

Heads Up

BTS BRAIN TUMOR SOCIETY
Research ♦ Education ♦ Support

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Information is Power...Symposium is a Success!

The Brain Tumor Society's sixth national symposium provided another excellent week-end of education and networking for the brain tumor community.

This year, the Friday welcome reception had an extra feature. There were two facilitated meet-and-greet sessions for attendees, one for those interested in the adult track, and one for the pediatric track. Both groups lingered after the scheduled hour was over, and those who connected with other patients and families in similar situations made certain to re-connect in sessions the following day. One attendee was "very appreciative for the pediatric track, separate from adult issues and treatment."

On Saturday, more than 350 people participated in the all-day conference. Robert Martuza, MD, Chief of Neurosurgical Service at Massachusetts General

Photo © Pierre Chitka



Saturday morning, the ballroom was full in anticipation of the first session of the Symposium.

Hospital, opened with an address on gene therapy for brain tumor patients. Participants spent the rest of the morning in panels of their choice. One guest summarized the experience succinctly: "Good information, good format, stimulating discussions, good questions."

Photo © Pierre Chitka



Dr. Friedman (l) and Dr. Martuza

The luncheon keynote address was given by Henry Friedman, MD, Co-Director of the Clinical Neuro-Oncology Program at The Brain Tumor Center at Duke University. Dr. Friedman, who is known for his work with brain tumor patients in clinical trials, gave research updates

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Many attendees were delighted to meet Nancy Conn-Levin (l) and Samantha Scolamiero, both prominent in the online brain tumor community since Scolamiero began the BRAINTMR mailing list and T.H.E. Brain Trust, and Conn-Levin founded the Meningioma List.



Photo © Pierre Chitka

For lunch, attendees regrouped at tables marked by tumor type or other special interest. The chance to share common experiences is especially valuable to patients who come from smaller towns or more rural areas, where the absence of local treatment centers, support groups and other community resources can exacerbate the feeling of isolation so common to those affected by brain tumors.

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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.

Survivorship Brings Change, Not Loss

In the summer of 2002, I had an awful, two-hour migraine headache. It returned a day later while my kids, husband and I were enjoying a hot August day at the pool. I made a quick retreat home after the initial blast of pain and spent a restless night sleeping with a dullness in my head. Even now when I hear the word “migraine,” I cringe.



Jody Powers

I called a nurse-line provided by my employer, and that conversation sent me to the hospital for testing. A CAT scan revealed a mass on my brain, and I was immediately admitted for additional testing. The next day, an MRI revealed the earth-shattering truth: a tumor that would require surgery to determine its nature.

Life seemed to be ending for me back at the age of 38. Coming from a family with a strong health history, including grandparents who lived into their nineties, I was shocked to hear that I had a brain tumor. I was devastated, and I realized how much I had taken my health for granted.

I had surgery, and it was determined that I had an anaplastic oligodendroglioma, grade III. It took me a year and a half to be able to say and spell it. I had a hard time being able to deal with just the thought of it.

Radiation and chemotherapy followed surgery. For chemotherapy, I had to choose between the various types of treatment options. I received three different opinions from specialists, and it was daunting, to say the least. This was such a tough time to determine what would be the best treatment for me – preferably one that would surely cure me!

Options are hard when you go through so much and just know that you want to live. I was blessed to have had the surgeon and medical team that I had. I also was fortunate to have the love and support of my husband, family and friends to get through the challenges of each day. Having children who were then only 9 and 4 years old added greatly to my fighting spirit and will to live.

I am glad to be here and have a new outlook on life, people, and challenges. After going through every stage of this challenging process, life seems more interesting. I live each day with abundant hope for the future. While my body helped fight this disease, my attitude had to mature in a different way to accept the circumstances and live in a new manner. Yet when I look at other people, I see that we all have challenges. Unfortunately we don't get to choose which ones, nor when they will alight upon us. For me, the key is to realize that I have been changed by what has happened to me, but I have not been reduced by it.

Jody Powers lives in Chester County, Pennsylvania with her family. She worked in the healthcare field for over 15 years.

