

Faces of Hope



Pediatric Brain Tumor Foundation
cure the kids

2006 Annual Report

Facing the future with hope

There is a fine line between a healthy life and one filled with daunting medical challenges. This is the line that children diagnosed with a brain tumor walk each day of their lives.

The path they follow is filled with countless obstacles that are nearly overwhelming in comparison to physically healthy children.

Furthermore, if they even survive the rigors of this all-consuming disease and the devastation of their treatment, they then embark upon a long and often immensely frustrating journey to adulthood.

As these children experience an ongoing decline in mental and physical capabilities, it impacts their self-esteem, their ability to retain learned information, and their ability to engage in physical activities. Often they face second cancers brought on by their treatment. The things that come as second nature to other children can be monumental hurdles in their daily lives.

In spite of these setbacks, every young patient that we have met over the past 23 years has been incredibly determined to make their life the best it can possibly be. They press on despite their challenges, demonstrating a courage we normally assign to combat heroes.

However, we have not forgotten the children who are no longer with us. The memory of them inspires us every day to work even more diligently on behalf of the children of the future.

This work has always been the essence of the Pediatric Brain Tumor Foundation's efforts. Until a cure is found, we will continue our search for new noninvasive, more effective treatments.

Our achievements in this effort are borne magnificently on the shoulders of each of you. It is through your combined talents and resources that the Pediatric Brain Tumor

Foundation has become the most significant voice in the world for childhood brain tumors. With your continued support we can and will fulfill our mission to help the children. Their faces, which fill the following pages, powerfully demonstrate the hope you give to them.

We are extremely grateful to each of you for your compassion and considerable efforts. We wish you great success in the coming year.

On behalf of the children,

Mike Traynor
Dianne Traynor

Mike and Dianne Traynor
Co-Founders



On the cover

Nicholas and Marisa, during and after their brain tumor treatment.



Our Mission

When the Pediatric Brain Tumor Foundation was created in 1991, the diagnosis of a brain tumor was virtually a death sentence for a child. Because there was very little research being done into the disease, most treatments were ineffective or harsh, and most children did not survive to adulthood.

The PBTf is working hard to change that reality. Researchers are developing new therapies that extend the lives of children, and we believe that their work will ultimately lead to a cure for this most devastating of childhood cancers. In 2006 we funded 40 research laboratories in the U.S. and other countries.

As the largest non-governmental funder of childhood brain tumor research in the world, we're dedicated not only to eradicating this disease, but to supporting families. We enhanced our educational resources in 2006 by translating our pediatric brain tumor booklets into Spanish. Now we can deliver comfort and hope to more of the patient population. Our college scholarship program also continued to expand in 2006, giving brain tumor survivors a boost for the future.

Through our efforts to raise public awareness, more attention has been focused on this deadly disease. Whether addressing congressional briefings or funding international conferences, the PBTf is an unwavering advocate.

Together, we're making a difference in the lives of children with brain tumors. And with your continued help, we will cure the kids!

Mission statement

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

- find the cause and cure of 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.

Board of Directors

Mike Traynor, President
Glenn Wilcox, Vice President
Chris Kernion, Treasurer
Dianne Traynor, Secretary

Chris Hoefflin, Director
Larry Little, Director
Bill Manson, Director
Jack McGinnis, Director
Wayne Toyota, Director

Fulfilling our mission ...



“When the doctors came and took our daughter from our arms for her surgery, we felt so alone. To know that people like you are there to help us when we fall is amazing.”

— **Jim and Sheila,**
parents of
brain tumor patient Maya

“The Pediatric Brain Tumor Foundation is the single most successful philanthropic organization working to improve the lives of children with brain tumors.”

— **Dr. Jonathan Finlay,**
Childrens Hospital Los Angeles



“Going to college would have been impossible without the scholarship I received from the PBTF. You helped me pursue my dream.”

— **Lindsey,**
2004 PBTF Scholar



... but our work isn't done

We continue to fight to save the lives of children and adolescents diagnosed with a brain tumor. However, brain tumors remain the deadliest of all childhood cancers, and many of them have no cure. The faces of the young people who are no longer with us continue to be the driving force behind our efforts to find new treatments that will result in a cure.

