

Caring Hand

Family Support and Research Edition
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Vogelstein delivers first Traynor lecture at Duke

One of the world's leading cancer researchers, Dr. Bert Vogelstein of Johns Hopkins, discussed "Cancer Genomes and Their Implications for Research and Patients" at the inaugural Mike and Dianne Traynor Lecture at Duke University on June 15.

Vogelstein was the first scientist to reveal the molecular basis of a common human cancer, and his work on colorectal cancers forms the model for much of modern cancer research.

Vogelstein's lecture at Duke noted that to date, science has identified 89 genes that have the potential to cause cancer (oncogenes), all of which fit into one or more of the 12 core cancer pathways. He outlined three ways that scientists can use this information to treat and cure cancer:

1. Create targeted chemotherapy agents to be used in combination with each other.
2. Develop pathway-targeting drugs.
3. Immunotherapy.

"Research's goal should be to eradicate cancer deaths and prevent advanced cancers," he said. At the 50th Traynor Lecture in 2061, he predicted, scientists would be able to announce an 80 percent reduction in cancer deaths, in equal thanks to improved therapies and prevention and early diagnosis.

Last year Vogelstein and a team of researchers at Johns Hopkins mapped the genome for



Dr. Bert Vogelstein delivered the inaugural Mike and Dianne Traynor Lecture at Duke in June.

medulloblastoma, the most common form of cancerous brain tumors in children. This work was made possible in part by the use of tissue samples from the Pediatric Brain Tumor Foundation® Institutes at Duke, UCSF and SickKids.

The longtime member of the PBTF Scientific Advisory Board is now working on a PBTF-funded sequence analysis and comparison of pediatric low- and high-grade astrocytomas.

Vogelstein is the Clayton Professor of Oncology and Pathology, Investigator at the Howard Hughes Medical Institute, and director of the Ludwig Center for Cancer Genetics and Therapeutics at Johns Hopkins Kimmel Cancer Center in Baltimore. He is an inventor of more than 100 U.S. patents and, according to the Institute for Scientific Information, is the world's most highly cited scientist.

We hope you enjoy the new format of *Caring Hand* and *Helping Hand*. The two publications are now combined, giving everyone we serve—patient families, scientists, medical professionals, donors, fundraisers, and motorcyclists—the opportunity to see all facets of our work.

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About Us

The Pediatric Brain Tumor Foundation® is a 501 (c)(3) nonprofit organization that seeks to find the cause and cure of childhood brain tumors. We fund medical research, increase public awareness of the disease, promote early detection and treatment, and offer family support programs.

Federal employees may make donations to the PBTF using CFC #10190. We are also highly rated by Charity Navigator, the nation's leading guide to charitable giving.



The Caring Hand

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FROM THE PRESIDENT'S DESK Smiles of inspiration

At the Pediatric Brain Tumor Foundation®, we are surrounded by the smiling faces of children on our office walls.

There are faces of little girls and boys enjoying their first motorcycle ride at a Ride for Kids® event, or being interviewed by one of our ride managers, enjoying all the attention of being a Ride for Kids® star.



There are also the faces of young people wearing caps and gowns as they graduate from high school with a PBTF scholarship.

Most important among these are the smiling faces of those that will only live on in our memory. They will not be forgotten.

These photos are all of children that have taught us how to live without complaint, to enjoy each day with a smile. These are children who possess wisdom beyond their years.

We have been inspired by each and every one of their lives. They have given us a mission and a path to follow: funding research that will discover new treatments to save lives and allow them to live healthy.

In this combined edition of the *Caring Hand* and *Helping Hand* you will read about the activities that took place in the first six months of 2011 as a part of the programs of the Pediatric Brain Tumor Foundation®, programs directed at saving the lives of these children.

Please know that we are still pushing hard on the gas. If you are not already a part of the PBTF and the Ride for Kids®, we invite you to help us achieve our goal of saving and improving the lives of childhood brain tumor survivors.

Dianne S. Traynor
President and Chairman of the Board

153 brain tumor survivors receive college scholarships

This fall 153 students affected by brain tumors will head for college with the help of a Pediatric Brain Tumor Foundation® scholarship. Since the program began in 2002, we have offered 941 students funds for vocational schools, community colleges and universities around the U.S.

