2017
ANNUAL REPORT

...

2018
PROGRESS

A YEAR OF GROWTH

THECURESTARTSNOW®

www.thecurestartsnow.org

PIPER WANEKA:
A Cure Starts Now DIPG Warrior

LETTER FROM THE DIRECTOR

A reporter once asked me if I really thought I would find a cure for cancer. Not missing a beat, I responded, "yes!" He seemed surprised by the lack of hesitance in my answer. What may be an insurmountable goal to most people, like curing cancer, seems achievable with the right amount of focus and persistence to a "cancer parent."

When you have everything taken from you, there is nothing left to lose. That is why the families of The Cure Starts Now know we will find the cure – because our children have made us fearless and relentless. We have faced impossible decisions and lived through unbelievable realities. Accepting that the monster that robbed us of our children will continue to steal lives is not acceptable.

The Cure Starts Now focuses on being intelligent and innovative in our approach.

- Nearly $12 million in research funded
- $2 million coordinated in additional research with DIPG Collaborative partners
- Built a one-of-a-kind linked database for DIPG data which is being regarded as an example for all diseases

We consistently find new ways to insist on unprecedented collaboration with doctors, foundations, and families. Even today, we are building and funding a virtual hospital for patients to fast track promising treatments close to their home.

How has this happened? Because of fiercely dedicated parents who knew that it would take innovation, collaboration, and a relentless belief in achieving the impossible – a cure for the most difficult cancers to treat.

Thank you for supporting these families and fueling their passion to put an end to cancer.

Brooke Desserich
Co-Founder, Executive Director

RESEARCH IN A CONNECTED WORLD

In 2017, The Cure Starts Now announced the creation of CONNECT (The ***CO****llaborative* ***N****etwork for* ***NE****uro-oncology* ***C****linical* ***T****rials) for $2.7 million. A revolution in cancer research, its purpose is to investigate combinations of novel drugs with traditional therapies.*

CONNECT represents one of the first global initiatives that leverages the expertise of 16 institutions in the USA, Canada, Australia, Germany, the United Kingdom, and the Netherlands to bring treatments to children closer to home. In this way not only does it advance the pace of research but it also creates the first "virtual hospital" to fight Homerun cancers such as DIPG.

Prior to CONNECT, children with DIPG faced limited research, offered far from home, with experts that may only understand one aspect of how DIPG works. While these researchers may have had expertise in genomics or clinical trials, only 2-3 hospitals in the world had a team that represented the best in all aspects of treatments and diagnosis. As a result, families had to choose treatments on a map – moving to where they could get the next treatment, then packing up, moving, and starting again when the treatment failed – always wondering if they were getting good advice, never considering how these treatments may react with each other because no expert was there to provide a comprehensive viewpoint.

This is why we created CONNECT. After establishing the DIPG Registry in partnership with Cincinnati Children's and 77 other hospitals around the world, the next step was to align the expertise of the collaborations we helped develop into a model that would better serve patients. Setting aside funding and offering incentives to promote collaboration, we set up the foundation for CONNECT. In 2017, after finally developing the first basic understanding of DIPG, we were ready for the next big step.

In just six months, CONNECT has become a leader in new trials, providing a much needed operational structure for the 16 participating institutions to contribute expertise in all areas to better serve the patients. Starting in 2018, two of the first trials are being released – allowing patients to receive treatment closer to home. In time, CONNECT will grow to more institutions as both the funding and the model are developed.

Seven years in the making, CONNECT is a perfect example of how The Cure Starts Now impacts research through strategy and innovative design.

PIPER

PRINCESS WARRIOR

A princess with the heart of a warrior faces her battle with an awesome bravery that wins over hearts everywhere she goes.

A GLITTER EXPLOSION

That's how Piper's dad, Nelson, describes her: "Too much of a good thing… like a glitter explosion." And it shows. Just looking at pictures of Piper you can see bucketfuls of personality wrapped up in the body of a spunky three-year-old. Whether telling an imaginative story, or explaining to you why everything looks better in pink, Piper is sure to leave you with a fond memory.

A truly exceptional child, Piper walked and talked before other kids and excelled at school. She took her vitamins, brushed her teeth every night, ate healthy home-cooked meals, and was rarely ever sick. A perfectly healthy child.

But that changed in June of 2017.

OUR LIVES CHANGED IN A SINGLE DAY

On June 7th Piper developed a slight slur to her speech – one so minor that, if you didn't know her, you wouldn't have noticed. In fact, her parent's thought she was just talking like her baby sister to get a little more attention. Later, thinking that she may have picked up a cold while playing with family and friends at the zoo, her parents took her to the doctor who suspected she had a swollen tonsil.

> *"While Piper had suffered from increasing night terrors…there was absolutely no reason to believe she had, or would ever get, cancer."*

But Piper's condition worsened. She was having difficulty chewing and swallowing and was struggling to form words. The next morning, when Piper woke up she could barely walk or talk. Her parent's immediately took her to a children's hospital. After several tests a team of doctors informed Piper's parents that she had DIPG – a rare form of brain cancer – and that they were unable to do anything to stop it.

