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ANNUAL
REPORT



Pediatric
Brain Tumor
Foundation®



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TUMOR FOUNDATION**
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Dear Partners in Mission,

The Pediatric Brain Tumor Foundation continues to make great strides. With your generous support, I am proud to report our mission to **Care. Cure. Thrive.** remains resolute, and our progress towards a solution marches closer to reality as our collective voice gets louder.

As we ebbed and flowed through the erratic constraints of lockdowns, mask mandates and in-person meeting restrictions, we continued to push the boundaries of hope and possibility by:

- **providing leadership and funding** to accelerate the discovery of targeted therapies for children battling brain tumors.
- **continuing to support programs** at partner hospitals and safeguarding several critical initiatives through our Vs. Cancer grants.
- **reaching more patient families and survivors** with support for the profound challenges of a brain tumor diagnosis.

Without your advocacy, encouragement and benevolent sponsorship, thousands of PBTF families would be left in the shadows during their darkest of hours. Together we will lessen the burden of diagnosis and improve survival rates and patient family outcomes by continuing to provide the education, financial relief and emotional support families need and funding research to unlock new treatments.

Our work is not done and our commitment has not waned. For the remainder of 2022 and for as long as it takes beyond this calendar year, we will continue our fight for the future every child deserves. Through the support of donors, fundraisers, volunteers, and committed advocates like you, we will continue to accelerate the discovery of targeted therapies for children battling brain tumors. We will stay the course and continue providing the support their families need to navigate their children's diagnoses. We will look to you for your generous continued support as we battle to ensure every child has the chance to reach for their dreams rather than fight for their lives.

They need us. We need you. There's strength in numbers, and together we can do this.

Courtney Davies
President & Chief Executive Officer



36% INCREASE

year-over-year for new patient families reached



8 CLINICAL TRIALS

making a difference in patient families' lives today



\$5.95M OF FUNDING

currently approved, active and driving scientific discovery in PBTF's research portfolio

Basic and Translational Science: \$3,214,266

Clinical Trials: \$1,954,167

Survivorship: \$364,142

Core Resources: \$375,225

Education/Scientific Conferences: \$42,000

12 NEW GRANTS

approved through PBTF's research portfolio, totaling \$1.12 million in new funding



\$1,258 AVERAGE AMOUNT

of financial relief received per family



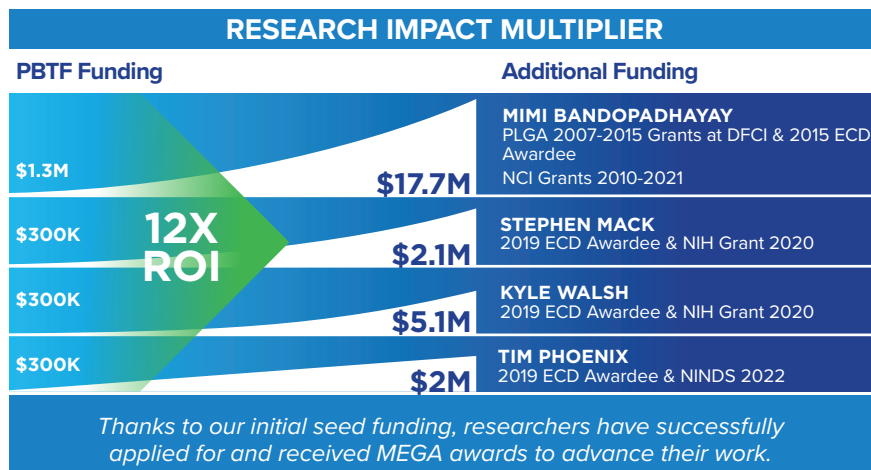
Follow us on social media for more highlights!

PBTF Research is Making an Impact

Over the past three decades, PBTF's seed funding has paved the way to a deeper understanding of the unique biology of childhood brain tumors, resulting in cutting-edge technologies that more quickly and accurately monitor disease progression, new therapies that target tumors' specific vulnerabilities, and multi-million-dollar grants that have multiplied our initial funding's impact and led to more clinical trials.

In 2021, despite the pandemic's lingering impact, PBTF's commitment to children with brain tumors and their families ensured progress towards a cure continued.

