

# Leaving a Legacy

---

## Donating pediatric tumor tissue to research for tomorrow's cures.

In the past few decades, pediatric cancer treatments have improved leading to increased survival rates; however, rare and more progressive cancers lag behind promoting the need for tumor samples to be used for research. The cures for tomorrow's patients may come from the selfless actions of pediatric cancer patients who the medical communities have not succeeded in providing a cure, despite state-of-the-art treatment.

### **What is a tumor bank?**

A tumor bank, often located at a hospital or research facility, is a place that collects, stores, and maintains tumor samples that are donated for research. Samples are de-identified and entered into a data base so researchers can search for availability of a certain type of cancer and then use those samples for research.

### **Why donate?**

Donating can help researchers and doctors understand the progression of cancer and any molecular changes that may have occurred over the course of the disease. Donating samples can also help researchers better understand drug resistance leading to the potential of new treatments and cures.

### **What happens with the samples?**

Samples are carefully prepared for various experiments in the lab and stored in a freezer at the bank for future

experiments. Samples can be distributed to highly qualified researchers across the nation who will use them to study the biology of the tumor and search for new therapeutics. If at any time you would like to withdrawal your samples, the bank can be notified and will discard the samples or return the samples to you.

### **How to donate?**

Donations can be made when a biopsy is taken at diagnoses or a recurrence, when surgery is performed, or at the time of death. It is of great value to have samples from all of these time points to help researchers understand the progress of disease. A post mortem biopsy or an autopsy can be performed at the end of life to provide tumor samples.

An autopsy is an examination performed by a pathologist, a highly trained medical doctor, who can recognize the effects of the disease in the body. The autopsy room is a valued place that allows one to gather medical knowledge, where the body is treated with honor and respect and the wishes of the family are maintained at all times. Small samples of each organ are taken for microscopic examination and tumor samples are taken to be sent to the bank. A few weeks after the examination, a written report is provided to the family and can be discussed with the physician or pathologist. In general, research results are not reported directly to the family but can be shared upon request.

### **Who requests a donation?**

Doctors or nurses can discuss donating with the family at the appropriate time or patients can inquire about the opportunity on their own. The autopsy cannot be performed without prior

consent from the patient or consent from the legally designated responsible party, usually the next-of-kin.

### **What are the benefits of donating?**

There are various ways in which donating tumor samples can help the gifting family and the future of medicine such as:

- ❖ Providing comfort and peace that the tumor can finally be removed
- ❖ Restoring a sense of control over the situation
- ❖ Hope for a better future for those who are currently going through the experience
- ❖ Added meaning to the child's struggles
- ❖ Providing quality tumor samples for research
- ❖ Increasing knowledge of how pediatric cancers form and progress
- ❖ Can lead to major strides for new treatments and cures

### **Common concerns about donating:**

#### *How much does it cost?*

There is no charge to donate tumor samples. Your donation is an extremely valuable gift to research.

#### *How long can I stay with my child?*

The most important thing is that you spend as much time as you would like with your child.

#### *Will an autopsy delay funeral arrangements?*

Your child will be handled with utmost respect and will not be altered in a way that would affect having an open casket. An autopsy can be performed in such a way that it will not delay a funeral. Physicians, pathologists, and funeral

directors will work together to ensure proper arrangements are made, even if the child dies at home.

#### *Are there religious conflicts with donating?*

The decision to donate tumor samples for research often parallels with one's beliefs about organ donation. Although most religions do not oppose autopsies, religious decisions are always personal and it may be best to discuss this opportunity with family and religious advisors.

#### *Will my child's privacy be protected?*

There is very little risk that your child could be identified through their donation. Samples are de-identified at the time of donation and given a number. Researchers will be able to access information about what type of cancer a certain sample is but will not know who the sample came from.

### **Questions?**

As you consider leaving a legacy for tomorrow's cures, questions about tumor banking and autopsies can be addressed by your physician. For more information please visit [www.ccurefast.org](http://www.ccurefast.org)

©2011. Northwest Sarcoma Foundation.

