

# 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.



## Improving Outcomes for Children with Brain Cancer through Tissue Donation

Brain cancer is the leading cause of cancer-related deaths among 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.

Tissue donation is a contribution that improves outcomes for children that **only families can make**. That is why the Gift from a Child program is focused on making post-mortem tissue donation accessible to all families who are considering that choice, while providing gentle, knowing support to those families.

## Introducing Gift from a Child

Gift from a Child (GFAC) is a national initiative created to increase post-mortem pediatric brain tissue donation through advocacy as well as the education of families enduring the worst... the loss of a child.

GFAC is 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.

## Enabling Donation and Tissue Sharing

Gift from a Child created a strategic infrastructure that enables participation from any family interested in the program and ensures that the precious gift of tissue donation is easily accessible to researchers through the Children's Brain Tumor Network (CBTN). The CBTN is the world's largest pediatric brain tumor database and bio-repository.

## Regional Centers of Excellence

Designated Centers of Excellence are regional sites for logistical coordination of procedures, tissue processing, storage, and sharing of donated tissue.

Each regional center is supported by a *Tissue Navigator* trained to companion families through the donation process and who coordinate all aspects of donations. Tissue navigators always put the families' wishes first.

1. Ann & Robert H. Lurie Children's Hospital
2. Arnold Palmer Hospital for Children
3. Children's Hospital of Philadelphia
4. Children's National Hospital
5. NewYork-Presbyterian/Weill Cornell Medicine
6. Stanford University Medical Center



Autopsy Tissue



Empowered Research



Medical Advances

*“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*

### Important Facts About the Program:

- There is never a cost to the family or the referring institution.
- Donation is available to families living anywhere in the country.
- Donation is possible whether the child dies at home, at the hospital, or at a hospice facility.
- After death, the family can spend as much time with the patient as they wish.
- The procedure will not limit funeral arrangements in any way (open casket is still possible). The donation team is on-call 24/7 to arrange rapid autopsy so tissue goes straight to the lab.
  - However, donations can still benefit research even after several days if decisions are delayed.
- Every doctor, researcher, and technician involved handles donations with great care.
- Families will be kept informed about research that was enabled through their program participation.
- A family companion program is in place to match interested families with others who chose to donate.
- There are helpful resources in various languages provided by GFAC for both medical teams and families.



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



**Arnold Palmer Hospital for Children**  
Dr. Amy Smith and  
Dr. Julia Hegert



**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



**NewYork-Presbyterian Hospital/Weill Cornell Medicine**  
Dr. Mark Souweidane and  
Dr. Jeffrey Greenfield

### Centers of Excellence

Centers of Excellence are regional autopsy sites for coordination, processing and storage of post-mortem materials.



GFAC Program Overview and Website