

BEING TOUGH FOR CHAD TOUGH



2019 IMPACT REPORT



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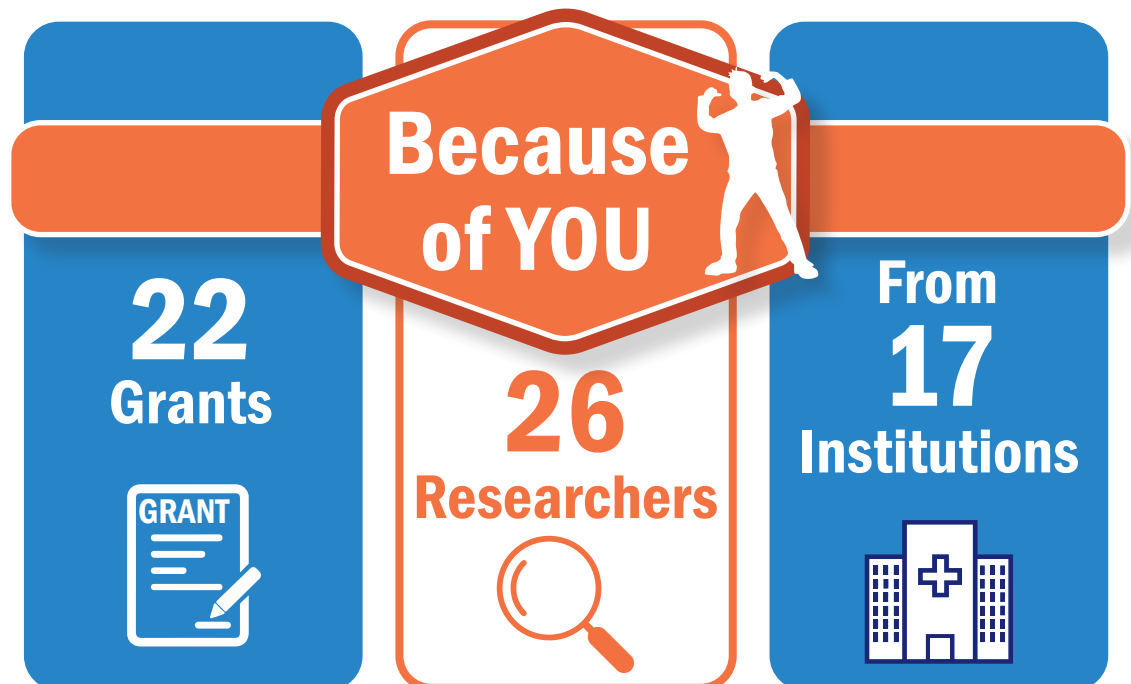
FUNDING TO FIND A CURE

**BECAUSE OF YOU, WE ARE ONE STEP CLOSER TO A CURE
FOR PEDIATRIC BRAIN CANCER**

ChadTough supporters helped raise over \$3 million in 2019, bringing the total raised since The ChadTough Foundation was founded to over \$10 million!

Your generosity and support make it possible for us to fund research that will one day find a cure. We keep moving forward to honor Chad, Tommy, Julian, Colt, Carter, Benjamin, and the other DIPG angels. Thank you!

In 2019, we committed to funding:





A LETTER FROM JASON & TAMMI CARR

Another year has passed, and we continue to be amazed with what becomes possible when people come together. When we started this foundation five years ago, we never imagined it would grow into what it has become. That has happened because of you, our supporters. Whether you have donated, sponsored, volunteered, fundraised, or attended an event, you have been a part of creating true, lasting change.

When Chad was diagnosed in 2014, we were given no hope. We could not accept that. We turned to you and asked for prayer. So many of you responded to that request. We were praying for a miracle. Although the miracle we wanted was not realized, we do feel Chad is at the center of a miracle in the making.

Change is happening, and it's gaining momentum. In a matter of just five years, doctors have evolved from hopeless to hopeful, believing a cure for DIPG will be found in our lifetime. That is significant. That is a miracle! And that is only possible because foundations like ours are funding DIPG research at a significantly increasing rate. This funding has attracted new researchers to the field of DIPG. It has served as seed money that has led to bigger federal grants. It has enabled the purchase of more advanced technology to study the disease.

Our vision is to ensure that DIPG is no longer a death sentence. We are on our way to realizing that vision...because of YOU. On behalf of our family and our partner families, we thank you for your continued commitment to our cause. The day is coming when we can celebrate the first survivor of DIPG. When that time arrives, we will know it happened because of supporters like you.

With appreciation,



Tammi and Chad



Chrislan and
Warde Manuel

Mission Statement

The mission of The ChadTough Foundation is to inspire and fund game-changing research to discover effective treatments for pediatric brain cancer, with an emphasis on Diffuse Intrinsic Pontine Glioma (DIPG).

