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ANNUAL
REPORT



Pediatric
Brain Tumor
Foundation®



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TUMOR FOUNDATION
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Dear Partners in Mission,

Thank you for all that you do to change the lives of children with brain tumors. Because of your generous support of the Pediatric Brain Tumor Foundation, the treatment landscape continues to improve.

Our research funding has led to a much better understanding of this complex disease and the discovery of new treatments. More families are connecting with resources and emotional support than ever before. And policymakers at both the state and federal levels are beginning to listen and respond with legislation to help address families’ needs.

But this change isn’t happening fast enough.

A report from the Central Brain Tumor Registry of the United States, funded by the Pediatric Brain Tumor Foundation and released in 2022, revealed the number of children facing the effects of a brain tumor diagnosis has grown by a staggering 45% in the past decade. Pediatric brain tumors are now the United States’ most commonly diagnosed childhood cancer.

Yet while the number of families in need of support continues to grow, funding for pediatric brain tumor research and resources to help patients, families, and survivors isn’t keeping up.

The Pediatric Brain Tumor Foundation has a plan to change this, and your generosity as donors, fundraisers, volunteers, and advocates is critical to this work. Throughout the pages of this annual report, you will find stories of how the Pediatric Brain Tumor Foundation’s efforts are leading the way to a world without childhood brain cancer, as well as how this community continues to step up in support of our shared mission.

While the stakes have never been higher or more urgent for kids with brain tumors and their families, I know that brighter futures are possible because this community, this movement, **you** refuse to let this disease steal kids’ futures. Together, we’ll end childhood brain cancer.

With gratitude,

Courtney Davies
President & Chief Executive Officer
Pediatric Brain Tumor Foundation

Impact At A Glance



67% INCREASE

year-over-year for new patient families reached

14 NEW PROJECTS

approved last year through PBTF’s research portfolio, totaling \$1.23 million in new funding

\$5.3M+ OF FUNDING

actively managed in PBTF’s research investment portfolio

Basic and Translational Science: \$2,845,029

Clinical Trials: \$1,788,000

Survivorship: \$364,122

Core Resources: \$331,225

**\$190k IN
VS. CANCER GRANTS**

awarded to hospitals’ child life and family support programs last year

**\$1,116
AVERAGE AMOUNT**

of financial relief received per family

Follow us on social media for more highlights!

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PBTF-Funded Report Underscores Urgent Need for Greater Investment in Pediatric Brain Tumor Research and Resources for Families and Survivors

Diagnoses, mortality rates, and number of survivors living with pediatric brain tumors’ long-term side effects continue to grow, while adult brain cancer patients experience declines in incidence and mortality rates.

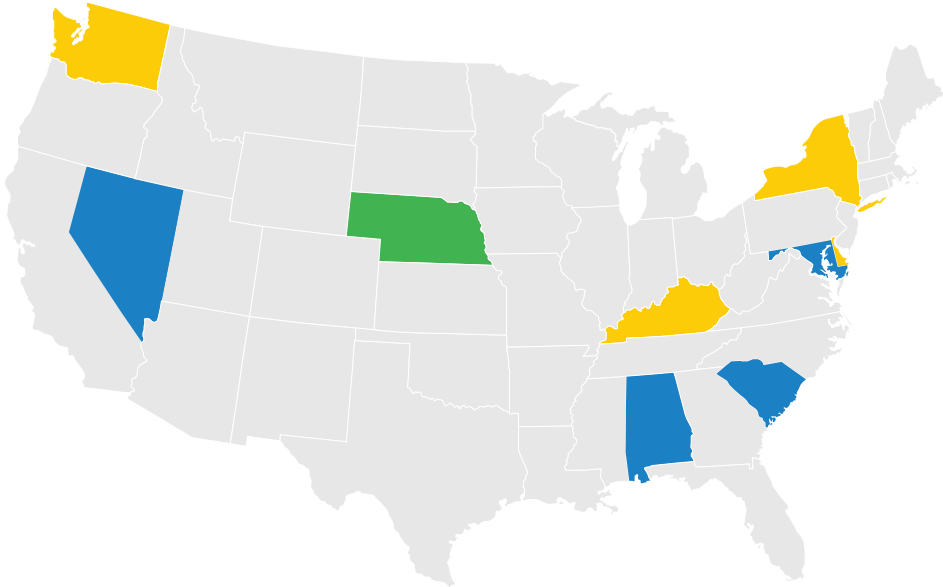
The reality is that this rare but devastating disease doesn’t receive the same level of attention, research or funding as adult cancers and other diseases. This won’t change until more policymakers, pharmaceutical companies, and people understand - and commit to addressing - the unique challenges families face.

