

CLARE RONNEBAUM
DIPG Warrior
see page 3

2020
ANNUAL REPORT

...

2021
PROGRESS REPORT

BIG MIRACLE LITTLE GIRL



THECURESTARTSNOW®

www.thecurestartsnow.org

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 10 trials.**

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



Brooke Desserich
Co-Founder, Executive Director



WHO WE ARE

STAFF

Brooke Desserich:

Executive Director/CEO

Robert Beaver

Developer

Christy Drinnen:

Accounting Coordinator

Delaney Flanagan:

Nerf Cancer Coordinator

Grace Desserich:

Social Media Intern

Heidi Varns:

Family Support and
Outreach Coordinator

Kelly Bogner:

Marketing and
Communications Specialist

Megan Schehr

Event Coordinator

Mike Weiner:

CIO

Shae Vasile-Beaver:

Designer

Sheila Tillman:

Director of Events and
Chapter Relations

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Stewart Goldman, MD

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ChB, FRACP, PhD

Cynthia Hawkins, MD, PhD

Daniel McPherson, PhD

Michelle Monje Deisseroth, MD, PhD

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Neely Agin

Abby Arpano

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Jim Benedict

Dave Carlin

Carla Eng

Jared Kamrass

Libby Korosec

Amanda Orlando

Oliver Rhine

Jen Suttmueller

Greg Vehr

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Steve Healey

Patrick Dunion

Keith Desserich

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Gavin Baumgardner, DO, Vice Chair

Doug Desserich, Treasurer

Terry Regan, Secretary

Tamara Ekis

Melissa Saladonis

Alyssa Hawranko



CLARE is sunshine mixed with a little hurricane!

MIRACLE IN THE MAKING

Clare is a bright and bubbly little 5-year-old girl who was diagnosed with DIPG at the age of two. She is super sweet with just the right amount of sassy sprinkled in to keep you on your toes. She is definitely the rainbow after the storm!

Clare began walking on her toes and developed a slight limp. Clare would drool from time to time and occasionally she choked while drinking liquids. Most of her initial symptoms were attributed to being a toddler. Then, the day before she was diagnosed, she could barely walk and had slurred speech. Something was obviously wrong.



Diagnosis day and the days following remain the hardest so far in this journey for Clare and her family. It took a solid month for her parents to comprehend what her diagnosis truly meant. They lived in a fog for weeks. Clare was so little, so every treatment felt extreme. From her port surgery to radiation treatments to EKGs and MRIs, everything was big and scary to a 2-year-old. Despite everything, Clare has proven to be so brave and resilient and her beautiful smile is always on display.

Clare loves to bake – she expertly picks the eggs to use when making cookies and stirs the batter with vigor when making muffins. Her creations are yummy too!

Clare is a serious artist and her Heart Art was auctioned off at our 2021 Once In A Lifetime Gala and sold for over \$6,000! All the proceeds from that auction go towards pediatric brain cancer research.



FUNDING IS A PART OF THE CURE

Clare has participated in a clinical trial funded by The Cure Starts now and has responded very well to her treatment. She is 40 months post-diagnosis and is showing the world just what she is made of - sunshine mixed with a little hurricane.

Because of funding for pediatric brain cancer research, there are treatment options available now that families didn't have just five years ago. Clare is doing as well as she is because of the research and opportunities children have today.

Clare's parents understand the importance of research. They are willing to do everything they can to help in funding research and clinical trials because they have experienced the hope it can bring a family, and the hope it can bring a child – a child like Clare. The good news is that Clare is a miracle and a fighter. She has beaten the odds before and she can certainly beat the odds again.

To donate go to donate2csn.org/clare ♥



RESEARCH: IT'S WHAT WE DO!

THE RACE TO BEAT CHILDHOOD CANCER NEVER ENDS.

The Cure Starts Now has funded a pediatric trial for a “revolutionary” new drug used to attack Diffuse Intrinsic Pontine Glioma (DIPG). The cancer is usually diagnosed in children and is credited with a survival rate of less than ten percent.

Keith and Brooke Desserich know these grim statistics all too well. Their daughter, Elena, died of the rare childhood brain cancer when she was 6 years old. After experiencing little support on their journey, the Desserichs decided to start The Cure Starts Now to create a new way to approach and carry out cancer research while working to eradicate DIPG.