“When we started this program nearly 10 years ago, we were delighted to be able to fund a scholarship for one survivor at that time,” notes PBTF President Dianne Traynor. “As time has passed, we now are beginning to see more survivors of this disease, which tells us that we are having success in extending the lives of these children.”

Letters from scholarship recipients reveal not only their heartfelt gratitude, but also just how life-changing these awards actually are.



PBTF scholarship recipient Ethan is a rising freshman at Washington State University.

“College is helping me achieve my goal of being an occupational therapist and helping other survivors like me,” writes Annie. “This is my senior year and it’s going to be a good one, thanks to the scholarship.”

Ethan, a rising freshman, is also thankful for the PBTF’s support. “I want to express how honored I feel to have received this scholarship, and to thank all of the donors that make this scholarship possible,” he says.

The PBTF’s college scholarship program is supported in part by the Tim and Tom Gullikson Family Support Fund and the *Cycle World* Joseph C. Parkhurst Education Fund.

A full list of this year’s scholarship recipients will appear in the next issue of *Caring Hand*. Scholarship applications for brain tumor survivors attending college in the 2012-13 academic year will be available in October 2011. For more information, call 800-253-6530.

HOPE SPRINGS ETERNAL This survivor has no time for regrets

It was 2008, and Brittany was sure that her daily bouts with headaches, fatigue and vomiting were the result of nothing more than normal high school stress. She had just joined the marching band, and despite the rigors of intense competitions and biweekly late night practices, she was elated.

“Marching band quenched my desire to feel accepted and to feel a part of something, a dream I had always hoped to reach in my high school experience, she explains. “I enjoyed every minute of every performance, I enjoyed the people, and most of all I enjoyed the euphoria that flowed with doing something you’re passionate about.”

But the headaches continued. And when she was finally diagnosed with a brain tumor, Brittany was initially filled with regret.

“Each day I bashed myself, thinking how could I have been so naive, unable to realize something as serious as a brain tumor,” she recalls.

Eventually, however, she tapped into her optimism to move past those feelings.

“Regret is something that stays with you for a long time,” she says. “It takes time to heal the open wounds that regret leaves behind and haunts you in your heart for ages.... I forgave myself through the help of family

and friends who reminded me of how strong I was and how hard I had worked to fight through my diagnosis with positivity.”

These days, Brittany is a testament to the power of positive thinking. Now a college-bound student with hopes of one day becoming a clinical pharmacist specializing in pediatric oncology, she exudes a confidence and wisdom that belies her youth.

“I am ready and eager to accept the challenge of moving forward with my goals,” she says with conviction. “I am inspired to do something more with my life and bring to others what I found for myself -- the magic of life and the magic of living. I have found the mindset that will get me through any hurdle life throws my way.”

Brittany’s new motto? “Life is all about opportunities, the ones you take, the ones you embrace, and the ones you let go,” she says.



This fall Brittany will attend Rutgers University with the help of a PBTF scholarship. She hopes to become a clinical pharmacist.

In a Parent's Words

The beast is back

by Suzanne Leigh

It is a cloudless August day and we are waiting inside the clinic where we will learn the results of our daughter's MRI. Natasha is 10 years old, olive-skinned, lean and vital. Her brain tumor had been resected two and a half years ago and her life has long since returned to normality: school, crazy playdates, running along the ocean trying to reach the two-mile mark, and sneaking peeks at Lady Gaga on YouTube when the parents are out of sight.



The author and her daughter Natasha.

We are tense and hypervigilant as we wait for Natasha's neuro-oncologist to show. I think Natasha is at ease, but I can't be sure. During these past 31 months as she has morphed from little girl to almost-teen, a part of her has picked up on our "scanxiety" as MRIs approach every four months.

When our doctor gently compliments Natasha on her hairstyle and asks her to leave us to talk in private, I sense that I am entering a new, uniquely tortuous chapter of my life. The radiologist saw something, she says. We shoot out of our seats; I gasp, sob and pace. The beast is back. There will be more surgery, radiation, and eventually chemo. Once again we will witness our vibrant girl transition to a limp, fragile wisp, whose eyes reflect silent resignation to a journey that she alone must take.

I turn to our doctor. "I love my child," I mutter under my breath. It's an irrelevant remark that represents a primal pleading scream from my heart.