In 2022, the Pediatric Brain Tumor Foundation funded a first-of-its-kind statistical report to increase understanding of the scope and severity of this childhood disease. The results of the Central Brain Tumor Registry of the United States’ report underscore the urgent need for a greater investment in the development of new treatments and resources for patient families. Because, while the problem is growing, research funding isn’t keeping up.

The PBTF-funded statistical report revealed that the estimated number of children and adolescents living with brain cancer’s after effects has increased by 45% since 2010. It is now the most commonly diagnosed childhood cancer and the deadliest childhood disease.

Pediatric brain cancer doesn’t discriminate but is a disproportionate threat to children of color, who experience lower survival rates than white children.

There are also significant disparities in incidence of diagnosis and mortality among states.



Top 5 States With Highest Incidence & Mortality of pediatric brain or CNS tumors per 100,000 people (2014-18)

Highest Incidence Rate:		Highest Mortality Rate:	
Kentucky	1	Alabama	
New York	2	Maryland	
Washington	3	Nebraska	
Delaware	4	South Carolina	
Nebraska	5	Nevada	



Your Support Fuels Our Response

Through our research funding, family support, and advocacy efforts, the Pediatric Brain Tumor Foundation leads the way toward ending childhood brain cancer. For the first time ever, we know the human impact of childhood brain cancer at the state level. In response to the report’s insights, we have:

- Expanded our federal advocacy efforts and focused greater attention on state-level health policy. Through our state cancer plan initiative, we organize and work with activists and policymakers to have the needs of childhood brain cancer patients addressed through states’ CDC-funded cancer resource plans.
- Redoubled our commitment to fund promising research that addresses gaps in doctors’ understanding of pediatric brain tumors and drug development. Every dollar PBTF invests in research attracts an average of 12 more dollars in follow-on funding.
- Continued to expand our reach to ensure every family has access to the care they need. Guided by families’ experiences, we offer information, financial relief and emotional support resources to complement care teams’ work with patients, survivors, parents, caregivers and siblings.

Children with brain cancer, their families, and doctors count on the Pediatric Brain Tumor Foundation to make sure progress doesn’t stop. Your continued support makes that possible.





49ers Legend Bryant Young and Family Champion the Pediatric Brain Tumor Foundation’s Mission During Pro Football Hall of Fame Enshrinement

San Francisco 49ers legend and Pediatric Brain Tumor Foundation Special Ambassador Bryant Young never missed an opportunity to put in the work. In his rookie year, the first-round draft pick helped the 49ers win Super Bowl XXIX and went on to become the team’s all-time sack leader, NFL Comeback Player of the Year, and four-time Pro Bowler and All-Pro pick before retiring in 2007.

In recognition of his leadership on and off the field, the NFL awarded Bryant their ultimate honor in 2022: enshrinement in the Pro Football Hall of Fame. But as Bryant received his gold jacket, bronzed bust, and place in football history, one person was missing from the celebrations: his son Colby, who passed away from brain cancer at 15.

Colby loved football and helping others. Shortly before he passed away, he organized a *Change for Change* fundraiser for PBTF, raising more than \$50k with the help of his school Charlotte Christian.

When Bryant was selected for enshrinement, he, his wife Kristin, and Colby's siblings saw it as an opportunity to raise awareness for children with brain tumors. Leading up to and throughout Enshrinement Week, the Youngs shared Colby's story and championed PBTF's mission in media interviews and PSAs. They also partnered with the Hall of Fame to give one pediatric brain tumor survivor a once-in-a-lifetime experience.



Left: Bryant Young with brain tumor survivor Zion at the Pro Football Hall of Fame’s 2022 Enshrinement Week game; Top Right: Bryant’s son Colby Young; Bottom Right: Bryant’s Pro Football Hall of Fame bronze bust.

As PBTF’s behind-the-scenes ambassador, 14-year-old Zion chronicled the week’s events and Bryant’s enshrinement over social media, even presenting the game ball to officials at the start of the NFL’s annual Hall of Fame game.

And when Bryant delivered his acceptance speech, televised to NFL fans around the world, his heartfelt words about Colby, what he’s learned along the way, and his support of PBTF inspired everyone who saw it.



"From my pain, I found purpose," he shared. "Letting someone grab my hand is as important as reaching for theirs. In an isolated world, personal connections matter more than ever. I keep my gaze on Christ and pour myself into good works, including the Pediatric Brain Tumor Foundation."