CHILDREN ARE DIFFERENT

The day Piper was diagnosed with DIPG, the doctors told her parents that the disease was "uniformly fatal" and "incurable" because no treatment had been developed to stop or slow it. "If I was diagnosed with a terminal brain tumor and given 9 months to live, I would be angry, and depressed, and demoralized… Children are different," Nelson says. And he's right.

Piper and children like her that are battling cancer do so with the strength and fortitude of a warrior. From surgeries and radiation

Continued on page 4

Piper images courtesy C. Roese Ramp Photography and the Waneka Family.

Continued from page 3

to chemotherapy and medication, these children face it all with incredible bravery. Every time. They put on their uniform – which may just happen to be a superhero outfit, or princess dress – and face the challenge of the day.

FIND THE CURE

The National Cancer Institute spends roughly 4% of its annual budget on pediatric cancer. It was this realization that drove Piper's parents to help change the state of pediatric cancer funding.

> *"No one person, patient, or family can make the change necessary to solve this alone. Only unified action as aggressive as DIPG itself will have the power to overcome this cancer."*

Over 12 months post diagnosis, Piper continues to enjoy life and maintains most of her abilities. Her parents attribute this to her personalized treatment plan, their unyielding hope, and their determination to take as many adventures as a family as Piper sees fit. "Our greatest wish," states Carrina, "is that through awareness and continued research funding, a cure for DIPG will be found."

Inspired by their princess warrior's strength and determination, Nelson and Carrina have partnered with The Cure Starts Now on various fundraising efforts to find the Homerun Cure for Cancer. In partnership with local businesses and supporters, they have helped raised over $16,000 for research in Piper's honor.

You can also fund research in Piper's honor by donating to her tribute fund at donate2csn.org/piper.

RESEARCH FUNDED

2018

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 Gesu (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*
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

** Denotes grants funded with our DIPG Collaborative partners.*

RESEARCHER SPOTLIGHT KOSCHMANN

The International DIPG Registry is opening doors for expanding understanding of other cancers.

The International DIPG Registry, created through funding by The Cure Starts Now, recently collaborated with Dr. Carl Koschmann on his study of “Secondary DIPGs” that result from the treatment therapies of medulloblastoma. We sat down with Dr. Koschmann to discuss what led him to perform this study, and what role the Registry helped play in its completion.

WHAT BROUGHT YOU TO DO THIS STUDY?

Dr. Koschmann: “I have now been involved with the care of three children with DIPG at the University of Michigan with a more remote history of a different brain tumor, medulloblastoma. We looked and saw little written about this connection and wanted to find out more. More children are surviving medulloblastoma than ever before, and the field is continuing to learn about the complications of the therapy required, including radiation of the brainstem. There were no studies that reported on the biology of these so-called ‘secondary DIPGs,’ which we were also interested in exploring.”

WHAT HAVE YOU LEARNED?

“Through the International DIPG Registry and reports from previous medulloblastoma clinical trials, we found 12 cases of ‘radiation-associated DIPGs,’ or tumors that formed after a history of medulloblastoma therapy involving radiation of the brainstem. We estimate the risk of this complication is around 1-2% of medulloblastoma survivors with similar radiation treatment. Children with these radiation-associated DIPGs have a prognosis that is even worse than those with newly diagnosed DIPG. We were able to do molecular testing of three of these tumors and found that they harbor molecular attributes closer to those of adult GBM and not the classically found mutations of DIPG (such as H3 K27M).”

WHAT IS THE NEXT STEP IN YOUR RESEARCH?

“Our work continues to build treatments targeted to the unique genetic alterations of each tumor, and we are treating one of our current patients with a radiation-associated DIPG with a therapy targeted to his tumor’s sequencing results. Perhaps the most important result of this work will be to encourage those treating medulloblastoma to design treatments to reduce radiation exposure to the brainstem when possible. Prevention of DIPG is rarely discussed, but is very relevant in the case of this specific form of DIPG.”

WHAT ROLE DID THE DIPG REGISTRY PLAY IN YOUR RESEARCH?

“We needed a large and well-organized clinical database of children with DIPG – which was only possible through the Registry. As well, Dr. Fouladi and the Registry were able to connect our team to the researchers and clinicians at other hospitals with similar cases, and facilitate collaboration, data-sharing, and communication that was necessary to carry out this project.”

