



Pediatric  
Brain Tumor  
Foundation®

# ANNUAL REPORT FISCAL YEAR 2020





# Dear Partners in Mission,



In 2020, the Pediatric Brain Tumor Foundation community shone brighter than ever, a beacon of hope in a year of unprecedented challenges.

While the pandemic increased the heavy toll a child's brain tumor takes on families and threatened progress towards a cure, your commitment to lessen the emotional, economic, and physical impact of this disease ensured extraordinary change continued for the kids we serve. Because of your generous partnership:

- A PBTF-funded treatment was selected for pharmaceutical industry investment and awarded the FDA's Breakthrough Therapy Designation to get it to more kids, faster.
- Critical scientific discovery and family support programs at PBTF partner hospitals were safeguarded thanks to our \$2M+ annual investment in research and community grants.
- PBTF continued to deepen the support families receive, expanding our Butterfly Fund to more places, creating more connections through our peer-to-peer network, and providing more answers about the brain tumor journey through our new webinar series.

You are the reason we can continue to deliver on our mission to Cure. Thrive. -- nimbly responding to the community's evolving needs, while ensuring everyone's health and safety.

As we look back on one milestone year, we look ahead to the rest of 2021, which brings the anniversary of PBTF's 30-year partnership with Ride for Kids presenting sponsor American Honda. Thanks to the support of donors, fundraisers, volunteers, and partners like you, the legacy of our founders Mike and Dianne Traynor flourishes stronger than ever.

Though we're making measurable progress in the battle to give children with brain tumors a brighter future, we know our work is far from done and we don't have a moment to lose. Your kindness and generosity continue propelling us toward a cure.

Courtney Davies  
President and CEO, Pediatric Brain Tumor Foundation



## PEDIATRIC BRAIN TUMOR FOUNDATION BOARD OF DIRECTORS

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Pediatric  
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# 2020 IMPACT AT A GLANCE



**8** CLINICAL TRIALS  
MAKING A DIFFERENCE  
IN KIDS' LIVES TODAY



Clinical research is crucial to developing novel therapies and challenging "gold standard" treatments that leave lasting effects on kids with brain tumors.

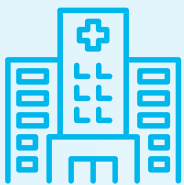


**\$5.6M**

The amount of funding currently approved, active, and driving scientific discovery in PBTF's research portfolio.

**\$1,251**

The average amount of financial relief sent to a family in crisis.

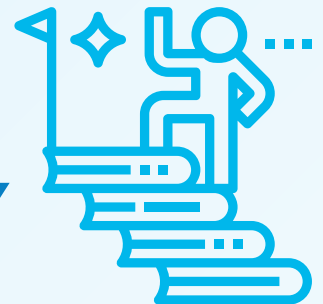


**95** HOSPITAL  
PARTNERS

delivering PBTF support resources to families, a 70% increase over 2019.

**1 PBTF-  
FUNDED  
THERAPY**

**SELECTED FOR  
INDUSTRY INVESTMENT**



In 2020, targeted therapy DAY101 was named by Day One Biopharmaceuticals as their first priority for widespread development and awarded the FDA's Breakthrough Therapy Designation.

**3,138**

The number of patient families reached through Vs. Cancer community grants.

**16%**

increase in patient family education accessed, including PBTF's Starfolio, Survivorship Resource Guidebook and new monthly webinar series.

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# PBTF Research At Work:

## Accelerating the discovery of targeted therapies for children today

The Pediatric Brain Tumor Foundation's research investment strategy is guided by our mission to maximize the number of life-changing therapies moving from development through commercialization to find targeted treatments for all kids battling brain tumors.

Curing pediatric brain tumors is a global challenge we can't tackle alone. Your support helps us:



Engage with every level of expertise across an array of scientific disciplines.

