



Elizabeth Minter (1991-2012), Founder of Elizabeth's Hope

From the Desk of...
Rob and Dana MacNaughton

For parents of a child who has had a brain tumor, our story thus far has been a happy one. We are thrilled to report that our son Stuart has been NED (No Evidence of Disease) for five years. Stuart's journey, however, has—and will continue to be—difficult. Brain cancer has affected him physically, mentally, and emotionally. Yet, he is with us, and thriving in many ways. For this we are very grateful.

Even if a child is “lucky” enough to have a brain tumor that can be removed (partially or entirely), therapeutic choices are limited and highly toxic. When Stuart was starting treatment there was no efficient way to attack the tumor cells left in his brain, so it was recommended that he receive some rounds of “high-dose” chemotherapy. An oncologist once described it as unleashing a nuclear bomb in his body in order to wipe out a very small target. But we realized how fortunate we were to have that option.



Stuart MacNaughton

During our initial journey through the world of pediatric brain tumors, we spent the better part of a year on the ninth floor of Memorial Sloan-Kettering. While we were inspired by the miracles being performed by the amazing doctors and nurses, in many other ways it was the one of the saddest places on Earth. So many of the children (and parents) we met each day did not have the same sense of promise, optimism, or hope that we had for Stuart.

In many cases the children had relapsed, or had brain tumors that were inoperable—the worst prognosis. While advances have been made in other cancers, survival rates for certain pediatric brain tumors have not improved. Research remains grossly underfunded, and that is simply not acceptable. All children deserve a chance at a long and full life. It's time to make pediatric medical research a priority.

For some time it has been our desire to get behind an organization that is doing something powerful to change the outcome for these
(continued on page 3)

Laboratory Update

Dr. Mark Souweidane and

Dr. Jeffrey Greenfield

Co-directors, Children's Brain Tumor Project

One of the interesting things about scientific research is that you don't always know what you'll find when you start looking at something, and you can't predict what seemingly minor discovery will turn out to be a stepping stone to a much larger one. That's what makes it so important to gather data, analyze it, and turn it over dozens of times, looking for clues you may not recognize at first or new questions you hadn't previously thought to ask.



Drs. Greenfield and Souweidane

We're proud to be contributing to the advancement of neuroscience at a faster pace these days, as the additional resources made possible by your donations allow us to gather and analyze more and more data, with some surprising results. Our team recently published three papers on new findings that add to the knowledge base on pediatric brain tumors:

The September issue of *Neurosurgery* will report on a study directed by Dr. Greenfield. This new study looked at 97 children—the single largest cohort of children ever studied—with a malignant brain tumor called glioblastoma. While beginning a more detailed genomic analysis, they first investigated more mundane parts of their clinical course such as surgery and radiation. The data confirmed in children what was already known for adults, which is that total resection leads to longer survival times than partial. That may be intuitive, but studying the data produced another, more puzzling result: When tumors can be totally removed, the improvement in outcomes is significantly greater for girls than for boys. Why? We don't know... yet. This gives the CBTP an important clue as we begin analyzing specific parts of these tumors' chromosomes and genomes, looking for potential clues as to where the gender bias might arise and if this could offer new targets to investigate as therapeutic options.

The July issue of the *Journal of Neurosurgery Pediatrics* reports on a case of a young man whose MRI had shown a tumor in the region of the midbrain called the tectum. An endoscopic biopsy, however, re-
(continued on page 2)

Laboratory Update

(continued from page 1)

vealed additional lesions on the floor of the third ventricle that turned out to be low-grade gliomas. This surprising find not only points out limitations of MRI (which is an excellent imaging tool), but also suggests the tumors spread through the cerebrospinal fluid. Analyzing these samples genetically also offers a fascinating glimpse into a tumor that *looks* benign, but that *spreads* like a malignant tumor! All these clues are part of the outside-the-box thinking that our genomic tools and resources allow us to investigate. Dr. Souweidane is the senior author of this paper.

