



Pediatric
Brain Tumor
Foundation®

ANNUAL REPORT

FISCAL YEAR 2019



Dear Partners in Mission,

Thank you.



Since joining the Pediatric Brain Tumor Foundation last December, I have been honored to be welcomed into this incredibly passionate, resilient, and diverse community.

As I've met with many of you over the past several months, your commitment to care for kids with brain tumors has been humbling and inspiring. You have shared your families' stories, your frustration at wanting to see more progress, and your eagerness to do whatever it takes for a cure.

I hear you, and I share that desire to do more, do it better, and do it faster. Because the reality is that although we are making progress, it is not nearly enough. And it won't be until every child diagnosed with a brain tumor has the opportunity to grow up, have the resources they need to follow their dreams, and live a long life free of side effects.

I know this vision of a world without childhood brain tumors is possible because I see this community's unwavering focus on mission reflected in the pages of our 2019 annual report.

Because of your generosity last year, our funding is addressing key gaps in the research and drug development pipeline so that kids with brain tumors have access to more effective, less toxic treatments, and our resources and programs are reaching more families across more parts of the pediatric brain tumor journey.

Your continued support has never been needed more, though, as so many of the families we serve struggle with the health and economic impact of COVID-19 and we continue to reimagine how we will raise funds during and after the pandemic.

Together -- and only together -- we will continue to lead the way in transforming how pediatric brain tumors are treated and how children and their families are cared for. Thank you for standing with us in this fight so that we can give kids with brain tumors the future they deserve, for years to come.

In Partnership,

Courtney Davies
President and CEO
Pediatric Brain Tumor Foundation



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You show up. You care. No matter what.

Care is what makes the Pediatric Brain Tumor Foundation community who we are. Wherever you live and however you choose to support the PBTF's mission to Care. Cure. Thrive., we are united by a commitment to care for children in need. Thank you for choosing to partner with us and showing you care for kids with brain tumors in all of these wonderful ways!



OUR VISION: A world without childhood brain tumors.
OUR MISSION: Care. Cure. Thrive.

Better Treatments, Faster Cures, Brighter Futures.



\$2.1 million

invested in research in 2019



231%

increase in research
funding year-over-year



43

leading research centers
engaged in 2019



19

grants approved
for funding

The Pediatric Brain Tumor Foundation won't stop until there's a cure for every childhood brain tumor. Through partnerships with leading medical institutions, organizations, families, and individuals, we have funded more than \$46 million in scientific discovery since our founding, and in 2019 we more than doubled our year-over-year financial commitment to cure the kids.

2019 Research Highlights

Clinical Trials on the Forefront

Challenging the "gold standard" treatment for brain tumor patients has long been on the agenda but with little advancement, until now. PBTF's funding support in 2019 propelled the clinical trial landscape forward with a record number of trials funded:

- Phase I Clinical Trial combining Hydroxychloroquine with an existing targeted therapy to help arrest mutant tumor cells' reproduction abilities
- Phase III Clinical Trial spanning 26 countries challenging standard chemotherapy with a targeted MEK inhibitor
- DIPG All-In Clinical Trials Consortium project focusing on a promising, novel combination therapy that targets cancer cells and spares normal brain cells

Rising Stars in Research

Attracting the brightest minds to the pediatric brain tumor field is of paramount importance, and the PBTF's Early Career Development program gives young scientists the freedom to take their ideas from drawing board to reality, to pursue bold theories, concepts and strategies. In 2019, we announced three new multi-year grants to propel the exceptional work of Timothy Phoenix, PhD, University of Cincinnati, Stephen C. Mack, PhD, Texas Children's Hospital, and Zachary Reitman, PhD, Duke University.

Basic Science Transforms

PBTF's commitment to supporting novel concepts brought forward by clinicians and scientists around the world lies at the very core of our philosophy that finding the next targeted therapy will only happen when new ideas, new strategies, new hypotheses have opportunity for testing. PBTF's funding of basic science grants in 2019 will help scientists create more effective mouse models for pre-clinical drug testing, understand the genetic components of one of the deadliest types of brain tumors, and facilitate crucial tumor tissue collection during surgery and biopsies -- all key to developing a pipeline of new, more effective and safer treatments for kids battling brain cancer.

