

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

September 2019

## "No Laughing Matter" to Honor Michael Minter and Emmie Hill

In support of life-saving research for children with brain tumors, the Children's Brain Tumor Family Foundation will host the second annual "No Laughing Matter" comedy night fundraiser on Tuesday, October 22nd. At this year's fundraiser, once again at the world-famous Carolines on Broadway in New York City, Michael Minter and Emmie Hill will be presented with the inaugural *Liz. Laugh. Love.* award in recognition of their committed effort to fund groundbreaking research.

"Almost nine years ago, a beautiful young girl named Elizabeth sat alongside her parents, Mike Minter and Emmie Hill, as I delivered the tragic news that she had a rare, inoperable brain tumor called gliomatosis cerebri. I had to tell them that it was unlikely she would survive," said Dr. Jeffrey Greenfield, cofounder of the Children's Brain Tumor Project at Weill Cornell Medicine. "Elizabeth's bright, positive energy, and inquisitive mind touched my heart and forever changed the course of my career in that instant."

The Children's Brain Tumor Project simply wouldn't exist if it wasn't for Elizabeth — Liz. She founded a nonprofit called Elizabeth's Hope before she passed away in 2012, which enabled the creation of a research lab at

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Elizabeth with her family: Will, Emmie, Trey, Elizabeth and Mike Minter.

From the Desk of...  
*Anthony Trimarchi*

## Advocating for Change

My daughter, Taylor, was diagnosed with a brain tumor in 2017. That was the first among many moments of complete shock as my family and I were thrown into discussions around treatment options, survival rates and the long-term side effects of aggressive surgery, chemotherapy and radiation. The initial shock was followed by a series of additional eye-opening revelations as I began researching treatment options, looking for advancements in the science so I could select the most innovative protocols available to her. What I discovered, instead, was a tremendous lack of awareness and funding for childhood cancers in general, and unique challenges in the research landscape for pediatric brain tumors, in particular.

My eyes were opened in an instant when I connected with various medical teams, researchers, and families, all of whom echoed the same message about the need for increased research. I couldn't believe what I was hearing, so I began hosting fundraisers of my own in an effort to help support the research being done by the Children's Brain Tumor Project at Weill Cornell Medicine to pay tribute to my daughter and all she had endured.

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## Combined Targeting of PI3K and MEK Effector Pathways via CED for DIPG Therapy

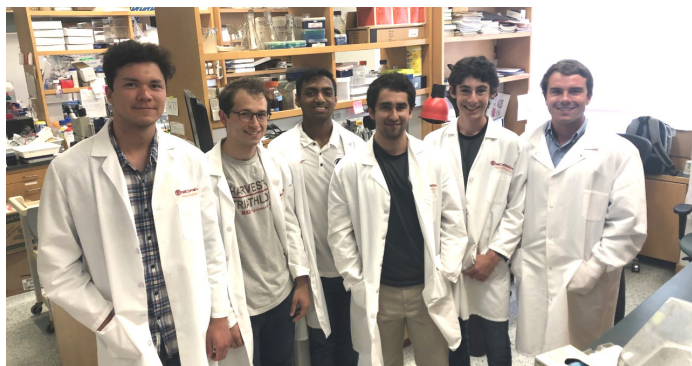
A new research study from the CBTP lab entitled "Combined Targeting of PI3K and MEK Effector Pathways via CED for DIPG Therapy," was published in *Neuro-Oncology Advances* on May 29, 2019. The published manuscript, submitted by Dr. Uday Maachani (Dr. Souweidane Lab) on behalf of the entire research team, showed the results of a comprehensive study of midline gliomas including diffuse intrinsic pontine gliomas (DIPG), and the relationship between amplified phosphatidylinositol 3-kinase (PI3K), mitogen-activated protein kinase (MEK), and the development of these particular tumor types.

Midline gliomas carry a poor prognosis and lack effective treatment options. Studies have implied that amplifications in the PI3K signaling pathway may result in tumorigenesis, and that the activation of parallel pathways (e.g., mitogen-activated protein kinase [MEK]) may be causing the resistance to PI3K inhibition that has been observed in the clinic. An accurate understanding of this relationship could open doors to potential new treatment options for children with DIPG and other midline gliomas in the future.