The June issue of the *Journal of Neurosurgery* includes a study that looked at radionecrosis, a devastating complication of external beam radiation that causes cell death months or even years after treatment, making radiation therapy particularly risky for young children. This new study, co-authored by Dr. Kramer of Memorial Sloan-Kettering and Dr. Souweidane, looked at the incidence of radionecrosis in young patients treated with intraventricular compartmental radioimmunotherapy (cRIT) instead of or in addition to external beam radiation. The study found none of the neurological damage caused by radiation necrosis in those treated with cRIT. This new finding makes radioimmunotherapy a potentially safer weapon against pediatric brain tumors than external beam therapy. It's part of our commitment to finding not only more effective but also gentler therapies for our children.

Each finding we can publish not only helps our own team as we strive to develop new therapies for rare and inoperable brain tumors, it also goes forth into the scientific community at large, where it just might mean a safer treatment for a child today, or a new piece of the puzzle that will fit into another piece a year from now. We're proud to be contributing, and we thank our donors for making it possible.

Onward,

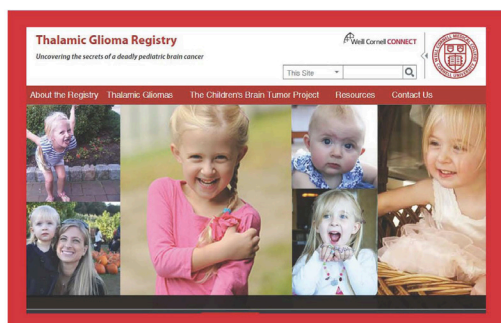
M.M. Souweidane

Registry News

It's official: This summer the Children's Brain Tumor Project launched its second pediatric brain tumor registry, this one for thalamic gliomas. We are so thankful

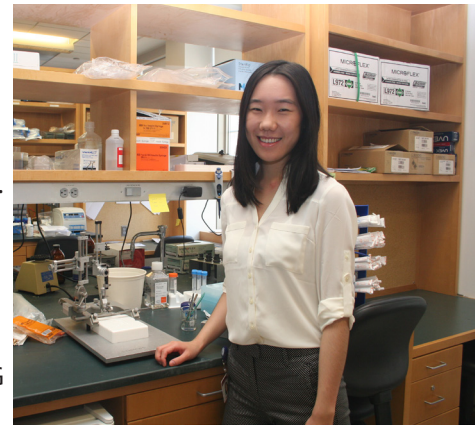
to Katherine Godfrey, whose generosity made the registry's new online presence possible. Katherine lost her daughter, Fiona, to a thalamic glioma in 2013. When Fiona was diagnosed, she says, it was impossible to find information about this rare tumor. We hope the new site fills some of that need for new families facing this diagnosis. The registry joins the Gliomatosis Cerebri International Registry site as part of our global effort to study these rare tumors.

Visit the new registry site at thalamicgliomaregistry.com



New Medical Student Fellow to Investigate DIPG Drug Resistance

Medical student Linda Wu is only 25, but she has a long-standing interest in oncology and neuroscience. Wu is a graduate of Cornell University in Ithaca, where she majored in biology with a concentration in neuroscience. She was then accepted into Weill Cornell Medical College, where she has completed three of her four years of study. Between her first and second years she worked on a pediatric neurology research project, and this summer she joins the CBTP lab full-time for a year to work on Dr. Souweidane's DIPG research.



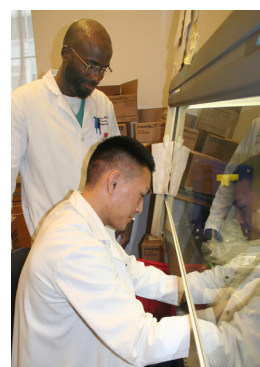
It might sound strange for a medical student to be taking a year off from her studies instead of spending that year completing her medical degree, but it's not at all surprising for Wu. Her passion for oncology research made this an easy choice once she heard about the new pediatric neurosurgery Medical Student Fellowship, made possible by a grant from the Rudin Foundation. After her application was accepted by Dr. Souweidane, Wu immediately dug into the project started by Ranjodh Singh (who returns to his medical studies this fall after his own year in the CBTP lab).