Symposium, continued from page 1

and a treatment review of malignant gliomas.

Breakout sessions with panels and individual speakers continued through the afternoon. "This Symposium was well-diversified to reach many people with different interests and varied levels of understanding," one attendee noted.

Between sessions, participants visited the exhibit tables for other brain tumor information or sought out doctors to ask questions about their personal situations. Many patients traded email addresses and phone numbers to share information about support groups or just to check in with one another after the Symposium.



Photo © Pierre Chiha

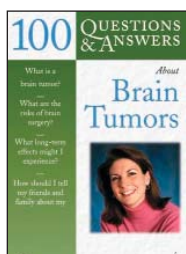
Vin Patrone (l) thanked the Young Adult Survivors Panel.

The day ended with a reception hour during which the recipients of BTS's 2004 research grant awards presented their project posters and talked about their research with visitors. Scientists and clinical professionals compared notes, and

patients had another chance to learn first-hand about the steps involved in learning how brain tumors work and, by extension, how they might be cured.

A number of patients and families Symposium stayed on for the award of the research grants during the Annual Meeting and Dinner (see page 4).

Audio recordings of most Symposium sessions are now available through www.tbts.org or 800.770.8287.



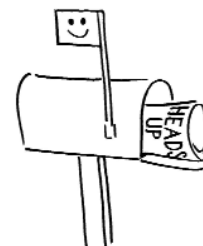
Co-written by a doctor and a brain tumor survivor, *100 Questions & Answers About Brain Tumors* is a detailed look at the essentials that is not overwhelming. It includes many of the basic answers covered in similar books, but it is set apart by its special features. There are guides for understanding pathology reports and MRI scans, and the charts of drug side effects and possible

interactions are great quick-reference tutorials for patients who want to ask the right questions of their medical teams. The index and glossary are thorough, but best of all are the definitions in the margins of the main text. Each page reads smoothly, but unknown vocabulary is explained alongside, saving the reader numerous trips to the glossary. Technical explanations are detailed but clear, and many sections include comments by the survivor half of the writing team, giving a personal perspective to the medical process. Finally, an appendix of other resources gives the reader numerous options for more learning.

Virginia Stark-Vance, MD
and M.L. Dubay

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Share your story



Email your survivor or caregiver story to resources@tbts.org or mail to the BTS office

We reserve the right to edit submissions.



Time.

Money.



Help us save both by joining the Brain Tumor Society's email list for news in the future.

Send a message from your preferred email address to admin@tbts.org with "email list" in the subject or body of your message.

Thank you!



Race for Hope

to benefit the Brain Tumor Society

Sunday, May 1st, 2005
in Washington D.C.

Registration opens soon
for individuals and teams.

www.tbts.org
raceforhope@tbts.org

Research Grant Awards Presented at Annual Meeting

This year's Annual Meeting included a State of the Society Address by Chair of the Board of Directors Vin Patron, followed by noted humorist Izzy Gesell's keynote talk about the "Healing Powers of Humor." The Roche Family Award for exceptional volunteers was presented to Nike Beddow for her remarkable efforts in organizing the Brain Tumor Society Cassidy & Pinkard Race for Hope in Washington, D.C. The highlight of the Annual Meeting, as always, was the presentation of this year's research grant awards. This year, BTS received the highest number of applications in the grant program's history and granted \$1.3 million to the most exceptional researchers:



2004 Research Grant Recipients, with BTS Founder Bonnie Feldman (top L) and Executive Director Neal Levitan (top R)

Thomas Biederer, PhD

Yale University

Molecular analysis of the SynCAM family of tumor suppressors in the brain

The activity of SynCAM proteins in brain tumors will be analyzed to determine whether they affect the invasiveness of tumor cells.

Gerard I. Evan, PhD

University of California, San Francisco

Defining the role of p53 in the suppression of glioblastoma

This study will use a mouse model to examine biological mechanisms that allow tumor-suppressor gene p53 to fail. Findings will also indicate how best to develop drugs that restore p53's function, thereby preventing the likelihood of progression.

