



# Children's Brain Tumor Project

powered by families



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

April 2015

From the Desk of...

*Maria and Geoff Gratton*

As all couples have, we've experienced those defining moments in our life together, including our wedding day and the births of our children. While those continue to resonate with us, we now have another defining moment—one that reset our concept of "normal."

That defining moment came on December 1, 2012, at Connecticut Children's Medical Center, when our son was diagnosed with an inoperable brain tumor. In less than five minutes our lives were forever changed, and we found ourselves desperately seeking answers in a world that we had never even known existed.



In our small town we learned of another family who had earlier faced a pediatric brain tumor diagnosis. That family encouraged us to reach out to Weill Cornell and the wonderful doctors who specialize in these tumors. It was in early 2013 at Weill Cornell that we learned the name of what had originally been diagnosed as a low-grade tumor: gliomatosis cerebri (GC). In this dark and lonely moment, our random Internet search led us to a comforting web site, Elizabeth's Hope.

We quickly learned the frightening statistics, including the gross underfunding of federal monies for research and the lack of awareness about pediatric brain tumors. We needed to do something, anything, because doing nothing was not an option.

That was the catalyst for the establishment of our organization, which we named Our Cure 4 Life. We held our first board meeting on January 25, 2015, with a mission to fund research, raise awareness, and provide support for those afflicted with rare, inoperable brain tumors. We quickly launched a web site ([www.ourcure4life.org](http://www.ourcure4life.org)), created a Facebook page, and are now executing our mission. To that end, we have two major events planned in 2015: our first annual "Giving on the Green" golf tournament (scheduled for May 29 at The Golf Club at Windham) and the Our Cure 4 Life Gala in September 2015, which aligns with Pediatric Brain Cancer Awareness month.

(continued on page 4)

## Laboratory Update

Dr. Mark Souweidane and

Dr. Jeffrey Greenfield

*Co-directors, Children's Brain Tumor Project*

This issue's lab update is more like a chorus of "On the Road Again," as we have both been traveling so much this spring. As reluctant as we always are to leave our work here, that travel has been invaluable in the sharing of information and the enhancing of our worldwide collaborations.



The DIPG Workshop in Barcelona in February brought together experts from all across the United States and Europe, from cities including Amsterdam, Helsinki, and London—not to mention institutions such as the NIH, Duke, Dana Farber, Northwestern, and Weill Cornell. The workshop is made possible through the efforts of the Alicia Pueyo Fund, a family foundation dedicated to finding treatments for brainstem gliomas and encouraging collaboration among researchers worldwide. We are honored to participate alongside other international leaders who are striving to defeat DIPG, and grateful to the dedicated families who are at the forefront of the effort, always refusing to take no for an answer.

March meant Paris, for the first-ever International Gliomatosis Cerebri Conference, organized and driven by families affected by GC. That groundbreaking meeting created a framework for important collaborations as we go forward. (Read more about both conferences on page 2.)

This month, we look forward to the annual meeting of the DIPG Collaborative in Chicago. The 2015 Symposium promises to be filled with new research and development about this tumor, which is one of the prime targets of our research efforts here at the CBTP.

Onward,

*M.M. Souweidane*

*J. Greenfield*

**Make a donation today at [ChildrensBrainTumorProject.org](http://ChildrensBrainTumorProject.org)**

# News From Barcelona and Paris

In February, Dr. Souweidane attended the Alicia Pueyo Workshop on DIPG in Barcelona, where he presented an update on the use of convection-enhanced delivery (CED) for DIPG to an international audience of scientists, clinicians, and family advocates. As Dr. Souweidane's clinical trial approaches completion, other groups are highly interested in learning more about CED, as evidenced by the invitations he has received to present this innovative strategy: as a keynote speaker at the University of Alabama Birmingham/Children's Hospital of Alabama for its annual Pediatric Neuro-oncology Symposium on May 1, at the DIPG Collaborative Symposium in April in Chicago, and as the 2015 E. Bruce Hendrick Visiting Professor at the University of Toronto/Hospital for Sick Children on May 22.

In March, an unprecedented constellation of scientists and oncologists met in Paris to discuss the status of diagnosis, treatment, and scientific inquiry into gliomatosis cerebri (GC), a disease so close to many of us at the CBTP. Dr. Greenfield cohosted the two-day gathering, which took place at the Institut Curie. Developments included an agreement that Weill Cornell will host the International GC Registry with back-end analytic support from the DIPG community. The ICB in



Above: Dr. Souweidane addresses the February DIPG meeting in Barcelona. Below: Dr. Greenfield with some of the family members and neuroscientists who attended the International GC Conference in Paris.