Board of Directors

Michael Ben
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Tammi Carr
Randy Glick
Sarah Harbaugh
Shani Inge
Chrislan Fuller Manuel
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Lloyd Carr

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Amy Lepore - Director of Events
Elizabeth Guzik - Special Projects

*Designed by Marji Wisniewski
at Blue Zebra Marketing Solutions*

BOARD UPDATE

WELCOME CHRISLAN FULLER MANUEL, OUR NEWEST BOARD MEMBER

Chrislan worked in the health industry for 18 years before becoming a full-time visual artist. She has been involved in many different aspects of ChadTough including co-chairing, along with her husband, Warde, the 2018 Champions for Change Gala. We are so excited to have her join us as a ChadTough board member!

"I'm honored to join the Carr family and the entire foundation team in the fight to defeat DIPG and pediatric brain cancer. Together we will continue to make strides towards finding a cure." - Chrislan Manuel

WHEN YOU GO UP AGAINST THE WORST,
YOU HELP FIND A CURE FOR THE REST.

EMERSON'S JOURNEY

THE CLINICAL TRIAL THAT IS ALLOWING HER TO JUST BE A KID

Ami Hoogendoorn is mom to Emerson, an 8-year-old little girl with Diffuse Midline Glioma, a brain tumor similar to DIPG. Instead of ending her year of kindergarten happy and healthy, Emerson slept for hours on end, was plagued with headaches, and eventually told her mom she was “seeing two of things.” At just 6 years old, Emerson and her family received the devastating news: Emerson had a tumor that was putting so much pressure on her brain that her spinal fluid couldn’t drain and her life was in danger.



Emerson, age 8

The days that followed Emerson’s diagnosis at Helen DeVos Children’s Hospital in Grand Rapids, MI, contained a series of doctors, massive surgeries, and treatment. Emerson went through two brain surgeries and several months of chemo and radiation before she qualified for an experimental trial of a drug called ONC 201. Ami says, “ONC 201 has allowed Emerson to live as normally as possible. She doesn’t look like a little girl fighting something so horrible. She can go to school every day, participate in her hip-hop classes and piano lessons. Without the trial, her journey would have been significantly altered.”

• • •

The Hoogendoorns had heard of The ChadTough Foundation for years. But when they began this trial, they realized what an instrumental role the foundation had played in providing the awareness and funds that made this trial available to Emerson. Ami and Emerson even traveled to Washington, D.C., to testify to the FDA on behalf of this trial and to tell about the opportunity and life it has given to Emerson. Now the Hoogendoorns are on another mission. They are raising money for pediatric cancer research for The ChadTough Foundation, which is the very same organization that helped fund the experimental treatment they credit for saving Emerson’s life.



Dr. Carl Koschmann,
Michigan Medicine

*“After decades of little to no progress, researchers are now making new discoveries almost on a monthly basis. Government funding for pediatric cancer is still minuscule, so the majority of the funds for research are now coming from family foundations like ChadTough,” said Dr. Koschmann. “It’s a very different model of research. If you talk to the researchers in my lab, they know we’re in direct communication with the families, and it drives them. **They work harder, they stay longer.**”*

CHADTOUGH GRANTS

Your generous support helped fund 22 grants in 2019. The ChadTough Foundation awards grants to researchers at the forefront of DIPG research. Focusing on a cure for the most complex version will also help to find a cure for other pediatric brain cancers.

FELLOWSHIP GRANT: 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: Funding newly independent DIPG researchers in establishing new DIPG research labs – OR – funding established researchers (who have not previously conducted brain tumor research) to encourage them to start DIPG research.

RESEARCH GRANT: Supporting the work of existing DIPG researchers by providing funding for hypothesis-driven research projects. The proposed research must represent an innovative approach to a major challenge in DIPG research.

SPECIAL GRANT: Providing funding to a lab working with projects involving DIPG to use at their discretion for DIPG research.

GRANT PARTNERSHIPS

Through partnerships with other like-minded foundations, The ChadTough Foundation is able to take your support and stretch it even further. *TOGETHER WE ARE TOUGHER!*

MICHAEL MOSIER DEFEAT DIPG

The ChadTough Foundation and Michael Mosier Defeat DIPG Foundation partnered together in 2019 to fund 10 new DIPG research projects for the next three years totaling \$2.8 million, with two of the grants made in partnership with the SoSo Strong Pediatric Brain Tumor Foundation. All of the grants are multiyear grants, allowing researchers to spend more of their time in the lab and less time seeking additional funding for future years. The Carr and Mosier families originally connected in the months following their sons being diagnosed with DIPG. ChadTough and Defeat DIPG have funded together a total of \$6.7 million in DIPG research since 2016.



