

## **Pioneering Change:**

Progress in the Fight Against DIPG/DMG













Founded by the families of Chad Carr and Michael Mosier and fueled by our Family, Research, and Navigator Partners

### A MESSAGE FROM OUR FOUNDERS

#### **Ten Years. A Decade of Determination. A Future of Hope.**

Ten years ago, our sons, **Chad and Michael**, were diagnosed with the deadliest childhood brain cancer — DIPG — a disease with no cure, no effective treatment options, and no real hope. Like so many families before us, we were forced to hear the words no parent should ever hear: "There is nothing we can do."

But because of you, that is no longer the only answer.

A decade later, the landscape of DIPG research has transformed — and you have been part of that change.

With your generosity, during this time the ChadTough Defeat DIPG Foundation has:

- Funded 90 researchers across the globe, bringing new scientific minds into the fight.
- Supported groundbreaking discoveries that are opening doors to real treatment options.
- Launched My DIPG Navigator, ensuring that no family has to navigate this nightmare alone.

You have helped us fuel a movement that is rewriting the future for children diagnosed with DIPG. There is **now real hope** where there was once only heartbreak.

But this fight is far from over.

With your continued support and the strength of our Family, Research, and Navigator Partners, we are tougher than ever, pushing for bold research, better treatments, and, ultimately, a cure.

From the bottom of our hearts, **thank you** for standing with us. Your generosity is changing lives. Together, we will Defeat DIPG.

With gratitude,

**The Carr Family** 

Family

The Mosier Family

The Mosier Family







### THE DIFFERENCE YOU MAKE

ChadTough Defeat DIPG Foundation brings hope to patients and families facing DIPG/DMG. Your support helps us advance critical research to find cures for this devastating disease. Together, we are making strides toward a future where every child can overcome brain cancer.



**DIPG/DMG Nurse Guidance** 

# A Lifeline for Families Facing the Unimaginable

DIPG is a diagnosis that no family is prepared for. The sudden, devastating news leaves parents with overwhelming questions:

- · What do we do next?
- Where can we find the best care?
- How do we make the most informed decisions for our child?

That's where **My DIPG Navigator** steps in. Launched in 2022, this free, personalized resource connects families with expert **Nurse Navigators** who provide education, connection, and unwavering support through every step of the DIPG journey. Learn more at **MyDIPGNavigator.org**.



#### **Social Worker Added to the Team**



Alison Blom, MSW, LCSW, has over a decade of experience in pediatric oncology. She earned her B.S. in Human Services and Criminal Justice from Northeastern

University and her MSW from the University of Denver, graduating with honors in Health and Wellness. She previously supported families as the Solid Tumor Social Worker at Children's Hospital Colorado.

As My DIPG Navigator's Social Worker, Alison works alongside our Nurse Navigators to provide emotional support and to connect families with vital resources, including counseling, financial assistance, and specialized care. She ensures families have the guidance and support they need at every step of their journey.

### HELPING FAMILIES IN THE FIGHT

#### **Meet Maddie**

On October 16, 2023, Madison "Maddie" Constable, a vibrant 17-year-old from Brooklyn, NY, was rushed to the hospital after feeling disoriented and unwell. What began as a routine concern quickly became a life-altering diagnosis — a 4.8cm tumor was

discovered in her brain, roughly the size of a lime. Shortly after, Maddie and her family received the devastating news: diffuse midline glioma (DMG), an aggressive and relentless form of brain cancer.

The diagnosis sent shockwaves through her family, turning their world upside down. Maddie is more than just a patient — she is a bright, ambitious, and compassionate young woman with dreams of making a difference. She had her entire future ahead of her, but now, she faces a battle no teenager should ever have to fight.

#### A Relentless Battle, A Fierce Spirit

Navigating a brain cancer diagnosis is overwhelming, and Maddie's family turned to the ChadTough Defeat DIPG Foundation's My DIPG Navigator program for one-on-one guidance to

help them make informed decisions at every step. From understanding treatment options to managing side effects and exploring clinical trials, **My DIPG Navigator provided the expertise and support they needed during this challenging time.** 

Determined to fight, Maddie endured three brain surgeries at Cornell, where doctors worked tirelessly to remove as much of the tumor as possible. With remarkable resilience,



she then began weeks of radiation, five days a week, at Memorial Sloan Kettering in NYC. The treatment was grueling, but crucial in her battle. Through it all, Maddie pushed forward, fueled by the love and unwavering support of her family.

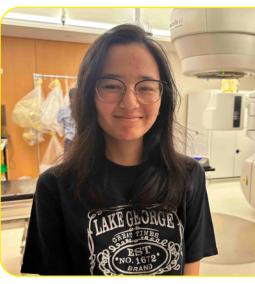
By the summer of 2024, a glimmer of hope emerged — Maddie was accepted into a clinical trial at NYU for ONC201, a promising new treatment. She celebrated her 17th birthday, completed school virtually, and continued fighting with the same determination that has defined her journey.

