

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

Fall 2022

Patient Josh Fiala Celebrates Ten Years Tumor-free and a Milestone Birthday



In 2012, Josh Fiala underwent two back-to-back surgeries to remove a JPA tumor with Dr. Mark Souweidane, Vice Chairman of the Department of Neurological Surgery at New York-Presbyterian/Weill Cornell Medicine.

This year, Josh celebrated his 30th birthday while also commemorating ten years of living his life tumor-free. That, in itself, was the best birthday gift of all.

"I had a huge birthday party in Brooklyn," said Josh. "Ten years ago I faced a very real fear that I might not see my thirtieth birthday, but here I am! I blew out those candles knowing how lucky I am to be happy, healthy, and surrounded by loved ones thanks to Dr. Souweidane."

Josh remembers with clarity the day he went to pick up his cap and gown for his high school graduation. He had suddenly dropped his cap, lost feeling in his hand, felt numbness in his face, and developed his first migraine accompanied by vomiting. Thankfully, the symptoms dissipated quickly.

At the time Josh was working as a lifeguard and a day habilitation specialist at United Cerebral Palsy of NYC. He was also an active snowboarder and cyclist who looked forward to getting his driver's license. Unfortunately, the migraines started to return frequently, and they became debilitating.

An MRI soon revealed that his brain was hemorrhaging due to a tumor known as juvenile pilocytic astrocytoma (JPA). The diagnosis was especially frightening to Josh and his family, having lost his father to a meningioma brain tumor just two years earlier.

During Josh's first surgery at the age of 18, his surgeon was only able to remove part of the tumor. One year later, an MRI determined that the tumor was growing, and he was faced with needing another surgery. Although a gross total resection would grant Josh the best outcome, he consulted with a number of neurosurgeons across the country who told him over and over again that the tumor could not be removed in its entirety. That is, until he met Dr. Mark Souweidane.

"The surgery will be a marathon, but I can get the job done," said Dr. Souweidane.

"Upon hearing that, I shook his hand," said Josh. "I immediately noticed his strong, steady grip and I knew he was the right surgeon."

Surgery indeed proved to be a marathon. Dr. Souweidane performed a 10-hour operation and was able to remove 90 percent of the tumor. Then he performed a second surgery the following week, and he was successful in removing the rest of the tumor. Josh was declared tumor-free.

"Not only is Dr. Souweidane a master surgeon, but he's also such a nice guy with a great sense of humor," said Josh's mother, Lois Silver Zini. "I am confident that we found the very best surgeon, and we are eternally grateful." *(continued on page 2)*



Josh Fiala with his mother, Lois Silver Zini

(continued from page 1) After surgery, Josh studied at the Culinary Institute of America, and has worked as a cheesemonger in several high-end NYC restaurants. The tumor impacted his peripheral vision in the long term, leaving him with some disabilities. He never did get his driver's license. But Josh knows that it's a small price to pay for feeling great, and he lives his life with gratitude.

Happy 30th Birthday, Josh. We can't wait to see what you do over the next 30 years!

No Laughing Matter

A COMEDY NIGHT GALA

BRAIN TUMORS ARE NO LAUGHING MATTER,
BUT SOMETIMES LAUGHTER IS THE BEST MEDICINE.

The annual comedy night fundraiser, hosted by the Children's Brain Tumor Project Foundation, will return on Friday, **October 14th**, at the **New York Athletic Club** (180 Park Avenue South).

Several comedians, including **Jordan Klepper** and **Roy Wood, Jr.** from **The Daily Show**, have volunteered to perform at the fundraiser. We encourage all ages to join in on the fun.

This year, we will be honoring **The Marsano Family** for their generosity toward Dr. Jeffrey Greenfield's precision medicine program.

For sponsorships, tickets, or to make a donation:

NOLAUGHINGMATTER2022.ORG

New York-Presbyterian Ranked #1 Children's Hospital in New York

On behalf of our combined Weill Cornell and Columbia pediatric neurosurgery service, it is with great pride that we pass along our 2022-23 US News & World Report's ranking for "Best Children's Hospitals." New York-Presbyterian has been ranked as a top children's hospital for 16 years in a row, and we could not be more proud to be recognized as #1 in New York. NewYork-Presbyterian provides pediatric care in every area of medicine at two major sites: NewYork-Presbyterian Morgan Stanley Children's Hospital and NewYork-Presbyterian Komansky Children's Hospital. It is also the nation's only hospital affiliated with two world-class medical schools, Columbia University Vagelos College of Physicians and Surgeons and Weill Cornell Medicine.