Michael Mosier



DIPG COLLABORATIVE

The DIPG Collaborative is made up of over 20 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. The ChadTough Foundation has given over \$400,000 to the Collaborative's nearly \$8 million in DIPG research.



ALEX'S LEMONADE STAND FOUNDATION

The ChadTough Foundation has partnered with Alex's Lemonade Stand Foundation (ALSF) to support research in DIPG. ChadTough and Alex's Lemonade Stand share a vision of funding childhood cancer research to ultimately find cures for all children with cancer. ChadTough funded \$50,000 in partnership with ALSF in 2019.



RESEARCHERS MAKING A DIFFERENCE

Because only 4% of all federally funded cancer research dollars are allocated to all pediatric cancers combined, researchers are dependent on private foundations like The ChadTough Foundation. Below are researchers who currently are funded by ChadTough.

CHADTOUGH-FUNDED RESEARCHERS

Baylor

Stephen Mack*

Boston Children's Hospital

Alan Jiao with Yang Shi*

Columbia University

Xu Zhang with Zhiguo Zhang*

Dana-Farber Cancer Institute

Daphne Haas-Kogan*

Eshini Panditharatna

with Mariella Filbin*

Pratiti Bandopadhyay*

Duke College

Zachary Reitman*

Fred Hutchinson Cancer Research Center

Nicholas Vitanza*

Hospital for Sick Children (Toronto)

Cynthia Hawkins

The Johns Hopkins University School of Medicine

Eric H Raabe**

The Regents of the University of California

Nalin Gupta and Daniel Lim*

University of California Davis

Wolf-Dietrich Heyer**

University of Colorado Denver

Sujatha Venkataraman*

*In partnership with Michael Mosier Defeat DIPG Foundation

**In partnership with Alex's Lemonade Stand Foundation

University of Michigan

Chan Chung*

Stefanie Galban*

Nneka Mbah*

Sriram Venneti

University of New Castle (Australia)

Matthew Dun*

University of Pittsburgh

Sameer Agnihotri*

University of San Francisco

Hideho Okada*

University of Vermont

James Stafford*

Weill Cornell Medical College

Mark Souweidane

RESEARCHER UPDATE

DR. MICHELLE MONJE

Dr. Michelle Monje is a pediatric neuro-oncologist at Stanford University in California and one of the world's top researchers in the study of high-grade gliomas. Dr. Monje is a 2017 and 2018 Research Grant recipient of the joint collaboration between The ChadTough Foundation and Defeat DIPG. An article regarding her research appeared in the September 2019 issue of the research journal *Nature*.



"In the past five years, a number of laboratory studies on DIPG have identified new promising treatment for DIPG, from immunotherapy to novel drugs targeting epigenetic, metabolic, and microenvironmental vulnerabilities of DIPG. Several new clinical trials based on these laboratory studies are now opening.

We know more about the biology of DIPG than ever before, and soon that new knowledge may lead to effective therapy." - Dr. Michelle Monje

WHY WE FIGHT

THE FACTS ABOUT DIPG

- 0% survival rate - for now.
- Most commonly strikes children between 5 and 7 years old.
- Brain tumors are the leading cause of cancer-related deaths in children.
- DIPG is responsible for 15% of all pediatric cancer deaths each year.



CHAD CARR PEDIATRIC BRAIN TUMOR CENTER

TWO DIPG-SPECIFIC GRANTS AWARDED BY THE NATIONAL INSTITUTE OF HEALTH

Because of YOU, The ChadTough Foundation is funding researchers at the Chad Carr Pediatric Brain Tumor Center at Michigan Medicine who are fueling innovative research and delivering new therapies for children with brain cancer.

Two DIPG-specific grants were awarded by the National Institute of Health (NIH) last year. The success rate of applicants applying for grant money from NIH hovers around 19%. That means out of 51,000 applicants, only 9,690 would be awarded funding, making this an incredibly competitive grant.

Husband and wife duo Dr. Pedro Lowenstein and Dr. Maria Castro, both of Michigan Medicine, received the first ever DIPG-specific grant early last year.

Dr. Lowenstein and Dr. Castro will implement an innovative gene therapy on mice in an attempt to find a treatment for DIPG. The therapy stimulates a patient's own immune system to kill brain tumor cells. Drs. Castro and Lowenstein credit The ChadTough Foundation for the initial seed money needed to collect critical data important for grant consideration.

Later in the year, Dr. Sriram Venneti of Michigan Medicine also received a grant from the National Institute of Health. The hope of finding a cure for DIPG continues to grow.