We remember those who left us in 2006:

*Karla Asch-Rosen
Cameron Birch
Samantha Brown
Tara Clarke
Allana Creager
Noah Davis
Andan Dea
Guy Grazier G'Sell
Dan Haugaard*

*Caroline Keeney
Kyle Kerpan
Jenna Grace Painter
Emily Perez
Carmela Taibi
Nicholas Tysen
Will Vossen
Luke Taylor Wood
Justis Yanez*



Cameron Birch



Dan Haugaard



Will Vossen



Caroline Keeney



Kyle Kerpan



Jenna Grace Painter

Research Grants & Programs

Thanks to your support of the Pediatric Brain Tumor Foundation, scientists in the United States, Canada and Australia are making strides in the search for the cause and cure of childhood brain tumors.

In 2006 the PBTF continued its fourth year of funding for the Pediatric Brain Tumor Foundation Institute at Duke and the first year of Pre-Institute programs at the University of California at San Francisco, Childrens Hospital Los Angeles, and the Hospital for Sick Children in Toronto. A key component of these Institute programs is research collaborations which will accelerate discoveries of potential pediatric brain tumor targets for novel therapies.

We also awarded six basic and translational research grants for projects at Cornell University, Duke University Medical Center, Memorial Sloan-Kettering Cancer Center, Stanford University, and Washington University School of Medicine.

“With the help of our esteemed Scientific Advisory Board, we choose to fund research projects with the most potential to produce viable results,” says Dianne Traynor, the PBTF’s director of research funding and advocacy. “We’re confident that we’re funding the best and brightest scientists in the arena of pediatric brain tumor research.”

Basic Research Awards



Eric Holland, M.D., Ph.D.
Memorial Sloan-Kettering Cancer Center

“Multi-drug resistance to phenotype of the side population in medulloblastoma models.”



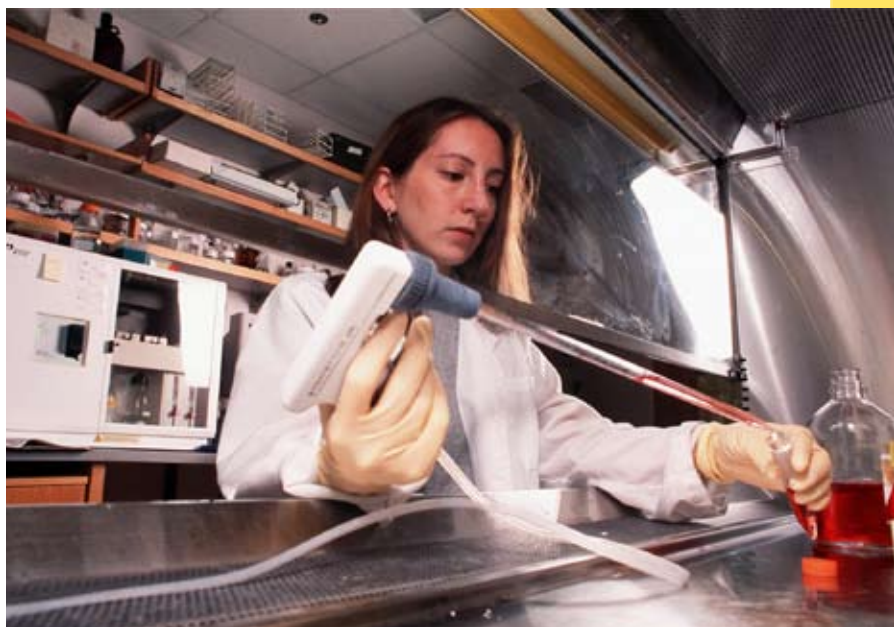
Anna Marie Kenney, Ph.D.
Memorial Sloan-Kettering Cancer Center

“Translation regulation by TXC2 in normal cerebellum and medulloblastomas.”



Sally Kornbluth, Ph.D.
Duke University Medical Center

“Elimination of pediatric brain tumors through activation of the apoptosome.”



Joshua Rubin, M.D., Ph.D.
Washington University School of Medicine

“Modulation of intracranial brain tumor growth and therapeutic responses by cAMP.”

(Nikki White Memorial Research Grant Award)



Mark Souweidane, M.D.
Cornell University

“Convection-enhanced delivery of recombinant immunotoxin 8H9-PE38 for the treatment of pediatric infiltrative brainstem tumors.”

(Nikki White Memorial Research Grant Award)



Irving Weissman, M.D., Ph.D.
and Michael Edwards, M.D.
Stanford University

“Identification of medulloblastoma tumor stem cells using self-renewal pathways.”



