



Children's Brain Tumor Project

powered by families



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

October 2014

From the Desk of...
David Bernstein

I read with great interest Cindy Campbell's story in the previous issue of this newsletter about the devastating heartbreak her family endured during the loss of their beautiful 5-year-old son Ty. One can't fathom why these deadly diseases take our children from us at such a young age, nor can anyone fully understand the toll it takes on the family and community throughout the entire journey of care.

My family lost our beloved Zachary on March 12, 2014. He was diagnosed with a diffuse intrinsic pontine glioma (DIPG). The disease took our beautiful boy in nine months. He was 11 years old. As parents, we do everything we can to try to insulate and protect our beautiful children, and nurture them into the adolescents and adults we dream of. Unfortunately, for some of us there are those unforgiving moments in which we join the elite "club" (not by choice) of those who truly understand the emotional roller coaster, and who know what we would give up for "One More Day."



Zachary Bernstein
2002-2014
DIPG
Children's Brain Tumor Project
powered by families

Zachary was one of the children commemorated on a banner at The Bronxville Road Race last month.

September was Childhood Cancer Awareness month, a time to honor and remember children and families affected by these rare diseases, and to help give kids with cancer better outcomes by supporting the foundations, charities, nonprofits, hospitals, and other organizations that share the mission of raising funds for research.

After Zachary passed away, I had heart-to-heart conversations with our medical team. I asked them, "how far off are we from finding a cure for children with DIPG and other pediatric brain cancers?" To my surprise they all claimed we are four to six years away. My immediate question was "Why?" They all responded... "Lack of funding."

I was stunned to learn that as much progress as appears to have been made...we are still so far away from a cure. Consider this:

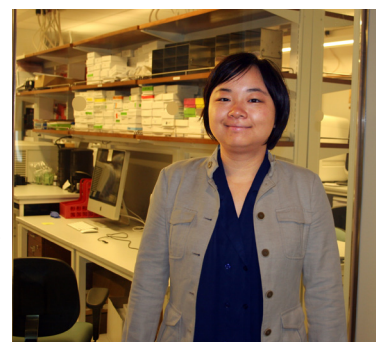
- 96 percent of federal funding for research is for adult cancers,

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Laboratory Update

Sheng Li, Ph.D.
Ty Louis Campbell Fellow

I am so grateful for the opportunity to work with the Children's Brain Tumor Project as the first Ty Louis Campbell Fellow. I thank Cindy and Lou Campbell and the TLC Foundation for funding this creative position. My passion is bioinformatics and computational biology, both of which play critical roles in decoding tumors such as DIPG, gliomatosis cerebri, and AT/RT—the cancer that claimed Ty's life two years ago.



After receiving a bachelor's degree in biotechnology from Sun Yat-sen University in Guangzhou, China, I came to Weill Cornell in 2009. I've been here for the past five years as a Ph.D. candidate in computational biology, during which time I have published research articles on high-throughput sequencing data analysis for cancer biology in *Nature Biotechnology*, *Nature Genetics*, *Journal of Clinical Investigation*, and *Genome Biology*. I've also been a lecturer in cancer genome data analysis for courses at Weill Cornell Medical College and the Institute of Computational Biomedicine's EpiWorkshop. I completed my doctoral dissertation on the topic of cancer epigenetic dysregulation, and I'll be further pursuing that research in this fellowship.

The science of epigenetics is relatively new, and it's emerging rapidly. The term refers to changes in the ways genes are expressed that don't change the DNA itself. Disruptions in the epigenome are thought to play a fundamental role in how cancer develops, but how those disruptions happen are only just now starting to be understood. Because they occur spontaneously, they cannot be predicted—which is why the rare and inoperable tumors that strike children seem to come from out of the blue. There are no known risk factors, no family history, no warning signs—just a child who is healthy one day and terminally ill the next.

For answers, we must comb through a staggering amount of data that can now be produced through sequencing and other studies. Today's high-throughput sequencing methods

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Make a donation today at ChildrensBrainTumorProject.org

Event Highlights

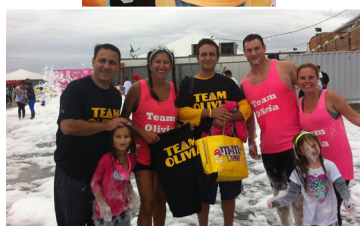


September was Children's Cancer Awareness Month, filled with fund-raising events and awareness campaigns from coast to coast. The #GoGold movement came on strong this year, with football teams sporting gold shoelaces and landmarks including the Coney Island Parachute Jump and Times Square lighting up in honor of children with cancer. Sadly, the movement did not reach the White House or the Empire State Building, but thanks to the Boccuzzi family and many others, the #EmpireGoGold campaign inspired thousands of people to raise their voices as one. Maybe next year.

