

## How to Donate Tissue

For the family, once a decision has been made to donate, only two things are required. The first, prior to the child's death written consent is needed for the child to become a tissue donor, and the second is a single phone call to the tissue navigator at the time of death to initiate the process.

## What Families Need to Know:

- There is no cost to the family.
- Donating is available to families living anywhere in the country.
- Donation is possible whether a child dies at home, the hospital or in hospice.
- After death, the family may spend as much time with the child as they care to.
- All donation arrangements are taken care of for the family.
- Donation will not interfere in any way with funeral arrangements (open casket is possible).
- The donation team will be on call and the tissue will be immediately sent to the appropriate labs.
- Every doctor, researcher, lab technician who interacts with the tissue samples handles them with the highest level of respect and care.

## Our Family Companion Program

can match you with a parent whose child has donated to answer questions only another parent can answer.

Visit [GiftfromaChild.org](http://GiftfromaChild.org) for more details.



**To learn more**  
Call 844-456-GIFT  
[info@GiftfromaChild.org](mailto:info@GiftfromaChild.org)  
[GiftfromaChild.org](http://GiftfromaChild.org)

### Centers of Excellence



**Ann & Robert H. Lurie  
Children's Hospital of Chicago**  
Dr. Angela Waanders



**Children's Hospital of Philadelphia**  
Dr. Jane Minturn & Dr. Mateusz Koptyra



**Children's National Hospital**  
Dr. Javad Nazarian



**Stanford University Medical Center**  
Dr. Michelle Monje



**New York Presbyterian Hospital-Weill  
Cornell Medicine**  
Dr. Mark Souweidane and  
Dr. Jeffrey Greenfield

**Centers for Excellence** are regional autopsy sites for coordination, processing and storage of post-mortem materials. They make up a collaborative and are an example of best practice in family/patient care.



A Swifty Foundation Initiative

# When a Child's Life Ends Too Soon,

donating tissue is a way for the child and family to take a final stand against cancer.

## Stalled Research, Lagging Advancements & Increased Fatality Rates

Tissue donation is a contribution that improves outcomes for children with brain cancer that **only families can make.**

Brain cancer has overtaken leukemia as the leading cause of cancer related death for children. The reason children succumb to their cancer will remain a mystery until researchers are able to study the diseased tissue of those children who do not survive their disease.

Gift from a Child's mission is to increase postmortem pediatric brain tissue donations through advocacy as well as the education of families enduring the worst ... the loss of a child. We have formed partnerships with the best researchers and medical providers who value information and data sharing. **These strategic partnerships will accelerate breakthrough cancer research, improve treatments and ultimately find cures for childhood brain cancer.**

*Donating Michael's tissue was one of the few positive things we were able to do during those final tragic days of his life. Knowing his tissue may save another family from suffering the loss we have endured has consoled us as we continue to grieve and miss our Michael.*

— Patti Gustafson, Michael's Mom





## Who is Gift from a Child?

Gift from a Child is a national initiative supported by families who have lost children to brain cancer, private foundations, researchers and medical professionals. It currently receives the majority of its funding from the Swifty Foundation.

Gift from a Child has developed strategic partnerships with regional Centers of Excellence across the country and the Children's Brain Tumor Tissue Consortium to ensure the very best stewardship of the precious gift of a child's donated tissue.

The Centers of Excellence are regional sites for coordination, processing and storage of donated tissue. The centers work as a collaborative, are an example of best practice in family and patient care, sharing biospecimens and data widely across the international research community.

Each regional center is supported by a Tissue Navigator trained to companion families through the donation process and will coordinate all aspects of the donation.

**The Children's Brain Tumor Tissue Consortium (CBTTC)** is currently the planet's largest pediatric brain tumor database, including tissue and genomic data. It offers open-access, freely available data to researchers around the world. Tissue donated through the Centers of Excellence is stored at both the Center as well as the CBTTC bio-repository. CBTTC provides logistical and operational support for Gift from a Child.

### The Centers of Excellence are:

Children's Hospital of Philadelphia  
Philadelphia, PA

New York Presbyterian Hospital-Weill  
Cornell Medicine  
NYC, NY

Children's National Hospital  
Washington, DC

Ann & Robert H. Lurie Children's Hospital of Chicago  
Chicago, IL

Stanford University Medical Center  
Palo Alto, CA

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## Why Donate Tissue?

*Autopsy tissue donation is absolutely critical if we want to cure more children with pediatric brain tumors. The biology of the tumor changes over time, and quite obviously the tumor at the time of death is the tumor that evaded therapy. It's this tumor we need to learn about in order to treat it.*

— Michael Taylor MD, PhD Hospital for Sick Children, Toronto

## Brain Cancer is Complex

Brain cancer is not a single disease. It consists of a dozen types and countless subtypes. Researchers need a critical mass of tissue samples to fully understand the pathology of each type and to better predict how tumors will behave and respond to targeted treatments.

How do we treat a tumor that keeps changing? Researchers need to study a child's tumor at diagnosis, recurrence — and if necessary, after death. Only then will we understand why treatments work for some children and not for others.



Autopsy Tissue



Empowered Research



Medical Advances