



The Children's Brain Tumor Project Newsletter

Summer 2012

Vol. 1, No. 1

From the Desk of...

*Michael Minter and Emma Hill*

Dear Friends and Supporters,

It was just over a year ago that Elizabeth and we decided to join Dr. Greenfield in pursuit of his long-held goal to make a difference for children and adolescents with inoperable brain cancer—to eventually offer real hope to other young people who receive these difficult diagnoses. By November, the Children's Brain Tumor Project (the research project) and Elizabeth's Hope (a funding mechanism) were launched. Elizabeth lived to see the project become a reality.

We are so grateful for the initial outpouring of support. We have raised over \$500,000. So many people have given. Most satisfying are the number of generous, creative people who have stepped forward to organize events or sell products for her cause. Our early success gives us confidence, and we want to maintain the momentum.

Knowing that tremendous strides are being made in the treatment of many adult cancers, while watching a child relentlessly attacked physically, emotionally, and intellectually by brain cancer and ultimately succumbing is devastating. However, believing we can ultimately make a difference for other children like Elizabeth inspires us. There is so much to be done. We feel privileged to have you join us.

With heartfelt gratitude,

*Mike Emma*

## Laboratory Update

Jeffrey Greenfield, MD, PhD  
Director, Children's Brain Tumor Project

All of us at the Weill Cornell Pediatric Brain and Spine Center mourn Elizabeth's passing, a devastating loss to her family and community. Elizabeth's remarkable vision for this foundation, and our promise to her, motivates us every day in our search for new treatments for gliomatosis cerebri and other rare and inoperable brain tumors of childhood. Elizabeth's Hope lives on as her legacy, and turning her dream into a reality has been made possible by the outpouring of support from her community—supporters like you.



As you know, we are committed to using the latest in genetic medicine and innovative delivery techniques to create new hope for families facing these terrible diagnoses. This summer, Elizabeth's cancer was the first gliomatosis cerebri tumor from any patient in the world to be completely sequenced, a very proud but bittersweet moment for the scientists in our lab. The process generates a dizzying amount of data, and our lab has an urgent need for a PhD fellow with expertise in bioinformatics to begin to perform the computational analysis. Thanks to the generosity of Elizabeth's Hope donors, we are now recruiting a scientist to start in the fall to work on gliomatosis cerebri and other rare and inoperable pediatric

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

## MEET THE TEAM

By Dr. Jeffrey Greenfield

For this first issue of the Elizabeth's Hope newsletter, I wanted to introduce key players in the research you are so generously funding.

**Dr. Mark Souweidane** is the director of pediatric neurosurgery at the Weill Cornell Pediatric Brain and Spine Center. Dr. Souweidane and I are a unique team—as my laboratory concentrates on identifying the genetic commonalities in tumors, Dr. Souweidane's focus is on searching for optimal ways to deliver cancer-fighting agents into parts of the brain that are surgically inaccessible. Dr. Souweidane recently treated the first patient in a ground-breaking new clinical trial testing the safety of convection-enhanced delivery (CED) of a radioactive agent against DIPG, another rare and inoperable childhood brain tumor. That patient, a beautiful four-year-old girl, is currently doing well three months after her treatment.

**My current laboratory staff** consists of Yujie Huang, PhD; Karen Badal, MD; Prajwal Rajappa, MD; Caitlin Hoffman, MD; and Heather McCrea, MD, PhD. In addition to their invaluable contributions to the gliomatosis project and Elizabeth's Hope, they are each working on ground-breaking research in various pediatric brain tumors.

**Dr. Huang** studies the role of inflammatory immune system cells that

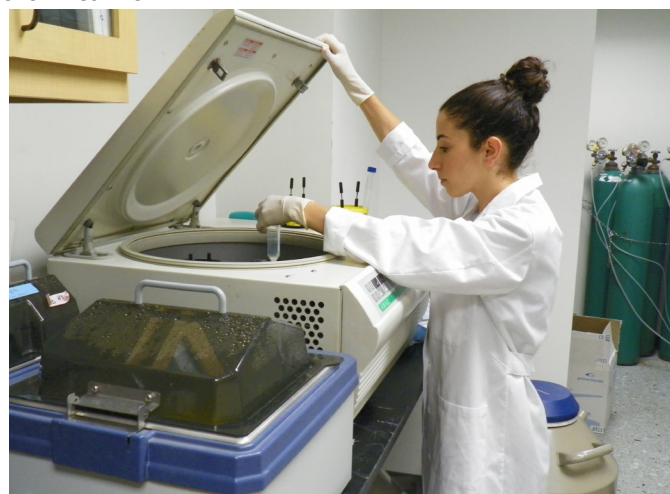
are found in the bone marrow. These cells travel to brain tumors to help set up the environment that supports their malignant growth. He recently discovered a new pathway that helps tumors create new blood vessels. Blocking this pathway could play a role in treating almost every type of



Dr. Jeffrey Greenfield, left, and Dr. Mark Souweidane

malignant pediatric brain tumor.

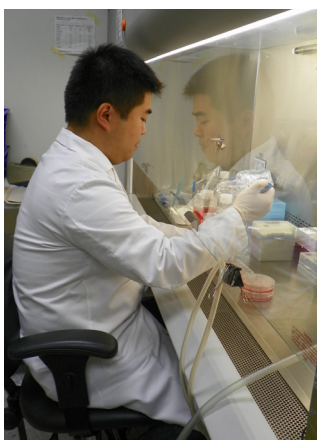
**Dr. Badal**, in conjunction with **Dr. Hoffman**, studies a pediatric brain tumor called medulloblastoma, the most common malignant brain tumor of childhood. Together they have identified a new drug, commonly used for blood diseases, that can stop the spread of this tumor in mice.



