

BEING TOUGH FOR CHAD TOUGH

2018 Impact Report - Because of YOU!



The ChadTough Foundation®
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FOLLOW US!

Get updates about our upcoming
events, volunteer opportunities,
and more!

FROM THE BEGINNING

By Ann Friedholm, Executive Director

I met Tammi well before Chad got sick, working on a project to benefit our community's schools. As Chad's disease progressed, I felt compelled to help. Once Tammi and Jason established The ChadTough Foundation, I found my role - leverage my business experience to get things organized and off the ground.

At the beginning, I remember sitting in the Carrs' kitchen, which continues to be our conference room, discussing goals.

"We need to settle on size to determine resource needs." I suggested an annual target of \$1 million. Tammi bristled ... a lot! "\$500,000 - I don't want to feel the pressure of a huge goal!" So we compromised to \$750,000. I was officially hired part-time, along with two others, in June of 2016.

A few short years later, I cannot believe how much has been accomplished. We have an unbelievably talented, part-time staff of six; over 400 volunteers; countless folks who lead fundraisers; and incredible partners ... who together raised over \$2.5 million in 2018. Attention and funding has attracted more doctors to focus on diffuse intrinsic pontine glioma (DIPG). U-M established the Chad Carr Pediatric Brain Tumor Center. We have granted over \$4.2 million for research. Discoveries have led to new treatments. And doctors now say a cure will be found in our lifetime!



Ann with her husband Jon,
Tammi, & Jason

Through it all, I see Chad. He gives us what we need exactly when we need it. He creates opportunities for this foundation to grow. We are simply following the path he lays before us.

I feel incredibly blessed to be a part of something as special as The ChadTough Foundation and am truly thankful for the opportunity.



Mission Statement

The mission of The ChadTough Foundation is to fund research and raise awareness for Pediatric Brain Tumors with an emphasis on diffuse intrinsic pontine glioma (DIPG).

Board of Directors

Michael Ben
Jason Carr
Tammi Carr
Randy Glick
Sarah Harbaugh
Shani Inge
Board Member Emeritus - Lloyd Carr

Advisory Board

Brian Bird
Matt Friedman
Greg Hacias
Carl Koschmann
Dave Latcha
Dave Robertson
Neil Weissman

Staff

Jason Carr, President
Ann Friedholm, Executive Director
Amy Lepore, Director of Fundraising
Kristina Behncke, Director of Stewardship
Lesley Hundley, Director of Operations
Chrissie Wywrot, Director of Communications

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Designed by Marji Wisniewski at Blue Zebra Marketing Solutions

A LETTER FROM JASON & TAMMI CARR

Thank you....the most important thing we can say to all of you. Thank you for every hour volunteered, thank you for every dollar donated, and thank you for every conversation that adds another member to our ChadTough family. Each of you is like a pebble, and the huge ripple effect of this group of supporters is why there is now hope when it comes to DIPG. You are the reason why our little boy's name will never be forgotten and why one day there will be a cure for this monster of a disease. All of the impact that this foundation is making, that is only possible because of the commitment and passion of all of you.

Losing a child is one of the most difficult things that anyone can ever go through. The pain never goes away, and every day is a struggle. But you, our ChadTough family, have helped to dull that pain. You are helping to ensure that the loss of our precious little boy is not in vain, and your efforts are ensuring that children down the road will have a treatment plan and ultimately a cure.

So when you volunteer, or donate, or advocate...please think about that ripple. Please know that you are part of a much bigger mission and think about those families down the road who will not have to go through what we did because of this foundation. That is an incredible legacy, and we are grateful to each and every one of you for helping us to honor our boy. One day, we will be having a huge party celebrating what we have all accomplished together!

Thank you for sticking with us from day one. We are forever grateful.

The Carr Family:
Tommy, Tammi, Jason,
Chad, CJ & Tootie



BOARD UPDATE

We are excited to announce that Shani Inge, Chad's Godmother, and Michael Ben, current foundation advisor, recently joined The ChadTough Foundation's Board of Directors.

"Chad's legacy is extremely important to me," said Shani, "I look forward to continue spreading awareness and raising research money for DIPG in my new role."

"The ChadTough Foundation has inspired my family and countless others to join the Carr family in honoring Chad's legacy and all other children who have battled DIPG. I will continue to advocate for all of our children until we can find a cure." said Michael.

THANK YOU FOR BEING CHADTOUGH!

When you go up against the worst, you help find a cure for the rest.

Because of YOU:

**\$7+
Million**

Raised since 2015

Because of YOU:

**\$2.2
Million**

Research grants
funded in 2018

Because of YOU:



Hospitals in
North America
participate in DIPG-specific
research funded by
The ChadTough Foundation

How YOU
MAKE A
DIFFERENCE –
THANK YOU!

