



## 2023 ANNUAL REPORT



**Pediatric Brain Tumor**  
FOUNDATION

# Impact At A Glance

**\$1171  
AVERAGE  
AMOUNT**

of financial relief  
received per family



*"I cannot begin to express my appreciation for the assistance I have received from the Pediatric Brain Tumor Foundation. Your help has helped lift a burden during this time of life-altering events and allowed me solely to provide care for my daughter without the stress of having to make ends meet.*

*Thank you." - Patient Mom*



**135%  
INCREASE**

year-over-year in the  
number of support  
group members

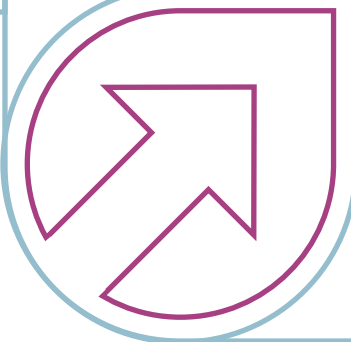
**98%  
INCREASE**

year-over-year in  
families accessing  
Spanish-language  
support



**21%  
INCREASE**

year-over-year for  
new patient families  
reached



**\$148K+ IN VS.  
CANCER GRANTS**

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



**MORE THAN \$7.4  
MILLION** of active funding in  
our research investment portfolio

**13 NEW  
RESEARCH  
PROJECTS**

totaling \$1.5 million  
in funding, across  
10 institutions



Dear Partners in Mission,

Thank you for answering the call to help children with brain tumors. Your commitment to the Pediatric Brain Tumor Foundation's mission leads us toward brighter futures, offering families the knowledge, hope, solace, and support they need.

Throughout the pages of this annual report, you'll read stories about how your support in 2023 accelerated the discovery of safer ways to diagnose and treat pediatric brain tumors, fostered a strong and welcoming community for families, and drove crucial policy changes to improve patients' and survivors' lives.

You have made progress possible. Yet, pediatric brain tumor diagnoses continue to increase. The survivor population is rapidly growing. The resources needed to address our communities' needs aren't sufficient. Our work together is far from done.

The Pediatric Brain Tumor Foundation remains committed to improving the survival and quality of life of all children affected by pediatric brain tumors. In the first half of 2024, our efforts continue to build momentum beyond the work detailed in this report. We hosted a patient-focused drug development meeting that brought the voices of patient families directly to the FDA and pharmaceutical industry, expanded and increased research funding to address a broader scope of pediatric brain tumor types and projects, and launched new resources to support survivors' unique needs as they navigate young adulthood and beyond. We celebrated FDA approval of Day One Biopharmaceutical's OJEMDA (tovorafenib) and the efforts of pioneering families from the PLGA Fund who provided critical funding of research that identified tovorafenib's promise as a treatment for pLGG. And our continued focus on board development resulted in the addition of neurosurgeon and CNN chief medical correspondent Dr. Sanjay Gupta to our board.

I am deeply grateful and continually inspired by this incredible community. Every donor who generously supports our mission, every fundraiser and volunteer who gives their valued time, every family who reaches out to help others facing the same challenges they once endured – you are the driving force powering progress for children, survivors, and families everywhere.

So much work remains to rid the world of pediatric brain tumors, and it's your determination and compassion that will make it happen.

With heartfelt gratitude,

Courtney Davies  
President & Chief Executive Officer  
Pediatric Brain Tumor Foundation



## PEDIATRIC BRAIN TUMOR FOUNDATION BOARD OF DIRECTORS FOR FISCAL YEAR 2023

### Officers

Andrew "AJ" Janower, Chair  
Kristin Young, Vice Chair  
Jeff Gelfand, Treasurer  
Anne Sutton, Secretary  
Courtney Davies, President

### Members

Chuck Boderman  
Jeff Gelfand  
Peter Krause  
Larry Little  
Karl Mueller  
Ken Murphy  
John Ragnoni  
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# Donor-Supported Research Funding Accelerates Treatment and Diagnostic Advances for All Children with Brain Tumors

The Pediatric Brain Tumor Foundation funds scientific research, provides educational, emotional and financial resources, and advocates for policies that improve outcomes and quality of life for pediatric brain tumor patients and survivors, and their families.

Donors' generosity makes this commitment to change the status quo for children, survivors, and caregivers possible.

In 2023, PBTF invested in 13 new research projects at 10 medical institutions in the US, 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.

