



Dr. Jeffrey Greenfield and Dr. Mark Souweidane, co-directors of the Weill Cornell Medicine Children's Brain Tumor Project

From the Desk of...

*Cindy Campbell, CBTP Program Director*

I am humbled and honored to accept the position as the new Program Director at the Children's Brain Tumor Project. My heart is filled with gratitude for the families and individual supporters who believe in the work we are doing here, and I am so excited to support the progress of this lab. I feel a tremendous sense of responsibility to honor each and every child impacted by a brain tumor diagnosis, and I am eager to apply my extensive public relations, marketing and nonprofit management experience to the Children's Brain Tumor Project. The work we are doing here is all so very personal to me as a brain tumor parent, myself.



My life was ripped into two – a before and after – the moment I saw the MRI on the screen; life before my son's brain tumor diagnosis, and life after. I looked in the mirror and saw a completely different person looking back at me. The energetic young mom who smiled often was gone – a stranger. I lived with tremendous hope and optimism while he was in treatment, but on that crisp autumn afternoon, every ounce of that hope floated out the window on the heels of his very last breath.

In 2013, six months after losing him, I returned to work. I was a public relations professional for fifteen years, and my job as Marketing Director at PricewaterhouseCoopers was waiting for me. But, my team didn't recognize me when I walked through those doors. I was consumed with grief, utterly and completely uninspired by the work that was expected of me. I remember sitting at my desk on the first day back, looking at my shoes, and thinking about the last time I wore them. It was before my world turned upside-down. It felt so long ago and I had changed so much since wearing them last, that they were stiff and didn't fit well. I found myself so uncomfortable wearing the same shoes that were once so familiar.

Soon after, I told my team "this just isn't right for me." I made the decision to focus my career on trying to make a difference for children like Ty, and there was a fire inside that filled me with purpose again. The same day I gave notice at PricewaterhouseCoopers, I met with the team at Solving Kids' Cancer, a NYC-based nonprofit, and they hired me on-the-spot.

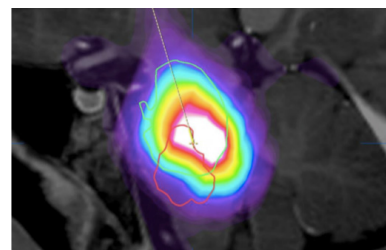
Between running the nonprofit my husband and I founded in Ty's memory, and supporting the work at Solving Kids' Cancer, I finally felt my self-worth returning. That same year, my husband and I launched the Muddy Puddles Project and funded the "Ty Louis Campbell Fellowship" at the Weill Cornell

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## Dr. Souweidane's Break-through Clinical Trial Findings to be Published in The Lancet Oncology

The peer-reviewed journal Lancet Oncology has accepted for publication the highly anticipated results of Dr. Mark Souweidane's first-ever dose escalation study using convection-enhanced delivery (CED) in patients with diffuse intrinsic pontine glioma (DIPG). Publication in such a prestigious journal underscores the importance of these results, which validate the use of direct drug delivery as a viable treatment option for children with DIPG. The results are so promising they are expected to eventually change the landscape of future pediatric brain tumor protocols.

The milestone Phase I clinical trial, which was conducted at Memorial Sloan Kettering Cancer Center, investigated the safety of using CED to bypass the blood-brain barrier and administer a drug directly to a brain stem tumor site. Over the course of five years, 28 patients who had previously received radiation therapy were successfully treated (some children received multiple infusions). The trial tested seven dose levels and resulted in no serious adverse effects and no dose-limiting toxicity; researchers conclude that the technique is safe to use in children.



These extremely promising results bring forth a new potential for an effective treatment for one of the deadliest brain tumors in children, with a median survival of less than 12 months. By delivering the agent into the tumor through a surgically placed infusion cannula, the procedure drastically increases the concentration of the drug at the site of the tumor while avoiding the dangerous systemic toxicity that accompanies IV or oral chemotherapy.

The therapeutic agent <sup>124</sup>I-8H9 consists of the 8H9 antibody, which is produced by mice and has been shown to attack many kinds of tumors, combined with the radioactive substance <sup>124</sup>I. Earlier studies have shown this combination to be effective, as 8H9 binds to the tumor and <sup>124</sup>I kills cancer cells with radiation. This clinical trial was the first time CED was used to administer <sup>124</sup>I-8H9 to a human brain.

