



# elizabeth's hope



The Children's Brain Tumor Project Newsletter

Fall 2013

Vol. 2, No. 2

From the Desk of...

*Michael Minter and Emma Hill*

September is Pediatric Cancer Awareness Month, represented by the color gold. Did you know that? We didn't until two years ago, when we were at the hospital for Elizabeth's treatment and the staff were giving out small gold ribbons. Why is it that we know pink ribbons stand for breast cancer but are ignorant about gold ribbons?



Why is it that we parents, our children's best advocates, have failed to create greater awareness and urgency for funding of new treatments for our children, who have decades of potential and contributions ahead of them?

It's not because we aren't trying. It's because the subject matter is raw and unpleasant. Pediatric cancer is on emotional par with torture, rape, incest, abuse, and poverty—subjects we would prefer not to discuss. It's also a topic that makes us feel like failures. Thousands of children die and suffer each year as a result of cancer. We feel helpless to stop the random killing of about 50 children each week (the equivalent of two classrooms) by a relentless serial murderer.

Pediatric cancer was not even on our radar screen three years ago. Sometimes we wish it weren't now. Each time we hear of a child with a new diagnosis, we are knifed in the heart and relive Elizabeth's nightmare. We would love to be innocent again, but we will never be.

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## Laboratory Update

Jeffrey Greenfield, M.D., Ph.D.

Director, Children's Brain Tumor Project

We have some extremely exciting news to report this month: Yujie Huang, PhD, of our Children's Brain Tumor Project laboratory, has been awarded a three-year, \$400,000 grant from the Department of Defense. Dr. Huang was awarded the grant for a project called "Characterizing and Targeting Bone Marrow-Derived Inflammatory Cells in Driving the Malignancy and Progression of Childhood Astrocytic Brain Tumors." Gliomatosis cerebri is one of the most difficult—if not the most difficult—to cure of all astrocytic brain tumors, so getting this project funded is a significant step forward for us.



News like this makes it more and more clear how critical the support of *Elizabeth's Hope* is to us. Department of Defense grants are not easy to secure, and an award of this size required us to file an application with supporting data based on previous research. That data assures the DoD that its grant money is going to projects that are based on sound science and have good chance of success. How could our lab have done the foundational work, and generated the data, if not for you, our loyal supporters?

Even more exciting, some of the data used in support of this grant application was generated by Emma Vartanian, who joined the lab on a summer fellowship from the Saint Baldrick's Foundation. As

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**Make a donation today at [ElizabetsHope.com](http://ElizabetsHope.com)**

## Laboratory Update

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you may recall from our Spring 2013 newsletter, Emma's project uses mouse models to study the effects of an inhibitor drug on gliomas, with the goal of preventing low-grade tumors from progressing into fatal ones. If we can learn how to stop bone marrow cells from signaling the distant tumor to grow, we may be able to keep low-grade gliomas from developing into high-grade tumors like gliomatosis cerebri.

Under Dr. Huang's guidance this summer, Emma and the team initiated the transplant phase of the study and performed bone marrow transplants on more than 20 animals. Now those mice will be treated with an experimental inhibitor drug to test its ability to limit tumor growth. As the treatment progresses in Dr. Huang's newly funded phase of this study, our research team will be able to analyze how the transplanted bone marrow-derived cells move and

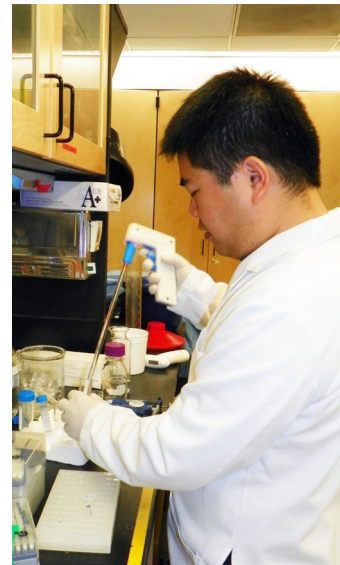
participate in tumor progression. We already have histological and radiographic data, in the form of brain tissue slides and MRI images, suggesting far better tumor outcomes and survival patterns in drug-treated transplant mice, as compared to untreated control animals. This is exciting stuff indeed.

*"Gliomatosis cerebri is so challenging, but this \$400,000 grant to open a new avenue of research is a significant step forward for us."*

I am so energized by how our work is all coming together. With *Elizabeth's Hope* making our lab work possible, we gave St. Baldrick's the confidence to award

us the summer fellowship. With the addition of a summer fellow, we were able to generate the promising data that won us the Department of Defense grant. We are moving ahead, making progress, and growing fast—and we owe *Elizabeth's Hope* our deepest gratitude.