Importantly, in the category of Neurology & Neurosurgery, our service is ranked as one of the top programs in the United States! This year we achieved a well-earned jump, rising 5 spots from last year's ranking, now putting us in the top 15 children's neurological services in the nation. This is a testament to the work of all members of our pediatric neurosurgical team, all of whom work so hard. It shows how each of them, individually and as a team, matters in creating a highly sought-after service for children regionally and throughout the country.

Given the disproportionate impact the COVID pandemic has had on our community here in New York, this national recognition speaks even more loudly about our team's dedication, pride, and work ethic.

With pride and gratitude to our colleagues,

Dr. Mark Souweidane and Dr. Jeffrey Greenfield

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New York's #1 Children's Hospital

STAY AMAZING

WITH WORLD-CLASS DOCTORS FROM
COLUMBIA Weill Cornell Medicine

NewYork-Presbyterian

Meet Our New Tissue Coordinator, Christopher Padilla



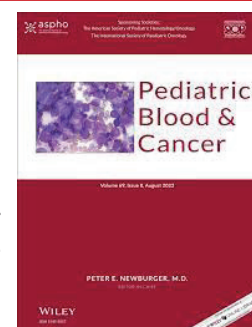
My name is Christopher Padilla and I am the Tissue Coordinator for the Children's Brain Tumor Project laboratories at Weill Cornell Medicine. After growing up in Manhattan, NY, and recently completing my undergraduate studies in Neuroscience and Philosophy from the University of Notre Dame, I have found my way back to New York City to join the research initiative against pediatric brain cancer.

During my undergraduate studies, I uncovered a strong curiosity for the intersection of science and philosophy, specifically where the body meets the mind. I found neuroscience to be at the core of this juncture as a school of thought dedicated to exploring human identity and dignity through the natural lens of science. After experience working in neuroscience labs, I felt the urge to serve a vulnerable population from one of humanity's most difficult medical problems by working on pediatric brain cancer at the Children's Brain Tumor Project.

My additional role as part of the Gift from a Child (GFAC) network is an incredible honor because of its importance in furthering the collaborative effort to model and treat pediatric brain tumors. The generosity of families who choose to donate through GFAC has already yielded incredible results and will continue to be a powerful aid in the fight against these cancers. I am grateful to be working with such a talented team and I believe the collaboration between families, the GFAC network, and scientific institutions across the country will bring us ever closer to finding curative treatments in the fight against pediatric brain cancer.

CBTP Program Director Co-authors Research Paper on Ethical Practices Among Nonprofits Funding Clinical Trials in *Pediatric Blood and Cancer*

CBTP Program Director Cindy Campbell has been an active member of the Coalition Against Childhood Cancer (CAC2) since its inception in 2013. Over the past two years, Cindy has also been one of eight participants on the CAC2 Ethics Think Tank team, which explores the potential ethical issues charities face when funding research and the Best Management Practices (BMPs) they use in dealing with those issues.



The mission of CAC2 is collaboration, and in that spirit eight authors were named on a recent paper published in *Pediatric Blood & Cancer*. In addition to Cindy Campbell, authors included Caitlyn Barrett (Curesearch for Children's Cancer), Robin French (Morgan Adams Foundation), Donna Ludwinski (Solving Kids' Cancer), Amy Weinstein (Pediatric Brain Tumor Foundation), and Susan Wolfert (The Taylor Matthews Foundation) along with individual member Vickie Buenger and medical ethicist Vasiliki Nataly Rahmzadeh, PhD. The authors contributed to an extensive literature audit prior to developing the comprehensive article, titled "A systemic literature review to identify ethical, legal, and social responsibilities of nonprofit organizations when funding clinical trials in pediatric cancer." The article explores the practice of funding clinical trial research and the ethical obligations of charitable organizations as they relate to various stakeholders, including patients and families, researchers, donors, and industry and academic trial sponsors.

To learn more about the research process and to read the paper, visit childrensbraintumorproject.org/publications.

September Is Childhood Cancer Awareness Month

In September, the childhood cancer community hosts events, displays gold ribbons, and shares information via news and social media to raise awareness for childhood cancer. We would like to remind you that while awareness



is so important, turning that awareness into action makes an even greater impact. Anything helps, no matter how big or small. Taking action can mean hosting a fundraiser, making a donation, wearing a gold ribbon, or simply sharing posts on social media. We appreciate your help.

