

Heads Up



BRAIN TUMOR SOCIETY

Research ♦ Education ♦ Support

800.770.8287 ♦ www.tbts.org

Glioma Research

Angiogenesis and infiltration



Two hallmarks of malignant human gliomas are their invasion of surrounding brain tissues and extensive tumor angiogenesis.

Dr. Shi-Yuan Cheng Angiogenesis is the process of new blood vessel development into a tumor from the healthy surrounding tissue.

An understanding of how gliomas develop new vessels and spread within the brain is critical in order to design new therapies that counteract these processes. Angiogenesis is a major factor for the growth of gliomas since blood vessels provide nutrients to and remove waste products from the interior of the tumor. Understanding how gliomas infiltrate healthy tissues is also essential to their control and eradication. The invasive aspects of glioma cells render many current treatments ineffective and are also the reason that gliomas recur with such frequency.

The goal of our research is to improve therapy for patients with malignant gliomas through a better understanding of the molecular mechanisms of these two processes. We have made significant progress on research projects that were generously supported by the Brain Tumor Society.

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the biggest BTS events of the year!



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Race for Hope
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Navigating the Healthcare System

If you have been diagnosed with a brain tumor or are caring for someone with a brain tumor diagnosis, there may be help through a hospital-based patient navigator program. Patient navigators are seasoned professionals in the field who will guide you through the healthcare maze. Because the impact of a new diagnosis is challenging, locating the right professionals is essential. A patient navigator can direct you to hospitals that specialize in the treatment and management of brain tumors and help locate physicians experienced with your tumor type.

Understanding a brain tumor diagnosis and treatment can be overwhelming. However, having medical information is a plus. A navigator can assist you in identifying educational materials that are specific to your diagnosis, are not loaded in medical terms, and reflect current trends in treatment. Some programs have navigators who are advanced practice nurses. These professionals play an on-going role in educating patients about their disease, treatment course and help families find the answers to their questions in a timely way. Some may also have experience working with patients who are enrolled on clinical trials and can help you understand the specifics about this treatment option.

Patient navigators help bridge the communication gap that can sometimes exist between a patient and family and members of

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Color Me Hope Resource Guide 4th Edition

The updated 4th 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 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 or visit our website at www.tbts.org.

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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 Executive Director



Neal P. Levitan, Esq.
Executive Director

The first Sunday of every May marks the start of Brain Tumor Action Week, sponsored by the North American Brain Tumor Coalition (NABTC). Brain tumor advocates from across the country assemble to walk the halls of Congress to present policy issues of concern to the brain tumor community. This year the policies were discussed in advance during an informative nationwide teleconference/webcast on April 21st so that advocates could prepare themselves for meetings with their respective legislators.

NABTC's Advocacy Committee selects those issues that are most timely for the brain tumor community and are often germane to the general cancer community, as well. This year, three position papers were presented. The first addressed strengthening the brain tumor research effort at the National Cancer Institute and the National Institute of Neurological Disorders and Stroke by providing sufficient funding to carry out important research studies and to appoint new leaders for brain tumor programs and activities.

The second position of the NABTC was a request to eliminate the two-year waiting period for Medicare benefits for brain tumor patients. Under current policy, once Social Security determines that a brain tumor patient is eligible to receive disability benefits, there is a period of two full years before Medicare coverage can begin. This can deprive brain tumor patients of vital treatment at a critical time in their disease. Many patients will not survive the two-year waiting period without access to quality health care.

The final issue relates to the Genetic Information Nondiscrimination Act that was passed in the Senate but thus far has failed to pass in the House of Representatives. Research in brain tumors as well as in other cancers has developed a great deal of knowledge about the genetics of cancer cells. Individuals with certain brain tumors already benefit from this knowledge in terms of the efficacy of certain treatment options, and it is hoped that more brain tumor patients will soon benefit from genetic information. However, this body of knowledge may create a backlash against those with life-threatening illnesses because of the potential for employment and health insurance discrimination. Passage of this Act by the House will ensure that individuals do not suffer discrimination on the basis of their genetic profile.

The legislative offices I visited were all very receptive to the issues advanced by the NABTC, and it is my hope that each issue will garner the attention it deserves.

Neal P. Levitan, Esq.

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the healthcare team. Communication is the cornerstone of excellent clinical care. Remember: as a patient or caregiver, YOUR voice is important. Having a navigator find opportunities for you to engage with members of the medical team is as important as the treatment itself!

