

TAKE A FINAL STAND AGAINST CANCER – DONATE TISSUE

My son, Jacob, was a beautiful, happy, kind, funny, serious, inquisitive, articulate, contemplative, exuberant, talkative boy. He loved all sports, playing keyboards and vocals in rock bands, spending time with his little brother, Ben. When Jacob was 8, he was diagnosed with medulloblastoma. Jacob struggled with brain cancer for two years. Finally, on January 16, 2009, at age 10, he lost that struggle. One step we took that has brought us great comfort was to request an autopsy tissue donation. We hope that through this donation, we might one day prevent another child from suffering Jacob's fate. Tumor tissue is scarce and much research for pediatric brain cancer is delayed or never undertaken because there isn't enough tissue available. Tissue donation is one of the few positive steps we can take during this trying time. And it is a contribution that only we, the parents of children with brain cancer, can make.

Jacob's tissue was sent to several pediatric cancer researchers. We are happy to report that even this one step has promoted scientific understanding of pediatric brain cancer. One research team reported a new observation as a result of a genetic analysis of Jacob's primary and metastasized tumor tissue. Another research team was successful in developing the first xenograft autopsy tissue mouse model.

Nancy Goodman
Founder and Executive Director
Kids v Cancer



Pediatric brain cancer research is not proceeding as fast as it could because autopsy tissue is so scarce. A child's end of life is a tragedy, but by donating your child's autopsy tissue, you can contribute to childhood brain cancer research and help find better treatments for other children. Autopsy tissue is an invaluable resource that can come only from us, parents whose children have terminal brain cancer.

Many families have found that consenting to autopsy tissue donation is one of the few positive steps they can take during the difficult time of their child's end of life. We hope you will consider autopsy tissue donation.

Kids v Cancer is working to make autopsy tissue donation more common, so that researchers can obtain the tissue they desperately need. We invite you to use our website to learn more about autopsy tissue donation. www.kidsvcancer.org.

What arrangements need to be made in preparation for autopsy tissue donation? The first step is to talk with your oncologist, social worker, or nurse. They will make a plan that works for your family. It is best to speak with your oncologist, nurse, or social worker as soon as possible, because it can take time to make the necessary arrangements.

What is the cost of donating autopsy tissue? There is no cost to your family. Your donation is a gift that makes research possible.

Will my child look the same after the autopsy? Can we have an open casket? Yes. In most cases you can have an open casket and you will not be able to tell that an autopsy has been performed. We

Can I choose an autopsy donation if my child dies at home? Yes. If your child dies at home your funeral home will transport your child to the autopsy site and then back to the funeral home.

How soon after death does the autopsy tissue donation need to happen? You can stay with your child for as long as you wish after his or her passing. While many researchers prefer tissue donated within 12 hours, they also understand that your family's needs come first.

How long does it take to perform the autopsy tissue donation? It takes only a few hours. Even for families who wish to hold the funeral as soon as possible, timing is generally not an issue.

Can I choose where the tissue will go? Yes. If you are interested in choosing where the tissue will go you should speak with your medical team. It is usually possible to send tissue to more than one researcher.