Survivorship Reimagined

The impact that treatment has on pediatric brain tumor survivors can range from subtle disruptions in cognition, gross motor abilities and everyday functioning to more pronounced, long-term side effects. It is critical to identify changes in a child's cognition as early as possible so that interventions can be initiated quickly to improve long-term outcomes. A new grant from the PLGA Fund at PBTF is helping a multi-institutional team harness computer-based assessments for neuropsychological functioning to study the impact of a child's brain cancer journey on their quality of life.

PBTF Unites the Global Scientific Community for a Cure

Global collaboration in the scientific and healthcare communities is the single most important ingredient in accelerating our pursuit of a cure for pediatric brain tumors.

Academic-driven international research conferences and symposiums serve as crucial opportunities for the childhood cancer and brain tumor communities to build relationships that spur innovation.

PBTF's Translating Discoveries to Cure the Kids meeting and support of and participation in the following 2019 conferences helped hundreds of researchers, clinicians and nonprofit leaders from around the world forge new partnerships and learn about the most promising science and clinical practices:

- Society for Neuro-Oncology's Pediatric Oncology Basic and Translational Research Conference
- Dana-Farber Cancer Institute / Heidelberg PLGA Meeting
- PLGG Coalition Workshop-Heidelberg
- Association of Pediatric Oncology Social Workers Conference
- Association of Pediatric Hematology Oncology Nurses Conference
- International Brain Tumor Alliance World Summit



The Power of Partnerships to Accelerate Investments in Immunotherapy

In 2019, the Pediatric Brain Tumor Foundation announced a new partnership with the Samson Research Fund and the Charles Woodson Clinical Research Fund, both at the University of Michigan C.S. Mott Children's Hospital, to invest in a novel immunotherapy approach for pediatric high-grade gliomas (pHGG). pHGG is a common form of highly aggressive pediatric brain cancer that is difficult to treat through surgery, chemotherapy and radiation.

"Kids diagnosed with brain tumors do not have the luxury of time. As such, we are thrilled to have the opportunity to streamline the research process by leveraging a Michigan Medicine treatment strategy approved for adults, in order to benefit the often-neglected community of

pediatric patients. Collaboration between committed foundations and dedicated medical professionals is the only way to change the currently unacceptable outcome for the 13 children diagnosed each day in the United States with a brain tumor," says Kimberly Gilman, Chairperson of PBTF's Think Fit for Kids, which raised the funds invested in this project.

PBTF's 2019 commitment of \$500,000, with an additional \$300,000 committed in 2020, will enable scientists to perform the experimental work needed to get FDA approval to implement this desperately needed immunotherapy in children.



Supporting Families from the Moment of Diagnosis, Through Treatment and Beyond

No family should have to face their child's brain tumor journey alone. Each year, PBTF connects thousands of families with patient and family education, financial relief, and a thriving community of support.

FAMILY SUPPORT IMPACT IN 2019



23% increase

in family support provided year-over-year through programs, resources, and events across the country.



1,058

educational guides distributed to patient families, including the Starfolio for the newly diagnosed and Survivorship Resource Guidebook.



56

partnerships with best-in-class children's hospitals.



\$409,580

in emergency financial relief provided through The Butterfly Fund.



New Guidebook Equips Survivors With Tools Needed to Thrive

When treatment for a child's brain tumor ends, a new chapter of the journey begins: survivorship. To help pediatric brain tumor survivors and caregivers navigate this new part of the journey, PBTF launched the Survivorship Resource Guidebook in 2019.

"PBTF's Survivorship Resource Guidebook is a must-have manual for families and providers caring for survivors of childhood brain cancer... a go-to resource for its completeness, easy-to-use format, inspirational stories, and practical checklists," says Dr. Julia Meade, Pediatric Oncologist and Assistant Professor, University of Pittsburgh School of Medicine.

