



The Children's Brain Tumor Project Newsletter

Fall 2012

Vol. 1, No. 2

From the Desk of...

Michael Minter and Emma Hill

The process of grieving and recovery is like falling into a deep dark hole and feeling lost, sad, and lonely. Eventually, you figure how to climb out of the hole, only to fall back in. The goal is to be able to walk around the hole without slipping in again. We are making progress thanks to the support of so many friends (Liz's and ours) and family. Certainly, *Elizabeth's Hope* has been important in alleviating our feelings of powerlessness against a horrific serial killer of random children, pediatric brain cancer. *Elizabeth's Hope* has also provided us many opportunities to make new or renew connections with friends of Elizabeth and people who want to help to find better treatments for brain cancer.

It's been a busy fall. Thanks to friends of Elizabeth who held fundraisers at Williams College, Georgetown University, the University of Virginia, and Gettysburg College, *Elizabeth's Hope* has received more than \$10,000 in contributions. There are more in the works. The energy and commitment of these young people are so inspirational!!



On October 13, our family was able to walk around the "grief" hole thanks to the outpouring of support at the 10K run in Prospect Park in Brooklyn, New York, spearheaded by Tessa Naso and Liz Haughton. Well over 200 attended in support of the cause—most ran, a few walked, and a couple cheered. It was a gorgeous sunny autumn day, filled with energy and love for Liz. Incredibly, the event raised more than \$46,000. The day ended with a party at the Saloon in NYC, where friends gathered and celebrated to raise yet more funds for the cause. The day was a huge success and there is a general call to make it an annual event!!

Through this journey we have made new friends: parents, patients, and children whose lives have been turned upside down by brain cancer. Take a look at "The Power of Families" on page 2 of this newsletter to meet some of those families.

It's been just one year since the Children's Brain Tumor Project and *Elizabeth's Hope* were launched. We are so excited to see Dr. Greenfield's team make a contribution to the scientific and medical community and the fundraising effort is strong and continues to broaden. The point of all this is to say thank you for supporting Elizabeth's cause and legacy, *Elizabeth's Hope*. We have momentum, and we do believe that together we can make a difference.

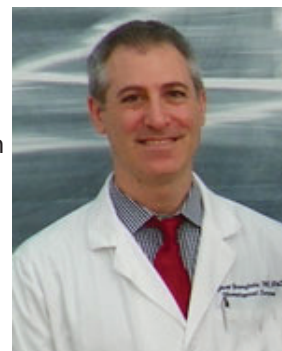
Mike *Emma*

Laboratory Update

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

Director, Children's Brain Tumor Project

It has always fascinated me the way seemingly unrelated strands of information can unexpectedly come together with a resounding bang—one plus one can suddenly equal so much more than two if the strands are the right ones. In this age of instant global communication, the work of researchers on opposite sides of the globe can unexpectedly collide and produce remarkable results.



That amazing confluence of events happened just recently, as new discoveries in how genetic mutations can cause cancer suddenly meshed with a lifetime of research by a basic science lab. C. David Allis, Ph.D., the head of the Laboratory of Chromatin Biology and Epigenetics at Rockefeller University, has spent the last 25 years doing basic scientific research on the DNA-histone protein complex called chromatin—his lab has pursued a better understanding of the science underlying the process of DNA folding and unfolding.



Dr. David Allis

Histones are the on/off switches that control which genes are active in any given cell. Knowing how to turn a gene off could theoretically head off certain diseases, but Dr. Allis's work has not been connected to any disease-specific research. It's basic science, focused on a specific histone called H3.3—pretty esoteric stuff.

That is, until it turned out that H3.3 mutations are significantly associated with pancreatic neuroendocrine tumors (PanNETs), raising the possibility that Dr. Allis's

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Make a donation today at ElizabethsHope.com

The Power of Families

The amazing circle of love and support that formed around Elizabeth during her illness made it possible to launch the Children's Brain Tumor Project—a research program aimed solely at rare and inoperable brain tumors that strike children. It's a sad fact that major funding sources don't support pediatric brain cancer research—such tumors are simply too rare—but it's gratifying to see families step up to fill the void. After all, who knows better than the families and friends of our children just how cruel these tumors are? And who could be more committed to finding the answers—to creating hope?

