

# 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:

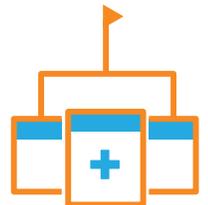
It's easier for families. Families are informed and invited, and only need to contribute two things: *written consent* to become tissue donors and a *single phone call* at the time of a child's death to initiate the process. Donating is free for families and has no effect on funeral arrangements or on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



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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**