



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

From the Desk of...
Kelly Fisher

"Your marriage must be so strong."

I have heard this statement often over the past three years. My 3-year-old daughter, Allie, died of gliomatosis cerebri in June of 2013. My husband, Kyle, and I are still together, and our marriage has survived this tragedy. But the truth is that it has been extremely difficult to rebuild our lives after cancer stole so much from us.

Kyle and I married on June 12, 2004. We both had had easy childhoods and neither of us had ever struggled in life. Our marriage started out the same way. It was easy. We loved each other. We had good jobs. We got a rescue dog. We wanted kids, and I had no trouble getting pregnant. Our first daughter, Evie, was born. Then, a few years later, we were blessed with another daughter, Allie. Both girls were born healthy.



Allie and Kelly

Evie and Allie were quite the pair. Evie loved being an older sister to Allie. Evie would come home from kindergarten wanting to teach Allie what she had learned that day. Evie's favorite thing to do was to have Allie spend the night in her room. And Allie just loved everything about life. She was high energy but always easygoing and full of joy. Allie hugged everyone she met and often said, "I love everybody in the whole entire world!" Kyle and I had everything, and we knew it.

A violent wind blew in unexpectedly and our fairy tale went completely off script. One morning I went to wake Allie up, and she was unresponsive and seizing. Suddenly Kyle and I were living in a children's hospital and watching Allie suffer: the endless tests, her tiny bruised veins, and medication that changed her personality. Kyle and I always agreed on Allie's treatment plan, and we were such a good team during those long hospital stays. But we were also exhausted and terrified for what the future held. We watched as the brain tumor chiseled away at Allie's function over 12 weeks. First her energy went, followed by her speech, and then her ability to walk. The seizures became relentless and her bowels shut down. During Allie's final stay at the hospital, she coded and our worst fears had come true. The staff was able to put her on life support, and we knew this was the end. We were powerless to save our precious daughter from the aggressive tumor.

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Laboratory Update

Mark Souweidane, M.D., and
Jeffrey Greenfield, M.D., Ph.D.

Partnership Is Powerful

One thing we've known from the beginning of our research on pediatric brain tumors is that none of us will be able to do this alone. We must work too fast, and find answers too quickly, to operate in silos. The old model, in which researchers guard their work carefully until they publish results, simply won't work.

We are so glad that our colleagues in this quest feel the same way. Across the street and around the globe, investigators are working with us—and welcoming us into their projects—in ways that you don't often see in medical research. Here are two such partnerships that we'd like to highlight:

In May we were invited to join the Children's Brain Tumor Tissue Consortium (CBTTC), a multi-institutional research program whose mission is to develop a bank of high-quality brain tumor specimens. This collaborative effort is centered at the Children's Hospital of Philadelphia and also includes Seattle Children's Hospital, the Children's Hospital of Pittsburgh, the Ann & Robert H. Lurie Children's Hospital of Chicago, Benioff Children's Hospital at UCSF, and the Lucile Packard Children's Hospital at Stanford University, with satellite operations at Meyer Children's Hospital in Florence, Italy, and the Cancer Institute of New Jersey at Rutgers. We are proud to have been invited to participate as one of the primary member institutions of this consortium, which will make it possible to obtain cell lines and their related genomic data for further study—the results of which we will in turn make available to the other partners and the global research community.

Closer to home, we are working with Drs. Ching Tung, Richard Ting, and Ben Law of the Department of Radiology on molecular imaging, drug labeling, and nanofiber conjugation. This collaborative team already has one manuscript ready for submission, and was recently awarded a \$250,000 grant from Alex's Lemonade Stand to develop the work. Together, we will find answers. Onward,

HUMANS OF NEW YORK

Those of you who follow the Humans of New York photo project on Facebook don't need to be told what happened last month, when a two-week-long story about Memorial Sloan Kettering's pediatric cancer service broke all kinds of traffic records. The final two days of the series, which had been developed as a fund-raiser for MSK, featured first Dr. Souweidane and then Julie, the mother of a former DIPG patient. The result was a veritable tsunami of comments, likes, shares, and donations. What started out as a \$1 million campaign ended up with a total \$3.85