November marks the first anniversary of the founding of *Elizabeth's Hope*, and in that year we've had several other families join this effort. Just in the few months since our summer newsletter, we've seen a nationwide movement start to take hold—families joining forces to raise awareness and funding for the Children's Brain Tumor Project:

Ty "SuperTy" Campbell was diagnosed with an atypical teratoid/rhabdoid tumor (AT/RT) shortly before his third birthday. AT/RT is extremely rare and extremely lethal, with survival times measured only in months. Ty's mother, Cindy, recalls his doctors telling her that with treatment they could give Ty one more good summer. But time after time, little Ty defied the odds and beat all expectations—this summer, two years after



Dr. Greenfield with Cindy, Gavin, Ty, and Lou Campbell at a 5K fundraiser in July

his diagnosis, he was one of the Race Ambassadors at a Miles for Hope 5K to benefit the Children's Brain Tumor Project. The cancer reappeared this fall and Team

SuperTy turned out in force to show their support for him at the Rock'n'Roll Marathon's 10K, joining scores of runners from *Elizabeth's Hope* in a massive awareness event to get the word out about pediatric brain cancers. Ty lost his battle on October 17, just days after his fifth birthday.

TEAM Sean

participated in the Miles for Hope 5K as well as in the Rock'n'Roll Marathon 10K. Sean Ries was diagnosed in February with a dysembryoplastic neuroepithelial tumor (DNET), a slow-growing glioma located close to his speech and motor centers. Originally told that the tumor's location made it inoperable, the Ries family investigated every treatment possibility until they found Dr. Greenfield, who carefully mapped the tumor's location and was able to remove more than 90 percent of the tumor in May. Sean started kindergarten in September, but he faces a lifetime of therapy, treatment, and monitoring for recurrence. One of the goals of the Children's Brain Tumor Project is to find alternative treatments for children, to spare them the long-term consequences of harsh chemotherapy and radiation.

Kathleen Clark lives in Homer, Louisiana, and found *Elizabeth's Hope* as she was researching her father's diagnosis of gliomatosis cerebri. Although the tumor is most commonly diag-



nosed in children and adolescents, it can occur in adults as well. Kathleen has become a passionate supporter of *Elizabeth's Hope* and



Sean Ries with Dr. Greenfield (left) and his mom Brenda Ries with Emmie (above).

the Children's Brain Tumor Project, holding fundraisers and awareness events almost 1,500 miles away from where *Elizabeth's Hope* was born.

Jacob "Jake the Hero" Grecco

of Phillipsburg, New Jersey, was diagnosed at age 7 with gliomatosis cerebri. His parents pursued every option for him, taking him to Germany this summer for one last chance at treatment. When he died in August at age 8, Jake's parents asked that, in lieu of flowers, supporters make donations to *Elizabeth's Hope* and the Children's Brain Tumor Project. We mourn Jake's passing, as we mourn the senseless loss of all these beautiful children, and we join his family in our commitment to creating hope for children facing these diagnoses in the future.

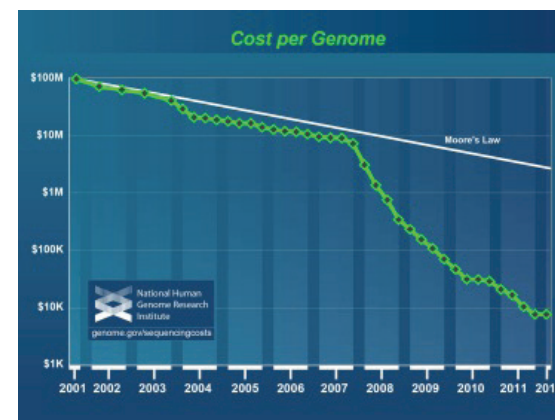


Laboratory Update

(continued from page 1)

lab might hold a new key to those cancers. And now the real news: H3.3 mutations are also found in pediatric gliomas. And Dr. Allis is not on the other side of the globe from where I'm doing the work of *Elizabeth's Hope*—he's right across the street from me here in New York.

So today I'm ecstatic to announce a new collaboration between Dr. Allis's lab and the *Elizabeth's Hope* project. We're going to dig a lot deeper into H3.3 to find out just why the mutation causes gliomas—including gliomatosis cerebri—to happen. We're evaluating candidates now for a fellowship position dedicated to this research, which has the potential to produce some amazing breakthroughs. Our collaboration could be another example of one plus one equaling much more than two.



I'm also pretty excited about how the cost of gene sequencing continues to fall. Just a decade ago sequencing cost almost **\$100 million** per genome. Five years ago the cost began a precipitous descent that may soon put sequencing within reach for many patients. The new collaboration investigating the H3.3 mutation, plus access to genomic sequencing at a reasonable cost, changes the whole landscape of our research.