Previous years' seed funding also continued to deliver results, with investments in diagnostic advances, more translatable animal models, and the development of novel treatment approaches leading to researchers continuing to win multi-million-dollar grants from the National Cancer Institute/ National Institutes of Health and other government and industry funders – ensuring every donor dollar achieves its fullest potential to improve kids' lives.



**Learn More About How Your Support of PBT Accelerates the Pace of Discovery Around the World**

## FDA Approves First Combination Targeted Therapy for Most Common Pediatric Brain Cancer

PBTF's funding of MEK pathway-related studies from basic science through clinical trials has contributed to the discoveries of new targeted therapies for children with brain tumors, such as Novartis' Tafinlar + Mekinist, a targeted therapy approved by the FDA in 2023 for children with low-grade gliomas with a BRAF V600E mutation. Low-grade gliomas are the most common pediatric brain tumor, and children with the BRAF V600 mutation typically experience poor survival outcomes and a less favorable response to chemotherapy. As a first line treatment, children with this tumor type and mutation will now be given the opportunity to take Tafinlar + Mekinist without having to first go through other treatments like chemotherapy with its toxic side effects.



[Read the Full Story](#)

## Quality of Life Study to Define New "Gold Standard" Treatment for Early Childhood Medulloblastoma

As survival rates for medulloblastoma and other types of pediatric brain tumors rise, it's critical that researchers, patient advocacy organizations, and families understand how different treatments will affect survivors' cognitive, physical, social, and emotional well-being over time. Studying a treatment's long-term impact can help determine its true effectiveness and ultimately lead to improved

quality of life for survivors and their families. In 2023, PBTF and the Christopher Brandle Joy of Life Foundation teamed up to fund a prospective international SIOPE/CONNECT phase-III study that will compare the outcomes for two highly effective medulloblastoma treatment regimens, defining the new "gold standard" of treatment for young children with this malignant and fast-growing form of brain cancer.



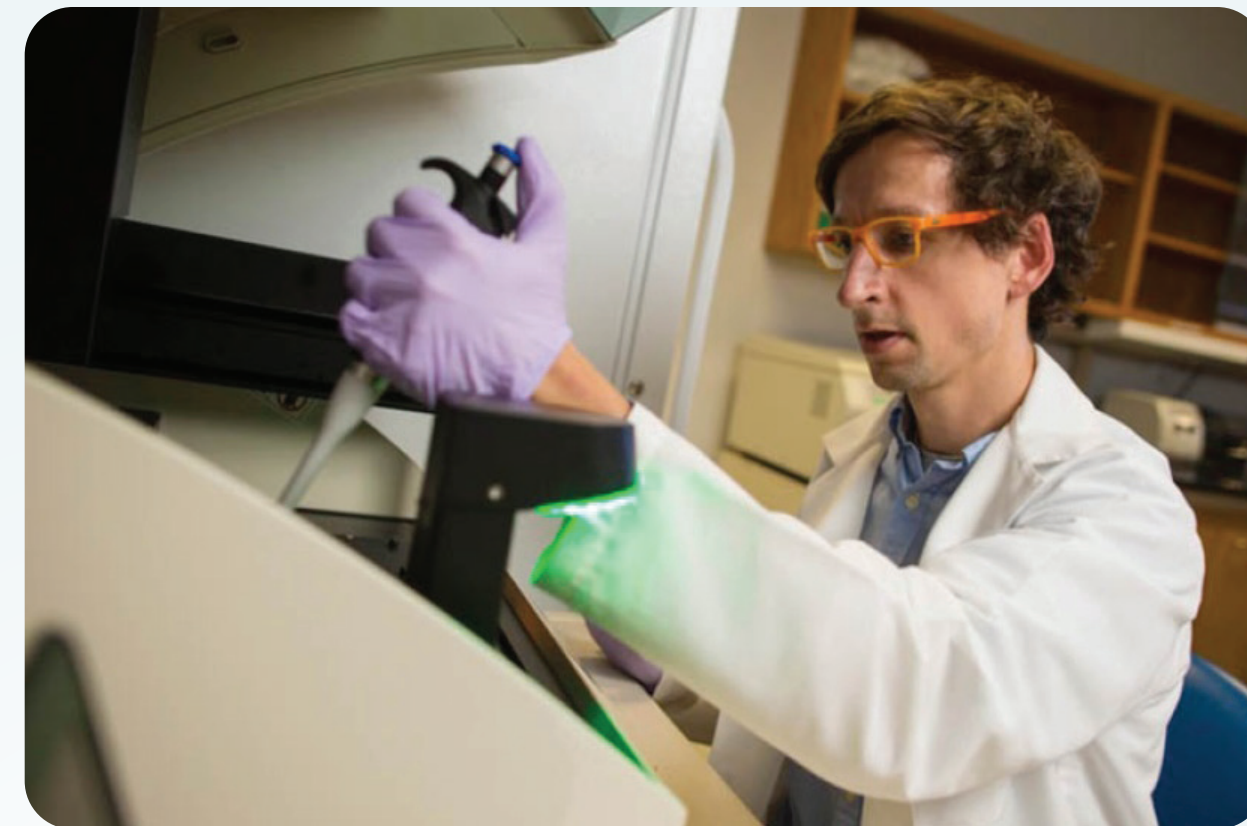
[Read the Full Story](#)