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"I've been on a mission for seventeen years. It's my holy grail. I'm trying to cure a brain tumor called DIPG that kills 100 percent of the children who have it. It only affects 200 kids a year so it's never gotten much attention. But if you saw a child die from DIPG, you'd understand why I care so much. It's awful. It's just awful. Parents come to me in droves asking me to help. They say: 'This can't happen. Please do something.' But there's nothing I can do. Their child will be dead in a year. It's horrible. It's been a very tough thing to care about. I didn't get into neurosurgery to watch kids die. I chose this job to heal people. And DIPG has been seventeen years of watching kids die. It's a very dark place to work. But if I can find a cure, so much of that pain will be paid back in a single instant. And on that day I will feel like there has been some justice."

See all four of Dr. Souweidane's posts, along with Julie's DIPG posts, on humansofnewyork.com or facebook.com/humansofnewyork

Our 2016 "Summer Sprint"

This summer is going to be an amazing one in the Children's Brain Tumor Project laboratory. Thanks to grants and gifts from families and foundations, we will have six summer researchers conducting several different lines of investigations, which will give our research a tremendous boost.

Emilie George and Raymond Chang are testing new drugs and drug combinations against gliomatosis cerebri and DIPG. Emilie is funded by a summer fellowship grant from the St. Baldrick's Foundation, and Raymond by a grant from the American Brain Tumor Association (ABTA).

Umberto Tosi is using PET imaging to evaluate the cancer drug dasatinib and molecularly targeted compounds such as panobinostat, modified to fluoresce, in mice models with DIPG. The position is funded by the Alex's Lemonade Stand Foundation (ALSF) Pediatric Oncology Student Training (POST) program.

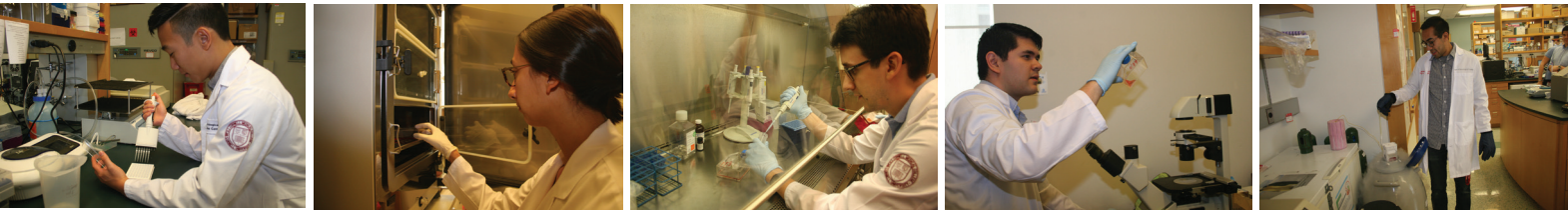
Christopher Marnell will test two-dimensional peptide-based nanofibers (NFP) as drug carriers to slow clearance rates and improve the distribu-

tion of chemotherapeutics injected into a DIPG tumor. His work is funded by the Neurosurgery Research and Education Foundation (NREF) of the American Association of Neurosurgeons (AANS).

Kunal Garg is working on a project studying the transformation of low-grade gliomas into malignancies, under Dr. Greenfield's mentorship. His work is funded by Weill Cornell Medical College.

The team will soon be joined by Matthew Bernstein, a student intern dedicated to acquiring samples of thalamic gliomas for future study. Matthew's work has been funded by the Samuel Jeffers Childhood Cancer Foundation.

Many thanks to three members of the Cristian Rivera Foundation board of directors for stepping up to help supply these researchers with the materials they need to conduct their research. Board members Darlene Rodriguez, Andy Epstein, and Craig Serra each made personal donations, and Craig arranged a matching gift from Pfizer. With their help, we are able to supply our summer fellows with the drugs, animal models, and infrastructure they need to do their work.



Left to right: Raymond Chang, Emilie George, Umberto Tosi, Christopher Marnell, and Kunal Garg are working on the "summer sprint" in the CBTP lab.