What can one person do?



Change the world.

VOLUNTEERING

We are grateful for you. Thank you for your time, energy, and dedication.
We are 400+ volunteers strong!

PARTICIPATING

Thousands have attended our events. Thank you for being there.
All 50 states were represented in RunTough for ChadTough through our virtual run.

SPONSORING

Thank you for covering expenses, maximizing dollars for research.
Only 4% of our total raised goes to administrative costs.

FUNDRAISING

Events organized by you raised nearly \$600,000 in 2018. Thank you for baking, bracelet making, swimming, golfing, and so much more!

DONATING

We are thankful for your unwavering generosity. Your gifts have helped us fund research across North America.

BEING A CHADTOUGH CHAMPION

Thank you for being our warriors and continuing to spread Chad's story every day.

Have you seen our public announcements on TV? Thank you to Comcast Spotlight for its unbelievably generous donation to help spread awareness of our mission.



CHADTOUGH GRANTS

Your generous support funded grants totaling over \$2,200,000 in 2018. Through an objective medical advisory group, The ChadTough Foundation has funded researchers at the front of DIPG research. Finding a cure for the deadliest will help to find a cure for other pediatric brain cancer.

FELLOWSHIP GRANT

The Defeat DIPG ChadTough Fellowship Grant is intended to attract and support promising scientists embarking on careers involving DIPG research. By providing funding to outstanding postdoctoral fellows under the guidance of a mentor, The ChadTough Foundation seeks to assist in the development of the next generation of leaders in the field of DIPG research.

NEW INVESTIGATOR GRANT

The Defeat DIPG ChadTough New Investigator Grant provides two years of funding to a new DIPG investigator for hypothesis-driven research projects.

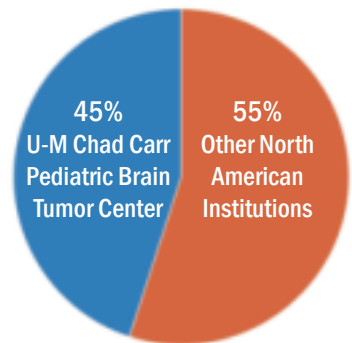
RESEARCH GRANT

The Defeat DIPG ChadTough Research Grant provides three years of funding for hypothesis-driven research projects. The proposed research must represent an innovative approach to a major challenge in DIPG research. The funded projects must have the potential to lead to groundbreaking discoveries in the field and to transform our understanding of the tumorigenesis process or our ability to treat or detect DIPG.

SPECIAL GRANT

The Defeat DIPG ChadTough Special Grant is awarded to a lab working with projects involving DIPG. This award goes to a lab to use at their discretion for DIPG research.

Grant Funding Distribution



GRANT PARTNERSHIPS

PARTNERSHIP WITH MICHAEL MOSIER DEFEAT DIPG

The ChadTough Foundation and Michael Mosier Defeat DIPG Foundation have partnered to fund five diffuse intrinsic pontine glioma (DIPG) - specific research projects over the next three years (2018 - 2020) totaling \$1,600,000, with each foundation committing \$800,000.

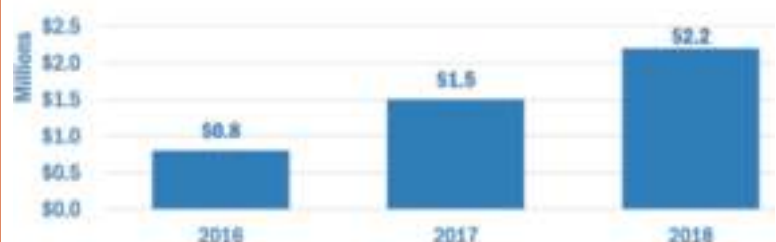
The Carr and Mosier families originally connected in the months following their sons being diagnosed with DIPG in September 2014. They quickly uncovered their shared passion for honoring their sons through raising research dollars.

The grants (including one fellowship grant, two research grants and four new investigator grants) are awarded to scientists conducting research at prominent institutions across North America. They are chosen by an objective medical advisory group. The projects range from research on novel immunotherapy treatments for children with DIPG to exploration of key questions about the fundamental biology of the disease.

PARTNERSHIP WITH DIPG COLLABORATIVE

The DIPG Collaborative is made up of family foundations representing children fighting or who have passed away from DIPG. With guidance from a medical advisory group, each family within the collaborative gives money to the general pool and then votes on which grant requests will receive funding. So far, the Collaborative has funded nearly \$8,000,000 in DIPG research.