In 2018, Dr. Venneti was one of the first researchers at the Chad Carr Pediatric Brain Tumor Center to receive a grant from The ChadTough Foundation. He is a physician-scientist whose lab works on understanding the biology of DIPG in order to develop a cure. Dr. Venneti's grant explores how DIPG cells need specific nutrients for their survival. His goal is to develop a drug that will kill DIPG cancer cells.

"Receiving this grant would not have been possible without the early support from The ChadTough Foundation that enabled us the ability to gather the data necessary to strengthen our grant application," said Dr. Venneti.



CHAD CARR PEDIATRIC
BRAIN TUMOR CENTER
MICHIGAN MEDICINE



Dr. Maria Castro & Dr. Pedro Lowenstein (top)
and Dr. Sriram Venneti (bottom)

AN INVITATION FOR COLLABORATION

In summer of 2019, **Pacific Pediatric Neuro-Oncology Consortium (PNOC)** invited the Chad Carr Pediatric Brain Tumor Center at Michigan Medicine to join their consortium of 18 of the world's top childhood cancer centers, all pushing to cure brain tumors in children.

While brain cancer is the deadliest form of childhood cancer, only three cancer drugs have been approved for use in children since 1980, and pediatric brain cancer only receives 1% of federal research funding. PNOC is dedicated to bringing new therapies to children and young adults with brain tumors by conducting trials more often and at a quicker pace, while sharing data in real time with other collaborating researchers from around the world. Michigan Medicine will join some of the world's leading pediatric cancer hospitals from the United States, Canada, Europe, and Australia.

Late last year, The ChadTough Foundation and Michael Mosier Defeat DIPG Foundation committed to fund an innovative collaboration through PNOC and the DIPG Centre of Expertise in Zurich, supporting preclinical and clinical work across multiple institutions.



Pacific Pediatric
Neuro-Oncology
Consortium

PNOC Fast Facts

Mission:

To understand how brain tumors develop in children and identify personalized treatment strategies

Values:

Drive Innovation
Collaborate
Be Bold

Reach:

Brain Tumor Specialists from
Australia, Canada, Europe, and
United States

FAMILY PARTNERSHIPS



Tommy
The Ruddy
Family



Julian
The Boivin
Family



Colt
The DelVerne
Family



Carter
The Jones
Family



Benjamin
The Reinhold
Family

We are grateful for our partner families who have committed to help us raise funds to support our mission. Together, the Ruddy (Team Tommy), Boivin (Team Julian), DelVerne (Team Colt), Jones (Team Carter) and Reinhold (Team Benjamin) families are continuing to make an impact for The ChadTough Foundation in honor of their children who lost their lives to DIPG.

We are thankful to have them as family partners as we continue to work together to inspire and fund game-changing research.

“Being a partner family to The ChadTough Foundation has allowed us to channel our grief into something greater while honoring Tommy’s life and legacy. Through the like-minded efforts of the other partner families in the foundation, our impact has been **MORE POWERFUL TOGETHER.**” - Amanda Ruddy, Tommy’s mom



Amanda & Tommy Ruddy



Nettie & Julian Boivin



Shannon & Colt DelVerne



Connie & Carter Jones



Gina & Ben Reinhold

OFFICIAL CHADTOUGH PARTNERS

Thank you to **The Alvin L. Glick Foundation, Bose, The Jones Family Foundation, Latcha+Associates, The M Den, Michigan Fuels, The Sanger Family Foundation, and Red Effect** for being part of The ChadTough Foundation’s Partnership Program.

Founded out of a desire to **ensure that 100% of donations go to 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 organizations are allowing us to do that. We are thankful to have them as our partners.

THANK YOU!

YOU ARE MAKING A DIFFERENCE!

Volunteering | Participating | Sponsoring | Fundraising | Donating | Being a ChadTough Champion

EVENTS BY YOU!

TO SUPPORT CHADTOUGH



P.O. Box 907
Saline, MI 48176
www.chadtough.org

Events hosted by YOU have raised over \$2,100,000 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.

OVER A MILLION REASONS TO BE THANKFUL

The ChadTough Foundation hosted four major events in 2019, including our gala, our run, and several golf outings. These events raised over \$1.7 million to help fund research. We thank our sponsors, donors, partner families, partner businesses, volunteers, and participants who helped us surpass our goals.

A special thank you to John and Kathleen Beilein, who co-chaired the Champions for Change Gala in 2019. We are excited to announce Erik and Jiffy Bakich, and Brandon and Shani Inge as our co-chairs for the **Champions for Change Gala 2020 on May 16**.

Other 2020 ChadTough event dates are as follows:

- 6.15.20 Tee'd Off: Driving Out DIPG
- 7.27.20 Coach Carr Classic
- 9.26.20 RunTough for ChadTough

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