I return to Natasha in the waiting room. I am wearing my capable mommy mask. I kiss the top of her head. It's OK, Honey. A setback. We'll deal with it. We walk out of the hospital, the same hospital where a decade ago, I had proudly placed my flawless firstborn from a crib into something called a car seat (car-free and child-free for so long, I'd never heard of such a thing). The sun had dazzled that day. Today the sun dazzles.

We go to the ice cream parlor with Natasha and her 6-year-old sister. A photo captures two smiling girls with their parents whose own frozen smiles contradict their stunned grief.

In the weekend prior to surgery, we book a hotel in the suburbs away from the summer chill of San Francisco. Natasha gorges on tacos and ice cream, cavorts with her sister in the pool, giggles and cartwheels. Behind closed doors, my husband and I exchange despairing whispers: "Our child had a brain tumor. And now the brain tumor has come back."

Meanwhile something is happening to my own body while the tiny tumor blossoms inside my child's brain. When I stand up, I black out. I find myself clutching walls, tables and people as I struggle to reach an upright position. I am not sick; I am robust. Months later, while Natasha makes a meandering recovery with many highs and many lows, I see that period of blackouts as the perfect metaphor for Natasha's re-diagnosis. I could not stand it.

Postscript: *Natasha is now 11 and at press time is preparing to start middle school. She continues treatment.*

Suzanne Leigh is a freelance writer whose account of Natasha's first diagnosis was published in the Washington Post. Her article on post-traumatic stress in parents of young cancer patients was published in the San Francisco Chronicle.

PBTF supports pediatric oncology social workers

Social workers are advocates for people in need, and families of children with cancer need more support than most. Professionals who work in pediatric oncology meet annually to learn from each other, and the Pediatric Brain Tumor Foundation® is proud to support them.

This year we have continued our longtime sponsorship of the Association of Pediatric Oncology Social Workers (APOSW) conference. Family Support Program Director Pat Korpik attended the May meeting in Atlanta along with over 150 social workers from the U.S. and Canada.

The annual conference facilitates the highest professional practice of the social workers doing clinical work with children and families impacted by childhood cancer. Most attendees practice in major medical centers as members of medical treatment teams.

For those social workers who work exclusively with brain tumor patients, the conference is an opportunity to advance knowledge, develop advocacy strategies, and form a network of colleagues to discuss the developmental and emotional impact of brain tumors on children and families.

Clinical skills, advocacy, and broadening knowledge of resources are addressed through presentations, small working groups, and exhibit and poster presentations throughout the conference.

Topics of presentations included late effects of treatment, quality of life, disability rights, Internet resources for teens and young adults with cancer, resilience in siblings of children with cancer, grief and loss, the complexities of cultural and spiritual beliefs, and how to support families within the medical setting.

“As an exhibitor, we were able to give attendees more information about the resources we offer them and the families with whom they work,” Korpik says. “It was also a chance for me to meet social workers from areas near Ride for Kids events, and encourage them to invite families to participate.”

Korpik notes that although most APOSW members work with patients within the entire pediatric oncology field, the PBTF is a useful resource. “They rely on us as a source of specialized information, and share our brochures and Informed Parent and Survivor Internet Conference CDs with patient families,” she says.

IN MEMORIAM

Matthew David Brandt

**June 10, 2005 -
May 5, 2008**

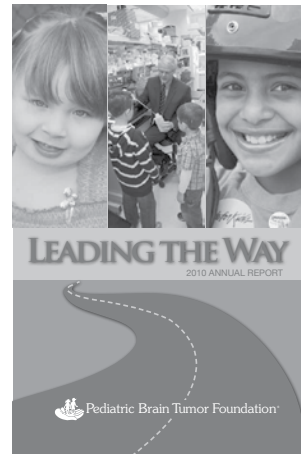
If you would like us to memorialize your child in the Caring Hand, please send your child's name, birthday and date of passing to familysupport@pbtfus.org. You can also call our Family Support team at 800-253-6530.

Annual report, video now available

Our 2010 annual report, “Leading the Way,” is a record of our work at the forefront of childhood brain tumor research and patient family support. In it we outline the achievements of the past year, including our funding of new research grants and college scholarships.

We're also proud to introduce a new video about the foundation's work. The five-minute spot features brain tumor survivor Hannah Lawson and her parents, as well as Dr. James Rutka of the PBTF Institute at the Hospital for Sick Children.