DR. DAVID ZIEGLER,
SYDNEY CHILDREN'S HOSPITAL

“It’s one of the toughest cancers out there,” Keith Desserich said of the rare form of childhood brain cancer. “We believe fundamentally through The Cure Starts Now that you have to focus on those cancers that are elusive for treatments, those cancers that are kind of your biggest bullies. And so we focused in on this cancer.”

For more than a decade, The Cure Starts Now has joined forces with partners around the world to develop a different “Achilles heel” style attack strategy to beat the cancer. In February, results were released from a groundbreaking Australian trial involving mice and a CSN-backed drug known currently as AMXT 1501. Desserich said the test showed the two-thirds of DIPG tumors in mice disappeared after begin injected with the new drug.

The results from the mice study came to light in a fast progression resulting in clinical trials three times faster than typical trials. Desserich said the landmark move to human trials is “tremendously exciting.”

“At the end of the day this trial has never happened before,” Desserich said. “We’ve never seen these types of results and that is heartwarming to see that something is happening and we’re seeing some results. It’s good for mice right now, and what we hope for is it’s eventually good for children and it’s good for adults and everybody else. We lost our daughter to this type of cancer. We didn’t realize how much of a homerun implication it had until now and we hope that we get there,” Desserich said with tears welling in his eyes. “We hope that we see the cure. We hope that we see a bunch of families and kids that survived this,” he

said. “That’s our dream. That’s our hope and ultimately, we don’t have to do this anymore,” he said referencing The Cure Starts Now.

The pediatric trials are set to begin in early 2022 in 16 hospitals across the world including Cincinnati Children’s Hospital and Medical Center. He said potentially a dozen patients could participate in the study. Only patients who have been recently diagnosed with DIPG at the time of the study will be able to participate. The Cure Starts Now is working on funding a new trial to include kids who are further along in their cancer journey.

There’s no time to take a victory lap for the new drug making it to human trials. We funded more grants to explore other possible cures.

For Desserich, more than a decade of advocacy, dedication, fundraising and creating a network of resources is more than focusing on curing one type of pediatric cancer. For his family, changing the strategy can result in an even bigger outcome.

“Thinking behind it is,” Desserich said. “If this strategy actually beats DIPG, we might be able to beat all other cancers and that’s what we call a home run cure.”

-Reprint with permission. Original article produced by Meredith Stutz, reporter for Cincinnati WLWT5

**GAME CHANGER
FOR DIPG PATIENTS**

*“MOST EFFECTIVE TREATMENT EVER TESTED...
SURVIVAL IN TWO-THIRDS MICE”*

e	Vehicle	DFMO + AMXT 1501

THECURESTARTSNOW



COVID & CANCER

COVID AND THE EMPTY RESEARCH LAB

In 2020 and 2021 we all felt the impact of COVID-19. From lines at the grocery stores, the masks, essential vs. non-essential workers, home schooling and even the scarcity of toilet paper it was tough to ignore. Then there was the personal impact and the immeasurable loss of those we loved to COVID. Still the greatest impact we may see as a society in 2020 and 2021 may not come from COVID but instead from what we forgot during the pandemic: cancer.

It is estimated by a recent study published in JCO Clinical Cancer Informatics that screenings for some of the largest cancers (breast, colon, prostate and lung) dropped dramatically between 56-85% at the peak of the pandemic in April 2020 compared with 2019. Ultimately not only does this have implications for treatment options the later a patient is diagnosed, but with roughly 606,000 deaths per year from cancer in the United States alone, many experts expect these numbers to climb for years after the suspension of basic diagnostic and treatment services.

It may have been even more severe with pediatric brain cancers. Of just the trials funded by The Cure Starts Now and its Collaborative partners, nearly 30% of them were either delayed by at least 6-months or critical translational work completely lost. Test tube data, vital tissue growth called organoids and even mouse models often had to be discarded when research was deemed non-essential for weeks at a time. "It's heartbreaking for the people that do the work, patients that donated the tissue, and for the future of research that now cannot proceed," notes Dr. Susanne Wells, Director of Epithelial Carcinogenesis and Stem Cell Program at Cincinnati Children's Hospital.

