

2017 PROGRESS & 2016 ANNUAL REPORT  
FALL 2017

#HOMERUNCURE

CARSON, AGE 5

A PUBLICATION FOR THE FRIENDS OF:



THE CURE STARTS NOW®  
[www.thecurestartsnow.org](http://www.thecurestartsnow.org)

# LETTER FROM THE EXECUTIVE DIRECTOR

The homerun cure has been our mission since 2007. And this year we mark our ten year anniversary revolutionizing how we fight cancer: by the science and not just by the numbers. Since starting The Cure Starts Now in our basement, it has grown to an innovative and grass roots charity that today spans 3 continents and 32 chapters worldwide. And while our efforts at funding research number over 70 research protocols at 40 or more independent medical institutions; our focus has always been on the children. After all, we measure our effectiveness by curing cancer, one child at a time.

The Cure Starts Now has always been about the power of positive inspiration. Whether that was through the notes of love my daughter Elena left for us to find after her passing, or the challenge to us all by Lauren Hill to “never give up”, this charity is not about desperation or looking back.

Instead we honor our children by letting their legacies thrive in the development of real cures and new ways of fighting cancer that have never been explored.

We are also successful in this strategy. From innovative delivery methods such as convection enhanced delivery in brain cancers, to the ground-breaking International and SIOPe DIPG Registries, to breakthroughs in histone level understanding, the research we partner with is changing lives today and with all cancers worldwide.

Our tenth year and forward promises to be equally revolutionary, from the development of new consortiums designed to deliver constant treatment options around the world, to unparalleled translational trials never before attempted in cancer research, we pledge to fight cancer in ways that have never before been attempted.

Our tenth year also has meaning on a practical level. Not only do we honor your support with some of the lowest overhead costs in the charity world, but in our tenth year, we will also reach \$10 million in new research implemented from The Cure Starts Now! (That number is even bigger when combined with our partners of the DIPG Collaborative.)

10 years, \$10 million in new research. It's all because of the enduring faith and support you give daily to The Cure Starts Now. Thank you is never enough!



**Brooke Desserich**  
**Co-Founder/  
Executive Director**  
**The Cure Starts Now**



## \$10 MILLION IN DIPG RESEARCH



**That is \$10 million in 10 years! Thank you to our chapters, donors and volunteers for making it possible.**

Since the Fall of 2015, we have been doing something special for our research grant recipients. We wanted to surprise them and thank them for their continued hard work and dedication to furthering research to find the homerun cure.

So, The Cure Starts Now and members of the DIPG Collaborative set out in person and via webcam to surprise these researchers, Publisher's Clearing House style.

We are often asked how we decide which grants to fund. Easy, we ask the experts. Our Medical Advisory Committee is made up of experts in neuro-oncology from around the world. These researchers review all of the grants submitted and only select the grants that show innovation in their ideas and feasibility in their execution.

Our Medical Advisory Council also reviews grants to ensure there is no duplication of research around the world and that no unnecessary overhead is funded.

Check out some of our surprise research grant presentations on our YouTube channel!

[www.youtube.com/user/curestartsnow](http://www.youtube.com/user/curestartsnow)

# MEET SUPER CARSON

*The story of how our friend Carson, who is battling DIPG, is living every day to the fullest with his family.*

Carson Hall was born in January 2012 and is the first born son to his parents. Carson loves to be active! He loves swimming in the summer, playing water balloons, playing on his swing set and most of all playing with his brother, Colton. He enjoys going to school and visiting the zoo – what little boy wouldn't!

Around the age of one, he began having respiratory issues, which were diagnosed as Viral Induced Asthma. However, he was otherwise healthy. He was meeting every milestone and was an extremely happy and loving child. There was no inclination that anything was, or ever would be, wrong with him.

In April of 2016, his parents started noticing changes in Carson. His behavior was different, his gait was off and he seemed dizzy a lot of the time. After weeks of persistent doctor's appointments and phone calls, his behavior warranted a trip to the Emergency Room. The ER doctor did not realize the severity of the symptoms he was showing and told his mother that nothing was wrong, other than possible vertigo.

Fortunately, the ER trip expedited a neurology appointment. On May 11, 2016 he saw a neurologist that was concerned and ordered an MRI as soon as possible.

May 12, 2016 Carson's family received the devastating news that Carson had an inoperable tumor on his brainstem, which is almost always fatal. He had, on average, 9 months to live.



*In case you missed it, Carson is featured on the cover of this year's progress and annual report!*

"We made an appointment for a second opinion because as parents you can't believe someone is telling you that your child will not make it," said Lindsay, Carson's mom.

On May 13, 2016 the Halls learned the name of the tumor was Diffuse Intrinsic Pontine Glioma, DIPG, and the prognosis was indeed correct.

Carson received the standard 30 days of radiation therapy, which was completed in July of 2016. Prior to radiation, he was unable to walk or feed himself and was also very hard to understand.

Shortly after radiation, besides the side effects from the steroids, you would not know anything was wrong with him. His tumor shrank an amazing 50% and he was back to himself!

In February 2017, a routine follow up MRI showed tumor progression. At this point he was not showing any symptoms, but his family was told they would see them in approximately 6 weeks. The doctor was spot on. They started noticing increased symptoms about 6 weeks later. The Halls contacted Carson's doctors and came to an agreement to do re-irradiation.

Carson is now 17 months past diagnosis and is 100% a normal 5-year-old boy. He runs and jumps and plays. The best thing post-diagnosis that his family has done to make memories is to travel. His Make A Wish trip was a Disney Cruise and they have traveled to Mexico to go to the beach, one of his favorite things to do!

He lost his first tooth and he started Kindergarten, both things they never thought they would get to experience with their son.



