

**AYLA SLIVKA**  
**DIPG Warrior**  
*see page 3*

**2021**  
ANNUAL REPORT  
...  
**2022**  
PROGRESS REPORT

**AYLA'S ARMY**  
**SWEET. SASSY. STRONG.**



**THECURESTARTSNOW®**

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

# LETTER FROM THE DIRECTOR

It's a problem we've wanted for a long time. Back when we started The Cure Starts Now in 2007, research on these homerun cancers was scarce. Experts were even harder to find. And all we wanted were options, hope and a cure for these families. We always knew that one day it would grow – in fact – so much that we wouldn't be able to keep up. That time has now come.

In this year's grant cycle we funded our **largest ever** grant round: **a staggering \$4.5 million over 19 grants in 9 countries**, along with our incredible chapters, ambassador families, partners in the CONNECT funding group and the DIPG/DMG Collaborative. **That's a remarkable amount, and it's thanks to your dedicated support that The Cure Starts Now has grown by nearly 60% to respond to this need.**

Still, as I write this letter, there are four grants that we cannot fund. To me it means four opportunities to cure cancer. And while I am beyond proud that we helped build a community that boasts 81 trials for children fighting today, I desperately also want to be able to respond to

every opportunity with the funding it needs.

Like I said, it is a problem we've wanted for a long time and it means progress is being made. Life expectancies for children diagnosed with these cancers today are double what they were when my daughter Elena fought this 10 years ago, but it is not enough. We need that cure and we are grateful to have your help in this fight. And with any luck, maybe we might be able to even add a few grant fundings to the list.



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



## PUTTING OUR KIDS FIRST

Giving Tuesday comes after Black Friday, Small Business Saturday, and Cyber Monday, leaving so little left over to support important causes. More than 4,000 children are diagnosed with brain cancer each year, and they deserve more than leftovers. The Cure Starts Now believes those kids should come first.

Over 100 families came together on November 15th for Giving First, an entire two weeks before Giving Tuesday, to fundraise for pediatric brain cancer research. It was a day filled with the unique stories of each family being shared across Facebook and Instagram, spreading hope and perseverance.

*"Thankful doesn't even begin to describe how we feel about our supporters that donate to The Cure Starts Now because to our family, donations mean hope. Hope for vital research to be funded. Vital research that can save Addison's life and so many other children. No donation is too small. Every penny matters. Just like every child matters."*  
– The Varns Family, for DIPG warrior Addison

At the same time, The Cure Starts Now headquarters went live for 8 hours on Facebook to interview these families and talk about their hardships, the research that donations

**OVER \$500,000  
RAISED AND GROWING!**



would help fund, and the importance of collaboration on every level. At the end of November the supporters of these families raised enough to fund nearly 5,000 hours of research.

***There is still time to help fund more research!  
To donate go to [give-first.org](https://give-first.org)***

# THE ARMY BEHIND THE GIRL



## A LITTLE GIRL WITH A BIG IMPACT

When your family faces a diagnosis like DIPG, the world can feel like it's crashing down around you. But that's when the world surprises you and sends you people to help shoulder the load. For the Slivkas, they found an entire army ready to follow their daughter Ayla into battle.

Ayla was 5 years old when she was diagnosed with DIPG at Nationwide Children's Hospital in Columbus, Ohio. The Slivkas moved frequently and had unintentionally created a nationwide network of people motivated to battle alongside Ayla. After Ayla's diagnosis, she rallied her banners and the army charged into battle alongside her, fundraising for the cure and outpouring support for their little warrior. This community was dubbed "Ayla's Army."

*"The Cure Starts Now is an incredible organization I knew nothing about before, and now I will stick with this organization for the long haul so that one day we can find the cure."*

*– Tim Slivka, Ayla's father*

It was easy to rally behind a girl like Ayla. With her big personality, vibrant light, and creative soul, her sassiness brought so much joy to her family and she lit up the lives of everyone she knew. She was the first to grab the microphone and get on stage, the first to keep you in check, and the first to make you laugh. Ayla always had happy dreams thanks to her mom filling her head with stories of unicorns, sunshine, and candy. Her creative spirit first appeared with her love of sticker books before it spread



to loving art through painting, drawing, coloring books. That love then evolved to creating performances such as movies or dances with her friends. Ayla was outgoing, sassy, smart, and sweet. She was larger than life and a beast of a little girl. Ayla wasn't just in the spotlight; she was the spotlight. She wasn't show stopping, she was the show.

## FAMILY NEVER FIGHTS ALONE

Ayla passed in June, 2022 after battling for almost a year. In that year, she turned 6, welcomed a new baby sister Aspen (who she nicknamed Penny), and lived a life of joy and love. Ayla was an inspiration to so many and left a lasting impact on us all — an impact felt to this day. Ayla's Army gathered around Ayla to support her and her family during her battle, and has continued to do

so since her passing.