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**Make a donation today at [ChildrensBrainTumorProject.org](http://ChildrensBrainTumorProject.org)**

# CBTP Summer Staff — Making Strides in Research



Eric, James, Sai, Sergio, Justin and Tyler

Every summer, the Children's Brain Tumor Project welcomes students to work in the lab for a mutually beneficial experience. This year the CBTP was lucky to have the assistance of six summer interns who enabled the lab to increase productivity while exploring new ideas that are fueling follow-up research projects. This was one of our largest summer teams to date.

## James Agolia

James is completing a research year at Weill Cornell Medicine before returning to Harvard Medical School as a fourth-year medical student. James is a wonderful addition to the team who has been working on characterizing the immune microenvironment in gliomas following radiation treatment. He hopes to identify novel therapeutic combinations for the treatment of gliomas.

## Saiteja (Sai) Damineni

Sai, a rising senior at Penn State, joined the CBTP in order to strengthen his level of research experience. He worked diligently on becoming

proficient in a range of techniques, from cryosectioning to immunoblotting, in order to increase our general knowledge of glioblastoma.

## Tyler Garman

Tyler, a rising second-year med student at Weill Cornell, spent his summer researching choroid plexus carcinomas, a rare pediatric brain tumor. Tyler tested various chemotherapies against these tumors to be used in a clinical trial that will provide meaningful tumor response with reduced systemic toxicity when delivered intra-arterially.

## Justin Gurvitch

Justin, a high school sophomore at Horace Mann in Riverdale, has been assisting with investigations into possible treatments for gliomas. In the lab, he can be found cutting precise slices of brain tissue, broadening his horizons with academic literature, aiding in our fundraising efforts, or working on any one of a variety of experiments with his colleagues. *Read more about Justin on page 4.*

## Sergio Wesley Guadix

Sergio, a rising second-year med student at Weill Cornell, worked on using CED to deliver a chemotherapeutic agent of interest directly into the tumor sites of DIPG mouse models. Through this delivery method, he was able to evaluate gains in overall survival compared to that of systemic delivery, paving the way for clinical application.

## Eric Kohut

Erik Kohut, a rising sophomore at Cornell University, worked on elucidating the role of a specific gene in the development of blood cells at different embryonic stages. He extensively used polymerase chain reaction (PCR) and other molecular biology techniques in the hopes of learning more about the neuroimmune system.

## Save the Dates

**SEPTEMBER 1-30** - Childhood Cancer Awareness Month (everywhere)

**SEPTEMBER 1-30** - Go Gold with Team Campbell Lawn Signs (email [info@teamcampbellfoundation.org](mailto:info@teamcampbellfoundation.org) for availability)

**SEPTEMBER 14** - TYathlon Sprint Triathlon and 5K, Ty Louis Campbell Foundation (Mahopac, NY)

**SEPTEMBER 16** - Brooke Healey Golf Outing (Bedminster Twp, NJ)

**SEPTEMBER 19** - IronMatt Dinner and Auction (New York, NY)

**SEPTEMBER 26-27** - 7th Annual "Liz Laugh Love" Round Robin for Cancer Research, Elizabeth's Hope (Bronxville, NY)

**OCTOBER 18** - Play it Forward Golf Tournament, McKenna Claire Foundation (Huntington Beach, CA)

**OCTOBER 22** - No Laughing Matter 2019 (New York, NY)

**NOVEMBER 3** - NYC Marathon with the Children's Brain Tumor Family Foundation (New York, NY)

**NOVEMBER 13** - Cristian Rivera Fdn. Celebrity Gala (New York, NY)

**MARCH 7** - The Greatest Gala, Ty Louis Campbell Fdn. (Greenwich, CT)

## Running for Research

The Children's Brain Tumor Family Foundation (CBTFF) is an official charity partner for the TCS New York City Marathon. Dr. Greenfield will be joining the team for the second year in a row as they complete 26.2 miles across all five boroughs in honor of children with brain tumors. Please visit [greenfieldmarathon.org](http://greenfieldmarathon.org) to support his race!



