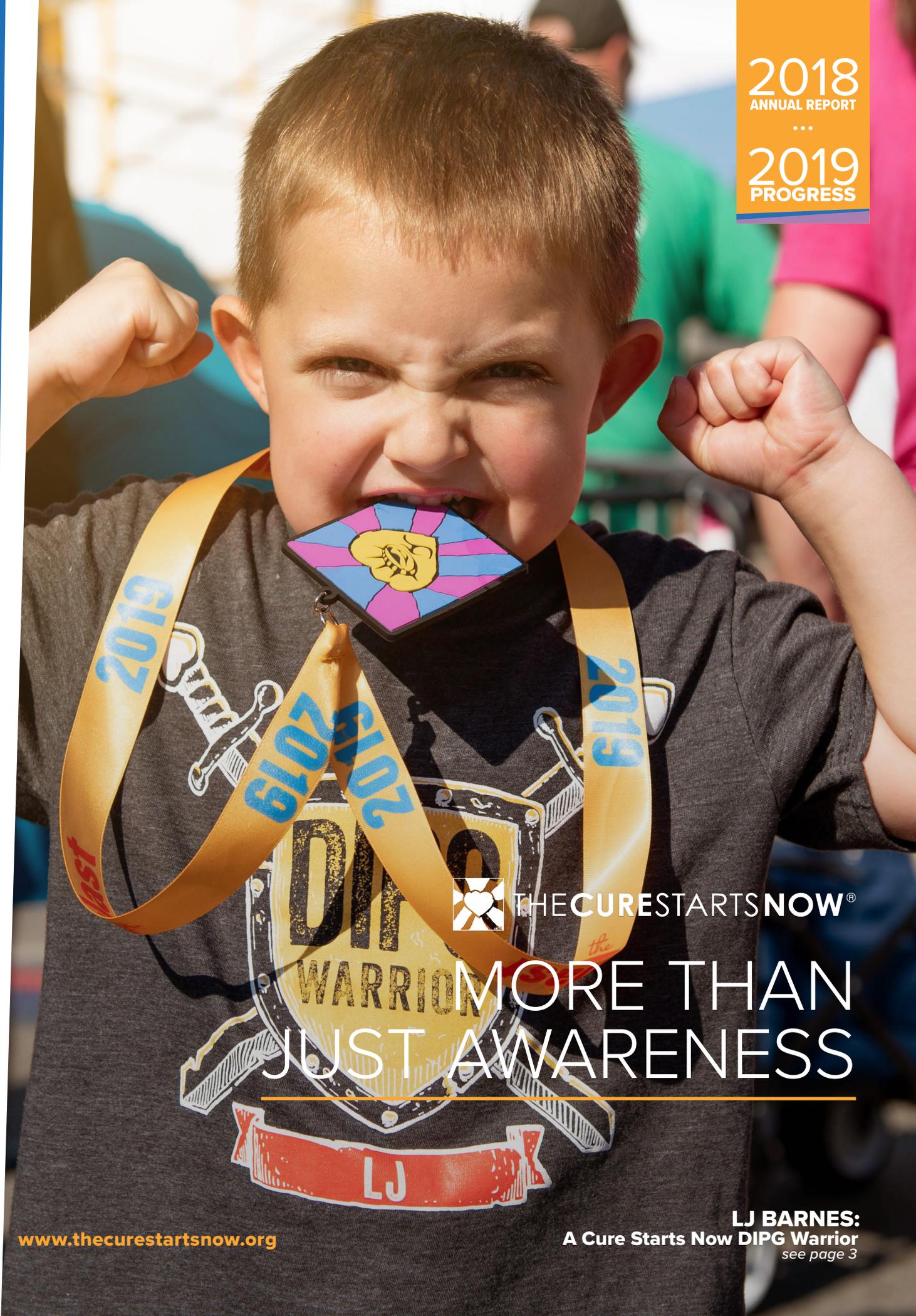


2018  
ANNUAL REPORT  
...  
2019  
PROGRESS



THE CURE STARTS NOW®

MORE THAN  
JUST AWARENESS

[www.thecurestartsnow.org](http://www.thecurestartsnow.org)

**LJ BARNES:**  
A Cure Starts Now DIPG Warrior  
see page 3

# LETTER FROM THE DIRECTOR

*There are so many amazing advancements to report about this year: from revolutionary breakthroughs in research to the building of infrastructures to bring trials to children quicker and closer than ever before. These advancements have placed pediatric brain cancer research miles ahead of where we were when we started.*

In attending the recent DIPG Symposium in Australia, it was humbling to be approached by researchers we have been funding over our 12 years and have them genuinely thank us for funding the vital building blocks in advancing their science. They praised our vision towards the future and focus on elevating the science so that they are able to advance their trials without worry of funding. Can you imagine where the pediatric brain cancer field would be if there weren't amazing donors like you to give researchers the tools to succeed?

In this report, you will read about LJ who only had a chance at a trial because The Cure Starts Now actively funds multiple clinical trials. You made that investment into hope; into LJ's hope. Over the years, we have seen more and more children being enrolled into our funded trials – trials that without your support and efforts we would not be able to continue to support.

As we come to the end of the year, please consider how you or your organization might continue to support these kids. Every little bit helps, just ask LJ and the Barnes family. Thank you for making such a huge impact on so many little lives.



**Brooke Desserich**  
Co-Founder, Executive Director



## WHO WE ARE

### STAFF

**Brooke Desserich:**  
Executive Director

**Christy Drinnen:**  
Accounting Coordinator

**Heidi Feyerherm-Smith:**  
DIPG Collaborative and  
Monkey In My Chair Administrator

**Alli Felts:**  
Event Coordinator

**Rick Merk:**  
Family Outreach Coordinator

**Preston Saunders:**  
Communications and Public  
Relations Coordinator

**Joshua Thompson:**  
Director of Marketing

**Sheila Tillman:**  
Event Coordinator

**Shae Vasile-Beaver:**  
Designer

**Mike Weiner:**  
Technical Director

### MEDICAL ADVISORY COUNCIL

Gavin Baumgardner, DO, Chair

Alberto Broniscer, MD  
Shana Coley, MD, PhD  
Maryam Fouladi, MD, MSC, FRCPC  
Stewart Goldman, MD  
Nicholas Joseph Gottardo, MB  
ChB, FRACP, PhD  
Cynthia Hawkins, MD, PhD  
Daniel McPherson, PhD  
Michelle Monje Deisseroth, MD, PhD  
Roger J. Packer, MD

### STRATEGIC COUNCIL

Alyssa Hawranko, Chair  
Michelle Bjornberg  
Neely Agin  
Vicky Bridier  
Erica Bonner  
Brooke Desserich  
Melissa Fleming  
Kim Kuck  
Frank LaFountain  
Althea Lee  
Mark Newmiller  
Jane Midgley  
Ren Pedersen  
Ginny Pritchett  
Jesse Shumaker  
Robyn Staub  
Lynn Whittington