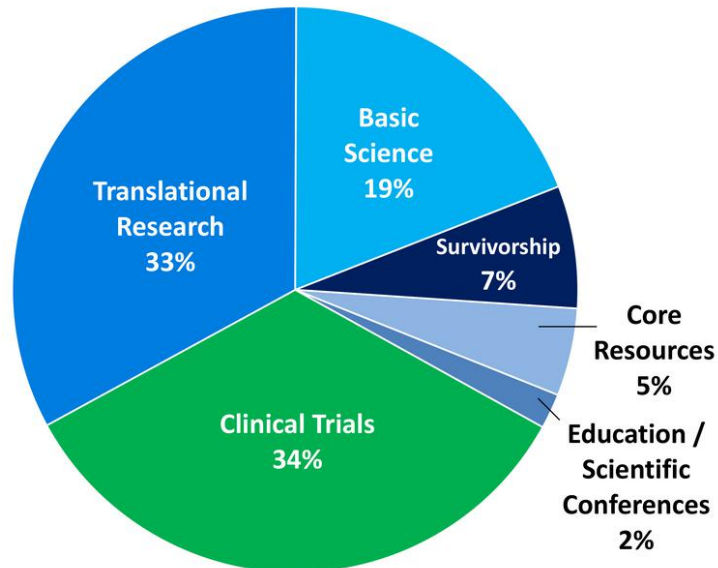


Provide seed funding at every stage of the targeted therapy pipeline



Collaborate with a wide spectrum of international partners

### \$5.6 Million in Approved and Active Research Through 2022



## 2020 Research in Numbers

# \$2.1M

invested in  
scientific discovery

# 8

clinical trials making  
a difference today

# \$580K

approved for  
new research grants

# New PBTF-Funded Treatment Unlocks Hope for Today and a Roadmap for Tomorrow

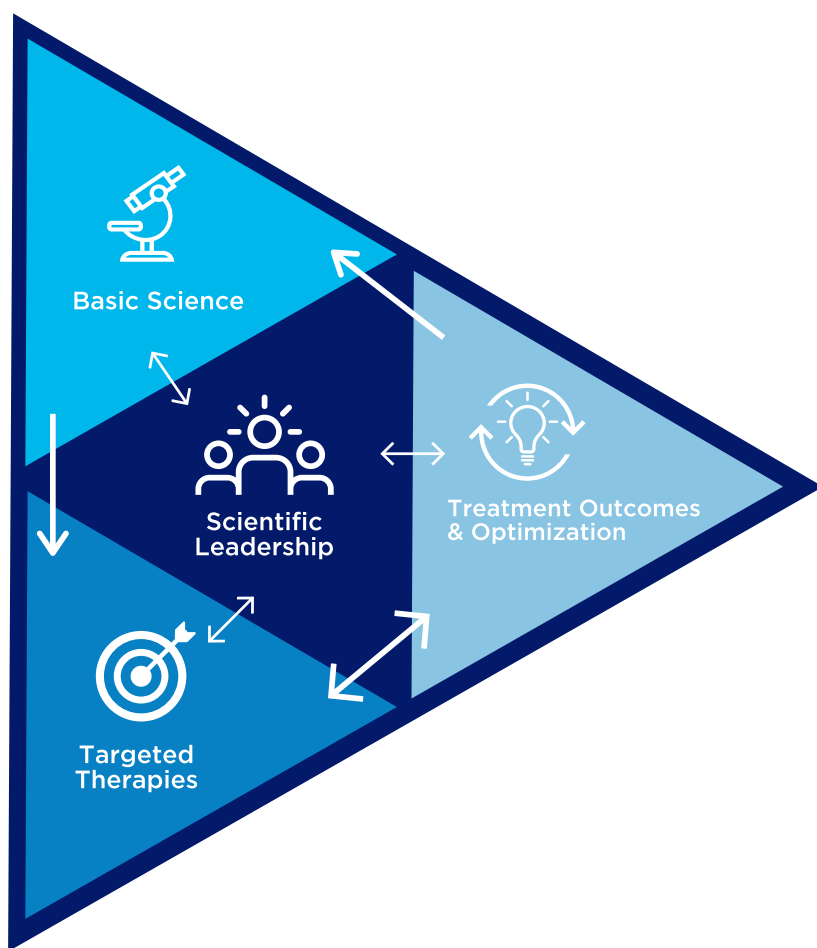
Finding a cure for pediatric brain cancer -- a cure that delivers the long-term survival and exceptional quality of life every child deserves -- will first take someone seeing a new idea or treatment's promise and lighting the way for others. Because the reality is that while the development of new treatments requires monumental support from the pharmaceutical industry and the government, the level of support that's needed requires proof of concept.