43

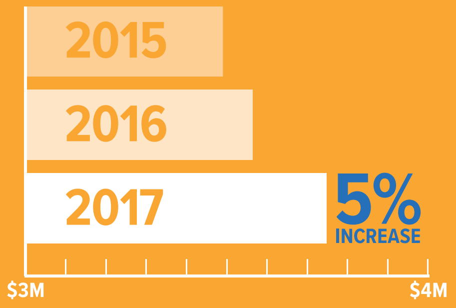
CHILDREN PER DAY
ARE EXPECTED TO BE DIAGNOSED
WITH CANCER

National Pediatric Cancer Foundation

2017 ANNUAL REPORT

TOTAL REVENUE, GAINS, AND OTHER SUPPORT

$3,747,767



BALANCE SHEET

As of December, 31 2017

ASSETS

Cash and cash equivalents	$600,381
Inventory	$130,119*
Other assets / prepaid expenses	$158,384
TOTAL ASSETS:	**$888,884**

LIABILITIES

Accounts payable	$38,255
Grants payable	$2,148,918
Other liabilities:	
Accrued Compensation	$23,292
Deferred revenue	$71,026
TOTAL LIABILITIES:	**$2,281,491**

NET ASSETS

Unrestricted	($1,392,607)
Temporarily restricted	$0
TOTAL NET ASSETS:	($1,392,607)
TOTAL LIABILITIES & NET ASSETS:	**$888,884**

STATEMENT OF ACTIVITIES & CHANGES IN NET ASSETS

For the Fiscal Year Ended December, 31 2017

REVENUE, GAINS, & OTHER SUPPORT	UNRESTRICTED	TEMPORARILY RESTRICTED	PERMANENTLY RESTRICTED	TOTAL
Contributions	$987,516	$3,960	-	$991,476
In-kind donations	$220,204	-	-	$220,204
Special event revenue	$2,603,804	-	-	$2,603,804
Investment return	-$67,717	-	-	-$67,717
Net assets released from restrictions	$3,960	($3,960)	-	-
TOTAL REVENUE, GAINS, AND OTHER SUPPORT:	**$3,747,767**	**$0**	**-**	**$3,747,767**
EXPENSES				
Program services:				
Medical research	$4,679,940	-	-	$4,679,940
Monkey in My Chair	$126,322	-	-	$126,322
Medical symposium	$226,782	-	-	$226,782
Family support program	$325,800	-	-	$325,800
Fundraising	$1,270,182	-	-	$1,270,182
Management and General	$101,424	-	-	$101,424
TOTAL EXPENSES:	**$6,730,450**	**-**	**-**	**$6,730,450**
Increase (Decrease) in Net Assets	($2,982,683)	-	-	($2,982,683)
Net Assets - Beginning of year	$1,590,076	-	-	$1,590,076
Net Assets - End of year	**-$1,392,607**	**-**	**-**	**-$1,392,607**

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

***Money was accrued in 2016 to manage the increase in expenses over income due to the DIPG Symposium*

2017 TOP DONORS

$50,000+

Abstract Displays
Aidans Avengers
Allstate Foundation
Keith & Brooke Desserich
Graeter's Manufacturing
Grant's Ginormous Gift Foundation
HP Blast Corporation
Julian Boivin Courage for Cures Foundation
PI Foundation Inc
Save Sara Ringgaard

$25,000-$49,999

Austin Strong Foundation Inc
Bruce & Nancy Axmacher
John Backman
Brooke Healey Foundation
Capital Group Co Charitable Foundation
Chadtough Foundation
i&eye
Jersey Mike's Subs - Houston
Laurens Fight for Cure Inc
Michael Mosier Defeat DIPG Foundation
Musella Foundation
Ryans Hope
Supreme Lending
Veterans of Foreign Wars of the United States

$10,000-$24,999

Appica
Credit Suisse Americas Foundation
Dannie Kemp Cancer Support Fund
Kevin & Marie Douglas
Everett Financial, Inc
Exvoto
John Feradi
James & Melissa Fleming
GBA Girl's Basketball Assoc Inc
GM Financial
Gold Star Chili
Koons Arlington Toyota
Lily Larue Foundation, Inc
Bank of New York Mellon
Milligan Memorial Golf Tournament
Scott E. O'Neal
Pep
Pray Hope Believe Foundation
Prestige
Proctor & Gamble
Reflections of Grace
Reis
Ryan Litherland
Sarah Spofford
Sonepar Management US, Inc
Star 93.3
State Street Bank
April Tsui
Union Pacific
Andrew & Crystal Wash

$5,000-$9,999

Aggreko LLC
American Childhood Cancer Organization
Analog Devices
Braxton Brewing Company
Brew Ha Ha Cincinnati LLC
Henry & Katie Burnett
Cincinnati Children's Hospital - CBDI
Citigroup Payment Services
Mike & Carla Eng
Estate of Eshter Shelby Fund
Esther & George Jaruga Charitable Foundation
Deanna Evans
Glen Gonzalez
Tim & Cindy Hayden
Infintech
Integrity BioFuels
Jeffrey Thomas Hayden Foundation
JP Morgan Chase & Co
William Keefe
Keysmart Inc
Kira Foundation
Henry & Althea Lee
McCormick Family Foundation
Kyle & Elizabeth McLaughlin
Michael Shalley, Property Tax
Omaha Community Foundation
Operation Dough-Nation
Perfect Pallets, Inc
Plante Moran
Prasco Laboratories
David & Virginia Pritchett
Rahr Corporation
Rob Linkins Hoosier Air Transport
Ken & Terry Segerberg
Bruce and Laura Shelby Family Fund
Smile For Brooklyn Inc
Jon & Connie Stiles
Tatonut Shop
Wayland Villars DIPG Foundation Inc.
Andrew Whitmire

