



For more information call **1-(833) 879-5983** or email **[postmortemdonation@cbttc.org](mailto:postmortemdonation@cbttc.org)**

# GIFT

The gift of a post-mortem tissue donation benefits other children diagnosed with a pediatric brain tumor and can provide families with hope and consolation during a time of loss.

Thanks to the Swifty Foundation, a new program was created by the Children's Brain Tumor Tissue Consortium to empower patients and families in the discovery of better treatments and cures for pediatric brain cancers.



**To enroll or to learn more about participating call**

**1-(833) 879-5983**

**or email**

**[postmortemdonation@cbttc.org](mailto:postmortemdonation@cbttc.org)**

Donating brain tissue at the time of a child's passing is a personal decision that is unique to each family. The CBTTC Post-Mortem Tissue Donation Program provides patients and families with the opportunity to advance cancer research through a simple donation process. Donated brain tissue allows researchers to better understand how brain tumors form, and it is crucial to discovering more effective treatments for children in the future.

**Just two things are required from families who wish to donate tissue:**



**Written consent** before the time of death



**One phone call** at the time of death



To learn more about this important program, call or email the CBTTC or visit **[www.cbttc.org/patients-and-families/postmortemtissue](http://www.cbttc.org/patients-and-families/postmortemtissue)**

# THE VIDEO YOU HAVE IN YOUR HAND

**WhyDonateTissue.org** is a site created to offer the free download of a video explaining the need for pediatric brain cancer post-mortem tissue donation to any institution that wishes to use it. Institutions may use the video to educate and advocate for why post-mortem tissue collection is essential to advancing research and improving outcomes for children diagnosed with brain cancer.



Any institution downloading the video is welcome to edit it in any way and include its own institutional branding to serve the purposes of its mission. The video offers the scientific and familial reasons why post-mortem tissue collection is valuable. If you need a higher quality video it can be downloaded at [WhyDonateTissue.org](http://WhyDonateTissue.org)

## THE 11-MINUTE VIDEO:

- highlights why whole brain donation is important to improving outcomes for pediatric cancer patients
- highlights why donation is an important consideration for the family who is confronted with the impending loss of a child
- sounds a call for removing the obstacles that can keep families from choosing to donate their child's tissue

## HOW TO USE THIS VIDEO:



Add it to your website



Share on social media



Use it in a presentation



Email to supporters



Share with families who may want to advocate



Rebrand it



Build a case for launching a tissue donation program in your institution



Share with your community to raise awareness

## WE WISH TO THANK THOSE WHO SHARED THEIR EXPERIENCE AND STORY:



**Dr. Peter Adamson**  
**Dr. Stewart Goldman**  
**Michael Gustafson**  
**Patti Gustafson**  
**Dr. Michelle Monje**

*(Children's Hospital of Philadelphia)*  
*(Ann & Robert H. Lurie Children's Hospital of Chicago)*  
*(Pediatric Post-mortem Donor)*  
*(Michael's Mom)*  
*(Lucile Packard Children's Hospital Stanford)*

## WHY IS THE SWIFTY FOUNDATION FOCUSED ON POST-MORTEM TISSUE DONATION?

Until more post-mortem tissue is collected, brain cancer will continue to be the leading cause of cancer related deaths in children. The brain tissue of children who succumb to their disease is essential in helping investigators understand why some tumor types do not respond to treatment. Studies have shown that although less than 5% of post mortem tissue is collected, 90 percent of families would consent to tissue donation if asked. When it's easier for families to donate tissue, and easy for researchers to access tissue, we move Together Toward Hope.

The three Swifty initiated efforts to improve the quality and quantity of tissue donation are listed below:



### THE CBTTC POST-MORTEM TISSUE DONATION PROGRAM

Since 2016, Swifty has partnered with the Children's Brain Tumor Tissue Consortium (CBTTC), a consortium of 17 children's hospitals from around the world, on a program that could rewrite the rules on how cancerous brain tissue is donated for research after death, allowing more families to make voluntary tissue donations than ever before.

#### Because of the program:

It's easier for families. Families are informed and invited, and only need to contribute two things: *written consent* to become tissue donors and a *single phone call* at the time of a child's death to initiate the process. Donating is free for families and has no effect on funeral arrangements or on the possibility of open-casket funerals for those who want them.

It's efficient for technicians. The necessary autopsy tech, pathologist and lab tech are all on call and available to coordinate with funeral homes to collect and process donated tissue quickly.

