

Heads Up



BRAIN TUMOR SOCIETY

Research ♦ Education ♦ Support

800.770.8287 ♦ www.tbts.org

Immunotherapy

Fighting gliomas with HSV-1



Jacqueline Parker, PhD

Herpes Simplex Virus type 1, or HSV-1, is well known as the virus that causes cold sores.

Our laboratory is studying how this virus can be genetically modified for use as a potent new weapon against brain tumors. HSV-1 has a gene, called $\gamma_134.5$, which enables it to replicate in non-dividing cells found in the brain. A recombinant virus that has both copies of its $\gamma_134.5$ gene deleted (referred to herein as $\Delta\gamma_134.5$ HSV) is only able to replicate in actively dividing tumor cells in the brain; these same viruses die after infection of non-dividing cells, such as normal brain cells in adults. Our research demonstrated in a Phase 1 clinical trial that up to 3 billion HSV particles can be safely and directly injected into a patient's brain. To improve the tumor-killing activity of these $\Delta\gamma_134.5$ HSV, we are also trying to stimulate a patient's own immune system to enhance tumor cell killing. We inserted different mammalian genes into the HSV genome that encode proteins, called cytokines or interleukins, known to activate cell types (lymphocytes)

Immunotherapy, continued on page 4

Kids Who Care: Our Young Donors

Too often, young people feel like they will have to wait for adulthood before they can make a difference in the world. Maybe adults have more options for getting involved, but it is also true that kids can make remarkable contributions. At the Brain Tumor Society, we know from experience that young donors are as creative and dedicated as their adult counterparts.

Some young donors organize events through their schools. This year's Race for Hope in Washington, DC received a contribution from the eighth grade class from Middletown Middle School in Middletown, Maryland. Math teacher Tracey Athey told the eighth graders heard about the involvement of her neighbors, Lionel and Sandy Chaiken, in the brain tumor cause. When the students discovered that two of their classmates



Abe Laxague at the Ride for Research

are brain tumor survivors, the class voted to support the Race for Hope as their service learning project. They raised more than \$2,100.

The Brain Tumor Society also receives contributions from many individual young donors. At the Ride for Research, Abe Laxague donated the money he had earned from chores "like setting the table and getting the mail and dusting the piano," he explained. This year, Abe chose to donate to BTS. His family makes up much of Team Judy Olson; Judy was Abe's aunt. "It made me feel good to give my money to BTS because I don't want thousands and thousands and thousands of people to die from brain tumors," Abe said.

Casey Redpath made another special donation at the Ride for Research. Her father Rick passed away after fighting a brain tumor, and she decided to forego gifts for her ninth birthday. Instead, Casey asked friends and family to contribute to BTS, and she presented her collected donations at the Ride.

Kids, continued on page 3

Brain Tumor Society's **ANNUAL MEETING** *Featuring* Presentation of the 2004 **Research Grant Awards** Saturday, October 30th Newton, Massachusetts **Need details or tickets?** www.tbts.org or 800.770.8287



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 Chair of the Board of Directors



Vincent Patrone, Esq.
Chair

Usually in the "Letter from the Chair", I report to you on some of the more recent accomplishments of the Society. In this issue of *Heads Up*, however, I would like to take this opportunity to thank all of our donors for their most generous donations. Without your financial support, our accomplishments would not be possible.

You have demonstrated your generosity and commitment in numerous ways. We appreciate your support through your donations to our Annual Appeals, Memorial or Honorary Tributes and special fundraising programs. We are grateful for your contributions as a sponsor, participant or pledgee in our Ride for Research, Race for Hope and LINKS to a Cure. The Society is the recipient of proceeds from numerous fundraising events across the country, from a walk-a-thon in Arizona to a day hike in the Catskills of New York, a "Strike Out Brain Tumors" bowling event in Boston, and an ice skating event in Indiana, to name a few. In addition to raising much-needed funds, these events raise public awareness of the Brain Tumor Society and the brain tumor problem.