$2,000-$4,999

360 Plumbing and Gas Solutions LLC
Adage Capital Management, L.P.
AdEx
American Youth Soccer Organization
Architectural Precast Association, Inc
B&B Kennels, LLC
Kenneth & Marilyn Barnes
Gavin & Fatema Baumgardner
Michael Bonham
Chuck Braddock
Dennis & Loretta Brady
Briggs Equipment
Brown Brothers Harriman
Bryan Radiology Associates
Caprock Emergency, LLC
CCP Commercial Real Estate
Jamie & Amy Charlton
Chipotle
Robert Chody
John Civitillo
College Station Medical Center
Jeff & Leslie Combs
Commercial Van Interiors RJ Kloessner
Josh & Julie Couture
CyberGrants Inc
Jennifer Davis
Joseph Dentice
Dennis & Mary Jo Desserich
Deutsche Bank Americas Foundation
Scott Dishman
Donnelly Financial
Bill & Vicie Dorsey
Stefano Dukcevich
Michele Duncan
Durkee Construction
Julie Edwards
Epping Well & Pump Co, Inc
Sam & Ellen Flannery
Fleming & Conway LLC
Stephen & Kristin Foley
Vanessa Freytag
Gartman Letter LC
Adam Gingras
Give With Liberty
Global Wireless LLC
Kathy Graeter
Jamie Hacker
Joe Hinnenkamp
Yvette Holguin
Home Builders
Syed & Mary Hossain
Verna Hultman
Industrial Coverage
John Istre
Krista Joenjis
KDM
Jenny Kelly
Kendall Pond Pizza
Elizabeth Kiessling
Kathy Kinane
GM Lam
Brandon & Jamie Larson
Susan Laupola
Lewisville Independent School District
Chris Lipkin
Dustin Lloyd
Michael Longman & Channon House-Longman
Lutheran High School Association
Magruder Homes LP
Matt Young, Attorney at Law
Craig Maurer
Rick & Lynne Merk
Ron & Jane Midgley
ITF For Khylee Monson
MTX Wealth Management, LLC
National Christian Foundation South Florida
Bill Nelson
Northern Design Precast, Inc
Northwestern University
Paddles Up
Penn Station, Inc
John Perentesis & Stella Davies
Prograde
Anthony & Catherine Ramstetter
Angela Reindl
Brooke Ridenour
Amber Ringo
Cynthia Ritner
Ryan & Kara Rybolt
Wayne Saiz
Robert & Constance Schroeck
Jason Setser
Jesse & Corrie Shumaker
Doug & Rosemary Siewert
Frank & Ashley Slaughter
Phil & Jill Smith
Libbey Spiess
St. Maximilian Kolbe Parish
Stratford School, Inc
David & Patrice Striet
Jennifer Taylor
Thomas Dale High School
Jesse & Alison Thompson
United HealthCare Svs Inc
Donald & Leanne Verhaalen
Dimitri Vigushin
Wallenius Wilhelmsen Logistics
Elizabeth Walser
Ward's Hardwood Floors
Gerald & Carol Wash
Kelly & Gus Wegener
Michael & Melissa Weiner
John & Lynn Whittington
Clayton Wigley
Brian & Candice Winterringer
Wyoming Ohio Cycling Foundation
Xavier University
Nick Usher & Alyssa Hawranko
James R. Young

4% FEDERAL CANCER RESEARCH FUNDING HISTORICALLY DEDICATED TO PEDIATRIC CANCER

National Pediatric Cancer Foundation

OUR GLOBAL REACH

The Cure Starts Now has had tremendous growth over the past year and has nearly 40 chapters in 4 countries including The United States, Australia, Canada, and India.