Michael C. Jensen, MD

City of Hope National Medical Center

Enhancing survival and function of glioma-specific T-cells in the tumor microenvironment

This research focuses on genetic engineering of T-cells to engage glioma cells, in conjunction with an FDA-approved feasibility study.

John Y.H. Kim, MD, PhD

Baylor College of Medicine

Jun- and MEF2-mediated apoptosis in medulloblastoma

Certain target genes cause "cell suicide." This study will determine how this is achieved, in the hopes of developing more effective, less toxic therapies.

Boris R. Minev, MD

University of California, San Diego

A new target for immunotherapy of glioma

Parts of a naturally-occurring protein will be used to "educate" white blood cells to recognize and kill tumor cells in glioma patients.

Duane A. Mitchell, MD, PhD

Duke University Medical Center

Identification and immunologic targeting of HCMV antigens expressed in malignant gliomas

This research will investigate antigen expression in gliomas and evaluate ways in which these antigens can be used as targets for immunotherapy.

Dimitar Nikolov, PhD

Memorial Sloan Kettering Institute

Structural and biophysical investigation of plexin and the semaphorin system, as receptor-ligand complex implicated in the progression of brain tumors

The communication pathways within the brain are essential for normal development but also increase the invasiveness of tumors. This study will examine this signal system to understand better how it functions and relates to brain tumor formation.

Luis F. Parada, MD

Southwestern Medical Center

A tumor suppressor mouse model of glioblastoma

This research is believed to have already identified the genes that cause astrocytomas. Continued work seeks to understand tumor formation and improve therapies.

Lawrence A. Quilliam, PhD

Indiana University

Rheb GTPase as a chemotherapeutic target of farnesyl transferase inhibitors in brain cancer

This study will establish whether the Rheb molecule is required for malignant transformation of GBM cells and will demonstrate how Rheb affects cell signaling and tumor growth.

The Brain Tumor Society's Annual Meeting and Dinner was generously sponsored by



MERCK
Research Laboratories

2004 Grants, continued

Samuel D. Rabkin, PhD

Massachusetts General Hospital
Dendritic cells, oncolytic HSV vectors and brain tumor immunotherapy
This study will combine two existing immunotherapy modalities to further evaluate how the brain and the immune system interact.

Hong Sun, PhD

Yale University
Identification of novel molecules that function in the PTEN/PI 3-kinase regulated signaling pathway in human glioblastoma cells
The tumor suppressor PTEN appears often in brain tumors. This study will determine the molecular mechanisms by which the p27 molecule is regulated by PTEN and how inactivation of this suppressor can lead to tumors.

Terry A. Van Dyke, PhD

University of North Carolina at Chapel Hill
Modeling progression from low grade astrocytoma to GBM in genetically engineered mice
This mouse model of high-grade astrocytoma will examine the development of tumor angiogenesis and invasion as well as characterizing the molecular pathway(s).

Robert J. Wechsler-Reya, PhD

Duke University
Mice, chickens and hedgehogs: A new transgenic system to study medulloblastoma oncogenes
Mutations to a certain gene, patched, are common in many cases of medulloblastoma. This research will develop a strain of mice into which genes can be introduced directly and specifically in order to test the ability of the patched gene and others to promote medulloblastoma.

BTS Scientific Advisory Council

The members of the Scientific Advisory Council (SAC) form the heart of our research grant program. The grant program is coordinated by Carrie Treadwell, our Director of Research Programs, but it is the SAC members who review and evaluate each grant application. All of the SAC members are renowned researchers; some are also clinicians. They pool their expertise to select a promising range of projects planned by research laboratories across the United States.

The review process for grant applications is modeled on the National Institute of Health's peer-review system to evaluate federal grant requests. First, Category Chairs (members of the SAC skilled in a specific research area, such as immunotherapy or chemotherapy) review the applications and select two reviewers for each application. Each reviewer then gives the application a grade from 1 to 5, and the average of these two scores becomes the first score. A list of all scores is sent to the full SAC prior to the full-Council teleconference meeting.