Some navigators serve as patient advocates. Brain tumor patients may experience numerous challenges in the course of their illness. A navigator can help clarify your concerns, find solutions, and identify supportive resources that may benefit you. Similarly, a navigator may help you coordinate your care and build a supportive network using resources of your preference.

Not all treatment centers offer patient navigator programs. Expanded funding for and use of patient navigators is proposed by the bipartisan "Patient Navigator, Outreach, and Chronic Disease Prevention Act of 2003" (S.453/

H.R.918). This pending legislation has received strong support from many health organizations and hospitals. The Act would establish additional grants to create model Patient Navigator programs and would enhance the existing National Cancer Institute (NCI) Navigator Program. Since 2002, NCI has funded new Patient Navigator programs at six treatment centers in traditionally underserved communities, primarily in areas with high minority populations or a large number of lower-income and/or uninsured patients.

Overall, a patient navigator serves as your eyes and ears as you proceed through this difficult time. Be sure to find out if this assistance is available to your family.

Nancy Lee, RN is a patient navigator for the Department of Medical Oncology at Cambridge Health Alliance. Nancy is an advanced practice nurse and especially enjoys working toward empowering patients and families as well as ensuring the quality of their medical experience.

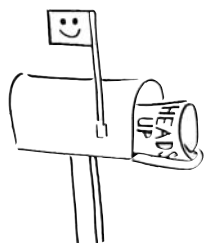
BTS Wish List

Can you make an in-kind donation of one of these items? Your generosity keeps our operating expenses down, and your gift is tax-deductible.

- ◆ 2-wheel hand cart/dolly
- ◆ Photoshop 7.0 or CS
- ◆ Digital camera
- ◆ Mid-/full-size refrigerator
- ◆ High-volume color printer
- ◆ PC - Pentium III or higher
- ◆ Laptop - Pentium IV

For more information about in-kind donations, contact Director of Development Tom Leavitt at 800.770.8287 ext 14 or development@tbts.org

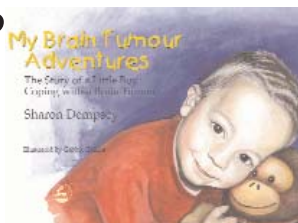
Share your story



Email your survivor or caregiver story to resources@tbts.org or send by regular mail to:
BTS - Heads Up
124 Watertown Street, Suite 3H
Watertown, MA 02472
We reserve the right to edit submissions.

Have you read...?

Sharon Dempsey could not find a book that explained her son's brain tumor well enough - so she wrote a picture book to guide other children through this experience. Illustrated by Gabbie Collins, *My Brain Tumour Adventures: The Story of a Little Boy Coping with a Brain Tumour* is ideal for children under 8 years old. It follows Owen from his initial headaches and blurry vision through his treatment. Throughout his surgery, radiation and chemotherapy, Owen uses his imagination to turn these strange events into imaginary adventures. The CAT scan is a space mission, his operation is a pirate's voyage, and Owen's story is an excellent way to introduce children to the unexpected world of brain tumors. This is an informative and reassuring book for a young child with a brain tumor or with a sibling or friend who has been diagnosed.



Available online and at local booksellers.
ISBN 1-84310-125-4

Research, continued from page 1

We investigated the roles of three molecules by using a glioma model system. In this model, cells of an established human glioma cell line are separately implanted into the brain or under the skin of mice. Each mouse that received glioma cells would develop tumors at these two different locations.

We engineered the glioma cells by introducing one of the three relevant molecules into the cells. We compared the behavior of the engineered tumor cells to the original cells, first housed in culture dishes, and then assessed the effect of each molecule's expression on glioma vessel growth and sizes or tumor cell spread into nearby healthy brain tissues:

- ◆ We showed that members of a major angiogenic factor family, vascular endothelial growth factor (VEGF), displayed different activities depending

upon where the tumor cells were implanted. We further found that different VEGF activities are influenced by certain molecules that are present outside the tumor cells.

- ◆ Another angiogenic factor we examined was platelet-derived growth factor-B (PDGF-B). PDGF-B manifests at high levels in primary human glioma tissues and stimulates growth by attracting additional cells to growing blood vessel tubes. We found that expression of PDGF-B by the implanted glioma cells greatly enhanced glioma angiogenesis and growth. It also stimulated VEGF expression in the tumor vessels.
- ◆ Lastly, we demonstrated that the angiogenic molecule angiopoietin-2, which is also involved in vessel growth, converts non-invasive glioma cells into highly invasive cells.

