



Love Never Dies

Through Gift From a Child, parents can turn loss and grief into action.

When a child's life ends too soon because of cancer, donating tissue for research is a way for a family to take a final stand against the disease.

Although cancer in children is rare, it is still the leading cause of death by disease past infancy among children in the United States. Because of survival improvements in more recent years, brain cancer has replaced leukemia as the leading cause of cancer death among children.

For example, diffuse intrinsic pontine glioma (DIPG), an extremely rare pediatric brain tumor that typically strikes children between the ages of 5 and 7, infiltrates the brain stem and has a near 0% survival rate. Although there are several known long-term survivors, there is no commonality to those cases. Some children diagnosed with this disease will go into hospice at the time they are diagnosed.

Despite the overall decrease in cancer mortality, approximately 1,800 children and adolescents die of cancer each year in the United States, indicating that new advances and continued research to identify effective treatments are required to further reduce childhood cancer mortality. There has *never* been a drug developed and approved specifically for malignant pediatric brain tumors; thus, it's not surprising that brain cancer represents 29.9% of total childhood cancer deaths.

Many times, no biopsy can be performed due to the location of the tumor. In other cases, only small amounts of tissue can be collected, and what is collected is needed for diagnostic purposes.

Postmortem tissue donation in brain and central nervous system cancers is crucial because of the quantity and type of tissue it provides. Tissue donation at death allows for the greatest amount of tumor tissue to be collected. This collection can provide more than 50 vials of tumor tissue to multiple researchers for basic laboratory research. It also allows for the collection of non-tumor tissue, which cannot

be obtained during a routine surgery. This allows for comparison of the tissue down to the cellular level and for DNA extraction for molecular studies, which could reveal valuable information about the tumor. It also gives a view into what happens to this tissue during the course of any treatment. Without this tissue, new clinical trials for human subjects to improve and create new treatments that are more effective and less toxic to a child cannot occur.

In 2013, before his death at age 15, Michael Gustafson chose to donate his tissue. The teen knew he wouldn't survive his cancer, and he wanted to further research to help other kids.

Gustafson, who had always wanted to be a scientist when he grew up, instead created the Swifty Foundation to raise awareness and funds for pediatric brain cancer research, and he requested that his tissue be donated to research labs.

Gift From a Child is a Swifty-led national initiative supported by families that have lost children to brain cancer and by private foundations, researchers and medical professionals (giftfromachild.org). Its mission is to increase postmortem pediatric brain tissue donation through advocacy and the education of families enduring the unimaginable loss of a child. The Gift From a Child initiative has coordinated more than 150 research autopsies since its creation.

Medical journal articles report that many bereaved parents who have lost children to brain cancers are interested in supporting medical research through postmortem tissue donations. Their greatest hope is that families in the future will be spared the same loss because of scientific advancements enabled through these research donations.

The overall program is meant to be gentle on families that make the decision to donate. They are provided with information about how the program works and a general timeline of the process, and will

“What we have done for ourselves alone dies with us. What we have done for others and the world remains and is immortal.”

– AMERICAN AUTHOR ALBERT PIKE

“Our family loves this quote because it reminds us that Michael is still with us. Little did we know that Michael’s wish to donate his postmortem tissue would one day become a national program fueling research across the country. One small wish creating a tidal wave of impact.

“That impact is Gift From a Child, a Swifty initiative that educates families about the need for postmortem tissue and creates the infrastructure to make this precious donation possible anywhere in the country. Gift From a Child provides researchers with tissue they need to find cures for brain cancer, and it gives families hope that they can prevent other families from experiencing a similar loss.”

Patti Gustafson, Michael’s Mom
Executive Director, The Swifty Foundation

sign a consent for the tissue donation (research autopsy). Donation can take place wherever the death occurs – hospital, home or hospice – and the family is given all the time they want and need with their child at the time of death. All professionals helping to care for the family (medical professionals, hospice, social workers and funeral home) are provided with the details of the donation as soon as they are known. (It is preferred, but not essential, that arrangements are made prior to death to simplify coordination efforts.)

The donation can take place at the hospital or funeral home by using a pathology autopsy service. Ideally, the donation should take place as soon as possible after death. The funeral home provides an

essential function to this donation process through not only supportive care but by assisting with transportation to the hospital or assisting with arrangements for the pathology service to use its preparation facility. The donation process uses the standard cranial autopsy incision, and in some cases, the spinal cord might also be removed. The embalming and preparation of the donor after the research autopsy follows standard embalming protocols, and the funeral home can be reimbursed for its charges for these services.

The family never pays for their donation. Gift From a Child receives its funding from the Swifty Foundation, a 501(c)(3) organization. One hundred percent of donations to the Swifty Foundation fund pediatric brain cancer research.

A cure for pediatric central nervous system cancer is possible. We sincerely thank all the funeral homes around the country that have made brain tissue donation possible. Funeral service is defined by compassionately serving families. We cannot do this research without your help and your willingness to support these families’ wishes.

To request brochures or learn more about the Gift From a Child program, visit giftfromachild.org.

The Swifty Foundation is a 501(c)(3) organization founded by Allen and Patti Gustafson in memory of their son, Michael. One hundred percent of donations to the Swifty Foundation fund pediatric brain cancer research.

Gift From a Child Centers of Excellence

Any of the Gift From a Child Centers of Excellence and their tissue navigators can help to coordinate a donation anywhere in the United States and will also help with international donations. To request brochures or learn more about the Gift From a Child program, visit giftfromachild.org.

Ann & Robert H. Lurie Children’s Hospital of Chicago

Tissue navigator: Melissa Williams
Principal investigator: Angela Waanders, M.D.

Orlando Health/Arnold Palmer Hospital for Children

Tissue navigator: Migdalia Martinez
Principal investigators: Amy Smith, M.D., and Julia Hegart, M.D.

Children’s Hospital of Philadelphia

Tissue navigator: Elizabeth Frenkle
Principal investigator: Jane Minturn, M.D., and Mateusz Koptyra, Ph.D.

Children’s National Hospital (Washington, D.C.)

Tissue navigator: Augustine Eze
Principal investigator: Javad Nazarian, Ph.D.

Stanford University School of Medicine

Tissue navigator: Isabelle J. Chau
Principal investigator: Michelle Monje, M.D./Ph.D.

Weill Cornell Medicine

Tissue navigators: Cindy Campbell and Esteban Uceda
Principal investigators: Mark Souweidane, M.D., and Jeffrey Greenfield, M.D./Ph.D.