Pediatric Brain Tumor Foundation Institute Award



Darell Bigner, M.D., Ph.D.
Director, PBTFI at Duke University

Project 1: *Establishment of Cell Lines, Xenografts and Monoclonal Antibodies*, Darell Bigner, M.D., Ph.D.

Project 2: *Serial Analysis of Gene Expression of Childhood Brain Tumors*, Hai Yan, M.D., Ph.D.

Project 3: *Signal Transduction in Pediatric Central Nervous System Cancers*, Jeremy Rich, M.D.

Project 4: *Gene and Radiotherapy*, Michael Zalutsky, Ph.D.

Project 5: *Definition of Non-AGT/DNA Mismatch Repair Deficiency Mechanisms of Resistance to Temozolomide*, Henry Friedman, M.D.

Project 6: *Epigenetic Regulation of Drug-resistant Genes in Medulloblastoma*, Francis Ali-Osman, D.Sc.

Project 7: *Investigational New Drug and Reagent Preparation Core*, Michael Graner, Ph.D.

Project 8: *Tissue Bank Core*, Roger McLendon, M.D.

Project 9: *Pilot Project Core*, Darell Bigner, M.D., Ph.D.

Project 10: *Fibroblast Growth Factor as a Therapy for Medulloblastoma*, Robert Wechsler-Reya, Ph.D.

Project 11: *Investigation of Signal Transduction Pathways in Medulloblastoma*, Marc G. Caron, Ph.D.

Pre-Institute Awards



Mitchel Berger, M.D.
**Principal Investigator,
University of California, San Francisco**

“Program on Pediatric Brain Tumor Biology and Therapeutics.”

Project 1: *Central Nervous System Development and Brain Stem Glioma Tumorigenesis*, David Rowitch, M.D., Ph.D., and Arturo Alvarez-Buylla, Ph.D.

Project 2: *Pediatric Brain Tumor Xenograft Panel*, David James, Ph.D.

Project 3: *MYCN and Medulloblastoma Tumorigenesis*, William Weiss, M.D., Ph.D.

Project 4: *Genome-based Marker and Therapy Development in Pediatric Brain Tumors*, Graeme Hodgson, Ph.D.

Project 5: *Convection-enhanced and Intra-nasal Delivery of Therapeutic Agents*, Natlin Gupta, M.D., Ph.D.

Project 6: *Administrative and Statistical Core*, Mitchel Berger, M.D.

Project 7: *Tissue Bank and Neuropathology Core*, Scott Vandenberg, M.D., Ph.D.

Robert Seeger, M.D.
Principal Investigator,
Childrens Hospital Los Angeles



"Biology and Therapy of Pediatric Brain Tumors: Saving Lives, Saving Neurons."

Project 1: *Genomics*, Robert Seeger, M.D.

Project 2: *Microenvironment and Angiogenesis*, Anat Erdreich-Epstein, M.D., Ph.D.

Project 3: *Immunotherapy*, Leonid Metelitsa, MD, Ph.D.

Project 4: *Experimental Therapeutics*, Patrick Reynolds, M.D., Ph.D.

Project 5: *Molecular Imaging*, Stefan Blumi, Ph.D.

Core 1: *Pathology, Tissue Banking and Cell Lines*, Floyd Giles, M.D.

Core 2: *Pediatric Brain Tumor Core*, Anat Erdreich-Epstein, M.D., Ph.D.

Core 3: *Imaging*, Mike Rosol, Ph.D.

Core 4: *Biostatistics*, Richard Sposto, Ph.D.

James Rutka, M.D., Ph.D.
Principal Investigator,
Hospital for Sick Children, Toronto



Project 1: *Identification of Interstitial Germline Deletions in Children with Complex Clinical Syndromes that Include Medulloblastoma*, Michael Taylor, M.D., Ph.D., Eric Bouffet, M.D.

Project 2: *High Resolution Genotyping of a Large Cohort of Pediatric Medulloblastomas*, Michael Taylor, M.D., Stephen Scherer, Ph.D., James Rutka, M.D., Ph.D.

Project 3: *Ultrahigh Resolution Genotyping of Highly Purified Medulloblastoma*, Peter Dirks, M.D., Ph.D.

Project 4: *Identification of Truncating Mutations in Pediatric Medulloblastoma*, Peter Dirks, M.D., Ph.D., James Rutka, M.D., Ph.D., Michael Taylor, M.D., Ph.D.

