

2021

ANNUAL REVIEW



TOGETHER WE WILL FIND A CURE

Founded by the families of Chad Carr and Michael Mosier to fund game-changing pediatric brain cancer research, with an emphasis on DIPG

 **\$16.6M**
FUNDED

 **45**
RESEARCHERS

 **28**
INSTITUTIONS



A MESSAGE FROM OUR FOUNDERS

Wow, what a year!

Although 2021 was full of uncertainties, we never wavered in our mission to Defeat DIPG, the deadliest pediatric brain cancer and the disease that robbed us of our children, Chad and Michael.

In January of last year, The ChadTough Foundation and Michael Mosier Defeat DIPG Foundation united to become the ChadTough Defeat DIPG Foundation. After collaborating for years as two of the leading foundations in the world of pediatric brain cancer research funding, we realized that, by formally coming together, we could amplify our impact on finding a cure for the leading cause of cancer-related deaths among children.

This past year proved that we are indeed TOUGHER TOGETHER as we achieved a record-breaking funding year, awarding an additional \$4.5 million in new research grant commitments, bringing our total to over \$16.6 million! It is truly exciting to see progress being made from the work we are supporting!

We know that it is because of your generous support 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 this annual review, you'll read exciting updates about the incredible projects we helped fund, inspiring stories of DIPG warriors, and more about our Family Partners from across the United States and Mexico who have joined us in our mission.

As the new ChadTough Defeat DIPG Foundation, we have more resolve than ever to continue to fund effective treatments for DIPG. We hope you'll continue to join us in our fight to #DefeatDIPG.



Jason Carr *Tammi Carr*

The Carr Family



Michael Mosier *Jenny R. Mosier*

The Mosier Family

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A FAMILY FINDS HOPE IN THE FACE OF DIPG

LONDYN BUSS IS TAKING ON CANCER ONE DAY AT A TIME

Londyn Buss has always danced to her own tune. Just a few months after her 12th birthday, the sweet, sassy girl from Nebraska was enjoying all the things preteen girls love: music, performing, and spending time with friends and family.

But in early May, she started having severe headaches and double vision. Her mom, Jessica, knew something was very wrong. However, nothing could have prepared her that day, on May 11, 2021, for her daughter's DIPG diagnosis.

"One thing my diagnosis has shown me is just how many people love me. I never realized that before this."

Londyn Buss, age 13

"The doctors told us there was no treatment, no cure, and no survivors for the aggressive, debilitating tumor inside Londyn's brain," said Jessica. "I had no words, and all hope was ripped out from under me."

After being told Londyn likely had just 9 months to live and the best thing to do was go home and make memories, Jessica left the hospital heartbroken, still knowing very little about the disease that threatened to rob her of her daughter.

"Giving up isn't Londyn's way," thought Jessica, "so I have to fight."

The single mom looked to the internet for help and found the hope she so desperately needed through other families who had walked her path before.

"These families took me under their wing and helped me get in touch with different doctors. Some of these families have children who are currently fighting, and some have already gone through the pain of losing their child," said Jessica. "The common thread among all of us is hope."

Londyn began radiation on May 17, which Jessica quickly learned was DIPG Awareness Day. What are the odds, she thought, that her daughter would start treatment for a disease very few people had ever heard of, on the one day meant to spread its awareness.

Now, 9 months into her diagnosis, Londyn is doing well and currently enrolled in the ONC201 clinical trial through Dr. Carl Koschmann of Michigan Medicine.

"It is always a pleasure when we have Londyn in our clinic," said Dr. Koschmann. "She is one of my funniest and most unedited patients. Her mom is amazing as well. She has never thought twice about traveling across many states in order to get Londyn treatment with our clinic."

ChadTough Defeat DIPG Foundation played an instrumental role in providing funds to make the ONC201 trial possible, which is the first of its kind to show promising results for high-grade gliomas. The drug, taken orally, works by killing cancer cells while leaving normal cells healthy. The Buss family is hopeful that the ONC201 trial will help Londyn until an ultimate cure is discovered.