The teleconference is a phone discussion with all SAC members, the BTS Research Chair, Executive Director and Director of Research Programs. This virtual meeting focuses on projects with high scores and those that require more discussion, such as an application that received very different scores from its two reviewers.

During the teleconference, each application is presented by its two reviewers and the category chair. All SAC members discuss its merits and assign it a grade. These grades are averaged to give the application its final score. The SAC uses these grades to recommend research grant awards to the Board of Directors, who ultimately vote on the grant recipients.

This process gives BTS and our supporters confidence that our research funds are truly invested in science that is likely to lead to a cure. The Scientific Advisory Committee is central to our role in funding innovative and effective research. We are extremely grateful for their expertise and invaluable contributions to our essential research mission.

Brain Tumor Awareness Ribbon Pins



The Brain Tumor Society is proud to offer brain tumor awareness ribbon pins. By wearing this gray ceramic pin, you help spread the word about the brain tumor problem. Awareness is progress.

Make it known.

Pins are \$5 each. Order yours by sending a check to:
Brain Tumor Society, 124 Watertown Street, Suite 3H
Watertown MA 02472-2500

Helping a Brain Tumor Family

The family and friends of a brain tumor patient and caregiver often want to help but are unsure of how to be most useful. "Call if you need anything" is a common refrain, but many people feel awkward asking for help. If you are able to provide help to a brain tumor family, let them know your general schedule and make a list of specific ways you are able to help. Some ideas include:

- ◆ **Drive** to doctors' appointments or other meetings.
- ◆ Organize a group to do **yardwork**, clean gutters, or shovel snow.
- ◆ Do **laundry** or Drop off/pick up clothes from a dry cleaner.
- ◆ Make **dinner** or drop off packed lunches.
- ◆ Help out with **housecleaning** or washing the car.
- ◆ Take out the **garbage** and recycling each week.
- ◆ Help with grocery **shopping** or Call from the grocery store to see if the family needs milk or bread.
- ◆ Give the patient and caregiver **breaks**. Stay with the patient so that the caregiver can run an errand alone, or take the caregiver out for lunch.
- ◆ House-sit or **pet-sit** during hospital stays.
- ◆ Help the family keep in touch with others by addressing cards, returning calls, or setting up a free website to **update** with health news.
- ◆ Have the family's **children** over for dinner or a movie to allow the parents some quiet time together.
- ◆ Go to the kids' sports **games** or school events when a parent is unable to attend.
- ◆ Offer your talents or **professional skills**. Whether you're a plumber or a lawyer, your specialty might prove invaluable at some point.
- ◆ **Stay in touch**. Call to talk with the patient and caregiver, and leave messages when they are out. Even if they don't have time to return your calls, your messages provide encouragement and reassurance.



ASK THE EXPERT



"I have to travel for treatment, but how can I afford travel expenses on top of healthcare costs?"

Fortunately, there are many resources to help patients who must travel far from home for their care. Some hospitals have an affiliated residential facility, so be sure to ask your medical team about resources near the treatment center. The **National Association of Hospital Hospitality Houses, Inc.** (nahhh.org; 800.542.9730) offers a directory of no-cost temporary housing for patients across the United States.

There are also a number of organizations that provide flights at no cost to patients and, sometimes, family members. These include:

AirCare Alliance

888.260.9707 aircarealliance.org

Corporate Angel Network

866.328.1313 corpangelnetwork.org

National Patient Air

Transportation Hotline

800.296.1217 npath.org

Finally, there are many smaller foundations that provide in-kind services and/or financial assistance. You can find such organizations in your state by checking with **CancerCare** (cancercare.org; 800.813.4673), your local branch of the **United Way** (unitedway.org; 800.411.8929) and the **American Cancer Society** (cancer.org; 800.227.2345).