Ayla's Army has fundraised hundreds of thousands of dollars in Ayla's name for The Cure Starts Now, and they have no intention of stopping. Ayla's father Tim says, "To just give up after we watched that fight and watched that support doesn't feel at all like the right thing to do. We want to stay in this. I don't want to see other families have to go through what we went through. I want to see treatments improve. I want to see options improve. I want to see access to medication improve. I think that's what's fair for families that are in this fight. Families that are in this fight battling cancer don't deserve to go through it and have the ending that we just had."

Ayla's Army will keep fighting in Ayla's name, and The Cure Starts Now is proud to be part of the cavalry.

[To donate go to \[donate2csn.org/Ayla\]\(https://www.donate2csn.org/Ayla\)](https://www.donate2csn.org/Ayla)

# RESEARCH: THE DIPG/DMG REGISTRY

All journeys start with a map. For the Homerun Cure™ and DIPG/DMG, that map is the collective knowledge of patient data. Knowing this, in 2011, The Cure Starts Now worked with Dr. Maryam Fouladi, previously at Cincinnati Children's Hospital Medical Center and Dr. Dannis van Vuurden previously at VU University Medical Center.

Incomplete data was a problem, and not just within pediatric brain tumors. What Keith Desserich and others found was that nearly all registries were unlinked, relational datasets that only told part of the picture. Each dataset was often limited to just a few patients and questions, which when combined with other datasets, often delivered false conclusions to researchers.



*“The most effective databases are often those with strong data integrity and a full patient record. This way, not only can we see patterns between patients, but we can also sometimes understand why these patterns occur because we have the history of each case.”*

*– Dr. Lindsey Hoffman of Phoenix Children's Hospital, Chair of the International DIPG/DMG Registry*

But it's even more beneficial than that for the patient. In a recent study published in “Neuro-Oncology” magazine, it was discovered that central radiological analysis by the

International DIPG/DMG Registry identified a nearly 20% incidence of abnormalities not otherwise identified at diagnosis. Nearly 8% of diagnoses might have even been another type of brain tumor. This means that through the Registry and the free central review of MRIs, patients may actually have improved options to customized care to help them beat their cancers. And this is in addition to over 400+ free consults by the Registry team since 2012.

Today, the International DIPG/DMG Registry is a worldwide effort. In association with the European SIOPE, the DIPG/DMG Registry (also funded by The Cure Starts Now) reaches over 17 countries and 219 hospitals and contains full records on nearly 2,000 patients. No longer just a necessity for impactful funding decisions, the Registry now serves as a model for many other cancer registries as one of the first linked and organic databases in existence for cancer.

An investment of nearly \$4 million since 2012 by not only The Cure Starts Now, but also with initial partnerships by the Reflections of Grace Foundation and the Jeffrey Thomas Hayden Foundation, today the Registry has grown into a much larger partnership with all 22+ members of the DIPG/DMG Collaborative. But most importantly – it is also a tribute to families united to bring clarity and strategy to the cure we all desire.

[Learn more at dipregistry.org](http://dipregistry.org) 

## THE CURE STARTS NOW CLINIC OF CINCINNATI CHILDREN'S MEDICAL HOSPITAL

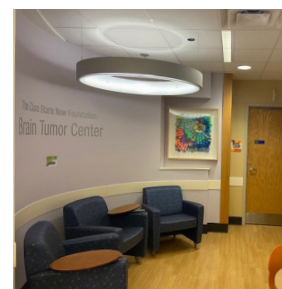
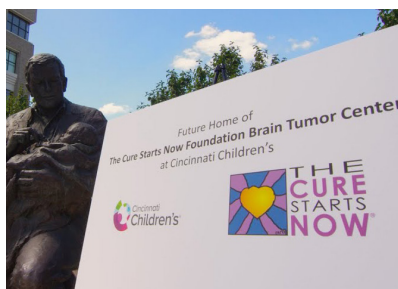
In 2020, Cincinnati Children's Hospital announced the naming of The Cure Starts Now Foundation Brain Tumor Center as part of a multimillion-dollar donation to fund pediatric brain cancer research.

“It is a promise to support breakthrough strategies that will fundamentally change how we fight all cancers. We call this a ‘homerun cure’ and are proud to help partner with Cincinnati Children's,” said Brooke Desserich, Elena's mom.

The Cure Starts Now Foundation has generously funded millions of dollars in brain tumor research as well as the DIPG/DMG Registry at Cincinnati Children's since 2008. The naming of the center not only recognizes the current partnership but also a collaboration for future innovative research. Your donations make this important work possible.

