

IF A CHILD'S LIFE WAS IN DANGER, YOU WOULD DO SOMETHING, WOULDN'T YOU?



Children's Brain  
Tumor Project  
powered by families



Weill Cornell  
Medicine

Winter 2021

## Reflecting on a Decade of Hope Remembering Elizabeth Minter on Her 30th Birthday

As a sophomore at Denison University, Elizabeth Minter was contemplating a major in communications or biology, with perhaps a study abroad program in Italy or Australia. Her entire life was ahead of her, and everyone who knew Liz knew she was bound to do great things.

Her opportunity for greatness came far too soon, in a most unexpected and tragic form. Diagnosed with terminal brain cancer in the middle of that sophomore year, Liz didn't crumble in defeat; rather, she founded a nonprofit called Elizabeth's Hope. She explained that her hope was "that medical research will continue and that there will be more treatment options—and even a cure!" Elizabeth's Hope led to the launch of the Children's Brain Tumor Project—a one-of-a-kind research lab focused on rare pediatric brain tumors at Weill Cornell Medicine. It was Elizabeth's Hope that started it all, just ten years ago.

We are celebrating this "Decade of Hope" in honor of Elizabeth's 30th birthday on February 11th. Visit [DecadeofHope.org](http://DecadeofHope.org) for more information and to make a donation in loving memory of Liz.



## A Chance Meeting That Changed the Research Landscape by Dr. Jeffrey Greenfield

There are days that I'll never forget. Some of them were joyful like graduation day or my wedding, and some were overwhelming like the days my children were born. Then there are the days that start off as routine and end up being life changing. Like the day I went to visit a new consult in the hospital and met Elizabeth Minter for the first time.

As a pediatric neurosurgeon in New York City, I've had to deliver devastating news to so many families newly faced with a pediatric brain cancer diagnosis. As the first person looking at their child's scan, showing parents a mass in their baby's brain, or returning news of a concerning biopsy after surgery, it is a part of my life that I accept and have become better at over the years, but it's never easy. I think the moment deserves honesty, but also hope and compassion. It's a delicate balance. After more than a decade I've learned to move on to the next emergency surgery with a clear head, or go home to focus on my family.

That day, however, I will never forget how Elizabeth looked at me—her shiny blonde hair framing her face and her smiling blue eyes intently focused on mine—she was so beautiful and full of life with a promising future ahead. And my job was to forever alter that future, to completely reshape and shorten it, with the news of her terminal diagnosis of gliomatosis cerebri (GC). I envisioned the next year of her life in an instant, and it was as if I was watching a lifetime of hopes and dreams draining from her eyes. Then surprisingly, a sudden spark showed she was not going to accept the news with tears or self-pity, but with a remarkable energy and passion. What followed was a barrage of questions from Elizabeth and her parents, Mike and Emmie. What did we know? How could we learn more? Why did we have to accept the status quo? I explained to them just how little we know about rare and inoperable brain tumors like GC, and how little genetic information is available to the scientific community.

Elizabeth listened to my musing, then challenged the heart of what neuro-oncology accepted. She forced me to articulate part of what my vision had always been—but that we hadn't had the resources to deliver on. "Theoretically," I explained, "if we could study these tumors at the biological level, we could look for targetable mutations and perform drug screening, but there has never even been a successful sequencing of GC."

Elizabeth was inspired to help advance the science, and her passion inspired me to further pursue the development of a dedicated lab that would study the wide range of rare pediatric brain tumors that feel far from rare to me.

They say the days are long, but the years fly by. It was December of 2010 that the seeds of a dedicated nonprofit to study rare and inoperable brain tumors, Elizabeth's Hope, were first planted. Over these ten years, there have been many long days going from the OR to the lab, building the scientific initiative that we now call the Children's Brain Tumor Project.

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

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I can proudly say that so much of Elizabeth's Hope has been realized. She and her family made the decision not only to allow me to sequence her biopsied tumor tissue, but also to donate her entire tumor to the lab upon her passing. This contribution enabled the Children's Brain Tumor Project to become the first lab in the world to uncover important genetic information about GC and to make that tumor tissue available to other labs around the world, a resource that continues to inform scientific discovery today.