Results are multiplied. CBTTC shares tissue data openly with researchers through its database. To learn more about this program, call **(833)879-5983** or email **PostMortemDonation@CBTTC.org**

### TISSUE NAVIGATOR AT LURIE CHILDREN'S HOSPITAL

In 2018, Ann & Robert H. Lurie Children's Hospital of Chicago added a first-of-its-kind Tissue Navigator position to its pediatric cancer staff with Swifty's support. This person educates patients, families and staff about the value of tissue donation; assists patients and families with the logistics related to tissue donation; and coordinates tissue donations from other local and regional centers without formal donation programs.



Our ultimate aim is to replicate this position at large children's research hospitals across the country.

### WHYDONATETISSUE.ORG



WhyDonateTissue.org is a website we created that provides the free download of a video, produced by Swifty Foundation, that explains the need for pediatric brain cancer post-mortem tissue donation. The video offers the scientific and familial reasons why post-mortem tissue collection is so valuable.

Institutions downloading the video are welcome to include their own institutional branding to serve the purposes of their mission.

In time, WhyDonateTissue.org will include personal testimonials from families who have chosen post-mortem tissue donation, as well as a library of research made possible through post-mortem donation.

*For information on getting involved please email*  
**info@SwiftyFoundation.org**

# WHY IS CHILDHOOD BRAIN CANCER SO TOUGH TO BEAT?



**Brain tumors are the #1 cancer killer among kids in the United States.**

## WHY?

We just don't have enough information. Without a deeper understanding of the biology behind brain tumors, we can't improve our treatments.

## RESEARCH IS DIFFICULT

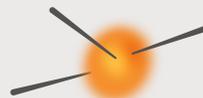
### Tumors change from spot to spot.

Measure 3 parts of a tumor, and you'll get 3 different sets of data. For the best research, we need to study the whole brain – not just a small biopsy sample.



### Tumors change during treatment.

Kids' bodies grow fast anyway – but when we treat brain tumors, they actually change even more as a response to treatment. For the best research, we need to study tissue after death – not just at diagnosis.



To fully understand childhood brain tumors, researchers need to look at the whole brain. And they need to do it after death. But that's not easy.

## DONATING IS DIFFICULT

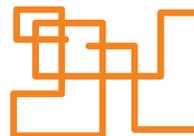
### Families don't know.

The decision to donate must be made before a child dies – but when is the right time to talk to families? Right now, many never hear about donation until it's too late to give.



### Donating is complex.

Most kids who don't survive brain cancer choose to die at home. Within 24 hours, 3 different experts – an autopsy tech, a pathologist, and a research technician – must retrieve and process tissue for a successful donation. And it all must happen without extra cost to families or to their insurance. That's a lot to ask.



Tissue donation is the only way we'll really get a deeper understanding of the tumors that too often take our children's lives. This problem is worth solving.

# HOW DO WE IMPROVE PEDIATRIC BRAIN CANCER RESEARCH?

Without post-mortem tissue donation from children who lose their lives to brain cancer, we'll never know enough about the disease. But donating isn't easy.

A new program in Philadelphia is changing that, requiring just two things from families who wish to donate tissue:



Written consent before the time of death



One phone call at the time of death

Here's how Swifty, the Children's Hospital of Philadelphia (CHOP) and the Children's Brain Tumor Tissue Consortium (CBTTC) have partnered to solve the problem of donation:

## 1. TELL FAMILIES IT'S AN OPTION.



### Research.

Interview current patients, families and care providers to learn when and how we can most lovingly present donation as an option.



### Communicate.

Develop the right messaging and materials to explain donation to future patients and families.



### Train.

Educate medical professionals and social workers on how to talk about donation with children and their families.

## 2. MAKE DONATING EASY.



If a patient dies, the family makes one phone call



On-call Autopsy Tech works with funeral home to collect donated tissue



On-call Pathologist and Lab Tech process donated tissue at the hospital



Anonymous genomic and proteomic data are cross-indexed and shared with other scientists through the consortium

## 3. MULTIPLY RESULTS.

### Year One:

Piloting the above improvements at CHOP is expected to increase tissue donations by 1000%.

### Year Two:

Sharing improvements and training with CBBTC's other member hospitals will multiply results across the country – and the world.

This means more and better data for researchers – which means better treatments for children diagnosed with brain cancer in the future. And that means a measure of comfort for families who've lost kids to pediatric cancer. We should know. We're one of them.



Donate now at [swiftyfoundation.org](http://swiftyfoundation.org)