I know that we are all inundated with requests for donations. Often it feels like we can't open our mail or answer our phone without being asked for a donation. We want you to know that every donation, whether large or small, fosters our continued growth and furthers our mission of Research, Education and Support. In Fiscal Year 2003, the Society returned 84 percent of every dollar raised to its programs and services. We work very hard to ensure efficiency in our operations to make the most of your generosity.

On behalf of our staff and Board of Directors, all of the patients, survivors and families to whom we have been able to offer assistance, and for all those whose lives have been touched by this devastating disease, please accept our most sincere thanks and help share our hope that someday there will be a cure.

Vincent R. Patrone, Esq.

Kids, continued from page 1

Danielle Houle, then a fifth grader at St. Mary-Sacred Heart School in North Attleboro, Massachusetts had a chance to be "Principal for a Day" last spring. She allowed the students to skip the school's uniform and wear whatever they wanted - for \$1. Then Danielle sent all \$272 no-uniform dollars to BTS in memory of her grandfather. She hoped that her donation would make a difference, and her mom Joanne knows that her father, Danielle's grandpa, would be proud.

Pamela Selman of Buffalo Grove, Illinois, saw her upcoming Bat Mitzvah as an opportunity to



Photo © Pierre Chihra

Director of Development Tom Leavitt accepted Casey Redpath's donation as mother Roberta and brother Ian watched.

give back to her grandmother, who had recently been diagnosed with a brain tumor. For her mitzvah, or good deed, Pam considered a lot of options but "didn't like the idea of helping just one person." She organized a garage sale with items

donated by friends and neighbors and gave all proceeds from the sale to BTS, so that many people could be helped by her efforts.

Young people like these are learning about the importance of philanthropy at an early age. They make valuable contributions to BTS - not only with the money they give, but also with the hope that they bring to patients, survivors and families. Our young donors are also great promoters of our cause, as they talk to others about the importance of knowing about and fighting brain tumors.

We offer our gratitude to the remarkable kids and teens who work on behalf of the Brain Tumor Society and the people we serve. Young donors do us - and themselves - a tremendous service.

Research, continued from page 1

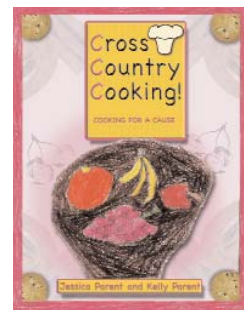
involved in immune responses. In the presence of dead and dying tumor cells, these signaling proteins stimulate host immune response cells to attack remaining tumor cells. One of these viruses, called M002, expresses a protein known as interleukin-12 (IL-12). IL-12 has been shown to elicit potent anti-tumor activity in animal model systems. We demonstrated that, in mice with brain tumors, treatment with M002 significantly prolongs survival compared to mice that received no virus treatment, or to mice which received treatment with $\Delta \gamma_1 34.5$ HSV that do not express IL-12. This virus is currently awaiting production for high quality clinical grade material for use in humans. Once available, it will be the first time an HSV that expresses a cytokine will be tested in a clinical trial for treatment of brain tumors.

We test our cytokine-producing viruses in various combinations to determine which are best able both to kill tumor cells and to send signals to the patient's own immune cells to recognize and attack remaining tumor cells. We recently identified a combination of two proteins which is very effective at reducing flank tumors of neuroblastoma in an immunocompetent mouse model. We continue to study this combination, and others, of immune system signaling molecules in a clinically relevant mouse model of patient-like brain tumors. We hope to identify new combinations of immunotherapy and advance the most promising ones to clinical trials in patients.

Dr. Parker's research at the University of Alabama at Birmingham has been funded by a grant from the Brain Tumor Society. Studies mentioned in this article will soon be published in the scientific journal Cancer Gene Therapy.

Have you read...?

Jessica Parent is a 9-year-old from Ann Arbor, Michigan, who spent her summer undergoing treatment for a medulloblastoma and preparing for the release of *Cross Country Cooking: Cooking for a Cause*.



