

2022

ANNUAL REVIEW



TOGETHER WE WILL FIND A CURE

Founded by the families of Chad Carr and Michael Mosier and fueled by nearly 40 Family Partners

 **\$23M**
FUNDED

 **58**
RESEARCHERS

 **31**
INSTITUTIONS



A MESSAGE FROM OUR FOUNDERS

When we lost our sons, Chad and Michael, to DIPG in 2015, it was hard to imagine a future without them. It remains just as painful every day. But we draw strength from watching glimmers of progress, as we continue our mission of funding research for a cure. Finally, slowly but surely, families like ours, who are facing the deadliest form of childhood cancer, are seeing new treatment options that were not available when our boys were fighting.

With your help, our HOPE for a better prognosis for DIPG is becoming a REALITY. Yet there is much more work to do. We are honored to work alongside our ChadTough Defeat DIPG Family Partners from 19 states plus Mexico who join us in battling this devastating disease. We are Tougher Together.

In this Impact Report, you will read about some of the incredible projects we have funded and amazing children who have inspired us. Thank you for standing with us to honor all of the children who have fought or are currently fighting brain cancer. YOU are making an impact by ensuring that we change the future for these brave kids. Together, we will Defeat DIPG.



Jason Carr, Pam Carr
The Carr Family



Mark Mosier, Jenny R. Mosier
The Mosier Family

A LETTER FROM OUR CEO

When I first joined the fight in 2015, I was shocked to learn how little scientific progress had been made over the years toward the deadliest form of childhood brain cancer. But now, just 7 years later, we are finally seeing the type of breakthroughs necessary to change the future for families in the fight.

I'm so proud to lead this foundation, which has now become the largest source of private funding for DIPG research worldwide. Working together with our founding families, the Carrs and Mosiers, along with almost 40 ChadTough Defeat DIPG Family Partners, we've been able to fund 58 researchers across 31 institutions so far. Progress IS being made from the work we are supporting, and researchers are more optimistic than ever that a cure will be found in our lifetime. But with so little of government cancer research funding directed toward childhood brain cancer, researchers cannot be successful without funding from foundations like ours.

We know it is because of the generous support from people like you that we have been able to make such strides toward a cure, and we cannot thank you enough! Whether you have volunteered, helped spread the word about the work we do, or donated, we cherish your contributions in our effort to Defeat DIPG!

Ann Friedholm

Ann Friedholm

CEO, ChadTough Defeat DIPG Foundation



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MY DIPG NAVIGATOR

106 FAMILIES SERVED SO FAR

In 2022, the ChadTough Defeat DIPG Foundation launched a nationwide program called My DIPG Navigator, designed to give much-needed, FREE, individualized guidance for patients and their families facing a childhood brain cancer diagnosis. This program, led by dedicated Registered Nurses with years of oncology experience, empowers patients and their families with the proper information and resources necessary to make the most-informed decisions throughout their cancer journey.

Following Elowyn's DIPG diagnosis in July of 2022, her parents, April and Justin, turned to My DIPG Navigator for help. Nurse Lauren helped the family seek radiation treatment at C.S. Mott Children's Hospital, and Elowyn is currently enrolled in the cutting-edge CAR T-cell clinical trial at Seattle Children's Hospital.



"The devastation that comes with a pediatric brain cancer diagnosis can leave patients and families in shock and disbelief. We want to ease their journey as much as possible by helping them understand the disease, connect with the proper resources, and make informed decisions as quickly as possible."

*Leslie Jared
My DIPG Navigator Director*



Nurse Navigators (L to R): Ashley, Leslie, & Lauren

MEET THE NURSES

The My DIPG Navigator program is run by Registered Nurses with more than 60 combined years of oncology experience.

"Ashley has been a huge help. She's given us information and most importantly hope! I don't know where we would be if it wasn't for her. We are forever grateful."

My DIPG Navigator family

WELCOME TO THE TEAM

Nurse Emily, who has years of pediatric care experience, with a significant portion spent in hospice and palliative care, joined the team in January 2023.



Scan the code to visit
My DIPG Navigator now.



THANK YOU TO OUR NAVIGATOR PARTNERS WHO HELP MAKE THIS FREE PROGRAM POSSIBLE.
WWW.MYDIPGNVIGATOR.ORG/ABOUT-US/PARTNER-ORGANIZATIONS

LEADING THE WAY TOWARDS CHANGE

THIS YEAR WE AWARDED OUR 50TH GRANT

 **20**
FELLOWSHIPS

 **16**
NEW INVESTIGATOR

 **14**
GAME CHANGER

Our comprehensive grant program encourages young researchers to focus on DIPG through our Fellowship and New Investigator Grants and supports the work of seasoned researchers through our Game Changer Grants. The ChadTough Defeat DIPG Scientific Advisory Council (SAC), comprised of leading DIPG experts, engages in a rigorous review of the research funding applications the foundation receives, to ensure the foundation uses its resources effectively to fund the most promising DIPG research.