Tricia Verhaalen

### INVESTMENT ADVISORY COUNCIL

Terry Regan, Chair  
Doug Desserich  
Richard Graeter

### BOARD ADVISORY COUNCIL

Melissa Saladonis, Chair  
Ryan Addcock  
Jim Benedict  
Dave Carlin  
Carla Eng  
Jared Kamrass  
Libby Korosec  
Amanda Orlando  
Oliver Rhine  
Jen Suttmueller  
Greg Vehr

### DIPG COLLABORATIVE COUNCIL

Trent Hummel, MD, Chair  
Tim Hayden  
Keith Desserich

### MONKEY COUNCIL

Dustin Glavin, Chair  
Melissa Duerr

Heidi Feyerherm-Smith

Michael Freeland  
Tori Glavin  
Katie Lidgett  
Ken Miller

### BOARD OF DIRECTORS

Keith Desserich, Chair  
Gavin Baumgardner, DO, Vice Chair  
Doug Desserich, Treasurer  
Trent Hummel, MD, Secretary  
Tamara Ekis  
Melissa Saladonis  
Dustin Glavin  
Alyssa Hawranko  
Terry Regan



# LJ

WARRIOR. AMBASSADOR.  
INSPIRATION.

## WHIRLWIND OF JOY

There is nothing little about LJ's energy, spirit or his inspiration to others. At first glance, he's a whirl. Playing hide and seek in an ice cream parlor, he loves to dance, he loves to run, and he loves to fly. LJ shows up and everyone gets a high five. He likes the things a four-year-old likes – Legos, Mr. Potato Head, monster trucks, little airplanes.

His energy is contagious. His mom, Christina Barnes, talks about that. "His energy makes him different. He's just super full of joy and just super compliant. I think what makes all of it easier is just his willingness to do anything we need him to do."

There are a lot of things LJ needs to do because he has DIPG.

## JUST A BAND-AID

The symptoms first started appearing in November 2017. He quit walking, started crawling, and belly sliding down the stairs. "He stopped talking," recounts Christina. "People couldn't understand him anymore. I was translating for my almost-three-year-old."

His father, Joshua, was stationed with the United States Air Force in Anchorage, Alaska. No one in Alaska had an answer for what LJ was experiencing. Then the MRI in February 2018. The news was not good. "We were told by an oncologist that it was less than hopeful," recounts Christina. "The initial diagnosis was pretty traumatic. They told us what DIPG was, gave us a life expectancy of nine to 12 months, and told us that radiation would be just a band-aid. We were told there were no clinical trials, no biopsy available."

Christina needed a different answer. "We sent his MRI to every children's hospital in the nation," recalls Christina. "Then one night – 10:00 pm Cincinnati time – an oncologist at Cincinnati Children's called my cell phone and asked how were we doing. You know, just how we were doing, asked about the well-being of our family. She just cared about our feelings."

## A FIGHTING CHANCE

Two years before LJ's diagnosis, in November of 2015, Cincinnati Children's Hospital was preparing to launch a radical and promising Phase 2 study of LEE011. Funding was rapidly running out for the year and without it the possibility of this study would be lost or delayed for years. With no governmental or institutional funding available, The Cure Starts Now stepped in and funded the trial – the exact trial LJ is going through.

## FOCUSING ON WHAT MATTERS

LJ has been fighting DIPG since early 2018, but the four-year-old still has a bit of anxiety. His mom, Christina has a bit of anxiety, too. "One of the difficulties we face every day, I think, is still being a parent and not letting our whole focus be our son's cancer diagnosis. He's still a child, he still needs discipline and because he is doing so well – while he's not very symptomatic – personally, our biggest struggle is parenting a seemingly normal child that has a terminal diagnosis. It's really challenging."

*"One of the first things I do every day is to make sure I can hear his breathing. That's not something a normal parent, or you know, a parent without a diagnosis like DIPG, goes through."*

LJ does not show any of his original symptoms and has been busy serving as The Cure Starts Now Ambassador for the Hyde Park Blast, and inspiring teams of Graeter's employees for Cones for the Cure.

The Barnes family counts on The Cure Starts Now for support. "They are battling this disease for me, for our family, and for LJ," says Christina. "To us, it's an organization that's doing what I want to do. I want to focus on my child so it's letting me focus on LJ. The Cure Starts Now is in the fight."

You can help LJ and fund promising trials like the one he is benefiting from at [donate2csn.org](https://donate2csn.org). 

# MORE THAN JUST AWARENESS:

## WORLD-RENOWNED CANCER SYMPOSIUM SPOTLIGHTS GROUND-BREAKING RESEARCH

*With over two years of planning, the DIPG/DMG Symposium – an initiative of The Cure Starts Now Foundation and developed in coordination with the DIPG Collaborative – took place in Sydney, Australia at the beginning of August.*

The first symposium of its kind to be presented in Australia, its objective was to not only feature the efforts of local researchers, but to spark new collaborations between the USA, Canada, Europe and Australia. In just two weeks of open registration, over 174 leading researchers, and 74 foundations joined together quickly filling the conference to capacity, and exceeding previous enrollment by nearly 30%.

Originally envisioned as a Homerun Cure™ conference in 2011, the DIPG/DMG Symposium quickly defined itself as the preeminent collaborative conference on both DIPG, and unique strategies to attack pediatric brain cancers. Renewed in 2013 on a biennial basis, the conference that had now been hosted in Cincinnati and Chicago continued to exceed attendance expectations. Now a showcase of new ideas, such as convection-enhanced delivery, cancer model development and consortium creation, the conference has helped to focus over \$12 million in new research through over 80 trials in 15 countries toward DIPG, DMG and other rare pediatric cancers that experts believe will offer us clues to a larger cure for cancer.

### FOCUSING ON SUCCESS

Unique to the 2019 Symposium, two days were dedicated to special sessions on the successful International DIPG/DMG Registry, and the CONNECT Consortium. Nearly 12 institutions were represented in the Registry workshop – discussing a variety of topics including: new protocols, improved data collection, diffused intrinsic pontine glioma versus diffuse midline glioma collection methods, and how to assist families through some of the most difficult days of the disease. Then on the final day of the conference, at a gathering of 18 institutions, the inaugural meeting of CONNECT was held to premier over 5 new protocols planned to release in the next year. An initiative of The Cure Starts Now and Cincinnati Children's Hospital (later joined by the Brooke Healey Foundation and Reflections of Grace Foundation), CONNECT is a revolutionary partnership of foundations, hospitals and pharmaceutical companies that serves as a new model for cancer research strategy.