When you invest in PBTF's mission, you fund today's urgent needs while planting seeds that will blossom into large-scale returns, new scientific exploration, and expanded reach to families.



Achieving our vision of a world without childhood brain tumors demands strong financial stewardship, an aggressive strategy, and partners like you.

Your support helps us:

- Fund pioneering ideas and discover new research talent
- Proactively invest in forward-thinking pediatric research
- Identify and commit resources to tomorrow's scientific leaders



Accelerating the Pace of DNA Sequencing for Highest Risk Brain Tumors

Recent breakthroughs in genetically sequencing pediatric brain tumors have opened the door to more accurate, real-time diagnoses that are crucial to effective disease management. The problem: the current method of collecting tissue samples through surgical biopsy carries significant risk, and DNA sequencing of the tissue typically takes two to four weeks. Many patients can't wait this long, though. Highly aggressive brain tumors like DIPG and pediatric high grade gliomas mutate quickly and sequencing results are often outdated when treatment begins.

The Pediatric Brain Tumor Foundation partnered with Catching Up With Jack in 2021 to fund a new initiative at the University of Michigan's Koschmann Lab that has unlocked a way to provide doctors faster, more accurate test results for children battling these high-risk brain tumors. The project, "Rapid Molecular Testing of High-Risk Pediatric Brain Tumors," applies technology using liquid biopsies from cerebrospinal fluid and blood to analyze genetic mutations in DIPG tumors.

Preliminary results, recently published in Neuro-Oncology, show that the lab's method created a panel of the most common mutations two to three times the size of traditional panels for analyzing tumor biomarkers and assessed the mutation burden as it was developing, sooner than an MRI could detect growth. This means that doctors can catch a rapidly mutating tumor faster and bring a more 'real time' therapy into the mix, rather than waiting for the traditional MRI.

PBTF is thrilled to have supported these efforts to produce a significant, tangible advancement for children and teens with the most aggressive brain tumors, with the potential to help children and adults battling other forms of cancer.



Addressing the Shortage of Pediatric Brain Tumor Tissue for Childhood Cancer Investigators

Pediatric brain tumor tissue banking plays a critical but often overlooked role in groundbreaking childhood cancer discoveries. Researchers need to study tissue samples at diagnosis, recurrence, and after death from patients. Unfortunately, these researchers face a shortage of tumor tissue samples to study as they work to translate laboratory discoveries into targeted clinical therapies that lead to less toxic treatments and improve survival.

PBTF recognizes the importance of working with families and the medical community to build a meaningful tumor tissue and clinical data repository. In 2021, we continued to fund a two-year grant to support the Dana Farber/Boston Children's Cancer and Blood Disorders Center CRA position by providing support for the David Andrysiak Clinical Research Assistant Award to Keith Ligon, MD, PhD, Neuropathologist at Dana-Farber/Boston Children's. This \$132,000 grant is the sixth consecutive investment the PLGA Fund at PBTF has made to support this position since 2009.

Patient tissue samples ensure that Dr. Ligon and others across the research community have the material necessary to better understand why some tumors are vulnerable to specific treatments and resistant to others.

PBTF Family Support in 2021



Adjusting to Our Challenging Times

None of us imagined the ongoing obstacles Covid-19 would inflict upon healthy families, let alone those dealing with a diagnosis of pediatric brain tumors. We have learned that there is strength in numbers and that kindred support fosters strength and resiliency in a family's capacity to deal with anguish, even in the most challenging of times.

By continuing to improve the organization's approach to patient family support, growing our collaborations with hospital care partners and expanding virtual offerings to include new support groups and digital resources, PBTF increased its engagement with families by 14.5% year-over-year and increased its reach to new families by 36% year-over-year.

Branching Out to Brighter Days

Webinar Series Expansion Helps Families Find Answers

In 2021, our 10 webinars covering the full continuum of care helped more survivors and family members navigate post-treatment life year-over-year. Featured speakers included healthcare experts and family caregivers who provided first-hand perspectives on topics ranging from cognitive and social skill challenges to relationships with siblings and survivorship care plans.