Thanks to PBTF supporters' generosity and our integrated approach to funding research, a new target was identified leading to the development of the groundbreaking therapy DAY101. Named by Day One Biopharmaceuticals as their first priority for widespread development and commercialization, DAY101 was awarded the FDA's Breakthrough Therapy Designation in 2020. Seed funding from the PLGA Fund at PBTF not only launched Dana Farber's PLGA Research Program, which discovered the BRAF target that unlocked DAY101's potential, our community's support also helped underwrite the Phase 1 clinical trial work for the compound that became DAY101.

With the pharmaceutical industry and government support now speeding DAY101's development, this targeted therapy has the potential to deliver outcomes that current "gold standard" treatments like chemotherapy and radiation cannot.

As we look to the future, DAY101's success underscores the crucial role the PBTF community's leadership and funding play in eradicating pediatric brain cancer once and for all. It also provides a roadmap to accelerate the development of other targeted therapies. We'll need an arsenal of treatment options to defeat the more than 100 different types of brain tumors, and we need partners like you to help PBTF get seed funding to the researchers that are building it.

**Special thanks to Team Jack Foundation, Thea's Star of Hope, Why Not Me?, and the Geared Up For Kids, Par For Kids, Think Fit For Kids, and Starry Night Knoxville events whose partnership and support helped make DAY101 possible.**



*PBTF's integrated research investment strategy has fundamentally changed the scientific landscape, and our clinical trials are making a profound difference in kids' lives today.*



# PBTF Family Support At Work:

## Empowering families to face COVID-19's new normal head on

A child's brain tumor diagnosis is an isolating and complicated experience, one that was made even more isolating and complicated in 2020 by the COVID-19 pandemic. From the disease's impact on patients' health and families' financial stability to the unintended consequences of stringent hospital safety protocols on patient care, the pandemic posed significant risks to kids with brain tumors.

With your generous support, the Pediatric Brain Tumor Foundation adapted its programming so that families were equipped with the resources needed to make informed decisions during the pandemic and beyond:

- Increased emergency financial relief provided to families and added patient funds at two new partner institutions
- Launched a monthly webinar series focused on different aspects of the journey and how families' needs were evolving during the pandemic
- Launched our Peer to Peer Mentoring program, matching patient families with trained mentors who have experienced the challenges of the childhood brain tumor journey
- Created a COVID-19 Family Resource Center and Digital Care Package to equip families with evidence-based advice and activities to help children navigate challenging times

**"Knowing we are able to get solid and accurate information from the Pediatric Brain Tumor Foundation, who has had our backs since before the virus, is a source of comfort. The virus may be novel, but our feelings of uncertainty are not. Again, the PBTF is here to deliver family support to us."**