London and Weill Cornell in New York were also selected as the European and North American sites for sample collection and comprehensive genomic analyses. The panel discussed new scientific projects to focus on and the concept of a GC-specific clinical trial within two years. This cross-continental initiative is truly a remarkable example of the efforts that can result from collaboration and synergy.

## Registry News

Last April we launched the International Gliomatosis Cerebri Registry at [GCRegistry.com](http://GCRegistry.com), and we are amazed at how quickly word has spread about it. We now have registrants from across the United States, plus Europe, Africa, and India. We are so grateful to the Joshua Bembo Project for making the web site possible.



This spring we are delighted to be launching another registry, the Thalamic Glioma Registry. The web site (to be hosted at [ThalamicGliomaRegistry.com](http://ThalamicGliomaRegistry.com)) is made possible thanks to Katherine Godfrey, whose daughter Fiona Lundell succumbed to a thalamic glioma at age 5 in 2013. During Fiona's illness, her mom reports, it was virtually impossible to find any information about this inoperable glioma. The launching of the new site will not only help researchers gather information about this rare tumor, but we hope it will also provide a place where families facing the diagnosis can find information and community.

## Alex's Lemonade Stand Awards Grant to CBTP to Investigate Drug Distribution in CED

The Alex's Lemonade Stand Foundation has awarded a \$5,000 grant to Melinda Wang, a medical student at Weill Cornell Medical College, to conduct research into the distribution of the therapeutic agent delivered during convection-enhanced delivery (CED). Dr. Souweidane's clinical trial for DIPG has been testing the safety of using CED to get tumor-fighting drugs directly to the site of a brainstem tumor. A special contrast agent can trace large molecules as the drugs are infused, but there has not been a reliable way to measure the concentration of the smallest molecules. Wang, a first-year medical student, will modify two small-molecule kinase inhibitors, dasatinib and everolimus, to allow them to be monitored by positron emission tomography (PET) and near-infrared fluorescence (NIRF). This will provide, for the first time, accurate real-time images of how small-molecule drugs perform when infused during a CED procedure.



## Brothers and Sisters

Sixteen-year-old Jordan Wetzel wrote a thoughtful essay for us in December when we asked for contributions to the Brothers and Sisters column. We could run only a short excerpt in that issue, so we wanted to share the whole essay with you now.

### The Story of the Siblings

By Jordan Wetzel

When you read about cancer families, you tend to hear a lot about the cancer kid and the parents. Siblings are mentioned, but are considered to be the silent supporters in the family. Being a cancer sibling myself, I understand the everyday struggle of living with cancer kids and the responsibilities you hold within the home and outside of it.



“Sisters by chance, friends by choice.” My sister and I were very close, and we told each other everything. Don’t get me wrong, we did fight just like all the other siblings in the world, but in the end we always reverted to being the giggling girls playing with each other and making messes.

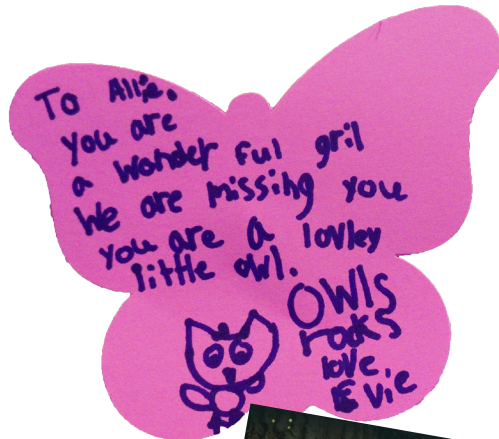
As a sibling, you let your parents deal with the medical stuff, and your job is to remain the sibling. This may seem like a very simple task, but I assure you, it can feel like you’re carrying the weight of the world. When my sister was diagnosed I was very confused. I was 12 years old and at 12 you’re not told very much. All I knew was that she was very sick and was going to be in the hospital a lot.

Having a sick sibling makes you grow up a little faster than you want to, but you’re playing a huge role in keeping your family sane during the tough days. Because everyone asked questions about my sister and my parents, I never explained how I felt. Everything bottled up rather quickly, and I became good at hiding it. Not once for the sake of my family did I tell them what I was really feeling. Any sign of stress or anxiety was soon covered by a fake smile and an escape to a friend’s house. People tried their best to treat my sister just as they had before she was diagnosed and didn’t talk to her about her illness. But with siblings, people have the urge to say something when a situation can relate to them in any way. They say things like, “I know how you feel.” I have never hated a phrase so much in my entire life.