Grant Funding History



RESEARCHERS MAKING A DIFFERENCE

Brilliant researchers are working together to find a cure, but we aren't there yet. With your help, one day there will be a cure. The survival rate will no longer be 0%.

Concentrated research on rare brain tumors like DIPG has the potential to open up new avenues of treatment not just for children with brain tumors, but also for other childhood and adult cancers. What doctors uncover about DIPG and other high-grade gliomas will shed light on the genetic defects and cellular behavior of all cancers.

CHADTOUGH-FUNDED RESEARCHERS



Dr. Cynthia Hawkins
Special Grant
The Hospital for Sick Children,
Toronto



Dr. Carl Koschmann
Research Grant
Chad Carr Pediatric Brain
Tumor Center,
Michigan Medicine



Dr. Mark Souweidane
Special Grant
Children's Brain Tumor Project,
Memorial Sloan Kettering



Dr. Sriram Venneti
Research Grant
Chad Carr Pediatric Brain
Tumor Center
Michigan Medicine

PARTNERSHIP WITH MICHAEL MOSIER DEFEAT DIPG FOUNDATION FUNDED RESEARCHERS



Dr. Sameer Agnihotri
New Investigator Grant
University of Pittsburgh



Dr. Stephanie Galban
New Investigator Grant
Chad Carr Pediatric Brain
Tumor Center
Michigan Medicine



Dr. Nneka Mbah
Fellowship Grant
Chad Carr Pediatric Brain
Tumor Center
Michigan Medicine



Dr. Nicholas Vitanza
New Investigator Grant
Fred Hutchinson Cancer
Research Center



Dr. Sujatha Venkataraman
New Investigator Grant
Children's Hospital Colorado



Dr. Pratiti Bandopadhyay
New Investigator Grant
Dana-Farber Institute



Dr. Nalin Gupta
Research Grant
University of California
San Francisco



Dr. Daniel Lim
Research Grant
University of California
San Francisco

THE FACTS:

DIPG

Diffuse intrinsic pontine glioma is an aggressive and debilitating cancer of the brain stem.

0% DIPG Survival Rate

DIPG most commonly strikes kids between the ages of

5 - 9 years old.

Brain tumors are the leading cause of cancer-related deaths in children under the age of 10.

9 and 90%

The average survival rate from diagnosis is 9 months. 90% of kids will die within two years of a DIPG diagnosis.

Source: Dana-Farber/Boston Children's Cancer and Blood Disorders Center, Tribune News Service

WHY DIPG RESEARCH?

The ChadTough Foundation believes that every child deserves to survive cancer. Through our donors, sponsors, fundraisers, participants, and volunteers, we are raising money and funding research to make sure that one day every child will be able to survive.

The statistics are overwhelming. Nearly 100,000 children worldwide are expected to die from cancer this year, most likely from a brain tumor.

About 1 in 400 children will be diagnosed with cancer before the age of 15.

The type will most likely be leukemia or a brain tumor.

If it's leukemia, the child has a 90% chance of surviving.

If it's a brain tumor, the child has a 75% chance of surviving.

If it's the brain tumor called diffuse intrinsic pontine glioma (DIPG), the child has a 0% chance of surviving.

WE HAVE HOPE. Previously "impossible" cures have been found. In the last two generations, leukemia has gone from 0% survival to an almost 90% cure rate. DIPG remains uniformly lethal – but the cure can be found with the right amount of research support.

Advancements in understanding DIPG have exploded over the past 4 years driven by availability of tissue. Families began to donate tumors postmortem, then researchers discovered how to safely biopsy DIPG tumors in early-diagnosed patients. Funding from private foundations and media coverage has been climbing, attracting more and more researchers to the field. Doctors now believe a cure will be found in our lifetime.

But why focus on curing such a rare disease?

- Understanding a disease as complex as DIPG will uncover treatments and cures for less complex types.
- 300-400 children per year are being diagnosed with DIPG and currently none will survive.

The 0% survival rate for DIPG is about to change. Thank you for being part of our team!

STRATEGIES FOR SUCCESS



1
Raise awareness of DIPG
and of progress toward a cure

2
Inspire & support
game-changing research

3
Secure funding for
research and awareness efforts

CHAD CARR PEDIATRIC BRAIN TUMOR CENTER

This past year, with the raising of \$30 million in gifts, the Pediatric Brain Tumor Research Initiative at Michigan Medicine was officially renamed the Chad Carr Pediatric Brain Tumor Center (CC-PBTC).

Since Chad was diagnosed with DIPG in 2014, Jason and Tammi have been vocal about the need for a cure, attracting other DIPG families to look for answers at Michigan Medicine. The result has been Michigan Medicine taking a more vested interest in DIPG, becoming one of the top places in the United States to seek treatment.