This research is critical to not only understand rare pediatric brain tumors like DIPG, DMG and Medulloblastoma but to test nearly every new strategy that has been implemented in the last two years. Worse yet, many of the trials need to completely restart after tissue was discarded, resulting in lost time and lost funding. *"There's not generally more funding now that we lost all that time so now we have to do less in the long run as we try to catch up. And that funding*

is now not spent on research that is planned," says Dr. Wells.

"The need for funding is greater than ever," says Keith Desserich, Chairman and Co-Founder of The Cure Starts Now. "While we had certain controls that helped ensured results-based research, the reality is that we lost 2 years and probably a million dollars to a cancer that we can't afford to fall behind with. The goal now is to do twice as much in the next two years as we would normally."

Still even here we need more help. With event-based fundraising down by 20% over 2019 The Cure Starts Now has turned to online and campaign-based fundraising, making up approximately 6% of the difference. *"We are thankful to have generous supporters that understand this need,"* says Brooke Desserich, CEO and Co-Founder of The Cure Starts Now, *"They've attended the few events we've had and even contributed online through our Relay for Research and Cones for the Cure."*

The good news is that research is coming back. Although lighter than normal, The Cure Starts Now announced nearly \$1.5 million in new research funded through 8 projects across 3 countries – while other cancer charities have suspended all new research funding entirely. These projects include an ambitious genetics study to identify new mutations of DIPG and DMG, a clinical trial that already demonstrated total removal of cancer in 2/3rds of mice and trials that look at how we may interrupt the communications pathways of cancer cells to halt further growth. So even while others projects start again, we may limit the time lost and still have an impact against a cancer that we can't afford to ignore.

2020 ANNUAL REPORT

TOTAL REVENUE, GAINS, AND OTHER SUPPORT

\$4,016,635

BALANCE SHEET

As of December 31, 2020

ASSETS		LIABILITIES		NET ASSETS	
Cash and cash equivalents	\$1,959,653	Accounts payable	\$16,783	Unrestricted	\$1,861,093
Inventory	80,486	Other liabilities:		Temporarily restricted	345,000
Other assets / prepaid expenses	290,240	Accrued Compensation	\$15,470	TOTAL NET ASSETS:	<u>2,206,093</u>
TOTAL ASSETS:	<u>\$2,390,486</u>	Deferred revenue	\$30,950	TOTAL LIABILITIES & NET ASSETS:	<u>\$2,390,486</u>
		Paycheck Protection Program Loan	\$121,190		
		TOTAL LIABILITIES:	<u>\$184,393</u>		

STATEMENT OF ACTIVITIES & CHANGES IN NET ASSETS

For the Fiscal Year Ended December 31, 2020

REVENUE, GAINS, & OTHER SUPPORT		EXPENSES	
Contributions	\$2,509,911	Program services:	
In-kind donations	40,174	Medical research	\$3,216,905
Special event revenue	1,468,509	Monkey in My Chair	104,198
Investment return	(1,959)	Medical symposium	56,425
TOTAL REVENUE, GAINS, AND OTHER SUPPORT:	<u>\$4,016,635</u>	Family support program	427,794
		Fundraising	638,761
		Management and General	147,279
		TOTAL EXPENSES:	<u>\$4,591,362</u>
Increase (Decrease) in Net Assets	(\$574,728)		
Net Assets - Beginning of year	<u>2,780,821</u>		
Net Assets - End of year	<u><u>\$2,206,093</u></u>		

2021 TOP DONORS

\$50,000+

Brooke Healey Foundation
Facebook
Graeter's Ice Cream Company
Melina Michelle Edenfield Foundation
Morgan Stanley Global Funding Trust
Reflections of Grace

\$25,000-\$49,999

Aidans Avengers
Aubreigh's Army Foundation
Austin Strong Foundation Inc
Capital Group Co Charitable Foundation
ExVoto LLC
Hillary Fink
Jackson Hewitt Tax Service
Jeffrey Thomas Hayden Foundation
Keith and Brooke Desserich
Musella Foundation
Pray Hope Believe Foundation
Storm the Heavens Fund
Wayland Villars DIPG Foundation Inc.