Family Update

Spring brought with it a new season of the races, tournaments, and festivals that help spread the word about the Children's Brain Tumor Project and raise much-needed funds. Many thanks to the families that host these events, and to the communities that continue to support them. We could not do our work without you!



The Christian Koehler Foundation got some nice coverage in *Newsday* for its 2016 Lacrosse Tournament. Chris and Janine Koehler host this event each year in memory of their son, and they have donated a total of more than \$40,000 of the proceeds to the Children's Brain Tumor Project. Our thanks to Chris and Janine, as well as to the players and families who continue to turn out to support us each year.



The Olivia Boccuzzi Foundation hosted the annual kids' marathon and festival in Brooklyn on June 4. This event supports not only the CBTP but local families with children diagnosed with serious illnesses. We are so grateful to the Boccuzzis for their continued support.

Also on June 4, but on the other side of the country, the McKenna Claire Foundation hosted its annual Party with a Purpose fund-raiser, this time the Bootlegger Ball. We continue to be amazed at how our project has grown from a few researchers working in borrowed lab space to being an international participant in advancing the science, supported by families from coast to coast. We are deeply thankful to Dave and Kristine Wetzel for their support.



The third annual "Cheering for Caitlin" event was bigger than ever this year, with more than 1,000 runners, walkers, and chalk artists participating in Oviedo, Florida, and 150 more taking part from afar. Supporters from coast to coast participated in virtual events—including Dr. Souweidane and family, who participated from Toronto. Now part of the Children's Brain Tumor Family Foundation, the event has expanded from the original 5K event in 2014 to a family festival that raised more than \$40,000 for the CBTP this year. Many thanks to Denise Downing, Katie and Joni Chandler, and all the many volunteers who give their time to make this event such a success.



The Cristian Rivera Foundation raised \$20,000 for the Children's Brain Tumor Project at a cocktail party generously hosted by NBC anchor Darlene Rodriguez and her husband, David. This was the second annual cocktail party, and we are so grateful to Darlene and David, and to John Rivera, for their continued support.

REMEMBER: If you hold an event, email details and photos to info@childrensbraintumorproject.org so we can include the event in our next newsletter.

Upcoming Events

- July 30: Muddy Puddles Annual "Mess Fest" (Camp Kiwi, Mahopac, NY)
- August 11: Cocktails for Cam (The Beatrice, NYC)
- August 28: Head for the Cure 5K Run/Walk (Kansas City, MO)
- September 10: Somerset Patriots Childhood Cancer Awareness Game (Bridgewater, NJ)
- September 17-18: Rock'n'Roll 5K and Half Marathon (Philadelphia, PA)
- September 17: TLC Foundation's TYathlon (Mahopac, NY)
- October 6-8: Allie's Sale (Overland Park, KS)
- October 8: Rock'n'Roll Half Marathon (Brooklyn, NY)
- October 14: McKenna Claire Foundation Play It Forward Golf Tournament (Huntington Beach, CA)
- October 15-16: Rock'n'Roll Half Marathon (St. Louis, MO)
- November 4: Elizabeth's Hope Fifth Anniversary Cocktail Party (Bowery Hotel, NYC)
- December 3-4: Rock'n'Roll Kids Rock, 5K, 10K, Half Marathon, Relay, and Marathon (San Antonio, TX)

Be sure to check the CBTP calendar for updates. If you're planning an event, let us know and we'll include it. ChildrensBrainTumorProject.org/cbtp/events/

New Publication From the CBTP

American Journal of Neuroradiology (Published online in advance of print)

Dr. Souweidane co-authored "A Novel Methodology for Applying Multivoxel MR Spectroscopy to Evaluate Convection-Enhanced Drug Delivery in Diffuse Intrinsic Pontine Gliomas." The research examines a new way of evaluating "local response" (the reaction to the drug at the infusion site itself) in Dr. Souweidane's clinical trial of convection-enhanced delivery (CED). Evaluating local response at the infusion site is critical because it may indicate that the drug had some effect at the tumor site even when whole-tumor response is undetectable. As Dr. Souweidane's clinical trial approaches its conclusion, interpreting and evaluating results will be key to determining next steps. This important paper establishes that multivoxel MR spectroscopy may be used to find potential value in a drug that might otherwise be discarded in the search for a cure.



