Co-Chairs included Governor Janet Napolitano, Congressman J.D. Hayworth,

Sheriff Joe Arpaio, Superintendent of Public Instruction Tom Horne, Jerry Colangelo, BTS Executive Director Neal Levitan, and Dr. Adrienne Scheck. Amid cadences called by the Corps of Cadets from Project Challenge, the honorary Co-Chairs joined students from each school in the walkathon's ceremonial first lap.

The top student fundraisers will attend a Diamondbacks game at which Logan Kresel, a third-grader diagnosed with a brain tumor in 2003, will throw the first pitch. Logan raised the most money for any individual fundraiser.

The three BTS cross-country bike riders and their driver joined SSBTR at Barrow's Neurological Institute for an emotional check presentation ceremony.



Walk Chairman Brian Wright (l) and Steve Glassman, event founder and Student Advisor, present the check.

### SPECIAL THANKS

- Parent Volunteer Committee, presided over by Denise Badahir
- Student Organizing Committee, headed by Chairman Brian Wright, President of the Student Body at Horizon High School
- Faculty Advisor and event founder Steve Glassman from Pinnacle High School

### PRESENTING SPONSORS

Airpark Chrysler Jeep, Clear Channel Radio and Outdoor, KISS-FM, Desert Ridge Marketplace, Fasturtle Technologies, Graphics 2, Harkins Theatres, MedPro, and Superpumper

## Hope and Research

more online at [www.tbts.org](http://www.tbts.org)



Look for news about the Race for Hope and 10<sup>th</sup> Anniversary Ride for Research in the summer *Heads Up*

## An Evening Committed to a Cure

Friends and family of Alan and Carol Bernon celebrated the Bernons' long-term support of BTS with an elegant gala in November. The festive evening of gaming, auctions, dinner and dancing took place at the Boston Harbor Hotel as a well-deserved honor for the Bernons. The couple has been involved in most of the Society's major fundraising campaigns and events since the Founding Contributors Campaign, and they have sponsored a Chair of Research for the last eight years. Alan Bernon's humbling and moving remarks paid tribute to the work of the Brain Tumor Society and to all of the Gala attendees for their support of the Bernons' many philanthropic efforts over the years.

Photo © Pierre Chitha



BTS Executive Director Neal Levitan (l) presents Alan Bernon with a gift.

You are just one click away from a great new resource for a variety of brain tumor information!

[www.tbts.org](http://www.tbts.org)

- ◆ Find support groups in your area
- ◆ Read survivor and caregiver stories
- ◆ Submit your questions to our professionals
- ◆ Learn about types of brain tumors
- ◆ Find out more about BTS and our activities



FAX ORDER FORM

Ms./Mrs./Mr. \_\_\_\_\_

Address \_\_\_\_\_

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

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

To keep our mailing lists updated, please let us know of any address changes, corrections to your name or duplications. Thank you!  
 Email: [admin@tbts.org](mailto:admin@tbts.org) ◆ Fax: 617.924.9998

- Add me to your mailing list.
- Please send:
  - \_\_\_\_ Fact Sheet(s) on Brain Tumors
  - \_\_\_\_ Copies of the current Heads Up newsletter
  - \_\_\_\_ Color Me Hope Resource Guide
  - \_\_\_\_ Copies of the Brain Tumor Book List
  - \_\_\_\_ Support Group Leader Information Packets
- Send information about planned giving.
- Please make a note of my new contact info.
- Remove me from your mailing list.

**Join our community of online news recipients!**

**Help us save paper and time. Send an email from your preferred address to Holly Kiernan at [admin@tbts.org](mailto:admin@tbts.org) to be included in our e-news list.**

***Heads Up***

The Newsletter of



124 Watertown Street, Watertown MA 02472-2500

ADDRESS CORRECTION REQUIRED

Visit us on the web at  
[www.tbts.org](http://www.tbts.org)

Nonprofit Org.  
 U.S. Postage  
**PAID**  
 N. Reading, MA  
 Permit No. 140