#### **Hope in the Face of Uncertainty**

But cancer is an unforgiving opponent. Despite the best efforts of her medical team, an emergency MRI revealed that the tumor had started growing again. The news was heartbreaking, yet Maddie and her family refuse to give up. They hold onto hope — hope in new treatments, hope in research advancements, and most of all, hope in Maddie's incredible strength.

Through every setback, Maddie's family stands by her, believing that progress in childhood brain cancer research will bring new possibilities, new interventions, and ultimately, a cure. Maddie is not just fighting cancer —she is fighting for a future, for every dream she has yet to chase, and for the life she deserves to live.

Her story is one of resilience, love, and unwavering faith in the power of hope.



# GLOBAL FRONTRUNNER IN BRAIN CANCER RESEARCH FUNDING

# **Driving an Unprecedented Surge in DIPG/DMG Research**

ChadTough Defeat DIPG Foundation is the world's leading private funder of DIPG/DMG research, fueling a seismic shift in the fight against childhood brain cancer. Through our efforts, we have not only **accelerated scientific discovery** but also dramatically **expanded the number of researchers** dedicated to finding a cure.

Through a diverse grant program, the foundation not only funds **cutting-edge research** but also encourages **new scientists** to enter the field while inspiring seasoned researchers to push the boundaries of discovery. With every grant awarded, ChadTough Defeat DIPG strengthens the fight against DIPG/DMG, bringing hope to families and moving closer to a cure.

Guided by a **Scientific Advisory Council** composed of leading experts in childhood brain cancer, the foundation ensures that every grant supports high-impact research. The council carefully reviews applications and recommends funding for the most promising projects, maximizing the potential for breakthroughs.

The momentum is undeniable. In the last four years, the **number of research grant applications we received has more than tripled** — from 32 to 105 — reflecting the surge of scientists now focused on DIPG/DMG. To keep pace, we've expanded our Scientific Advisory Council, ensuring that every proposal receives expert review and the best science gets funded.

**But the work is far from over.** As more researchers dedicate their efforts to DIPG/DMG, the need for funding has never been greater. ChadTough Defeat DIPG Foundation is committed to meeting this demand — but we can't do it alone. Continued support from our donors and partners is critical to ensuring that groundbreaking research receives the resources it needs to turn scientific progress into life-saving treatments. **Together, we can accelerate the fight against DIPG and bring real hope to families who need it most.** 

#### **Research Project Spotlight**



**Dr. Deblina Sarkar** Massachusetts Institute of Technology New Investigator Grant Recipient

# Nanoelectronics-Based Treatment for DIPG: A Breakthrough Approach

Dr. Sarkar is developing the first nonsurgical brain implant for bioelectric therapy, using nanoelectronic devices that travel through blood vessels, autonomously detecting and targeting tumors. These devices generate controlled electric fields to selectively destroy cancer cells without harming healthy tissue.

This portable, noninvasive therapy could reduce treatment time, improve quality of life, and integrate with existing therapies.

With low-cost production and high accessibility, this innovation has the potential to revolutionize DIPG treatment, bringing new hope to families facing this devastating disease.





### IMPACTING CLINICAL TRIALS

#### Advancing Hope: CAR T-Cell Therapy for DIPG/DMG

CAR T-CELL THERAPY is a cutting-edge form of immunotherapy that uses a patient's own immune system to fight cancer. This approach has already shown remarkable success in treating certain blood cancers. Now, researchers are exploring its potential to combat solid tumors, including DIPG and DMG.

#### Dr. Michelle Monje: Leading the Way in CAR T-Cell Therapy for DIPG/DMG

Dr. Monje of Stanford Medicine has emerged as a **global leader** in the fight against DIPG/DMG, recently gaining **national recognition** for the success of her groundbreaking CAR T-cell clinical trial. Her pioneering work has helped establish CAR T-cell therapy as **one of the most promising advancements in DIPG/DMG treatment.** 

In 2018, Dr. Monje and her team discovered that DIPG tumor cells express GD2, a surface marker that CAR T-cells can be engineered to recognize and attack. Early preclinical studies showed remarkable promise, leading to a clinical trial that is reshaping the fight against DIPG/DMG.

In the trial, 11 patients received CAR T-cell therapy, and nine showed significant benefits, including improved mobility and tumor shrinkage. Notably, four patients had tumor reductions



Drew, walking on his own after treatment

over 50%, and one, Drew, **experienced a complete response** — his tumor disappeared from brain scans.

Diagnosed in November 2020, Drew faced worsening symptoms that left him in a wheelchair. Enrolling in the Stanford clinical trial in June 2021, he received

To date, the ChadTough
Defeat DIPG Foundation has
committed over \$1M to help
support the CAR T-cell trial at
Stanford University.

CAR T-cell infusions that, despite initial side effects, **led to a dramatic improvement.** In May 2022, he walked unassisted at graduation, receiving a standing ovation from his classmates.