Here are just a few of the events our families hosted or participated in as they went gold for September:



TEAMSean and his football teams went gold for September, and Sean made a special appearance on News12 New Jersey... The Ty Louis Campbell Foundation held a beachfront luau in Long Beach... The Olivia Boccuzzi Foundation fielded teams at the ROC (Ridiculous Obstacle Challenge, pictured at left) 5K as well as at CureFest in Washington, D.C.... The Cristian Rivera Foundation held a Monday Night Football experience with pro players Jason Pierre Paul and Antrel Rolle... Team Little Owl has been on Fox and ESPN in Kansas City



to promote Allie's Sale this month... The kids of Bernardville, New Jersey (top right), sold bracelets and cupcakes, with proceeds donated to the CBTP in memory of Campbell Hoyt... Finally, Cheering for Caitlin friends enjoyed the opening of Lemon Lily's Tea Shop, where its "Caitlin cupcake" (right) sells out daily, with proceeds donated to the CBTP.



PLUS...

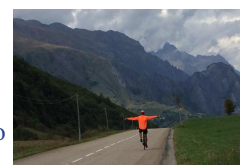
TY-Athlon

At the second annual TY-Athlon, Cindy and Lou Campbell presented Dr. Greenfield with a check for \$65,000 to support the Ty Louis Campbell Fellowship.



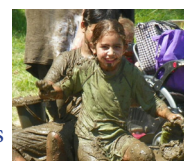
Classic Tours Charity Challenge

Denise Downing's college friend Andrew Soares never even met her daughter Caitlin, but he dedicated his ride in the French Alps to her, and to raising money for the CBTP.



MessFest

Yes, we know the MessFest is held in August, but we consider it something of a kick-off for September's events. And it's just so much fun! Many thanks to the Ty Louis Campbell Foundation and the Muddy Puddles Project for hosting this amazing day again this year.



Laboratory Update *(continued from page 1)*

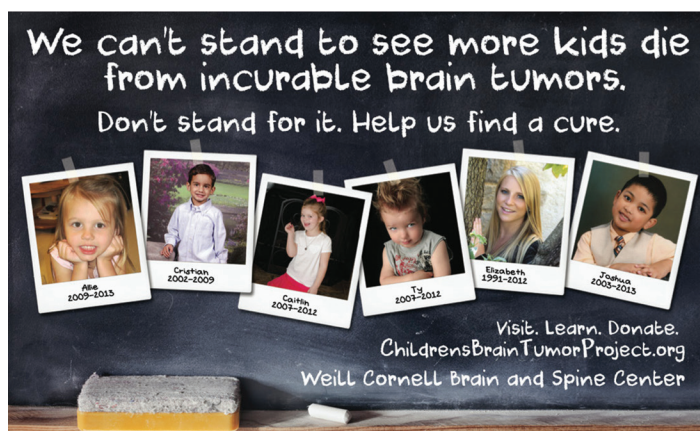
are faster and more accurate than they were even just a few years ago, but each tumor sequenced produces an avalanche of data that must be pored over and analyzed by a bioinformatics specialist in order to find answers and draw conclusions—or at least identify new pathways for future studies.

I am proud to be playing a role in the Children's Brain Tumor Project's multi-pronged research efforts—banking tissue for future study, sequencing tumors from a wide range of patients, interpreting the data produced from sequencing those samples, and then testing new drugs and new delivery methods selected specifically for that individual tumor.

The Department of Neurological Surgery is working with the Department of Pathology, the Cancer Center, and the Center for Precision Medicine here at Weill Cornell as well as collaborating with other research institutes around the world. We are working hard, together, to accomplish the goal we all share: New hope for children and families facing a diagnosis of a rare and inoperable brain tumor.

Sheryl W

Don't Stand for It

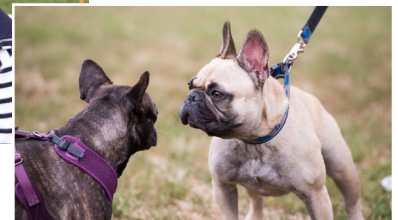
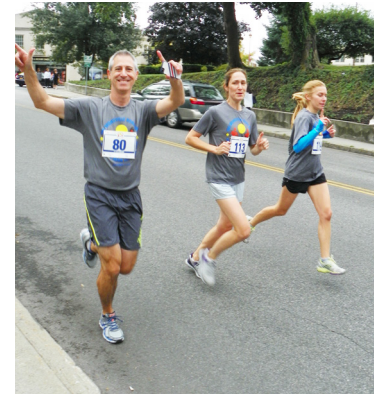


Look for our new public service ad campaign, which will be appearing this fall in *Crain's New York* as well as on the Captivate network of video screens in 700 New York office building elevators. The campaign features some of the CBTP children lost to rare and inoperable brain tumors, and urges the public not to stand for it. Many thanks to David Bernstein for arranging this amazing outreach for us at no cost.