During the main conference, in an aggressive schedule conducted over two 16-hour days, both the successes and

failures of over 30 unpublished new trials were presented – inspiring new collaborations and generational studies for the future. Trials ranging from drug delivery, development, and cellular communication were discussed, stimulating new trials that will no doubt form the basis for future funding by The Cure Starts Now and the DIPG Collaborative. Followed by open workshops on parent-patient advocacy and the role of ethics in drug development, the Symposium ended with participants feeling both energetic and optimistic about cure strategies leading up to the 2021 conference in Houston, Texas.

To see more about the DIPG/DMG Symposium and hear from the researchers themselves, visit [dipg.org/symposium](https://dipg.org/symposium). 



# WHY WE FIGHT

## WORDS FROM OUR CHAPTERS

### COLORADO

“The Cure Starts Now represents hope – and hope is absolutely critical in this fight. Although a cure didn’t come in time for my daughter, Piper, I realized that improved outcomes are only attainable through dedicated research, which isn’t being prioritized through national funding. CSN fills that funding gap and has been pivotal in identifying the problems and opportunities that will help us better understand pediatric brain cancer. Starting the Colorado Chapter has allowed me to work hand-in-hand with other incredible DIPG families who believe that by honoring our children, we will help save the next.”

### HOUSTON TEXAS

“We were able to witness the research with our own eyes at the DIPG Symposium. We have become friends with some of the researchers and they understand that it’s personal for us – not just a job. Among the chapters and collaborative members, the relationships that have formed help spur us to keep fighting for those who can’t fight. I would have never guessed that Nicole’s life would be cut short at such a young age and that her fight wouldn’t end September 2009. Her fight continues through us and through everyone who supports. Her victory will be for kids just like her who have yet to understand what DIPG means.”

### SOUTHERN CALIFORNIA

“It’s so important to me to be a part of The Cure Starts Now because I lost my

beautiful Sarah to DIPG. I couldn’t do anything to save her, but I never want another family to go through what we did. I don’t want to see another child suffer like I watched my daughter suffer.”

### ARKANSAS

“Being a part of The Cure Starts Now is important because childhood cancer research is sorely underfunded! We started our chapter in memory of Maylea Estridge – my dear friend’s niece. I watched her journey throughout and it was just heart-breaking. There is no reason that we should be allowing this to continue. We must step up and be a voice for these kids. The cure starts with adults willing to put in the time and effort to make a real change.”

### NEBRASKA

“It is important for us to be part of The Cure Starts Now, so we can work together as families to find a cure in honor of our children. Children should not have to face what our kids went through. They deserve a future.”

### AUSTIN TEXAS

“During Brock’s battle, he was determined for the cancer to be gone and him to be a kid again. When Brock died, we had to decide if we were giving up or would keep fighting in his honor and for all kids. We are doing what Brock wanted and that is to “Kick Cancer in the Nuts!” We chose The Cure Starts Now because we can see the impact of our efforts. We

love the accountability and collaboration with doctors and hearing their results every two years at the DIPG Symposium. We are making a difference.”

### WISCONSIN

“Why being a part of The Cure Starts Now is so important to me is because my daughter Ali deserved to grow up. She deserved a carefree childhood full of scrapes and boo-boos, not chemo, radiation and losing her every ability before losing her breath. I will fight until my very last breath to find a cure for the worst evil I have ever known... DIPG.”

### NORTHEAST OHIO

“Our community loves to support The Cure Starts Now. The Youngstown community has been enormously generous. We are the epitome of “those with the least give the most,” especially when it comes to children. We don’t ever want another family to experience the pain and heartache of watching a child go through cancer treatment or experience this type of heart-wrenching loss.”

### CONNECTICUT

“People have joined my fight and have vowed to fight until we hear the words that a cure has been found. I also want our efforts to make others realize that people are genuinely kind. Sometimes it’s hard to see that in this crazy world, but daily I am blown away by the generosity and kindness and love that this chapter has surrounded me with.”

**43** CHILDREN PER DAY ARE EXPECTED TO BE DIAGNOSED WITH CANCER

National Pediatric Cancer Foundation

**4%** FEDERAL CANCER RESEARCH FUNDING HISTORICALLY DEDICATED TO PEDIATRIC CANCER

National Pediatric Cancer Foundation

# 2018 ANNUAL REPORT

TOTAL REVENUE, GAINS, AND OTHER SUPPORT  
**\$4,971,643**



## BALANCE SHEET

As of December, 31 2018

### ASSETS

Cash and cash equivalents	\$1,044,388
Inventory	\$113,805*
Other assets / prepaid expenses	\$224,628
<b>TOTAL ASSETS:</b>	<b>\$1,382,821</b>

### LIABILITIES

Accounts payable	\$56,056
Grants payable	\$0
Other liabilities:	
Accrued Compensation	\$16,246
Deferred revenue	\$48,708
<b>TOTAL LIABILITIES:</b>	<b>\$121,010</b>

### NET ASSETS

Unrestricted	(\$1,261,811)
Temporarily restricted	\$0
<b>TOTAL NET ASSETS:</b>	<b>(\$1,261,811)</b>
<b>TOTAL LIABILITIES &amp; NET ASSETS:</b>	<b>\$1,382,821</b>

## STATEMENT OF ACTIVITIES & CHANGES IN NET ASSETS

For the Fiscal Year Ended December, 31 2018

### REVENUE, GAINS, & OTHER SUPPORT

Contributions	\$2,539,091
In-kind donations	\$153,732
Special event revenue	\$2,280,605
Investment return	-\$1,785
<b>TOTAL REVENUE, GAINS, AND OTHER SUPPORT:</b>	<b>\$4,971,643</b>

### EXPENSES

Program services:	\$1,181,011
Medical research	\$1,181,011
Medical research grant release**	-\$772,096
Monkey in My Chair	\$145,481
Medical symposium	\$41,536
Family support program	\$483,125
Fundraising	\$1,107,012
Management and General	\$131,156
<b>TOTAL EXPENSES:</b>	<b>\$2,317,225</b>

Increase (Decrease) in Net Assets	\$2,654,418
Net Assets - Beginning of year	-\$1,392,607
<b>Net Assets - End of year</b>	<b>\$1,261,811</b>

\* Inventory consists of stocking Monkey in My Chair kits to prepare for demand.  
 \*\*Former grant recipient who returned grant amount awarded

# 2018 TOP DONORS

## \$50,000+

Abstract Displays  
Allstate Foundation  
Brooke Healey Foundation  
Columbus Foundation  
Keith & Brooke Desserich  
Graeter's Ice Cream Company  
Hope for Caroline, Inc.  
HP Blast Corporation  
Jeffrey Thomas Hayden Foundation  
Julian Boivin Courage for Cures Foundation  
Love, Chloe Foundation  
Reflections of Grace  
Supreme Lending