BIRMINGHAM, ALABAMA
Director: Elizabeth Adams
Inspiration: Madeline

MOBILE, ALABAMA
Director: Erica Bonner
Inspiration: Aiden

ARIZONA
Director: Kristen Warren
Inspiration: Jade

ARKANSAS
Director: Nicole McCoy
Inspiration: Maylea

NORTHERN CALIFORNIA
Director: Jackie Harrison
Inspiration: Khylee

SOUTHERN CALIFORNIA
Director: Shannen Nelson
Inspiration: Sarah

CONNECTICUT
Director: Robyn Staub
Inspiration: Lea

GEORGIA
Director: Caitlin McColloch
Inspiration: Claire

COLUMBUS, INDIANA
Director: Lynn Whittington
Inspiration: Peyton

FRANKFORT, INDIANA
Director: Amber Price
Inspiration: Kaylee

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

TOPEKA, KANSAS
Director: Christine Kottman
Inspiration: Morgan

KENTUCKY
Director: Brandi Durham | Matt Branham
Inspiration: Railee

CENTRAL MASSACHUSETTS
Director: Abby Arpano
Inspiration: Kate

MASSACHUSETTS
Director: John Mackintosh
Inspiration: Nicole

MICHIGAN
Director: Kim Ricker
Inspiration: Brison

NEBRASKA
Director: Jesse Shumaker
Inspiration: Madelyn

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

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

SOUTHERN OHIO
Director: Brooke Desserich
Inspiration: Elena

NORTHEAST OHIO
Director: Jane Midgley
Inspiration: Lauren

WESTERN PENNSYLVANIA
Director: Alyssa Hawranko
Inspiration: Alyson

EASTERN PENNSYLVANIA
Director: Alissa Grove
Inspiration: Josie

AUSTIN, TEXAS
Director: Melissa Flemming
Inspiration: Brock

CEDAR HILLS, 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

INDIA
Director: Ritesh Khana
Inspiration: Vani

INTERESTED IN BECOMING A CHAPTER? CONTACT US AT INFO@THECURESTARTSNOW.ORG

CHAPTER SPOTLIGHT NEBRASKA

Chapter Director Jesse Shumaker reflects on his daughter, Maddie, and the journey that led him to The Cure Starts Now.

MADDIE HAD THE WARMEST HEART

Maddie liked horseback riding, summer camp, rock-climbing, and downhill skiing. She loved painting, music, crafts and table games. Over her short life she was on the school swim team, played soccer, basketball, and tennis, and loved attending high school athletic events. She also enjoyed participating in gymnastics, dance, and piano. She truly loved all animals and debated which occupation would provide the most contact with them. Maddie was a natural leader and would organize many of her classmates to do fun projects together, like throw a class party (much to the surprise of her teacher).

Even with her extensive interests, family remained the center of her world. Over her last two months, Maddie planned and made Christmas gifts for her family, despite her setbacks. Her greatest loves, after her family and friends, were her cat, her fish, and pandas.

We witnessed the extent of Maddie's compassion as she began her battle with DIPG. She had her 8th birthday the month after her diagnosis. When she received an outpouring of gifts and money for her birthday, she sent money to a charity in Guatemala that was building a chapel in memory of her Grandpa Marty who had helped raise money for a rural health clinic. She said the people in Guatemala needed the money more than she did.

MADDIE'S BATTLE WITH DIPG

Maddie was diagnosed with DIPG on January 26, 2015 and she earned her wings on December 10, 2015. Madelyn received treatment for DIPG as part of a clinical trial at St. Jude Children's Research Hospital in Memphis. Her initial response to treatment was impressive and she tolerated the maintenance chemo well. She enjoyed seven symptom free months that we still treasure. During that time, we continued to research additional treatment options.

In the fall, Maddie had a biopsy performed at Sloan Kettering in NYC due to the return of symptoms. Genomic analysis was performed as part of the Molecular Guided Therapy trial at Helen DeVos Children's Hospital in Grand Rapids, Michigan. The molecular analysis led to a combination therapy of four chemos that targeted the mutations in her tumor. Initial results were promising and we saw several weeks of improvement; however, things took a rapid turn for the worse. As no more viable treatment options were available, we headed home to hospice. Maddie's decline was mercifully swift and she passed away in our arms.

WHAT BROUGHT US TO CSN

Several months after Maddie was diagnosed, I attended the DIPG Symposium in Chicago. Diving into the research had become part of my way of coping. I was nervous about attending, but felt compelled to see what I could learn. I was amazed at what I found. All these families had come together to fund important research that would otherwise not be funded. The researchers were passionate and compassionate people that were dedicating their lives to finding a cure. I found that the researchers that published the papers that I had read were in attendance, and they were more than ready to speak with me about the research and the questions I had. During the presentations, I learned that the The Cure Starts Now was the funder and organizer behind much of the research as well as the symposium that brought everyone together.

After Maddie passed away in December 2015, we wanted to do something to honor her memory, help kids in the future, and be part of the solution in finding a cure. Starting the Nebraska chapter of The Cure Starts Now was the clear next step. Losing a child is absolutely devastating, but The Cure Starts Now helped us see that we weren't alone in this experience, and realize how helpful it is to be part of a community of families working together to make a difference in memory of our children.

Continued on page 10

Continued from page 9

The Cure Starts Now staff provide the tools and organization so that chapters can focus on reaching out to our networks and creating events and fundraisers, rather than dealing with the paperwork it takes to run the charity. We are so much more powerful when we work together as The Cure Starts Now than if we tried to do this separately. We are inspired by the work of the other chapters and hope to provide inspiration to the newer chapters. That's the way this works, we lean on each other.

OUR SIGNATURE EVENT

Our major fundraiser is the Nebraska Race Against The Odds, a 5K run/walk, in April. We are fortunate to have tremendous support from family, friends, Maddie's school, and the community, as well as from our employer. Corrie and I both work for Union Pacific Railroad, a sponsor for the event, who matches employee donations – magnifying their impact.

Along with the 5K, we do a raffle, and dine and donate in partnership with Granite City Brewing. We have a committee that helps plan the event and have a great team of volunteers on race day that make this possible. We are very grateful for their help!

THE CURE STARTS NOW – IT'S ALL ABOUT COLLABORATION

Looking back at when I first got to know The Cure Starts Now at the first DIPG Symposium in 2015, I realize that it was an inflection point. Since then I have seen the organization grow to include new chapters, raise more funds, and impact more research.

