

IF A CHILD'S LIFE WAS IN DANGER, YOU WOULD DO SOMETHING, WOULDN'T YOU?



Children's Brain
Tumor Project
powered by families



Weill Cornell
Medicine

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Pediatric Brain Tumor Research Initiative Carries Legacy Forward as Elizabeth's Hope Becomes the Children's Brain Tumor Project Foundation



Founders of Elizabeth's Hope, a nonprofit organization that funds pediatric brain tumor research at Weill Cornell Medicine, has announced a new name—the Children's Brain Tumor Project Foundation—as a reflection of its expanded mission. The new foundation will welcome the support of more patient families who have been impacted by a pediatric brain tumor diagnosis.

Elizabeth Minter created Elizabeth's Hope after she was diagnosed with a terminal brain tumor at the age of 19. That local fundraising initiative grew to become a certified nonprofit organization and the cornerstone for launching a pediatric brain tumor research laboratory called the Children's Brain Tumor Project (CBTP) at New York Presbyterian/Weill Cornell Medicine. At the time of her passing in 2012, Elizabeth couldn't have predicted just how important this endeavor would become, or how many other patient families would get involved in supporting the important research that is now underway at the lab.

Elizabeth's parents, Michael Minter and Emma Hill, have elected to change the name of the organization in order to support the growth of the lab and ensure the sustainability of Elizabeth's vision to cure kids with brain tumors. The new name and brand are closely aligned with the Children's Brain Tumor Project laboratory at Weill Cornell Medicine, which accurately demonstrates its mission to exclusively fund the lab.

"Elizabeth started something that aims to change the way children with brain tumors are treated in the future, but we can't do it alone," said Emmie. "I want the lab to continue to thrive and to make scientific contributions toward cures and better treatment options for children. The new brand is more inclusive of that vision."

The lab is led by Dr. Mark Souweidane, Vice Chairman, Department of Neurological Surgery, Director of Pediatric Neurosurgery, New York-Presbyterian/Weill Cornell Medicine, and Dr. Jeffrey Greenfield, Associate Professor of Neurological Surgery and Pediatrics, Vice Chairman of Academic Affairs, New York-Presbyterian/Weill Cornell Medicine.



The project started more than a decade ago with a couple of experiments at cluttered borrowed benches in other labs. It has since grown into a team of 20 neuroscientists and technicians who work in a dedicated lab space at Weill Cornell Medicine. The team has published more than 100 peer-reviewed articles and brought five clinical trials to fruition, bringing new treatment options to children in the clinic.

"Almost ninety percent of our research is funded by families and family-founded nonprofits who have been impacted by a pediatric brain tumor diagnosis, many of whom were my patients, including Elizabeth," said Dr. Greenfield. "That brings a tremendous sense of purpose, urgency, and accountability to our work."

The Fisher family is another one of those families. Kyle and Kelly Fisher lost their daughter, Allie, to gliomatosis cerebri, the same deadly tumor that claimed Elizabeth Minter's life. The Minters are thrilled to have them join the new board of directors, along with several others who have shown dedication to the cause.

"We have always shared this vision with the Minter family, and it brings us comfort to honor the memory of our daughter by teaming up with them and helping to lead this organization," said Kyle.

Moving forward, the Children's Brain Tumor Project Foundation remains committed to exclusively funding the groundbreaking research at Weill Cornell Medicine's Children's Brain Tumor Project. The two initiatives share the same single goal: to bring hope to children and their families who are confronted with the diagnosis of a rare and often incurable brain tumor.

For more information or to get involved with the Children's Brain Tumor Project Foundation, visit <http://cbtpfoundation.org> or email cbtpf@cbtpfoundation.org.

Follow them on Facebook @CBTPF



Research Findings Accepted for Presentation at Prestigious International Symposium on Pediatric Neuro-Oncology (ISPNO) in Hamburg, Germany

The Children's Brain Tumor Project (CBTP) will be well represented at the 20th International Symposium on Pediatric Neuro-Oncology (ISPNO), which is scheduled for June 12–15 in Hamburg, Germany. Dr. Mark Souweidane has been invited to deliver a plenary on the topic of "Augmented Drug Delivery for Pediatric Diffuse Midline Glioma using Convection Enhanced Delivery." All five abstracts submitted by the CBTP have been accepted, including:

- Long-term survival from a Phase 1 dose-escalation trial using convection-enhanced delivery (CED) of radioimmunotherapeutic ¹²⁴I-omburtamab for treatment of diffuse intrinsic pontine glioma (DIPG). (Souweidane et al.)
- Enhanced Efficacy of CDK4/6 Inhibitors via Long-term Exposure for Pediatric Central Nervous System Tumors and Development of an Intrathecal Delivery Platform in Preclinical Models (Guadix et al.)
- Durability of an Early Management Strategy Facilitating Endoscopic Removal of Recurrent Choroid Plexus Carcinoma (Guadix)
- Laser Interstitial Thermal Therapy as a Radiation-Sparing Approach for Patients with Underlying Cancer Predisposition (Guadix)
- Endoscopic Third Ventriculostomy (ETV) and Tumor Biopsy are Not Associated with Relapse Rate or Patterns in Primary Central Nervous System Germ Cell Tumors (Yan)

The ISPNO is the most prominent international scientific meeting for pediatric neuro-oncology. The bi-annual event hosts a global community of multi-disciplinary professionals involved in the scientific research, diagnosis, treatment, and rehabilitation of children with central nervous system (CNS) tumors. In December 2020, the ISPNO was held in Japan and incorporated a virtual option to accommodate all audiences during the pandemic. They will continue to offer a flexible hybrid meeting in Germany, as well, but the majority of participants are expected to attend in person.