*“This is about creating a new and different way to attack DIPG and other rare, lethal cancers. By working together, we can move this important work forward and one day lead us toward a cure.”*

*– Dr. Perentesis, Head of Oncology*





# OUR GLOBAL REACH

The Cure Starts Now has had tremendous growth over the past year and has 39 chapters in 3 countries including The United States, Australia, and Canada.



## ALABAMA (BIRMINGHAM)

Director: Elizabeth Adams  
Inspiration: Madeline



## COLORADO (WARRIORS FOR PRINCESS PIPER)

Director: Carrina Waneka  
Inspiration: Piper



## CONNECTICUT

Director: Robyn Staub  
Inspiration: Lea



## CONNECTICUT (MILFORD)

Director: Stacey Arisian  
Inspiration: Serena



## FLORIDA (EAST CENTRAL)

Director: Jamie Franzini  
Inspiration: Anthony



## ILLINOIS

Director: Sarah Carlton  
Inspiration: Makanda



## INDIANA (FRANKLIN)

Director: Zach & Kate Jessen  
Inspiration: Adalynn



## INDIANA (LAUREN HILL)

Director: Lisa Hill  
Inspiration: Lauren



## INDIANA (RYLIE STRONG)

Director: Elizabeth Bennett  
Inspiration: Rylie



## KENTUCKY (LEXINGTON)

Director: Robin Dodd  
Inspiration: Bruce



## MASSACHUSETTS

Director: Lisa & John Mackintosh  
Inspiration: Nicole



## MASSACHUSETTS (CENTRAL)

Director: Abby Arpano  
Inspiration: Kate



## MASSACHUSETTS (SOMERSET)

Director: Ken & Michelle Oehmen  
Inspiration: Selina



## MARYLAND

Director: Bonnie Corcoran  
Inspiration: Brenna



## NEBRASKA

Director: Jesse Shumaker  
Inspiration: Madelyn



## NEW HAMPSHIRE (NORTH)

Director: Jesse Thompson  
Inspiration: John



## NEW YORK

Director: Kim Kuck  
Inspiration: Mandy



## NORTH CAROLINA (CHARLOTTE)

Director: Adrena King  
Inspiration: CJ



## NORTH CAROLINA (RALEIGH)

Director: Mark Newmiller  
Inspiration: Ella



## NORTH DAKOTA (CONNOR'S CURESADERS)

Director: Brooke George  
Inspiration: Connor



## OHIO (JTHF)

Director: Tim Hayden  
Inspiration: Jeffrey



## OHIO (NORTHEAST)

Director: Jane Midgley  
Inspiration: Kasey



## OHIO (SOUTHWEST)

Director: Brooke & Keith Desserich  
Inspiration: Elena



## PENNSYLVANIA (WESTERN)

Director: Alyssa Hawranko  
Inspiration: Alyson



## TEXAS (AUSTIN/ROUND ROCK)

Directors: Melissa & James Fleming  
Inspiration: Brock, Katelyn, Alexis



## TEXAS (CEDAR HILL)

Director: Tanika Pierce  
Inspiration: Sarai



## TEXAS (CENTRAL)

Director: Vicky Bridier  
Inspiration: Jade



## TEXAS (ELIANA'S LOVE)

Director: Kariny Flores  
Inspiration: Eliana



## TEXAS (HEARTS FOR MK)

Directors: Gena & Harrison Keller  
Inspiration: Mary Katherine



## TEXAS (HOUSTON)

Director: Althea Lee  
Inspiration: Nicole



## TEXAS (NORTH)

Director: Michelle Bjornberg  
Inspiration: Sydney



## TEXAS (PARKER COUNTY)

Director: Cassy Ballinger  
Inspiration: Robert



## VIRGINIA

Director: Ginny Pritchett  
Inspiration: Morgan



## WASHINGTON

Director: Julie Caplan  
Inspiration: Victor



## WASHINGTON, DC

Director: Neely Agin  
Inspiration: Alexis



## WISCONSIN (AWESOME ALI SHINES ON)

Director: Tricia Verhaalen  
Inspiration: Alison

## INTERNATIONAL CHAPTERS



## AUSTRALIA

Director: Eleni Millios-Hullick  
Inspiration: Amy



## CANADA (EDMONTON)

Director: Amanda Nevesley  
Inspiration: Naomi



## CANADA (VICTORIA)

Director: Cari Comboye  
Inspiration: Liam

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

# \$29,506,047

**RAISED IN RESEARCH AND SUPPORT SINCE 2007  
IN CONJUNCTION WITH OUR DIPG/DMG COLLABORATIVE PARTNERS**

## 2021 ANNUAL REPORT

### BALANCE SHEET

For the Fiscal Year Ended December 31, 2021

ASSETS		LIABILITIES		NET ASSETS	
Cash and Cash Equivalents	\$3,025,236	Accounts Payable	\$23,692	Unrestricted	\$3,023,426
Other Assets - Prepaid Expenses	\$399,813	Grants Payable	\$100,000	Temporarily restricted	\$225,000
<b>TOTAL ASSETS:</b>	<b>\$3,425,049</b>	Other Liabilities:		<b>TOTAL NET ASSETS:</b>	<b>\$3,248,426</b>
		Accrued Compensation	\$52,932	<b>TOTAL LIABILITIES &amp; NET ASSETS:</b>	<b>\$3,425,049</b>
		<b>TOTAL LIABILITIES:</b>	<b>\$176,624</b>		