Elizabeth's Hope and the Children's Brain Tumor Project

The CBTP was founded in 2011 when the dedication of Dr. Mark Souweidane and Dr. Jeffrey Greenfield, neuroscientists at Weill Cornell Pediatric Brain and Spine Center, met up with the determination of Elizabeth Minter, a remarkable young woman diagnosed with gliomatosis cerebri. Inspired by Elizabeth, Drs. Souweidane and Greenfield joined forces on a monumental task: finding new treatment options for rare and inoperable brain tumors that strike children, adolescents, and young adults. These tumors strike "only" a few hundred patients a year, so they don't get federal funding or support from larger foundations. That's why we say the CBTP is "powered by families"—because families know all too well that even one child is too many to lose.



Elizabeth Minter (1991-2012)

Ways to Give

1. By Check

You may make your gift by check, payable to Weill Cornell Medical College, with "Children's Brain Tumor Project" in the memo area.

Please mail checks to:
Ana Ignat, Dept. Administrator
Weill Cornell Pediatric Brain and Spine Center
525 East 68th Street, Box 99
New York, NY 10065

2. By Credit Card

Visit childrensbraintumorproject.org to use a credit card to make a secure online donation or a monthly pledge.

3. Stock, Matching Gifts, and Other Options

To discuss corporate matching programs, donations of securities, or other options, please contact Ana Ignat, Department Administrator, at ani7003@med.cornell.edu.



Follow the CBTP on Facebook

From Kelly Fisher (continued from page 1)

We spent our ninth wedding anniversary bedside in the pediatric ICU with Allie on a ventilator. We had to make decisions that no parents should ever have to make. Once the end-of-life plan had been put into place, the sounds on the vital machines were turned off. Kyle and I lay on each side of her and sang her favorite song, "Baby Beluga," as the monitors eventually showed no signs of life. That is how our fairy tale ended. It was exactly nine years from our wedding date.

In the first month after Allie passed, we contacted Dr. Jeff Greenfield at the Children's Brain Tumor Project. Kyle and I both agreed that we wanted to donate Allie's brain tumor tissue in hopes of helping others. We knew it needed to be studied and better understood for the next child who would be diagnosed with gliomatosis cerebri.

Adjusting to our new reality at home started out ugly. Distance set in between Kyle and me, and I shut down emotionally. We worked more and talked less, and I wanted to spend more time alone. It was the only way I could find to still function with the heavy grief, and deep down, I wanted to run away. This wasn't the life I had signed up for, and I was desperate to escape it.

However, Kyle and I were lucky. The pieces were already in place for us to survive this together. We had been surrounded by awesome people our entire lives. Friends and family rallied to support us, and each did what was in their power to help. We started sharing Allie's story to raise funds for the Children's Brain Tumor Project. We found strength from this and a renewed purpose. We began to see that Allie's beautiful spirit lived on as we clawed our way back to each other. Our bond is richer now, and we share a perspective on life that very few can understand. With time and grace, we learned to love and accept the brokenhearted versions of each other.

As I reflect back on our struggles, I wonder how many other families have been ripped further apart from a pediatric brain tumor. Kyle and I are very fortunate to have pulled through this together, but not every marriage will survive the aftermath of childhood cancer. We are also energized to save the next young family from enduring such a hopeless and unfair situation.

And, in only three years since Allie's death, we have already witnessed incredible progress being made. We have toured the new CBTP lab space, we have seen the data from the sequencing of every tumor sample, and we have viewed the live gliomatosis cerebri cells under the microscope. We have also united with other families from across the country to form the Children's Brain Tumor Family Foundation, a 501(c)(3) organization. The foundation is an all-volunteer charity committed to raising awareness and funds for the Children's Brain Tumor Project.

The fairy tale may have ended, but our new story has so much more depth. Our purpose is clearly defined. Together with the researchers and the other families of the Children's Brain Tumor Project we fight, we rally, and we work toward a cure.

Kyle and I just celebrated our 12th wedding anniversary full of hope, and we thank every Children's Brain Tumor Project supporter for that gift.

Kelly