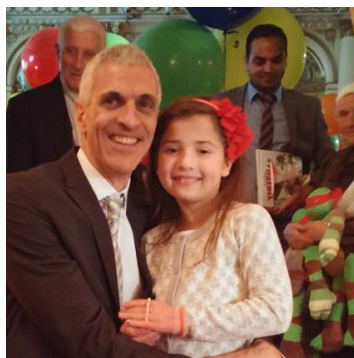
The study validates CED as a safe and efficient method to deliver drugs directly into a tumor with minimal to no systemic exposure. The average dose safely absorbed was more than 1,200 times that of the mean whole-body dose, providing an astronomical benefit over standard chemotherapy for DIPG and other types of malignant glioma.

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# CED Results to be Published in The Lancet (continued)

"I find myself at the threshold of something very meaningful, and I have never felt more optimistic. Now more than ever, I'm determined to keep going, to get to the next level, and to get my hands on a real cure for this killer," said Dr. Mark Souweidane.

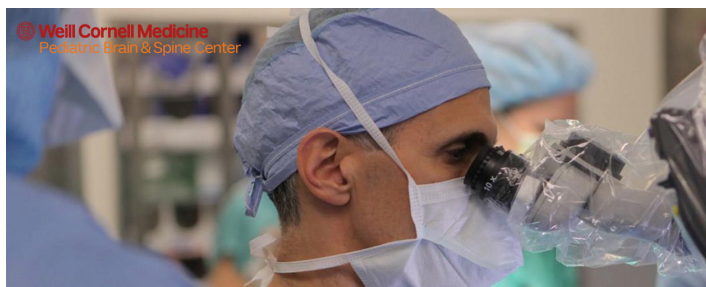
Direct drug delivery methods have a very specific advantage for patients with disease in the central nervous system. Historically, the delivery of drugs orally or intravenously proved ineffective because of the blood-brain barrier – a highly protective layer that prevents the agent from reaching the brain tumor itself, yet the rest of the body is affected by the medicine's harsh side effects. Because of this barrier, very high doses of chemotherapy are required to get even a small amount of medicine to the tumor, which is toxic to the rest of the body and poses great risk of severe long-term side effects. By placing the agent outside the blood vessels, directly into the tumor, the team is able to greatly reduce that toxicity while maximizing the attack on the tumor itself.



Dr. Mark Souweidane and patient, Brooke.

CED clearly merits further development in clinical studies for children with DIPG. Based on the results of the study, Dr. Souweidane is nearing the launch of a formal, multi-institution expansion of the clinical trial that will explore new agents and combinations delivered via CED. This next step will allow more children to be treated nationwide, testing different doses and agents in a quest to find a cure.

Dr. Souweidane has been working on DIPG research for more than twenty years. His dedication to finding hope for his patients has been unwavering, and this trial represents an enormous leap forward in DIPG research.



*"This trial is about hope," says Dr. Souweidane. "It's about admitting that we have been failing these children for decades, and taking a huge departure from the standard protocols in order to provide children with more effective options, less toxicity and increased hope for the future."*

## CBTP Volunteer Spotlight

The Children's Brain Tumor Project (CBTP) is powered by families, who in turn are powered by their volunteers. In this issue we highlight three extraordinary individuals: Tessa Naso, Mara Harris and John Naso. These creative and energetic volunteers were critical to the launch and continued success of Elizabeth's Hope (EH), but have gone on to extend their commitment to the greater CBTP.

At the launch of Elizabeth's Hope (EH) in 2011, Tessa – a childhood friend of Elizabeth Minter – sprung to action organizing a SoulCycle event for Elizabeth's peers that raised more than \$40,000. She went on spearhead three EH galas in NYC, each attended by approximately 600 persons. She is on the EH Board, but more importantly, she has assisted the CBTP on numerous projects. Tessa now lives in Los Angeles where she works as a marketing and PR professional.

Mara Harris was a sorority sister of Elizabeth's at Denison University and helped with several EH events there. After college she moved to New York and joined Tessa in promoting and creating the EH gala. In the last year, Mara provided the crucial



link between DDB Health, an advertising agency and her employer, and the CBTP. She played a pivotal role in inspiring DDB Health to provide the creative for a CBTP advertising campaign pro-bono.