We are grateful for the Youngs’ commitment to our shared mission, and we will continue to honor Colby’s name by standing with families today, tomorrow, and every day to come.

PBTF Accelerates Scientific Discovery for Pediatric Brain Tumor Patients and Survivors

The largest patient advocacy funder of pediatric brain tumor research, the Pediatric Brain Tumor Foundation funds and advocates for scientific studies wholly dedicated to improving pediatric brain tumor patients' survival and quality of life.

In 2022, PBTF invested in 14 new cutting-edge research projects at a dozen medical institutions around the country. These studies targeted two of the rarest and deadliest forms of pediatric brain tumors, with the launch of a new infant pineoblastoma research fund and the expansion of our DIPG/DMG research investments, as well as continued investments in the study of the most common form of childhood brain tumors, pediatric low-grade glioma.

Across the different tumor types, PBTF’s funding led to diagnostic advances, the development of more translatable animal models, the discovery of new therapeutic targets, and the development of novel treatment approaches designed specifically for pediatric patients. Previous years’ seed funding also continued to deliver results, with numerous scientific manuscripts written and accepted for publication and the successful application by PBTF-funded researchers for multi-million-dollar NCI/NIH grants to continue their work.

To ensure our research funding has the maximum impact, PBTF works with the scientific experts on our Research Advisory Network and patient families to identify and address critical gaps in pediatric brain tumor research. By funding basic science exploration, fostering collaboration in the field, creating opportunities for early career investigators to establish productive labs, and supporting key infrastructure, networks and consortia, the Pediatric Brain Tumor Foundation is accelerating the pace of discovery around the world.

Visit curethekids.org/research to learn how your support of PBTF is changing the treatment landscape for children with brain tumors, survivors, and their families.





New Research Made Possible by Blake Vince Payne Star Fund Gives Hope to Families Facing Deadly Brain Cancer in Infants

Little is known about infant pineoblastoma, a fast-growing type of brain cancer deep inside the pineal gland. Because pediatric pineoblastoma is rare -- accounting for about 1 of every 100 brain tumors in children -- infants are often treated with chemotherapy drugs developed and approved decades ago for adults. Although these drugs made for adults can be some infants' best chance for survival, they can also do more harm than good.

For 9-month-old Blake Vince Payne (pictured right), this was the case. The young son of CNN correspondent René Marsh and her husband Kedric Payne went into cardiac arrest after his first round of chemotherapy, with his oncologist later determining one of his chemotherapy drugs caused the near-fatal reaction.