It acts by activating enzymes that break down materials surrounding the tumor cells.

This valuable information about the growth process of gliomas supplies critical information. An understanding of how these tumors develop is the groundwork for treatments that can slow this process or stop it from occurring.

Shi-Yuan Cheng, PhD is an assistant professor at the University of Pittsburgh Cancer Institute and an award-winning researcher. His research on human primary glioma was funded in part by BTS grants (1999-2001).

BTS Notecards

Each \$25 box has 12 blank cards with unique seasonal photos



800.770.8287 or www.tbts.org

ASK THE EXPERT "How is a metastatic brain tumor different from a primary brain tumor?"



A primary brain tumor originates in the brain. Secondary or metastatic brain tumors, also called brain metastases, arise from cancer cells outside of the brain. These are the most common complication of cancer, occurring in 20-40% of cancer patients. The process of cells traveling through the body to another part of the body, often through the blood stream, is called **metastasizing**. While lung, breast, kidney, colon cancer and melanoma pose the greatest risk, brain metastases have been associated with other cancers. Although brain metastases contain the cells of the primary cancer, it is not uncommon for the site of the primary cancer never to be found. The patient's immune system may have destroyed the original cancer before it caused symptoms, but not before the cells traveled to the brain. Contrast-enhanced magnetic resonance imaging (MRI) is often used in diagnosing brain metastases. Although this scan is sensitive enough to detect small tumors and determine the location and number of metastases, only a biopsy can confirm the type of cancer. This also provides important information if the primary cancer site wasn't found through previous tests. Surgery is generally limited to single metastasis and used if the primary cancer is controlled. Whole-brain radiation is often recommended for multiple tumors, and recently, stereotactic radiosurgery has been used to treat small metastases in deeper regions of the brain. The effectiveness of chemotherapy in treating these tumors is being explored.

Please contact Sarah Duggan, LICSW at support@tbts.org or 800-770-8287 ext 25, with your question for Ask the Expert. Remember, BTS can provide general information but cannot address your specific medical situation.

The Tenth Annual Ride for Research

It was the tenth successful year for the Ride for Research. There were 800 registered riders, and the donation total to date is nearly **\$615,000**. It continues to grow thanks to your ongoing generosity. More photos of the day are now online for viewing and purchase. Visit **www.tbts.org** and follow the 10th Annual Ride for Research link!

All photos © Pierre Chihra



First there were the volunteers. Then came the bike clinic and opening ceremonies. Trooper Dan sang the national anthem for the 50-mile riders and the 25-mile riders.



Wayland Middle School's jazz band played in support of classmate Jeremy Pivor and team All for Jeremy.

And they're off!



Many teams wore special shirts, but only Kyle's Krew brought a team RV, decorated with signs to match!



The rain began after the Riders launched but still early enough to soak everyone. No spirits were dampened, though, and the massage therapists stayed busy until the end.

Race for Hope marks its seventh year of success in DC

Just after dawn on Sunday, May 2nd, nearly a hundred volunteers gathered to prepare Freedom Plaza in downtown Washington, DC for the arrival of 3,500 runners and walkers. The cause was serious but hearts were light as participants took off for a 5K race in support of the Brain Tumor Society (BTS). The Cassidy & Pinkard Race for Hope has grown each year since its 1998 inception and is the largest all-volunteer event of its kind in the Washington, DC area.

Co-chair Barry Glassman was clearly moved by the day's events. "I've been doing this for quite a few years now," he said, "and when I see the survivors and their families, standing side by side with the friends and families of people who've lost their personal battles with brain tumors, I feel as if all the work that goes into making this event happen is well worth it. If we can raise enough money to help researchers discover a cure one day sooner, every one of us will benefit in the end."

Cathy Fawell, the marketing director for Cassidy & Pinkard and a Race volunteer, reported that this year's total is expected to be more than double that of last year. "The website [www.curebraintumors.org] gave us phenomenal exposure and the opportunity to spread the word from friend to friend via email," Fawell said. "It is amazing just how many lives have been touched and changed forever by the diagnosis of a brain tumor. There are so many stories of courage and compassion out there."



5K runners and walkers gathered at the starting line.