## \$25,000-\$49,999

Aidan's Avengers  
Austin Strong Foundation, Inc.  
Capital Group Co Charitable Foundation  
Michael & Christa Doran  
Jackson Hewitt Tax Service  
Musella Foundation for Brain Tumor Research & Information, Inc.  
Operation Grace White Foundation  
Pray Hope Believe Foundation  
Storm the Heavens Foundation

## \$10,000-\$24,999

Bruce & Nancy Axmacher  
Benevity Causes  
Benny's World  
BNY Mellon  
Capital Group  
John & Julie Cohen  
Credit Suisse Americas Foundation  
Dawson  
Kevin & Marie Douglas  
Fidelity Charitable  
Gaunt Family Charity Foundation  
GBA Girl's Basketball Assoc Inc  
GM Financial  
Gold Star Chili  
Joy in Childhood Foundation

Julia Barbara Foundation  
Laurens Fight For Cure Inc  
Pep  
Ryan's Hope  
State Street Bank  
Todd Lubas  
Truist  
Union Pacific GivePlus Program  
Walgreens Family of Companies  
Wayland Villars DIPG Foundation Inc.  
Whitley's Wishes  
Winston & Strawn  
Andrew & Crystal Wash

## \$5,000-\$9,999

Adjusters Give Back Inc  
Allstate Insurance Company  
American Youth Soccer Organization Region 88  
Analog Devices  
Elisabeth Barner  
Bonnie Bass  
Brew Ha Ha Cincinnati LLC  
Brown Brothers Harriman  
CCP Commercial Real Estate  
Cedar Springs Public Schools  
Celgene Corporation  
CGI  
Cincinnati Children's Hospital  
Citi Bank  
Craig Maurer  
Demond Martin  
Donnelly Financial  
Esther & George Jaruga Charitable Foundation  
Grant's Ginormous Gift Foundation  
Integrity BioFuels  
Jesse & Alison Thompson  
JP Morgan  
Kendra Scott LLC  
Microsoft  
Middletown Community Foundation  
Sparky & Sally Merk  
Moses Heredia  
Omaha Community Foundation  
Perfect Pallets, Inc

PNC Institutional Asset Management  
Popp Hutcheson PLLC  
Prasco Company  
Rahr Corporation  
Gary & Becky Rutledge  
Schwab Charitable  
Soar with Grace  
Hal & Brenda Stevenson  
Thomas Dale High School  
TSYS Merchant Solutions LLC  
Turnstone Corporation  
Daniel & Oris Weiner

## \$2,000-\$4,999

360 Plumbing and Gas Solutions LLC  
Laurie Allain  
Alex and Ani, LLC  
Andy Chan & Cynthia Woo  
Architectural Precast Association, Inc  
Ascension  
Hugh Balkin  
Kenneth & Marilyn Barnes  
John Boswell  
Briggs Equipment  
Caprock Emergency, LLC  
CharitySmith National Society of Memorial Funds  
Jamie & Amy Charlton  
John Civitillo  
Emma Combs  
Tina Cote  
Customink LLC  
CyberGrants, Inc  
Dough & Sherri Desserich  
Stefano Dukcevic  
Mike & Carla Eng  
Epping Well & Pump Inc  
James & Melissa Fleming  
Adam Gingras  
Georgia Riders RC  
Dave Golder  
Thomas Hatfield  
High Bridge Board of Education  
Lisa Hill  
Inwood Bank  
Janet Johnson  
KDM  
KFK Dancing for Life Inc  
Elizabeth Kiessling  
Kristi King and Warriors for Princess Piper  
Susan Laupola  
Henry & Althea Lee  
Lewisville Independent School District  
Richard & Lynne Merk  
Richard & Lynneann Milligan  
MTX Wealth Management  
Network for Good  
NFL Foundation  
Nisbet Family  
Norwood City School District  
Bradford Oddo  
On Display  
Endre & Jennifer Pekarik  
John & Stella Perentesis  
Plante Moran  
Point Bank  
Port Jefferson Sports Realty, LLC  
Prestige Audio Visual  
Dee & Ginny Pritchett  
Reis Promotions  
Terry & Maureen Regan  
Kimberly Ricker  
Rodney & Diane Sawyer  
Arnie & Ruth Schlittenhart  
George Shaughness  
Stock Yards Bank  
Stratford School, Inc  
Jon & Connie Stiles  
Suzie's Diner  
Tasc Cfc Distri  
Triton Construction  
Union Pacific Railroad Company  
United Way of Benton & Franklin Counties  
Nick Usher & Alyssa Hawranko  
Elizabeth Walser  
Nelson & Carrina Waneka  
Ward's Hardwood Floors  
Elizabeth Weiner  
Zac Margo

# OVER \$12,000,000 IN RESEARCH FUNDED

See grants funded prior to 2017 at [www.thecurestartsnow.org/grants](http://www.thecurestartsnow.org/grants)

## 2019

Dayton Children's Hospital: \$69,600\*  
The University of Sydney: \$100,000\*  
The Institute of Cancer Research: \$121,863\*  
University of Michigan Hospitals: \$157,856\*  
Bambino Gesù Children's Hospital: \$49,803  
Telethon Kids Institute: \$49,512\*

## 2018

Children's Cancer Institute: \$175,089\*  
Cincinnati Children's Hospital: \$540,742\*  
Johns Hopkins: \$50,000  
Bambino Gesù Children's Hospital: \$99,382\*  
The Institute of Cancer Research: \$106,647\*

The Institute of Cancer Research: \$100,000\*  
St. Jude Children's Research Hospital: \$50,000\*  
Ann and Robert H. Lurie Children's Hospital of Chicago: \$50,000\*  
Sydney Children's Hospital, Randwick: \$175,089\*

## 2017

SickKids Hospital: \$100,560\*  
Northwestern University: \$100,000\*  
Gustave Roussy: \$101,868\*  
CONNECT: Cincinnati Children's: \$2,759,496  
Dana Farber: \$100,000\*  
Lowy Cancer Research Centre: \$185,706\*  
Anchutz Medical Campus: \$50,000\*

SickKids Hospital: \$162,828\*  
Institute of Cancer Research UK: \$102,432\*  
Texas Children's: \$200,000\*  
The Campbell Family Institute for Cancer Research: \$100,000\*  
Stanford University: \$200,000\*  
University of California: \$70,000\*  
Children's National: \$200,000\*  
Memorial Sloan Kettering: \$100,000\*  
Massachusetts General Hospital: \$50,000\*  
Ospedale Pediatrico Bambino Gesù (Italy): \$98,987\*

\* Denotes grants funded with our DIPG Collaborative partners.