*Carson with his parents, Lindsay and Matthew and his little brother, Colton.*

Carson's mother says, "Although our future is unknown, we are choosing to live each day to the fullest. We are busy making memories that will last a lifetime no matter what our future brings. What we do know, however, is that childhood cancer is extremely underfunded. DIPG is unknown to most people. We need to raise awareness. We need to increase funding. Most of all, we need a cure. We have to continue to work together to advocate for our kids and continue to spread awareness. Not just for DIPG, but for all pediatric cancers."

## CSN IS LED BY CANCER PARENTS

**The Cure Starts Now (CSN) was founded by parents of children with cancer. Nearly all of our chapters are also run by cancer families in honor of their children. What does this mean? We are passionate about funding DIPG research in the most effective and efficient way possible. We are also acutely aware of what newly diagnosed families are facing and the support they need!**

# RESEARCH FUNDED

## 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\*  
 Anschutz 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\*

## 2016

Cold Spring Harbor Lab - \$100,000\*  
 SickKids Hospital - \$194,260\*  
 Children’s Cancer Institute - \$143,884\*  
 Gustave Roussy - \$93,071\*  
 Sick Kids Hospital - \$50,000\*

## 2015

SickKids Hospital—\$190,065\*  
 Stanford University—\$200,000\*  
 Centre for Evolution and Cancer—\$99,470\*  
 Children’s National—\$200,000\*  
 Cincinnati Children’s—\$200,000\*  
 Children’s Cancer Institute AU - \$145,341\*  
 VUMC, Netherlands - \$932,917\*  
 Cincinnati Children’s—\$699,935\*  
 Dana Farber—\$100,000\*  
 Boston Children’s—\$110,000\*  
 UCL Institute of Child Health—\$200,000\*  
 Cincinnati Children’s—\$100,000\*  
 Children’s National—\$125,000\*  
 Texas Children’s—\$200,000\*  
 Jewish General Hospital—\$100,000\*  
 Memorial Sloan Kettering—\$99,980\*



# \$12 MILLION

Since 2007, The Cure Starts Now has funded over \$12 million in DIPG research with our partners in the DIPG Collaborative.

# 70 GRANTS

The Cure Starts Now, in conjunction with the DIPG Collaborative, has funded 70 innovative research grants in 6 countries.



## 2015 CONT.

Lowy Cancer Research Centre - \$81,683\*  
 Stanford University - \$50,000\*  
 Lurie Children’s - \$50,000\*  
 Cincinnati Children’s - \$100,000\*  
 Dana Farber—\$100,000\*  
 VUMC, Netherlands - \$92,950\*

## 2014

UCSF—\$100,000\*  
 SickKids Hospital—\$99,400\*  
 Institute of Cancer Research UK—\$95,325\*  
 VUMC, Netherlands - \$32,529\*  
 Cincinnati Children’s—\$176,186\*

## 2013

Monash Institute—\$108,840\*  
 SickKids Hospital—\$100,000\*  
 Texas Children’s—\$100,000\*  
 Dana Farber—\$50,000\*  
 Children’s Cancer Institute—\$100,000\*  
 Cincinnati Children’s - \$205,000\*  
 Lurie Children’s—\$100,000\*  
 Children’s National—\$99,979\*  
 Yale—\$100,000\*  
 Duke Children’s—\$85,394\*

## 2012

Cincinnati Children’s - \$219,000\*  
 Stanford University—\$35,589  
 Texas Children’s—\$100,000\*  
 St. Jude—\$15,000\*

## 2011

Sydney Children’s—\$100,000  
 Doernbecher—\$100,000\*  
 Duke Children’s—\$82,049\*  
 Texas Children’s—\$100,000\*

## 2010

Weill Cornell—\$91,470  
 Cincinnati Children’s - \$75,000  
 Cincinnati Children’s - \$35,000  
 St. Jude—\$35,000

## 2009

St. Jude—\$10,000  
 Cincinnati Children’s - \$50,000  
 St. Jude—\$50,000

## 2008

St. Jude—\$25,000  
 Cincinnati Children’s - \$50,000

\* denote grants funded with our partners in the DIPG Collaborative.



# YOUR DONATIONS IN ACTION

*We sat down with two DIPG researchers and asked them to explain their research to the donors who make it all possible.*

## DR. MICHELLE MONJE, STANFORD UNIVERSITY

*Dr. Michelle Monje has been one of the leaders in DIPG research in the United States. Winner of the 2017 Innovative Researcher award from the DIPG Collaborative, recipient of both the 2015 DIPG Collaborative Snap Grant and 2017 Snap Grant and recipient of over \$500,000 from The Cure Starts Now and DIPG Collaborative. Dr. Monje also serves as a crucial voice on our Medical Advisory Council in determining promising grant opportunities.*



“Our most recent grants from The Cure Starts Now and the DIPG Collaborative have helped us to explore the idea that the activity of neurons - the central cell type responsible for the various functions of the nervous system - promotes both DIPG growth and invasion through distinct mechanisms.

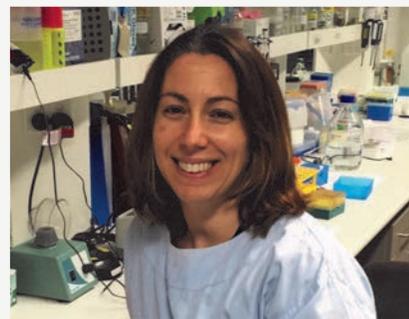
What this line of research has taught us is that DIPG depends on growth signals regulated by neuronal activity for growth and for invasion. We have identified key targets to therapeutically disrupt communication between active neurons and DIPG cells. We are continuing to work to fully understand how DIPG takes advantage of these growth signals, and how to best translate these findings to the clinic in order to provide better DIPG therapy. One particularly promising therapeutic strategy has already come to light, and we are working hard to bring it to clinical trial as quickly as we can for children with DIPG.

In addition to developing a deeper understanding of the intrinsic vulnerabilities of DIPG cells, we are closer to effective therapies targeting the tumor microenvironment and therapies leveraging the power of the immune system for DIPG. The possibility for convergence of complementary, cooperative strategies was particularly evident at the recent 2017 DIPG Symposium.

