

# Working together to CARE.CURE.THRIVE.



Pediatric  
Brain Tumor  
Foundation

## DEAR PARTNERS IN MISSION,

Over the last few years, you've heard us say we're "stronger together," and in 2018 the Pediatric Brain Tumor Foundation lived out that vision and value once again. Through our merger with A Kids' Brain Tumor Cure, we broadened and enriched our research strategy to include low-grade glioma, the most common form of pediatric brain tumor, as a key program component.

**Now more than ever, the PBTF has distinguished itself as the leader in the childhood brain tumor community.**

The PBTF is answering the increasingly urgent call to put an end to this devastating disease through a multi-pronged research strategy. Through this approach, we believe we can make the most progress in curing all pediatric brain tumors. Our funding continues to fuel cutting-edge clinical trials, research collaboratives and initiatives that are paving the way for a better understanding of pediatric brain tumors and new treatment approaches.

As we make progress in finding a cure, we continue to strengthen our family support programs and presence in regions across the country. Completed in 2018, our Community Health Needs Assessment serves as a roadmap for delivering

meaningful help today and walking alongside pediatric brain tumor families no matter where the journey takes them.

I was honored to join the PBTF in February. It has been a delight meeting donors and advocates, researchers and healthcare professionals, families, friends and nonprofit leaders who make up the network of hope in the pediatric brain tumor community.

Together, we are gaining momentum in pursuit of our shared vision of a world without childhood brain tumors. **It's a big, bold vision and it will take all of us to move the mission forward to that dreamed-for outcome.** We need you and we appreciate you.

I look forward to working alongside you as we serve the children and families who are the heart of our mission.

In partnership,



**Bill Tiller**  
President & CEO  
Pediatric Brain Tumor Foundation

## Imagine a world without childhood brain tumors.

As the world's leading nonprofit funder of pediatric brain tumor research, that's the vision we fight for every day.

While funding the most promising research for a cure, we also provide meaningful care to families across the country who are facing this diagnosis.



# CURES THROUGH COLLABORATION



The Pediatric Brain Tumor Foundation won't stop until there's a cure for every childhood brain tumor. Since 1991, we have funded and partnered with organizations to fund more than \$44 million in lifesaving scientific discovery. This research funding has fueled cutting-edge clinical trials, research collaboratives and initiatives that have paved the way for a better understanding of pediatric brain tumors' cellular and molecular biology.

In 2018, the PBTF and A Kids' Brain Tumor Cure merged to take a massive leap forward in curing all childhood brain tumors. Joining forces means more cures funded, more families served and a louder voice for kids with brain cancer.



Pediatric  
Brain Tumor  
Foundation®



**A Kids' Brain Tumor Cure**  
**PLGA Foundation**

**FUNDING RESEARCH ► FINDING CURES**

## **MORE CURES FUNDED**

The newly launched PLGA Fund at PBTF is the most recent addition to the PBTF's research portfolio. Dedicated to funding the most promising pediatric low-grade glioma and astrocytoma research, the PLGA Fund continues AKBTC's work of funding more than \$16.5 million in research that enabled scientists to win multi-million-dollar grants from the National Cancer Institute and resulted in five new clinical trials that have helped shape the direction for less toxic, more effective, targeted therapies.

## **MORE FAMILIES SERVED**

PLGA brain tumors represent the most common form of childhood brain cancer. PBTF welcomes the patients and families served by AKBTC into the PBTF family support network of programs. Uniting with AKBTC's

strong presence in the Northeast region, through events such as Think Fit for Kids and Geared Up for Kids, has also strengthened the direct family support and reach in the region.

## **LOUDER VOICE FOR KIDS WITH BRAIN CANCER**

Under the longtime guidance of Dr. Joanne Salcido, the PBTF's Vice President of Research and Advocacy, and Amy Weinstein, our new PLGA research and advocacy director, the PBTF is now funding and advocating for research across the widest breadth of pediatric brain tumors. Leveraging the combination of AKBTC's capital investment in the PBTF and the advocacy efforts of both organizations, the PBTF is positioned to effect the change needed to achieve our vision of a world without childhood brain tumors by working collaboratively with like-minded philanthropies, government officials, medical institutions and the pharmaceutical industry.

# The Transformative Power of Research Becomes Personal

As someone who works in drug development, I was shocked by the limited treatment options available for my son Nathan when he was diagnosed with an inoperable, incurable brain tumor. He faced the same chemotherapy treatments that had been used for four decades... since before I was even born.