Singh spent the past year testing combinations of drugs to fight DIPG; Wu will continue that work by focusing on how tumors might develop resistance to those drugs. Her research will involve monitoring changes along the molecular pathway and investigating which inhibitors would work to defeat the tumor's resistance.

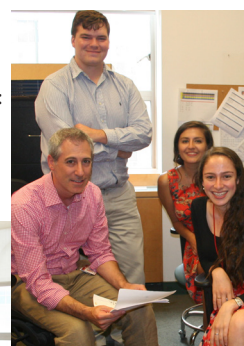
Wu will return to medical school in the fall of 2016 to complete her fourth year and earn her medical degree.

Other Happenings at the CBTP

Things are hopping in the lab these days, with new investigations going on and with summer help and new hires giving us the capacity to get more work done. We've recently welcomed lab technician and manager Melanie Schweitzer; instructor Ude Macchani, PhD; medical student Shaikha Al-Qahtani; research assistant Rachel Yanowitch; summer clinical interns Samantha O'Brien and Nicole Michelson; and summer marketing intern Michael Sapunor.



Left: Sixth-year resident Babacar Cisse, MD/PhD, oversees fellow Raymond Xu preparing samples of ependymoma cells for study; below: Dr. Prajwal Rajappa and lab manager Melanie Schweitzer; right: Dr. Greenfield and our summer interns Michael, Samantha, and Nicole.



The Bronxville Road Race 2015

The CBTP is so grateful for all the support and help we receive from our families and their communities. We are deeply indebted to supporters around the country—from as far away as Kansas, California, and Florida, and from many communities right here in New York, New Jersey, and Connecticut—but we have a special place in our hearts for the tiny Westchester village of Bronxville. The support of this community (Elizabeth Minter's hometown) for *Elizabeth's Hope* gave us the momentum to launch the Children's Brain Tumor Project, and we are delighted to be hosting our second annual fund-raiser there. Coincidentally, Bronxville is also home to another CBTP family, the MacNaughtons, as well as the co-director of the project, Dr. Jeffrey Greenfield.

As anyone who's ever planned an event like this knows, keeping costs low is critical to maximize the funds that ultimately go to support the cause. We are so very thankful to all the Bronxville businesses, large and small, who have stepped up to help us host this event again this year, footing the bill for our expenses in order to allow every dollar raised in donations to go directly to the research. As this newsletter went off to the printer, we were delighted to have commitments from the following generous sponsors, the majority of them from Bronxville:

Houlihan Lawrence	Womrath Bookshop
Pepe Auto Group	J. McLaughlin
Bronxville Running Store	Boyden Global Executive Search
KIND Snacks	Underhills Crossing
Rivkin Radler LLP	Gregory Sahagian & Son
The Nella Company	Awning Company Inc.
Inspirato	Eastchester Italian-American Citizens Club
Kensington Paper	Korth and Shannahan
Concordia College	Painting Inc.
Sarah Lawrence College	Pure Barre
Braxton Engineering	Bronxville Farmers' Market
Ballet Arts	Silver Spoon
Silk Road	Boo Games
Maison Rouge	
Soul-Cycle	

We are also grateful to the the Bronxville School, the Village of Bronxville, the Bronxville Police Department, the Westchester Parks Department, and the Village of Tuckahoe for their help and support in producing this event. We couldn't do it without you!

Please visit childrensbraintumorproject.org to register to walk or run, to volunteer to help with logistics, or to make a donation. Our sponsors page on that site will be updated regularly as new supporters sign on. Thank you so much!



From Rob and Dana MacNaughton

(continued from page 1)

children, so that even kids with the most difficult-to-treat brain tumors have hope and a reason to look forward to the future. We are also interested in supporting research into effective yet less toxic treatments, so that children like Stuart wouldn't have to pay such a high price for survival.

The Children's Brain Tumor Project is that organization. The research being conducted by Drs. Greenfield and Souweidane and their teams is incredibly exciting and is already changing the playing field for children diagnosed with a brain tumor. What's more, their work may have applications in treating various other kinds of tumors.