# CHAPTER SPOTLIGHT VIRGINIA

*Next Million Dollar Chapter*



## LADYBUG

Morgan Pritchett was nicknamed “Ladybug” by her family. She loved arts and crafts, dancing and singing, planning parties, dressing up like a princess, and eating neon blue cotton candy ice cream. Though shy at times, she was capable of making very silly faces, and had a contagious, deep belly laugh. She adored her younger brothers, Matthew and Jason, and her eyes would absolutely sparkle when she waved to others. More than anything, Morgan loved making others happy.

In October of 2007, Ginny and Dee Pritchett learned that Morgan, their 5 year old daughter, had DIPG – a form of brain cancer that, because of its difficult location as well as its vine-like growth pattern, has a less than 5% survival rate.

She had just started Kindergarten and her days of dancing and singing were soon filled with hospital visits and radiation treatments. The tumor’s location on the left side of the pons caused increasing weakness on the right side of Morgan’s body. She was right-handed but very quickly adapted and learned to use her left hand. She was also unable to walk without assistance, but she insisted on walking everywhere she could instead of being pushed in a wheelchair.

Morgan’s determination and courage were inspiring to so many and she battled for 20 months before passing away in June of 2009 – two weeks shy of her seventh birthday.

## A NEW CHAPTER

Ten years ago, to honor Morgan and help children battling DIPG like she had, Ginny and Dee Pritchett stepped up to form one of the first chapters of The Cure Starts Now: the Virginia chapter. “We were driven by a strong desire to honor Morgan’s life and her story by raising awareness and money for pediatric brain tumor research,” Ginny declares. “We hope that our efforts will

help lead to a cure for this awful disease so that one day, no other children and families will have to go through what Morgan and our family have been through.”

## A MILLION DOLLAR MISSION

Ginny and Dee, both accountants, set out on their fundraising mission. They held their first annual golf fundraiser, On Course Fore a Cure, in 2010. They reached out to friends, families, emailed visitors to their website, and networked with contacts who knew Morgan’s story and supported the Pritchett’s cause.



“When we started ten years ago, raising a million dollars was not even in our realm of consideration,” remembers Ginny. They were hopeful that in that first year they could make \$35,000. They didn’t. They made \$60,000. “It just kind of took off at that point,” says Ginny.

Every year, their success grew. “We were just so thrilled with the response and felt like we had a lot of momentum”, Ginny remembers. “We just wanted to continue to build it and make it bigger and better. “

## ACCOUNTANTS SEEKING ACCOUNTABILITY

As accountants, they wanted to be held accountable for the funds they raised. They constantly reminded their network, supporters, and friends how their generosity was producing results. To keep their donors enthusiastic about the cause and motivated to give, they consistently shared the latest news and information on the strides being made in DIPG research.

“We thought it was important for our donors to see the results, so they know that their participation is making a difference.



Many of them have been with us since the very first year, and they've been able to see some of the published research that's happened as a result of their contributions.”

The Pritchett's passion, focus, and determination resulted in achieving what they couldn't imagine was possible: \$1,000,000 in cumulative net proceeds raised in ten years. They credit their amazing supporters for their achievement and, of course, their Ladybug who inspired so many to give year after year to continue her legacy. [❤️](#)



## THE DNA OF COLLABORATION

### AN AWARD LONG OVERDUE

Since 2010, Dr. Chris Jones from The Institute of Cancer Research in the United Kingdom has been a fixture of the DIPG community. One of the first international attendees to the DIPG Symposium, his concentration of identifying the genomic make-up of pediatric gliomas quickly became critical to the larger research industry. He defined himself as a leader in the field by identifying variations in the genomic makeup, and establish genetic differences between adult and childhood versions of these cancers.

There are also few researchers as collaborative as Dr. Jones, whose research and samples you will often find in nearly every publication on the genomics of DIPG. His comprehensive analyses form the backbone of many current registries as well as ongoing research even today. His reach even expands internationally with collaborations in over 15 different countries and expanding with the help of the SIOPe DIPG Registry and



the International DIPG Registry – both supported by The Cure Starts Now. With research focused on ACVR1 mutations, evolutionary dynamics, and beyond, Jones seeks to expose the vulnerabilities of DIPG and other pediatric brain tumors.

At the 2019 DIPG Symposium, Dr. Jones was recognized for both his work and leadership in the DIPG Community as he received the “DIPG Researcher of the Year” award. As one of our most awarded researchers totaling over \$400,000 and four research grants from 2014-2018, it truly was an award long overdue.

You can see more about Dr. Jones and his collaborative efforts by visiting [\[LINK\]](#)

# GRAETER'S CONES FOR THE CURE SETS RECORD YEAR

*The power of Graeter's and The Cure Starts Now's 11-Year partnership*

## SWEET BEGINNINGS

Our successful partnership with Graeter's Ice Cream did not happen overnight. In fact, it began eleven years ago when Graeter's gave The Cure Starts Now the chance to auction off the once-in-a-lifetime opportunity for an individual to create their own Graeter's flavor. The Grotekes family won the auction, and with the help of master flavor expert Bob Graeter, crafted the now-beloved Elena's Blueberry Pie ice cream – named after Elena Desserich, the inspiration for The Cure Starts Now. Since then, Graeter's has given their heart and soul into honoring Elena and all children battling cancer with their annual Cones for the Cure fundraiser.

September 2019 marked a record-breaking year for the cornerstone event of the Graeter's/CSN partnership. Thanks to a growing retail base, and exceptionally generous guests, the 11-day Cones for the Cure campaign raised over \$220,000 – an increase of over 37% from the 2018 record year of \$166,000.



More than 50 Graeter's retail stores in five states participated in the fundraiser – with nearly half of the retail locations setting new individual store records. The Cure Starts Now Co-Founder, Keith Desserich explains, “Graeter's has been an incredible partner for The Cure Starts Now

for more than eleven years. The fact that they can inspire the local community to come out in support of our mission year after year and continue to raise more money is amazing and humbling. We couldn't be happier with the results of this year's campaign, and are proud to have Graeter's as part of The Cure Starts Now family.”