You can read our annual report and see our new video online at pbtfus.org.



Annual Steck award, lecture salute landmark discoveries

Dr. Peter Steck co-discovered the MMAC/PTEN tumor suppressor gene, which is key to the development of glioblastomas and several other forms of cancer. His promising research career was cut short by his death in 2002. In the years since the Pediatric Brain Tumor Foundation® has sponsored the Steck Memorial Award and Lecture at M.D. Anderson Cancer Center in Houston.

This year's recipient of the young investigator award was Michelle Monje, M.D., Ph.D., of Stanford University. The PBTf has supported her research into diffuse pontine gliomas (DIPGs), a highly aggressive pediatric brain tumor that is almost always fatal.

Monje worked with Dr. Siddhartha S. Mitra and a team of researchers at Stanford University and the University of California, San Francisco to create the first reported cell culture of human DIPG cells, as well as the first DIPG xenograft model. Her research also suggests that the Hedgehog (Hh) signaling pathway represents a potential therapeutic target for this devastating disease.

Dr. Lewis Cantley, discoverer of the phosphoinositide 3-kinase (PI3K) pathway, delivered this year's Steck lecture. Cantley is a cell biologist and biochemist and a professor in the departments of Systems Biology and Medicine at Harvard Medical School, and the Director of Cancer Research at the Beth Israel Deaconess Medical Center in Boston.



Dr. Michelle Monje discusses her work with DIPGs, which is supported in part by the PBTf.

Why do children get brain tumors?

This compelling question was the topic of a talk by Dr. Richard Gilbertson at the University of California, San Francisco. Gilbertson, a pediatric oncologist at St. Jude Children's Research Hospital, delivered the Mike Traynor Pediatric Brain Tumor Foundation® Lecture in March. Last year's inaugural lecture was given by Dr. Daniel Fults of the University of Utah.



PBTFI research review yields promising papers

Members of the Pediatric Brain Tumor Foundation® Institute (PBTFI) program held their fourth research review meeting in New Orleans in May 2011.

Forty researchers from the PBTFI Institutes at Duke University, the University of California, San Francisco and the Hospital for Sick Children attended the meeting, which included 22 research presentations.

Topics included CNS development and

tumorigenesis; molecular studies aimed at finding potential targets for novel therapies; and the use of advanced genomic techniques and bioinformatics capabilities to validate potential targets utilizing “in vitro” and “in vivo” disease models.

“The research projects presented at this year’s meeting demonstrate the impact these collaborative research efforts are having on the advancement of our knowledge of brain tumors in children and on the

potential for the translation of this knowledge into novel therapies,” says PBTFI President Dianne Traynor.

The PBTFI research institutes seek to provide scientific evidence as to the causes of specific pediatric brain tumor types, and to translate research discoveries into novel targeted therapies. Their collaborations have led to new peer-reviewed research grant funding from the NCI to support additional pediatric brain tumor research studies.

Meeting highlights basic and translational research in pediatric neuro-oncology

The second Pediatric Neuro-Oncology Basic and Translational Research Conference brought together more than 200 scientists from 13 countries.

The PBTFI created this meeting in 2009 to focus exclusively on basic and translational research into the disease of brain tumors in children. One of its goals is to give researchers from around the world an opportunity to share their discoveries with each other while stimulating new research collaborations.

The Society for Neuro-Oncology (SNO) organized this year’s conference in New Orleans, with primary sponsorship from the PBTFI. Dr. James Rutka, director of the PBTFI Institute at the Hospital for Sick Children, led the scientific program, assisted by a scientific advisory board made up of basic and translational scientists who are members of SNO.

Many attendees commented favorably on the scientific content of the meeting. Plans are underway for the next conference to be held in 2013.

Kyrie Foundation makes second grant to PBTFI



When 17-month-old Kyrie Thome died of her brain tumor in 2007, her family decided to memorialize her by raising funds to fight the disease. Her aunt and uncle, Megan Thome and Chad Eickholt, recently joined her father, Jordan Thome (far right), in New Orleans to present their second \$50,000 grant to the PBTFI. Accepting the check was PBTFI President Dianne Traynor, who says, “These funds make possible the expensive collection and storage of pediatric brain tumor tissues, which are essential to advancing research to find a cure for the disease.”



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