Jessica and her mother, Kelly, collected 475 recipes for this cookbook, which will be available in late September. Jessica will donate the proceeds from the book to the National Childhood Cancer Foundation in order to help children with all types of cancers.

Available only at Jessica's website www.cookingforacause.info

Planning for Peace of Mind

It has been a year since my husband, Gregory Weiss, passed away from a glioblastoma multiforme. No one likes to think about their own mortality. Unfortunately, the diagnosis of a brain tumor forces one to confront this. It can be challenging to open the lines of communication on end of life issues because they are so emotional, but this is exactly why they are so important to discuss.

Our most important goal was for me to specifically understand, as Greg's medical power of attorney, what his wishes were should he be unable to express them himself. We discussed whether Greg wanted to be at home or in a hospital, who he wanted nearby, his life support/resuscitation preferences, and whether he preferred cremation or burial. We discussed these topics periodically throughout the progression of the disease, in case his wishes changed. I derived

great peace of mind knowing that, instead of making these extremely difficult decisions on my own, I could make choices in accordance with Greg's wishes.

We discussed when or whether to consider children. We wanted to have kids together, but we had so many questions. If I were pregnant, would I be able to be the caregiver and advocate for Greg in the coming months? Could we handle the additional stress and responsibility of a new life in our relationship under these circumstances? While each couple's answers will be different, it is important to open a dialogue.

Maybe the most important end of life issue is learning to live life in the present. People dealing with serious illnesses like brain tumors may feel like they are in some warped game of "beat the clock." How does one cram a 40 year future into whatever prognosis the



Photo courtesy of Barbara Scott

doctors have given to you?

Someone has to be in that "long term survivor" category, so why not believe it will be you? I don't advocate living in denial—no one can know for sure how long a brain tumor patient will live, or how long on earth any of us have, for that matter! If you must believe in statistics, believe that you are the group that is going to beat the odds. Have a positive attitude, be happy in what you do, and live whatever time you are given on this planet to its utmost potential. Never give up!

Barbara Scott lives in Leesburg, Virginia with her dogs Cobweb and Henri, and cats Gene, Nefi, and Gatina.

Advance Directives: Empowerment through Preparation

An advance directive is a legal document that outlines how you want medical decisions handled if you become unable to make those choices. Most of us have contemplated end-of-life issues, such as whether we would want to be kept on life support under certain circumstances, but haven't discussed this with many people. Life is unpredictable, and everyone, regardless of age or health status, should complete an advance directive. This is vital because it informs medical staff of your wishes at the most critical time.

These documents are strictly for medical care, not for money or property, and only go into effect when you become unable to make decisions; for example, if you were unconscious or in a coma. You can change your directives at any time as long as you are competent to make decisions. Remember, your doctor needs to know that you have an advance directive! Consider making copies for your medical record, family members, and/or close friends.

Although advance directives are recognized by all states, specific requirements vary. Check with your doctor or social worker for more information. The most common documents are a **living will**, which outlines what type of medical care you want, such as artificial life support, if you become unable to make decisions; and a **power of attorney for health care**, or health care proxy, which appoints a person you trust to make medical decisions if you are unable to do so. This can be the most useful because your proxy can assess the situation, and ideally, make the decisions you would want.

To find other resources for preparing advance directives, contact BTS at 800.770.8287 or support@tbts.org

ASK THE EXPERT



“I want to have children someday. Can my cancer treatments cause infertility?”

Cancer treatments such as chemotherapy and radiation may cause infertility. The goal of chemotherapy is to kill rapidly dividing cells in the body. Since sperm cells and cells surrounding eggs share this quality, infertility can be a side effect. Radiation also destroys rapidly dividing cells, but only in a focused area; consequently, radiation to the pelvic area or to a hormone control center in the brain may cause infertility. After treatment, it is often suggested that patients wait two years before trying to conceive. Although this varies on an individual basis, it is believed that any genetic damage to eggs from treatment is repaired within 6 months, while this can take up to two years with sperm. Fertility options vary before and after cancer therapies, so it's important to discuss the risks of your treatment with your oncologist. Fertile Hope (www.fertilehope.org; 888-994-HOPE) is dedicated to helping cancer patients with fertility issues. The American Infertility Association (www.americaninfertility.org; 888-917-3777) and RESOLVE: The National Infertility Association (www.resolve.org; 888-623-0744) also provide advocacy, education and support.