"We aren't giving up, and we are here to help other Nebraska families who hear there is no hope for their child," said Jessica. "Even when faced with an unimaginable prognosis, these are our children, and we have to do better."



"Advancement in treatments due to ChadTough Defeat DIPG funded projects is providing HOPE and precious bonus months of memories until we find the ultimate cure."

Shannon DelVerne
ChadTough Defeat DIPG
Family Partner



BRAIN CANCER IS NOW THE LEADING CAUSE OF CANCER-RELATED DEATHS IN KIDS. DIPG IS RESPONSIBLE FOR NEARLY 50% OF THOSE DEATHS.

RECORD-BREAKING FUNDING YEAR

\$4.5M IN NEW RESEARCH GRANT COMMITMENTS IN 2021

In early 2021, The ChadTough Foundation and Michael Mosier Defeat DIPG Foundation united to become the ChadTough Defeat DIPG Foundation. With this powerful alliance came a record-breaking funding year, with the foundation granting nearly \$4.5 million to DIPG research. This brings the total amount funded over the last 5 years to more than \$16.6 million across 28 institutions around the world.

MAKING EVERY DOLLAR COUNT

The ChadTough Defeat DIPG Scientific Advisory Council, made up of leading experts on childhood brain cancer, serves as a critical guide in ensuring that the research funded by our foundation is based on sound science and is incremental to research already being conducted. Our formal 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. We also support Special Projects that show great promise but fall outside the grant program guidelines.

“The result of this uniquely designed granting process is that a broader range of new and innovative ideas can be pursued by outstanding scientists at different stages of their research careers.”

*Dr. Suzanne Baker
ChadTough Defeat DIPG Scientific
Advisory Council Chair*

DMG-ACT

The Diffuse Midline Glioma - Adaptive Combinatorial Therapy (DMG-ACT), a collaboration through the Pacific Pediatric Neuro-Oncology Consortium (PNOC) and the DIPG Centre of Expertise in Zurich, is a biology-informed, adaptive, and progressive trial, designed to deliver more rapid progress for



“Simply put, the DMG-ACT would not have been possible without the support of the ChadTough Defeat DIPG Foundation. For those of us involved, we feel this will finally provide the jumps in improved survival for DMG that was seen in leukemia 40 to 50 years ago,”

*Dr. Carl Koschmann
Michigan Medicine*

children suffering from DMG. This year, ChadTough Defeat DIPG awarded over \$500,000 for the second year of the DMG-ACT, bringing the total amount funded for this trial to over \$1.3 million.

CAR T-CELL THERAPY FELLOW

CAR T-cell therapy is a revolutionary process in cancer treatment that genetically alters a patient's own T-cells to attack cancer cells. In 2021, recognizing the emerging gap in support for new clinical trials, the ChadTough Defeat DIPG Foundation awarded a grant to Dr. Michelle Monje of Stanford University, allowing her to employ a clinical fellow, Dr. Jasia Mahdi, to assist in her CAR T-cell clinical trial. The results of the trial have been very promising, with most patients seeing dramatic tumor reductions, making this one of the most exciting, sought-after DIPG trials going today. This fellowship enables more patients to be treated now, and also develops expertise in the next generation of clinicians, helping ensure broader availability of promising clinical programs in the future.



“It has been landscape shifting for me, for the [CAR-T] program, to have this consistent, additional support. My hope is that, each year, as we train new fellows, we’re able to disseminate this knowledge and this skillset to help bring these kinds of programs on board across the country and internationally.”

*Dr. Michelle Monje
Stanford University*

HOPE IN THE FACE OF TRAGEDY

DR. MATT DUN CONTINUES QUEST FOR A CURE AFTER LOSS OF DAUGHTER

When his 2-year-old daughter, Josie, was diagnosed with diffuse intrinsic pontine glioma (DIPG) in 2018, New Zealand cancer researcher Dr. Matthew Dun did everything in his power to save her.

