



elizabeth's hope



The Children's Brain Tumor Project Newsletter

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From the Desk of...

Michael Minter and Emma Hill

Before Elizabeth's diagnosis, pediatric brain cancer was not something we ever thought or worried about. After traveling Elizabeth's journey, however, we have become passionate about this issue. Some sobering facts:

- Each year 4,200 children in the U.S. are diagnosed with a brain tumor.
- The causes of pediatric brain cancer remain a mystery, and thus there are no known preventive measures.
- Brain tumors are one of the deadliest forms of childhood cancer, and one of the costliest in terms of lost potential: Each death represents a loss of approximately 70 years in life expectancy.
- Pediatric brain tumor survivors are likely to suffer permanent physical, intellectual, and emotional challenges that will adversely impact the quality of life into adulthood.



A ray of sun beams down on the spot where some of Elizabeth's ashes were scattered in Jackson, Wyoming.

Each case of childhood cancer is hugely tragic. Many young brain tumor victims are diagnosed early in childhood; they suffer difficult surgeries, isolating hospitalizations, and poisonous and debilitating treatments, only to succumb. The emotional strains on parents and siblings are intense, and a cancer diagnosis can be financially ruinous for a young family. Elizabeth lost the opportunity to live a full life because of her cancer. While she enjoyed 20 full years and may not have suffered as badly as some, her passing is tragic and unfair.

Early in her illness, Elizabeth was told that she was in the fight of her life—but that there were few treatment options for her disease. She knew that the only hope for victims like her would

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Laboratory Update

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

Director, Children's Brain Tumor Project

One of the most important—and challenging—aspects of working with a disease like gliomatosis cerebri is access to tissue samples. The best way for us to study this tumor is by seeing, testing, and studying many different examples of it, and finding out as much as we can about the young patients diagnosed with it. We believe that's the key to personalized medicine: Exploring what these tumors, and these patients, have in common, and how they're different, will help us understand how GC works and how we can defeat it.



That's no easy task—there are only a handful of individuals each year diagnosed with gliomatosis cerebri, so the universe starts out as a small one. If the patient happens to live in a major urban area, with access to a comprehensive medical center, odds are that the surgeons there know about the Children's Brain Tumor Project and will alert us to the case. In smaller towns and cities across the United States, though, a patient will often be seen and treated first at a local hospital, and we won't find out about the diagnosis—at least not right away.

That's one of the most critical pieces—timing is everything when it comes to tissue samples. We're grateful for the number of samples we've already received from our partners, but too often these samples are taken during an autopsy, after the tumor has won the battle. Those samples bear the scars of that battle—the tumor has been irradiated or subject to chemotherapy, which changes its molecular makeup. Our lab can learn a lot from these samples, but we could learn so much more

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Laboratory Update

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if we had access to tumor tissue taken during the original biopsy, before the tumor has been affected by treatments.

The challenge is not only one of spreading the word, but of putting the infrastructure in place to retrieve those samples. Imagine what's entailed in this: First, the medical and surgical teams at a hospital have to know we even exist and need the samples. Then a frightened and overwhelmed patient and family have to learn about us and our work, and give their consent to donate samples. Finally, the sample has to be taken during a biopsy and then shipped to us overnight in a freezer package so it can be received here and stored safely in our lab for study. You can imagine how it would be easy to overlook this entire process in a small hospital, with a medical team that has probably never seen a single case of gliomatosis cerebri before.

There's more to a registry than just tissue samples, too. We want *Elizabeth's Hope* to be a source of support and hope to families receiving a diagnosis of gliomatosis cerebri. Thanks to our supporters we have

begun the effort—if you type “child with gliomatosis cerebri” into Google you'll find the *Elizabeth's Hope* web site, built and maintained with donor dollars, right up there with giants like St. Jude and the Children's Hospital of Boston. We have heard from patients all around the United States who have found us online. That exposure is exactly what we need to get the word out about what we do, but it's an ongoing effort that needs to keep growing every day.

So the task at hand is as daunting as it is important. The first part—forming the partnerships with major hospitals—is already in place. The second—getting the word out to the surgeons and hospitals that might be doing a GC biopsy today and to the patients and families who might be getting that diagnosis tomorrow—is much more difficult and will take a lot more day-to-day effort.

I remain ever grateful for the support of our donors as we continue this important work—not only in the lab but on all the other fronts where we're fighting this battle.