*“This campaign is a winner every year for Graeter's. The community loves Elena's Blueberry Pie ice cream, summertime, and finding a way to give back. Charity campaigns that help our local community are always a win/win – and something we look forward to doing every year.”*

*- Chip Graeter, fourth-generation owner of Graeter's Ice Cream*

## RECIPE FOR SUCCESS

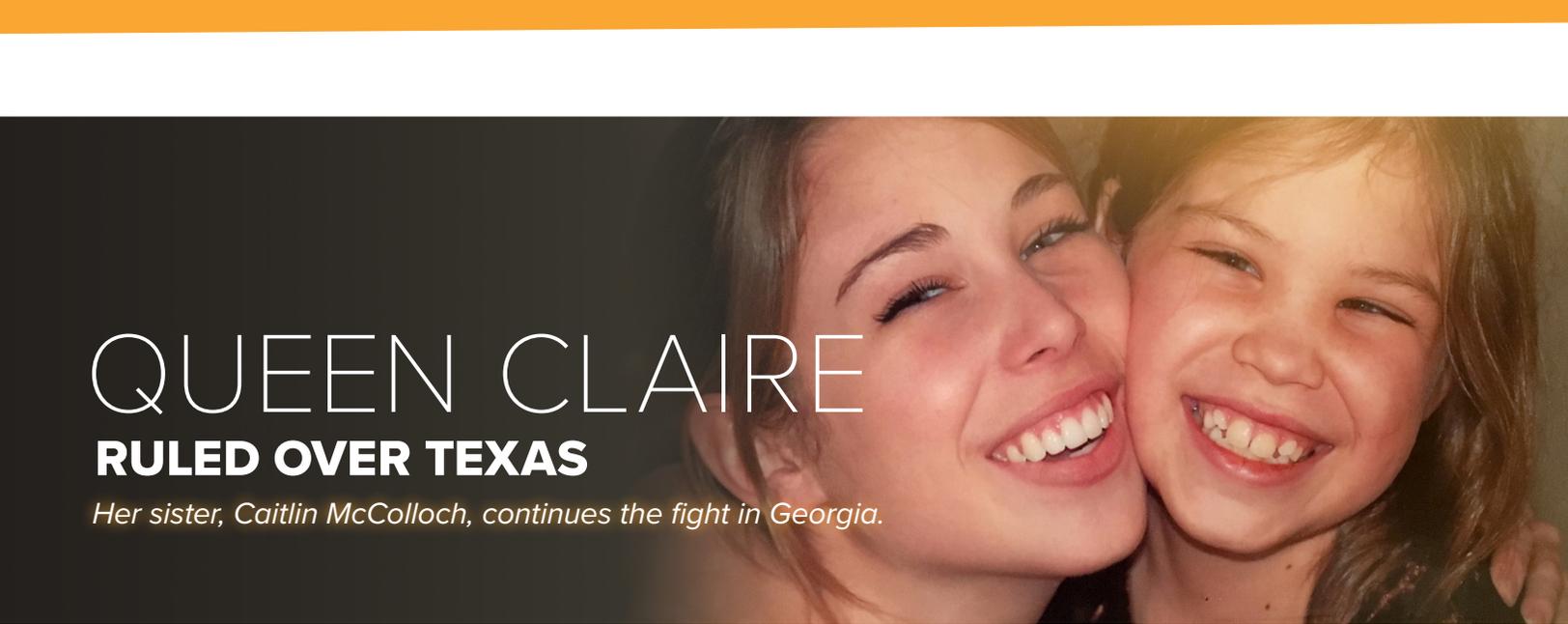
During Cones for the Cure, every Graeter's guest is asked to make a donation to fund pediatric brain cancer research. Guests making donations of five dollars or more receive a coupon book with \$20 of savings. Each donation is tracked with a “scoop” that is displayed inside the store. In addition to the in-store fundraiser, Graeter's also donates a portion of the proceeds from every pint of Elena's Blueberry Pie Ice Cream. This includes sales from all of the country including the Central Markets in Texas, who did a free tasting event throughout all their stores for a day during the fundraiser.



This year three amazing ambassadors shared their stories, inspired guests to donate, and cheered on employees as they asked guests to participate. Addison, David, and LJ made frequent appearances in the retail stores, and online. David stopped by Louisville stores on a regular basis to post the progress online. LJ's family showed up during Graeter's employee training to tell their story and provide inspiration. Addison made visits in the Indianapolis area and even autographed coupon books for her many fans.

The results were sweeter than ever before. Cones for the Cure donations over the life of the partnership are nearing \$1,000,000 – enough to fund five to eight new trials. 





# QUEEN CLAIRE

## RULED OVER TEXAS

*Her sister, Caitlin McColloch, continues the fight in Georgia.*

### A BELOVED QUEEN

Claire was a fiery young girl from North Texas who loved school, pink and being the boss. She was a smart, kind and a hero to many – including her older brothers and sister.

Caitlin McColloch, director of the Georgia Chapter of CSN, remembers her sister well. “Brave, strong, smart and sassy. Queen Claire ruled the house from the time she was born, and knew how to get exactly what she wanted.” Caitlin also remembers that Claire also dominated at games – her favorites were Sudoku and Bookworm.

*“If Claire had been given the chance, she would have grown up to be either the President or a teacher like her mom.”*

Claire was diagnosed with DIPG in December 2006 at 8-years-old. Her family’s priority was to help her live longer and better. Claire spent her time during therapy in typical Claire fashion: playing tricks on her doctor, having wheelchair races down the halls of the hospital, and races where someone would have to run up many flights of stairs to see if they could beat her on the elevator.

### ON THE SAME MISSION

They enrolled Claire in a new trial in 2008, “Mainly to support research and help Claire live out the rest of her life with as little pain as possible.” Caitlin recalls. With bravery and grit, along with her dog Lucky, Claire lived three years past her initial date of diagnosis – unusual for this type of tumor.

The Cure Starts Now was key in helping support the family from the beginning. “My mother met Brooke back in the CSN early years after Claire was diagnosed,” Caitlin recalls. “Knowing a family that had gone through the same thing meant a lot to my parents. Brooke was kind, empathetic and passionate about finding a cure for the terrible cancer that was killing my little sister.”