\$10,000-\$24,999

Allstate c/o Cybergrants
Benevity Causes
Benevity Causes Matching Fund
Blackbaud Giving Fund
Bruce and Nancy Axmacher
Cincinnati Children's Hospital
Covelli Enterprises, Inc
Credit Suisse Americas Foundation
Daniel and Oris Weiner
David and Virginia Pritchett
Estate of Esther Shelby Fund at the Houston Jewish Community Foundation
Fidelity Brokerage Services, LLC
Fidelity Charitable
Frontstream
Glenn and Dayna Osako
GM Financial
Gold Hope Project
Greater Cincinnati Foundation
Jersey Mike's Corporate Advertising Fund
Laurens Fight For Cure Inc
Lily Larue Foundation, Inc
Livestrong
Love Chloe Foundation
Marlees Mission Fund
Milligan Memorial Golf Tournament
Popp Hutcheson PLLC
Ronald and Jane Midgley
Ryan's Hope
State Street Bank & Trust Co.

Whitley's Wishes
Winston & Strawn

\$5,000-\$9,999

Andrew and Crystal Wash
Austin Cops for Charities
Blasius Cadillac
Chris Wood
Citi Business Services
Combined Federal Campaign
Craig and Kristin Maurer
DMSI Software
Esther & George Jaruga Charitable Foundation
Grant Cottingham
Gunners Magic Train
Henry and Althea Lee
James and Jennifer Sawyer
James and Melissa Fleming
Jamie Girard
Jeremy Hamilton
Jesse and Alison Thompson
Jesse and Corrie Shumaker
JPMorgan Chase & Co
Kevin and Marie Douglas
Matthew and Tricia Verhaalen
McCormick Family Foundation
Nicholas Usher and Alyssa Hawranko
Operation Dough-Nation
Patrick Mahomes
Perfect Pallets, Inc
Renaissance Charitable Foundation Inc
Richard Winstead
Virginia Li

\$3,000-\$4,999

Alex and Emma MacDonald
Architectural Precast Association, Inc
Bank of America Charitable Gift Fund
Bing Yao
Brandon and Jennifer Salazar
Briggs Equipment
ClubCorp Service Center
Coldwell Banker
David Nix
Dr. Hal and Brenda Stevenson
Epping Well & Pump Inc
Evin and Mikah Macaluso
FBW Investments, LLC
Infintech
John and Allie Gillies
Josh and Dwan Evans
Kim Bledsoe
Mary Susan Edris
McLaughlin Wealth Mgmt Group at Morgan Stanley
Michael and Pia Yuffee
Nelson and Carrina Waneka

Ryan Norfolk
Thomas and Stephanie Hatfield
Tina Day
Trevor Chapman
Zoran Cupic

\$1,500-\$2,999

AccessIT Group
Alice Minnick
Amazon.com
Amy's Ice Creams, Inc.
Anthony and Heidi Varns
Austin Rohr
Benny's World
Betsy Lane
BNY Mellon
Brad Oddo
Bradley and Daryl Thompson
Brady Family Fund of the Goldman Sachs Philanthropy Fund
Brent Austin
Brett Parrish
Brian and Carrie Bullard
Brian and Tamara Ekis
Cari Murray
Chet & Catherine Hammack
Christina Arumi
Christine Edwards
Chuck and Connie Collins
Clint Turner
David and Kimberly Chen
Disney Worldwide Services, Inc.
Don Verhaalen
Endre and Jennifer Pekarik
Eric and Felice Chen
Evan and Mary Lowe
Force Construction Company, Inc
Frances and Jeremy Clouse
Garden Catering - Old Greenwich, LLC
Gavin and Fatema Baumgardner
Gillmer Kroehle Foundation
Hugh Poindexter
James Mason
James Mpcpartland
Jean Chiang
Jeremy and Melody Wang
John & Lynn Whittington
Katherine Warren
Kayla Beth Fletcher
Kenneth Barnes
Kevin and Connie Rau
Kroger Community Rewards
Kush Shah
Kyle Sattler
Laura Shelby
Lee and Elizabeth Yamauchi
Leonard and Connie Mcmillin
Mark Iuzzolino
Martyn and Lynne Redgrave