Funding from The Cure Starts Now and the DIPG Collaborative has been a crucial pillar of support for my research laboratory. This support has been substantial enough and consistent enough that I can say without hesitation, The Cure Starts Now and the DIPG Collaborative have helped to make possible every major DIPG research contribution from my lab. We would not be where we are now without this funding, and without the collaborative DIPG research community that The Cure Starts Now has helped to create.”

## DR. MARIA TSOLI, LOWY CANCER RESEARCH CENTRE (AU)

*A senior scientist at Lowy Cancer Research Centre, Dr. Maria Tsoli is helping to lead the charge to focus on the deadly disease of DIPG in Australia. Dr. Tsoli is the recipient of over \$225,000 in research grants from The Cure Starts Now and our DIPG Collaborative partners.*



“The CSN funding has been pivotal in establishing our DIPG Research Program at the Children’s Cancer Institute. This is the first established laboratory in Australia with a program specifically focused on developing novel treatments for DIPG.

Each grant received has allowed the program to explore diverse therapeutic approaches and generate preliminary data to attract additional funding from larger national grant schemes. More importantly it has led to one of our recent discoveries (CBL0137)—shown to have promising therapeutic efficacy in DIPG preclinical models — to be developed as a COG Phase 1 trial.

We should expect a plethora of new therapeutic approaches to be introduced and trialed over the next five years. These include biotherapeutics, antibodies, immunotherapies, sequential drug treatments, as well as new methods to overcome the blood-brain-barrier.

I would like to thank the donors and those involved in securing funding for our lab and other teams globally. Without funding we would not be able to develop pre-clinical models of DIPG, examine the therapeutic efficacy of drugs and understand the biology of this tumour.”

### DID YOU KNOW?

**100% of general donations go directly to fund pediatric brain cancer research.**

*(If paying by credit card, a small processing fee is deducted)*

# 2016 ANNUAL REPORT

## Financial Analysis

### Balance Sheet

For the Fiscal Year Ended December 31, 2016

#### Assets

Cash and cash equivalents	\$1,757,376
Inventory	\$104,952 *
Other assets - Prepaid expenses	\$522,772
<b>Total assets</b>	<b>\$2,385,100</b>

#### Liabilities

Accounts payable	\$29,771
Grants payable	\$705,275
Other liabilities:	
Accrued compensation	\$5,747
Deferred revenue	\$54,231
<b>Total liabilities</b>	<b>\$795,024</b>

#### Net Assets

Unrestricted	\$1,590,076
Temporarily restricted	\$0
<b>Total net assets</b>	<b>\$1,590,076</b>
<b>Total liabilities and net asset</b>	<b>\$2,385,100</b>

### Statement of Activities and Changes in Net Assets

For the Fiscal Year Ended December 31, 2016

#### Revenue, Gains, and Other Support

	Unrestricted	Temporarily Restricted	Permanently Restricted	Total
Contributions	\$773,486	\$82,635	-	\$856,121
In-kind donations	\$159,670	-	-	\$159,670
Special event revenue	\$2,517,586	-	-	\$2,517,586
Investment return	\$19,308	-	-	\$19,308
Net assets released from restrictions	\$93,872	(\$93,872)	-	-
<b>Total revenue, gains, and other support</b>	<b>\$3,563,922</b>	<b>(\$11,237)</b>	<b>-</b>	<b>\$3,552,685</b>

#### Expenses

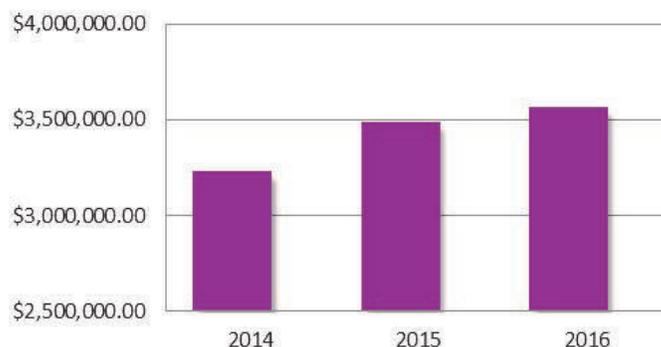
Program services:				
Medical research	\$1,199,216	-	-	\$1,199,216
Monkey in My Chair	\$155,980	-	-	\$155,980
Medical symposium	\$61,817	-	-	\$61,817
Family support program	\$292,140	-	-	\$292,140
Fundraising	\$922,535	-	-	\$922,535
Management and general	\$85,129	-	-	\$85,129
<b>Total expenses</b>	<b>\$2,716,817</b>	<b>-</b>	<b>-</b>	<b>\$2,716,817</b>

#### Increase (Decrease) in Net Assets

	\$847,105	(\$11,237)	-	\$835,868
<b>Net Assets - Beginning of year</b>	<b>\$742,971</b>	<b>\$11,237</b>	<b>-</b>	<b>\$754,208</b>
<b>Net Assets - End of year</b>	<b>\$1,590,076</b>	<b>-</b>	<b>-</b>	<b>\$1,590,076</b>

\*Inventory consists of stocking Monkey in My Chair kits to prepare for demand.

## REVENUE GROWTH OVER TIME



## 3% OVERHEAD

For the last 3 years The Cure Starts Now has had less than 2% overhead.

## 2017

In 2017, The Cure Starts Now was rated a top non-profit by Guidestar and GreatNonprofits for sharing our progress and results to make a difference in the lives of children battling cancer.