Isolating a cure

Ongoing funding support for our Pediatric Brain Tumor Foundation Institute programs is achieving great results. For instance, Dr. Jeremy Rich, a researcher at the PBTf Institute at Duke University, isolated brain tumor stem cells from a pediatric brain tumor cell line that were capable of surviving radiation and

chemotherapy therapy through their DNA-repair response. The ability to block DNA-repair response may offer a potential strategy for overcoming the resistance of these tumors to treatment.

We also watched the collaborative research efforts of PBTf Institute-funded researchers grow, offering hope for our ability to fast-forward research discoveries.

Peter Steck Memorial Research Award and Lecture

M.D. Anderson Cancer Center

Young Investigators Award: Gurpreet S. Kapoor, Ph.D.,
University of Pennsylvania

Guest Lecture Award: Gordon Mills, M.D., Ph.D., M.D. Anderson Cancer Center

Basic Research

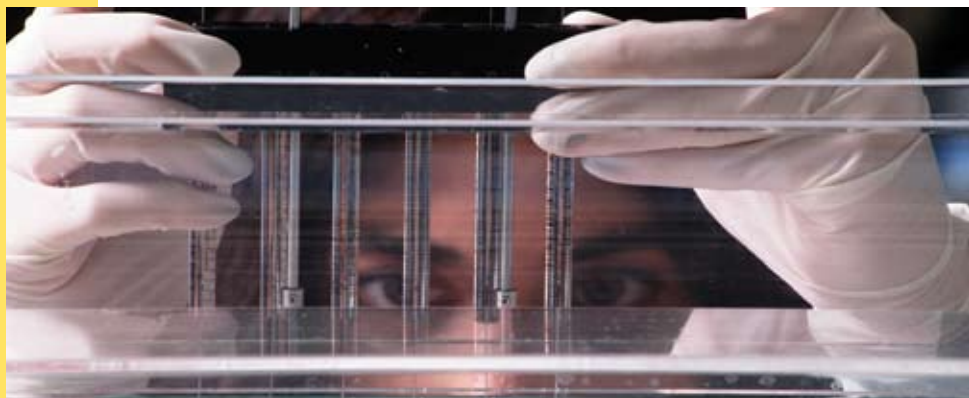
- “The role of gangliosides on immunosuppression and tumourgenicity in brain tumours,” David M. Ashley, Ph.D., and Denise A. Caruso, Ph.D., Murdoch Children’s Research Institute, Melbourne, Australia
- “A microfluidic system to investigate ERK proteins during medulloblastoma dispersal,” Maribel Vazquez, Sc.D., the City College of the City University of New York
- “Adoptive immunotherapy for medulloblastoma with ErbB2-specific T-cells,” Stephen Gottschalk, M.D., Baylor University
- “Identification of genes involved in medulloblastoma,” Martine F. Roussel, Ph.D., St. Jude Children’s Research Hospital

Epidemiology

- Central Brain Tumor Registry of the United States

Awards & Programs

- Society of Neuro-Oncology: Platinum Sponsor, SNO Foundation
- SNO Pediatric Brain Tumor Foundation Basic Research Award of Excellence: Robert Wechsler-Reya, Ph.D.
- Brain Tumor Epidemiology Consortium Meetings
- International Pediatric Neuro-Oncology Symposium, Nara, Japan
- International Symposium on Brain Tumor Research and Therapy, Napa, Calif.





“We cling to hope, and hope lies in research.”
 — **Marianne, mother of brain tumor patient Lauren**

PBTf Scientific Advisory Board

Chairman, Darell D. Bigner, M.D., Ph.D., Duke University Medical Center
 Francis Ali-Osman, D.Sc., Duke University Medical Center
 David Ashley, MBBS, Ph.D., Royal Children’s Hospital, Australia
 James M. Boyett, Ph.D., St. Jude Children’s Research Hospital
 Webster Cavanee, Ph.D., Ludwig Institute, University of California, San Diego
 Glenn Dranoff, M.D., Harvard Medical School, Dana-Farber Cancer Institute
 Henry Friedman, M.D., Duke University Medical Center
 G. Yancey Gillespie, Ph.D., University of Alabama at Birmingham
 Eric Holland, M.D., Ph.D., Memorial Sloan-Kettering Cancer Center
 Peter Houghton, M.D., St. Jude Children’s Research Hospital
 Mark Israel, M.D., Dartmouth Hitchcock Medical Center
 C. David James, Ph.D., University of California, San Francisco
 Larry E. Kun, M.D., St. Jude Children’s Research Hospital
 Bartlett D. Moore, Ph.D., University of Texas, M.D. Anderson Cancer Center
 Roger Packer, M.D., Children’s National Medical Center
 Peter Phillips, M.D., Children’s Hospital of Philadelphia
 Ian Pollack, M.D., Children’s Hospital of Pittsburgh
 Ralph A. Reisfeld, Ph.D., Scripps Research Institute
 James T. Rutka, M.D., Ph.D., The Hospital for Sick Children, Canada
 Bert Vogelstein, M.D., Johns Hopkins University
 W.K. Alfred Yung, M.D., M.D. Anderson Cancer Center