Struck by the stark lack of scientific knowledge and treatment options for the deadly disease that was robbing him of his daughter, Dr. Dun channeled all of his efforts into saving Josie.

He immediately reached out to leaders in the field of pediatric brain cancer, such as Dr. Michelle Monje of Stanford University, and set out to learn everything he could about the aggressive and complicated tumor.

“Working in my own lab, using a hypothesis-based approach, I knew that we needed to sequence the cells, compare them to other cells, then determine what drugs might be used to change the natural course of the disease,” explained Dr. Dun.

A Race Against Time

After sequencing Josie’s tumor, allowing him to identify the genetic mutation of the cells, Dr. Dun began investigating a new, nontoxic drug called GDC-0084. He began working day and night, conducting rigorous experiments that combined GDC-0084 with another cancer-fighting drug, ONC201. This work would ultimately buy Josie an entire year of time.



Loss and Discoveries

Josie fought DIPG for 22 months, exceeding her life expectancy upon diagnosis by more than a year, before she passed away on December 14, 2019.

“Many will never understand the lengths Matt went to to give our girl every possible opportunity to beat this cancer,” said Josie’s mom, Dr. Phoebe Dun. “By night, he was researching and executing plan B, C, D, E, F, and G, trying to keep one step ahead of the enemy, despite knowing—deep down—he was fighting a losing battle.”

The day before Josie’s funeral, Dr. Dun received a call from The ChadTough Foundation and Michael Mosier Defeat DIPG Foundation (now united as the ChadTough Defeat DIPG Foundation) with news that he had received a New Investigator Grant. Funding from the grant would allow him to continue the cutting-edge research he started while Josie was sick.

The Future of DIPG

Navigating through tremendous heartbreak, Dr. Dun continues to channel his grief toward finding more effective treatments for future kids like Josie.

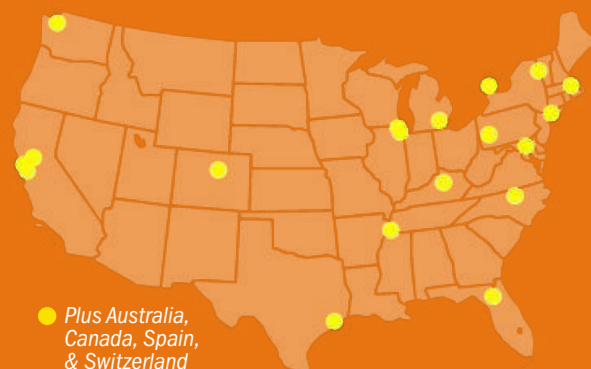
“This disease is such a devastating and horrific journey,” said Dr. Dun. “My gratitude goes out to families such as the Carrs and the Mosiers, who have had the courage to fight for the next generation of kids. Our research is where it is today because of the support of these families and private foundations like ChadTough.”

To read more about game-changing research we are funding, visit www.chadtough.org/research



WE'VE AWARDED MORE THAN \$16.6 MILLION IN GRANTS TO 28 INSTITUTIONS AROUND THE WORLD TO FUND PROMISING PEDIATRIC BRAIN CANCER RESEARCH

Baylor College · Boston Children'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 · Stanford University · St. Jude Children's Research Hospital · University Children's Hospital Zurich · University of California Davis · 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 Pittsburgh · University of Vermont · Weill Cornell Medical Hospital



2021 HIGHLIGHTS



SUPERHERO SPRINT & 6K

2,734 participants
\$288,178 raised



TEE'D OFF GOLF OUTING

132 participants
\$44,676 raised



CHICAGO GOLF OUTING

112 participants
\$107,535 raised



COACH CARR CLASSIC GOLF OUTING

188 participants
\$301,174 raised



RUNTOUGH 5K & 1M FUN RUN

2,229 participants
\$401,105 raised

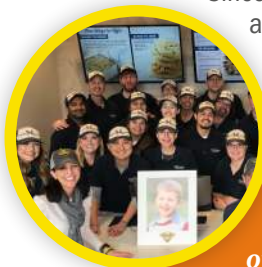
\$900,000 RAISED: BIGGEST #GIVINGTUESDAY EVER!