#74602

# INSPIRED GIVING

2016 Top Individual Donors\*



**DID YOU KNOW?** Donors who are 70.5 years old are able to redirect their IRA minimum distribution to a qualified charity such as The Cure Starts Now until 12/31/17. **Contact us at [info@thecurestartsnow.org](mailto:info@thecurestartsnow.org) to learn more.**

## DONORS \$50,000+

The ChadTough Foundation  
Defeat DIPG Foundation  
Keith & Brooke Desserich  
Graeter's Manufacturing  
Hyde Park Blast  
Julian Boivin Courage for Cures Foundation  
Musella Foundation for Brain Tumor  
Research & Information  
Walgreens Family of Companies

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

Bruce and Nancy Axmacher  
John Backman  
Brooke Healey Foundation  
Capital Group Companies  
Community Foundation Loudoun  
& N. Fauquier Smashing Walnuts  
Hope For Caroline, Inc.  
Lauren's Fight For Cure Inc.  
Mandy's Mark Memorial Golf Outing  
Milligan Memorial Golf Tournament  
The Operation Grace White Foundation  
Pray Hope Believe Foundation  
Reflections of Grace  
Smiles for Sophie Forever

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

Justin Bailey  
The Bank Of New York Mellon  
Benny's World  
Kevin & Marie Douglas  
Everett Financial, Inc., dba  
Supreme Lending  
Melissa and James Fleming  
GBA Girl's Basketball Assoc Inc  
GM Financial  
Hogs for a Cause  
Immedion  
Jeffrey Thomas Hayden Foundation  
Jersey Mike's  
Julia Barbara Foundation  
Koons Arlington Toyota  
Kroger Co Foundation  
Steven LaFountain  
Love, Chloe Foundation  
Procter & Gamble Company  
Ryan's Hope  
Schwab Charitable Fund  
Terry & Ken Segerberg  
State Street Bank  
Vanguard Charitable  
Andrew & Crystal Wash

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

Aidan's Avengers  
American Trucking Assoc  
Analog Devices  
Benevity Causes  
Brew Ha Ha Cincinnati LLC

Alan Burt & Vicky Zwissler  
Cincinnati Childrens Hospital  
Citi Business Services  
Citibank Investors Services  
Cure Starts Now Australia  
Delhi Township Firefighter Local 3389  
Michael & Carla Eng  
Esther & George Jaruga  
Charitable Foundation  
Ex Voto LLC  
Fidelity Charitable Gift Fund  
Freedom Title LP  
Adam Gingras  
Glen Gonzalez  
High Bridge Board of Education  
Ideal Ambient  
Jewish Community Foundation of  
Greater MetroWest NJ  
Johnson & Johnson  
JPMorgan Chase & Co  
Betsy Kiessling  
Lily Larue Foundation, Inc  
The McCormick Family Foundation  
Oodle  
Paddle for the Cure  
Point Bank  
Prasco Laboratories  
Plante Moran PLLC  
Rahr Corporation  
Anthony & Catherine Ramstetter  
Amber Ringo  
Jason Setser  
Smile For Brooklyn Inc  
Soar with Grace  
Stock Yards Bank & Trust  
David & Patrice Striet  
Tafel Motors  
Topeka Community Foundation  
Truist  
Joe Ventola  
Wacoal America  
John & Lynn Whittington  
Mark & Leslie Williams  
Xavier University  
Your Home Free LLC  
Jayms Zimmerman

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

Neely Agin  
Alms Energy, LLC  
Anderson Athletic Boosters  
Annunciation Catholic Academy  
Architectural Precast Association, Inc.  
Chris Arinton  
Backstreet Bar and Grill LLC  
Badin High School  
The Bank Of America  
Charitable Foundation  
Beechwood Schools  
Roxane Bockenstedt

Loretta and Dennis Brady  
Cheviot Eagles  
Connecticut Mason Contractors, Inc  
Continental Capital Partners, LLC  
Credit Suisse Americas Foundation  
Brian and Shelly Cree  
CyberGrants Inc  
Arthur Dawson  
Delhi Athletic Association  
Dennis & Jody Desserich  
Stefano Dukcevic  
Jennifer Dye  
Josh Dzurick  
Eagle Club Boosters  
Epping Well & Pump Co., Inc.  
Dave & Heidi Eveleigh  
Chris Faulkner  
Don Fischer  
Fusion Medical Staffing  
Dennis & Margaret Gartman  
Give With Liberty  
Gopher Industrial, Inc.  
Greater Orange Area Chamber  
of Commerce  
Roslyn Harris  
Tim & Cindy Hayden  
Heidelberg Distributing Company  
Henkel  
Joe & Carol Hinnenkamp  
Huffines Chrysler Jeep Dodge Ram  
Izzy Lugs  
Jason A. Clapp D.D.S., P.A  
Pirooz & Ellen Joodi  
Kendra Scott LLC  
Douglas Klock  
Kohl's  
Althea and Henry Lee  
Lewisville Independent School District  
Long Island Lutheran  
Lutheran High School Association  
Shane Mason  
David Mette  
Ron and Jane Midgley  
Mario and Carin Minelli  
MTX Wealth Management  
Morgan Stanley Smith Barney, LLC  
David Nelson  
Northern Design Precast, Inc.  
Old Dominion University  
Steve Osborne  
Judy Philips  
Pound Ridge Elementry School  
Dee and Ginny Pritchett  
Prograde  
Jannette Quattlebaum  
Roy Rea  
Reis Promotions  
RR Donnelley  
Ryan & Kara Rybolt  
Wayne Saiz

Michael J. Schneider  
Robert & Constance Schroeck  
Scotts Miracle-Gro Products, LLC  
Jesse and Corrie Shumaker  
Doug and Rosemary Siewert  
Silicon Valley Community Foundation  
Jeff Smith  
Snap Entertainment  
Sports & Fitness  
Patrick Staudt  
Stay, Play, Made Simple LLC  
Jon & Connie Stiles  
Sunny Delight  
Clint Terrell  
Thomas Dale High School  
Jesse and Alison Thompson  
The Til Foundation  
Molly Tindle  
Tri State Society of Healthcare  
Engineers, Inc  
Samuel and Vicky Tuten  
Dean & Cathy Ueckert  
Union Pacific  
United Way of Benton &  
Franklin Counties  
UP Railroad Company  
Nick Usher & Alyssa Hawranko  
Vani Khanna Charitable Trust  
Nathan Wagler  
Betsy Walser  
Kelly & Gus Wegener  
Clayton Wigley  
Charlotte Wilcox  
Wyoming Ohio Cycling Foundation  
Todd Yawit



## DID YOU KNOW?

In 2016 we had **8,754** donors! This goes to show that finding the homerun cure is truly a grass-roots effort led by passionate families across the globe.