Thank you so much for your continued faith in our lab, and for continuing to support us as we start new initiatives and open up new fronts in this ongoing battle against pediatric brain tumors.



## Stylish, Unique, and Generous As Well

Brook Stroud says he will never forget the phone call he received from Will after our family first found out about Elizabeth's diagnosis. Brook and Will had gone to high school together and had been roommates for all four years of college, so Brook knew Elizabeth well. "I could

not believe his outgoing, quick-witted, fun-loving, and highly driven sister Liz could possibly have a rare and inoperable form of brain cancer," he says.

Brook is the co-founder of La Matera, which makes unique belts, wallets, and other items using beautiful Argentine fabrics. (If you

saw the famous photo of Prince William introducing his infant son to the world this summer, you've seen one of La Matera's belts, since the proud new dad was wearing one that day.)

Now Brook has generously offered to donate to our cause a large portion of each sale made to an *Elizabeth's Hope* supporter. "Elizabeth's courage and attitude

throughout her battle continues to inspire her family and many friends," says Brook. "La Matera is proud to be collaborating with *Elizabeth's Hope*. For each individual belt and or wallet purchased online using discount code "Elizabeth" at checkout, we will donate \$25 to *Elizabeth's Hope*."

We're grateful to Brook and his colleagues at La Matera for this campaign on our behalf—as well as to the many friends who have already participated in this special offer. The belts are truly beautiful (Mike, Trey, and Will all have them!) and make wonderful holiday gifts.

This special offer runs through the first week in October, so be sure to place your order soon!



Visit the La Matera online store at [lamaterashop.com](http://lamaterashop.com).



# Event Update

It was an exciting spring and summer for *Elizabeth's Hope* and the Children's Brain Tumor Project!

At Williams College this spring, Mack Von Mehren and the men's lacrosse team dedicated their season to Elizabeth, raising money from supporters with every goal scored. The team's April 20 home game was a tribute to Elizabeth. Thanks so much to Mack, and to everyone who contributed to this effort!



In April, we visited Denison College for a pre-graduation celebration and to attend a "Lax for Liz" game. Both the men's and women's lacrosse teams held fundraisers for *Elizabeth's Hope*, organized by Molly Cornbrooks. This should have been Elizabeth's graduation year, so our visit was a bittersweet and deeply moving experience for us. Elizabeth was remembered in the graduation program in May, as was another young woman who died of cancer. We are so grateful to everyone at Denison for their numerous fund-raisers, even as we mourn for all Elizabeth missed out on.



June brought the Second Annual Ride for *Elizabeth's Hope* at Soul Cycle in Greenwich, organized by

Amanda Hudson along with our intrepid Volunteer Coordinator, Tessa Naso. We couldn't help but think back to the

first ride, also organized by Tessa, when Elizabeth was still with us. Little did we know that day that it was to



If you hold an event, be sure to email photos to [info@elizabethshope.com](mailto:info@elizabethshope.com) so we can include you in the next newsletter!

be the first of many events in support of the Children's Brain Tumor Project. A million thanks to you, Tessa, for all you do!

In July, Tessa hosted an exuberant gathering of our college Ambassadors in New York City. The fundraising these young men and women have done for *Elizabeth's Hope* is beyond amazing; they have carried Elizabeth's name and story to everything from entire field hockey and lacrosse seasons to tennis tournaments in her honor. Even more exciting, those Ambassadors are now committed to pairing up with recent graduates of Bronxville High School to help pass the torch to them and carry on this important work. Thank you, Ambassadors!



In August, our good friend Tom Jones fulfilled his lifelong dream of climbing Mt. Kilimanjaro in Tanzania, and we were honored that he dedicated his climb to Elizabeth. Tom trained hard for his climb but wasn't sure he'd make it to the summit—but make it he did, carrying an *Elizabeth's Hope* flag with him to unfurl at the peak. In addition, Tom rallied friends and colleagues from around the world to donate to *Elizabeth's Hope* in support of his climb, raising tens of thousands of dollars for the Children's Brain Tumor Project. Thank you so much to Tom and to all the donors who contributed to the effort!



## Coming Up...

We're delighted that Elizabeth's message continues to spread, and that this fall brings several new fund-raisers. Many thanks to:

**Emily Kuschner**, who is running (again!) for *Elizabeth's Hope* on Team Zachys at the Westchester Running Festival on October 13.