These are exciting times indeed, and I remain truly grateful to *Elizabeth's Hope* for its support, which allows me to pursue innovative solutions and take advantage of surprising opportunities when they arise.



Event Update

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

It's been a busy fall! It's so very gratifying to watch the *Elizabeth's Hope* phenomenon spread across the country—carried onto college campuses, playing fields and courts, even formal dances. We are so grateful to all the friends and supporters who are helping in this effort!

The 10K run in Prospect Park on October 13 was such an inspiring event—*Elizabeth's Hope* fielded a team of nearly 200 runners, walkers, and cheerleaders and raised almost \$50,000 for the Children's Brain Tumor Research Project.

Annie Longobardo and her teammates on the Williams College field hockey team (right) dedicated their season to Elizabeth and gathered pledges that top \$150 per goal! The team racked up 22 goals over the season and raised more than \$5,000 for *Elizabeth's Hope*.



Elizabeth's Denison University sorority sisters at Pi Beta Phi held numerous fundraisers, including selling "Love4Liz" bracelets and "Lattes for Liz."

UScoop held a fundraising campaign on Facebook that accepted \$10 pledges for *Elizabeth's Hope*—and every pledge earned the donor a koozie!



Georgetown University's Party-for-a-Cause dedicated its 2012 Homecoming Formal (left) to *Elizabeth's Hope*. More than 500 guests attended the sold-out event. Special thanks to Katherine Hackett for petitioning the event to the University!

Erin Hackett organized a tennis tournament at Gettysburg University, where she also sold T-shirts (they sold like hotcakes!)

Matt Easley held a raffle at Ohio Wesleyan University—the grand prize winner scored some OSU football tickets!

Chanler Rutherford and her Tridelt sorority sisters at UVA held a Capture-the-Flag fundraiser called "Tridelt Presents Capture for a Cure!" Right after the tournament, Brad Taylor, another Bronxville classmate of Chanler and Liz, hosted a fundraiser through his fraternity, St. Elmo Hall. By the time the day was over, UVA students had contributed more than \$1,700 to *Elizabeth's Hope*!

Emily Kuschner ran in the Westchester Running Festival with Team Zachys for the Quarter Mile on Oct. 7 in Elizabeth's honor.

Yohannes Constable is climbing Mount Kilimanjaro for *Elizabeth's Hope*! (You can sponsor his climb at rally.org/elizabethshope.)



Kathleen Clark in Homer, Louisiana, organized three fundraisers, including a tailgate party at an LSU game. That's Kathleen at left being held up in the middle by her pals, all wearing their gold brain tumor shirts!

The momentum continues with more events coming up at Denison, the University of Chicago, and Williams. We are so grateful for the ongoing energy and support!

Brain Tumor Research In the News

Genetic Breakthrough for Brain Cancer in Children

January 30, 2012

<http://www.sciencedaily.com/releases/2012/01/120130102522.htm>

This Science Daily report explains the recent findings about H3.3 mutations (originally published in the journal Nature) in layman's terms.

An Open Letter to Harold Varmus

October 24, 2012

A heartfelt message to the head of the National Cancer Institute from a father who lost his daughter to DIPG.

http://www.huffingtonpost.com/jonathan-agin/harold-varmus-cancer_b_1998294.html

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 create 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.

Introducing LIZ LAUGH LOVE From Gretchen Scott Designs

We are amazed and delighted by the support of our good friend Gretchen Scott, who is donating 100 percent of her proceeds from the sale of specially designed *Elizabeth's Hope* shirts to the Children's Brain Tumor Project. The navy blue autumn version shown here is now available; we hope it's as popular as the summer top, which generated tens of thousands of dollars for *Elizabeth's Hope*.

We also love the story Gretchen tells on her web site:

We remember Liz calling years ago and asking to work for a day at a wholesale trade show. Of course we agreed, and she did a great job—full of curiosity, delight, and a sense of wonder. She carried herself beautifully. The next day a customer came to change an order she had written with "a pretty blond woman, about thirty"—we had no such person. They were talking about 16-year-old Elizabeth!

This very special shirt personifies Elizabeth's zest for life. 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.

Both tops are available at gretchenscottedesigns.com.



The Elizabeth's Hope Store

The *Elizabeth's Hope* online store features 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 of hope 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.



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