**As I watched Nathan suffer through two grueling and toxic treatment regimens, I pledged that he'd have access to state-of-the-art clinical trials and better treatment options if his tumor ever grew again.** We began supporting research that targets the most-common mutation found in these tumors, the BRAF-KIAA1549 fusion mutation. This work identified an adult melanoma drug, TAK-580, which looked like a promising treatment option. For the past two years, we've worked with our family and friends, A Kids' Brain Tumor Cure, and now the Pediatric Brain Tumor Foundation's PLGA Fund to support a \$1.6 million clinical trial.

Recently, our work became even more personal. After nearly four years of stability, Nathan's brain tumor started growing again. Shortly after, he was having trouble using his right side. He never complained, never

missed a hockey practice, never stopped trying to ski, and he never let it slow him down. A few months later, the TAK-580 trial—the trial we've worked so hard for years to fund—finally moved into Phase I.

**Nathan became the first child in the world to enroll.**

Two months later, we received stunning news. For the first time in Nathan's battle, his brain tumor had shrunk. Nathan could ski again! He could throw a ball! I see him riding his bike down the street now, and I still have a hard time believing it's real.

**Through this journey, I have seen concrete evidence of the transformative power of funding pediatric brain tumor research.** Nathan has a long road ahead, but he's made tremendous progress in recent months. Together, we will make better treatments and cures possible for all children and teens with brain tumors!

**Evan Hecker, PhD**

Northeast Regional Advisory Board  
Pediatric Brain Tumor Foundation



## 2018 RESEARCH IMPACT HIGHLIGHTS

### The Cutting Edge of Therapy

PBTF is funding a cutting-edge research project at Massachusetts General Hospital (MGH) for children with medulloblastoma. In collaboration with AKBTC's funding support of medulloblastoma research at MGH, researchers hope this project will point the way to new therapies for this complex form of brain cancer that's often resistant to treatment.

### Bold New Approaches in Immunotherapy

Through a funding partnership with the Brain Tumor Funders' Collaborative (BTFC), the PBTF launched the first part of our multi-year Immunotherapy Research Initiative. The PBTF's contribution of \$450,000 over three years will be leveraged six-fold to fund projects that examine vaccine strategies, the tumor's micro-environment, anti-tumor T-cells, and personalized immunotherapy approaches.

### "All In" on Curing DIPG

PBTF awarded \$100,000 in funding for Project "All In DIPG," forging an innovative public-private partnership between researchers and funders across sectors to accelerate the validation of drug candidates for the clinic.

### Mapping the Future of Treatment

PBTF's voice at the table drove inclusion of pediatrics in a pilot study sponsored by the National Cancer Institute to create a cellular and genomic atlas from single-cell analyses of patients' brain tumor samples. These advocacy efforts led to the dedication of \$3M in federal funding to Project H.O.P.E. (High-Grade Glioma-Omics in Pediatric and AYA).



# A COMMITMENT TO CARE



The Pediatric Brain Tumor Foundation works every day to support families in meaningful ways from the moment of diagnosis — no matter where the journey leads. With your support, we're providing life-changing programs and resources to more families across the country.

## UNDERSTANDING FAMILY NEEDS

As the PBTF expands family support programming to communities across the country, we wanted to hear from pediatric brain tumor families about their challenges and where they need the most support. In partnership with the USC Sol Price Center for Social Innovation and with generous support from Coverys, the PBTF conducted and released a national Community Health Needs Assessment in 2018. The results define the nature and extent of the challenges families face following a child's brain tumor diagnosis and identify existing gaps in services and resources we can help fill. **Below are four ways we're making an impact based on the core areas of need:**

### INTERPERSONAL AND EMOTIONAL DISTRESS

The PBTF expanded the emergency financial assistance Butterfly Fund to include support for professional counseling for individuals, couples, and families, and grief counseling.

### LOGISTICAL SUPPORT AND FINANCIAL HARDSHIP

40% of parents and caregivers cite logistical and financial hardship as a key challenge. The PBTF's Butterfly Fund provided \$392,213 in emergency financial assistance in 2018, helping 319 families with housing, transportation, and other expenses often not covered by insurance.

### INFORMATION ABOUT THE PEDIATRIC BRAIN TUMOR JOURNEY

Distributed 360 Starfolio resource notebooks to newly diagnosed families and 800 educational booklets that help answer key questions families ask when their child is diagnosed with a brain tumor.

