

TISSUE DONATION IN PEDIATRIC BRAIN CANCER

The Institute of Clinical Bioethics at Saint Joseph's University

Project Research Team: Peter A. Clark, S.J., Ph.D., Brendan Gleason, Michael DiMuzio, and Brant Edmonds.

Michael's Story

Pediatric Brain Cancer Research is very important to the Institute of Clinical Bioethics and certainly this one is very near and dear to our hearts, Michael Gustafson was the son of our good friends Patti and Allen Gustafson. Al has been an Institute of Clinical Bioethics External Board member since 2006.

This research was both Michael's conception and wish. While Michael battled this disease he never lost his faith, gracious demeanor, humor, or his extraordinary compassion for helping others with brain cancer. With the Swifty Foundation we are continuing Michael's wishes for research in "Pediatric Brain Cancer," and most importantly to celebrate the brief but memorable life of Michael Gustafson.

Nov. 16 would have been Michael's 17th birthday. To mark the event, his twin sister Bridget and friend Kira Couch elected to have their heads shaved at the Gustafson's home in Woodridge to raise money and awareness for pediatric brain cancer and support the foundation Michael helped start before his death. Former Naperville North High School student Michael Gustafson didn't live long, but the courageous and upbeat youngster, who succumbed to brain cancer on Jan. 6, 2013, continues to live on in a powerful way.

The Swifty Foundation was something both Michael and our family feel very passionate about, as there is really no money spent on pediatric brain cancer," Michael's mother Patti Gustafson said. "The fact is only 4 cents of every dollar available for cancer research is spent on pediatric brain cancer. The average age of death for a child with cancer is age 8, causing a child to lose 69 years of expected life. Multiply that by the 15,700 new childhood cancer diagnoses each year and you have a staggering number of never-to-be-lived years of growing, loving, and learning. Swifty is working to change those incredibly poor statistics for our most vulnerable cancer patients.'

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Investigation of Tissue Donation Levels in Pediatric Brain Cancer

Cancer is the leading killer of children, yet there is a paucity of tissue samples with which to conduct research. As a result, survival rates, specifically for brain cancer, have not changed in approximately fifteen years. Tissue donation is a crucial element of cancer research. There is a particular shortage in brain tissue and as a result, children with central nervous system tumors do not have as favorable of a prognosis as those with other types of cancers. With more tissue donation, research in this field can function more efficiently to better understand pediatric tumor biology. This would lead to more effective therapies, and ideally, improvement in survival rates.

Medulloblastoma is the most common brain tumor in children. About one out of every five pediatric brain tumors is a medulloblastoma. There are well over 300 new cases in the United States each year, with most occurring at between 5 and 10 years of age. In the past 40 years, the mortality rate in medulloblastomas has only fallen approximately twofold. Improvement in survival rates will require improved understanding of the biology of medulloblastomas. The study of tissue collected by autopsy is the best source of this information.

This project examines three methods of tissue procurement: doctor – patient dialogue, organ and tissue procurement agencies, and hospice care. Today, there is not a standard method of approaching families of children with cancer about tissue donation. As a result, there are varying levels of success on the part of physicians. We will propose ways to encourage physicians to discuss the donation of biopsy and autopsy tissue with the families of children with cancer. In order to do this, methods of approaching families will be outlined in order to provide the most comprehensive information to families, and reduce the amount of stress and tension that can result from such a difficult decision. Additionally, specific protocols for limited autopsy will be examined, as the samples recovered by these autopsies is the primary source of tissue used in research in this field.

The ultimate goal of this project is to increase the frequency of tissue donation in pediatric brain cancer through the education of patients' families as well as physicians. With increased levels of tissue donation, much needed research can be conducted in this field. Physicians must be educated as to the most effective, considerate, and ethical manners of communicating the tissue donation process to families. An ethical analysis of all potential solutions will be conducted, forming the basis of recommendations and conclusions which will be made.