



# LEADING THE WAY

2010 ANNUAL REPORT



Pediatric Brain Tumor Foundation®

## LEADING THE WAY

When the Pediatric Brain Tumor Foundation® began over 19 years ago, very little was known about brain tumors in children. The disease got scant attention from researchers or the public. We were determined to change that, and since then we have led the way forward by funding research and raising awareness around the world.

Our knowledge about the deadliest of the childhood cancers has grown substantially, and 2010 was a year of even more discoveries. Prestigious medical journals cited multiple research projects that we have supported, and other PBTF-funded projects developed new clinical trials of potential targeted therapies.

We also led the way with our support programs for patient families. In 2010 we added two educational booklets, and continued to celebrate the growth of our scholarship program for survivors. This program is one of our greatest accomplishments. When we started it in 2002, we had only one applicant; last year we awarded our 788th scholarship.

All of this speaks to the success of our mission to find the cause of and cure for this deadly disease and to provide resources for patient families and survivors. The staff of the PBTF would like to thank our volunteers,

fundraisers, donors and sponsors for the many successes of 2010.

You are helping us lead the way to save children's lives.

### Dianne S. Traynor

Co-founder, President and Chairman of the Board



## OUR MISSION

The Pediatric Brain Tumor Foundation®, a nonprofit charitable 501(c)(3) foundation, seeks to:

- find the cause of and cure for childhood brain tumors through the support of medical research
- increase public awareness about the severity and prevalence of childhood brain tumors
- aid in early detection and treatment of childhood brain tumors
- support a national database on all primary brain tumors
- provide hope and emotional support for the thousands of children and families affected by this life-threatening disease.

### Executive Officers

Dianne Traynor, President  
Glenn Wilcox, Vice President  
Don Goden, Secretary

### Board of Directors

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## AT THE FOREFRONT OF RESEARCH

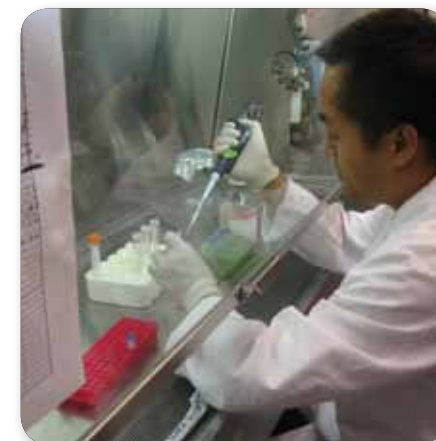
When the founders of the Pediatric Brain Tumor Foundation® began raising funds for childhood brain tumor research in 1984, very little was known about this deadly disease. Today we are proud to say that researchers around the world are working to unlock its secrets, and many children are living longer as a result.

Our strategy is to fund promising, child-focused research at the world's finest medical institutions. We require the researchers we fund to share their results with each other, and this has fostered a unique learning environment. The goal is to translate basic research into clinical trials, so that young patients everywhere can benefit from better standards of care.

We worked toward this goal in 2010 by continuing to fund our Pediatric Brain Tumor Foundation® Institute programs and basic and translational research grants at Duke University, the University of California, San Francisco, and the Hospital for Sick Children in Canada.

We also supported a prominent lecture series, recognized a promising young investigator, funded epidemiology studies and sponsored many leading scientific meetings and conferences.

Countless donors and fundraisers have helped put the PBTF at the forefront of childhood brain tumor research. Someday, this research will lead to a cure, and every child diagnosed will survive.



### Senior Scientific Advisor

Philip Frost, M.D., Ph.D.

### Scientific Advisory Board

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Johns Hopkins University  
W.K. Alfred Yung, M.D.  
M.D. Anderson Cancer Center

## PBTF INSTITUTE PROGRAM

### Pediatric Brain Tumor Foundation® Institute at Duke

**Grant Award 2003-2010: \$12 million**

**Director:** Darell Bigner, M.D., Ph.D., *Administrative Core, Developmental Research Core and Career Development Program*

Hai Yan, M.D., Ph.D., *Systematic Oncogenomic Profiling of Pediatric Astrocytoma*

Yiping He, Ph.D., *Identification of Medulloblastoma Antisense Transcripts as Potential Biomarkers*