Michael McVicker
Minter Construction
Mistie Hill
Mr & Mrs. Larry Li
Nadia's Performing Arts Centre
Nancy Hesko
Nathan and Tina Wagler
National Consumer Cooperative Bank
Nazareth Regional High School
Neely Agin
Paul and Krista Lang
Perkins for Sheriff Campaign Account
Peter and Lisa Schraufnagel
Randy Davignon
RDI Corporation
Rick and Lynne Merk
Russ Walter and Angie Walter
Sandra Keegan
Sandra Kennedy
Saxon Financial
Schmidt's Restaurant
Schwab Charitable
Scott and Virginia Johnson
Severin Mulligan
SPG Roofing and Restoration LLC
Standard Insurance Company c/o YourCause, LLC
Stefano Dukcevic
Steven Sidney
Stock Yard Bank & Trust
Sylvan Feldstein
Tim and Joyce Redgrave
Town & Country Buildings
Tri City National Bank
TSYS Merchant Solutions LLC
Union Pacific Charity Custodial Account
Union Pacific GivePlus Program
Union Pacific Railroad Company
United Way of Benton & Franklin Counties
Vanguard Charitable
Vincent and Thuy Kau
Walden Country Club
Wanda Weniger
Warrior Kids Foundation
Who Cares Reunion
Will and Suzanne Russell
William and Nancy Eggar
William Hunt
Woody and Nancy Wright

OVER \$17.5 MILLION* IN RESEARCH FUNDED

See grants funded prior to 2019 at www.thecurestartsnow.org/grants

2021

Sydney Children's Hospital: \$195,327*
Institute of Cancer Research: \$612,463*
Children's Hospital of Colorado: \$200,000*
Cincinnati Children's Hospital: \$200,000*
University of Queensland Diamantina Institute: \$100,000*
Children's Cancer Institute: \$50,000*
Duke University Hospital: \$50,000*
UPMC Children's Hospital of Pittsburgh: \$50,000*
International DIPG/DMG Registry and Repository: \$1,508,198*
Massachusetts General Hospital: \$50,000

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*
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*

* Denotes grants funded with our DIPG/DMG Collaborativepartners. All numbers reflect financial data accurate at time of print.



GRANT & JULIA

TWICE THE JOY.
TWICE THE LOVE.
TWICE THE BLESSINGS FROM UP ABOVE.

\$8 BY OUR 8TH BIRTHDAY

Grant and Julia Wolf are fraternal twins, who created their bond well before birth! They had a way of always bringing out the best in each other. Grant and Julia were as close as two people could be. During his battle they shared a love of stuffed dogs, and had quite the selection. They would play with them for hours on end together.

Grant passed away in January of 2021 from Medulloblastoma and during his funeral Julia came up with a brilliant idea to honor her brother on their upcoming birthday. *“She had been worried about how to have a birthday without her brother being there,” said Sara Wolf, Julia and Grants mother.* Julia wanted to do two things – give stuffed dogs to kids with cancer, what she and Grant loved to play together, and raise money for brain cancer research. Her initial goal was \$240 but she crush that by raising over \$56,000! Julia has a huge heart and is determined to help find a cure for brain cancer after losing Grant. When Julia found out she raised enough money to fund a grant her question was pure and sweet. *“Do they always call them grants or is that just for us?”*

Julia turned an \$8 request into funding for a full research grant! She’s simply amazing! The fundraiser surpassed her initial goal within the first hour of the event. This showed a wonderful statement of love coming from Julia to her brother.

“We are amazed by Julia’s tenacity and outstanding support in honor of Grant. At such a young age, we are floored by what she has accomplished with just one fundraiser. Her birthday effort will help so many other families, and it provides the chance to, hopefully, bring us closer to the cure.” – Brooke Desserich, Executive Director of The Cure Starts Now

GRANT’S WOLF PACK

Grant was diagnosed with medulloblastoma, a malignant tumor in the cerebellum region of the brain, in September of 2019. During his first year fighting it was rough to say the least but he was winning. He had a great summer with stable scans. Unfortunately, the cancer came back in the following year.

He fought with courage and bravery during his difficult battle and continued to smile no matter how tough it became. He inspired the community of Loveland and his supporters, known as “Grant’s Wolf Pack,” to find joy in challenging times and never give up even when the odds are stacked against them. Sadly, Grant passed away on January of 2021, just over 16 months after his diagnosis.

BIG IDEAS! BIG HEART!

Grant really has some pretty awesome siblings between Julia and his older brother Matthew. Matthew wanted to do something to help fund pediatric brain cancer research and decided to participate in The Cure Starts Now Caps for the Cure.



Matthew’s intermediate and middle school participated in honor of Grant Wolf. The 2 buildings collected \$1,121 during the event! The Wolf Pack community members donated an additional \$765 bringing the grand total to \$1,886 for pediatric brain cancer research.