While it's too soon to know if Drew's tumor will return, his remarkable response offers **new hope.** ChadTough Defeat DIPG Foundation is proud to fund this groundbreaking research, ensuring that more children have access to life-changing therapies. **With every breakthrough, we move closer to rewriting what's possible for DIPG/DMG patients and their families.** 

# CAR T-Cell Trial for DIPG/DMG Launching at the University of Michigan

A CAR T-cell clinical trial for brain tumors recently opened at the Chad Carr Pediatric Brain Tumor Center (CC-PBTC), marking a significant step forward in advancing innovative treatments for DIPG/DMG.

"We believe CAR T-cell therapy will play an increasingly vital role in the future treatment of DIPG/DMG," said Dr. Carl Koschmann, Clinical Scientific Director at CC-PBTC.

"This trial would not have been possible at the University of Michigan without the unwavering support of the ChadTough Defeat DIPG Foundation."



Learn more about the research we've funded by scanning or clicking the QR code.



#### 2024 Highlights



**Superhero 6K** 2,072 participants \$272K raised



**ChadTough Gala** 852 participants \$1.8M raised



Chicago Golf Outing 144 participants \$225K raised



**RunTough** 2047 participants \$419K raised



Sparkle & Shop 162 participants \$138K raised

#### **GI₩ING**TUESDAY

Thanks to the support of 2,106 donors, we raised \$674,355, allowing us to continue our work to give HOPE and HELP to families fighting childhood brain cancer.

We express out heartfelt gratitude to Covington & Burling LLP and Select Equity Group Foundation for their significant and unwavering support.

#### **2024 Playmakers**

We're grateful for our donors and organizations supporting our mission at \$100,000+













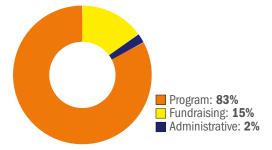




Weiser Family



# 2023 AUDITED FINANCIALS



<b>Total Revenue</b>	\$7,562,052
<b>Total Expenses</b>	\$7,465,827
Program	\$6,184,477
Fundraising	\$1,123,908
Administrative	\$157,442

#### **BOARD OF DIRECTORS**

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# POWER IN PARTNERSHIP

No one fights DIPG/DMG alone. ChadTough Defeat DIPG Foundation is built on the belief that **collaboration is the key to progress.** Together, we are transforming loss into purpose, determination into action, and hope into real impact.

#### **Family Partners**

Families that embrace the foundation as their own, honoring their child's legacy by raising funds to advance research and support other affected families.



#### **Research & Navigator Partners**

Organizations that collaborate with the foundation to drive groundbreaking DIPG/DMG research forward and to ensure My DIPG Navigator remains a free resource for families in need.

Austin Strong Foundation\*
Avery's Little Army\*
Cal's Angels
Cannonballs for Kayne
Foundation
Dean's Dream Foundation
Domino's Pizza
Dylan Jude Harrell DIPG
Foundation
Elle's Angels Foundation\*
Emily's Light Foundation
Lace 'em up for Libby
Love for Linley Foundation\*
Luke's Posse: DIPG Ends Now!
Magic for Maddie\*

Mark Massey Legacy Foundation
McKenna Claire Foundation\*
Mighty Madison DIPG Research and Awareness Fund
Mithil Prasad Foundation
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NoahBRAVE Foundation\*
Pediatric Brain Tumor Foundation
Prayers From Maria Foundation
Rossi Family Foundation
RUN DIPG
Shaker Family Charitable Foundation
SoSo Strong Pediatric Brain Tumor Foundation\*
Storm the Heavens Fund
TaterTough
Taylor Anne Foundation

Team Buddy Forever Foundation
Team Cozzi Foundation
Team Landon Clay Foundation
Ted & Jane Von Voigtlander Foundation\*
The Alvin Glick Foundation\*
The Archer Foundation\*
The DEKM Fund
The Finn Family Foundation
Tough Like Jack Foundation
Tough2gether Foundation\*
Violet Foundation for Pediatric Brain Cancer
WhyNotDevin Foundation to End DIPG
Zatkoff Family Legacy Fund\*

<sup>\*</sup>Collaborating as both a Research Partner and Navigator Partner







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### 2024 ANNUAL REVIEW

Look inside to see how your support can offer **HOPE** and **HELP** to families battling the leading cause of cancerrelated deaths in children.

# GIVE HOPE

Make a lasting impact by becoming a monthly donor. With just \$19 a month, you can fuel research and provide essential support to families in need.

From participating in events to creating your own fundraiser, explore the many ways you can help make a difference in the fight against childhood brain cancer at www.ChadTough.org



**Give Hope Today** 



#### **Host a Fundraiser**

From bake sales to social media fundraising, your efforts play a vital role in making a meaningful difference in the lives of children battling brain cancer.



#### **Participate in an Event**

Throughout the year we host several runs, both locally and virtually, so you can make a difference anytime, anywhere!



#### **Follow and Share**

Help us raise awareness in the fight against the deadliest disease known to kids!