"In the last two years, each year we've seen an incremental jump in the number of patients with DIPG coming to U-M to receive their care," said pediatric neuro-oncologist Carl Koschmann. "A lot of that has been referrals from patients who otherwise wouldn't have gotten their care here."

In 2018, Michigan Medicine hired Alyssa Paul as Clinical Subjects Coordinator, a position fully funded by ChadTough. Alyssa's primary responsibility is to coordinate clinical research involving pediatric brain tumors being treated at U-M for the next five years. In addition to seeing more patients, Michigan Medicine has also led three clinical trials and participated in five multi-institutional trials for children with DIPG and other high-risk pediatric brain tumors.

The CC-PBTC has seen a 300% increase in new pediatric brain tumor referrals in the last 6 months, with patients traveling from San Francisco, Idaho, Nebraska, and Philadelphia for clinical trials as well as for unique clinical expertise and clinical research.



OUR PARTNER FAMILIES

THE RUDDY FAMILY & THE BOIVIN FAMILY

The ChadTough Foundation has announced a new partner family. Joining Tom, Amanda, and Isabella Ruddy (Team Tommy) are Brad, Nettie, Mirabelle, and Bastian Boivin. Julian passed away on July 3, 2011 after a six-month battle with DIPG. The Boivin family (Team Julian) has chosen to dissolve their Courage for Cures nonprofit (established in 2010) and direct all funds to The ChadTough Foundation.

"We're all working toward the same goal, we're only 45 minutes away from each other, and we're funding many of the same projects, especially at Michigan Medicine," said Nettie. "The Carr family and The ChadTough Foundation have been so generous and thoughtful in honoring Julian within their events, it just made sense to officially join forces and fold our efforts into their larger organization and broader reach."

The Ruddys have been a ChadTough partner family since shortly after their son, Tommy, passed away on November 3, 2016. Now, two years into honoring Tommy, Amanda and Tom believe they have found their fundraising niche within their local community of Grand Rapids, Mich. "This is a huge running community," said Amanda. Many Grand Rapids locals have raised money for The ChadTough Foundation by participating in races such as marathons and triathlons. Since Tom took up running as an outlet for his grief, it is a perfect fit. "He was completely swept up by the culture," said Amanda. "He ran the 2018 Chicago Marathon to honor Tommy and support ChadTough, as did other friends and neighbors of ours. He will be running the marathon again this year."

The ChadTough Foundation is honored to have both the Ruddys and the Boivins as partners and looks forward to seeing the impact we can make together.



Julian with his parents,
Brad & Nettie Boivin



Amanda, Isabella,
Tommy & Tom Ruddy

CHADTOUGH PARTNERS

Thank you to **The Alvin L. Glick Foundation**, **The Jones Family Foundation**, **The M Den**, and **Michigan Fuels** for being part of The ChadTough Foundation's Partnership Program.

Founded out of a desire to ensure that **100%** of donations go to diffuse intrinsic pontine glioma (DIPG) research, companies and foundations choose to be ChadTough Partners by committing a minimum of \$50,000 per year with 30% earmarked for operating expenses.

No organization operates without expenses, but it is important to The ChadTough Foundation that all of our general donations go to research - that is why people donate. These businesses are allowing us to do that. We are thankful to have them as our partners.



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EVENTS BY YOU TO SUPPORT CHADTOUGH

Events hosted by YOU have raised over \$1,500,000 for The ChadTough Foundation! We are thankful to benefit from community events hosted by individuals. These events have included school fundraisers, sporting events, swim-a-thons, garage sales, Facebook fundraisers, golf outings, and lemonade stands. There are so many possibilities! The funds you raise further our mission of finding a cure. If you are interested in hosting an event for The ChadTough Foundation, please contact Amy Lepore at amy@chadtough.org.



SAVE THE DATE

Upcoming Events Benefiting The ChadTough Foundation



February 22
March 4 - 10
March 7
March 9
May 18
June 24
June 28
June 29 - 30
July 12 - 14
July 24
August 8
August 12
August 17
August 19
September 28

Plymouth Comedy Night
ChadTough Week at The Grotto
Dancing with the Michigan Stars
ChadTough Block Out DIPG
Champions for Change Gala
Tee'd Off Golf Event
Oak Pointe Charity Classic Golf Event
The ChadTough Softball Tournament
Trackside Baseball Tournament
Walnut Creek Doe Day
Whitecaps Game
Coach Carr Classic
Brandon Inge's Dingers for DIPG
UM Club of Greater Detroit Golf Event
RunTough for ChadTough & RunTough for Team Tommy



To learn more about these events
visit chadtough.org/events