When someone you love is diagnosed, the effect is different for everyone. Nobody fully comprehends the way a sibling feels unless that person is a sibling too. It’s a scary, full-time, and sometimes hopeless position that can only be filled by you. You may be a silent supporter when it comes to headlines, but you play a big role by just being there for the person you love.

We would love to hear from other siblings as well as grandparents and other family members who would like to share their experiences. Please email your stories to [info@childrensbraintumorproject.org](mailto:info@childrensbraintumorproject.org).

Evie Fisher, now 8, wrote this note to her sister, Allie, at a remembrance ceremony held by Children’s Mercy Hospital. This month Allie’s mom, Kelly Fisher, appears in a new documentary short film making its debut at the Tribeca Film Festival. *The Gnomist* is a true story about the mysterious appearance of fairy homes in a suburban forest.



### New Research on Ependymoma Made Possible Thanks to a St. Baldrick’s Summer Fellowship Grant and Family Donations

Scott Connors will continue his investigations into recurrent pediatric ependymoma in the CBTP lab this summer, funded by a fellowship grant from the St. Baldrick’s Foundation. St. Baldrick’s, a longtime supporter of the Children’s Brain Tumor Project, awarded the grant for research into the genomics and epigenomics of ependymoma. Much like DIPG and GC, ependymomas—which arise from ependymal cells that line the ventricles of the brain—are rare brain tumors that have been poorly studied to date compared with other pediatric cancers. Thanks to an outpouring of support from the family and friends of Campbell Hoyt, the CBTP has been able to expand seminal studies specific to understanding why recurrent ependymoma is so difficult to cure. The St. Baldrick’s grant will allow us to redouble our efforts on that research and lay the groundwork for future investigations and potential clinical trials.

### THE HOLE IN THE WALL GANG CAMP



Sean Ries was one of three children who spent a memorable week at The Hole in the Wall Gang Camp in Connecticut last summer thanks to Dr. Greenfield. The camp was founded by Paul Newman to provide an authentic camping experience to kids with serious medical conditions. Dr. Greenfield hopes to place four campers there this summer.

## From Maria and Geoff Gratton

(continued from page 1)

Today we live by a new set of rules about living in the present:

*The present moment is the only moment available to us, and it is the door to all moments.*  
— Thich Nhat Hanh

Together with our newfound family within the Children's Brain Tumor Project, we will make great strides in our combined missions. We remain hopeful and encourage you to help us spread the word, provide support, and raise the funds necessary to find a cure—Our Cure 4 Life.

*Geoffrey Gratton*  
*Maria Gratton*

### In Memoriam: Anthony Mason

All of us at the CBTP were saddened to learn of the passing of Anthony Mason. The former New York Knick was a valued Committee Member of the Cristian Rivera Foundation, which has raised nearly half a million dollars for the CBTP. Our condolences to Mason's family and to the Cristian Rivera Foundation, which considered him a family member as well.

### 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](http://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](mailto:ani7003@med.cornell.edu).



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## Event Highlights

Team Little Owl, which honors Allie Fisher, was the local beneficiary of an Alex's Lemonade Stand hosted by Olathe North High School in Kansas. The students raised \$900 and split it between ALS and Team Little Owl. Kyle and Kelly Fisher also report that their annual Allie's Sale has had to move to a new location for 2015 since it has outgrown its original location in their neighborhood.



Cindy and Lou Campbell (right) welcomed Scott Connors and Sheng Li to the TLC Foundation's Share the Love gala. Scott is a medical student taking a year off from his studies to complete a research fellowship in Dr. Greenfield's lab, and Sheng Li, PhD, the CBTP's first Ty Louis Campbell Fellow, is a specialist in bioinformatics and computational biology working to interpret data from the genomic sequencing of pediatric brain tumors.

## Save the Dates: 2015

**May 1:** Elizabeth's Hope cocktail party (Bowery Hotel, NYC)

**May 16:** Christian Koehler Lacrosse Tournament (Heckscher State Park, East Islip, NY)

**May 16:** "Come Fly With Me" —McKenna Claire Foundation Party With a Purpose (Huntington Beach, CA)

**May 17:** Cheering for Caitlin 5K (Oviedo, FL)

**August 8:** Muddy Puddles MessFest (Camp Kiwi, Mahopac, NY)

**September 12:** Bronxville Road Race (Bronxville, NY)

**September (date and location TBA):** Our Cure 4 Life Gala

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

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



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