**- Clare Desmelik, Mom of Holmes and Vincent**

## 2020 Family Support in Numbers

**16%↑**

increase in patient family education resources accessed year-over-year

**46k**

views of PBTF's family support video series

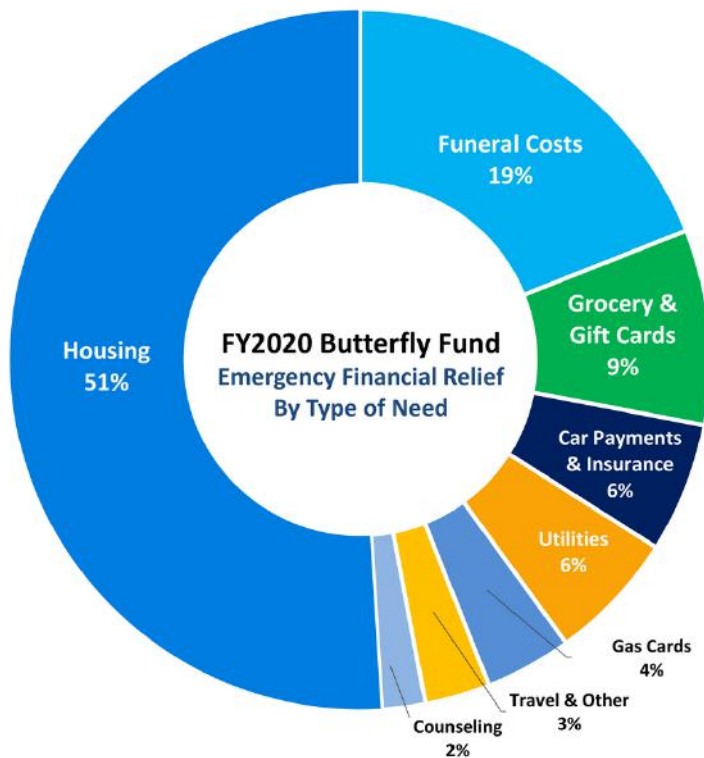
**70%↑**

increase in care delivery partnerships with children's hospitals

**\$1,251**

average amount of financial relief received per family





One in four families report losing more than 40% of their annual household income because of work disruptions related to a child's cancer treatment. These financial hardships pose serious barriers to patient care. The Pediatric Brain Tumor Foundation's Butterfly Fund provides financial relief to hundreds of families each year who are in crisis following their child's brain tumor diagnosis. This support has never been more needed than in 2020, when COVID-19's economic impact increased patient families' vulnerability.

Fueled by your support, PBTF was able to increase the average amount of emergency financial relief each family received in 2020, as well as add relief funds at two new partner institutions, NewYork-Presbyterian Morgan Stanley Children's Hospital and MassGeneral for Children. By safeguarding this critical program, your generosity ensured families still had someone to turn to for support during an unimaginable time.

**Special thanks to the [PBTF Charity Classic](#), hosted by [Marsh & McLennan Agency Southeast](#) and [Think Fit for Kids](#) for their generous support of the 2020 Butterfly Fund.**

## Vs. Cancer Community Grants Close Gaps in Hospital Partners' Delivery of Family Support

2020 and the COVID-19 pandemic underscored the countless hours and tireless support that PBTF hospital partners commit each day to the children we serve. For nearly a decade, our Vs. Cancer program has helped these frontline healthcare teams deliver the care that children in treatment need -- closing gaps in hospital budgets that put vital family support programs at risk.

Last year alone, PBTF's Vs. Cancer grants funded patient support that reached 3,138 pediatric brain tumor families across the country. Because of your generosity, PBTF-funded resources like Children's Hospital of Los Angeles' psychology consultant program are possible, helping pediatric brain tumor patients cope with diagnosis, treatment, and survivorship.



**\$253,571 Funded  
at Partner Hospitals**



**3,138 Brain Tumor  
Families Reached**



# PBTF Supporters Shine Strong in 2020

During a year when the world faced the unthinkable, the Pediatric Brain Tumor Foundation community never lost sight of our shared mission to [Care](#). [Cure](#). [Thrive](#). From Ride for Kids and Vs. Cancer to the Starry Night Walk and community partners, your support continued to light the way -- inspiring hope and showing families they're never alone.