### STATEMENT OF ACTIVITIES & CHANGES IN NET ASSETS

For the Fiscal Year Ended December 31, 2021

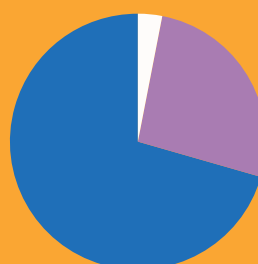
#### REVENUE, GAINS, & OTHER SUPPORT

Contributions	\$2,852,948
In-Kind Donations	\$98,579
Special Event Revenue	\$1,917,892
Other Support Program Revenue	\$433,260
Investment Return	\$963
<b>TOTAL REVENUE, GAINS, AND OTHER SUPPORT:</b>	<b>\$5,303,641</b>

#### EXPENSES

Program Services:	
Medical Research	\$1,997,548
Monkey in My Chair	\$166,625
Medical Symposium	\$351,879
Family Support Program	\$773,078
Fundraising	\$844,138
Management and General	\$146,515
<b>TOTAL EXPENSES:</b>	<b>\$4,279,783</b>

Increase (Decrease) in Net Assets	\$1,023,858
Net Assets - Beginning of year	\$2,224,568
<b>Net Assets - End of year</b>	<b>\$3,248,426</b>



**IN 2021**  
**77.65%** PROGRAM EXPENSES & RESEARCH FUNDED  
**2.23%** OVERHEAD  
**20.12%** FUNDRAISING EXPENSES

# 2021 TOP DONORS

## \$50,000+

Abstract Displays  
Bob and Dawne Litterst  
Brooke Healey Foundation  
Cincinnati Children's Hospital  
Facebook  
Fidelity Charitable  
Graeter's Ice Cream Company  
Melina Michelle Edenfield  
Foundation

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

Aidan's Avengers  
Aubrey's Army Foundation  
Benevity Causes  
Hyde Park Blast Corporation  
Jeffrey Thomas Hayden  
Foundation  
Musella Foundation for Brain  
Tumor Research  
Nancy and Bruce Axmacher  
Wayland Villars DIPG Foundation  
Inc.  
Whitley's Wishes

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

Allstate Foundation  
Andrew and Crystal Wash  
Bruce and Laura Shelby Family  
Fund  
Capital Group  
Capital Group Co Charitable  
Foundation  
Craig and Kristen Maurer  
David and Ginny Pritchett  
Dr. Hal and Brenda Stevenson  
Esther and George Jaruga  
Charitable Foundation  
ExVoto LLC  
Frontstream  
Fujiyama of Indianapolis, LLC  
General Electric Credit Union  
Gold Hope Project  
Gold Star Chili  
Greater Cincinnati Foundation  
Hugh Poindexter  
Isabella and Marcus Foundation  
John and Julie Cohen  
Julie and Jonathan Hopkins  
Kevin and Marie Douglar  
Lauren's Fight For Cure Inc.  
Mez Saheli  
Oodle  
Paypal  
Popp Hutcheson PLLC  
Prodigy, Inc.  
PTC Therapeutics, Inc.  
Reis Promotions  
Ronald and Lora Ogden  
Ryan's Hope  
Schwab Charitable  
Seamus and Laurie Walsh  
State Street Bank and Trust Co.  
Tom Riegel  
Yourcause, Blackbaud Giving Fund