# CHAPTER QUOTES

*We asked our families to tell us why being a chapter is important to them.*



“James told me that Brock can't fight anymore. We have to fight for him and change this. I love being surrounded by people who get what we have been through and are an unspoken support.”  
- Melissa Fleming, Texas (Austin/Round Rock) Chapter

“We can't let the loss of our sweet girl be for nothing. There's a reason why all of us at the CSN bond and that's because we were all given the strength that our children had to keep fighting for them.”  
- Brandi Durham, Kentucky Chapter



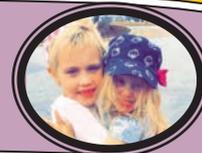
“I want to make a difference. I want to help. I want to see an end to the suffering we have all had to endure.” - Lynn Whittington, Indiana Chapter

“CSN gave us the support we needed to continue Alyson's fight. It enabled us to contribute in a way that we could targetedly make a difference. We connected with others on the same tough road and are all pulling our resources together to reach a common goal. - Alyssa Hawranko, Western PA Chapter



“My daughter Ali fought like hell for her life and I will fight just as hard to find a cure.”  
- Tricia Verhaalen, Wisconsin Chapter

“We do this for the kiddos who can't fight for themselves like Maylea and because we believe in a homerun cure for all cancers. We are honored to be part of this great organization that is full of hope, promise and genuine love.” - Nicole McCoy, Arkansas Chapter



“At the darkest moment of my life, my 4-year-old Jade guided me towards CSN and gave me the direction to fulfill my last promise to her: to find a cure so no other children/family would go through this devastating ordeal.” - Vicky Bridier, Central TX Chapter

## CHAPTER SPOTLIGHT: NEW HAMPSHIRE

*The New Hampshire chapter of The Cure Starts Now was started by Jesse and Alison Thompson, to honor their son, John, who passed away from DIPG. Below, Jesse reflects on being a chapter.*

### 1. What's your favorite memory of John?

My fondest memory is when we were on our Make-A-Wish trip in St. Lucia. John wished to get his summer back since we spent most of the summer getting treatment in Memphis. We went on a Catamaran Cruise one day and on the way back to the resort, the guys put on some music and John started a reggae dance party that took over the boat. He got the adults rolling and the cats running the boat pretty much offered him a job.

**2. What has been your favorite moment since becoming a chapter?** Seeing the jump in attendance, communication and progress from one DIPG Symposium to the next. It's so satisfying to see that our efforts, albeit small on an individual level, are making a difference collectively.

### 3. What does being a chapter and a part of CSN mean to you?

We're members of the most exclusive club that no one wants to be in. But our chins are up, our hearts are full and we know that together we can make a difference. This comradery helps us heal and motivates us to do good - all in memory of John.



*New Hampshire Chapter Director, Jesse Thompson and his family, including son, John (top right), pose for a family photo.*



Interested in becoming a chapter? Email [info@thecurestartsnow.org](mailto:info@thecurestartsnow.org)

## CHAPTER LOCATIONS

**ALABAMA (MOBILE)**— Erica Bonner  
**ALABAMA (BIRMINGHAM)**— Elizabeth Adams  
**ARKANSAS**— Nicole McCoy  
**ARIZONA**— Kristen Warren  
**AUSTRALIA**— Ren Pedersen  
**CALIFORNIA (NORTHERN)**— Jackie Harrison  
**CALIFORNIA (SOUTHERN)**— Shannen Nelson  
**DISTRICT OF COLUMBIA**— Neely Agin  
**GEORGIA**— Caitlin McColloch  
**INDIA**— Ratesh Khanna

**INDIANA**— Lynn & John Whittington  
**KANSAS (SALINA)**— Heidi Feyerherm  
**KANSAS (TOPEKA)**— Christine Kottman  
**KENTUCKY**— Brandi Durham and Matt Branam  
**MASSACHUSETTS**— Lisa & John Mackintosh  
**NEBRASKA**— Jesse Shumaker  
**NEW HAMPSHIRE**— Alison & Jesse Thompson  
**SOUTHERN NEW HAMPSHIRE**— Frank LaFountain  
**NEW YORK**— Kim & Tom Kuck  
**NORTH CAROLINA (RALEIGH)**— Renae & Mark Newmiller  
**NORTH CAROLINA (CENTRAL)**— Erin Dougherty

**OHIO**— Brooke & Keith Desserich  
**NORTHEAST OHIO**— Jane Midgley  
**PENNSYLVANIA (READING)**— Alissa Grove  
**PENNSYLVANIA (WESTERN)**— Alyssa Hawranko  
**TEXAS (AUSTIN/ROUNDROCK)**— Melissa Fleming  
**TEXAS (CENTRAL)**— Vicky Bridier  
**TEXAS (HOUSTON)**— Althea Lee  
**TEXAS (NORTH)**— Michelle & Steve Bjornberg  
**TEXAS (SOUTHEAST)**— Cristy Burnett-Smith  
**VIRGINIA**— Ginny & Dee Pritchett  
**WASHINGTON**— Julie Couture  
**WISCONSIN**— Tricia Verhaalen



*“Doing something to help make a difference helps bring me some sense of peace and purpose after losing my daughter to this dreadful disease. Doing nothing was not acceptable to me. I am very grateful for being a part of this wonderful organization.”*  
 - Jackie Harrison, Northern CA Chapter

## CHAPTER SPOTLIGHT: HOUSTON

*The Houston, TX chapter of The Cure Starts Now was started by Althea and Henry Lee, to honor their daughter, Nicole, who passed away from DIPG. Below, Althea reflects on being a chapter.*

### 1. What's your favorite memory of Nicole?

I would put Nicole to sleep nightly by lying next to her in bed. We would cuddle and tell stories. One night she asked me what heaven was like, because she was afraid of death. Mind you, we never told her that this horrible disease was going to take her life one day, so she always believed she would be cured. I told her that the streets were paved of gold, that she would have her own room in heaven and she would be able to talk with God everyday. After that, she said she wasn't afraid anymore and she was happy about going to heaven, which gave me so much peace that she wasn't afraid of what was to come. We know one day we will be reunited with Nicole in heaven.