Sally Kornbluth, Ph.D., *Eliminating Brain Cancer Cells Through Apoptosome Activation*

Wei Chen, Ph.D., *Clinical Treatment of Pediatric Medulloblastoma Using Novel Small Molecule Inhibitors of Smoothed Activity: A Translational Approach*

Hui-Wen Lo, Ph.D., *Targeting STAT3 as a Novel Therapy for Pediatric Medulloblastomas*

Robert Wechsler-Reya, Ph.D., *Initiation and Propagation of Medulloblastoma*

Oren Becher, M.D., *Genetically Engineered Mouse Model of Diffuse Intrinsic Pontine Glioma: A Preclinical Tool to Test Efficacy of Novel Agents*

John Sampson, M.D., Ph.D., *Dendritic Cell Vaccines Targeting Medulloblastoma and Medulloblastoma Stem Cells*

Michael Zalutsky, Ph.D., *Targeted Radiotherapy of Medulloblastoma*

Darell Bigner, M.D., Ph.D., and Chien-Tsun Kuan, Ph.D., *Specific Antigen-Targeted Immunotherapy of Medulloblastoma*

Roger McLendon, M.D., *Biorepository Core*

Darell Bigner, M.D., Ph.D., and Henry Friedman, M.D., *Cell Lines and Xenograft Core*



### Pediatric Brain Tumor Foundation® Institute at the University of California, San Francisco

**Grant Award 2005-2010: \$1,300,000**

**Director:** Mitchel S. Berger, M.D., *Administrative and Statistical Core*

David Rowitch, M.D., Ph.D., and Arturo Alvarez-Buylla, Ph.D.,

*Central Nervous System Development and Brain Stem Glioma Tumorigenesis*

William A. Weiss, M.D., Ph.D., *MYCN and Medulloblastoma Tumorigenesis*

Nalin Gupta, M.D., Ph.D., and C. David James, Ph.D., *Novel Therapeutic Strategies for Pediatric Brain Tumors*

Joanna Phillips, M.D, Ph.D., *Core A – Animal Models and Pre-Clinical Therapeutics Core*

C. David James, Ph.D., *Core B – Tissue and Neuropathology Core*



### Pediatric Brain Tumor Foundation® Institute at the Hospital for Sick Children

**Grant Award 2005-2010: \$1,300,000**

**Director:** James Rutka, M.D., Ph.D.

James Rutka, M.D., Ph.D., Michael D. Taylor, M.D., Ph.D., and Peter Dirk, M.D., Ph.D., *The Role of Isochromosome 17Q in the Pathogenesis of Pediatric Brain Medulloblastoma*



## 2010 AWARDS, GRANTS AND SPONSORSHIPS

### Research Grant Awards

Johns Hopkins University School of Medicine

Grant Award 2010: \$100,000

Bert Vogelstein, M.D., *Sequence Analysis and Comparison of Low- and High-Grade Astrocytomas in Pediatric Patients*

University of California, San Francisco

Grant Award 2007-2010: \$50,000

Fredrik Johansson Swartling, Ph.D., *Characterizing and Treating Cancer Stem Cells Isolated from a MYCN Medulloblastoma Model*

Hospital for Sick Children

Grant Award 2009-2010: \$100,000

Uri Tabori, M.D., Principal Investigator, *Predictors of Functional and Neuro-Cognitive Outcomes in Long-Term Survivors of Pediatric Low-Grade Gliomas*

### Peter A. Steck Memorial Lecture and Young Investigator Award

**Guest lecturer:** Inder Verma, Ph.D., Professor and Jacobs Chair in Exemplary Life Science at the Salk Institute, discussed "Cancer: A Malady of Genes" at the University of Texas M.D. Anderson Cancer Center in July 2010.

**Young Investigator Award:** The 2010 award went to Hongwu Zheng, Ph.D., formerly with the Dana-Farber Cancer Institute, now with Cold Springs Harbor Laboratory.