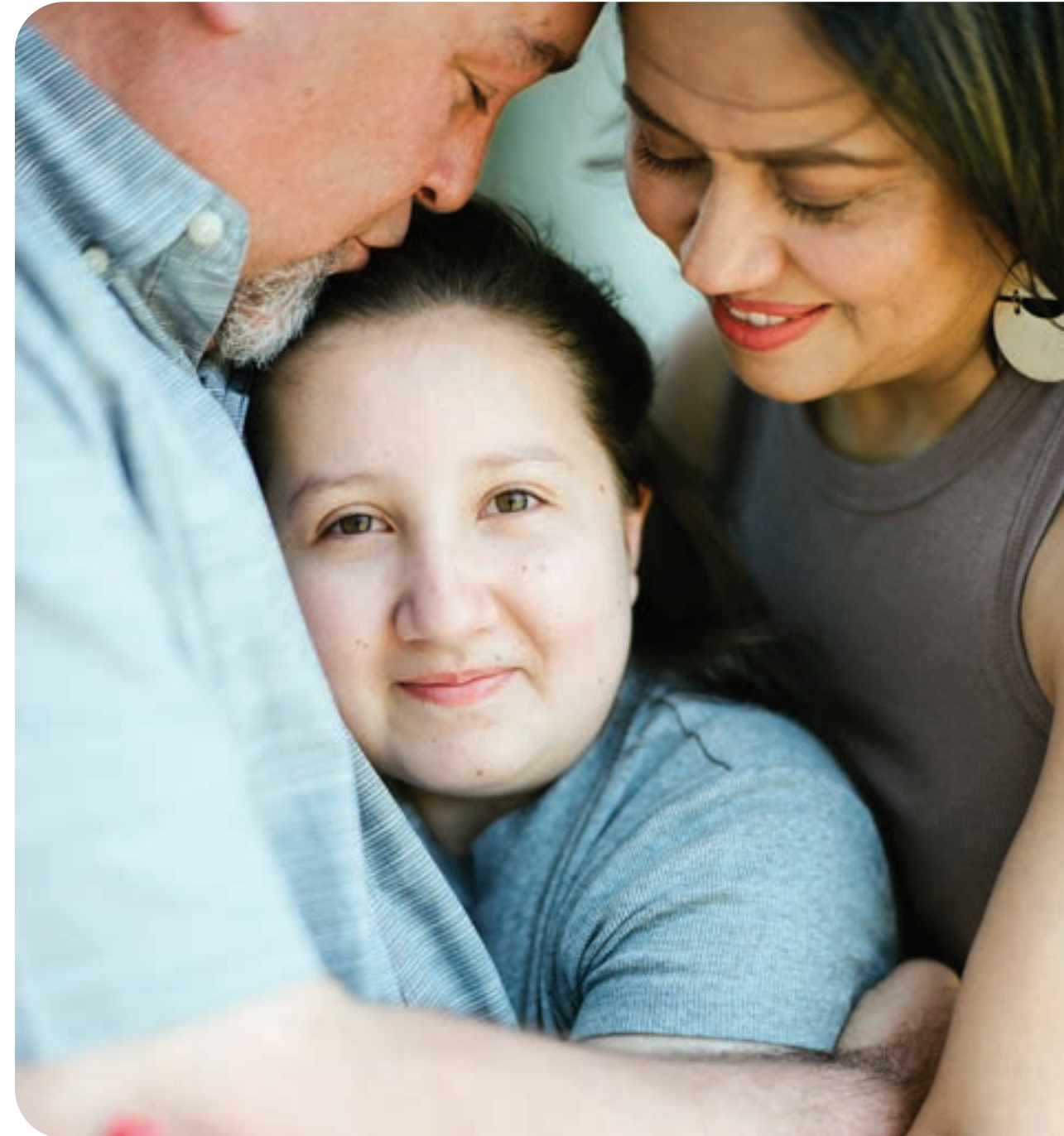
After Blake passed away one month after his second birthday, René and Kedric turned to the Pediatric Brain Tumor Foundation to see how they can help other children diagnosed with brain cancer and their families. PBTF partnered with them to establish the Blake Vince Payne Star Fund in his honor. Through donors' generosity and proceeds from René's children's book *The Miracle Workers: Boy vs. Beast*, the fund is the largest known fundraising effort dedicated to infant pineoblastoma research.

In 2022, the Blake Vince Payne Star Fund at PBTF funded two pioneering new research projects helmed by Dr. Paul Northcott at St. Jude Children's Research Hospital and Dr. Annie Huang at SickKids hospital in Toronto. Both projects received unanimous funding approval by PBTF's scientific advisors.

Dr. Huang's project, Targeting the *Achilles heels of Pineoblastoma* -- a rare orphan baby brain cancer, combines CRISPRi technology with a Zebra Fish brain tumor model to uncover key druggable pathways for RB1/MYC-

driven infant pineoblastoma. Dr. Northcott's project, *Rare But Unforgotten*, is developing preclinical models of high-risk pineoblastoma subgroups and using them to identify therapies designed for the specific biology of these brain tumors. Together, these two research projects serve as an important and timely foundation for launching an intensive attack on pineoblastoma, with the vision of translating findings into the clinic and improving outcomes for children and their families.

There's hope for life-changing therapies when brilliant minds like Drs. Northcott and Huang are able to turn their attention to the unique challenges of this disease because of the Pediatric Brain Tumor Foundation's seed funding. We're honored and humbled by René and Kedric's commitment to help other families going through the unthinkable. Through their partnership and supporters' continued generosity, we can ensure resources remain available for researchers -- attracting more new talent to the field and paving a clear path forward to change and save children's lives.



PBTF Mobilizes Community in Response to Rising Gas Prices, Provides Financial Relief to Patient Families During Moments of Need

100 miles. That's the average distance families drive for one trip to the hospital for their child's brain cancer treatments.

When gas prices skyrocketed in 2022, the Pediatric Brain Tumor Foundation mobilized to identify areas where increased costs most severely impacted patient families. We teamed up with PBTF fundraisers to provide gas cards to families at seven hospitals in those areas.

"More families are finding travel to treatment a real burden on their finances. If you could see the look of relief that comes over their faces when they are offered assistance, it would make you smile," shared Patrice, a social worker at one of the hospitals.

Each year, the Pediatric Brain Tumor Foundation's Butterfly Fund provides critical financial relief to families at partner hospitals across the country. In addition to last year's gas card initiative, we provided \$425,999 of financial relief in 2022, with an average of \$1116 per family to assist with housing needs, groceries, funerals, and other out-of-pocket expenses.