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

Ace American Insurance Co.  
Adage Capital Management, L.P.  
Alyssa Hawranko and Nicholas  
Usher  
Amanda and Bryan Kilgore  
Amy and Jamie Charlton  
Andrew and Jana Cottril  
Brent and Jessica Austin  
Charities Aid Foundation of  
America  
Christie Clark  
Citi Business Services  
Cory Pistulka  
Courtney Ortner  
Daryl and Tiffanie Papp  
David and Leslie Prothro  
Deloitte  
DMSI Software  
Elk's Lodge #521  
Galley Hatch Restaurant Inc  
Gavin and Fatema Baumgardner  
GBA Girl's Basketball Assoc Inc.  
Glenn and Dayna Osako  
Global Payment  
GM Financial  
Heath and Staci Poindexter  
Honey Lemonade Gifts  
Integrity BioFuels  
Jackson Jewitt Tax Service  
Jeffery Routte  
Jesse and Alison Thompson  
Jesse and Corrie Shumaker  
John and Alexandra Gillies  
John Perentesis and Stella Davies  
Katherine Brown  
Keith and Brooke Desserich  
Kim Bledsoe  
Mark Evans  
Mary and Russ Walter  
McCormick Family Foundation  
Melissa and James Fleming  
Michael McVicker  
Midatech Ltd  
Mikah and Evin Macaluso  
Patricia Giffin  
Patricia Trangenstein  
Perfect Pallets, Inc.  
Pioneer Natural Resources  
Raymond James Global Account  
Ro and Charles "Shorty"  
Whittington  
Robin Kovacs  
Thomas and Stephanie Hatfield  
Tim and Sherri McKinney  
Timothy Bratz  
Todd Chapman  
Tricia and Matthew Verhaalen  
United Way Worldwide  
Verna Donovan  
William Dorsey

## \$1,500-\$4,999

360 Plumbing and Gas Solutions  
LLC

Abby Mc Nerney  
Ajit and Hema Prasad  
Alan and Anne Posnack  
Alex MacDonald  
Althea Lee and Henry Lee  
Amanda and Eric Mann  
Amazon  
Aminex Therapeutics  
Amy Armstrong  
Andrea Dresmann  
Andrew and Rachel Morbey  
Andy and Cynthia Chan  
Anne McDaniel  
Architectural Precast Association,  
Inc.  
Arthur Mabbett  
Avelino and Martha Guevara  
Bank of America Charitable Gift  
Fund  
Bastin Logan Water Services, Inc  
Becton, Dickinson and Company  
Ben Klopp  
Blake Stovall  
Bradford Oddo  
Bradley and Daryl Thompson  
Brady Family Fund  
Brandywine Elementary School  
Bret Buckman  
Brynny's Battle  
Carolyn Bridier  
Carrie Nicastro  
Carrina and Nelson Waneka  
Catherine Hammack  
Chick-fil-A  
Chris and Karen Chiappinelli  
Chris D'Alessandro  
Christopher Belknap  
Dr. Charles and Connie Collins  
Combined Federal Campaign  
Community Oven Inc.  
Cors and Bassett  
D. Chris Downey  
Daniel and Andrea Neal  
Daniel and Oris Weiner  
Darren Clough  
David Chen  
Dennis and Jody Desserich  
Don Chidester Rentals  
Doug Tracy  
Dustin Eash  
Edward Bruciati  
Edward Jones  
Elizabeth Weiner  
Emily and Jeremy Ronnebaum  
Endre and Jennifer Pekarik  
Eric and Carrie Goetsch  
Eric Kelley  
Erin Darling  
European Watch Company  
Farm Credit Services of America  
Fight like Emilie Foundation  
Founders 3 Retail Services, LLC  
Garrett Hicket  
Gemini  
Gerald and Carol Wash  
GO Marketing Services, Inc.  
Grace's Gold Ribbon Gang  
Grammer Logistics, Inc.

Graphic Village  
Greg and Tricia Niland  
Greg Stevens  
H and B Packing Co., Inc.  
Hamilton School District  
Henry Isefuku  
Indeco Sales, Inc.  
Infintech  
Isabel Torres  
Jacqueline Dover  
James Dodson  
James Pulsipher  
Jane and Ronald Midgley  
Janis Holvay  
Jason Cummings  
Jay and Kaylah Bendes  
Jayson and Brooke Nicholas  
Jeff and Allison Thomas  
Jeff and Sheila Wyatt  
Jeffrey and Silvana Bostock  
Jeffrey Judson  
Jeffrey Litterst  
Jessen Funeral Homes  
Jillian Nickerson  
Jim and Suzanne Sunvison  
John Healy  
John Whittington  
Jonathan Duarte  
Joseph Dentice and Karen Dentice  
JP Morgan Chase  
Karl and Leslie Slivka  
Katherine Bader  
Kay Ward and Tim Ward  
Ken and Terry Segerberg  
Kenneth Barnes  
Kevin and Connie Rau  
Kevin and Kelly Larkin  
Kroger Community Rewards  
Kush Shah  
Kyler Humphrey  
Kyle Sattler  
Allstate to Laura Harris Allstate  
Agency  
Levin Sitcoff Waneka P.C.  
Linda Craft and Team, Realtors  
Lisa Clemens  
Lonnie and Jeri Hollingsworth  
Lorrie and Dennis Brady  
LP Ladoucuer  
Lynn Collicott  
Maria Molnar  
Maria Schoonover  
Marianne Schaffer  
Mark and Elizabeth Thornton  
Mark Burns  
Mark Hatfield  
Martyn and Lynne Redgrave  
Matt Garabedian  
Matt Kahle  
McNamara Barre Studio  
Meagan Nelson  
Melanie and Philip Maguire  
Melissa and Michael Weiner  
Michael and Barbara Chatron  
Michael and Sara Wolf  
Michael DeBlasio  
Michael Thompson  
Michelle Olsen