Butterfly Fund Continues to Grow

PBTF delivered \$456,962 in financial relief (a 3% increase year-over-year), with an average of \$1,258 provided to each family to assist with housing needs, funerals, and travel for treatment. Our Butterfly Fund partner hospital network also expanded to include C.S. Mott Children's Hospital, increasing the total number of hospital partners to 19 institutions nationwide.

Our Community Grows through Empathy and Compassion

Our Peer Mentor program fosters relationships between caregivers of newly diagnosed patients and trained mentors who have experienced firsthand the challenges of a childhood brain tumor diagnosis. This shared experience has proven invaluable to patient families and has generated an overwhelming, pay-it-forward sense of community among PBTF families across the United States.



Translating the Language of Hope

In 2021, PBTF expanded its support of the Hispanic and Latinx patient family community with the introduction of the Starfolio Resource Guidebook in Spanish. We also broadened our monthly, Spanish-language support groups to reach a nationwide patient family audience.





Maintaining Our Visibility & Awareness

PBTF leadership shared family support insights with the broader healthcare and medical communities by presenting and exhibiting at the annual meetings for the Society for NeuroOncology, Association of Pediatric Oncology Social Workers, and Association of Pediatric Hematology Oncology Nurses.



PBTF's Vs. Cancer Grants Flourish

Through Vs. Cancer teams' incredible fundraising efforts in 2021, PBTF was able to support programs at 49 children's hospitals across the country. Despite the pandemic's continued impact on the ability to host games and fundraise in-person, **PBTF's Vs. Cancer grants reached 1,203 pediatric brain tumor families in teams' local communities and safeguarded several critical initiatives, including:**

UMass Memorial Health's Music Therapy program

increased its music therapist's schedule 20 hours on the inpatient floor and 4 hours in the pediatric outpatient hematology/oncology clinic, teaching evidence-based methods to relax and manage anxiety with meaningful, patient-selected activities.

MD Anderson's AYA

Scholarships initiative helps survivors and families thrive by easing the lasting financial burden of treatment and follow-up care. Scholarships empowered survivors to pursue their education and career goals at vocational schools, community college, four-year universities, and in post-graduate programs.

Phoenix Children's Hospital Hardship Fund,

in conjunction with PBTF's Vs. Cancer funding, offers relief to low-to-moderate income families living at or below poverty level. PBTF's 2021 Vs. Cancer grant will help approximately 84 families cover incidental costs associated with hospital stays, including meal assistance, gas, lodging and transportation, enabling them to prioritize their children's treatment.

Duke's Pediatric Neuropsychology Patient Evaluation Efforts,

funded by PBTF's Vs. Cancer grant, will benefit approximately 30 pediatric brain tumor patients. Neuropsychologists work with members of the social work team to outline necessary support at school and to guide advocacy for accessing those supports.

The PBTF Community Keeps Growing

The word keeps spreading and our friends, partners, and supporters keep shining the light on our shared mission and laser-focused initiatives to **Care. Cure. Thrive.**

In 2021, despite the ongoing challenges posed by an international pandemic, our community strengthened our collective resolve and raised our voices to advocate on behalf of families who too often go unseen. A heartfelt thank you to those who joined us in our pursuit of a world without childhood brain tumors. We are steadfastly committed to keeping the momentum going!

“*This book will help parents teach children the abstract concept of hope so they will be better equipped for the challenges life guarantees.”*

René Marsh
CNN Correspondent

Turning Pain into Purpose

When CNN correspondent René Marsh's son Blake died of brain cancer in April 2021, she committed herself to changing the cruel reality of the deadliest disease facing this country's children. She and her husband joined forces with the Pediatric Brain Tumor Foundation to raise funds for a pioneering new research initiative to develop treatments for pineoblastoma, Blake's disease.

Over the course of her son's journey, René penned a children's book, *The Miracle Workers: Boy vs. Beast*. The tale teaches children and reminds parents of a moral missing from many children's books: the first step to overcoming any challenge in life is believing you can. It's a story that reveals the power of hope and faith. Proceeds from sales of the book at ReneMarsh.com fund pediatric brain cancer research through PBTF.

A committed childhood cancer advocate, Marsh also addressed members of Congress in 2021 about the personal impact of cancer on young patients and their families, raised awareness on Dr. Sanjay Gupta's "Chasing Life" podcast about the disparities in adult and pediatric research, and helped other families find their voice during PBTF's Engaging in Advocacy webinar.