From the Minters

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come through research. While she could not return to school or work, she did have an important purpose: to support brain cancer research to improve treatment options through better understanding of this horrific disease.

We are grateful for your support of Elizabeth's and Dr. Greenfield's goal of improving treatment options for young victims of brain cancer, and of unlocking the genetic secrets to these terrible tumors. Thanks to your support of *Elizabeth's Hope* and the Children's Brain Tumor Project, we have laid the groundwork for a national gliomatosis cerebri registry, which will extend our reach across the country and bring hope to every child and every family facing this horrible diagnosis. Already, every child diagnosed with a brain tumor at the Weill Cornell Pediatric Brain and Spine Center has that tumor genetically sequenced, an important first step in better understanding the disease. Soon, we hope every child in the United States who is diagnosed will become part of the project through the GC registry. Thank you again for your unwavering support of *Elizabeth's Hope*.

Breaking News From Rockefeller University

By Dr. Jeffrey Greenfield

In the last issue of this newsletter, I told you about Dr. David Allis, my colleague across the street at Rockefeller University, and how his basic science research on histones had suddenly emerged as an important element in pediatric brain tumors. I'm thrilled to be working with Dr. Allis on this important research. As I write this issue, a brand-new paper by Peter Lewis has just been published confirming some of our best hopes.

Dr. Lewis is a post-doc researcher who works with Dr. Allis, and he was intrigued by the research that linked the H3 histone mutation with the pediatric brain cancer called DIPG. That's big news in itself, since histone mutations had never before been linked to a specific disease. But Dr. Lewis dug further into the data and made another

remarkable finding. A single mutated amino acid on the histone can prevent the process of methylation—the process that “silences” the genes that may make cancer grow. Without that methylation there is no silencing, and without the silencing the gene becomes activated and a tumor can grow. As many as 17 percent of DIPG tumors may be caused by this one tiny aberration in one amino acid. When we find out how to turn methylation on in these cases, we just may have a new way to fight DIPG in those children with this mutation.

I'm thrilled by these findings, since they support my belief that the answer to these rare tumors lies in personalized medicine. If we know how to turn on methylation and we can identify those kids whose DIPG is caused by this mu-

tation, we have hope for those children. When we discover the five or ten or more other reasons a tumor can grow, we can develop strategies specific to those tumors as well. Cancer is not one-size-fits-all, and the cures won't be, either.

The findings were published in the April 1 issue of *Science Daily*. You can read the full article online at sciencedaily.com (or Google “Mechanism of Mutant Histone Protein in Childhood Brain Cancer Revealed” to find it).



Summer Research Project Aims To Unlock One of the Secrets of Gliomatosis Cerebri

Emma D. Vartanian, a medical student at Weill Cornell Medical College, has been awarded a prestigious Summer Fellowship from the Saint Baldrick's Foundation to work in Dr. Greenfield's research lab this year. Emma will be dedicated to an exciting project focused exclusively on gliomas.


For this research project, Emma will investigate what causes a major difference between low-grade and high-grade gliomas. Low-grade gliomas grow slowly, and individuals diagnosed with these tumors can live for decades. But high-grade lesions are extremely aggressive, and their rapid proliferation means that a patient usually survives less than two years from diagnosis. If we can learn more about how and why these tumors grow so fast, we may be able to find ways to slow them down and make them behave more like their low-grade cousins. That's not a cure—but if there's a way to turn a relentless and fatal tumor into a chronic condition, that would be an amazing first step.



Dr. Greenfield will mentor Emma Vartanian this summer during her St. Baldrick's Summer Fellowship for the Children's Brain Tumor Project.

mas can grow quickly is because they develop an almost boundless blood supply. A vast network of new blood vessels form at the tumor site in a process called neovascularization, fed by signals from the bone marrow and allowing the tumor to double and redouble in size. This summer's project aims to test ways to block those signals and prevent neovascularization.

Under Dr. Greenfield's guidance, Emma will use mouse models to study the effects of an inhibitor drug on the progression of gliomas. Using special stains to track which types of cells are mobilized as the tumor grows, and comparing disease progression in treated versus untreated mice, Emma hopes to be able to show that the bone marrow is indeed "recruiting" the cells that drive those new blood vessels to form, and that using inhibitor drugs can successfully delay disease progression by impeding this process.

We're delighted to have Emma on board for such an innovative laboratory project, and we're grateful to the St. Baldrick's Foundation for their ongoing support for childhood cancer research. 