“A significant number of DIPG patients are now getting 6 months or more of additional survival from newer therapies, including ChadTough Defeat DIPG funded projects like ONC201 and CAR T.”

Dr. Carl Koschmann
Clinical Research Director
Chad Carr Pediatric Brain Tumor Center



“Private funding, including those granted by ChadTough Defeat DIPG, is critical for moving the field of DIPG forward.

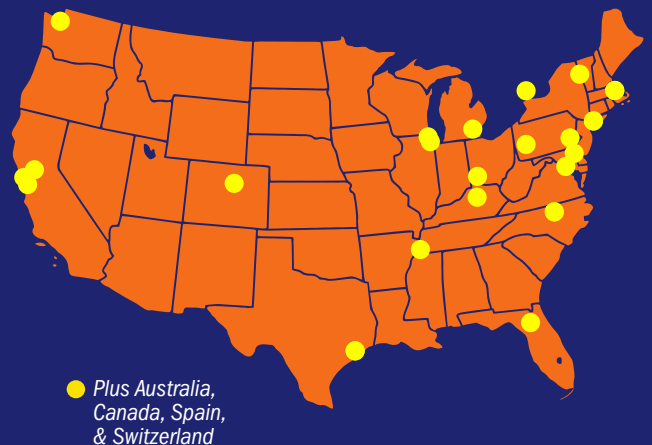
Foundations that specifically fund DIPG research not only enable but encourage researchers to include DIPG as a primary focus of their research.”

Dr. Tara Barron
2021 Fellowship awardee



WE HAVE AWARDED MORE THAN \$23 MILLION IN GRANTS TO 31 INSTITUTIONS AROUND THE WORLD

Baylor College · Boston Children's Hospital · Brigham & Women's Hospital
Children's National · Oncoceutics · Columbia University · Dana Farber
Cancer Institute · Duke University · Fred Hutchinson Cancer Research
Center · Hospital for Sick Children Toronto · Hudson Institute of Medical
Research · Johns Hopkins University · Lurie Children's Hospital of Chicago
Northwestern University · Sanford Burnham Prebys Medical Discovery
Institute · Stanford University · St. Jude Children's Research Hospital
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University of California San Francisco · University of Cincinnati · University
of Colorado · University of Florida · University Hospital of Navarra, Spain
University of Kentucky · University of Michigan · University of Newcastle
University of New South Wales · University of Pittsburgh · University of
Vermont · Weill Cornell Medical Hospital



THANK YOU TO OUR RESEARCH PARTNERS!
YOUR SUPPORT ACCELERATES OUR PROGRESS TOWARDS A CURE.
WWW.CHADTOUGH.ORG/RESEARCH/RESEARCH-PARTNERS

FOUNDATION-FUNDED TRIALS ARE OFFERING FAMILIES THE GIFT OF TIME

DMG-ACT

For the third year in a row, the ChadTough Defeat DIPG Foundation announced its support for a first-of-its-kind trial platform called Diffuse Midline Glioma - Adaptive Combinatorial Therapy (DMG-ACT), bringing the total dollars committed to more than \$1.5 million. This promising project is a collaboration between the world's leading brain cancer experts, encompassing 30 research groups from 7 countries around the world.

By the end of 2022, 52 patients had been enrolled in the DMG-ACT, and researchers have investigated more than 100 drugs in the lab. A combination of 5 different drugs is now being vetted for addition to the trial.

One goal for ChadTough research grants is to provide funding for development of promising new ideas in the field of DIPG. With early support, researchers can gather the foundational data needed in order to procure larger government funding. The grants provided by ChadTough for preliminary research through DMG-ACT helped lead to an additional \$6.4 million in federal grants, thus magnifying the impact of the dollars we are investing in this critical work.

Ryder Knechtle lived more than 2 years after he was diagnosed with DIPG in July of 2020. His family believes the drug ONC201 allowed for extra time to make incredible memories.



"The extra time Sophie had to leave an impact on this world allowed us all to focus on living rather than dying."

Kim Varney
Sophie's mom



Sophie lived nearly 24 months after she was diagnosed. Her family credits the drug ONC201 for allowing her to live more than a year past the average life expectancy for DIPG patients.

"DIPG is the deadliest cancer known to man. We cannot send kids home with one oral drug and expect that to help. Using a combination of drugs is crucial in order to make significant progress in the treatment of DIPG."