René continues to harvest hope that miracles can and will happen for other children when more research funding results in better treatments, and she views each child who reads her book as a miracle worker, carrying on Blake's legacy by helping support that cause. Thank you, René, for drawing further attention to the need for greater funding and better treatments to defeat this terrible disease.





Inaugural National Ride for Kids Day Raises \$1.3 Million

Since 1984, when PBTF founders and AMA Motorcycle Hall of Fame inductees Mike and Dianne Traynor hosted the first Ride for Kids in support of a colleague's child, PBTF has inspired the powersports community to raise tens of millions of dollars for children with brain tumors.

In 2021, PBTF's Ride for Kids celebrated a milestone year with national presenting sponsor American Honda and welcomed new partners and riders.

PBTF launched the inaugural National Ride for Kids Day in September. Twenty-four communities across the nation hit the road during Childhood Cancer Awareness Month, raising over \$1.3 million.

American Honda celebrated 30 years of partnership in the fight against pediatric brain tumors, generously donating three Repsol-edition CBR1000RR sport bikes from their private collection to be auctioned through Iconic Motorbikes in support of the PBTF and five new Honda motorcycles to help increase participation and fundraising.

Ride for Kids welcomed the Comoto Family of Brands as a new industry partner. Comoto's RIDE. DONATE. SHOP. promotion, through their RevZilla, Cycle Gear, J&P Cycles, and REVER brands, generated critical funds in support of PBTF's mission, recruited new riders and motorcycle industry partners, and included the company's largest "shop to support" campaign on National Ride for Kids Day.

"The work that is being done by PBTF is both personally and professionally close to my heart. By joining forces with industry giants like Honda, we hope to help inspire the entire powersports community to make Ride for Kids one of the industry's most prolific philanthropic events for years to come. We're grateful to be able to do our part, and hopefully, motivate our communities to make a difference in the lives of these children and their families."

Ken Murphy

President and CEO, Comoto Holdings

Through our new "Ride Anywhere" model, anyone can now participate in Ride for Kids by attending one of our in-person events on National Ride for Kids Day or by turning any ride into a fundraiser. Whether it's a day trip to your favorite state park, a group ride with friends, or a cross-country journey, every mile gets us closer to a cure.



Ed Apelian Cross Country Trip – From the beaches of North Carolina to the Oregon coast, Ed Apelian completed his epic ride and raised over \$10,000 for PBTF.



Broken Enduro Group Ride – In 2021, this southern California-based dual sport club used PBTF's online fundraising platform to generate \$13,200 for our mission.

#GoHead2Head Challenge Nets \$166,000 for Childhood Cancer Awareness Month

From a feature article on CNN.com to PBTF's national campaign appearing on the Thomson Reuters digital sign in Times Square, our #GoHead2Head to Cancel Childhood Cancer initiative generated significant year-over-year awareness. More than 100 partners joined us in September to raise over \$166,000 for research and family support programs, including a generous matching grant from the Sontag Foundation.

“To stop this problem in its tracks and find a solution – a cure – for the children and teens battling this disease, support must grow. We are grateful for the dedication and enthusiasm of our awareness month partners, and we encourage others to join our community in calling attention to the profound challenges and lack of resources patient families face.”

Courtney Davies
President & CEO, PBTF



Advocacy in Action

PBTF worked with patient families, survivors and other members of the cancer community in 2021 to advocate for better treatments and more funding for research.

Action Days

In partnership with the Alliance for Childhood Cancer, Action Days resulted in over 300 pediatric cancer advocates from 39 states who met with over 200 congressional leaders to amplify the voices of the childhood cancer community.

Head to the Hill

In partnership with the National Brain Tumor Society, Head to the Hill resulted in 410 brain tumor advocates from 46 states taking part in 286 congressional meetings to do the same.

Curefest

The nation's largest family-led, family-attended advocacy event drew attendees from 50 states and 68 countries to Washington, DC, was live-streamed to over 36,000 viewers across the globe, and was supported by a PBTF grant for the inaugural Tough2Gether Against DIPG/DMG Breakfast.