We now have a world-class precision medicine program in which we are sequencing ALL biopsies and performing high-throughput drug screening to identify new therapeutic options for children who are currently in treatment—a vision that has finally come to fruition. But a cure for this disease, Elizabeth's greatest hope right up until the end, is still sitting on the horizon, still just out of reach.

It is an even mixture of sadness and thankfulness that buoys my thoughts of Elizabeth a decade later. I don't know if we would be anywhere near where we are today if she hadn't fallen ill, if I hadn't happened to meet her that day, if she and her parents hadn't challenged me, and if I hadn't been willing to accept their challenge with humility. One truth about medicine, which is becoming true of science more and more each day, is that we always learn something from our patients. Despite the pain that will never go away for those who loved her, I am simply thankful that I met Elizabeth, that I listened to her, and that she allowed me and us to be a part of her world long enough to inspire us for a lifetime.

Happy 30th Birthday Liz.

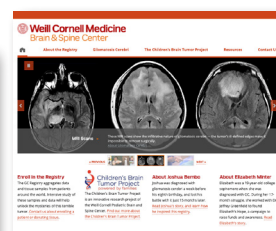
Thank you for continued love and inspiration.



Elizabeth's mother, Emma Hill, stands with Dr. Jeffrey Greenfield in front of Liz's photo that is on display at the CBTP lab.

Jeffrey P Greenfield MD PhD

## Decade of Hope



### 2011

**December 2010** - Liz is diagnosed with a rare and inoperable brain cancer called gliomatosis cerebri. She meets Dr. Jeffrey Greenfield.

- Liz turns 20.
- Elizabeth's Hope is founded.
- Website launched.
- First Soul Cycle event raises \$40,000.

### 2012

- Liz turns 21 and sadly passes away four months later.
- Her tumor is first to be sequenced.
- The Children's Brain Tumor Project is launched.

### 2013

- Institute for Precision Medicine opens at WCM.
- Gretchen Scott sales benefit EH.
- Denison team hosts Lax for Liz.

### 2014

- WCM GC Registry goes live.
- EH raises \$1M.
- The CBTP Family Council is formed.
- First Bronxville Road Race.

### 2015

- CBTP opens lab on campus.
- First bi-annual GC conference is held in Paris.
- Second Bronxville Road Race.
- First EH cocktail party in NYC.

elizabeth's hope



# When the Loss of a Child Offers Hope to Another

## Leaving a Legacy

Elizabeth Minter's mom, Emmie, has said that Liz's decision to donate her brain to research at the time of her passing was perhaps her greatest and most enduring gift to the research community. Her contribution fueled the search for better treatment options by providing a better understanding of the disease.

Chase Balay's mom, Julie, said that she wanted the scientists to have an example of his tumor in the lab because it was so rare and she wanted them to learn from it. She chose to donate his tumor via rapid autopsy.

Both Elizabeth and Chase were diagnosed with rare brain tumors deemed inoperable because they were diffuse and infiltrated vital areas throughout the brain and spine. Inoperable tumors—such as gliomatosis cerebri, diffuse intrinsic pontine glioma, and thalamic glioma—have posed a great challenge to the scientific community because up until recently they were rarely (if ever) biopsied, leaving no tumor tissue to study in the lab. The scientific community is greatly limited when tumor tissue is scarce, because it leaves no material to study and no historical data from other tumors with which to make comparisons that can potentially inform treatment.

Liz Minter's tumor was the first to be donated to the Children's Brain Tumor Project, kicking off the lab's original Legacy Program, an initiative intended to present the opportunity for post-mortem donation to more families. But the Legacy Program was limited in scope, and there were missed opportunities among nearby families who expressed regret that they hadn't known about it in time.