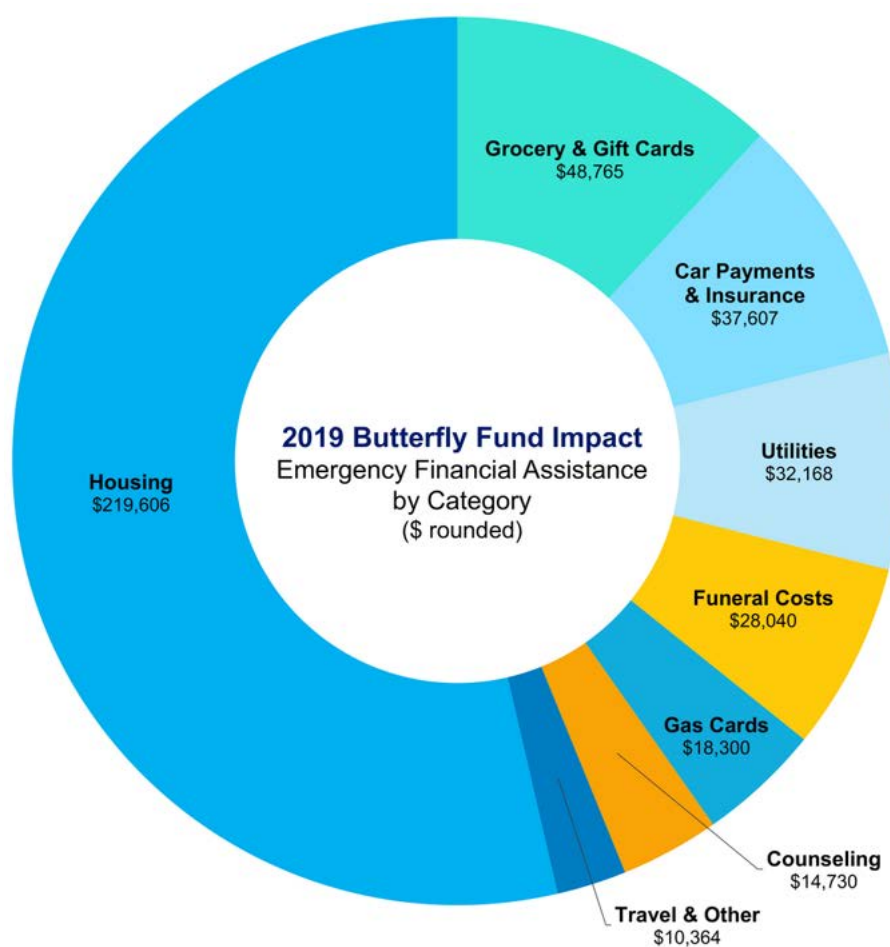
Published with generous support from Coverys and in partnership with Friends of Jaclyn Foundation, more than 40 experts in the fields of pediatric oncology, education, and disability rights, along with parents and survivors, answered questions about what survivors can do to stay healthy, keep health insurance as they get older, thrive in school, find a job, and navigate life after treatment ends.



Treating a child's brain tumor comes at a steep cost. Childhood brain tumor treatment regimens are long and intense, requiring many parents to take unpaid leave from work to focus on their child. These financial hardships pose serious barriers to patient care and can have devastating effects on family members.

PBTF's Butterfly Fund provides critical financial relief to families in crisis during their child's treatment.

Because of PBTF supporters, 357 families received \$409,580 in 2019, helping with out-of-pocket expenses, such as housing, transportation, professional counseling, and other essentials not covered by insurance. And we continue to do more: increasing the 2020 Butterfly Fund budget to \$500,000 in response to COVID-19's impact on families and recently adding patient funds at New York-Presbyterian Morgan Stanley Children's Hospital and MassGeneral for Children.



PBTF's Vs. Cancer Grants Change Kids' Lives in the Clinic

From coast to coast, PBTF partners with hospitals and healthcare teams to connect children and families with the support they need, when they need it. In 2019, nearly \$300,000 in Vs. Cancer grants funded resources at children's hospitals, such as:

- **Children's Hospital of Pittsburgh's** first neuro-oncology Survivorship Symposium, a free symposium that provided survivors of childhood brain and spine tumors and their families with improved access to information.
- An Education Liaison at **Ann and Robert H. Lurie Children's Hospital of Chicago** to ensure pediatric brain tumor patients have a smooth transition back to school.
- Adding a psychologist to **Children's Hospital of Los Angeles'** outpatient neuro-oncology clinic who is dedicated to delivering emotional support to pediatric brain tumor families.
- Neuropsychological testing materials to help the pediatric brain tumor team at **Levine Children's Hospital in Charlotte** understand the cognitive impact of treatment on patients and equip families with the best resources for long-term support.