Grant’s strength, courage and smile has inspired so many. Grant’s Wolf Pack, are determined to make an impact in pediatric brain cancer research in memory of Grant.

To donate go to donate2csn.org

A LETTER FROM JULIA

Hi this is Julia,
In one week it is my birthday. In honor of Grant, my 7-year-old twin who passed away from brain cancer we are having a fundraiser to find a cure for cancer and give kids with cancer stuffed dogs.
Grant loved stuffed dogs and sports. He made a great brother and friend. On February 11th it is our 8th birthday. This is my idea of what to do for Grant on our birthday
My mom and I bought 30 dogs to donate to Carley at Proton so she can give them to other kids with cancer like Grant.
I am asking if you can donate \$8 by our 8th birthday to remember Grant and help cure cancer too. The Cure Starts Now wants to cure brain cancer and I do too.
Love,
Julia



CHAPTER SPOTLIGHT

HEARTS FOR MK - TEXAS CHAPTER

HEARTS FOR MK - TEXAS

Mary Katherine was a whirlwind of creativity, independence, love, and light. She was so joyful and energetic and had the best belly laugh. She enjoyed creating art, playing outside, taking care of her baby dolls, and playing in her kitchen. She was always up for an adventure and wanted to be a part of every experience, no matter how big or small. She adored her family's cats, but her eyes sparkled a bit brighter when she was playing with the dogs. *"Mary Katherine loved singing and dancing," reminisces her mother, Gena Keller. "She had the cutest little head bob whenever she heard "Uptown Funk" by Bruno Mars."*

In December 2017, Mary Katherine was diagnosed with DIPG, an inoperable and highly aggressive form of brain cancer. She underwent 33 rounds of radiation, countless needle pricks, and multiple medications, but because there is no cure for DIPG, her courageous 9½-month battle ended in September of 2018, at the age of 4. Mary Katherine was so young and had so much life left to live.



A COMMUNITY UNITED

During Mary Katherine's fight, the Kellers community rallied around the family and showed an overwhelming amount of support. The community has continued their support in various ways in order to raise money to find a cure for DIPG.

Friends of the Kellers and members of the community have hosted fundraisers for the Hearts for MK (Texas) chapter in honor of Mary Katherine. Mary Katherine loved ice cream, especially Amy's Ice Cream. Hearts for MK was able to create a partnership with Amy's beginning in 2020 where Amy's gave customers an opportunity to donate to The Cure Starts Now and made a special ice cream flavor in honor of Mary Katherine - the MK Special. The flavor was inspired by Mary Katherine's love of Belgian chocolate ice cream with crushed M&M's. Sounds delicious!

This is just one of several fundraisers in which the Keller's community of supporters have stepped up to help to find the Homerun Cure™.

JOINING A MOVEMENT

During Mary Katherine's battle, her parents, Gena and Harrison Keller, connected with The Cure Starts Now's Texas (Austin/Round Rock) Chapter directors, Melissa and James Fleming, who had lost their son, Brock, to DIPG in 2016. Through the Flemings, Gena learned a great deal about the foundation and its mission to fund research for the cure.

The Fleming's passion for and involvement with the foundation truly resonated with the Kellers. After Mary Katherine passed, Gena and Brooke Desserich, Executive Director of The Cure Starts Now, had dinner to discuss the charity and the possibility of starting a chapter in Mary Katherine's honor.

"Everyone at The Cure Starts Now is incredibly committed to its mission and so humble," says Gena Keller. "Not to mention the foundation's focus aligned with our goal of funding research, so it was fitting that we joined the cause as a chapter."

In 2020, the Kellers founded Hearts for MK (Texas) Chapter of The Cure Starts Now in honor of Mary Katherine.

HOPE FOR THE FUTURE

It is the Keller's hope that through increased funding for pediatric brain cancer research, one day children will have more quality treatment opportunities, and, eventually, the cure for this devastating disease.

"It would be great to find the cure and effectively work ourselves out of a job," says Gena.

To learn more about the Hearts for MK (Texas) chapter and to make a donation in Mary Katherine's honor, visit donate2csn.org/HeartsForMK



WORKING TOGETHER FOR THE CURE



Four central Indiana children were diagnosed with DIPG and live within an hour of each other. Adalynn, Addison, Brynnley, and Rylie have all been diagnosed with DIPG. The four families joined forces to participate in a Blast Cancer Brain Tumor Walk to help fund pediatric brain cancer research for the Homerun Cure™.