**2. What has been your favorite moment since becoming a chapter?** I really loved the day we had our first 7 Rings of Gold Walk. It was like my wedding day, getting to see new and old friends come together, seeing months of planning take full effect, and witnessing the generosity of our community come together to make a difference in the lives of children who had no hope in the past. Now, there is hope for children in the future. There is hope, because people are listening, people are giving and researchers are joining families who are fighting to stop this merciless disease. A movement has been born.



*The Lee Family on vacation in Hawaii (Nicole bottom left).*

### 3. What does being a chapter and a part of CSN mean to you?

Being a part of The Cure Starts Now means that I am part of something that can change history forever. Our family's story of losing Nicole doesn't end with the death of our beautiful daughter. It continues when we decided to lock arms with other families who know that the fate of future children can be different. The Cure Starts Now doesn't believe that change can happen with just one story, but a collaboration of many resources from all over the globe of children, families, doctors and professionals. We are honored to be on a team of intelligent, resourceful and kind people and are proud to represent in Houston. Nothing will ever replace the hole Nicole left, but helping to advance pediatric brain cancer research has been healing for us and our community.

# COLLABORATING FOR A CURE

*Founded by The Cure Starts Now in 2011 in an effort to unify the DIPG cancer community, the DIPG Collaborative today is a unique initiative where independent foundations work together to fund the best cancer research available with the advice of The Cure Starts Now Foundation's Medical Advisory Council. The following is an article by one of the Foundational Partners of the DIPG Collaborative in support of the cause.*

Julian was not the first 4-year-old who imagined himself a brave knight or a superhero. But he sure was one of the best at it. With big dark eyes, raspy voice and huge imagination, watching our handsome guy bring his characters to life was a joy. He wore underpants over his pajamas "because that's how Superman and Batman wore theirs." He loved a good battle - classic good guy vs. bad guy stuff. But never in our wildest dreams could we imagine he'd have to face the most ruthless villain of all—DIPG.

On Thanksgiving weekend in 2010, seemingly overnight, Julian woke disoriented, lethargic and became ill. After a CT scan, doctors delivered the shocking news that they discovered a mass at the base of his brain. The only way we could think to explain to him what was happening was that doctors had just found something inside his head that made him a real life superhero. His smile came through and our mission began. Seven months later, Julian would pass away. We poured our grief into carrying on the fight Julian started and organized The Team Julian Foundation, now The Julian Boivin Courage for Cures Foundation. We knew how to plan events and raise money, but we also knew all that we wanted to accomplish could not be achieved on our own.

Still, in many ways, 2011 seems to mark a turning point in the battle against DIPG. That spring, The DIPG Collaborative held their first symposium just two months before we lost Julian. A year later we signed on as a partner joining about a dozen family foundations and an established, well-respected medical advisory council. While we were able to remain an independent foundation, we found comfort in the community of families and doctors who shared our mission, and we found peace of mind with the processes in place to efficiently fund the most promising research without doubling all our efforts.

In these last six years, Collaborative membership has flourished from 12 family foundations to more than 30. Researchers dedicated to cracking the code on DIPG has grown from those original six or so we found in 2010 to more than 50 today. Pooling our funds together, this collective of bereaved families has funded \$12 million for 46 research grants around the country and the world, a shining example of strength in numbers. Due much in part to this funding, we've seen the dedication and tireless efforts of researchers make great strides in a short time.

The DIPG Collaborative is like an army of one working to defeat our common enemy. No matter the level of each organization's contribution, here we can leave egos at the door, lean on each other, encourage each other and propel our shared mission forward. We've look forward to meeting the other families annually - the most poignant moments coming when we get the chance to talk about our children and explain why and how they continue to inspire us. And every two years, we appreciate the opportunity to hear from the researchers about the progress of the work we've funded, realizing the Collaborative's spirit of accountability, efficiency and sharing of ideas.

Moving forward, we hope to hear of continued and even stronger collaboration between research institutions across the globe. We hope to see drug companies willing to share drugs from their respective portfolios that could offer the magic combination for families in the fight. More than anything, we hope to see the extraordinary children we met at this last meeting showing up to attend our next meeting.

We understand DIPG is not an easy space to remain. For families like ours, any good news and breakthroughs can't come big enough or soon enough. But consider how far we've come in these last six years. Despite the days we've wanted to give up, the memory of Julian's courage and the community we've found in The DIPG Collaborative has helped us remain steadfast in the belief that we can play even a small role in bringing about a day when families no longer have to endure the words, "no known cause or cure."



*Nettie Boivin and Brad Boivin with their son, Julian.*



# FUN-RAISING

Check out these two unique ways that our supporters are raising money and awareness for the homerun cure for cancer.

## RACING FOR THE CURE

Our Indiana chapter, started by Lynn and John Whittington, has a very cool way that they are raising money to fund DIPG research. Meet the Peyton’s Angels Indiana Chapter race car! The three-quarter midget race car is driven by a family friend of the Whittington’s, Jason Setser. After every race, Setser has donated his winnings to the Indiana chapter in honor of Petyon Whittington. Setser has raised over \$5,000.

Back in the summer of 2017 during the Bartholomew County Fair in Bloomington, IN, Setser let longtime friend and former NASCAR driver, Tony Stewart race the Peyton’s Angels race car. Pretty cool!