Family Support Programs

When a family receives the horrifying news that their child has a brain tumor, the Pediatric Brain Tumor Foundation offers help in a variety of ways. Our family support programs include educational resources, patient services, advocacy efforts, college scholarships, and Ride for Kids®.



2006 Highlights

- We introduced the Spanish editions of our informational brain tumor booklets in January.
- Our latest Informed Parent & Survivor Internet Conference, “Risk Factors and Pediatric Brain Tumors,” was hosted by Dr. Patricia A. Buffler.
- We funded 73 college scholarships for brain tumor survivors, supported by the Cycle World Joseph C. Parkhurst Education Fund Silent Auction.
- Our family support program manager is a social worker who is available to assist patient families by phone or email.
- 310 families attended Celebration of Life programs at Ride for Kids® events.
- We launched a newly designed website, www.curethekids.org, which gives families a greater number of resources and easier access to information. The site also includes new survivor outreach information.
- We sponsored the Association of Pediatric Oncology Social Workers Annual Meeting Education Day and Lutheran General Hospital’s “Pedes in the Weeds” Picnic.

Educational Resources

- *The Caring Hand* national newsletter provides researchers and caregivers with the latest information on grants, funding and advances in the field of pediatric brain tumor research. It also includes stories of hope about survivors.
- *The Helping Hand* national newsletter focuses on the Ride for Kids® program and includes stories about patients and their families.
- We offer English and Spanish versions of seven educational brochures that contain in-depth information about the many different types of pediatric brain tumors, their treatments and post-treatment issues.
- Broadcasts of 11 of our Informed Parent & Survivor Internet Conference audio programs are available at www.curethekids.org or on CDs.

www.curethekids.org

Advocacy

Children with brain tumors and their families need a voice to speak on their behalf. The Pediatric Brain Tumor Foundation is that voice, advocating for

- quality care for pediatric and adolescent brain tumor patients
- development of new pediatric oncology drugs
- long-term follow-up care for survivors

As a founding member of the Alliance for Childhood Cancer, the PBTF worked to address these issues in 2006 through discussions with the Food and Drug Administration and with suggested language for quality care/survivorship legislation.

Dianne Traynor, director of research funding and advocacy for the PBTF, continued to serve as a patient advocate to the National Cancer Institute's Specialized Programs of Research Excellence (SPOREs).

In this role, she works to ensure that patients' needs and viewpoints are represented when research efforts are translated into clinical trials. In 2006 she was also the brain tumor patient advocate representative on the Patient Advocates Research Team (PART) Council for the NCI's SPORE in cancer.



Family Support

Scholarship Program

Thanks to cutting-edge research and improved treatment techniques, some brain tumor survivors are reaching adulthood. However, living with a life-threatening disease can create a substantial financial burden on families. The PBTF helps by offering scholarships to students who wish to attend a technical or vocational school, junior college or four-year college or university.

In 2006, the 73 young people pictured on these pages achieved their dreams of higher education with the help of the PBTF Scholarship Program, which is funded in part by the Cycle World Joseph C. Parkhurst Education Fund Silent Auction.

**CYCLE
WORLD**
MAGAZINE



Afton



Albert



Alexander



Andrea



Amanda



Annelda



Andrew



Ashleigh



Aubrey



Bailey



Bethany



Brian



Brystal



Caitlin



Catherine



Cayce



Chase



Chelsea



Chris



Dana



Daniel D.



Daniel M.



Daniel R.



Darla



David



Devin



Eli



Elizabeth



Ezekiel



Gary



Geoffrey



Grant



Ian



Jamie



Jason



Jennifer



Jessica Q.



Jessica T.



