

WHY IS CHILDHOOD BRAIN CANCER SO TOUGH TO BEAT?



Brain tumors are the #1 cancer killer among kids in the United States.

WHY?

We just don't have enough information. Without a deeper understanding of the biology behind brain tumors, we can't improve our treatments.

RESEARCH IS DIFFICULT

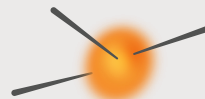
Tumors change from spot to spot.

Measure 3 parts of a tumor, and you'll get 3 different sets of data. For the best research, we need to study the whole brain – not just a small biopsy sample.



Tumors change during treatment.

Kids' bodies grow fast anyway – but when we treat brain tumors, they actually change even more as a response to treatment. For the best research, we need to study tissue after death – not just at diagnosis.



To fully understand childhood brain tumors, researchers need to look at the whole brain. And they need to do it after death. But that's not easy.

DONATING IS DIFFICULT

Families don't know.

The decision to donate must be made before a child dies – but when is the right time to talk to families? Right now, many never hear about donation until it's too late to give.



Donating is complex.

Most kids who don't survive brain cancer choose to die at home. Within 24 hours, 3 different experts – an autopsy tech, a pathologist, and a research technician – must retrieve and process tissue for a successful donation. And it all must happen without extra cost to families or to their insurance. That's a lot to ask.



Tissue donation is the only way we'll really get a deeper understanding of the tumors that too often take our children's lives. This problem is worth solving.

HOW DO WE IMPROVE PEDIATRIC BRAIN CANCER RESEARCH?

Without post-mortem tissue donation from children who lose their lives to brain cancer, we'll never know enough about the disease. But donating isn't easy.

A new program in Philadelphia is changing that, requiring just two things from families who wish to donate tissue:



Written consent before the time of death



One phone call at the time of death

Here's how Swifty, the Children's Hospital of Philadelphia (CHOP) and the Children's Brain Tumor Tissue Consortium (CBTTC) have partnered to solve the problem of donation:

1. TELL FAMILIES IT'S AN OPTION.



Research.

Interview current patients, families and care providers to learn when and how we can most lovingly present donation as an option.



Communicate.

Develop the right messaging and materials to explain donation to future patients and families.



Train.

Educate medical professionals and social workers on how to talk about donation with children and their families.

2. MAKE DONATING EASY.



If a patient dies, the family makes one phone call



On-call Autopsy Tech works with funeral home to collect donated tissue



On-call Pathologist and Lab Tech process donated tissue at the hospital



Anonymous genomic and proteomic data are cross-indexed and shared with other scientists through the consortium

3. MULTIPLY RESULTS.

Year One:

Piloting the above improvements at CHOP is expected to increase tissue donations by 1000%.

Year Two:

Sharing improvements and training with CBBTC's other member hospitals will multiply results across the country – and the world.

This means more and better data for researchers – which means better treatments for children diagnosed with brain cancer in the future. And that means a measure of comfort for families who've lost kids to pediatric cancer. We should know. We're one of them.



Donate now at swiftyfoundation.org