Karen Badal, MD

**Dr. Rajappa** leads our division studying an exciting new avenue of research called exosome biology. He has identified small particles that brain cancer cells actually shed—previously thought to be debris—which

**Yujie Huang, PhD**



carry important genetic material throughout the body.

They're all part of the Weill Cornell Pediatric Brain and Spine Center's research team and the Children's Brain Tumor

Project. All of our lab members work across the translational spectrum—from the moment tumors are removed in the operating room, to their preservation in the lab, to the acquisition of blood samples from all of our thriving patients, there is a continuous hum of energy between the hospital and laboratory.



Prajwal Rajappa, MD

In the coming months I'll continue to highlight specific projects, spotlight lab members, and report back to you on the work our lab is doing, thanks to your dedicated support. e





## Laboratory Update

(continued from p 1)

brain tumors. Your gifts make it possible for us to do the day-to-day work that will one day lead to real solutions.

We have also obtained 20 stored gliomatosis cerebri tumor samples from the archives of several leading hospitals around the country. It's the right way to start, but our research depends upon fresh samples as well as archival ones, so it's critical to get the word out. We are in constant contact with other research institutions about our work here, and about our commitment to advancing the science in this area.

We're also going to establish a national patient registry where we can track new cases, because examining as many new tumors as we possibly can is critical to finding solutions. Only by finding commonalities in these tumors can we then pursue the best therapeutic agents to attack them. The history of lung cancer research holds a great lesson for us: Laboratory researchers identified a fusion protein that presents itself in about 5 percent of cases. That's a small percentage, but before this protein was identified those cases were aggressive and intractable, with a survival time of about 90 days from diagnosis. After the protein was found, and a targeted drug was developed, survival times were extended to several years. As we continue to find similar clues within tumors, we can divide patients into groups that will fare better with very specific treatments and continue to extend survival rates for children and young adults with brain tumors.

On behalf of the Minter family, my lab, and everyone at the Weill Cornell Children's Brain Tumor Project, I thank you for that support, without which we could not continue to do the work of Elizabeth's Hope.



## The Elizabeth's Hope Store

This month we announce the opening of the Elizabeth's Hope online store, where a variety of products can help us spread the word about Elizabeth and the Children's Brain Tumor Project. The online store features shirts, 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 carrying them. Plus, the proceeds of every sale go toward Dr. Greenfield's laboratory and the Children's Brain Tumor Project. Products are available now on [elizabethshope.com](http://elizabethshope.com).



### Gretchen Scott Designs

Our friend Gretchen designed this top specifically for Elizabeth's Hope, and she's donating all of her proceeds to the cause. The blouse comes in two colors, and is available in retail stores that carry Gretchen Scott Designs as well as online at [GretchenScottDesigns.com](http://GretchenScottDesigns.com).



## Now on ElizabethsHope.com



Visit the site to read the family and friend remembrances from the June 6 Service of Celebration, and download an audio file of the service.

### Meet the Love4Liz Dream Team!

*They're organizing fund-raisers and putting their sweat into our cause.*

We are so thankful for those friends who have organized fund-raisers—special events that not only raise money but also help us spread the word about the project. Here's how you can help:

Elizabeth Haughton and Tessa Naso are hard at work organizing our first 10K run this October. We need runners as well as sponsors! Email [tessa@elizabethshope.com](mailto:tessa@elizabethshope.com) for instructions on how to register and start lining up supporters, and visit [elizabethshope.com](http://elizabethshope.com) for links to runners you can sponsor.

The wonderful folks at Panda Sunglasses will donate a portion of their proceeds to Elizabeth's Hope—visit [WearPanda.com](http://WearPanda.com) and be sure to enter code "love4liz" on the order form.

Tali Lekorenos at Denison hand-paints custom covers for laptops, iPhones, iPads and iPods, and is donating 10 percent of the proceeds to Elizabeth's Hope. See her designs at [Facebook.com/ToBloomLuxe](https://www.facebook.com/ToBloomLuxe).

## 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 since 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, MD, PhD, 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](http://elizabethshope.com) to make a secure online donation, or a monthly pledge, with a credit card.

### 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).

## Protect Your Donation

Your gift to Elizabeth's Hope goes to the Weill Cornell Pediatric Brain and Spine Center, so you may get letters and emails asking for other donations to Weill Cornell Medical College or NewYork-Presbyterian Hospital. Please note that those other gifts, although worthy, do NOT support Elizabeth's Hope. To be sure your gifts go only to Elizabeth's Hope, you can opt out of those other solicitations by emailing

**[optoutnyp@nyp.org](mailto:optoutnyp@nyp.org)**

and

**[optoutwcmc@med.cornell.edu](mailto:optoutwcmc@med.cornell.edu)**

and asking to be removed from their mailing lists.

## Brain Tumor Research In the News

### Genetic Gamble: New Approaches to Fighting Cancer July 8, 2012

A three-part series in *The New York Times* by Gina Kolata, exploring the frontiers of gene sequencing and personalized medicine—which is the strategy being pursued by the Children's Brain Tumor Project  
<http://www.nytimes.com/2012/07/08/health/in-gene-sequencing-treatment-for-leukemia-glimpses-of-the-future.html>

### Some Brain Tumors Are Linked to a Gene Defect July 26, 2012

You may have seen this *WSJ* article about a report in the journal *Nature* entitled "Dissecting the genomic complexity underlying medulloblastoma."  
<http://online.wsj.com/article/SB10000872396390444840104577551361806274348.html>  
<http://www.nature.com/nature/journal/vaop/ncurrent/full/nature11284.html>

## Go Green!

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