"I thought to myself, if there was one small chance that I could spare another parent from losing their child, then I would like to do something about that," said Katherine Godfrey, who lost her daughter Fiona to a thalamic glioma in 2013. "I had asked her oncology team about organ donation, but I was told she couldn't participate after treatment and that was the end of the conversation."

The diagnosis of an incurable brain tumor is an inconceivable challenge that no child or family should have to face. The hope of the scientific community is that one day fewer families will face such outcomes thanks to breakthroughs that result from post-mortem donations.

## Gift from a Child

Founded by the Swifty Foundation in 2016, Gift from a Child is a national initiative designed to increase access to post-mortem pediatric brain tissue donations through advocacy. Gift from a Child was designed by families who have endured the loss of their own children, ensuring that all donations are handled with the utmost care and that the wishes of participating families are prioritized.

In 2020, New-York-Presbyterian/Weill Cornell Medical Center was named a regional Center of Excellence in the Gift from a Child program. As a designated Center of Excellence, we are a regional site for coordination, processing, and storage of donated tissue. The centers work as a collaborative and an example of best practice in family and patient care.

As a Center of Excellence and a member of the Children's Brain Tumor Tissue Network (CBTN) we are dedicated to sharing tissue with researchers around the world to gain a wealth of invaluable information through molecular, cellular, and genetic analysis of the tissue. This information that is so essential to creating a brighter future for the



### 2016

- 5 years of EH cocktail party.
- CBTP partners with CHOP's Children's Brain Tumor Tissue Network (CBTN).
- First-ever GC xenograft achieved.

### 2017

- 2nd bi-annual GC conference in Washington DC.
- CBTP welcomes two new Principal Investigators, Dr. Babacar Cisse and Dr. Nadia Dahmane.

### 2018

- Third Summer Soirée for EH.
- Dr. Souweidane's results from his Phase 1 trial using convection-enhanced delivery are published in *The Lancet*.

### 2019

- Mike and Emmie Minter are honored at Comedy Night fundraiser.
- Lab visit from Elizabeth's friends to share with JCrew.

### 2020

- Precision Medicine program at the CBTP expands tremendously with gift from Marsano family.
- Lab is named a Center of Excellence by GFAC.

**Feb. 2021** - In honor of Elizabeth Minter's 30th birthday and ten years of Elizabeth's Hope, we are hosting a week-long fundraiser asking for donations in increments of three as a toast to 30. Visit [decadeofhope.org](https://decadeofhope.org).



# How Tumor Tissue Informs the Science

The greatest roadblock to advancing the science pertaining to rare pediatric brain cancer is the lack of information about these tumors. Although there are multiple types of pediatric brain tumors that are considered extremely rare, collectively brain tumors are the most fatal of all cancers among children. Therefore, families faced with a new diagnosis are often shocked to learn just how little research into rare pediatric brain tumors had been done in previous decades, and they are often inspired to do something about it. Over the years it has been the families – like that of Elizabeth Minter – who have been supporting labs like the Children's Brain Tumor Project and driving change among the research landscape in order to cure more children.

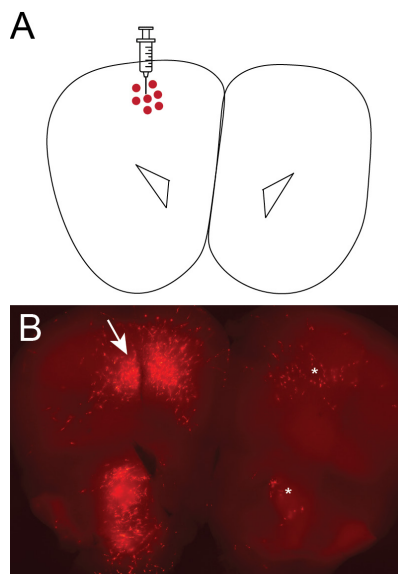
At the time of her diagnosis in December 2010, Elizabeth Minter first learned how little we knew about her tumor type, a subset of glioma called gliomatosis cerebri (GC), and she was committed to helping change that. Elizabeth donated her tumor tissue to research post-biopsy, followed by her greatest gift: a rapid autopsy tumor donation upon her passing in 2012. Her gift enabled our lab to complete the first identified full exome sequencing of a GC glioma.