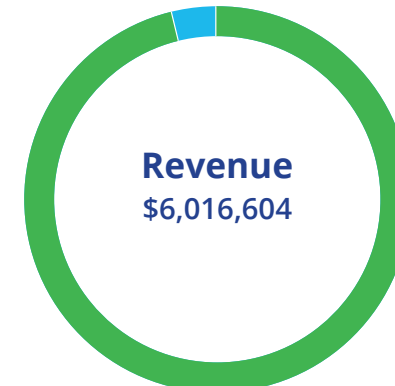
Fiscal Year 2021 Financial Highlights



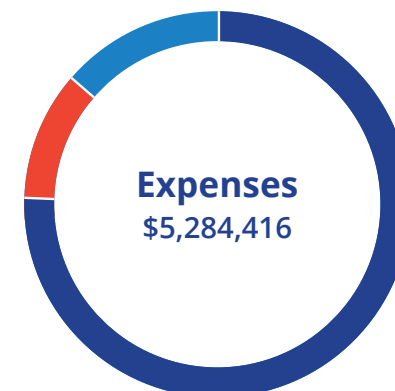
FY2021 Audited Financial Statements

| Statements of Financial Position | 9/30/21 | 9/30/20 |
|---|--------------------|--------------------|
| ASSETS | | |
| Cash and cash equivalents | \$2,257,178 | \$1,547,950 |
| Investments | 3,462,091 | 3,422,927 |
| Accounts receivable | 519,490 | 202,399 |
| Other assets | 27,545 | 33,859 |
| Property and equipment, net | 11,427 | 41,066 |
| Total assets | <u>\$6,277,731</u> | <u>\$5,248,201</u> |
| LIABILITIES AND NET ASSETS | | |
| Liabilities: | | |
| Accounts payable and accrued expenses | \$74,541 | \$238,563 |
| Grants payable | 772,299 | 310,935 |
| Total liabilities | <u>846,840</u> | <u>549,498</u> |
| Net assets: | | |
| Net assets without donor restrictions: | | |
| Board designated-quasi-endowment | 1,041,946 | 816,243 |
| Available for operations | 1,036,100 | 576,489 |
| Total net assets without donor restrictions | <u>2,078,046</u> | <u>1,392,732</u> |
| Net assets with donor restrictions | <u>3,352,844</u> | <u>3,305,971</u> |
| Total net assets | <u>5,430,891</u> | <u>4,698,703</u> |
| Total liabilities and net assets | <u>\$6,277,731</u> | <u>\$5,248,201</u> |

| Statements of Activities | 9/30/21 | 9/30/20 |
|--|--------------------|--------------------|
| Revenues, gains, and other support: | | |
| Contributions | \$6,170,284 | \$3,923,022 |
| Less direct benefits to donors | (268,552) | (230,775) |
| Non-cash contributions | 113,725 | 144,382 |
| Investment income, net | 1,147 | 14,529 |
| Total revenues, gains, and other support | <u>6,016,604</u> | <u>3,851,158</u> |
| Expenses: | | |
| Programs | 3,966,114 | 3,594,113 |
| Management and general | 600,700 | 501,057 |
| Fundraising | 717,602 | 532,465 |
| Total expenses | <u>5,284,416</u> | <u>4,627,635</u> |
| Changes in net assets | <u>732,188</u> | <u>(776,477)</u> |
| Net assets at beginning of year | <u>4,698,703</u> | <u>5,475,180</u> |
| Net assets at end of year | <u>\$5,430,891</u> | <u>\$4,698,703</u> |

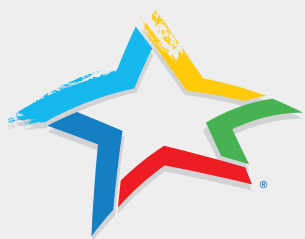


| | | |
|--------------|--------------------------|--------------------|
| 98.1% | Public Contributions | \$5,901,732 |
| 1.9% | Investment Income | \$114,872 |
| | Ending Net Assets | \$5,430,891 |



| | | |
|--------------|----------------------|-------------|
| 75.1% | Program Expenses | \$3,966,114 |
| 11.4% | Management & General | \$600,700 |
| 13.6% | Fundraising | \$717,602 |

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



**Pediatric
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Foundation®**

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

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