OFFICIAL CHARITY PARTNER

**TCS**  
**NEW YORK CITY**  
**MARATHON**



# Combined Targeting via CED for DIPG Therapy (continued)

In this comprehensive study, the research team tested both PI3K inhibitor *ZSTK474* and MEK inhibitor *trametinib*, alone and in combination, in vitro and in vivo, using various delivery methods. Three patient-derived cell lines and a mouse-derived brainstem glioma cell line were treated with PI3K (*ZSTK474*) and MEK (*trametinib*) inhibitors, alone or in combination. These agents were also used alone or in combination in a subcutaneous DIPG tumor model and in an intracranial genetic mouse model of DIPG, given via convection-enhanced delivery (CED).

The results showed that combination treatments were found to be synergistic with dosing across the cell lines tested, and significant tumor suppression was seen when given both systemically against a subcutaneous DIPG model, and via convection-enhanced delivery (CED) in an intracranial DIPG mouse model. Data indicates that *ZSTK474* and *trametinib* combination therapy inhibits malignant growth of DIPG cells in culture and in animal models, prolonging survival. The results warrant further investigation and the team is excited by the potential for a promising new combination approach to treat DIPG via convection-enhanced delivery.

This research was supported in part by Cristian Rivera Foundation, McKenna Claire Foundation, The Lyonhearted Foundation, Christian Koehler Foundation, Brooke Healey Foundation, Fly a Kite Foundation, Children's Brain Tumor Family Foundation, Joshua's Wish, Lily LaRue Foundation, and by the Alex's Lemonade Stand Foundation's Pediatric Oncology Student Training Grant (UT), and American Brain Tumor Association Medical Student Summer Fellowship in honor of Collegiate Charities Dropping the Puck on Cancer and Super Lucy (RC).



## September is Childhood Cancer Awareness Month

September is Childhood Cancer Awareness Month. Last year the CBTP made a statement about turning awareness into action. Building off of the CBTP's "do something" message, we hope the community will continue to spread the word about childhood cancer ACTION month. Taking action can be a grand fundraising activity, or something as simple as posting on social media. Any action brings us one step closer to cures. Follow our posts on Facebook for ideas on how you can take action this month, and, most of all, we hope you are touched by the individual stories we will be sharing about the children who are part of our family council. We are proud to say that we are, indeed, "Powered by Families."

## "No Laughing Matter" to Honor Michael Minter, Emmie Hill (continued)

Weill Cornell Medicine dedicated to the investigation of rare and inoperable pediatric brain tumors. In memory of Liz, her parents have honored her wishes by continuing to support the research underway at the Children's Brain Tumor Project. The *Liz. Laugh. Love* award is intended to show gratitude for their incredible contributions, and to inspire others to follow in their footsteps in memory of Liz, and in honor of all children who are impacted by a brain tumor diagnosis.

The award will be presented at the "No Laughing Matter" fundraiser, where an all-star comedy line-up will donate their time and talent to help raise research funding for rare and inoperable brain tumors at Weill Cornell Medicine. The inaugural event in 2018 raised \$450,000 to benefit the groundbreaking research of Dr. Mark Souweidane and Dr. Jeffrey Greenfield, and the goal for 2019 is to surpass that amount.

"We are so grateful to the Children's Brain Tumor Family Foundation, the dinner committee, the performers, the honorees, the sponsors and the event staff who make this event such a tremendous success — and so much fun!" said Dr. Mark Souweidane, cofounder of the CBTP and Director of Pediatric Neurosurgery at Weill Cornell Medicine. "We are proud to be the beneficiaries of such a fantastic event, and honored to present the Minters with this award."