## PBTF Funds Technology to Help Researchers Bring Liquid Biopsies from Lab to Clinic Faster

Delays in diagnosis lead to delays in treatment – time that kids with brain cancer don't have. In 2023, PBTF partnered with Catching Up With Jack to bring the QIAcube, an advanced centrifuge technology, to the University of Michigan's Koschmann Lab, accelerating their development of liquid biopsy tests. These tests offer a potentially game-changing approach to diagnosing and monitoring pediatric brain tumors that would screen patients' cerebrospinal fluid, blood, or plasma for the presence of circulating tumor DNA. Building on PBTF's previous funding of this faster and more accurate way to detect pediatric brain tumors, the technology funded through our most recent investment will help get this promising screening method out of the lab and into clinics faster.



[Read the Full Story](#)



*"The support from the Pediatric Brain Tumor Foundation and Catching Up With Jack has been essential for us to develop liquid biopsy tests. As we get close to the finish line with some of these tests, we realized we needed a device to standardize isolation of cell free tumor DNA from specimens. The QIAcube will certainly expedite our process of bringing these tests to the clinic." - Dr. Carl Koschmann, University of Michigan*

## Community of Support Expands to Reach More Families Along Their Journey

Because pediatric brain tumors are a rare disease, it can be difficult for patients, survivors, and their families to meet other people who share the same experiences. Through resources like our online support groups and peer-to-peer mentoring, the Pediatric Brain Tumor Foundation connects family members with a welcoming and understanding community where they can learn and find support from other families like them.

In 2023, we saw this community grow, with more families reaching out to help others facing the same challenges they once endured.

- Feedback from patient families and healthcare partners identified a significant need among native Spanish-speaking parents and caregivers for easier-to-understand information in Spanish. In response, PBTF expanded Spanish-language resources and outreach efforts in 2023, resulting in a 98% year-over-year increase in families accessing Spanish-language support.

- Participation in online support groups expanded, with support groups for newly diagnosed, bereaved, and Spanish-speaking families now meeting monthly. With the 2023 launch of our Sibling Space Art Support Group, siblings of children with brain tumors also have a haven to connect with one another and express their feelings through art.
- 2023 saw a significant increase in the number of parents and caregivers volunteering to offer one-on-one support to other families. Because of this, more families can now access peer-to-peer mentoring, including bereaved parents, with the number of bereaved mentors doubling year-over-year in 2023.



*“It’s nice to have this family of people who have gone through it, know your struggles, and can connect you with resources. People that I can reach out to and say ‘Hey, I need some help here.’*

**– Patient Mom about PBTF’s Community Support Programs**

## New curethekids.org Offers Robust Family Resource Centers in English and Spanish, Guided by Needs of Patients, Survivors and Families

Parents and caregivers of children with brain tumors are essential members of their child’s care team and deserve to feel confident in their ability to advocate for their children. But because practical resources are limited and can be hard to find, families often spend time they don’t have finding information they need.

That’s why the Pediatric Brain Tumor Foundation’s new website, launched in 2023, is one place where any family impacted by a child’s or teen’s brain tumor diagnosis can find reliable information for every phase of their cancer journey.

The new curethekids.org, which also introduced a new look for PBTF, offers robust resource centers in English and Spanish guided by families’ feedback on the topics that matter most to them.



**Newly Diagnosed** resource center offers information to help parents and caregivers anticipate what’s needed in the first few months after their child’s diagnosis.



**Life After a Brain Tumor Diagnosis** provides resources to help survivors, family members and caregivers navigate long-term effects, concerns about recurrence and progression, and ongoing care in the months and years following treatment.