On November 30, 2021, the whole world united in a celebration of generosity for the #GivingTuesday movement. ChadTough Defeat DIPG supporters showed up in full force for our #Give2DefeatDIPG initiative, coming together to raise over **\$900,000**, more than doubling the amount raised the year prior! Huge thanks to all of the donors who together provided **\$425,000** in matching funds to help drive record-breaking donations for the day!

TIFF'S TREATS JOINS THE FIGHT

After hearing about Connor Olympia, a local boy who passed away from DIPG in 2015, Tiffany Taylor and Leon Chen knew right away they wanted to do something to help. The couple, co-founders of the cookie company Tiff's Treats, donated all the proceeds of their Woodland, Texas, location's grand opening to support the work Connor's parents were doing to raise funds for DIPG research.

Since then, Tiff's Treats has been a loyal supporter and in 2021 named the ChadTough Defeat DIPG Foundation as its first Corporate Charity Partner.



"The fact that DIPG is so underfunded makes us want to help make any impact at all on the future of this disease."

Tiffany Taylor
Co-founder of Tiff's Treats

WE ARE GRATEFUL FOR OUR PARTNERS

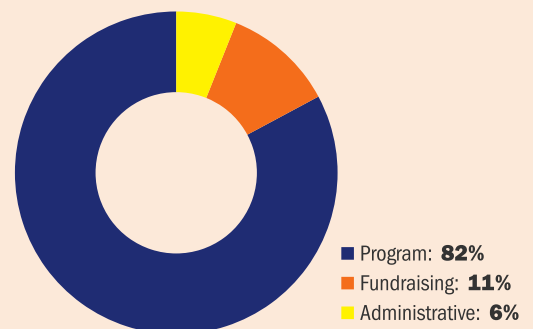
To our CureMaker and other special partners, we'd like to extend our deepest gratitude for your ongoing commitment to our mission.



Color Street • Covington & Burling LLP
Michael Kojaian • The Sanger Family Foundation
Sigma Financial • The Weiser Family

2020 AUDITED FINANCIALS

	MMDDF	CTF	COMBINED
Total Revenue	\$1,495,607	\$3,937,061	\$5,432,668
Total Expenses	\$933,079	\$1,906,496	\$2,839,575
Program	\$874,056	\$1,466,785	\$2,340,841
Fundraising	\$38,307	\$286,555	\$324,862
Administrative	\$20,716	\$153,156	\$173,872





IN HONOR OF OUR CHILDREN

WE ARE JOINED
BY FAMILIES
FROM 17 STATES
PLUS MEXICO IN
OUR QUEST TO
FIND A CURE.



Visit our website to learn
more about our Family
Partners.



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Kentucky



Austin
Michigan



Chika
Michigan



Colt
Ohio



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Texas



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Maryland



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Mexico



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Minnesota



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Utah



Hudson
Kansas



Hunter
Maine



Jack
Maryland



Julian
Michigan



Lucy
North Carolina



Luke
Maryland



Mattie
California



Olivia
Michigan



Owen
Illinois



Raegan
Florida



Sophie
Michigan



Tommy
Michigan



Vivian Rose
Washington



Vivienne
Connecticut

"You can't find a cure if you don't fund research. ChadTough is doing the research that we believe will bring us to the cure. We are tougher together and will continue to honor our daughter Vivienne's legacy by being in the fight."

*Mairead Finn
Vivienne's mom*



PO Box 907
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chadtough.org

2021 IMPACT REPORT

LOOK INSIDE TO SEE HOW YOUR
SUPPORT HAS MADE AN IMPACT
ON DIPG RESEARCH.

OUR MISSION

To inspire and fund game-changing
research to discover effective
treatments for pediatric brain cancer,
with an emphasis on diffuse intrinsic
pontine glioma (DIPG).

UPCOMING EVENTS



For a full list of 2022 events, visit our website at
www.chadtough.org/fundraising-events