The purpose of this fundraising event is to raise much-needed research funding for rare and inoperable brain tumors, while paying tribute to the children who will benefit from the research. Pediatric brain tumors are the most common tumors found in children, and the most fatal. The incidence of pediatric brain tumor diagnoses have been increasing over the past 40 years, yet little progress has been made in advancing cures. The Children's Brain Tumor Project aims to improve the outcome for children with brain tumors by advancing scientific discovery and clinical research that focuses on targeted therapy, effective drug delivery and low treatment-related toxicity.

Visit [nolaughingmatter2019.org](http://nolaughingmatter2019.org) to watch a touching highlights video from the 2018 event, and purchase tickets for the upcoming event on October 22.

## From the Desk of Anthony Trimarchi

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Anthony Trimarchi with his daughter, Taylor.

Thankfully, Taylor has finished treatment and she is doing extraordinarily well, but that doesn't mean I've lost sight of the thousands of children with brain cancer who have not had/may not have the same outcome. Instead, I remain an active advocate.

I recently worked closely with local representative Nita Lowey [D-NY17] to fight for the inclusion of a formal request for increased research funding in the appropriations committee report accompanying H.R. 2740, a bill that sets overall spending limits for the next year and was passed by the House of Representatives on June 19, 2019.

The bill is now under review by the senate.

SpendingTracker.org estimates H.R. 2740 will add \$43.8 billion in new spending through 2029, which reinforces the notion that the inclusion of a statement specific to pediatric brain tumor research support may influence an increased government spend in this area.

I am not alone in these efforts, and I am so proud of everything that has been accomplished by advocates in the childhood cancer community — where the parents of children in treatment are often running

marathons, hosting auctions and selling silicone bracelets in efforts to fund the research that may help their children. That alone demonstrates just how little government funding is currently available for childhood cancer research.

Less than 4% of the national budget for cancer research is designated to research all pediatric cancers, a percentage which gets even smaller when divided across the seemingly countless types of cancers that are unique to children.

That leaves a tremendous gap to fill by nonprofit organizations large and small such as the Children's Brain Tumor Family Foundation, the Cristian Rivera Foundation, the McKenna Claire Foundation and the Ty Louis Campbell Foundation, hundreds of which support the majority of these research projects through tireless fundraising efforts.

With input from my daughter's neurosurgeon, Dr. Mark Souweidane, Vice Chairman of Neurological Surgery and Director of Pediatric Neurosurgery at Weill Cornell Medicine, I submitted the following paragraph for inclusion. The statement can be found on page 81 of the appropriations committee report, where specific references are made pertaining to the National Institute of Health (NIH).

*The committee recognizes that brain cancer remains the most fatal of all pediatric cancers. Despite progress in other diseases, pediatric brain cancer survival rates have not improved for decades and has lagged behind the strides made in other cancers. The majority of children who survive may experience lifelong impairments and disabilities that result from high levels of toxicity associated with treatment. The committee strongly encourages NIH to expand funding on research on pediatric brain cancer, including but not limited to drug delivery methods and new therapies with reduced levels of toxicity and long-term complications.*

There are few official statements addressing pediatric brain tumors that are as clear and accurate as the one that congresswoman Nita Lowey helped deliver to the NIH. It seems anyone reading these simple facts would be compelled to do more, and I will not stop advocating until they do.

Anthony

## CBTP "Do Something" Spotlight Volunteering to Learn

Justin Gurvitch says he is learning something new every day while volunteering at the Children's Brain Tumor Project this summer, but ask anyone in the lab and they will tell you that they have learned a lot from him, too. First and foremost... they've learned not to underestimate a fifteen-year-old. From his very first day as a volunteer, Justin has shown the team maturity, dedication and a willingness to learn that is reflected in his outstanding performance.

A sophomore at Horace Mann School, Justin has been coming to the lab every weekday, willing to do whatever is needed — even if it means staying as late as 8PM. While still a newcomer in the lab, he has developed and refined his understanding of laboratory techniques in order to aid in both day-to-day and longer-term endeavors of the CBTP. Justin understands that children with brain tumors have unmet needs in the research landscape, and he is rolling up his sleeves to **do something** about it.



CBTP Volunteer Justin Gurvitch



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