**Support for Families** focuses on connecting parents and caregivers with information and programs that address the medical, psycho-social, financial, and practical challenges families face.

PBTF’s new website and visual identity come at a time when diagnoses, mortality rates, and the number of survivors living with pediatric brain tumors’ long-term side effects are on the rise.

It’s more important than ever for families to have the information they need to make critical decisions for the health of their child, and for supporters to help them along that path. Our new online presence provides families, donors, volunteers, and all other stakeholders invested in patients’ and survivors’ well-being a place where they can find answers, inspiration, and community – and support PBTF’s efforts to cure the kids.



## Growing Advocacy Community Drives Policy Change

In 2023, a growing number of survivors, families, and advocates spoke up about the need to make kids with brain tumors a priority – and policymakers at both the federal and state levels were listening.

When a Pediatric Brain Tumor Foundation-funded report by the Central Brain Tumor Registry of the United States revealed significant disparities in mortality and incidence rates across the country, PBTF launched an initiative to get language and funding specific to childhood cancer and pediatric brain tumors incorporated in every state cancer plan.

Funded by the CDC, state cancer plans act as blueprints for addressing the burden of cancer in local communities. While all plans focus on adult cancers, few address children with cancer and their families. PBTF's State Cancer Plan Initiative organizes working groups, comprised of patient families, survivors, patient advocacy organizations, and healthcare professionals, who advocate about pediatric patients' unique needs.

Throughout 2023, advocates in several states worked with policymakers to improve families' access to quality cancer care, setting the stage for important legislation in 2024.

### PBTF's Advocacy Community in Action

The **Accelerating Kids' Access to Care Act** gained significant momentum in Congress when Charlie, a 12-year-old brain tumor survivor and PBTF advocate, testified to the U.S. Senate Finance Committee about the hurdles families face when seeking treatment for their child. This bipartisan bill aims to eliminate potential delays in treatment for critically ill children who are on Medicaid and need to cross state lines for treatment.

The **Data for Pediatric Brain Cancer Act**, which was introduced in late 2023 by U.S. Representatives Ami Bera, M.D. and Mike Kelly, aims to establish a first-of-its-kind Pediatric Brain Tumor Real-World Data Registry Program and strengthen crucial data collection efforts to support pediatric brain cancer research. An early endorser of the act, PBTF has continued to take a leadership role in recruiting and engaging patient families and advocates in support of this landmark legislation for the pediatric brain tumor community.

The **Pediatric Cancer Neuropsychological Needs Assessment Act**, introduced in the New York State Legislature in Spring 2024, is the result of more than a year of hard work by members of PBTF's New York State Cancer Plan Working Group. This bill will require insurers cover the neuropsychological assessments pediatric cancer patients and survivors need to qualify for specialized learning resources.



Learn More About PBTF's Advocacy Community

## 12-Year-Old Survivor Testifies Before Congress, Inspires Support for Kids with Brain Tumors

When 12-year-old brain tumor survivor Charlie was given the opportunity for a dream trip, there was one thing he wished for more than anything else: to testify to Congress about a bill that would make it easier for kids like him to get the specialized care they need.

Charlie's wish came true in September 2023 when he testified before the Senate Finance Committee and urged Senators to co-sponsor the Accelerating Kids' Access to Care Act.

Because pediatric brain tumors are rare diseases that are difficult to treat, children like Charlie often must cross state lines for treatment. However, current Medicaid rules require families to go through a convoluted, time-consuming process to have out-of-state care approved.

That's time kids with brain tumors don't have. Delaying treatment even a month can have