### EDUCATIONAL AND VOCATIONAL ANXIETIES

Provided \$102,500 in scholarships to 95 survivors, expanded program to include scholarships for vocational, trade and technical institutions, and introduced the PBTF Scholar Service program, which gives recipients the opportunity to give back to others facing similar challenges by volunteering for the PBTF.



**2,643**  
families  
served



**906**  
families participated in  
the Community Health  
Needs Assessment



**360**  
free Starfolio resource  
notebooks distributed  
to newly diagnosed  
families



**\$392,213**  
in emergency financial  
assistance provided



**95**  
survivors awarded  
college and vocational  
scholarships



As a direct and immediate response to the PBTF's Community Health Needs Assessment (see opposite page), the PBTF expanded the Butterfly Fund emergency financial assistance program to include support for professional counseling services, such as individual and couples counseling, family counseling and grief counseling.

*"I cannot highlight enough the significant impact the Pediatric Brain Tumor Foundation's programs make for our patients and families. For parents who are juggling multiple stressors in light of their child's diagnosis and treatment, the availability of the Butterfly Fund's financial assistance can help lighten a load that at times feels overwhelming. Many families benefit from counseling support while coping with the demands of treatment, but the out-of-pocket costs can be prohibitive. The ability for families to dedicate these funds towards counseling has created new opportunities for families to strengthen their emotional well-being while focusing on their child's physical health."*

**Sarah Champlin**  
Neuro-oncology Social Worker  
Children's Healthcare of Atlanta



**Vs. Cancer** empowers any sports team, any athlete, any community to help kids with brain cancer. In addition to funding lifesaving research, Vs. Cancer teams fuel family support resources and child life programs at hospitals in their community.

In 2018, 278 teams helped provide more than \$220,556 in grants to 44 hospitals.



**44**  
hospitals  
received grants



**\$220,556**  
total received

#### WAYS THAT GRANTS ARE MAKING A DIFFERENCE:

- SickKids' Journey to Survivorship, a new program for patients and caregivers to enhance transition from active treatment to long-term follow up
- Brenner Children's Hospital's "Sophie's Place," a permanent music therapy room and fully equipped studio that serves as a place of physical and emotional healing for pediatric patients
- Cincinnati Children's Hospital's NjoyItAll Camp, a week-long, overnight summer camp for pediatric cancer patients and their siblings
- MD Anderson Cancer Center's outings for pediatric cancer patients, which include travel, full meals, and an activity that give children and their families a well-deserved break from the hospital and stress of treatment







DONNA AND KAREN,  
Runzel Shoot volunteers.



## CELEBRATING OUR COMMUNITY



*“It helps to stay involved when you can SEE the positive advancements from money raised. We ARE making a difference!”*

**Julie Runzel, Pediatric Brain Tumor Foundation Supporter**

Since their Gold Wing Road Riders Association began raising money through Ride for Kids in the mid-1990s, fundraising for the Pediatric Brain Tumor Foundation has always been a family affair for John, Julie and Johnny Runzel of Illinois. Through the PBTF, they met a family whose daughter was diagnosed with a brain tumor when she was just six months old—the same age as their son. Julie said, “We became very close to this family. Realizing how lucky we were to have a healthy child, we have continued supporting the PBTF even though our riding days have dwindled.”

For seven years, the Runzels have hosted a themed “Party in the Barn” and asked their friends to make donations to the PBTF. The party grew from there and now the family hosts an annual all-inclusive skeet shooting event. The first year raised just a little more than \$11,000, but with the addition of live auctions and sponsorships, the 2018 event raised over \$100,000 for the PBTF. “It helps to stay involved when you can SEE the positive advancements from money raised. We ARE making a difference!” says Julie.

## HOW YOU HELPED IN 2018



**310**  
events



**31,554**  
donors



**12,788**  
event participants



**29**  
states



**\$10.1M**  
raised

# WE COULDN'T DO IT WITHOUT YOU



*Thank you to all of our donors, fundraisers and volunteers for moving our mission forward.*

With gratitude, we recognize the following individuals, corporations, and foundations who have supported the Pediatric Brain Tumor Foundation through an annual donation or special gift of \$5,000 or higher.