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

Home and Office: New Ways to Manage Work

Even the most fortunate brain tumor survivors may discover cognitive changes that prove challenging. Returning to work can prove especially frustrating when routines that used to come easily now feel like a struggle. The suggestions below are drawn from the Job Accommodation Network's fact sheets, but many of these ideas might also help you with household tasks such as record-keeping and paying the bills.

Maintaining Concentration

- ♦ Reduce distractions in your work area.
- ♦ Use a white noise machine *or* Play soothing music on headphones.
- ♦ Increase natural lighting or provide full-spectrum lighting.
- ♦ Plan for uninterrupted work time.



Organization

- ♦ Divide large projects into smaller steps.
- ♦ Prioritize carefully and eliminate non-essential tasks.
- ♦ Make daily to-do lists and check off completed items.
- ♦ Use a calendar to keep track of meetings, appointments and deadlines.
- ♦ Find a mentor to help determine goals and provide guidance.

Memory Aids

- ♦ With permission, tape-record meetings and appointments.
- ♦ When possible, ask for written as well as verbal instructions.
- ♦ In addition to your calendar, keep a notebook of reminders.
- ♦ Use color coding and labels to distinguish at a glance.
- ♦ Assign specific locations to items so you always know where to look.
- ♦ Post instructions on frequently-used equipment.

Fatigue

- ♦ Schedule periodic rest breaks away from the work area.
- ♦ Create a flexible work schedule.
- ♦ Provide information or sensitivity training to co-workers and family.

Resources for Employers and Employees

Job Accommodation Network

800.526.7234 www.jan.wvu.edu

Employer Assistance Referral Network (EARN)

866.327.6669 www.earnworks.com

WorkSupport.com

804.828.1851 www.worksupport.com

Americans with Disabilities Act

800.514.0301 www.ada.gov

Family Medical Leave Act

866.487.9243 www.dol.gov/esa/whd/fmla/



Oceanside Golf and an Auction at LINKS to a Cure

On June 14, the rain held off just long enough for most of the golfers to finish their holes at the seventh annual LINKS to a Cure. At the seaside Kittansett Golf Club in Marion, Massachusetts, even overcast days are beautiful, and the course is always appreciated by true golfers. The players dried off in the clubhouse and got an early start on the Silent Auction. Winners look forward to enjoying their special box seats at football, baseball and hockey games, and other prizes included golf getaways to notable courses in several states. Conversation abounded during the buffet dinner, and the live auction provided an exciting end to the day. Once again, the LINKS Committee put together an excellent day of sporting and socializing.



Photo © Pierre Chihua

As always, LINKS Chair Moe Tarkinow, founder Mark Goldstein and Committee Member Reyn Parson organized an exceptional day of fun and philanthropy for BTS.

This summer was full of events to benefit the Brain Tumor Society, some of which are listed below. Our supporters organize these remarkable fundraisers with the help of friends and families and then donate the proceeds to BTS. Such efforts are greatly appreciated and make up an important portion of our overall fundraising efforts. Learn more about these events and others at www.tbts.org, under *Get Involved*.

Jackie Girard Night

This family night at a baseball game was organized in Jackie's memory and hosted by a minor-league team in Massachusetts.

Friends of Craig Classic

Craig Marini organized a golf tournament for friends and family in 1991 as a way for the group to spend time together. Now his loved ones hold an annual tournament in Craig's memory, and the reunion also serves as a benefit for BTS.

O'Gannon's Pub Summer Benefit Bash

The owner of this pub is also a brain tumor survivor. The pub held a night of live music and good fun and donated all raffle proceeds to BTS.

Patricia Papagno Golf Tournament

Another memorial golf classic, this tournament is held by the family of a long-time supporter.