It was truly amazing for us to find this project right in our own backyard. As Bronxville residents we are already part of a community that has shown itself to be unwavering supporters of *Elizabeth's Hope* and the groundbreaking research it funds at Weill Cornell. Being a part of this Bronxville community gives us even more hope, since we are surrounded by loyal supporters who continue to put their faith in what Elizabeth Minter started with Dr. Greenfield.

We are proud to support *Elizabeth's Hope* and the Children's Brain Tumor Project, and grateful to be part of a community that is so dedicated to ensuring a brighter future for our children.

Dana MacNaughton

Robert J. MacNaughton

Family Corner by Kathleen Clark

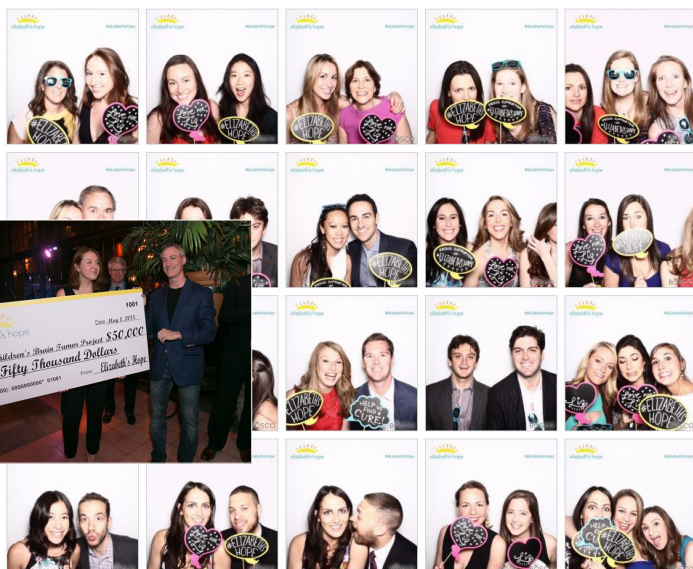
It's been two years this summer since my father, Daryn Clark, was taken away from us. I remember him looking me in the eye and saying he wanted to be remembered, but that "I don't want to be remembered as the guy who had brain cancer." I'm proud to say he is remembered every day, and that his thumbprint will be a part of research for years. His picture hangs in the CBTP research lab for all the researchers to see as they enter, to remind them that these "children's cancers" are not limited to children. My family's loss is different from what most of the other CBTP families have suffered, but my determination is like everyone else's in the group—to fight for better, more effective treatments, so we can stop these tumors from robbing families of their loved ones.

We would love to hear from other family members, including siblings, grandparents, and others who would like to share their experiences. Please email your stories to info@childrensbraintumorproject.org.



Event Highlights

Elizabeth's Hope Cocktail Party



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.



Ways to Give

1. By Check

You may make your gift by check, payable to Weill Cornell Medical College. Please indicate "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

Cheering for Caitlin Remembrance 5K



Olivia Boccuzzi Foundation "Stomp Out Cancer" Kids' Marathon



Christian Koehler Foundation Lacrosse Tournament



Upcoming Events

August 8: TLC Foundation's Muddy Puddles MessFest (Camp Kiwi, Mahopac, NY)

August 9: Fly a Kite Foundation's Brunch and Beyond (Oceanside, NY)

August 13: Cocktails for Cam (New York, NY)

August 15: Women's Mud Run, featuring Team Olivia (Aviator Sports, Brooklyn, NY)

August 23: Head for the Cure 5K, featuring Team Little Owl (Overland Park, KS)

September 12: Bronxville Road Race (Bronxville, NY)

September 12: Somerset Patriots GOLD game, hosted by Team Campbell (Bridgewater, NJ)

September 19: TYathlon and 5K (Mahopac, NY)

October 8–10: Team Little Owl's Allie's Sale (Grace Covenant Presbyterian Church, Overland Park, KS)

November (date TBD): Cristian Rivera Foundation Gala (New York)

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