Finally, John Naso, a friend of Elizabeth's (and Tessa's brother), has actively supported numerous EH events over the years. In fact, it was through their work for EH that John and Mara met and eventually found themselves in a relationship. Elizabeth was always about personal connections!! Last fall, Mara and John made a significant contribution by running as the first ever CBTP NYC Marathon team. Together they raised \$15,000. Thank you Tessa, Mara, John and the hundreds of passionate and selfless volunteers who support our families and foundations in their mission to fund the lab to find better treatment options pediatric brain cancer.

*If you are interested in volunteering for the Children's Brain Tumor Project, email [info@childrensbraintumorproject.org](mailto:info@childrensbraintumorproject.org).*

## Go Grey in May

Little Words Project and The Children's Brain Tumor Family Foundation (CBTFF) have designed a "Grey Matters" bracelet to be worn in the month of May by those currently battling a brain tumor, supporting a fighter, or grieving a warrior. The bracelets retail for \$18.00 and can be purchased online through the CBTFF. 30% of the profits will be donated back to the CBTFF.

Prettystore.org has also created limited edition "Go Grey" beaded bracelets available until supplies run out. 100% of the proceeds from all Pret\*ty store purchases directly benefit the TLC Foundation.





# Event Updates



On November 11, **The Joshua Bembo Project** hosted Music For Life: A Concert for a Cause. The event featured Jon Jovan, award-winning Broadway performer, at the Calgary Banquet Hall in Waldorf, Maryland. This amazing fundraising event was just one of the several projects in support of their continued efforts to find a cure.

**The Cristian Rivera Foundation** hosted a sold-out event at their Ninth Annual Celebrity Gala at Capitale on November 15. This fundraiser included a fully-catered dinner, passed hors d'oeuvres, open bar, entertainment, awards presentations and more. The exciting event also featured live and silent auctions with rare items and experiences, such as a dinner catered by Celebrity Chef Alex Garcia.



**The Isabella Rose Foundation** is grateful to everyone who donated to the care package project for the Valley Hospice Butterflies program. Brianna Romano, Isabella's sister, was able to drop off more than 100 care packages to patients under hospice care and she has received some very special thank you letters from the recipients. Brianna was able to garner enough support that she added an additional 50 care packages to her delivery.

**McKenna Claire Foundation** was the recent beneficiary of Wipeout Kids Cancer where kids and adults had a great time racing each other on a challenging inflatable obstacle course with some added twists. In addition, the MCF hosted an "Ohana Night" paint party at Mama's on 39 (Huntington Beach). "Ohana means family, and family means nobody gets left behind or forgotten." - Lilo.



Congratulations to the first ever **Children's Brain Tumor Project NY Marathon Team** — Mara Harris and John Naso! Well done. While small, this team raised over \$15,000! A special angel was cheering them on! Thanks to all who supported them and helped to make a difference. Hope their wonderful effort is the start of a marathon tradition for the CBTP!

For the month of March, our friends at **Veronica Beard** selected the Children's Brain Tumor Project as their monthly #VeronicaGivesBack recipient. Featuring the inspiring story of CBTP supporter Tara Lipton and her son, Walker, the retailer donated \$10 back from every purchase in the month of March, resulting in more than \$8,500! Thanks to all those who shopped for a cause at Veronica Beard this May.



**Olivia's Toy Drive**, in memory of Olivia Boccuzzi, was held at St. Bernadette Catholic Academy, where they collected an incredible amount of toys and gift cards from the generous and loving community of St. Bernadette. The tremendous efforts of the teachers and students helped to spread love and happiness to so many children that spent the holidays in a hospital fighting a battle NO child should have to endure.

## Upcoming Events

May 12 – Christian Koehler Lacrosse Tournament  
May 15 – Head for the Cure Strides and Sips  
May 17 – Team Campbell Rock for Hope  
May 19 – Chad Tough Gala  
May 19 – McKenna Claire Foundation Party with Purpose  
June 3 – Olivia Boccuzzi 5K  
June 9 – Cristian Rivera 5K  
June 9 – BANDs Together Against Childhood Cancer

June 11 – NY Yankees Hope Week  
June 16 – Lyonhearted Foundation Kickball Tournament  
July 21 – Cristian Rivera Freestyle Flashback Boat Ride  
August 4 – Muddy Puddles Mess Fest  
September 15 – TLC TYathlon (Triathlon and 5K)  
October 16 – No Laughing Matter – A Night of Comedy for the CBTP  
November 4 – NYC Marathon  
November 14 – 10th Annual Cristian Rivera Celebrity Gala

Be sure to check the CBTP calendar for details and updates. If you're planning an event, let us know—we'd love to include it!