BTS Sponsors the 1st Charles Wilson Award

The Brain Tumor Society was proud to sponsor the inaugural *Charles Wilson Award*, presented during the October meeting of the American Association of Neurological Surgeons/Congress of Neurological Surgeons (AANS/CNS) Section on Tumors. Mark L. Rosenblum, MD was honored for his work in the brain tumor program at Henry Ford Medical Center. The award recognizes a world-renowned leader in the field who has promoted multidisciplinary delivery of care and of research by organizing a Brain Tumor Center of Excellence. Charles B. Wilson, MD, for whom the award is named, is the Founding Director of the Brain Tumor Research Center at University of California in San Francisco. Dr. Wilson, who has held numerous other advisory and professional roles in the brain tumor treatment world, is a pioneer in brain tumor care.

Submit your question for the expert to support@tbts.org or call 800.770.8287 ext 25. Remember, we cannot address your specific medical situation.

Planned Giving Comes in Many Forms

An outright gift of cash to the Brain Tumor Society provides obvious benefits. For you, an income tax deduction may apply in that year, and for BTS, the gift is available for use upon its receipt. However, there are many other ways to ensure that your assets will help continue our mission of research, education and support.

Including BTS in Your Will

You can make a specific dollar-amount bequest or stipulate that BTS would receive a portion of your estate only under specific circumstances (i.e., if there are no surviving close family members).

Gift of Life Insurance Policy

If you no longer need a life insurance policy purchased years ago to provide replacement income for a surviving spouse or child, you can donate the policy to BTS. You may claim a charitable deduction for approximately the policy's cash surrender value.

Gift of Retirement Plans

Retirement plans are included in your taxable estate. A gift of these assets to BTS may avoid income tax and, when applicable, estate tax. Again, a spouse or child can be named as the primary beneficiary, with BTS as the contingent or secondary beneficiary.

Charitable Remainder Trust (CRT)

A CRT pays income to you, the donor, for life, after which the remainder of the trust is transferred to BTS. You receive an income tax deduction for the charitable portion of the transfer, avoiding capital gains tax and removing the asset from your taxable estate.

Charitable Lead Trust

The reverse of a CRT, a charitable lead trust pays income to BTS for a term measured by a number of years or the lifetime of a specific individual. The trust remainder - what is left at the end of the charitable term - usually passes to private beneficiaries, such as members of your family. Charitable lead trusts are most desirable when the payments can be made entirely from the income, therefore preserving the trust principal for your family members at a lower taxable value.



Research Chairs

Establishing a Chair of Research is a way to honor the life of a loved one and contribute to finding a brain tumor cure. Each Chair of Research sponsors the research of one grant recipient for a year. Funding for a Chair is often the result of hard work by family and friends who wish to pay tribute to a special person.

A Chair provides a wonderful opportunity for the donor(s) to be involved in research that will lead to a cure for brain tumors.

Each researcher receives a description of the Chair and the person it honors. Information about the Chairs is also distributed in each year's Grant Awards booklet. Researchers are honored by the awards and inspired by the stories behind the Chairs, which bring faces and names to the sometimes impersonal environment of the lab.

To learn more about Chairs of Research, contact Thomas Leavitt, Director of Development at 800.770.8287. You can also request a copy of the Research Grant Awards booklet to find out about this year's Chairs of Research.

thinking ahead for the 2005 Ride for Research



Registration for individuals, teams and virtual riders opens
November 15th
for the May 15th Ride

www.tbts.org

If you wish to consider incorporating the benefits of planned giving into your long-term financial planning, please call Tom Leavitt, our Director of Development, at 800.770.8287 ext 14. Naturally, you should discuss any financial decision with family members and your own financial planner or tax advisor before making a commitment.

Brain Tumor Research Grants

Available nationwide. Application deadline: March 16, 2005



The Brain Tumor Society awards grants to fund basic scientific research directed at finding a cure for brain tumors. Grants are awarded annually at a maximum of \$100,000 per year for up to 2 years. BTS grants may be used for start-up projects or for supplementary funding. Funds cannot be used for indirect costs.

For guidelines and application, visit **www.tbts.org**

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Please make a note of my new contact info.

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Heads Up

The Newsletter of



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