Patient Families Find a Community of Support through PBTF

When a child is diagnosed with brain cancer, parents, caregivers, patients and siblings need others they can turn to who understand what they’re going through. Unfortunately, because pediatric brain tumors are rare, finding a community of support can be a significant challenge for many families.

In response to this growing need, the Pediatric Brain Tumor Foundation expanded our emotional support programming in 2022 to provide family members with more opportunities than ever to connect with each other, including:

- **Virtual support groups** focused on bereaved families, families of children diagnosed within the past 5 years, and Spanish-speaking families. Facilitated by our family support team and mental health professionals, these online groups offer a safe environment where parents and caregivers can share difficult feelings, empower each other, and learn healthy ways to navigate their family’s cancer journey.
- An increase in survivor and bereaved parent mentors in our **Peer-to-Peer Mentor program**. This program connects individual family members with others who have gone through a similar experience and are trained to provide one-on-one support, relevant resources, and a space for mentees to discuss their journeys.
- Our new **Starry Night Community** for families. This Facebook group provides a place where anyone impacted by pediatric brain cancer is welcomed to share the ups and downs of their journeys, offer words of encouragement, and ask questions of each other.

These programs provide patient families across the country with the opportunity to give and receive comfort from others who know firsthand the unique challenges of life after diagnosis. Through these and other family support initiatives, we increased our year-over-year reach to new families by 67% in 2022, with nearly half of those families turning to our community within the first year of diagnosis.



Fiscal Year 2022 Financial Highlights



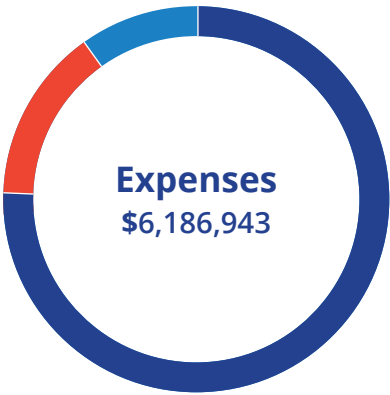
FY2022 Audited Financial Statements

Statements of Financial Position	2022	2021
ASSETS		
Cash and cash equivalents	\$1,407,813	\$2,257,178
Investments	3,491,679	3,462,091
Accounts receivable	963,326	519,490
Other assets	94,517	27,545
Property and equipment, net	35,725	11,427
Total assets	\$5,993,060	\$6,277,731
LIABILITIES AND NET ASSETS		
Liabilities:		
Accounts payable and accrued expenses	\$289,128	\$74,541
Grants payable	438,871	772,299
Total liabilities	727,999	846,840
Net assets:		
Net assets without donor restrictions:		
Board designated-quasi-endowment	1,473,767	1,041,946
Available for operations	951,802	1,036,101
Total net assets without donor restrictions	2,425,569	2,078,047
Net assets with donor restrictions	2,839,492	3,352,844
Total net assets	5,265,061	5,430,891
Total liabilities and net assets	\$5,993,060	\$6,277,731

Statements of Activities	9/30/22	9/30/21
Revenues, gains, and other support:		
Contributions	\$6,226,743	\$6,170,284
Less direct benefits to donors	(236,674)	(268,552)
Non-cash contributions	10,508	113,725
Investment income, net	20,537	1,147
Total revenues, gains, and other support	6,021,114	6,016,604
Expenses:		
Programs	4,680,458	3,966,114
Management and general	880,042	600,700
Fundraising	626,443	717,602
Total expenses	6,186,943	5,284,416
Changes in net assets	(165,830)	732,188
Net assets at beginning of year	5,430,891	4,698,703
Net assets at end of year	\$5,265,061	\$5,430,891

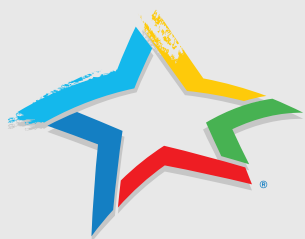


99.5%	Public Contributions	\$5,990,069
0.5%	Investment Income	\$31,045
Ending Net Assets		\$5,265,061



75.7%	Program Expenses	\$4,680,458
14.2%	Management & General	\$880,042
10.1%	Fundraising	\$626,443

Full audited financials and IRS Form 990s are available at curethekids.org/financials.



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

6065 Roswell Road NE, Suite 505
Atlanta, GA 30328 US
800.253.6530

curethekids.org

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