## **\$100,000 & Greater**

A Kids' Brain Tumor Cure  
American Honda Motor Co.  
Anonymous  
Coverys Community Healthcare Foundation  
Jason T. Gladwell, DDS, PA

## **\$50,000 TO \$99,999**

Christopher Brandle Joy of Life Foundation  
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Genentech Foundation  
J. Smith Lanier & Co.  
Kyrie Foundation

## **\$25,000 TO \$49,999**

Denise & David Chase  
Jill & Chris Kernion  
Nikki's Hope Foundation  
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## **\$10,000 TO \$24,999**

AmWINS Brokerage of Georgia  
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## **\$5,000 TO \$9,999**

Ace American Insurance  
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*"Along the way, we've gotten more than we've given. Partnering with the PBTF has taught us to not take time for granted because we've seen how precious it is. When a child is diagnosed with a brain tumor, time is stolen from them and their families... Months in the hospital. Years in recovery. And for the far too many children who pass away, decades of lives lost."*

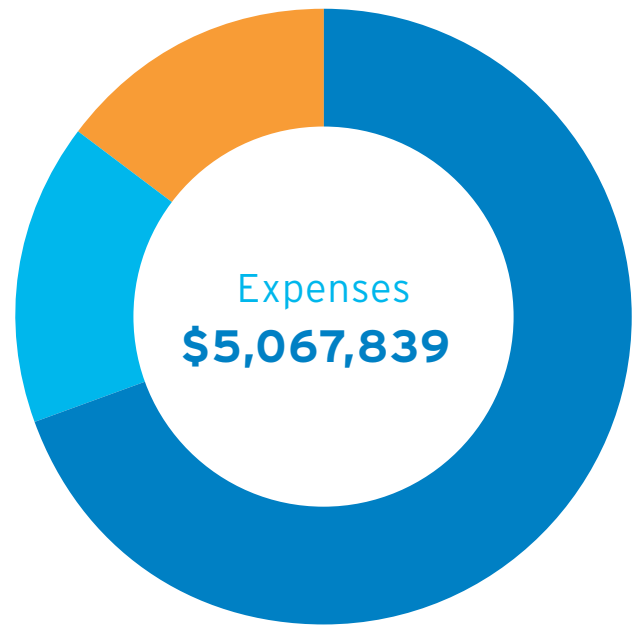
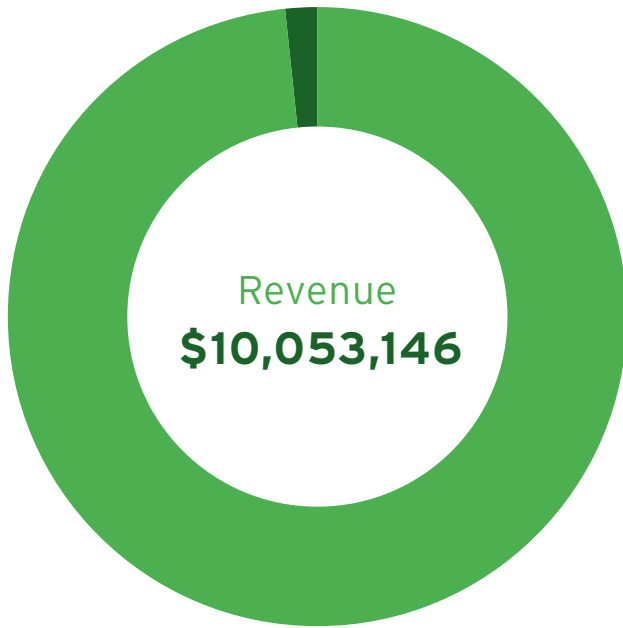
**Jeffrey A. Skelton, Managing Director UK and Ireland, LexisNexis® Risk Insurance;  
Southeast Regional Advisory Board, Pediatric Brain Tumor Foundation**

# 2018 FINANCIALS



69.68% of the funds raised were invested in research and family support programs.

2018 revenue includes a \$4 million capital investment in December from merger with A Kids' Brain Tumor Cure.



98.45%

**Public Contributions: \$9,897,814**  
including \$4M from merger with A Kids' Brain Tumor Cure

1.55%

**Investment Income: \$155,332**

Ending net assets of \$6,233,974

Source: Pediatric Brain Tumor Foundation's  
Form 990 for the year ending Dec. 31, 2018

69.68%

**Programs: \$3,531,447**

15.69%

**Management: \$795,343**

14.62%

**Fundraising: \$741,049**



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

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