**Pediatric  
Brain Tumor  
Foundation®**



**3.5M**  
Miles Ridden

**\$1M**  
Raised



**391**  
Teams Go Gold

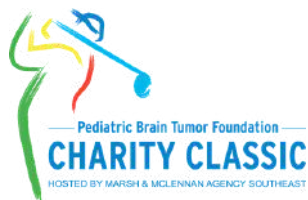
**\$662K**  
Raised



**226**  
Lanterns Lit

**\$203K**  
Raised

**More than \$588K Raised by  
PBTF Community Partners**



**Think Fit  
for Kids**



**Thank You To These and All of Our Community Supporters!**



# Online Gaming Community and PBTF Team Up to #CancelKidsCancer

In our pursuit of a world without childhood brain tumors, the Pediatric Brain Tumor Foundation is always exploring innovative ways to raise awareness and welcome supporters to the PBTF army. In 2020, we teamed up with the video game community to launch PBTF GameON, bringing new multiplayer memories to Star families and raising over \$130,000 for a cure.

"Pediatric brain tumor research is severely underfunded in this country," says Kristin Moran, whose son Brannon participated in a PBTF GameON livestream. "We are lucky that even though Brannon was high risk, he is still with us five years later. As a result of the effects of his treatment, he has been left with many challenges. Participating in the livestream really made Brannon feel so special and helped boost his self-esteem."

More than 70 Facebook, YouTube, and Twitch livestreamers, as well as corporate partners Empire Jerky, VRLA Tech and Ice Shaker, partnered with PBTF in 2020 to help kids like Brannon.

"I am inspired by the incredible strength and courage of the children the PBTF serves," says Facebook Gaming partner and PBTF global ambassador Starbeast. "At 21 years old, I underwent and overcame open brain surgery. When I was sitting in the hospital and looked around me, there were just so many kids who needed help. It's truly humbling to know I can now give back."

## PBTF GameON

## Corporate Partner Empire Jerky Powers Up PBTF GameON's Launch



Empire Jerky founder and PBTF global ambassador Dustyn Dahn is among PBTF GameON's biggest champions. Deeply committed to PBTF's work, Dahn lost a close relative to a brain tumor.

"I was brought up on the notion that if you're in a position to help others, you help," says Dahn. "PBTF's mission hits close to home for me."

PBTF GameON's launch sponsor recruited a third of the charity gaming initiative's 70-plus livestream partners and created a PBTF-branded

edition of teriyaki jerky that raised \$1,500 in online sales. Dahn's commitment continues in 2021, recently hosting a PBTF GameON event that raised another \$6,000 and launching an art contest for pediatric brain tumor patients.

"I saw a way that I could, at the very least, help spread awareness and that's what I am doing," Dahn adds.

**Interested in partnering  
with PBTF in 2021?**  
Email [info@curethekids.org](mailto:info@curethekids.org)

## NFL Center Matt Skura and Family Rally Ravens Nation to Help PBTF's Stars

Matt Skura and his wife, Emma – longtime Pediatric Brain Tumor Foundation supporters – understand overcoming challenges, on and off the field.

True champions, they've turned personal hurdles into opportunities to fight for the 13 children and teens diagnosed each day with a brain tumor. Emma's youngest sister Avery battled a brain tumor at age 2. Then Matt lost his grandmother Sandra in 2019 to glioblastoma, a fast-spreading brain cancer.

These experiences inspire the Skuras' commitment to PBTF, which was taken to the next level following the Baltimore Ravens' loss to the New England Patriots during the 2020 NFL season. When some viewers blamed the outcome on Matt's game performance and started harassing his family on social media, Matt took a stand - publicly taking ownership of his performance but declaring attacks on his loved ones out of bounds.