Dr. Greenfield to Present at CureFest's Brainstorm Summit

CureFest, an annual event in Washington D.C. to raise awareness for pediatric cancer, will be hosting its first event specific to pediatric brain tumor research. The "Brainstorm Summit" will be taking place on Friday, September 23, and Dr. Jeffrey Greenfield will be a panelist on "What Tissue Donation Means to Research." BrainStorm Summit will bring the pediatric brain tumor community together to share the latest information on: Alternative Therapies, Grief, Preclinical Research, Immunotherapy Options, the Value of Sharing Patient Data and Recent Advances from Shared Data, Emotional Support Strategies for Parents, Fighters, Siblings and Survivors, a Review of the new My DIPG Navigator and the DIPG DMG National Brain Tumor Board, and Advanced Therapies.

ChadTough Foundation Awards Dr. Mark Souweidane "Game Changer" Grant



Dr. Mark Souweidane and Chad Carr in 2015

The ChadTough Defeat DIPG Foundation will be funding a new research project at the Children's Brain Tumor Project over the next three years. The highly competitive "Game Changer" award is a multi-year grant (\$600,000 over three years) that allows researchers to spend more of their time in the lab and less time seeking additional funding for future years.

"Working collaboratively with other families and foundations in the DIPG community, we've been able to amplify our capacity to make significant investments in DIPG-specific research, said co-founder Jenny Mosier. "We are thrilled to be able to offer this grant to Dr. Souweidane's team and foster the next generation of DIPG researchers."

The project, "Development of a Comprehensive Direct Drug Delivery Platform for the Treatment of Diffuse Midline Glioma," aims to design novel and effective therapeutic

protocols for patients with diffuse midline gliomas. To accomplish this, Dr. Souweidane's game-changing strategy will consist of using a comprehensive set of drug delivery and drug imaging methods, including convection-enhanced delivery (CED), focused ultrasound BBB disruption (FUS-BBBD), intra-arterial delivery (IA), and intrathecal delivery (IT) that will more effectively target DIPG tumor sites, while avoiding the toxicities associated with conventional administration of drug therapies.

Drug delivery is key to effectively treating children impacted by DIPG due to the location of this particular tumor, and its obstruction by the blood brain barrier (BBB). The BBB drastically reduces the likelihood of drugs ever reaching the tumor when administered via standard systemic delivery. This is the first-ever comprehensive study of a wide range of alternative drug delivery mechanisms to determine the ideal approach for bypassing the BBB to effectively attack this type of brain tumor, while simultaneously lowering toxicity as a result of avoiding systemic delivery.

"I am honored and grateful that the ChadTough Defeat DIPG Foundation is supporting this work," said Dr. Souweidane. "My team and I expect the establishment of this drug delivery platform to act as an incubator for the translation of many cutting-edge therapies to early-stage clinical trials in the fight against DIPG."

Summer Fundraisers Show that Donors are Ready to Gather Again in Support of Nonprofits Funding Research

After two summers of social distancing, the 2022 summer fundraising season proved that donors are ready to gather again. The act of simply getting together in support of a shared cause is so meaningful, and it was greatly missed in previous years.

On June 18, the annual *Cristian Rivera Foundation 5K* in Van Cortlandt Park was a huge success. Hundreds of walkers and runners came to support DIPG research and to rally around honoree Jesselyn Silva, a local teen battling diffuse midline glioma. Dr. Mark Souweidane was there to share inspiring words, and founder John Rivera made sure it was a fun time for all who attended.

The annual *Muddy Puddles Mess Fest* to benefit the Ty Louis Campbell Foundation was held at Kiwi Country Day Camp on August 6, and close to 1,000 people attended. "We are finally approaching pre-pandemic attendance and it's been such a relief. The lab counts on these funds, and it feels good to be able to fulfill our promise as a donor to the Children's Brain Tumor Project," said cofounder Louis Campbell.

Smiles for Ellie was back for a second year at Pine Grove Day Camp in Wall, New Jersey, on August 28. Children enjoyed music, dancing, bounce houses, and more throughout the day. Ellie's family spoke beautifully about the reason behind creating the Ellie Ruby Foundation, and proudly presented CBTP program director Cindy Campbell with a donation of \$100,000!