Left photo: The Whittington Family posing with Tony Stewart after he raced the Indiana Chapter Race Car. Right photo: Jason Setser racing the Indiana Chapter car.

## RUNNING FOR THE CURE

Orange, Texas native, David Jones, has been a longtime supporter of our Southeast Texas chapter started by Cristy Burnett-Smith in honor of her son Corbin. This past spring Jones had the once in a lifetime opportunity to participate in the Boston Marathon. He ran the race in honor of Corbin and another local Texas boy, Indy. It was a tough and emotional race. Both of the boys’ moms said they felt like the boys were running with Jones. Jones talked about how he was exhausted during the last mile of the race.

“The crowd was yelling ‘Do this for Indy and Corbin’. And I thought to myself, these kids went through hell, I cannot not finish this race.”

Jones finished the race and raised over \$10,000 for DIPG research leading up to the Boston Marathon.



Left Photo: David Jones (left) presents a \$10,000 check to The Cure Starts Now. Right photo: Jones running in the Boston Marathon.



“The Cure Starts Now provides a unique opportunity and platform for parents to work together as part of a team that is capable of funding the most novel and innovative research. I am so grateful for the amazing friendships and network of parents that have become my CSN family.” - Neely Agin, Washington DC Chapter

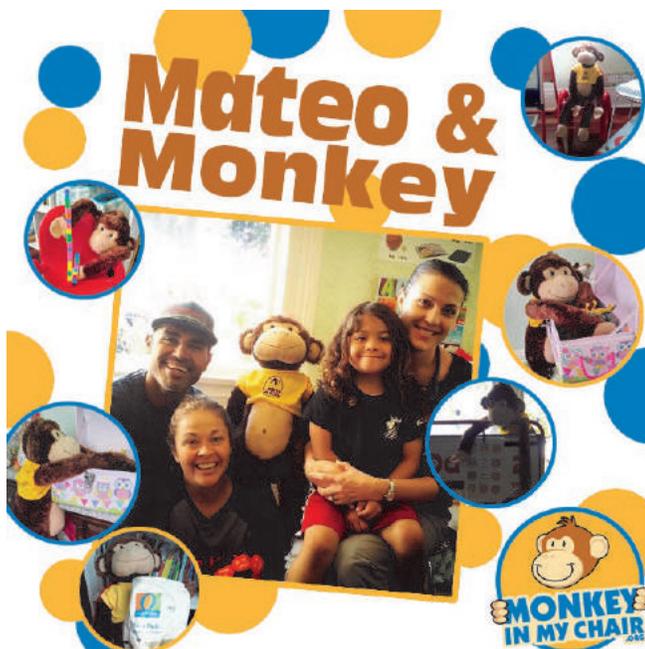
# MONKEYS MAKING CONNECTIONS

Just 11 days before his second birthday, Mateo “The Beast” Cota was diagnosed with Acute Lymphoblastic Leukemia (ALL). He started on his 3 ½ year treatment plan right away and began his journey to remission. Mateo began pre-school while he was still in treatment and his family began looking for a way to explain his absence to his classmates. They came across the Monkey In My Chair program and requested a kit for Mateo.

The program was presented to the class and the book was read to explain why there might be a monkey in the classroom. The children were engaged and asked many questions. They were able to learn about Mateo’s illness and how some of the medicines might affect him. Monkey In My Chair provided the family with the perfect resource to help Mateo and his classmates in this situation.

His parents shared, “This program has had a HUGE impact on him because he feels special not different because of “monkey” and because his classmates know about what he is dealing with. It’s absolutely amazing.”

Mateo’s treatment for ALL lasted for three years and three months. He celebrated his final treatment in December 2016. He was doing well and back to his everyday activities until September 6, 2017 when he relapsed. He is now undergoing treatment once again. Although he is beginning this journey again, he is determined to beat it. His nickname, “The Beast”, fits him well and shows his strength and perseverance with leukemia.



# VOLUNTEER SPOTLIGHT

Meet volunteer, *Tim Withrow*, and why he loves volunteering for CSN.

### 1. What do you do as a volunteer for The Cure Starts Now?

I have worked a booth at the Hyde Park Blast and the Beer, Wine and Food Festival, sold Split the Pot tickets at the Layup 4 Lauren event and was blessed to be a “Righthand Man” for Lisa Hill and Sheila Tillman at the Once in a Lifetime Gala. So to answer your question: anything they ask me to do!

### 2. Tell me about some of the people you’ve met while volunteering?

I have had the privilege to meet some of the young people that are the inspiration for why I volunteer my time. There is one young man in particular named Charlie from New York that I got the pleasure to meet, he is fighting DIPG and he makes me smile every time I see him.

### 3. What do you wish other people knew about The Cure Starts Now?

I wish people knew what a great group of dedicated people are behind this beautiful organization that tirelessly works to find a homerun cure for cancer. I have yet to meet anyone from The Cure Starts Now that has not given me a warm welcome. A few even greet me with a big hug.

### 4. What might someone be surprised to know about you?

I became a heart patient 10 years ago at the age of 37 and volunteering has literally saved my life. My doctor told me I needed to lower my stress level. Volunteering for organizations like The Cure Starts Now makes me feel like I am making a positive difference in so many young lives and helps lower my stress level.



*Tim volunteering at the 2017 Cincy Brew Ha Ha event in Cincinnati.*



“Being a chapter is a way to honor the memory of our child and work with other families who understand in order to make a difference.”  
- Jesse Shumaker, Nebraska Chapter

# MAKING A DIFFERENCE

At The Cure Starts Now we host over 80 events/fundraisers across the country each year thanks to our dedicated chapters and supporters. These are just a snapshot of some from this year.



# DIPG WARRIOR

*Learn how our newest program is helping spread awareness for DIPG*

Children battling cancer are true warriors and we wanted to give DIPG families an outlet for awareness, support, fundraising and more than anything, honoring their DIPG Warrior. So in the Fall of 2017, we launched the DIPG Warrior program. The program is free to all DIPG families whether they are currently battling or not.