From donated tumor tissue, genetic sequencing can be performed and the biological data collected can be analyzed and interpreted through bioinformatics. The more genetic data that is available, especially pertaining to rare tumor types, the more information researchers have to better understand the origin of these tumors, their behavior, and the therapeutic modalities that may be most promising against them.

From that tissue, researchers can also attempt to isolate and grow cell lines for studying in the lab. Cell lines are cultures that can be propagated repeatedly and sometimes indefinitely. In other words, genetically identical tumors can be continuously replicated from one cell in order to study the disease from multiple vantage points.

One such vantage point that has been a key area of exploration at the Children's Brain Tumor Project is the invasion and migration patterns of various pediatric brain tumors. GC is a type of glioma that has a highly invasive pattern of migration into multiple lobes of the brain, which has allowed our team of neuroscientists to study the behavior of this disease, looking to identify the factors that may enable the cells to migrate so extensively.

We have successfully created the first-ever orthotopic xenograft mouse models using GC cells, and the results have provided a wealth of knowledge about the behavior of this tumor.



Highly infiltrative human glioma cells were labeled with a red fluorescent protein and injected into the left side of the cerebral cortex of an immunocompromised mouse (at the level indicated by the arrow). Just a few weeks later, the glioma cells are found infiltrating the other side of the cerebral cortex as well as other region of the brain.

To better understand how glioma cells invade the brain, we labeled highly migratory and infiltrative glioma cells and injected them into the brain of an immunocompromised mouse, in which they formed a glioma. We thus generated a mouse model in which these glioma cells, in a similar fashion to what is seen in human GC tumors, migrate quickly and spread throughout the brain just a few weeks later.

These kinds of discoveries at the Children's Brain Tumor Project have been stepping stones toward the creation of what is now a much larger scientific community working together to study these tumors. Families and scientists have been coming together to host a bi-annual international GC conference since 2015; the GC Registry that was created at Weill Cornell Medicine in 2014 has evolved into a resource that collects a wealth of information from the patient community to inform science; and a GC research consortium has been created in partnership with Dana Farber Cancer Institute that is called the International Gliomatosis Cerebri Platform and includes 20 institutions around the world, including Spain, Italy, France, and the UK.

Perhaps the most important progress of all has been the recent expansion of the precision medicine program at Weill Cornell Medicine thanks to the generosity of the Patrick Bayly Marsano Foundation in memory of Patrick, who passed away from GC in 2016. This program has enabled us to sequence every biopsy and tumor resection, perform immunophenotyping, identify potential targets, perform high throughput drug screening, and leverage those findings to adjust treatment protocols for patients in our care.

As Dr. Greenfield stated, this program is *a vision realized*.

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children and families that this disease affects so mercilessly.

"The vision I have on this campus is that we can have rapid access to the tumor tissue from any child passing from a brain or spinal cord tumor, and that we can share those resources with the international community of scientists, oncologists, and anyone looking to explore better therapeutic options," explained Dr. Mark Souweidane.

The team at Weill Cornell Medicine, including Dr. Mark Souweidane and Dr. Jeffrey Greenfield, realizes that the decision to donate a child's brain tissue from rapid autopsy is multifaceted and highly emotional, and requires reflection and preparation. As a regional Center of Excellence, we have a designated tissue navigation team who can provide the information and guidance a family may need in the process. Most importantly, we admire the strength of family members in these most difficult times.

"There's no better legacy you can leave on this earth, than saving someone else's life. And Chase will have done that, with the other kids too," said Julie.

Together we are working toward changing the future of this devastating disease.

**To learn more about Gift from a Child:**

**Call: 844-456-GIFT**

**Visit: [GiftfromaChild.org](http://GiftfromaChild.org)**

**Email: [Cic2008@med.cornell.edu](mailto:Cic2008@med.cornell.edu)**



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