This year's race has raised over \$675,000 and donations continue to pour in from people who attended or participated. The 5K Committee believes the total may reach \$700,000. One factor in this year's success is a new alliance with the Brain Tumor Research Trust (BTRT), an organization committed to raising funds for brain tumor research. BTRT joined the 5K planning and fundraising effort this year and will use proceeds to fund grants through BTS.

The day of the Race, more than 100 survivors were identified by blue t-shirts and gathered at the Survivors' Tent. Before the start of the race and again during the

award ceremony, these survivors were cheered as the inspiration behind the annual event.

For the first time in the history of the Race for Hope, a significant number of teams formed to honor or celebrate the memory of someone with a brain tumor. Nearly 150 teams used web access to communicate and raise

funds. Many teams wore special team shirts and carried team banners as they ran or walked together as a group down Pennsylvania Avenue.

In 2000, Cassidy & Pinkard became involved in the Race as its title sponsor as the result of the diagnosis of its co-founder, Patrick Cassidy. Before he succumbed to his disease in 2001, Cassidy took great satisfaction in knowing that the company was taking a leadership role in raising funds for BTS. Cassidy & Pinkard is a locally owned and operated full service commercial real estate firm headquartered in Washington, DC.



From left:

- ♦ Bob Pinkard, CEO of Cassidy & Pinkard
- ♦ Mike Kwinn, the top individual fundraiser, who ran in memory of his son Michael
- ♦ Barry Glassman, Race for Hope co-chair
- ♦ Neal Levitan, Executive Director of BTS

Create Your Own Event!

Organizing an event to benefit the Brain Tumor Society is a fun, meaningful way to help BTS fulfill its mission - and have a good time doing it!

Events can be large or small and can include just about any activity you, your family and friends enjoy.


To learn more about planning a benefit for BTS, contact Barbara Goodman at 800.770.8287 ext 12 or events@tbts.org

Debut Events

The Brain Tumor Society is very fortunate to be named as the beneficiary for several brand-new fundraising events this spring and summer. Among them are:

Let's Strike Out Brain Tumors

Sunday, June 6th marked the Ted Friedberg Memorial Bowling Event. Held at a new bowladrome in Boston, this event honored the memory of Ted Friedberg, who was diagnosed with an aggressive brain tumor in the fall of 2003 and died within just three months of diagnosis. His wife Judi, along with their son Eric and other committee members, chose BTS as the recipient of the Bowling Event's proceeds, which reached \$19,000. Individuals and teams bowled with great energy, enthusiasm and fun, but all remembered that they were there to strike out against



In April, the fourth annual Skate for Blair took place in Carmel, Indiana. Blair Fitzgerald had a passion for hockey, and he skated throughout much of his 15-month battle with a brain tumor, which ended when he was 10 years old. The Fitzgerald family - Pat, Carol and 9-year-old Olivia - now honors his memory and the family's collective struggle with Skate for Blair, a night of family fun that centers around ice skating and includes a raffle and silent auction. The event raised over \$21,000 this year. In their letter to supporters, the Fitzgeralds said, "Dedication to the Brain Tumor Society and honoring Blair's memory are passions that will never wane."




Photo courtesy of the Fitzgerald family

brain tumors and pay tribute to their beloved family member and friend.

Dare to Dayhike Devil's Path

In May, Jay Hui led a pledge hike in the Catskills. Jay, whose mother is a brain tumor survivor, founded BTS through a fellow outdoor sporter who has biked in the Ride for Research for several years. Participants in the hike tackled the 24-mile Devil's Path trail, which *Backpacker Magazine* has called the hardest dayhike in America! Another pledge hike will be organized next year. Find out more about the adventure at www.viewsfromthetop.com.



The Blue Note Benefit Concert

On August 14, the Blue Note club in Cincinnati will host a benefit concert in memory of Ron Harden. For many years, Ron was the bass player in Naked Truth, one of the bands that will play the Blue Note that night. In addition to the live music, a silent auction and raffles are planned. Scott Hupp is organizing the concert in memory of his friend and as a way to support BTS in its mission.



Would you like to find a BTS benefit event near you? The Calendar at www.tbts.org shows local events like these, including times, venues and contact information, whenever available.

Let's Make the Impossible *Possible*

The Brain Tumor Society's Annual Gala will celebrate the life of

SAM GERSON

Saturday, November 20th ♦ Boston ♦ Fairmont Copley Plaza

Find out more: 800.770.TBTS (8287)

Time *and* Money

A nonprofit organization always needs a little more of each.

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Heads Up

The Newsletter of



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