Mindi Albers  
Mistie Hill  
Nancy Hesko  
National Philanthropic Trust  
New Hyde Park Memorial High  
School  
Nicole Seinen  
Oakland Youth Organization  
Operation Dough-Nation  
Patrick and Tara Dunion  
PB Newburyport LLC  
Pediatric Brain Tumor Consortium  
Foundation  
Perkins-Prothro Foundation  
Peter Schraufnagel  
Prestige Audio Visual  
Rachelle and Greg Covington  
Raymond James Charitable  
RDI Corporation  
Robert Litterst  
Rochelle Nevitt  
Ron and Beth Hatfield  
Saundra Bailey  
SPG Roofing and Restoration LLC  
Stacey Parrish  
Stefani and Steve Healey  
Stefano Dukcevic  
Stephen Beaumont  
Steven Johns  
Steven Pepe  
Stockyards Bank and Trust  
Stoltz Lawn and Landscape LLC  
Stony Creek Brewery LLC  
Stylecraft Builds, Inc.  
Sylvan Feldstein  
Ted Vick  
Therese Pinckney  
Thomas Gettelfinger  
Thomas Sullivan  
Tim and Angie Philpott  
Tim and Cindy Hayden  
Timothy McCarthy  
Tri City National Bank  
Twyla Kanada  
Union Pacific Charity  
Union Pacific GivePlus Program  
Union Pacific Railroad Company  
United Way of Benton and Franklin  
Counties  
US Bank Foundation Employee  
Matching Gift Program  
Vaughn and Kristin Cook  
Vicky Bridier  
Virginia and Larry Li  
Wallace Memorial UMC  
Wanda Weniger  
Warrior Kids Foundation  
Warsaw Community Schools DBA  
Wendy Doherty  
William and Karen Muehlbauer  
William Curran  
Bill and Nancy Eggar  
Youssef Berrada  
Zach and Kate Jessen

# OVER \$29.5 MILLION\* IN RESEARCH AND SUPPORT FUNDED

See grants funded prior to 2021 at [thecurestartsnow.org/grants](http://thecurestartsnow.org/grants)

## 2021-2022 CYCLE

University of Queensland Diamantina  
Institute: \$100,000  
Erasmus University Medical Center: \$432,354  
Cincinnati Children's Hospital: \$60,000  
Cincinnati Children's Hospital: \$153,867\*  
Hunter Medical Research Institute: \$232,932\*  
Sonlasense: \$198,436\*  
UPMC Children's Hospital of Pittsburgh:  
\$100,000\*

Ann & Robert H. Lurie Children's Hospital of  
Chicago: \$100,000\*  
The Hospital for Sick Kids (SickKids):  
\$100,000\*  
University of Texas MD Anderson Cancer  
Center: \$100,000\*  
Hunter Medical Research Institute: \$200,000\*  
Institute of Cancer Research: \$501,183\*  
Children's Hospital of Philadelphia: \$12,500  
Cincinnati Children's Hospital: \$50,000  
SIOPE DIPG/DMG Registry: \$779,018

CONNECT Consortium/Nationwide Children's  
Hospital: \$1,370,177  
Pediatric Brain Tumor Consortium: \$25,000  
Massachusetts General Hospital: \$50,000

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

# AWESOME ALI SHINES ON

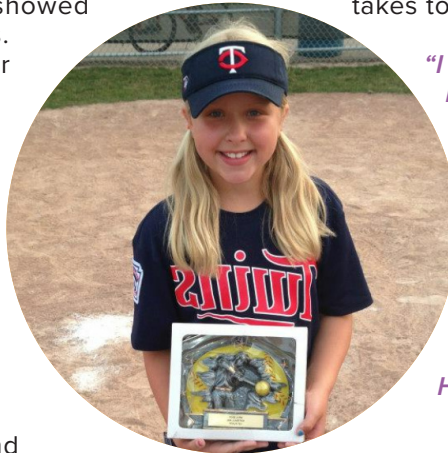


Alison Pearl was pure sunshine. Her love for life and for experiencing all that life had to offer was contagious. She had a huge heart and showed everyone she met exceptional kindness. Her sweet giggle was infectious and her smile could light up a room. She loved animals, art, and being with her family and friends the most.