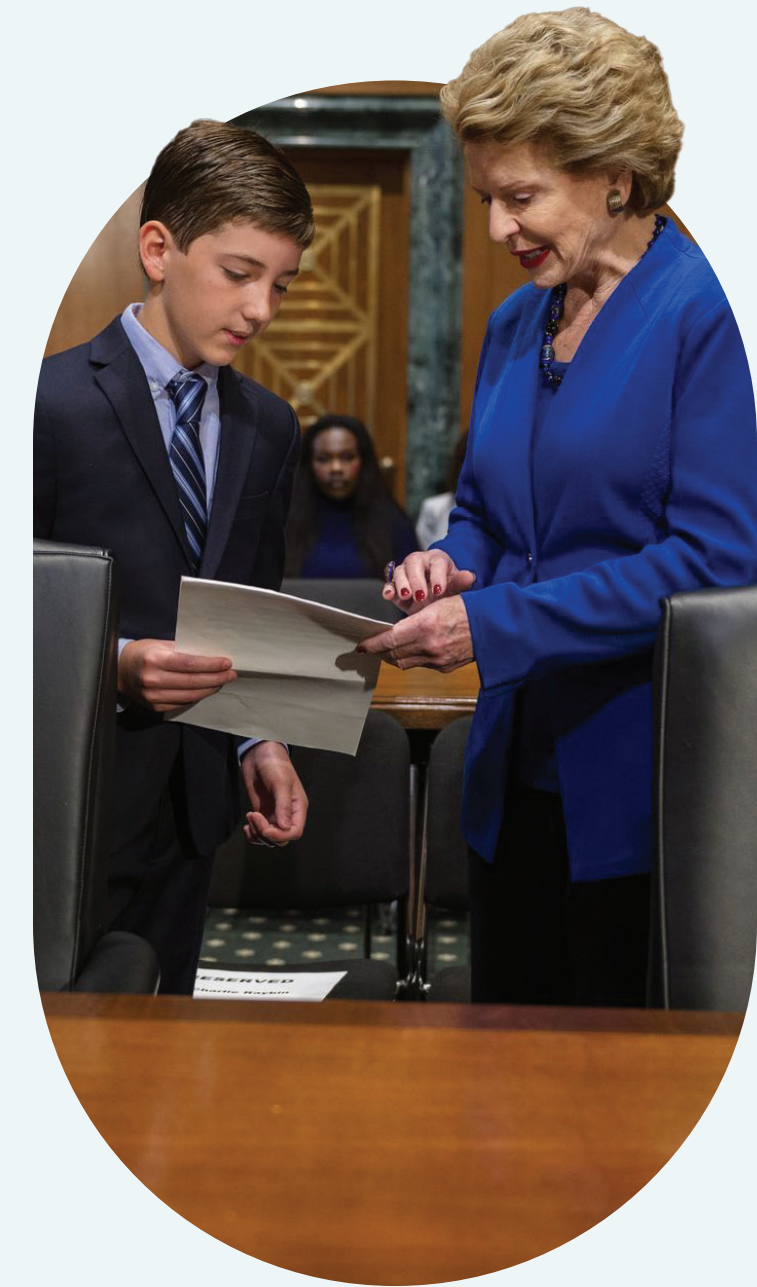
serious repercussions. So, when Charlie learned the Accelerating Kids' Access to Care Act could eliminate these delays, he felt compelled to speak out about it.

His family contacted PBTF, and our Director of Advocacy Mike Henry worked with Michigan Senator Debbie Stabenow and Iowa Senator Chuck Grassley, who originally introduced the bill, to make it happen. Charlie's testimony and meetings with Senators and members of the House of Representatives resulted in many new co-sponsors, a significant step toward getting it passed into law.



Read Charlie's Senate Testimony

*"About a year after I ended chemo, I joined an advocacy call my mom was doing and learned about the Accelerating Kids' Access to Care Act. I decided I wanted to follow this bill and see it passed. I felt like this was something I needed to do, especially because there aren't many brain tumor survivors who have recovered as much as I have."*



# PBTF's Constellation Award for Childhood Cancer Recognizes Outstanding Hospital Care Team Members

Every day in hospitals and clinics across the country, healthcare professionals work tirelessly to help families face the scariest and most stressful moments of their child's brain tumor journey – offering care, comfort, compassion, and support in ways both big and small.

In 2023, the Pediatric Brain Tumor Foundation launched the Constellation Award for Childhood Cancer to provide families an opportunity to express their gratitude for hospital care team members' exemplary dedication and kindness and shine a spotlight on the extraordinary individuals going above and beyond each day.

*“The Constellation Award for Childhood Cancer is a tribute to the incredible healthcare professionals who become like family to parents, caregivers, patients, and siblings navigating the challenges of pediatric brain tumors. These honorees represent the true constellations in the universe of care, providing a beacon of hope and support.”*

- Courtney Davies, President and CEO, Pediatric Brain Tumor Foundation

## Meet the Inaugural Constellation Award for Childhood Cancer Honorees



**Rebekah Doshi, CCLS II,** Cincinnati Children's Hospital Medical Center

“More than anyone, Bekah has been present during our journey. She was a constant during a massive time of chaos for our family, always bringing crafts, iPads for distraction, holding hands during anaphylaxis, and crying with us in our times of fear or celebration. Bekah was so much more than a Child Life Specialist. She became family.” – **Patient mom**