Soon after, sportswriter Matt Wise called attention to the Skuras' support of PBTF and challenged the Ravens Flock to "turn something ugly into something positive" by donating. They responded, giving over \$12,000 to Matt's Touchdowns Vs. Cancer campaign benefiting PBTF.

"Fans really showed an outpouring of support that we were very humbled by and thankful for," Emma says. While the Skuras say it was wonderful to see such positivity spring from something so negative, connecting with PBTF families has been their greatest reward.

One such family was a 15-year-old Carolina Panthers fan who had been battling brain cancer for 13 years and wanted to do something special for his sisters and mom during the holidays. With help from Baltimore Radcliffe Jewelers, the Skuras made this young man's wish come true with custom jewelry for his mom and all of his sisters representing the bond the family shared. For the young man himself, Matt and Emma surprised him with a personal video message from Ravens' quarterback Lamar Jackson and the Panthers' Christian McCaffrey.

The Skuras were honored to be able to provide this Star one more precious moment and memory before he passed away in early 2021. "I think every person could learn to be a little bit more like him," says Emma. "To really think about those around you no matter what your circumstances are in life."



**My wife Emma and I love working with the Pediatric Brain Tumor Foundation for many reasons. They share the same passion as us to find a cure for childhood brain cancer through fundraising efforts that go directly towards research and helping families. PBTF has also helped us find ways to support the families experiencing these emotional and difficult times. Emma and I both have personal connections to brain tumors. We appreciate all the support and guidance PBTF has given us these last few years and we are excited to continue working with them!**

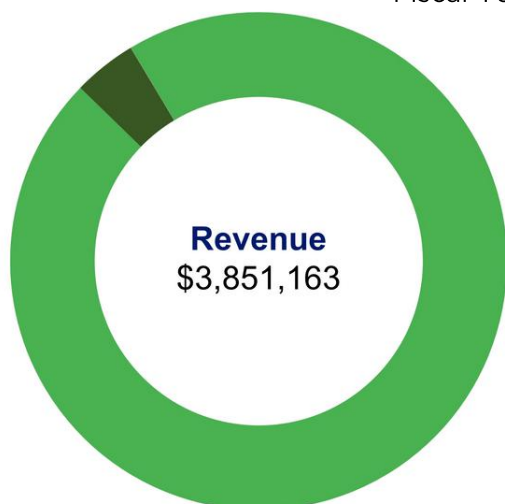
**- Matt Skura, National Football League Center**



# FISCAL YEAR 2020 FINANCIAL HIGHLIGHTS

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

In 2020, the Pediatric Brain Tumor Foundation's Board of Directors voted to change PBTF's fiscal year from a January-December calendar year to October-September fiscal year, resulting in a shortened Fiscal Year 2020 consisting of January-September.

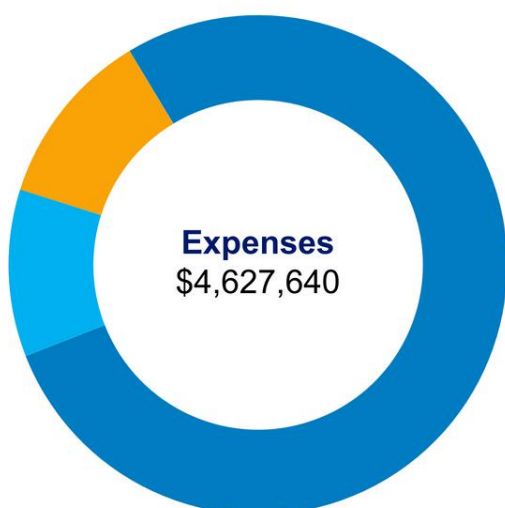


95.9% **Public Contributions:** \$3,692,247

4.1% **Investment Income:** \$158,916

**Ending net assets of \$4,698,703**

Source: Pediatric Brain Tumor Foundation's Form 990 for calendar year Jan. 1-Dec. 31, 2020