Diagnosed in 2014, Ali passed away just short of her 10<sup>th</sup> birthday from a type of brain cancer called DIPG. During her battle against this cancer, she was a fierce warrior. Her legacy of kindness, love, and courage not only carried her through a brutal battle with a debilitating disease, but also started a legacy of giving with friends, family, and classmates from the community.

Alison's mother, Tricia Verhaalen, started the Awesome Ali Shines On Wisconsin Chapter of The Cure Starts Now to continue Ali's legacy, and her community has not forgotten Ali.

From socials and blanket sales to fun runs and golf tournaments, Tricia is not afraid to try whatever it takes to raise money for kids fighting cancer.



*"I can no longer save my child but I can help save yours. There is no doubt in my mind that there will be a cure found in my lifetime. We need funding though. The research cannot happen without the funding. I have met the brilliant researchers face to face and feel their drive and passion. It's inspiring to be a part of an organization that WILL find the Homerun Cure™."*

*– Tricia Verhaalen, Alison's Mother*

The Cure Starts Now is so blessed to fight alongside the Verhaalens to find the cure for all cancers and make sure that Awesome Ali forever shines on!

**To donate go to [donate2csn.org/wi-awesomeali](https://donate2csn.org/wi-awesomeali) **





# A 'SOLE'FUL PARTNERSHIP

Australia and Seattle-based designer footwear company FRANKiE4 put their best foot forward towards helping fund the Homerun Cure™ with their Socks for a Cause campaign earlier in 2022. The Cure Starts Now was selected as their national charity because of their dedication to kids fighting cancer.

Pink and red hearts decorated the socks of families in the fight during Valentine's Day as FRANKiE4 donated pairs to cancer families to show that they are loved, and that they are not alone. Known for their comfort in footwear, FRANKiE4 will continue to comfort our families with their support of critical research that donations through their campaign will help to fund.

[Learn more at us.frankie4.com](https://us.frankie4.com)



*"Our partnership with The Cure Starts Now has emotional beginnings. Seeing the plight of families and children diagnosed with brain cancer firsthand—and knowing that a child is diagnosed with cancer every three minutes—inspired us to do everything we can to help."*  
— Caroline McCulloch, Founder of FRANKiE4

# STEAK, SUSHI, & SUPPORTING THE CURE

In the world of fundraising, 'dine out' events are the easiest way for a restaurant to help support a local cause. For the second year in a row, Fujiyama Steakhouse in Franklin, Indiana, has gone above and beyond to help fund pediatric brain cancer research in honor of Addie Mae Jessen.

Addie Mae was a beautiful, happy soul who fought DIPG for 10 months. To honor her, Addie Mae's family has started the Adalynn Strong Chapter of The Cure Starts Now in Franklin, Indiana.

*"We're so humbled for all the love and support and can't wait to keep our sweet girls fight and story alive and hopefully continue to change and save lives."*  
— The Jessen Family

The annual Dine Out for the Cure features 50% of all proceeds from dine-in and carry-out sales, as well as 100% of all sales from their drink special on the event day. There was no mistaking members of the community who came out to support the Jessens as they sported cozy sweatshirts emblazoned with a rainbow on the back and 'Adalynn Strong #choosejoy' on the front.

Thanks to their incredible community and staff, Fujiyama Steakhouse has raised over \$35,000 in Addie Mae's honor through their Dine Out for the Cure events.

[Learn more at donate2csn.org/AdalynnStrong](https://donate2csn.org/AdalynnStrong)



# EVENTS AND FUNDRAISERS OF 2022

From races to bake sales, art auctions to regattas, work outs to video games, we've got a fundraiser and event for every flavor. Here are just a handful of some of the amazing events and fundraisers we've done in 2022!

## RACES, WALKS, AND GOLF, OH MY!



**BLAST CANCER BRAIN TUMOR WALK — CONNECTICUT CHAPTERS**



**HEARTS FORE MK GOLF — HEARTS FOR MK TEXAS CHAPTER**



**IRONWOOD GOLF EVENT — AWESOME ALI SHINES ON (WI) CHAPTER**



**RACE AGAINST THE ODDS — NEBRASKA CHAPTER**

## FOR THE FOODIES AND THE DRINKERS



**LEMONADE STAND — EAST FLORIDA CHAPTER**



**POUR FOR THE CURE — CONNECTICUT CHAPTER**



**DINE FOR A CURE — RYLIE STRONG INDIANA CHAPTER**



**CONES FOR THE CURE — OHIO, INDIANA, & KENTUCKY CHAPTERS**

## INNOVATIVE AND CREATIVE



**2022 HEART AUCTION**



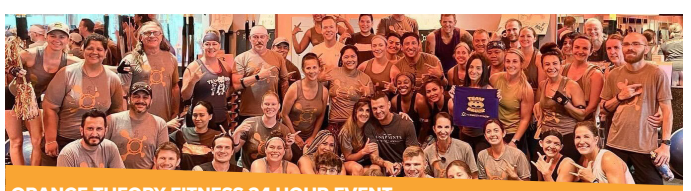
**THE DAD GAMING MINECRAFT — NERF CANCER**