[ChildrensBrainTumorProject.org/cbtp/events/](http://ChildrensBrainTumorProject.org/cbtp/events/)

REMEMBER: If you hold an event, email details and photos to [info@childrensbraintumorproject.org](mailto:info@childrensbraintumorproject.org) so we can include them in our next newsletter.

[ChildrensBrainTumorProject.org](http://ChildrensBrainTumorProject.org)

## Dr. Greenfield Named Vice Chair of Academic Affairs

Dr. Philip Stieg, Neurosurgeon-in-Chief of NewYork-Presbyterian/Weill Cornell Medical Center and director of the Weill Cornell Medicine Brain and Spine Center, has appointed Dr. Jeffrey Greenfield as Vice Chair for Academic Affairs in the Department of Neurological Surgery. In his added role, Dr. Greenfield will oversee and manage all of the department's diverse educational programs, with particular focus on the academic achievements of our medical students, neurosurgical residents, and junior faculty.

This newly created position reflects the importance the department places on both academic success and the mentoring of a new generation of neuroscientists. As Vice Chair for Academic Affairs, Dr. Greenfield will ensure the quality of all educational programs and their compliance with regulatory requirements as well as manage the administrative needs, policies, and procedures of these programs. He will advise Dr. Stieg on priorities, management, and support for educational programs across the department and will provide metrics on all departmental CME activities.

Dr. Greenfield graduated from Amherst College magna cum laude in neuroscience before receiving his M.D. and Ph.D. degrees from the Weill Medical College of Cornell University. Following completion of his neurosurgical residency and chief residency at NewYork-Presbyterian Hospital/Weill Cornell Medical Center, Dr. Greenfield received further training in surgical treatment of brain tumors, epilepsy, spinal dysraphism, complex spinal column injury, spinal cord tumors, and fetal surgery for myelomeningocele at The Children's Hospital of Philadelphia. In his position on the Weill Cornell Medicine pediatric neurosurgery team, Dr. Greenfield specializes in the treatment of Chiari malformation and is the director of the Chiari CARE program. He is also the co-director of the Children's Brain Tumor Project, where he leads a research team searching for new treatments for rare and inoperable pediatric brain tumors.



### From the Desk of Cindy Campbell

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Children's Brain Tumor Project. I was planning and executing multi-faceted fundraisers and attending research conferences across the country. I felt alive, invigorated and hopeful, again. I became confident that we can do more to advance cures for children with brain tumors, and that confidence has only grown, since. When the opportunity to become part of the team at Weill Cornell Medicine presented itself, I couldn't have felt more excited about the prospect.

I entrusted Dr. Jeffrey Greenfield with the care of my son while he was in treatment, and he was the most loving and compassionate of all his caregivers. It is hard to find the words to express how it feels knowing that he now entrusts me with the care of The Children's Brain Tumor Project. I have walked beside him every step of the way as this initiative grew, and I am confident that we are at a point where this lab will rise among the best in the world as a game-changer in the research landscape for children with rare and inoperable brain tumors. I hold myself accountable to each and every family that supports this project, and my renewed hope is driving me to do nothing short of my absolute best, every single day.



Follow the CBTP on Facebook

### CBTP Supports H.Res.69

H.Res.69 - The National DIPG Awareness Resolution is the first step toward generating widespread action, which leads financial support for funding the best research. That's why the Children's Brain Tumor Project supports H.Res.69 to officially establish DIPG Awareness Day as May 17 (which also happens to be our very own Caitlin Downing's birthday).

H.Res.69 was recently introduced to congress by Rep. Stephen Knight (CA) and we are asking our community to put forth a concerted effort via social media sharing and letter-campaigning to support these efforts.

As written in the resolution, H.Res.69 would ensure that congress:

- (1) supports the designation of "DIPG Awareness Day";
- (2) encourages all people of the US to become more informed about DIPG and the current challenges to the medical research system in designating sufficient research funding for pediatric cancers;
- (3) supports expanded research to better understand DIPG, develop effective treatments, and provide comprehensive care for children with DIPG; and
- (4) encourages the National Cancer Institute to elevate their consideration of mortality rate of a type of cancer as well as the life years lost as significant factors considered during the grant application process.

Please write your local representatives and ask them to support H.Res.69 and share via social media with the hashtag #HRES69 to encourage your followers to do the same. Visit [childrensbraintumorproject.org](http://childrensbraintumorproject.org) for a letter template and more information.