Brynnley Niederhaus from Fountaintown, IN is a kindergartner who was diagnosed in May of 2020 with DIPG. She is the kindest little girl who is big-hearted and funny. She loves to make the people around her laugh with her silly jokes! She is has so much courage and has been fighting this with all of her strength. She is very outgoing and loves everyone she meets and of course they love her right back! Brynnley is currently taking a trial medication that has been funded by The Cure Starts Now. She is beating the odds!

“Hope to us is everything,” Kristyn Niederhaus said. “Hope to me is being able to see her walk down the aisle one day and graduate high school.”

Thirty miles away in Franklin, IN, Adalynn “Addie Mae” Jessen was the center of the Jessen family. The 4-year-old was diagnosed in July of 2020. Addie Mae participated in a clinical trial that was funded by The Cure Starts Now. Zach and Kate Jessen believe that kept their farm-loving girl alive longer than expected. But in January of 2021, she was diagnosed with another form of rare cancer that spread to her spine and brain. Addie Mae sadly passed away in May of 2021 leaving her family and supporters heartbroken and even more eager to help find the Homerun Cure™.

“Addie Mae made such an impact on our community, I have no doubt she will continue to do great things,” said Kate. The Jessen’s became our 40th Chapter in June of 2021.

Addison Varns is a spunky 9-year-old from Bargersville, IN and was diagnosed in March of 2019. Addison is a fun-loving warrior with a heart of gold, who has so much more life to live. She’s been fighting DIPG for over 2.5 years and has completed 52 rounds of radiation. She is just simply amazing and strong. Addison has participated in two clinical trials funded by The Cure Starts Now and despite everything she has been through, she is a ray of sunshine!

Rylie Bennett is a fun loving 4-year-old cowgirl from Westport, IN and was diagnosed in November of 2020. She is currently taking a trial medication that has been funded by The Cure Starts Now. Rylie is fighting this disease with all she has. Her tumor has decreased in size which means that radiation did its job!

These four families have become a community through their battle with DIPG. *“They’re like our new family and when it hits one of them it hits us all,” Jessen said.*

Heidi Varns said, “Being a part of the Blast Cancer Brain Tumor Walk was an honor and an event we will never forget. It helped us connect with other surrounding families on a more personal level. Knowing that every person in attendance was connected specifically to one of the families and seeing all the smiles and love made our hearts feel so full. Helping coordinate, fundraise and organize was not only very easy with the help and guidance from The Cure Starts Now but it also allowed us to spread awareness and share our daughters story with our community while gaining the support for the event. We can’t wait for the walk next year!”



To donate go to donate2csn.org



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



FRANKLIN, INDIANA

Director: Zach & Kate Jessen
Inspiration: Adalynn



SOUTHEASTERN INDIANA

Director: Lisa Hill
Inspiration: Lauren



WESTPORT, INDIANA

Director: Elizabeth Bennett
Inspiration: Rylie



LEXINGTON, KENTUCKY

Director: Robin Dodd
Inspiration: Bruce



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: Jess Austin
Inspiration: Evan



NEW YORK

Director: Kim Kuck
Inspiration: Mandy



CHARLOTTE, NC

Director: Adrena King
Inspiration: CJ



RALEIGH, NC

Director: Mark Newmiller
Inspiration: Ella



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Director: Brooke Desserich
Inspiration: Elena



NORTHEAST OHIO

Director: Jane Midgley
Inspiration: Kasey



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Director: Alissa Grove
Inspiration: Josie



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Director: Alyssa Hawranko
Inspiration: Alyson



TENNESSEE

Director: Kiley Underhill
Inspiration: Adeline



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Inspiration: Brock



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Director: Tanika Pierce
Inspiration: Sarai



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Inspiration: Alexis



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Inspiration: Alison

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AUSTRALIA

Director: Ren Pedersen
Inspiration: Amy



BRITISH COLUMBIA, CANADA

Director: Cari Comboye
Inspiration: Liam

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



International Headquarters
 10280 Chester Road
 Cincinnati, OH 45215



OVER THE PAST 15 YEARS
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Addison, DIPG Warrior
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