John



Kaitlyn



Karina



Katherine M.



Katherine R.



Katie



Kerry



Kristen K. B.



Kristen C. B.



Lauren



Luke



Lyndsie



Mark



Mason



Melanie



Meredith



Michael D.



Michael M.



Michelle



Pamela



Nic



Rebecca



Rick



Robert B.



Robert L.



Ryan B. M.



Ryan T. M.



Spencer



Steven



Sueanna



Tayler



Tiffany A.



Tiffany S.



Yi



Zachary

Family Support

Ride for Kids® Program

Since 1984, when 100 motorcyclists in Atlanta, Ga., attended the first Ride for Kids®, the program has been a key element of the Pediatric Brain Tumor Foundation's family outreach efforts.

In 2006, 310 patient families joined more than 18,000 motorcyclists and volunteers at the 37 Ride for Kids® programs around the country.

At each of these PBTF Ride for Kids® events, motorcyclists join a wonderful program of support for kids affected by brain tumors. This unique "Celebration of Life" ceremony gives participants a chance to hear directly from kids, parents, doctors and researchers about how their efforts make a difference.

In 2006 Ride for Kids® motorcyclists raised more than \$4.4 million in donations to help cure the kids.





“Spend five minutes talking to any of these kids and you’ll understand why I raise money for research. No child should have to go through this. They deserve a chance for a full life.”
— Rick Montgomery, Chicagoland Task Force



Corporate Partnerships

The Pediatric Brain Tumor Foundation receives contributions from many companies that share our commitment to finding the cause and cure of childhood brain tumors.



Rider's Club of America™

The Ride for Kids® program is generously supported by the motorcycle division of American Honda Motor Co., Honda of America Manufacturing, Honda of Alabama, other Honda companies, and hundreds of Honda motorcycle dealers.

Since 1991, the Honda Rider's Club of America has been the program's presenting sponsor.

The enthusiastic commitment of HRCA and its members has been invaluable to our success.

Ride for Kids® is also fortunate to benefit from the generosity of a multitude of individuals, motorcycle dealerships, and industry supporters such as *Cycle World* magazine, the *Cycle World* International Motorcycle Shows, Advanstar Communications, Dailey & Associates, AGV Helmets, Dunlop Tire Co., Roland Sands Design, and Cobra Engineering.

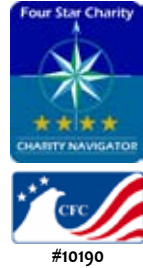
Project Brave Heart (below) was a collaborative effort between Honda, Roland Sands Design and a host of other motorcycle industry contributors. PBTF Scholar Michelle Higa and Sands unveiled the custom bike at the *Cycle World* International Motorcycle Show in Long Beach, Calif., in December 2006. The annual IMS drawing has raised more than \$300,000 for the Foundation since 2000.



Where Your Money Goes

We rely on the generosity of our donors, fundraisers and corporate partners to support our mission. It is our responsibility to be good stewards of the money entrusted to us, and we work diligently to uphold that trust.

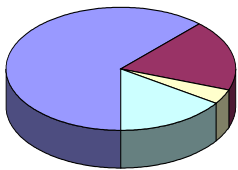
To that end, we are grateful to have earned a four-star rating from Charity Navigator, the nation’s premier charity evaluator. We’re also a proud participant in the Combined Federal Campaign.







2006 Financial Statement

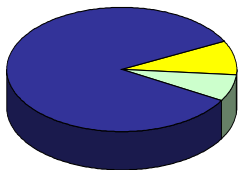
The Pediatric Brain Tumor Foundation’s independently audited Revenue and Expense Statement for the year ending Dec. 31, 2006, is reflected below. The programs of the PBTF are explained in the preceding pages of this report. Totals agree with the audited statement of activities for the year ending Dec. 31, 2006.




Source of Funds



	Direct Public Support	\$ 3,422,656	62.0%
	Corporate support	1,016,324	18.4%
	Honor, memorial donations	225,280	4.1%
	Non-cash and other	855,023	15.5%
	Total	\$ 5,519,283	

Use of Funds



	Program funds	\$ 4,453,551	84.2%
	Fundraising costs	467,014	8.8%
	Management, administration	370,697	7.0%
	Total	\$ 5,291,262	

Pediatric Brain Tumor Foundation
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Asheville, NC 28806
828-665-6891 • 800-253-6530 • 828-665-6894 (fax)
www.curethekids.org