We're Riding Chai

The Liat Chanina Foundation is a major supporter of BTS and our events. This August, the Foundation held its first annual 18-mile bike ride on the South Shore of Massachusetts. *Chai* is Hebrew for "life" and also represents the number 18, inspiring this ride's name and distance.

BTS is grateful to the many people all over the country that run events to benefit our mission of education, support and research.



Photo courtesy of Steve Glassman

If you would like to organize a fundraiser of your own, contact Barbara Goodman, Events Coordinator, at 866.633.9997 ext 12 or at events@tbts.org

update!
Ride for Research

With donations and matching gifts continuing to roll in, the Ride for Research fundraising total is up to **\$650,000** and counting. The Brain Tumor Society extends its deep gratitude to all of the Riders, donors and volunteers. We also want to recognize the generosity of our sponsors:

- | | |
|-----------------------------|-----------------------------|
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| Channel 5 WCVB-TV | Reese HitchFinder |
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Let's Make the Impossible Possible

On November 20, the Brain Tumor Society will host a gala evening to celebrate the memory of Sam Gerson, lifelong businessman and philanthropist, and will honor Sam's wish to provide those living with brain tumors more hope that a cure will be found. It is an evening for all to come together to make the *impossible possible*.

The gala will be held in Boston at the Fairmont Copley Plaza. Artist and songwriter Marvin Hamlisch will perform during the evening, which will also include a live auction with remarkable prizes, such as:

- ◆ Tickets to a Boston Bruins hockey game in a suite hosted by Bobby Orr
- ◆ A priceless children's birthday party at Toys 'R' Us Times Square

To learn more about this celebratory gala, contact Thomas Leavitt, Director of Development, at 800.770.8287 ext 14 or development@tbts.org.

Our Sustaining Partners

To recognize the unique interest of our most committed supporters, the Brain Tumor Society created the Sustaining Partners Fund. Our Sustaining Partners make an annual gift - payable at once or over the course of the year - that helps BTS plan steps toward our mission of research, education and support. Our Sustaining Partners stay involved with BTS activities throughout the year with special mailings and a Sustaining Partners' newsletter. We also recognize their remarkable support with special invitations to events.

To learn more about the Sustaining Partners Fund, contact Director of Development Tom Leavitt at 800.770.8287 ext 14 or leavitt@tbts.org.

SUSTAINING PARTNERS FUND ANNUAL GIFTS

Sustaining Partners	\$1,200 to \$2,399
Bronze Sustaining Partners	\$2,400 to \$4,799
Silver Sustaining Partners	\$4,800 to \$9,999
Gold Sustaining Partners	\$10,000 or more

Photo © Pierre Chihla



It's not too early to think about
Ride for Research 2005!

~ May 15, 2005 ~

You don't have to be on a bike or even be near Boston to have a team and participate. Register as a **virtual rider** to fundraise anywhere!

You can also hold your own **neighborhood bike ride** to benefit BTS, whether on the Ride for Research day or any other time.

Events Coordinator Barbara Goodman can tell you more about the options. Reach her at events@tbts.org or 866.633.9997

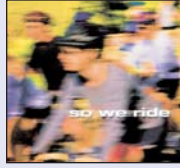
Look for updates on www.tbts.org

Looking for another way to help? Check out BTS Merchandise!

Call us at 800.770.8287
BTS Merchandise is coming soon to
www.tbts.org



LINKS to a Cure
Black caps
One size fits all
\$15 each



So We Ride
CD of the Ride for
Research song
\$10 each



Notecards
12 blank cards
Seasonal photos
\$25 per set

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Please let us know of any changes, corrections or duplications. Thank you!

Email: 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
 - ____ Diagnosis: Brain Tumor new patient brochure
- Send information about planned giving.
- Please make a note of my new contact info.
- Remove me from your mailing list.

Information is Power ... Power is Hope:

Connecting Patients, Survivors, Caregivers and Professionals

Registration deadline is October 1st!

Symposium
2004

www.tbts.org

Heads Up

The Newsletter of



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