77.7% **Program Services:** \$3,594,118  
*Includes \$2,119,642 in research, as well as direct aid to families, hospital grants for child life programs, patient and family education resources, and awareness and advocacy*

10.8% **Management & General:** \$501,057

11.5% **Fundraising:** \$532,465

## FY2020 Audited Financial Statements

### Statements of Financial Position

Sept. 30, 2020 and Dec. 31, 2019

	Fiscal Year Ending	
	9/30/2020	12/31/2019
<b>ASSETS</b>		
Cash and cash equivalents	\$1,547,950	\$1,142,192
Investments	3,422,927	4,200,039
Accounts receivable	202,399	349,082
Other assets	33,859	33,952
Property and equipment, net	41,066	55,614
<b>Total assets</b>	<b>\$5,248,201</b>	<b>\$5,780,879</b>

### LIABILITIES AND NET ASSETS

#### Liabilities:

Accounts payable and accrued expenses	\$238,563	\$280,699
Grants payable	310,935	25,000
<b>Total liabilities</b>	<b>\$549,498</b>	<b>\$305,699</b>

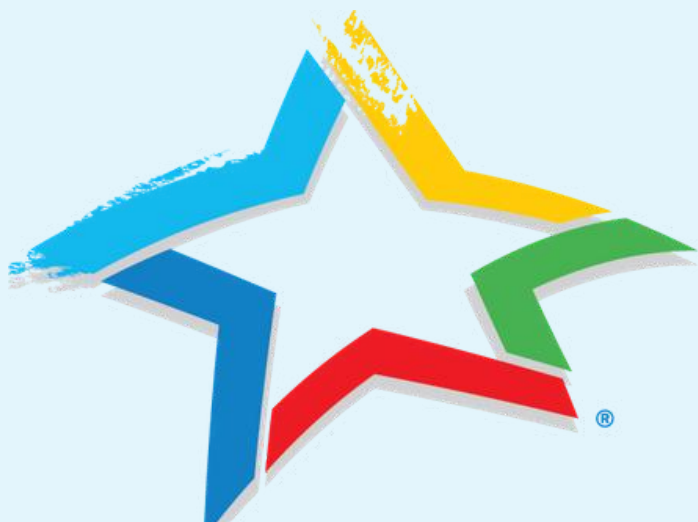
#### Net assets:

Net assets without donor restrictions:		
Board designated-quasi-endowment	816,243	816,243
Available for operations	576,489	5,955
<b>Total net assets without donor restrictions</b>	<b>1,392,732</b>	<b>822,198</b>
Net assets with donor restrictions	3,305,971	4,652,982
<b>Total net assets</b>	<b>4,698,703</b>	<b>5,475,180</b>
<b>Total liabilities and net assets</b>	<b>\$5,248,201</b>	<b>\$5,780,879</b>

## Statements of Activities

Nine-Month Period ended Sept. 30, 2020 and Year ended Dec. 31, 2019

	Fiscal Year Ending	
	9/30/2020	12/31/2019
<b>Revenues, gains, and other support:</b>		
Contributions	\$3,923,022	\$6,909,035
Less direct benefits to donors	(230,775)	(872,000)
Non-cash contributions	144,382	434,825
Investment income, net	14,534	52,085
Net assets released from restrictions	-	-
<b>Total revenues, gains, and other support</b>	<b>3,851,163</b>	<b>6,523,945</b>
<b>Expenses:</b>		
Programs	3,594,118	5,512,923
Management and general	501,057	853,676
Fundraising	532,465	916,140
<b>Total expenses</b>	<b>4,627,640</b>	<b>7,282,739</b>
<b>Changes in net assets</b>	<b>(776,477)</b>	<b>(758,794)</b>
<b>Net assets at beginning of year</b>	<b>5,475,180</b>	<b>6,233,974</b>
<b>Net assets at end of year</b>	<b>\$4,698,703</b>	<b>\$5,475,180</b>



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