2019 FINANCIAL HIGHLIGHTS

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

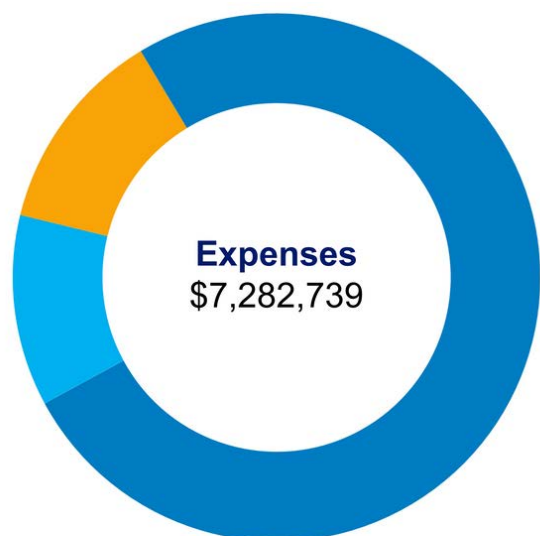


99.20% **Public Contributions:** \$6,471,860

0.80% **Investment Income:** \$52,085

Ending net assets of \$5,475,180

Source: Pediatric Brain Tumor Foundation's Form 990 for the year ending Dec. 31, 2019



75.70% **Program Services:** \$5,512,923
Includes \$2,060,531 in research, as well as direct aid to families, hospital grants for child life programs, patient and family education resources, and awareness and advocacy

11.72% **Management & General:** \$853,676

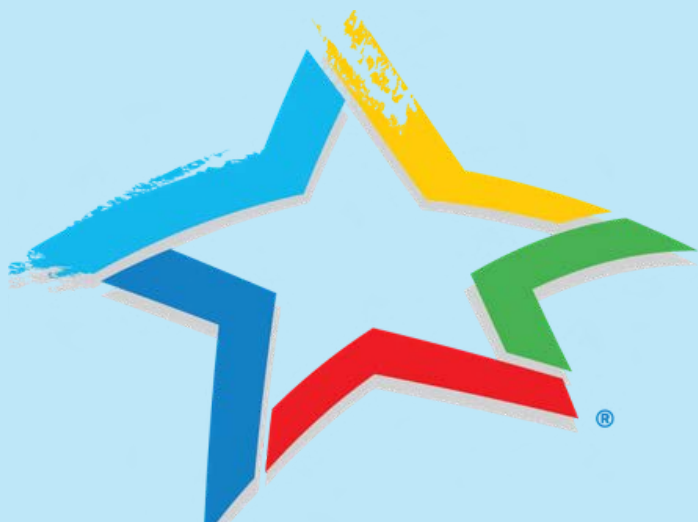
12.58% **Fundraising:** \$916,140

2019 Audited Financial Statements Statements of Financial Position

	12/31/2019	12/31/2018
ASSETS		
Cash and cash equivalents	\$1,142,192	\$4,823,644
Investments	4,200,039	1,135,829
Accounts receivable	349,082	333,812
Contributors receivable	-	14,625
Other assets	33,952	47,052
Property and equipment, net	55,614	74,441
Total assets	\$5,780,879	\$6,429,403
LIABILITIES AND NET ASSETS		
Liabilities:		
Accounts payable and accrued expenses	\$280,699	\$145,429
Grants payable	25,000	50,000
Total liabilities	305,699	195,429
Net assets:		
Net assets without donor restrictions:		
Board designated-quasi-endowment	816,243	1,016,243
Available for operations	5,955	338,902
Total net assets without donor restrictions	822,198	1,355,145
Net assets with donor restrictions	4,652,982	4,878,829
Total net assets	5,475,180	6,233,974
Total liabilities and net assets	\$5,780,879	\$6,429,403

Statements of Activities

	12/31/2019	12/31/2018
Revenues, gains, and other support:		
Contributions	\$6,909,035	\$10,407,561
Less direct benefits to donors	(872,000)	(893,008)
Non-cash contributions	434,825	412,941
Investment income, net	52,085	16,620
Total revenues, gains, and other support	6,523,945	9,944,114
Expenses:		
Programs	5,512,923	3,531,447
Management and general	853,676	790,768
Fundraising	916,140	770,729
Total expenses	7,282,739	5,092,944
Changes in net assets	(758,794)	4,851,170
Net assets at beginning of year	6,233,974	1,382,804
Net assets at end of year	\$5,475,180	\$6,233,974



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curethekids.org/impactreport