### Epidemiology

- Central Brain Tumor Registry of the United States
- Brain Tumor Epidemiology Consortium

### 2010 Meeting & Program Sponsorships

- Platinum Sponsor, 15th Annual Society of Neuro-Oncology (SNO) Conference
- 15th Annual SNO Neuro-Tumor Club Meeting
- 14th International Symposium on Pediatric Neuro-Oncology (ISPNO)
- 18th International Conference on Brain Tumor Research and Therapy

*"We've been very fortunate to form a partnership with the research and the medical community in fighting this disease. We provide grant funding, and they provide the brilliant minds that it takes to make these discoveries."*

— Dianne Traynor



**Dr. Inder Verma delivers the 2010 Steck Lecture at M.D. Anderson.**

## FAMILY SUPPORT PROGRAM

When a family gets the news that their child has a brain tumor, their world changes forever. The Pediatric Brain Tumor Foundation® is here to help. We give families the tools they need to learn more about this disease, and we give researchers the funds they need to find a cure.

Our family support resources include a staff social worker who answers questions and provides referrals.

We produce bilingual educational materials, an Internet conference series, and a research-focused national newsletter. Our website contains a wealth of information about subjects such as late effects of brain tumor treatments and medical advances.

We also offer hope in the form of college scholarships for brain tumor survivors. Our Ride for Kids® events are a terrific support system for patients and their families, and our Facebook page is a space for them to connect with each other.

All of these services are available at no charge to patient families, social workers and medical professionals.

### 2010 Accomplishments

- Made 8,732 contacts with patient families
- Awarded \$160,000 in college scholarships to 154 students affected by brain tumors
- Produced two new educational booklets, Basic Facts About Non-Malignant Brain Tumors and Basic Facts About Late Effects of Pediatric Brain Tumors and Treatments
- Attracted 264,269 unique visitors to our websites, [pbtfus.org](http://pbtfus.org) and [rideforkids.org](http://rideforkids.org), and logged a total of 384,609 unique page views
- Mailed 189,455 informational newsletters
- Sponsored the Association of Pediatric Oncology Social Workers' Annual Meeting

### Educational resources

- We serve families, caregivers and medical professionals with the *Caring Hand*, a publication that includes the latest news about grants, fundraising efforts and family support programs.
- The *Helping Hand* newsletter focuses on the Ride for Kids® program, and emphasizes patient family participation and support.
- We publish a series of free informational booklets about brain tumors and their treatment, available to the public, social workers and medical offices. Several editions are available in Spanish as well as English.
- Our Informed Parent & Survivor Internet Conference audio programs are available online at [pbtfus.org](http://pbtfus.org) or on CD.



## ADVOCACY

The more the public knows about childhood brain tumors, the more attention it will pay to the disease. The Pediatric Brain Tumor Foundation® recognized this early on, and is a founding member of the Alliance for Childhood Cancer.

This coalition of national patient advocacy groups and medical and scientific organizations works to advance research and cancer prevention policies, increase public awareness, and improve the diagnosis, treatment, supportive care and survivorship of children and adolescents with cancer.

We also give voice to brain tumor patients with our national radiothon program. In 2010 three PBTF radiothons reached over 496,000 listeners. Many patient families and medical professionals participated in these events, and their stories inspired over \$238,000 in donations.



## COLLEGE SCHOLARSHIP PROGRAM

When we began offering college scholarships to brain tumor survivors in 2002, we had one applicant. Survivorship rates have improved over the years, and applications have increased as a result. In 2010 we awarded our 788th scholarship. The program is supported in part by the *Cycle World* Joseph C. Parkhurst Education Fund and the Tim and Tom Gullikson Family Support Fund at the PBTF.

*"Providing knowledge gives patient families the power to fight this disease. Without it they feel totally alone, in a foreign land that they've never been a part of ... It also helps them to become an advocate for their child, to be able to be a part of the treatment team that will be a part of what happens to their child." – Dianne Traynor*



*"The Ride for Kids is awesome. What it's been able to do for pediatric brain tumor research is unlike anything of its kind anywhere in the world. The amount that has been raised through this effort to support research is absolutely spectacular. [The PBTF] has done more to advance the field of pediatric brain tumor research than any single organization."*

—Dr. James Rutka, Director of the PBTF Institute at the Hospital for Sick Children

*Ride for Kids*  
 benefiting the  
 Pediatric Brain Tumor Foundation®





## RIDE FOR KIDS® PROGRAM

People ride motorcycles for all kinds of reasons—for fun, transportation, or business. At the Pediatric Brain Tumor Foundation®, we ride for the greatest reason of all: to save kids' lives. Our Ride for Kids® program raised \$4.5 million in 2010 with 40 events around the United States and a variety of high-profile fundraising activities. The total also includes the value of donated goods and services.