"It is rare to have all abstracts accepted, and I am so proud of our team. It is an honor to have our work acknowledged at this prestigious event," said Dr. Mark Souweidane.

The program is known to include only the most cutting-edge preclinical and clinical research in neurosurgery, neuroradiology, neuropathology, biology, radiotherapy, pediatric neuro-oncology, immunotherapy, late effects, rehabilitation, and nursing. In addition, the event is host to state-of-the-art symposia, interdisciplinary sessions, and roundtables on the most challenging and timely topics in the field of pediatric neuro-oncology. For more information, visit <https://www.ispno2022.de/>.



Team CBTPF Participates in United Airlines NYC Half and the Upcoming TCS 2022 Marathon

After raising an outstanding \$21,000 in support of the lab, the Children's Brain Tumor Project team took to the streets on Sunday, March 20, as they ran 13.1 miles through Brooklyn and Manhattan. The United Airlines NYC Half Marathon was great fun for our dedicated team including several members of our clinical and research teams. We want to extend our thanks to all of our runners/fundraisers including Alexa Gura, Amanda Cruz, Caryn Grafton, Chloe Holland, Cindy Campbell, Janine Scarlatos, Dr. Jeffrey Greenfield, Jennifer Clayton, and Will Tower. Extra applause for Jennifer Clayton, who raised more than \$8,000 in memory of her son, Joey!

The United Airlines NYC Half is only the beginning. The Children's Brain Tumor Project Foundation has also been accepted as an official charity partner for the 2022 TCS NYC Marathon, scheduled to take place on November 6! Although it's still too early to register, we have begun making a list of runners who might be interested in joining our marathon team. Please email cbtpf@cbtpfoundation.org for more information.



Children's Brain Tumor Project Continues to Grow with New Team Recruits



Sheila McThenia, MD, is currently a pediatric oncology fellow at a joint program with Weill Cornell Medicine and Memorial Sloan Kettering Cancer Center. She is currently working on Dr. Greenfield's team at the CBTP lab studying resistance to radiation and chemotherapy treatments in pediatric ependymoma using patient-derived cell lines.

"My time in Dr. Greenfield's lab has greatly enhanced my training in pediatric oncology," says Dr. McThenia. I am grateful to be able to take care of children with cancer both in clinic and in the hospital, and then head over to lab to study their brain tumors in the lab. I am confident my time at the Children's Brain Tumor Project will help me to be a better doctor, inform future clinical trials, and ultimately, improve patient outcomes."



Rashika Rangaraj, PhD, ACRP-CP, is the clinical trials program manager for the Children's Brain Tumor Project (CBTP). She works on the development and implementation of CBTP research projects. Her responsibilities include writing protocols, designing clinical trials, reporting on trial results, coordinating with internal IRB/legal teams, and working with collaborative study sites. Rashika received her MS in Translational Science (2015) and PhD in Molecular Metabolism (2017) from the University of Chicago. Following her graduation, she worked at Lurie Children's Hospital managing research initiatives in cystic fibrosis and interstitial lung diseases in children and young adults.

"I'm thrilled to join an amazing team that exudes passion, focus, and commitment like no other, in their quest to conquering devastating and rare brain tumors by developing novel and personalized therapies," says Dr. Rangaraj. To be part of the CBTP and its mission while working alongside brilliant minds is not only intellectually fulfilling but also meaningful."



Madeline Laramée is currently working in Dr. Souweidane's lab as a research technician. She supports the efforts of her fellow team members to further the study of tumor development in mouse models and high-throughput drug screening to deepen the understanding of various pediatric CNS tumors. She has also helped to advance projects that have been accepted to present at multiple conferences around the world. Madeline graduated from Syracuse University in 2020 with a dual degree in Biology and Neuroscience and a minor in Psychology.

"My recent work in Dr. Souweidane's lab has furthered my understanding of pediatric cancer more than I ever thought possible and in turn, intensified my fervor to devote myself to finding cures," says Madeline. "My team's overwhelming kindness and willingness to teach has truly confirmed for me that research is something I want to dedicate my life to. I hope my time at the CBTP will help me grow as a scientist and aid in the effort to find new treatment options for the sake of the affected children and their families."



Corinne Smith is a new Research Technician in the Dahmane group. Corinne graduated from Florida State University with a Bachelor of Science in Psychology with minors in both Biology and Chemistry. She is working on several projects focusing on the mechanisms controlling cell differentiation in the developing brain with a focus on the function of the transcription factor RP58 in both normal brain development and pediatric brain tumors.