A big part of The Cure Starts Now has been encouraging researchers to collaborate in order to make more progress. The collaborative environment of the DIPG research community is unique, and it is making a difference. We are now seeing the results of the groundwork that has been laid over the last decade. The DIPG Registry now includes a rich set of genomic, imaging, and clinical data, which is pulled together so that researchers are empowered to ask and answer questions in a way that was never before possible.

Maddie's Class at the Race Against the Odds 2018

The CONNECT consortium will open trials in institutions across 6 countries, which will make it possible for children to get access to new treatments without leaving their country. Faster accrual of patients will help researchers more quickly learn which treatments have the most promise. The CONNECT consortium is possible because of the trust and relationships built among people at different institutions as part of the research already funded through The Cure Starts Now.

The DIPG Warrior program, recently started by The Cure Starts Now, will serve as a way to help families battling DIPG connect with each other and receive the latest information on clinical trials and research. This will be a crucial tool to families at a time when they need it most.

A YEAR OF EVENTS AND FUNDRAISERS IN SUPPORT OF THE HOMERUN CURE

FUN-RAISING

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

ANTARCTICA MARATHON

Tom Lubas made the brave and crazy decision to run the Antarctica Marathon in 2018 in honor of his niece Josie who battled DIPG in 2015. Joined by Josie's dad Matt, they set out, not only to run with the penguins for Josie, but to also raise money in her honor. Traveling from Argentina to Antarctica via boat for 2 days, they reached a brisk 15 degree morning to start their race across the earth's southern most regions. Battling the cold and terrain mixed with ice, snow, rocks, and mud, Todd was the first to cross the finish line with Matt finishing second in his age group. But even sweeter than that victory, they raised $14,000 for The Cure Starts now in Josie's honor.

BOCCE SOCIAL

Jane Midgley became a chapter after being inspired by so many children who fought valiantly against DIPG and other cancers. A mom of 3 grown children, Jane decided to use her work skills of sales and marketing to spread the message of the Homerun Cure in her area. Knowing what her friends and family would be supportive of, Jane set forth to marry a fundraiser with a Youngstown favorite...bocce! Very popular in Europe, this bowling type game has proven to be a fun and unique way to raise money and a great way to involve the community in her passion. Jane is proud to have raised over $120,000 so far toward the Homerun Cure since starting in 2016.

HAVE A UNIQUE FUNDRAISING IDEA?

The Cure Starts Now event staff is always ready to support any idea! Big or small, we have resources to help you make your impact on the Homerun Cure! Contact us at 513-772-4888 or email events@thecurestartsnow.org and ask for Lisa or Sheila.

CHAPTER SPOTLIGHT
TEXAS (CENTRAL)

Chapter Director Vicky Bridier is working to connect the Blue with the Gold to increase awareness of and support for DIPG.

IT HAPPENED SO FAST

Jade Bridier was a loving, gifted four-year old. She loved singing, dancing, and playing dress up. Though a princess at heart, you'd be just as likely to see Jade chasing lizards as you would to see her getting a pedicure. She was intelligent and clever beyond her years, and brought joy to all who met her.

In August of 2016, while on vacation, Jade slipped and bumped the back of her head. Later that evening, her eyes started to cross. Returning to Texas, Jade's parents, Vicky and Troy, took her to the ER where she was reported to have a negative CT scan. The following Monday, Vicky and Troy followed up with a neurologist who informed them that he saw something in the pons, and recommended an MRI.

Two days later Jade was diagnosed with DIPG. Her condition deteriorated rapidly the next day – no longer able to walk or hold her head up. Within two days she lost the ability to walk, eat, and talk. Jade passed just 5 days after diagnosis.

THE ROAD TO THE CURE

After the funeral, Jade's parents and little sister set out on a road trip – to get away, to find answers, and to visit places they'd always promised Jade they'd go. It was during this trip that Vicky had a chance to do research on DIPG. In her searching, one foundation kept popping up – The Cure Starts Now. As they continued their trip, Vicky realized that they'd pass through Cincinnati and knew she had to visit the foundation.

> *“I'm so sorry we just popped out of nowhere, but Jade is guiding me here, and I'm not sure why.”*

It was this chance meeting with Brooke and Keith Desserich, and Lisa Hill that ultimately showed Vicky why Jade was guiding her to The Cure Starts Now. To continue the fight. To start a chapter.

After forming a chapter, Vicky became a part of the CSN family. A family that is made up of over 40 other families who have experienced the same pain and grief and have the same desire to keep honoring their children. Vicky states, “The Cure Starts Now introduced me to parents that have now become family and being part of this family brings me a sense of happiness that I'm fighting so hard to fulfill my promise to Jade.”

THE THIN BLUE LINE

The Cure Starts Now isn't the only family Vicky has at her side – her husband, Troy, is a Texas State Trooper. However, it wasn't until Jade's diagnosis with DIPG that Vicky began to understand the true value of brotherhood shared by troopers and law enforcement families across the country. “They all came to support us: driving us home; escorting us to the airport to take Jade to Texas Children's hospital; taking shifts around the clock outside our hospital room just in case we needed anything; and providing everyday service needs that we had at home,” Vicky states.

Since forming her chapter at the end of September in 2016, Vicky has called on this brotherhood in many of her fundraising efforts. From the “romper challenge” in which Texas State Troopers vowed to trade their uniforms for rompers if $4,000 was raised, to Operation Gold Shield which has Blue families from Texas, Ohio, California, and Colorado raising money for the Homerun Cure.

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Over the last two years, three Texas law enforcement families have lost children to DIPG, including the Bridiers. It is Vicky's true belief “that every fundraiser in honor of these children will be a success, because they're supported by our [law enforcement] community and [the parents of] this Foundation.”

A NEW APPROACH TO DIPG SUPPORT

The Cure Starts Now is already the leader in DIPG research funding around the world with nearly $12 million in research funded, but we realized that there was a major lack of tools and support for the families battling DIPG. So we started a year-long mission to create expert tools and programs to help these families as well. We are proud to continue our history of being a leader in DIPG research and support.

DIPG WARRIOR WALK

The DIPG Warrior walk is sweeping the nation. After our successful inaugural walk in Ocean Springs, we now have walks scheduled in Alabama, Texas, and many other areas of the country.

> *“The energy surrounding these walks is amazing. We have wonderful communities coming out to celebrate all of these children and honor how they fight DIPG with the courage and bravery of a true warrior.” – Brooke Desserich*

The DIPG Warrior walk is a family friendly walk of various lengths with an emphasis on celebrating the DIPG Warriors. Hosting a DIPG Warrior Walk is easy and we have an amazing staff to walk you through the process, as well as be on-site to help you the day of the event.

Just contact us today! Call (513) 772-4888 and ask for Lisa or email dipg@thecurestartsnow.org.

DIPG WARRIOR APP

After a year of development, The Cure Starts Now launched a new tool for families battling DIPG: the DIPG Warrior App. Mindful that many families facing this type of cancer spend endless days in hospitals, we sought to create an app that would give them access to important information about DIPG, send notifications when new trials specific to DIPG open, and also provide them a safe environment to connect with other families to seek support and answers.

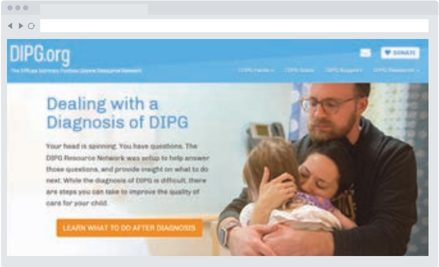
The app, which launched this spring, has had great response and we are continuing to roll out new features based on feedback from families.

We are proud of this first-of-its-kind tool and our ability to be a leader in support for DIPG families.

DIPG WARRIOR PROGRAM

The DIPG Warrior Support program continues to be very successful. With over 180 families set up, it continues to be the go-to place for families who are battling DIPG and want to increase awareness in their communities.

DIPG.ORG



Dealing with a Diagnosis of DIPG

Your head is spinning. You have questions. The DIPG Resource Network was setup to help answer those questions, and provide insight on what to do next. While the diagnosis of DIPG is difficult, there are steps you can take to improve the quality of care for your child.

This summer, The Cure Starts Now rolled out a new website whose primary purpose is to provide a comprehensive location of information for families and friends facing a DIPG Diagnosis.

DIPG.org seeks to answer all of the normal questions families have about this type of cancer and provides helpful support articles and tools. It also houses information from industry leaders about advances in the field and clarification to the most pressing issues and questions that can’t be found anywhere else.

The website has been an excellent source of up-to-date and expert information for families leading to an increase in consultation requests at many hospitals.

CHAPTER SPOTLIGHT WASHINGTON, DC

Neely Agin talks about her time as Chapter Director and what it's meant being a part of The Cure Starts Now.

TELL US ABOUT YOUR JOURNEY HERE & ABOUT YOUR DAUGHTER

We formed Team Alexis, the DC Chapter of CSN, in 2009 during the first year of my daughter Alexis' battle with DIPG. Alexis was 2-years-old when she was diagnosed in April 2008, and we were desperately hoping that we could help to find a cure that would save her life. Alexis fought very hard for almost 3 years, participating in five Phase 1 clinical trials and taking countless vitamins and supplements. Alexis never complained about her illness, and willingly took all of the medicines and supplements we gave her. She endured countless blood draws and needles, and yet was often smiling and found running through the hospital halls giggling, blowing bubbles or painting a picture in the doctor's office, or throwing pennies with glee into a nearby fountain.

Unfortunately, we weren't able to find a cure before Alexis passed away in January 2011, just before her 5th birthday. But through our work with Team Alexis, we have been able to help get closer to a cure, and I am confident that in my lifetime, CSN will be a critical player in finding that cure.

WHAT HAS BEING A PART OF CSN AND FUNDRAISING MEANT TO YOU AND HONORING YOUR DAUGHTER'S LEGACY?

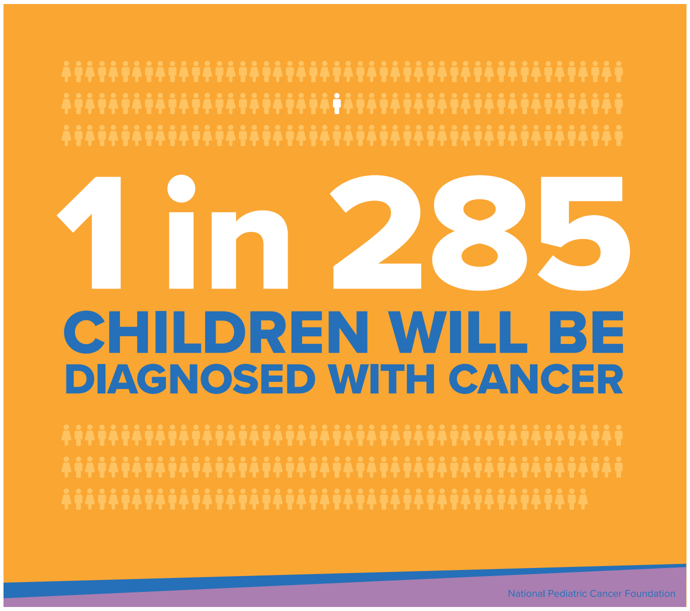
Being a part of CSN and leading Team Alexis is my way of continuing to parent Alexis. I direct the energy that I would be putting toward parenting her if she were still here on earth, and use it to organize fundraisers in her memory. People often tell me they are amazed that I find the time to do it, but it is just part of who I am – Alexis' mom – and that means making the time. It is such a labor of love that even when I'm putting in 20 hour days the week of the event, it feels good and worth every moment.

WHAT HAS BEEN YOUR FAVORITE MOMENT DURING YOUR TIME WITH CSN?

It's not a single moment, but rather the relationships that I have formed with other CSN directors and families. They are some of my dearest friends, and I am so grateful to be in the battle together with them.

WHAT DOES IT MEAN TO BE A PART OF A CHAPTER SYSTEM?

Being part of the chapter system is critical to my ability to fundraise in memory of Alexis. CSN provides the administrative support and backup that I need to organize an event, while still giving me the flexibility and control I desire. I can carry out my vision of the event to honor Alexis, and not worry about the details like website design or which software to use for mobile bidding.



1 in 285

CHILDREN WILL BE DIAGNOSED WITH CANCER

National Pediatric Cancer Foundation

WHY WE FIGHT

WORDS FROM OUR CHAPTERS

ARKANSAS

“Being a chapter is important because our children count on us to be able to help them. Funds for childhood cancer research are so limited … every little bit helps. Being a chapter allows us to help even more than we could otherwise. We are raising awareness and funds with a HUGE hope to help our children survive and live a better life.”

CENTRAL MASSACHUSETTS

“The innovative, forward-thinking swing this organization makes to find the Homerun Cure for cancer is truly amazing. Every dollar donated, each new person reached, every Warrior on our hearts, we will find the cure!”

MICHIGAN

“This disease is horrific – no child should have to go through this, and no parent should have to watch this happen to their precious child! Brison has made us forever Rickerstong and in his honor, we will share his story, we will advocate, and bring as much awareness to DIPG as possible, so we can together work towards a cure!”

NORTHERN NEW HAMPSHIRE

“Cancer has impacted each and every one of us, not just the families who are dealt a DIPG diagnosis. Nothing can bring back our son. But there are hundreds of families out there today who will soon have their lives turned upside down. That needs to change, we must find the Homerun Cure.”

CENTRAL NORTH CAROLINA

“We fight for Odin. We fight so no other family has to hear, “there is nothing we can do.” Most of all, we fight so that other children can have the chance he never had, to grow up and live a long and fulfilling life. To laugh in the sunshine and enjoy the wonders of the world.”

NORTH EAST OHIO

“Sometimes the biggest crisis in your family leads you to helping the people that need it the most. Even though they are few in numbers, they are the most desperate and deserving. More importantly, they are unknown and don’t have a lot of time. They have cancer. The worst kind. And they’re just kids. You also find a new family of families. This is what it means to me to be a CSN Chapter.”

SOUTHERN OHIO

“Our Elena was such a giver and was always quick to show her love. The Cure Starts Now is my way to continue her legacy by making sure no other child faces such a hopeless diagnosis.”

READING, PENNSYLVANIA

“Jo’s Everglow for The Cure Starts Now helps me channel my incredible love for Josie. I think of my events as celebrations for her. As her mother, I put all my love into trying to create an event that would make her happy. I know that if I focus on her the event will be a success because it is all about spreading her light and love.”

WISCONSIN

“Being a chapter is important to me because my daughter, Alison, fought with every ounce of her being to live. I fight in her honor, in the honor of all other DIPG warriors who left this earth way too soon, and for any DIPG warriors who will get this diagnosis.”

WHO WE ARE

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Monkey In My Chair Administrator
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THE CURE STARTS NOW®

HAS FUNDED
ALMOST $12,000,000
IN DIPG RESEARCH

FEDERAL EMPLOYEES:

Show some love and help fund DIPG research.
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