In 2010, 17,280 motorcyclists registered to attend Ride for Kids® events, which were organized by 2,430 volunteers and attended by 317 families of children with brain tumors.

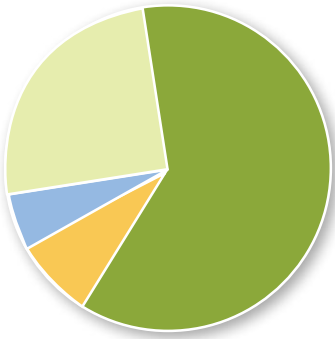
These families know that Ride for Kids® is an incredible support program. They are encouraged by motorcyclists' fundraising efforts, they make new friends, and they learn from and lean on other families. We celebrate the lives of all children with brain tumors at our events, and by doing so inspire the public to do more to find a cure.

Presenting Sponsor Honda Riders Club of America	National Insurance Sponsor GEICO	Event drawing prize sponsors AGV Cardo Systems Dunlop Tourmaster
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## 2010 Source of Funds

Total: \$5,485,147\*



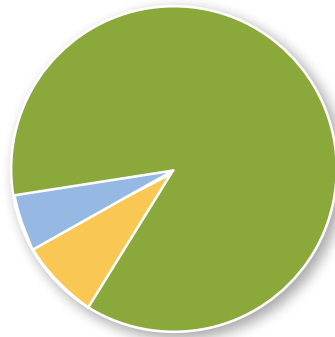
## 2010 FINANCIAL STATEMENT




The independently audited Revenue and Expense Statement for the Pediatric Brain Tumor Foundation® for the year ending Dec. 31, 2010, is reflected below. Please see the preceding pages of this report for a detailed explanation of our programs. Totals agree to the audited statement of activities for the year ending Dec. 31, 2010.

Direct public support	\$3,449,491	62.9%	
Corporate support	\$1,029,525	18.8%	
Honor, memorial donations	\$166,393	3.0%	
Non-cash and other	\$839,738	15.3%	

## 2010 Use of Funds

Total: \$5,867,603



Program funds	\$4,898,035	83.5%	
Fundraising costs	\$408,167	6.9%	
Management, administration	\$561,401	9.6%	

\*exclusive of investment gains and losses



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## THANK YOU FOR GIVING

The programs that you've read about in our annual report are made possible by the kind support of individual donors, organizations, businesses, and sponsors. There are many ways to give, and we encourage you to find the way that works best for you. Please go to [pbtfus.org](http://pbtfus.org) or call us at 800-253-6530 to learn more about how you can help.

- **Honor and memorial tributes** are a meaningful way to commemorate a friend or loved one, or even to celebrate a special event. Online donations are gratefully accepted in any amount between \$5 and \$5,000.
- **Personal online fundraising** is a secure, simple and convenient way to raise money online. Get started at [firstgiving.com/pbtfus](http://firstgiving.com/pbtfus).
- **Community fundraisers** raise awareness as well as money. From bowling tournaments to yard sales, your event can benefit the PBTF. Just be sure to complete our fundraising application in advance.
- **Your gift of \$1,000** will fund a college scholarship for a brain tumor survivor.
- **Legacy giving** is a lasting way to support our mission. By naming us as a beneficiary in your will, life insurance policy or retirement plan, you'll help fund research for years to come.
- **Matching gift programs** are offered by many employers. Ask your human resources department to find out if your donations to the PBTF are eligible.
- **Online auctions** on eBay give you the option of designating a percentage of the proceeds to the PBTF. Go to [ebay.com/givingworks](http://ebay.com/givingworks) to learn more.
- **Text to give** \$10 directly from your mobile device. Simply text "ride" to 50555 to make a one-time \$10 gift to the Ride for Kids®, or text "radio" to 50555 to contribute a one-time \$10 gift to PBTF radiothons.



No matter the method you choose, children with brain tumors will benefit from your generosity. Thank you for being a part of our mission in 2010, and for many years to come.



## Pediatric Brain Tumor Foundation of the United States, Inc.

302 Ridgefield Court · Asheville, NC 28806

800-253-6530 · [pbtfus.org](http://pbtfus.org)

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