Yohannes Constable took *Elizabeth's Hope* to new heights when he reached the top of Mount Kilimanjaro in Tanzania. Many thanks to Yohannes for his dedication, and also to the supporters who sponsored him on his climb.



This season brings with it a new round of events and fund-raisers, for which we

are so grateful. The Children's Brain Tumor Project relies heavily on these fund-raisers, so we thank all our friends—especially those continuing Elizabeth's legacy on college campuses.

Mack von Mehren and the Williams College men's lacrosse team are on fire for *Elizabeth's Hope* this spring, raising money from supporters who have pledged dollar amounts for each goal scored. The way the team is scoring, the Ephs will generate a very generous donation!

Many thanks to Richard J. Hurley and the Pi Kappa Alpha Fraternity, which is holding a fund-raiser for *Elizabeth's Hope* at Miami University in Ohio.

The Bronxville School's Bronco Bonanza in February was once again dedicated to *Elizabeth's Hope*. The school has been one of our most supportive friends, and we are so grateful.

The River Road Coffee House in Granville, Ohio, hosted the second annual "Lattes for Liz." Thank you!

Elizabeth's friends at Denison University in Ohio have been some of our most loyal supporters. For the second year in a row, Sigma Phi Epsilon at Denison is dedicating

their annual fashion show to *Elizabeth's Hope*. The men's and women's lacrosse teams will dedicate an April home game to *Elizabeth's Hope*—Lax for Liz! And thanks to the women of Denison who took *Elizabeth's Hope* with them on spring break this year by sporting their Gretchen Scott blouses. Sales of these tops, which Elizabeth helped design during her illness, benefit *Elizabeth's Hope*. (See page 4 for more about Gretchen Scott and LizLaughLove.)



STAY TUNED for information coming soon about events being planned for pediatric cancer awareness month in September.

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

Brain Tumor Research In the News

"Paradoxical activation and RAF inhibitor resistance of BRAF protein kinase fusions characterizing pediatric astrocytomas"

Proceedings of the National Academy of Sciences
Published online ahead of print March 26, 2013

This is pretty dense reading for a lay audience, but the conclusion assures us that we are on the right track: "...therapies must be tailored to the specific mutational context and distinct mechanisms of action of the mutant kinase." That's personalized medicine!

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. This rare and inoperable brain tumor strikes primarily children, adolescents, and young adults, but because it occurs in relatively small numbers it does not receive research funding from major foundations. Determined to foster hope in patients and families facing this diagnosis, Elizabeth created *Elizabeth's Hope*. Every dollar raised through *Elizabeth's Hope* goes to the Children's Brain Tumor Project at Weill Cornell Pediatric Brain and Spine Center, where researcher and neurosurgeon Jeffrey Greenfield, M.D., Ph.D., and his team are searching for a cure.

Ways to Give

1. By Check

You may make your gift by check, payable to WCMC Pediatric Brain & Spine Center. 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 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.



Follow Elizabeth's Hope on Facebook

Special Thanks to LIZ LAUGH LOVE From Gretchen Scott Designs

Our good friend Gretchen Scott is donating 100 percent of her proceeds from the sale of specially designed *Elizabeth's Hope* shirts to the Children's Brain Tumor Project. Sales have already generated tens of thousands of dollars for *Elizabeth's Hope*.

LIZ
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LAUGH MORE. SMILE LESS. IGNORE CRITICS. SAY YES. ORDER DESSERT. LOVE LIFE.!!

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"Liz was a force. A human hurricane who crammed years of living into her all-too-short 21-year life. One of the last things she did was to help design—along with longtime family friend and designer Gretchen Scott—a shirt. A very special shirt that personifies her zest for living and her vibrant personality. It's a shirt that is uniquely Liz."

When you buy the **Liz Laugh Love** shirt for family and friends, the proceeds go to the Children's Brain Tumor Project to help in the fight against pediatric brain tumors. **The top is available at gretchenscottedesigns.com.**

The Elizabeth's Hope Store

The *Elizabeth's Hope* online store features performance shirts, hoodies, water bottles, bags, and other accessories, all bearing the *Elizabeth's Hope* logo. Using these products will give you the opportunity to tell Elizabeth's story and get the message out to everyone who sees you wearing or carrying them. Plus, proceeds of every sale go toward the Children's Brain Tumor Project.

All products are available now on elizabethshope.com.