The Bronxville Road Race

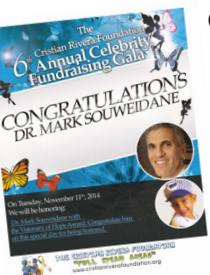
We developed a new appreciation for our families' fund-raising efforts when we hosted one of our own—it's a lot of work! But it really paid off on September 13, with the inaugural running of The Bronxville Road Race for the Children's Brain Tumor Project. Many thanks to all who helped us exceed our goal of \$100,000 that day (our sponsors are listed below, our top fund-raisers on the next page), and to all who helped us pull it off. It was a day

filled with hope, but the faces of the children lost to pediatric brain tumors kept us focused on why we do what we do. We'll let the pictures speak for themselves—visit bronxvilleroadrace.smugmug.com for lots more. Thanks to Lois Fiala for donating the photography, and to Tom Veltre for the video you'll find at weillcornellbrainandspine.org.



Coming Up

See childrensbraintumorproject.org for details about all events.



- Oct 10:** McKenna Claire Foundation's 3rd Annual "Play It Forward" Golf Tournament (Rancho Santa Margarita, CA)
- Oct 16-18:** Second Annual Allie's Sale (Overland Park, KS)
- Nov 6:** Tastefully Simple party (attend virtually by searching CT for Maria Gratton's party at tastefullysimple.com)
- Nov. 10:** Paint Social Art by Cure 4 Chris (Mansfield, CT)
- Nov 11:** Cristian Rivera Foundation's 6th Annual Celebrity Gala (New York, NY)

If you hold an event, email details and photos to info@childrensbraintumorproject.org

Thanks to Our Sponsors and Friends!



ChildrensBrainTumorProject.org

Top Fund-raisers at The Bronxville Road Race

Special thanks to these 18 participants and teams, who raised a combined \$40,000 for the Children's Brain Tumor Project!

Team Denison
Debbie Scully
Stacy Ulahel
Emma Hill
Shoshana Aminov
Jacqueline Paige Grand Pre
Winks and Rosie*
Jill Fisher
Ashley Mestl
Karen Driscoll
Kaitlin McTigue
Maria Gratton
Cindy Rajacic-Peiliker
Laura Romeo Sobel
Anna Mudrick
Mimi Greenfield
Tori Flannery
Eli Bunzel



**canine pals of Licia Hahn*

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 & 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 David Bernstein

(continued from page 1)

leaving only 4 percent for childhood cancers. Yet kids make up 20 percent of our population.

- Funding from large cancer organizations doesn't help very much; less than 1 percent of the American Cancer Society's total donations are directed toward childhood cancer research.

- Pharmaceutical companies fund 60 percent of all adult cancer research, but they do virtually no childhood cancer research because it's not profitable.

- About 900 adult cancer drugs are in the drug development pipeline, but almost none for children's cancers.

After Zachary's passing, my family was highly motivated to launch the Fly a Kite Foundation. The Fly a Kite Foundation is committed to children and families first. They are the primary reason for our existence. Our objectives are threefold:

1. Creating art packages to provide a creative and therapeutic outlet for young brain tumor patients suffering diminished motor function.
2. Providing grants to fund research and clinical trials for pediatric brain cancers.
3. Providing parent and patient support and advocacy to the newly diagnosed.

For example, I had a conversation with a family on the West Coast whose 8-year-old son was a candidate for an experimental drug owned by Novartis. They were having challenges obtaining the drug and called me to help. Within 36 hours we received confirmation from Novartis that the drug would be made available under compassionate use. This is just one example of the good work we are doing that has a direct impact on families and children. We wanted to make a difference from day one, and I can proudly say...we have.



Not enough attention or funding is being allocated to these causes, or to these beautiful children. One month a year is dedicated to our families' hardship and the honor we pay to the loss of our children. But the loss of a child to brain cancer should not be recognized over a 30-day period—it should be measured over a 30+ year lifetime. Moving forward, I will consider EVERY DAY to be September. We can't afford to lose momentum and most of all...HOPE!

I am proud to be affiliated with the Children's Brain Tumor Project and feel the heart and soul of this elite community is truly making a difference. On behalf of the Fly a Kite Foundation, we thank you from the bottom of our hearts.

Find out more at flyakitefoundation.org