How does the program work? Parents can register their child through [DIPGWarrior.org](http://DIPGWarrior.org) where they will customize t-shirts and wristbands in their child's honor. An initial shipment of 10 t-shirts and 25 wristbands will be sent to the family, free of charge, when they first register. The DIPG Warrior will receive their own spot in the DIPG Warrior online store where friends, family and supporters can order t-shirts and wristbands in their honor at a very low cost of \$10 per shirt and \$1 per wristband at [dipgwarrior.org/support](http://dipgwarrior.org/support). A tribute fund will be automatically created that alerts parents when donations are made in their warrior's honor. All donations go to fund DIPG research around the globe!

We also offer other DIPG Warrior support including:

- Monkey in My Chair for school aged kids
- Tribute funds – 100% of donations in honor of our warriors will go direct to DIPG research
- Emotional support from one of our The Cure Starts Now DIPG Chapter Parents
- Access to second opinions, consultation of the top DIPG specialists and current options for DIPG patients
- DIPG Warriors will receive special warrior goodies as we receive them
- If you would like to fundraise for DIPG, we have the tools to make this simple and customized to your warrior
- If you would like to host a fundraising event for DIPG, our The Cure Starts Now event staff can make it simple and support your event from beginning to end
- We will share warrior pictures and stories to inspire others to support DIPG research on the DIPG Warrior Facebook page and also the CSN Facebook page



Check out some of our DIPG Warriors and their amazing stories by going to the [DIPG Warrior Facebook page at www.facebook.com/DIPGWarrior](http://www.facebook.com/DIPGWarrior)  
Or sign up your DIPG Warrior at [www.dipgwarrior.org](http://www.dipgwarrior.org)



**Waging War on DIPG**

# UPCOMING EVENTS

*Throughout the year we sponsor fundraising events all over the world – from golf outings and runs to galas and festivals. Browse below and see how you can help support The Cure Starts Now while having fun doing it! Be sure to visit our event section on our website for the most up to date listing.*

**DECEMBER 7, 2017** – HOUSTON HEARTS OF GOLD WINE & DINE – HOUSTON, TX

**DECEMBER 15, 2017** – KENDRA SCOTT GIVESBACK PARTY – AUSTIN, TX

**FEBRUARY 3, 2018** – A NIGHT TO BEAT THE ODDS CASINO NIGHT – TYSONS, VA

**MARCH 3, 2018** – JBT MEMORIAL HOCKEY GAME – GILFORD, NH

**MARCH 24, 2018** – 7 RINGS OF GOLD WALK – HOUSTON, TX

**APRIL 7, 2018** – ONCE IN A LIFETIME GALA – CINCINNATI, OH

**APRIL 21, 2018** – RACE AGAINST THE ODDS NEBRASKA – OMAHA, NE

**MAY 4, 2018** – TEAM BROCK GOLF TOURNAMENT – AUSTIN, TX

**MAY 18–20, 2018** – GBA BASKETBALL TOURNAMENT – VARIOUS LOCATIONS

**MAY 19, 2018** – JADE’S BALL – COLLEGE STATION, TX

**JUNE 2, 2018** – RACE AGAINST THE ODDS NEW HAMPSHIRE – HUDSON, NH

**JUNE 9, 2018** – CARNIVAL FOR THE CURE – COLUMBUS, IN

**JUNE 30, 2018** – HYDE PARK BLAST – CINCINNATI, OH

**JULY 14, 2018** – JBT REGATTA – GILFORD, NH

**SEPTEMBER 6–16, 2018** – CONES FOR THE CURE – VARIOUS LOCATIONS

**WANT TO START YOUR OWN EVENT OR FUNDRAISER?  
EMAIL US AT [EVENTS@THECURESTARTSNOW.ORG](mailto:EVENTS@THECURESTARTSNOW.ORG).**



# THE EVOLUTION OF THE HOMERUN CURE

Good research isn't political and it doesn't take billions of dollars. Good research is based on science and takes a disciplined strategy to find the cure. And we've known this for nearly 100 years. In 1937, a researcher named Sydney Farber focused on those cancers that affected children, those cancers for which there was no alternative treatments and those cancers that were the hardest to beat and in doing so delivered a novel way of treating all cancers: chemotherapy.

Today, The Cure Starts Now Foundation is the only foundation focused on this very strategy of advancing research by focusing on those cancers that affect children, those that we believe may be the most pure and those cancers for which no other treatments exist. We call it the "homerun strategy" and this strategy alone may, in fact, be one of the biggest frontiers in cancer cures that we have ignored.

The Cure Starts Now Foundation started with simple goals: the development of homerun cure research, actually listening to the researchers on what they wanted to explore and the elimination of duplication between institutions. And even in 10 short years, we've already changed the face of cancer research with a very modest budget.

Harnessing the enthusiasm and partnering with cancer research experts, we developed one of the largest linked cancer databases in the world, serving as a model for other forms of cancer worldwide.

We've created the DIPG Symposium, bringing together the best minds in cancer research to share their data and ideas in an open forum that enhances collaboration and builds new initiatives.

We've formed collaboratives of foundations to cross competitive lines in the non-profit world and join forces to fund better and stronger protocols. We've also taken the next step in establishing an unprecedented network of 15 institutions across 3 continents to implement these research efforts quickly, efficiently and to make them available to patients close to home.

The homerun cure touches us all. Whether you fight lung, breast, colon or pediatric brain cancer, our goal as a society should be the total cure and not just a cure. And with it what may be cancer's worst diagnosis in pediatric brain cancer may also serve as our greatest victory.



**Keith Desserich**  
*Co-Founder/ Chairman of the Board*  
*The Cure Starts Now*



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The Cure Starts Now has funded  
over **\$10,000,000** in DIPG research.

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Please choose us as your charity organization:

