



EVAN AUSTIN:
DIPG Warrior
see page 3

MORE THAN JUST AWARENESS™



LETTER FROM THE DIRECTOR

It has been a crazy year, to be sure. Still in the midst of COVID-19, I continue to be humbled by the support you show The Cure Starts Now and the children fighting today. As a mother who lost our Elena to DIPG a little over 13 years ago, this battle is personal. And we continue to fight today in pursuit of the Homerun Cure™, starting first with those cancers we can learn from the most.

As you may know, this year is also when cancer returned to our family with my diagnosis of aggressive breast cancer. Although comforted with great care and a positive prognosis, this new fight has given me a front row perspective to what our children endure each and every day. And while I am blessed to have options, I learned first-hand what chemotherapy felt like as it pulsed through my veins and the emotional toll it took as I looked in the mirror each day to see the shell of what I was. I can only imagine what it feels like to fight this battle at the age of 6 – or even for a second time as the cancer progresses. Our children deserve more.

Ultimately, I have a cure and a roadmap – something we now need to deliver to our children fighting DIPG, DMG and medulloblastoma. Regardless of the pace of COVID-19, our obligation to our children must remain strong. Cancer doesn't

stop and neither should the support of our children. This is a mission we cannot ignore – and thankfully, due to your help we haven't. **This year alone, we will discover and fund with our partners over \$2.4 million in new research reaching 5 countries and with 6 trials.**

Thank you for continuing to support this mission and The Cure Starts Now!

Brooke Desserich
Co-Founder, Executive Director



WHO WE ARE

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EVAN

WARRIOR. AMBASSADOR.
INSPIRATION.

SPREADING POSITIVITY AND JOY

Sweet, active, handsome, playful and funny are just a few words that can be used to describe 6-year-old Evan, but he is so much more than meets the eye. He loves to play baseball and soccer, he loves fishing with his grandfather, he loves Star Wars and Legos, and he loves his big sister, Avery, very much. Evan has a heart of gold and a spirit that won't let anything hold him back. He is incredibly positive and lives life to the fullest by spreading joy to those around him.

At school, Evan takes on the role of class clown with pride. Jessica Austin, Evan's mom, jokingly recalls one of his preschool teachers telling her about Evan's classroom antics, "I think he just really likes to make the other kids feel the same joy he feels on the inside."

A LONG NIGHT

Evan's symptoms started slowly with mood changes and sleep-talking, before quickly progressing to more severe and sudden symptoms such as loss of balance, significant neck pain, and vomiting. "The week before Evan was diagnosed, he was at camp and he was fine," recounts Jessica. "None of the counselors had any concerns, and then it's just crazy how quickly the more severe symptoms came on. It was really scary."

Evan's parents first took him to see the pediatrician who recommended they go to the emergency room at Maine Medical Center where they could be seen by a pediatric neuro-oncologist. "Just based on his symptoms the emergency room doctors weren't clear on what it could be, but they did say it could potentially be some kind of mass on his brain that was causing the symptoms," says Jessica. "So, Evan had an MRI which was supposed to be 45 minutes, but it ended up being over 2 hours. The on-call pediatrician brought us into a little room and she said, 'I have bad news. They found a tumor in his brainstem. I'm not a neurologist, I can't really give you any other information, other than that he has a tumor.' Early the next morning, we met with the pediatric oncologist who explained to us that he had DIPG. It was a long night to say the least."

MAKING MEMORIES


Evan is currently symptom free and his tumor has remained stable since October 2019, so Evan and his family are focusing on what's important – family time. "We've been on tons of long weekends," says Jessica. "We went on a Disney Cruise through Make-A-Wish. In February, we did a big family trip to Disney World. Evan's been able to do a lot. We've been really trying to soak up the family time as much as we can. It's just kind of a guessing game. We don't know when it'll come back; we know it will, we just don't know when, so it's about making the most of everyday while we can."

"I think him being so positive all the time is really helping us get through this. We've been able to pull a lot of our strength from watching him." — Jessica Austin, Evan's mom

In addition to making memories, the Austin family has been busy actively helping to fund research with The Cure Starts Now in honor of Evan and all children battling cancer. "It's meant so much to us to have a group of people who are so knowledgeable about the subject and who have made themselves available to answer any questions and to point us in the right direction for accurate information," says Jessica. "There's so much out there on the internet and it can be kind of scary to try to sift through it all. It's really hard and the last thing that you want to be doing, so it's just so nice to have their support."

IT BEGINS WITH THE HEART

Evan Austin, The Cure Starts Now's 2020 Ambassador, is pictured on the cover with the one-of-a-kind heart he painted for the HeART Auction this past April. The annual HeART Auction, organized by Grace Desserich, began in 2017 as a way for Grace to honor her late sister, Elena, who lost her battle with DIPG, while also raising money to fund pediatric brain cancer research. Since its inception, the HeART Auction has raised over \$20,000 for DIPG research by auctioning off the masterpieces by heroes like Evan.

To help fund pediatric brain cancer research, make a donation today in Evan's honor by visiting donate2csn.org/EvanA 

FIGHT LIKE A REBEL FOR THE CURE

The Cure Starts Now's edgier, more out spoken counterpart, Cancer Rebel, started a revolution to unite people fighting cancer and to refute the notion that raising awareness cures cancer. It takes more than a ribbon, a color or a commemorative day; it takes action.

Cancer Rebel is about empowering people to stand up to cancer and find the Homerun Cure™ – the theory that to truly cure cancer we must focus on cancers that are the most difficult to treat, affect children, and are the biggest bullies with the highest death rate. To help rally support, Cancer Rebel created an ambassador program for cancer survivors and those currently battling to share their stories and struggles with the world.

“One thing that cancer has taught me, is who I truly am and how hard I can fight; I’m not one to back down.” – Chelsea Frye

One of Cancer Rebel’s recent ambassadors, Chelsea Frye, was diagnosed in September 2019 with an aggressive form of breast cancer, known as Invasive Ductal Carcinoma HER2 and ER+, at the age of 26. At the time, Chelsea’s two children were 2 and 4-years-old, which added a whole other layer of complications on top of her cancer.

“I never thought in a million years that I’d have to go through something like this at my age, but I was wrong,” says Chelsea. “This past year has been incredibly tough. Not only on me, but on my family. I’m the mother of two small children. There’s not a good way to explain to a small child that their parent is sick. So, when I had to shave my head or I was in the hospital, they didn’t quite understand and that was the hardest part.”

Since her diagnosis, Chelsea has endured a rigorous course of chemotherapy and surgeries, and while she will still need more chemotherapy sessions and years of hormone therapy, Chelsea recently completed her final surgery for her breast cancer, marking a monumental moment for her and her family. Chelsea is taking a stand and showing cancer how strong she is and not letting it get the best of her.

“Cancer Rebel has grown so quickly because it empowers the 1.8 million people who are diagnosed with cancer each year. We tell them that you don’t have to hide in your diagnosis, you can fight back and there is a whole group of rebels just like them ready to help. It is liberating for so many of them to share their story” – Brooke Desserich, Founder and fellow Cancer Rebel



“Thank you, Cancer Rebel, for helping people like me get our stories out there,” says Chelsea. “What you do is truly amazing.”

Join Chelsea and many other Cancer Rebel ambassadors on the frontline in the war on cancer. Become an ambassador, share your story, donate and show the world that ribbons are not the cure for cancer by visiting www.curecancer.org



ADVANCES IN RESEARCH FUNDED

DR. HAN SHEN, UNIVERSITY OF SYDNEY

In 2018, The Cure Starts Now and the DIPG Collaborative funded a research project that focused on targeting hypoxia and mitochondrial metabolism by repurposing drugs as an approach to radiosensitization for diffuse intrinsic pontine gliomas. We recently interviewed Dr. Han Shen to explain how this research is providing clues for new treatment options for diffuse intrinsic pontine glioma.

“DIPG is the most malignant childhood primary brain tumor arising from the brain stem. Radiotherapy is the only standard treatment, but almost all the DIPG eventually comes back with radial resistance, which means radiotherapy will no longer be able to kill this tumor’s cells. To tackle this urgent clinical problem, we’re trying to overcome radio resistance of the DIPG tumors, such that radiotherapy can eliminate as many tumor cells as possible. Radiation needs oxygen to kill tumor cells more effectively. And the DIPG tumors are recently reported to be hypoxic, a condition with reduced oxygen level. This biological feature may significantly contribute to radio resistance of DIPG cells.

We, therefore, repurposed antidiabetic drugs to reduce the oxygen consumption rate of the tumor cells so that the hypoxic condition can be improved by sparing more oxygen. The antidiabetic drugs are well tolerated in children, and have long

been used in clinic without significant side effects. We have seen very promising effects from this class of drug when combined with radiotherapy to kill DIPG tumors.

In the next step, we will be evaluating this combination therapy in our animal model. We’re also working on some predictive biomarkers to identify patients who will most likely benefit from this combination treatment. And this way, we will only give the right treatment to the right patient, so patients don’t end up receiving treatments with no therapeutic benefit.”



To learn more about Dr. Shen’s research, visit donate2csn.org/Shen 

MOST MEMORABLE MOMENTS

WORDS FROM OUR CHAPTERS

ARKANSAS NICOLE MCCOY

“My most treasured memory as a chapter would be the first Gala Jinx and I attended. I was beyond moved to tears, no words can explain just how moving it was to see all of these beautiful families and all of these supporters gathered together in honor and memory of all of those who passed away from this horrible DIPG monster. It was so emotional and so uplifting. I will never forget how that made me feel, how it drove us to want to help even more and how it forever changed our hearts.”

CENTRAL MASS. ABBY ARPANO

“Orientation for The Cure Starts Now - it was such an amazing moment to be surrounded by families like us, dedicated to finding a cure while feeling such incredible loss. I cried most of orientation... understanding how The Cure Starts Now came to be, hearing the stories of the

families surrounding me, and enduring the grief in my own heart. The tears turned to optimism, and all the potential we have as a community of families and loved ones, to DO GOOD! To raise funds for research to fight this monster. I was, and am still, inspired by the forward-thinking approach to The Homerun Cure™!”

CONNECTICUT ROBYN STAUB

“My most memorable moment was when I went to my first chapter meeting shortly after starting our chapter. Our hero Lea was still battling at the time and I was a bit overwhelmed with what I was going to be doing and if I was going to be able to help in any way. To be surrounded by a room full of literally the bravest and most selfless people I’ve ever met was life changing for me and my husband. I knew that I couldn’t fully understand what any of the parents were experiencing

because Lea is not my daughter, but I knew without a doubt that I was meant to be a part of the fight for a cure. That weekend truly changed me in so many ways.”

COLORADO CARRINA WANEKA

“My most memorable moment happened before we were technically a chapter, but it was when we received a box filled with hundreds of gold hearts with hand-written words of support and encouragement for Piper and our family. These Hearts Of Hope had a profound impact, reaching us just after we discovered Piper’s tumor was progressing. I would carry handfuls of hearts to her second round of radiation appointments and read them as I waited. It was a glimpse into the love and dedication behind this organization, and we knew we needed to be part of that.”

2019 ANNUAL REPORT

TOTAL REVENUE, GAINS, AND OTHER SUPPORT

\$4,087,218

BALANCE SHEET

As of December 31, 2019

ASSETS

Cash and cash equivalents	\$2,374,319
Inventory	\$91,631*
Other assets / prepaid expenses	\$289,762
TOTAL ASSETS:	<u>\$2,755,712</u>

LIABILITIES

Accounts payable	\$37,357
Grants payable	\$0
Other liabilities:	
Accrued Compensation	\$15,113
Deferred revenue	\$42,603
TOTAL LIABILITIES:	<u>\$95,073</u>

NET ASSETS

Unrestricted	\$2,388,786
Temporarily restricted	\$271,853
TOTAL NET ASSETS:	<u>\$2,660,639</u>
TOTAL LIABILITIES & NET ASSETS:	<u>\$2,755,712</u>

STATEMENT OF ACTIVITIES & CHANGES IN NET ASSETS

For the Fiscal Year Ended December 31, 2019

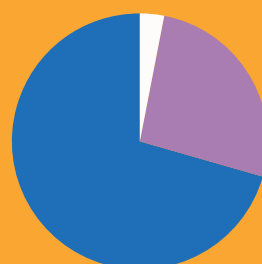
REVENUE, GAINS, & OTHER SUPPORT

Contributions	\$1,960,021
In-kind donations	\$80,703
Special event revenue	\$2,006,996
Gain on sale of property	\$38,839
Investment return	\$659
TOTAL REVENUE, GAINS, AND OTHER SUPPORT:	<u>\$4,087,218</u>

EXPENSES

Program services:	
Medical research	\$1,036,685
Monkey in My Chair	\$121,800
Medical symposium	\$274,783
Family support program	\$601,662
Fundraising	\$935,801
Management and General	\$184,207
TOTAL EXPENSES:	<u>\$3,154,899</u>

Increase (Decrease) in Net Assets	\$932,319
Net Assets - Beginning of year	\$1,456,466
Net Assets - End of year	<u>\$2,388,785</u>



SINCE 2007

3.34% OVERHEAD

25.14% FUNDRAISING EXPENSES

71.52% PROGRAM EXPENSES & RESEARCH FUNDED

2019 TOP DONORS

\$50,000+

Abstract Displays
The ChadTough Foundation
Facebook
Graeter's Ice Cream Company
Hyde Park Blast
Jersey Mike's
Morgan Stanley Smith Barney, LLC
Reflections of Grace

\$25,000-\$49,999

Aidan's Avengers
Austin Strong Foundation, Inc.
Bruce and Nancy Axmacher
Capital Group Co Charitable Foundation
Fidelity Charitable
Jackson Hewitt Tax Service
Jeffrey Thomas Hayden Foundation
Love, Chloe Foundation
Musella Foundation for Brain Tumor Research & Information
Pray Hope Believe Foundation
Storm the Heavens Fund

\$10,000-\$24,999

Allstate Insurance Company
Anna's Bake Sale Foundation
Aubrey's Army Foundation
Benevity Causes
BNY Mellon
Capital Group
Cincinnati Children's Hospital
Clermont County Sale Committee
Covelli Enterprises, Inc
Credit Suisse Americas Foundation
Keith and Brooke Desserich
Beverley Earle
Frontstream
GBA Girl's Basketball Assoc Inc
GM Financial
The Gold Hope Project
Gold Star Chili
JPMorgan Chase & Co
Harrison and Gena Keller
Kershner Trading Group, LLC
Koons Arlington Toyota
Jane and Ronald Midgley
Milligan Memorial Golf Tournament
Operation Dough-Nation
Pep Company
Dee and Ginny Pritchett
John Sloan
State Street Bank
Andrew and Crystal Wash
Union Pacific Give Plus Program

\$5,000-\$9,999

American Trucking Association
Analog Devices
Ascension/Dell Children's Medical Center
Dave Ashcraft
Gavin and Fatema Baumgardner
Benny's World
Brew Ha Ha Cincinnati, LLC
Bruce and Laura Shelby Family Fund
Ben and Dottie Buerger
Brian and Carrie Bullard
CCP Commercial Real Estate
Combined Federal Campaign
Community Council Charity Event
Conroe Police Officer's Association
Cure Starts Now Australia
Danni Kemp Cancer Support Fund
DMSI Charitable Fund
Kevin and Marie Douglas
Mike and Carla Eng
ESK Presents, LLC
The Estate of Esther Shelby Fund at the Houston Jewish Community Foundation
Esther and George Jaruga Charitable Foundation
Fiserv Solutions, LLC
Fleet Feet
Melissa and James Fleming
Susan Harmon
Thomas and Stephanie Hatfield
John and Julia Hinshaw Charitable Fund
Infintech
Integrity BioFuels
Kevin Johnson
Laurens Fight For Cure Inc
Henry and Althea Lee
Lily Larue Foundation, Inc
Evin Macaluso
Craig and Kristin Maurer
The McCormick Family Foundation
James and Cynthia Miller
Omaha Community Foundation
Glenn Osako and Dayna Yamabe
John and Stella Perentesis
Perfect Transportation, LLC
Plante Moran
Popp Hutcheson, PLLC
Todd and Erin Prewitt
Primrose School of Round Rock at Forest Creek
PTC Therapeutics, Inc
Rahr Corporation
Terry and Maureen Regan
Reis Promotions
Renaissance Charitable Foundation Inc

David Rutledge
David Saliba
Jesse and Corrie Shumaker
Smile For Brooklyn Inc
Libbey Spiess
Jeremy and Robyn Staub
Stylecraft Builders, Inc
Lisa Thomas
Jesse and Alison Thompson
Tiff's Treats RBD, Inc
Steven and Jennifer Trax
Turnstone Corporation
Union Pacific
Vanguard Charitable
Tricia and Matthew Verhaalen
Russ and Angie Walter
Daniel and Oris Weiner
Wings Charity Fund

\$2,000-\$4,999

ABC Supply Corp
Acorn Golf, LLC
Pat and Elizabeth Adams
American Youth Soccer Organization Region 88
Annunciation Catholic Academy
Architectural Precast Association, Inc
Christina Arumi
ASW Distillery
Derek and Kristine Blackwelder
Richard Bond
BPOE #521
Briggs Equipment
Brown Brothers Harriman
Busken Bakery
CapRock
Caprock Health
Frank Capuano
Jamie and Amy Charlton
Phoenix Children's Hospital
Citi Business Services
The Clemens Family
Darlene Crick
Zoran Cupic, MD
Deloitte
Disney Worldwide Services, Inc.
Frank Dooley
Stefano Dukcevic
Electric Events DC
Tom Estus
ExVoto, LLC
Kanga Roof Austin
Julie Fritz
Mark Gass
Andrew Grouten
Greg Hardig
Kristen Hemenez
Brian Janssen
Jones Lang LaSalle America
Kim Kaplan
KDM
Kinsley's Cookie Cart Corp
Kisses from Kaitlyn
KM Whitetails & Exotics
Tom and Kimberly Kuck
Kevin and Kelly Larkin
Lewisville Independent School District
Kyle and Elizabeth McLaughlin
Jo and Marty McMahon
Mecha Noodle Bar, New Haven
Mecha Noodle Bar SONO, LLC
Mecha Noodle Bar, LLC
Miramar Emp Fund MCF
Christine Mueller
Kathy Nace
Nadia's Performing Arts Centre
North Zulch I.S.D
Northern Trust
Stacey Parrish
Shaily Pasi
Randolph and Patricia Pike
Heath Poindexter
Alan and Anne Posnack
Prestige AV & Creative Services
Ernie Reed
The Rider Insurance Bleiwise Family Foundation
Robeson Library Fund
Ryan and Kara Rybolt
Robert and Constance Schroeck
Schwab Charitable
Ken and Terry Segerberg
George Shaughness
Somerset Berkely Regional High School
Dr. Hal and Brenda Stevenson
Stockyards Bank & Trust
Trung Tang
Jeff Thomas
Thomas Dale High School
Michael Thompson
Trinity Lutheran Church & Christian School
Tyler Area Builders Association
Anthony and Heidi Varns
Elizabeth Walsler
Ward's Hardwood Floors
Elizabeth Weiner
Western Regional Zone 2
Clayton Wigley
Woodtex of South Carolina, LLC

OVER \$15 MILLION* IN RESEARCH FUNDED

See grants funded prior to 2018 at www.thecurestartsnow.org/grants

2020

Children's Cancer Institute, Australia: \$99,251
The Hospital for Sick Children, Canada: \$100,000*
Northwestern Memorial Hospital: \$110,000*
Hunter Medical Research Institution, Australia: \$145,640*
International DIPG/DMG Registry and Repository: \$862,671*

2019

Sydney Children's Hospital, Australia: \$151,468*
Dayton Children's Hospital: \$69,600*
The University of Sydney, Australia: \$100,000*
The Institute of Cancer Research: \$121,863*
University of Michigan Hospitals: \$157,856*
Bambino Gesù Children's Hospital: \$49,803
Telethon Kids Institute: \$49,512*

2018

Children's Cancer Institute: \$175,089*
Cincinnati Children's Hospital: \$540,742*
Johns Hopkins: \$50,000
Bambino Gesù Children's Hospital: \$99,382*
The Institute of Cancer Research: \$106,647*
The Institute of Cancer Research: \$100,000*
St. Jude Children's Research Hospital: \$50,000*
Ann and Robert H. Lurie Children's Hospital of Chicago: \$50,000*
Sydney Children's Hospital, Australia: \$175,089*

* Denotes grants funded with our DIPG Collaborative partners. All numbers reflect financial data accurate at time of print.

CHAPTER SPOTLIGHT WESTERN PENNSYLVANIA

Finding strength in community.



FEARLESS ADVOCATE

Alyson Usher was kind and full of energy. She was truly a spitfire of a girl, who was a tomboy but at the same time was all about pink sparkles. She loved gymnastics, dance, softball and cared deeply about others. She didn't like to see anyone pushed around. "She was the kid on the playground that if somebody got pushed to the side, she went and stood up for them," reminisces Alyssa Hawranko, Alyson's mom, Director of the Western Pennsylvania Chapter, and board member of The Cure Starts Now.

"It didn't matter if they were older or bigger than her, she had no fear. You could call her fearless. She did not see herself as a little girl, she saw herself as an adult. She was always the advocate for somebody else."

— Alyssa Hawranko, Alyson's mom

In November 2011, 5-year-old Alyson was diagnosed with DIPG, a form of brain cancer with no effective treatment or cure. She was given 6-9 months to live. Alyson's days of handstands and dancing were soon filled with hospital visits and radiation treatments. Through it all, she found solace in arts and crafts. Alyson was constantly creating, whether it was coloring pictures, molding sculptures or making bracelets – Alyson loved art. In November 2012, exactly one year after her diagnosis, Alyson gained her angel wings.

"While our daughter was in the thick of the battle, I had to believe that she was the one that would beat it," recalls Alyssa. "As soon as her battle was finished, ours began. She was the most important piece for us personally, and once she was no longer with us we could put our attention to the bigger cause."

TOGETHER WE CAN MAKE A DIFFERENCE

The Hawranko-Usher family wasn't sure what would be the best way to honor Alyson, but they knew they had to carry on her legacy as an advocate for others, just as their daughter always did. Shortly after she passed, the Hawranko-Ushers held an arts and crafts drive at the local elementary school in Alyson's memory to benefit the radiation oncology department at Children's Hospital

of Pittsburgh. That year, they were able to donate 10 boxes of art supplies to the hospital so other children going through radiation would also have something to look forward to. In the years since, the arts and crafts drive has grown tremendously as they now receive upwards of 30 boxes to donate to the hospital.

The Hawranko-Ushers felt the need to do more. They looked into establishing their own charity but, ultimately, decided to join The Cure Starts Now as the Western Pennsylvania Chapter. "The one thing I was always impressed with, is The Cure Starts Now values the legacy that your child created," says Alyssa. "Your child does not disappear, they just become the inspiration for a much larger mission for the cure."




COMMUNITY STRONG: MAKING AN IMPACT

In the years since Alyssa and her husband, Nick Usher, began the Western Pennsylvania Chapter, their small rural community has united behind them and their family. The community has shown an outpouring of love and generosity by supporting events and fundraisers hosted by the Hawranko-Ushers, including their annual golf outing and auction. "When we started, my hope was to get 18 teams of four, now we get 36 teams of four and have to shut registration down because of the overwhelming response,"

says Alyssa. “We have been pretty successful and our community support is what makes it happen.”

The Hawranko-Usher’s passion for continuing Alyson’s legacy is inspiring. Alyson’s whole family, her mother, Alyssa, and her father, Nick, along with her big brothers Nick Hawranko and Noah Usher, are devoted to creating a lasting impact as advocates for Alyson and other families afflicted with DIPG. They want people to know, “you are not alone in this fight.”

The Cure Starts Now believes in giving the families dedicated to becoming chapters and fundraising the ability to be a part of the leadership of the charity. Alyssa is currently serving a 2-year term as Chair of the Strategic Advisory Council and as the Chapter Representative on the Board of Directors.

For more information about the Western Pennsylvania Chapter and to fund research in Alyson’s honor, please visit donate2csn.org/pa-western 



HOST TO INTERNATIONAL INNOVATION

THE CURE STARTS NOW'S REVOLUTIONARY SYMPOSIUM ENTERS ITS 10TH YEAR

It started as a challenge. Twenty of the world’s preeminent experts on neuro-oncology gathered in one room to consider the potential of a “homerun cure™.” Initially it was intended to be a one-day meeting with wide sweeping discussions to assess consensus, nothing more. What it became was a 2-day conference with over 100 experts, setting the future of what would become one of cancer research’s foremost conferences.

The meeting was the DIPG Symposium. 10 years ago, it became the foundation of nearly every advancement we see today in diffuse intrinsic pontine glioma, diffuse midline glioma and even other pediatric cancers. The partnerships achieved through this forum have led to the development of new drugs, new ways of administering radiation, new surgical procedures, new international studies, and most of all, a revolutionary way of sharing and analyzing data. At its core, it assembled a unique collaboration of both researchers and parents, unified to work as one in ways that previously had not been attempted.


In April 2021, The Cure Starts Now Foundation will host the 6th International DIPG/DMG Symposium at the Woodlands Conference Center in Houston, Texas. Planned as a four day session, it will feature workshops on the developments of the International DIPG/DMG Registry as it expands now to 15 countries worldwide, the second face-to-face meeting of the CONNECT Consortium to advance new trials for all types of brain cancers, and the core 2-day symposium. The first day will focus on new developments from previously funded research, leading into the second day where new strategies will be explored and funding offered – all in unison.



More than just a conference of medical experts, what makes the DIPG/DMG Symposium different is the collaboration between both researchers and families/foundations. Both come together to present, offer new ideas and join in a cure for cancer. Realizing that the best research comes from a multi-disciplinary approach, implementation teams are formed from basic, translational and clinical concentrations – all in the presence of and with the support of families and foundations to assist with insight and pre-secured funding channels.

This means that big ideas become **bigger**, not smaller and more restrictive. Here, research can be promoted in generational ways that leads to “next step” planning even before the conclusions are published. The result is efficient research in less time and “dream team” concepts that lead to unprecedented innovation.

Scheduled for April 22-25, 2021, even the location lends itself to collaboration, with a dedicated, inclusive conference center that surrounds the attendees with a multitude of workgroup meeting spaces and plenty of opportunities for networking.

To learn about sponsorship opportunities, contact us at keith@thecurestartsnow.org or 513-772-4888 

SPONSOR & CHAPTER SPOTLIGHT

Allstate Stands with Austin, Texas Chapter.



LITTLE MONKEY

Brock Fleming was lovingly nicknamed “Monkey” by his mom. He was a determined and active boy who was always smiling and positive. He loved Batman, playing soccer, swimming, painting killer whales, and playing Legos with his mom, Melissa Fleming, Director of the Austin, Texas Chapter of The Cure Starts Now. “He was just a very energetic kid,” reminisces Melissa. “He didn’t walk, he bounced everywhere. He just jumped around, bouncing as he walked.”

In May 2016, Brock was diagnosed with DIPG after hitting his head while walking the dog. Because of the tumor’s size, he lost the ability to walk, drink and talk. Brock didn’t understand why his body was doing this to him. With determination and perseverance, Brock was able to run and play soccer again after 6 weeks of hard work. He fought courageously for 7 months before his battle came to an end.

A COMMUNITY STANDING TOGETHER AGAINST CANCER

After Brock’s diagnosis, a family friend introduced Melissa to The Cure Starts Now, a foundation dedicated to funding DIPG research for the cure. “At that time, The Cure Starts Now was really the only resource for us and we were grateful to have them,” recalls Melissa. “They were helping us connect with doctors while we were trying to figure out our options, and Brooke would visit with me about my experience as needed. They were very helpful.”

Melissa immediately began fundraising in her community for the nonprofit and was able to raise about \$10,000 during Brock’s battle. Since then, Melissa and her amazing Team Brock Committee have hosted many successful fundraising events that their community is proud to participate in and show their support. “We definitely would not have been able to raise the money we have without the community’s support,” says Melissa. “It’s been everybody. We’ve been able to unite with other local families, whether it’s brain cancer or other types of childhood cancers.”



ALLSTATE FOR THE WIN

Throughout this difficult journey, the Flemings have been lucky enough to have a second family to rely on for extra support – Allstate, where Melissa has worked as an agent for last 10 years. To date, The Allstate Foundation has donated over \$200,000 to The Cure Starts Now in the four years that they have been connected.

Allstate donates money through their charitable nonprofit, The Allstate Foundation, to nonprofits based on their agents volunteering their time to attend events for worthy causes. Every year, when Melissa hosts the Annual “Team Brock Golf Fore a Cure” golf tournament, 25-40 of her fellow agents flock to attend so they can donate their time and, as a result, Allstate donates money to The Cure Starts Now to fund pediatric brain cancer research. “The agents come out because they care about the cause, they saw firsthand what happened with our family and what Brock had to go through,” says Melissa. “They do care about families, because in the end, Allstate is all about protecting families.”

“When Brock was diagnosed, it hit them all. That’s the good thing about Allstate here in Texas, we’re all like family. They were immediately reaching out to see how they could help us financially or help create fun events.” — Melissa Fleming, Brock’s mom


Melissa works day in and day out to honor Brock in everything she does. “I want my kids, and just all kids in general, to see that when things get really bad, it’s how you choose to react. And although it’d be really easy for me to crawl in a hole and escape, I want them to see that you get back up and you keep fighting and if you don’t like it, you find a way to change it,” says Melissa. “And that’s really at the heart of everything we do, is to fund research for the cure and show our kids that they matter.”

To learn more about the Austin, Texas Chapter and make a donation in Brock’s name, visit donate2csn.org/texas-austin

10 YEARS OF BOWLING FOR A CURE

Jackie Harrison-Harmon joined The Cure Starts Now as the Director of the Northern California Chapter in 2010, shortly after the passing of her lovebug, Khylee, from DIPG. Khylee was the perfect mix of little princess and tomboy, and is an inspiration for the chapter. Jackie was unsure how she was going to fundraise, when out of the blue the owner/operator of the local bowling alley, Gold Country Lanes, offered to let her use his venue for fundraising events. With that offer in hand, Jackie began hosting the annual “Bowling For A Cure” event.

Every year, their small-town community packs into the bowling alley to celebrate Khylee’s life and raise money for pediatric brain cancer research. In addition to bowling, attendees can participate in a basket raffle, have their face painted with The Cure Starts Now’s logo, donate money to see one lucky individual get their head shaved and enjoy good company while supporting a worthy cause.

Help celebrate Northern California’s 10th anniversary as a Chapter of The Cure Starts Now, by making a donation in Khylee’s honor at donate2csn.org/california-northern 




EX VOTO VINTAGE – BEAUTY OUT OF GRIEF

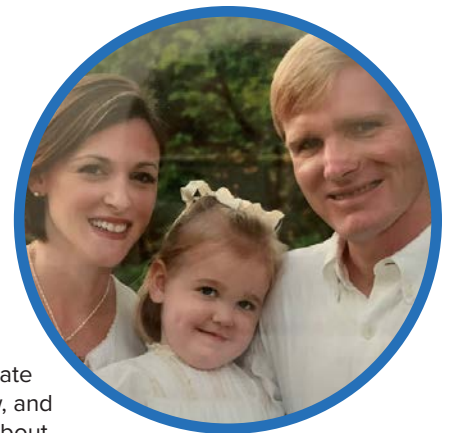
Madeline was a bit of a tomboy, she would happily dress up in a tutu but she’d have to add some cowboy boots to make it work. She had a firecracker personality and a sense of humor fit for a comedian. Madeline could make you laugh no matter the situation. “She was just funny,” recalls her mother, Elizabeth Adams, the Director of the Birmingham, Alabama Chapter of The Cure Starts Now. “If you tried to discipline her, half the time she would just end up making you laugh so hard. She had us laughing most of the time.”

Diagnosed with DIPG at just 3-years-old, Madeline valiantly battled her disease for 11 months before her short life was stolen and her family was left broken. In honor of Madeline, Elizabeth formed the Birmingham, Alabama Chapter; one of the original chapters of The Cure Starts Now. As a founding chapter, Elizabeth had a hand in building the chapter system that has allowed The Cure Starts Now to expand into the foundation it is today with over 40 chapters worldwide.

After Madeline passed, Elizabeth was left with a lot of empty time to fill and turned to art and jewelry making as a creative therapy. Eventually, her therapy turned into a successful business, Ex Voto Vintage, where she sells beautiful pendants that she fashions

out of broken pieces of vintage jewelry. Elizabeth donates a portion of all Ex Voto sales to the cause, holds gift basket raffles for customers who donate to The Cure Starts Now, and educates her patrons about DIPG. Many of Elizabeth’s customers are repeat shoppers because they love her jewelry and they love the cause. “People realize that there is a deeper purpose behind Ex Voto and they want to be a part of helping fund cancer research for children,” says Elizabeth.

To learn more about the Birmingham, AL chapter and to make a donation in Madeline’s honor, please visit donate2csn.org/alabama-birmingham 



CHAPTER SPOTLIGHT NORTH TEXAS

Education. Passion. Hope.

A NEED FOR HOPE

Sydney was an intelligent, vibrant, happy-go-lucky girl, who was so silly and had the best giggle. She loved Taylor Swift – one might even call her a Swiftie. Sydney also loved downhill skiing, swimming, playing the piano, and running, but most of all, she dearly loved her younger brother, Nicholas. “I don’t ever remember my kids fighting, although I wish I was able to see them fight,” reminisces her mother, Michelle Bjornberg. “Sometimes it’s not about the perfect memories, it’s more about the memories you’ll never have.”

In May of 2012, 11-year-old Sydney was diagnosed with DIPG, an inoperable form of brain cancer, one week before her 5th grade graduation. Her summer plans of fun were soon replaced with frequent trips to the hospital, CAT scans, MRIs, radiation, steroids and chemotherapy. Sydney battled with strength and bravery for 13 months, and at the age of 12 joined the ranks of angels.

“Above all Sydney wanted to have hope but there weren’t any effective treatments out there. She never wanted this to happen to another child or family again. So, I knew what I needed to do; fundraise for research and not anything else.” — Michelle Bjornberg, Sydney’s mom

JOINING A COMMUNITY UNITED FOR A CURE

Almost immediately after Sydney passed, Michelle jumped right into fundraising. “I thought I could save the world,” says Michelle. “And that’s what I wanted to do, because I didn’t want this to happen to another child. And then you come to the realization that you can’t do it by yourself.”

Michelle knew she didn’t want to start her own foundation, she wanted all of her time and money raised to be specifically put into research. After doing her due diligence on nonprofits, Michelle realized The Cure Starts Now’s passion for the cure and dedication to research aligned perfectly with her goals. She went on to start the North Texas Chapter of The Cure Starts Now to honor Sydney’s wish for the cure.

In doing so, Michelle joined a determined and passionate team of parents and families who are all working toward the same goal – funding research for the cure. “It’s kind of interesting when time goes by,” says Michelle. “We’re coming up on our 7th year now. It’s still about Sydney’s journey, but the more you move forward, it becomes just as much about not having it happen to another child or another family because it tears you apart.”

EDUCATION IS KEY

When Michelle fundraises, she doesn’t just ask her supporters to donate their hard-earned money, she first educates them on The Cure Starts Now, DIPG, and effective charitable giving, so they can make an informed decision. “I really educate my supporters,” says Michelle. “I challenge them to do a google search to find out what other nonprofits do, what their overhead is, and where their money is actually going.”

Probably the most important fundraising technique Michelle uses, is sharing her story of the tragic loss of her daughter in hopes that the money it raises will finally fund a research trial that will find the cure. “It’s not easy to relive your story on a daily basis, but not sharing your story doesn’t help find the cure. It doesn’t do any good to give up, and not share our experiences. All it does is hurt our children and they are our future. Our children are worth the fight.”

With Michelle’s hard work and perseverance, the North Texas Chapter is now one of The Cure Starts Now’s “Million Dollar” Chapters.

To learn more about the North Texas Chapter and to start a fundraiser in Sydney’s honor, visit donate2csn.org/texas-north



MONKEYS TO THE RESCUE

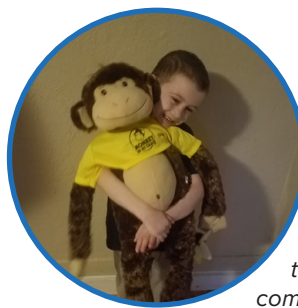
WORDS FROM PARENTS OF MONKEY IN MY CHAIR RECIPIENTS

Monkey in my Chair™ is saving the day for many children battling cancer during the current pandemic. While most of these kids would give anything to be able to attend school, unfortunately, they can't because they are immunocompromised. This is where Monkey in my Chair™ comes to the rescue. By providing these brave warriors with a life-sized stuffed monkey, it can attend school for them while they're out for treatment. This encourages classmates to write notes of support to their friends, thus helping cancer-ridden children stay connected with their classmates and school. In order to truly understand the importance of this program to children and their parents, The Cure Starts Now spoke with the parents of several kids who received Monkey in my Chair™ kits this year.

To learn more about Monkey in my Chair™ or to sponsor a kit, please visit www.monkeyinmychair.org 



"This school year, I anticipate Noah's monkey will help him stay connected to his class when he is out for treatment and help his classmates remain connected to him. This program is very therapeutic for Noah and helps give some of his childhood back. It provides comfort and eases loneliness." – Martha Sileno



"Bentley really enjoyed seeing pictures of his monkey going to classes last year in his place when he couldn't be there. Knowing that with the monkey, Bentley's friends won't forget about him and will have a better understanding of what he's going through when he's hospitalized is comforting. This is an amazing program for children who have to be gone from their friends more than regular children. Monkey in my Chair has been a very comforting experience and many children would definitely benefit from this program." – Jamie Wilson



"We cannot express our gratitude enough for this unique and exceptional program. We used it in a different way since Sloane's school closed during COVID-19, but it has given us the same results - comfort to our brave 4-year-old fighting AML - something no child should go through. Her disappointment in not being able to start school with her big sister is immense. Monkey in my Chair has given her hope that she will join her classmates someday "just like monkey is" she says. It is also a way for her to stay connected to her classmates and the world around her even though she is in the hospital. Just as if she was going, she is ecstatic to get monkey ready to go to school!" – Ashley Stadt



"We think it's such a great idea for our daughter's classmates to know when Allie is not feeling well or having a procedure. It also helps when the children bring the monkey (we named Itch) around to show Allie what she may have missed. I think it's such a great idea, especially for the young classmates, to not dwell on why the child isn't in school, but instead to help them learn empathy and responsibility." – Marybeth Pastore



"We're so grateful for programs like this that allow kids to stay involved and part of their normal lives while they battle cancer. This school year will be a little different with Penn starting kindergarten and his school being 100 percent virtual. With that said, we already talked to Penn's new kindergarten teacher about how we will handle times when he wants to be part of the virtual class meetings but doesn't want to be on camera because he isn't feeling well. We think the monkey will be an excellent placeholder for his face and we think that it will help Penn feel more confident and that he doesn't have to be on camera if he doesn't want to, making his transition to kindergarten while also battling cancer easier for him." – Annie Lampton



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FOR KIDS LIKE THESE**

www.donate2csn.org/monkey

CHAPTER SPOTLIGHT CENTRAL MASSACHUSETTS

Shenanigans and silver linings.



FLOWER CHILD

Kate was a spunky, spirited little girl with an old soul, who could brighten anyone's day. She loved smelling flowers and would often smell lilies with such gusto, her nose would end up covered in orange pollen. She also loved making people laugh, coming up with creative party ideas, and giving the biggest and best hugs. "Kate had the biggest, most infectious, contagious belly giggle," remembers her mother, Abby Arpano, the Central Massachusetts Chapter Director. "Before she could even talk she was already making connections with people. That was just who she was. She could always find the good in everybody."

When Kate was diagnosed with DIPG in August 2014, their lives were forever changed. Kate fought with bravery and strength for 17 months before she gained her angel wings.

A PLUNGE WORTH TAKING

After Kate passed, Abby felt a pull to give back and help find the cure, but just wasn't ready to become a chapter of The Cure Starts Now until the morning of what would have been Kate's 9th birthday. "When I woke up, I saw an email from Brooke Desserich, the Co-Founder and Executive Director of The Cure Starts Now. She didn't even know it was Kate's birthday. For me that was a sign. I emailed



Brooke that day and said 'let's do it.' That was the sign for me to take the leap."

"It feels good to be part of a solid organization that has a great mission, a strong core set of values and a really forward-thinking approach to research," says Abby. "Which is different than 99% of the other nonprofit organizations. The money that's raised is targeted to best serve the DIPG community and helping to find treatments and eventually, hopefully the cure."

Being a chapter of The Cure Starts Now, has given the Arpanos the added benefit of connecting with others who have also experienced the devastating loss of a child to DIPG.

"It has been great to be with and surrounded by other chapters and the people and families that have been through what we've been through." — Abby Arpano, Kate's mom

What they say about the people in a small town supporting one another during difficult times is definitely true about the Arpano's small Massachusetts community. "Since the day that Kate was diagnosed, we were engulfed with love and support from our family, our friends, strangers and people in the community that just wanted to reach out and help," says Abby. "They've been amazing. They raised money for us while she was battling and have donated since we've become a chapter."

At their first annual "Kate's Shots and Shenanigans" golf tournament last year, the community came out to show their overflowing support for the Arpanos. Shenanigans were definitely had, with a little golf sprinkled in-between. Each hole had a fun theme or activity, including one where golfers had to sit on a toilet to tee off. The event raised close to \$34,000.

Abby is dedicated to helping find the cure so other families in the future will have options other than palliative or experimental treatments. One thing that always keeps her going, is taking time to stop and smell the flowers just like Kate would have wanted.

To learn more about Kate and make a donation to the Central Massachusetts Chapter, visit donate2csn.org/central-mass



OUR GLOBAL REACH

The Cure Starts Now has had tremendous growth over the past year and has 41 chapters in 3 countries including The United States, Australia, and Canada.



BIRMINGHAM, ALABAMA
Director: Elizabeth Adams
Inspiration: Madeline



ARKANSAS
Director: Nicole McCoy
Inspiration: Maylea



NORTHERN CALIFORNIA
Director: Jackie Harrison
Inspiration: Khylee



SOUTHERN CALIFORNIA
Director: Shannen Nelson
Inspiration: Sarah



COLORADO
Director: Carrina Waneka
Inspiration: Piper



CONNECTICUT
Director: Robyn Staub
Inspiration: Lea



MILFORD, CONNECTICUT
Director: Kristen Arisian
Inspiration: Serena



EAST CENTRAL FLORIDA
Director: Jamie Franzini
Inspiration: Anthony



ILLINOIS
Director: Sarah Carlton
Inspiration: Makanda



COLUMBUS, INDIANA
Director: Lynn Whittington
Inspiration: Peyton



SOUTHEASTERN INDIANA
Director: Lisa Hill
Inspiration: Lauren



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



LEXINGTON, KENTUCKY
Director: Robin Dodd
Inspiration: Bruce Incorporated



CENTRAL MASSACHUSETTS
Director: Abby Arpano
Inspiration: Kate



MASSACHUSETTS
Director: Lisa & John Mackintosh
Inspiration: Nicole



SOMERSET, MASSACHUSETTS
Director: Ken Oehmen
Inspiration: Selina



MICHIGAN
Director: Kim Ricker
Inspiration: Brison



NEBRASKA
Director: Jesse Shumaker
Inspiration: Madelyn



N. NEW HAMPSHIRE
Director: Jesse Thompson
Inspiration: John



S. NEW HAMPSHIRE
Director: Frank Lafountain
Inspiration: McKenzie



NEW YORK
Director: Kim Kuck
Inspiration: Mandy



CHARLOTTE, NC
Director: Adrena King
Inspiration: CJ



RALEIGH, NC
Director: Mark Newmiller
Inspiration: Ella



SOUTHWEST OHIO
Director: Brooke Desserich
Inspiration: Elena



NORTHEAST OHIO
Director: Jane Midgley
Inspiration: Kasey



EASTERN PENNSYLVANIA
Director: Alissa Grove
Inspiration: Josie



WESTERN PENNSYLVANIA
Director: Alyssa Hawranko
Inspiration: Alyson



TENNESSEE
Director: Kiley Underhill
Inspiration: Adeline



AUSTIN, TEXAS
Directors: Melissa & James Fleming
Inspiration: Brock



CEDAR HILL, TEXAS
Director: Tanika Pierce
Inspiration: Sarai



CENTRAL TEXAS
Director: Vicky Bridier
Inspiration: Jade



HEARTS FOR MK TEXAS
Directors: Gena & Harrison Keller
Inspiration: Mary Katherine



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

INTERNATIONAL CHAPTERS



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Director: Ren Pedersen
Inspiration: Amy



BRITISH COLUMBIA, CANADA
Director: Cari Comboye
Inspiration: Liam

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



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 B ROUGHT AWARENESS TO MILLIONS ACROSS 23 COUNTRIES	 F OSTERED THE FOREMOST CONSORTIUM FOCUSED ON DIPG	 OVER \$12.8 MILLION LED FUNDING OF DIPG/DMG RESEARCH WITH 90+ TRIALS
 I NVENTED THE FIRST INTERACTIVE TRIAL FINDER APP FOR PATIENTS	 F OSTERED A NETWORK OF OVER 150 DIPG EXPERTS	 UNIFIED OVER 28 FOUNDATIONS IN THE DIPG/DMG COLLABORATIVE



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