Dr. Matt Dun
Biomedical scientist and DIPG dad to Josie, who passed away in 2019



CAR T-CELL THERAPY

CAR T-cell therapy is a revolutionary process in cancer treatment that genetically alters a patient's own T-cells to attack cancer cells.

This trial has shown great promise and after decades could finally offer patients with DIPG a new treatment option for a disease that has historically proven resistant to other therapies. ChadTough has proudly funded more than \$1 million to the cutting-edge work at Stanford Medicine, and we look forward to following the progress in Dr. Monje's lab.

"CAR T-cell therapy is an incredibly promising strategy and robustly effective against this disease. It truly feels as though we are finally taking steps in the right direction to treat this terrible disease."

Dr. Michelle Monje



2022 HIGHLIGHTS



SUPERHERO SPRINT & 6K

2,173 participants
\$253,258 raised



CHAMPIONS FOR CHANGE GALA

775 participants
\$1,453,486 raised



CHICAGO GOLF OUTING

150 participants
\$190,300 raised



RUNTOUGH 5K & 1M FUN RUN

2,728 participants
\$413,326 raised



DREAM BIG GALA

500 participants
\$470,000 raised

I RAN THE D 5K

This unique Detroit run, presented by Bally Sports, will take place on Saturday, May 6, 2023 and, for the second year in a row, will benefit ChadTough. In 2022, the event raised \$94,459!



RECOGNIZING OUR PLAYMAKERS

A collection of donors and organizations supporting our mission at \$100,000+



Michael
Kojan



The Weiser
Family



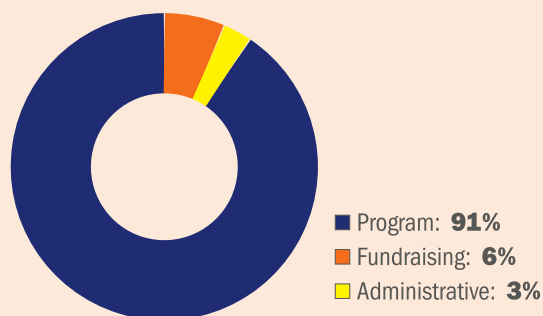
GIVINGTUESDAY

Thanks to nearly 2,300 donors, we raised over \$700,000! This allows us to fund an additional research grant AND expand our My DIPG Navigator program by hiring an additional nurse.

We are grateful to **Covington & Burling LLP** and **Select Equity Group Foundation** for their significant and unwavering support.

2021 AUDITED FINANCIALS

Total Revenue	\$3,944,696
Total Expenses	\$5,294,517
Program	\$4,799,933
Fundraising	\$338,500
Administrative	\$156,084





THANK YOU FOR HONORING OUR CHILDREN

We stand together in our mission to change the future for families in the fight against childhood brain cancer.



Visit our website to learn more about our Family Partners.



Arden
Kentucky



Austin
Michigan



Brody
Tennessee



Callie
New York



Chika
Michigan



Colt
Ohio



Connor
Texas



Dara
Maryland



Eliana
California



Elita
New York



Emerson
Michigan



Emma
Michigan



Eugenio
Mexico



Grant
Minnesota



Harrison
Utah



Hudson
Kansas



Hunter
Maine



Jack
Maryland



Julian
Michigan



Kambria
Michigan



Kenzie
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Lilian
North Carolina



Lucy
North Carolina



Luke
Maryland



Maddie
Pennsylvania



Mattie
California



Mirah
Maryland



Olivia
Michigan



Owen
Illinois



Raegan
Florida



Sophie
Michigan



Tommy
Michigan



Vivian Rose
Washington



Vivienne
Connecticut

"We are fortunate to have become a Family Partner, gaining support and strength from others who wish to honor their children. We are doing everything we can to increase awareness and funding for research into treatment options for this dreadful disease so that families do not have to suffer the loss that we did."

*Hanita Chhabra, M.D.
Mom to Mirah*



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LOOK INSIDE TO SEE HOW YOUR
SUPPORT HAS MADE AN IMPACT
IN THE BATTLE AGAINST
CHILDHOOD BRAIN CANCER

OUR MISSION

In the fight for a DIPG/DMG cure, we
help patients and families by funding
game-changing research and providing
navigation throughout their journey.

UPCOMING EVENTS



May 13, 2023



**CHADTOUGH
DEFEAT DIPG®
SUPER
HERO**
SPRINT & 6K

May 2023

CHICAGO
GOLF OUTING
July 24, 2023



RunTough
for ChadTough Defeat DIPG 5K & 1M

September 2023