"I am excited to be working in Dr. Dahmane's lab as part of the CBTP," says Corinne. "I am eager to apply my interest in developmental biology to such meaningful research. Coming into this group, I have experienced such a welcoming environment as a young scientist. I look forward to growing as a scientist here and learning more about developmental biology and pediatric oncology."

Upcoming Events in 2022 to Benefit the Lab - SAVE THE DATES

MAY 16 - Ellie Ruby Foundation Wine Tasting Cocktail Party, NYC
visit ellierubyfoundation.org

OCTOBER 14 - No Laughing Matter, New York Athletic Club
visit nolaughingmatter2022.org

JULY 18 - Cristian Rivera Foundation 5K, Van Cortlandt Park, Bronx
visit cristianriverafoundation.org

NOVEMBER 6 - TCS New York Marathon for Team CBTPF
email cbtpf@cbtpfoundation.org for information

AUGUST 7 - Mess Fest 2022, Kiwi Country Day Camp, Mahopac NY
visit messfest2022.org

NOVEMBER 16 - Cristian Rivera Foundation Gala, Capitale NYC
visit cristianriverafoundation.org

Cristian Rivera Foundation Breaks Record with \$300,000 Donation to DIPG Research

On Tuesday, November 30, also known as Giving Tuesday, the Children's Brain Tumor Project at Weill Cornell Medicine received a profound surprise from the Cristian Rivera Foundation (CRF)—a donation of \$302,120 in support of Dr. Mark Souweidane's research. This was a huge milestone, marking the largest single donation ever made by the organization, and the largest donation ever made to the lab by any family-run nonprofit.

Music producer and promoter John Rivera has been raising money since 2009 to find a cure for diffuse intrinsic pontine glioma (DIPG), a rare and uniformly fatal brain stem tumor that struck his son, Cristian. Cristian was only 6 years old when he succumbed to the devastating disease.

"I work so hard, I do all of this, because I miss my son," Rivera said recently. "He was my best friend."



Rivera created the Cristian Rivera Foundation just months after his son's death to raise DIPG awareness and to support hospitals and organizations researching cures for the disease. He has since been a loyal supporter of Weill Cornell Medicine, where his son was treated by Dr. Mark Souweidane, Vice Chairman of Neurological Surgery and Director of Pediatric Neurosurgery at New York-Presbyterian/Weill Cornell Medicine.

"I am a pediatric neurosurgeon who focuses on the surgical treatment of children, so when I first encountered a child with DIPG early in my career, I felt helpless learning that DIPG is inoperable and fatal," said Dr. Souweidane. "I knew instantly that I would dedicate my life's work to finding alternative ways to cure this tumor through groundbreaking surgical approaches. I promise you that we are making inroads."

DIPG is rare, affecting fewer than 300 kids a year, but the prognosis is extremely grim—survival time is measured in months, and there has been no significant decrease in the mortality rate in more than 30 years. Mr. Rivera knew he could make a difference and help change these statistics by leveraging his experience in the entertainment industry. He hosted his very first star-studded gala in New York City in 2009, and the event has grown ever year. Attendance and fundraising both hit record-breaking highs at the 12 Annual CRF Celebrity Gala, which was held on November 17th at Capitale.

"One day we are going to be able to raise a million dollars at the gala," said Rivera with confidence. The Cristian Rivera Foundation has already donated more than \$1.5 million to Weill Cornell Medicine over the years.

We hope you will consider donating to the Cristian Rivera Foundation and keep an eye out for news about the 13th annual CRF gala planned for November 16, 2022. The event is sure to be bigger and better than ever, thanks to John Rivera and his dedicated team. Visit www.cristianriverafoundation.org or www.facebook.com/cristianriverafoundation.

Andrew McDonough B+ Foundation Awards Competitive Grant to the CBTP

In December, CBTP principal investigator Nadia Dahmane was awarded a competitive grant through The Andrew McDonough B+ (Be Positive) Foundation (www.BePositive.org). Her project, "Therapeutic Reprogramming of DIPG cells", will receive a two-year, \$75,000/year grant for a total award of \$150,000.

The project aims to better understand the mechanisms that control pons development which—when deregulated—contribute to the development of a deadly pediatric brain tumor called Diffuse Intrinsic Pontine Glioma (DIPG). Dr. Dahmane will be studying a novel protein that is required for pons development, exploring how the potential affect that the expression of this protein, or lack thereof, may effect cell identity in the pons. The results will help to shed light on key mechanisms underlying DIPG growth and progression, and potentially uncover novel avenues for therapeutic intervention.

The Andrew McDonough B+ (Be Positive) Foundation honors the life of Andrew McDonough, who battled leukemia for 167 days before passing away in 2007. Andrew's B+ blood type became his family's and friends' motto throughout his fight against childhood cancer – to "Be Positive." The B+ Foundation is about kids helping kids fight cancer—raising money through events on college campuses, local events such as 5Ks and golf outings, corporate partnerships, merchandise sales, and more—to provide financial and emotional support to families of children with cancer nationwide and fund critical, cutting-edge childhood cancer research.