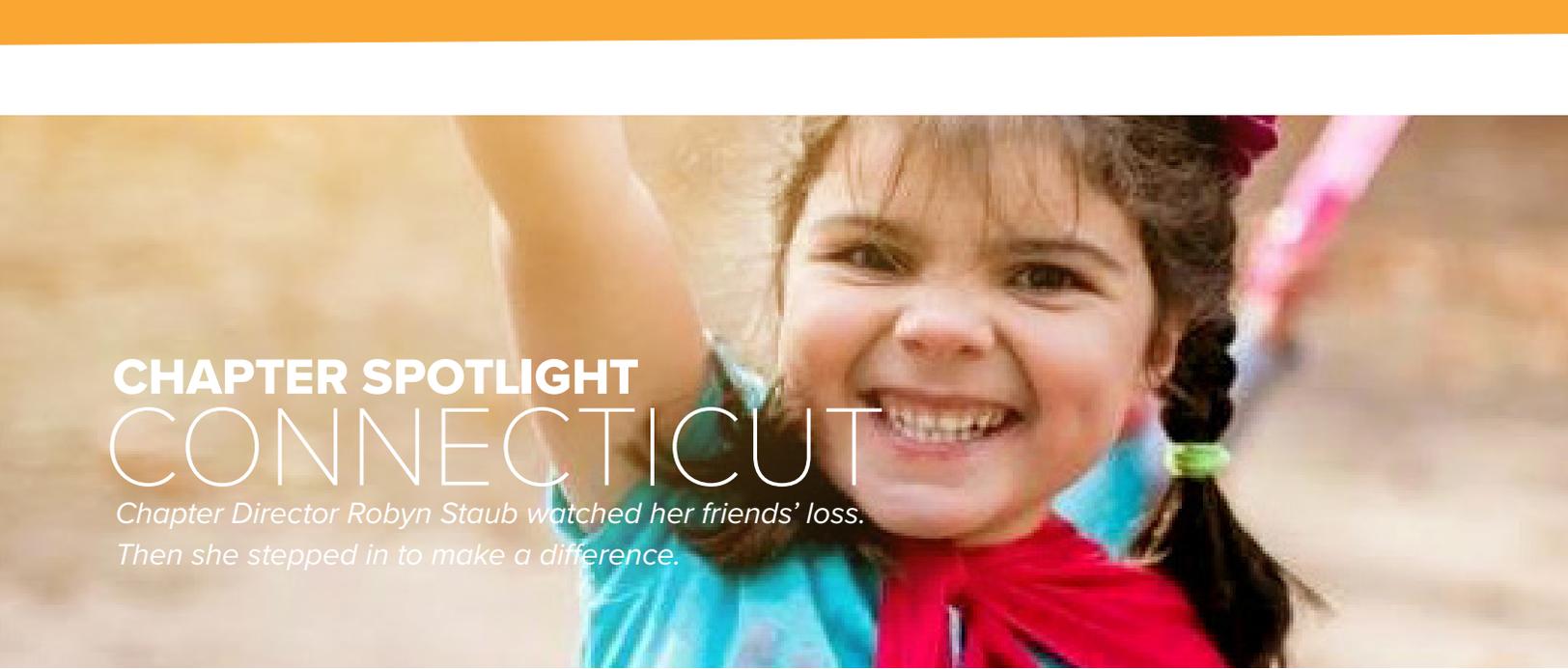
The mission and focus of The Cure Starts Now stuck with Caitlin, even as she moved to Atlanta. Realizing The Cure Starts Now had minimal representation in the south, Caitlin established the Georgia Chapter in 2017. “By joining and already established organization like CSN, it makes it easy to honor Claire and raise money for critical research” she says.

### COLLABORATION IS KEY

Caitlin used her contacts with ASW Distillery in Atlanta for an interesting approach to ‘fun-raising:’ a limited-edition, CSN whiskey bottle-release party, with proceeds going to The Cure Starts Now. The party included a raffle to win the actual barrel the whiskey was aged in. This is the first time ASW Distillery did a barrel pick for charity. The partnership with ASW Distillery on the limited edition CSN whiskey drew a huge crowd for the launch party.

Caitlin certainly has harnessed the power of partnerships with her chapter, “One thing you do with one business/organization can lead to something else with another. Your network is really important. Events like these are important, but it’s the collaborations with other organizations and institutions that are going to make the biggest difference. I think CSN is really focused on making those collaborations happen, and I really appreciate that. We’re not going to find a cure alone – we have to create strategic partnerships,” Caitlin declares.

Caitlin McColloch stepped in where there was no CSN chapter and was ready to organize, raise awareness, collaborate, and build resources. Her work honors her sister, helps other families facing cancer and funds the research for the Homerun Cure™. We think Queen Claire would approve of her sister’s efforts. 



## CHAPTER SPOTLIGHT CONNECTICUT

*Chapter Director Robyn Staub watched her friends' loss.  
Then she stepped in to make a difference.*

### LEA: WARRIOR. HERO.

Lea Doran was a thoughtful, joyful, creative spark of a girl who loved nature, and painting the world with her colorful artwork. She took over her mom Christa's office as her own personal workspace. Connecticut Chapter Director Robyn Staub remembers "She quite literally would brighten up an entire room with her smile. She made you smile instantly. Lea was a bright, funny, creative, kind and strong little girl."

In August of 2017, that kind, strong little girl was diagnosed with DIPG. Robyn Staub wanted to step up and help her friends, Christa and Mike Doran, Lea's parents, but didn't know where to begin.

"When I learned about Lea's diagnosis I had never heard of DIPG. So I did some research and was just devastated. I knew there was nothing I could really do to help my friends other than to just be there for them. I started looking up charities that I could at least donate to and The Cure Starts Now came up. I read about Elena's story and about Brooke and Keith Desserich and I was just blown away by what they have accomplished."

*"I thought maybe this was what I was supposed to do. I was supposed to start [a chapter]."*

### TAKING ACTION

Robyn decided to donate and become involved in the Connecticut chapter only to realize there wasn't one. So, she started the process of creating the chapter with the support of Lea's parents.

"As I went through the process, Lea began to decline and by the time I attended the chapter meeting in April of 2018 I knew she wasn't going to be with us much longer," Robyn recalls. "I struggled with my next steps and my role at that point. I wanted to help find a cure in time to save Lea, and it was becoming apparent that wasn't going to happen. I didn't know how to proceed."

Robyn sought out guidance from the very people she wanted to support. She spoke with Mike and Christa. "They said that no matter what, they were supporting me and this chapter and that Lea will always be its hero and warrior," recalls Robyn.

That hero and warrior, Lea Doran, died from DIPG in May 2018, at the age of 6. Just weeks after Lea's death, Robyn held her first event, Lessons From Lea Cocktail Social. The event was a wonderful outpouring of support and kindness that far exceeded Robyn's expectations.

### STRENGTH IN COMMUNITY

That support and kindness continue to inspire Robyn's work. "We are so lucky to live in a tight-knit community that has shown so much generosity toward us." And it's been more than financial generosity – Robyn quickly learned that the community wanted to help her. "People felt as helpless as I did, and this gave them a purpose. Lea has brought out the best in people"

Robyn founded a chapter to support her friends, but along the way it became about something more: helping all families impacted by cancer and DIPG. And she wants everyone to know that, "we can make a difference." 



# FUN-RAISING

Check out these unique ways our supporters are raising money and awareness for the Homerun Cure™ for all cancers.



## RIBBONS FOR RESEARCH

In honor of what would have been Alison Verhaalen's 5th birthday, family friend Amy Ausloos helmed a campaign to cover their hometown in bright blue ribbons (Ali's favorite color) and raised nearly \$2,000 for The Cure Starts Now Wisconsin Chapter.



## MAC-ING A DIFFERENCE

Cincinnati-area Panera Bread locations honored Lauren Hill with their Mac a Difference and Community Bread Box campaigns, raising close to \$24,000 towards the Homerun Cure™.