**Kara Kachurak, NP,** Children's of Alabama

“Kara is an unsung hero in the neuro-oncology department. She was a quiet warrior for our daughter Kelsie throughout her battle with glioblastoma. She was relentless in her fight for helping Kelsie survive. Kara was our anchor in the storm of cancer. She was calm and steady. Those attributes always gave us reassurance and peace.” – **Patient mom**



**Dr. Tyler Severance,** University of Missouri Health Care, Children's Hospital

“Consistently, Dr. Severance has been kind and patient with us. Our son struggled with the treatment protocol, and Dr. Severance provided very careful and thoughtful perspectives, coupled with knowledge of the academic work and lots of patience, to help us make informed decisions. Most importantly, he sees our son as a person!” – **Patient dad**

Parents, caregivers, patients, survivors and siblings can nominate any member of their hospital care team, with awardees named following a review by volunteer families and healthcare partners from the pediatric brain tumor community. Honorees receive a commemorative award designed to reflect the constellation of support they provide, guiding families on their cancer journeys.



Nominate a hospital care team member for the Constellation Award for Childhood Cancer

## Fiscal Year 2023 Financial Highlights

### FY2023 Audited Financial Statements

Statements of Financial Position	2023	2022
<b>ASSETS</b>		
Cash and cash equivalents	\$ 491,074	\$ 1,407,813
Investments	3,239,299	3,491,679
Accounts receivable	1,204,952	963,326
Contributions receivable	180,500	-
Other assets	56,927	94,517
Property and equipment, net	217,435	35,725
Total assets	<u>\$ 5,390,187</u>	<u>\$ 5,993,060</u>

<b>LIABILITIES AND NET ASSETS</b>		
Liabilities		
Accounts payable and accrued expenses	\$ 824,478	\$ 289,128
Grants payable	808,866	438,871
Total liabilities	<u>1,633,344</u>	<u>727,999</u>

Net Assets		
Net assets without donor restrictions:		
Board designated-quasi-endowment	1,473,767	1,473,767
Available for operations	270,649	951,802
Total net assets without donor restrictions	<u>1,744,416</u>	<u>2,425,569</u>
Net assets with donor restrictions	2,012,427	2,839,492
Total net assets	<u>3,756,843</u>	<u>5,265,061</u>
Total liabilities and net assets	<u>\$ 5,390,187</u>	<u>\$ 5,993,060</u>

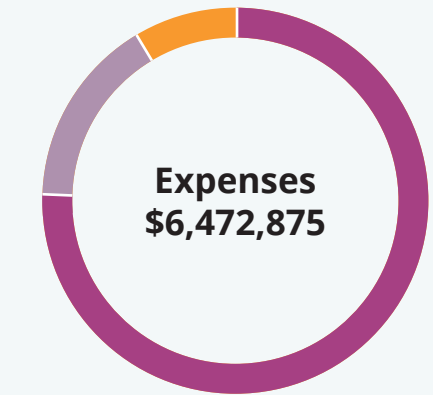
Statements of Activities	9/30/23	9/30/22
Revenues, gains, and other support:		
Contributions and grants	\$4,910,153	\$6,226,743
Less direct benefits to donors	(95,651)	(236,674)
Non-cash contributions	19,075	10,508
Investment income, net	131,080	20,537
Total revenues, gains, and other support	<u>4,964,657</u>	<u>6,021,114</u>

Expenses:		
Programs	4,827,808	4,680,459
Management and general	976,696	880,042
Fundraising	668,371	626,443
Total expenses	<u>6,472,875</u>	<u>6,186,944</u>

Changes in net assets	(1,508,218)	(165,830)
Net assets at beginning of year	5,265,061	5,430,891
Net assets at end of year	<u>\$3,756,843</u>	<u>\$5,265,061</u>



<b>97.0%</b> Public Contributions	\$4,814,502
<b>3.0%</b> Investment Income	\$150,155
<b>Ending Net Assets</b>	<b>\$3,756,843</b>



<b>74.6%</b> Program Expenses	\$4,827,808
<b>15.1%</b> Management & General	\$976,696
<b>10.3%</b> Fundraising	\$668,371

Full audited financials and IRS Form 990s are available at [curethekids.org/financials](https://curethekids.org/financials).



# Pediatric Brain Tumor

FOUNDATION

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

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**[curethekids.org](http://curethekids.org)**

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