**Lilly Santoro**, who is organizing the second annual tennis tournament to benefit *Elizabeth's Hope* at Gettysburg College, under the mentorship of Erin Hackett, who started the event last year.

Visit [elizabethshope.com](http://elizabethshope.com) to find out how to participate in one of these events, or to donate in support of them.

## In Memoriam: Daryn Clark

We were deeply saddened to learn of Daryn Clark's passing on July 20 after a heroic battle against gliomatosis cerebri.

Daryn's daughter, Kathleen Clark, became one of the most energetic supporters of our campaign against this deadly brain tumor after her dad was diagnosed. She discovered *Elizabeth's Hope* online and started holding fund-raisers and awareness events in support of the Children's Brain Tumor Project. This past

May Kathleen made a personal trip to New York to meet with us and with Dr. Greenfield, and to present him with a check.



Kathleen Clark (right) found *Elizabeth's Hope* when her dad (center) was diagnosed with GC.

Daryn was a husband, a father, and the creator of the inspirational site at [WhatsYourFight.com](http://WhatsYourFight.com)—he was so much more than just a patient. In extending our sympathies to the Clark family we also celebrate the life of a wonderful man, a man who did not deserve his diagnosis. Nobody does, and that's why we continue our own fight against these terrible tumors.

## From the Minters

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Pediatric cancer is bad, but a rare, inoperable brain tumor has to among the worst diagnoses. "Inoperable brain cancer" really means "pray for a miracle." "Rare" means there is no treatment protocol and few clinical trials. A tumor in the brain means that the patient will be robbed of their physical, emotional, and intellectual abilities. Inoperable brain cancer is more than an inconvenient or painful disease.

Thus we continue the work of *Elizabeth's Hope*, our daughter's dream of a cure for rare and inoperable brain cancers. Elizabeth was admitted into hospice in October 2012, just 9 months after her diagnosis. We were told that she had a few months to live at most. She had started work on *Elizabeth's Hope* in June, and we were anxious to launch the fund while she was still present. We launched in mid-November 2012. Elizabeth hung on. Dr. Greenfield paid her a bedside visit over the Christmas /New Year's holidays. It was an important visit, but Elizabeth was sad when he left our home. She was disappointed because she'd had the innocent hope that he would come with the cure that very day that would free her from her steady decline.

In this day and age, it is shocking to us that the only hope for so many patients is a miracle. We know we can do better. We eradicated polio, got a man to the moon, made AIDS a chronic disease. A cure is possible. It's about focus. We can do more for our innocent kids. So our task is to remain engaged in the effort, raising dollars for research and creating awareness.

Thank you all for supporting *Elizabeth's Hope*. The fund has raised nearly \$900,000 for the Children's Brain Tumor Project research effort for rare and inoperable brain cancer. The team at the Children's Brain Tumor Project, led by Drs. Souweidane and Greenfield, are focused, passionate, and making progress.

We dream of the day when there is no need for a CBTP. Until then, however, we will continue to raise dollars to support those devoting their lives to helping these innocent victims.

*Elizabeth's Hope* owes its success to you. Thanks again for caring.

### About *Elizabeth's Hope*

*Elizabeth's Hope* was founded in 2011 by Elizabeth Minter and her family and friends, after Elizabeth was diagnosed with gliomatosis cerebri, a rare and inoperable brain tumor that strikes primarily children, adolescents, and young adults. To support new research into GC and other tumors, Elizabeth created *Elizabeth's Hope*, which supports the Children's Brain Tumor Project at Weill Cornell Pediatric Brain and Spine Center.

### Ways to Give

#### 1. By Check

You may make your gift by check, payable to Weill Cornell Medical College. Please indicate "Elizabeth's Hope" in the memo area.

Please mail checks to: *Elizabeth's Hope*, c/o Ana Ignat  
Weill Cornell Pediatric Brain & Spine Center  
525 East 68th Street, Box 99  
New York, NY 10065

#### 2. By Credit Card

Visit [elizabethshope.com](http://elizabethshope.com) to use a credit card to make a secure online donation or a monthly pledge.

#### 3. Stock, Matching Gifts, and Other Options

If you would like to discuss corporate matching programs, donations of securities, or other options for giving, please contact Licia Hahn, Director of Strategic Marketing for *Elizabeth's Hope*, at [licia@elizabethshope.com](mailto:licia@elizabethshope.com).



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