**GREEK WEEK — INDIANA ADALYNN STRONG CHAPTER**



**GOLD OUT GAMES**



**ORANGE THEORY FITNESS 24 HOUR EVENT — AUSTIN/ROUND ROCK TEXAS CHAPTER**

# A NEW LEVEL OF COLLABORATION



One of the pillars of finding the Homerun Cure™ is collaboration. This year saw two major mergers of foundations and families in Ohio dedicated to this cause combining their efforts with The Cure Starts Now and the Desserich family.

## THE ANGEL RUN

Sophie's Angel Run has been a staple of the West Side of Cincinnati. The Meinhardt Family originally started the event in 2007 after losing their daughter Sophie to a rare and aggressive brain tumor. The community rallied behind them in order to honor Sophie and raise money for medical research and educational scholarships. In 2021 the campaign was able to raise over \$85,000 which benefitted Cincinnati Children's Hospital and \$5,000 in scholarships to students of several local catholic schools.

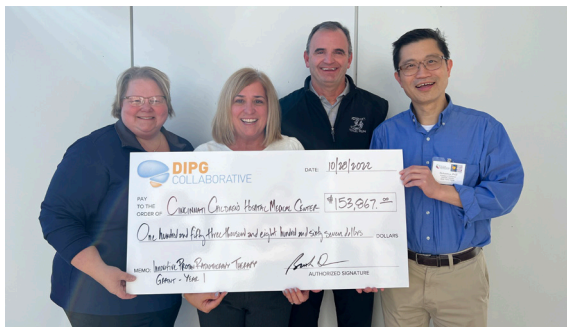
*"Immediately after Sophie died it was so important for us to not only let everyone know what happened but to also celebrate her life. Anyone that knew Sophie knew she was full of life."*

*– Mark & Missy Meinhardt, parents of Sophie*



This year the race transitioned from the Meinhardt family to another family whose loss was equally as difficult. The event was renamed "The Angel Run" and event coordination turned over to the families of The Cure Starts Now to honor Elena Desserich as well as Sophie Meinhardt.

This year thanks to the efforts of both families and their combined communities, the event raised over \$47,000.



## JTHF

In September of 2004, 12-year-old Jeffrey Hayden lost his battle with brain cancer. Shortly after his death, his family established the Jeffrey Thomas Hayden Foundation with the purpose of raising money to fund research and help affected families.



JTHF has been a major contributor to the DIPG Registry, which is located within Cincinnati Children's Hospital. The DIPG registry is funded by non-profit organizations similar to JTHF, with the united goal to find a cure for not only DIPG cancer, but for all pediatric cancers. To date, the foundation has collected over \$650,000 in donations that have funded research projects at The Ohio State University and Cincinnati Children's Hospital Medical Center.

This year JTHF merged with The Cure Starts Now for their annual Fall Golf Classic. Having been a core part of the DIPG/DMG Collaborative for many years alongside The Cure Starts Now, the joined efforts towards the same goal of finding the cure for all cancers just made sense. As of January 2023, JTHF will be an official chapter of The Cure Starts Now to continue Jeffrey's legacy by funding promising research.

[Learn more at donate2csn.org/JTHF](https://donate2csn.org/JTHF)





International Headquarters  
10280 Chester Road  
Cincinnati, OH 45215



SINCE 2007,  
THE CURE STARTS NOW HAS:



HOSTED 5 INTERNATIONAL  
DIPG/DMG SYMPOSIUMS



AUTHORED THE LEADING  
INFORMATIONAL WEBSITES  
DIPG.ORG AND  
MEDULLOBLASTOMA.ORG



HELPED CREATE THE  
LARGEST LINKED  
DIPG/DMG SPECIFIC REGISTRY



FOSTERED A NETWORK OF  
OVER 150 BRAIN TUMOR EXPERTS



LAUNCHED WARRIOR PORTALS  
TO PROVIDE SUPPORT  
FOR 600+ FAMILIES



FOSTERED THE  
FORMOST CONSORTIUM  
FOCUSED ON DIPG



UNIFIED OVER 25 FOUNDATIONS  
IN THE DIPG/DMG COLLABORATIVE



OVER 600 WARRIOR FAMILIES  
FIGHTING TOGETHER

OVER  
\$29.5 MILLION

LED FUNDING OF DIPG/DMG  
RESEARCH WITH 120+ TRIALS



**FAMILY NEVER  
FIGHTS ALONE**

**DONATE2CSN.ORG**

DIPG Warrior Addison

Photo courtesy of Milestone Moments Photography