# CHAPTER COMMUNITIES IN ACTION



# FIRST RESPONDERS “BEARD IT UP”

*If your men in blue look a little scruffier than usual this November, it may be our fault. Beard it Up, a campaign that gives law enforcement officers the opportunity to pay to grow a beard, has quickly become one of The Cure Starts Now’s largest nationwide fundraisers – raising over \$168,000 in its first year.*

“Beard it Up” was the brain child of CSN Chapter Directors, and Texas families Troy and Vicky Bridier, and James and Melissa Fleming. Troy was serving as a Texas State Trooper when his 4-year-old daughter Jade was diagnosed with DIPG – passing just 5 days later. James was an Austin City Police Officer when his son Brock was diagnosed with DIPG at 7 years old and – passing 7 short months later. “Beard it Up” became a way for the families to unite the support of their Blue Family with their passion of finding the Homerun Cure™ to all cancers.

2018 marked the first year of the “Beard It Up” campaign, and the Bridiers and Flemings did a lot of the heavy lifting by personally reaching out to and recruiting agencies from all over the country for the fundraiser. A task that became easier over time as larger departments, like Houston who raised over \$50,000, came on board. And it wasn’t only about beards. Not wanting to leave out

female officers, we paired it with Color for the Cure – allowing those who donate the chance to dye their hair or get creative with their nails.

The law enforcement community latched on to the campaign and championed the cause – often recruiting other agencies, or starting friendly competitions with other departments. By the end of the campaign the joint effort of over 65 law enforcement agencies nationwide raised over \$142,000.

## SO WHAT’S GROWING FOR 2019?

Aside from even more law enforcement agencies participating this year – from Florida to Hawaii – we’ve upped the ante on encouraging our “Above Average Joes” to participate. This year we have teamed up with MEAN Beard, an amazing company offering the world’s MEANest beard care products, to provide both incentive prizes as well as a few epically bearded ambassadors to help encourage our new recruits in their bearded journey. And it’s worked. Beardsmen, from truckers to doctors to cats (yes... a cat) have come out en masse to support the campaign and our littlest warriors.

Visit [bearditup.org](http://bearditup.org) to see how the campaign is going, or to support your favorite beard. 





# OUR GLOBAL REACH

The Cure Starts Now has had tremendous growth over the past year and has 43 chapters in 3 countries including The United States, Australia, and Canada.



**BIRMINGHAM, ALABAMA**  
Director: Elizabeth Adams  
Inspiration: Madeline



**MOBILE, ALABAMA**  
Director: Erica Bonner  
Inspiration: Aiden



**ARKANSAS**  
Director: Nicole McCoy  
Inspiration: Maylea



**NORTHERN CALIFORNIA**  
Director: Jackie Harrison  
Inspiration: Khylee



**SOUTHERN CALIFORNIA**  
Director: Shannen Nelson  
Inspiration: Sarah



**COLORADO**  
Director: Carrina Waneka  
Inspiration: Piper



**CONNECTICUT**  
Director: Robyn Staub  
Inspiration: Lea



**GEORGIA**  
Director: Caitlin McColloch  
Inspiration: Claire



**ILLINOIS**  
Director: Sarah Carlton  
Inspiration: Makanda



**COLUMBUS, INDIANA**  
Director: Lynn Whittington  
Inspiration: Peyton



**FRANKFORT, INDIANA**  
Director: Amber Price  
Inspiration: Kaylee



**SOUTHEASTERN INDIANA**  
Director: Lisa Hill  
Inspiration: Lauren



**SALINA, KANSAS**  
Director: Heidi Feyerherm-Smith  
Inspiration: Chloe



**TOPEKA, KANSAS**  
Director: Christine Kottman  
Inspiration: Morgan



**LEXINGTON, KENTUCKY**  
Director: Robin Dodd  
Inspiration: Bruce Incorporated



**CENTRAL MASSACHUSETTS**  
Director: Abby Arpano  
Inspiration: Kate



**MASSACHUSETTS**  
Director: Lisa & John Mackintosh  
Inspiration: Nicole



**SOMERSET, MASSACHUSETTS**  
Director: Ken Oehmen  
Inspiration: Selina



**MICHIGAN**  
Director: Kim Ricker  
Inspiration: Brison



**MINNESOTA**  
Director: Marisa Magnuson  
Inspiration: Tyler



**MISSOURI**  
Director: Karyn Lee  
Inspiration: Kaylee



**NEBRASKA**  
Director: Jesse Shumaker  
Inspiration: Madelyn



**N. NEW HAMPSHIRE**  
Director: Jesse Thompson  
Inspiration: John



**S. NEW HAMPSHIRE**  
Director: Frank Lafountain  
Inspiration: McKenzie



**NEW YORK**  
Director: Kim Kuck  
Inspiration: Mandy



**NORTH CAROLINA**  
Director: Mark Newmiller  
Inspiration: Ella



**CENTRAL NORTH CAROLINA**  
Director: Erin Dougherty  
Inspiration: Odin



**OHIO**  
Director: Brooke Desserich  
Inspiration: Elena



**NORTHEAST OHIO**  
Director: Jane Midgley  
Inspiration: Kasey



**WESTERN PENNSYLVANIA**  
Director: Alyssa Hawranko  
Inspiration: Alyson



**EASTERN PENNSYLVANIA**  
Director: Alissa Grove  
Inspiration: Josie



**AUSTIN, TEXAS**  
Director: Melissa & James Fleming  
Inspiration: Brock



**CEDAR HILL, TEXAS**  
Director: Tanika Pierce  
Inspiration: Sarai



**CENTRAL TEXAS**  
Director: Vicky Bridier  
Inspiration: Jade



**HOUSTON, TEXAS**  
Director: Althea Lee  
Inspiration: Nicole



**NORTH TEXAS**  
Director: Michelle Bjornberg  
Inspiration: Sydney



**SOUTHEAST TEXAS**  
Director: Cristy Smith  
Inspiration: Corbin



**VIRGINIA**  
Director: Ginny Pritchett  
Inspiration: Morgan



**WASHINGTON**  
Director: Julie Caplan  
Inspiration: Victor



**WASHINGTON, DC**  
Director: Neely Agin  
Inspiration: Alexis



**WISCONSIN**  
Director: Tricia Verhaalen  
Inspiration: Alison



**AUSTRALIA**  
Director: Ren Pedersen  
Inspiration: Amy



**BRITISH COLUMBIA, CANADA**  
Director: Cari Comboye  
Inspiration: Liam

INTERESTED IN BECOMING A CHAPTER? CONTACT US AT [INFO@THECURESTARTSNOW.ORG](mailto:INFO@THECURESTARTSNOW.ORG)



THE CURE STARTS NOW®

International Headquarters  
10280 Chester Road  
Cincinnati, OH 45215



THE CURE STARTS NOW®

# 100 FAMILIES STRONG

*FOR THE HOMERUN CURE™*

Tune in December 3rd for our annual Giving Tuesday Give-A-Thon as families fundraise for the Homerun Cure™.

[facebook.com/TheCureStartsNow](https://facebook.com/TheCureStartsNow)

