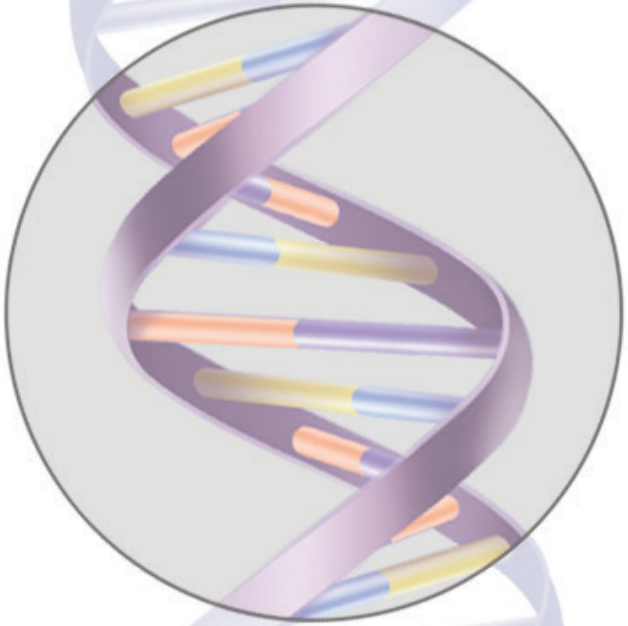
Creating Hope for the Future

The Legacy Donation Program of the Children's Brain Tumor Project



"After five years of fighting, we could not let it be the end of her fight. She could still fight on, for all of the other children that battle this disease. For us, it was an easy decision, and what we thought Campbell would have wanted. The gift that she was to us, she could be to others as well."

-Robin and Greg Hoyt

Weill Cornell Medicine
Brain & Spine Center

Building a Lasting Legacy

The diagnosis of an incurable brain tumor is an inconceivable challenge that no child or family should have to face. We at the Weill Cornell Pediatric Brain and Spine Center share your frustration and grief in receiving a diagnosis that has no cure. This impossible situation is the driving force behind the Children's Brain Tumor Project. In the laboratory, in clinical trials, and in vast data warehouses, we are working hard every day to achieve a single goal: bringing hope to the hundreds of patients and families each year who confront the heartbreaking diagnoses of rare and inoperable pediatric brain tumors.

The field of cancer biology is a rapidly evolving environment. These dynamic times have brought about a revolution in what we call precision medicine. That means that unraveling the cellular and molecular mechanisms of malignancies may lead to more effective patient-tailored therapies in the near future—drugs and treatments developed individually for a specific patient's tumor. Financial investment in research is an important aspect of this goal, but tissue donation is equally vital in the path to changing the prognosis. The more samples we can study of each tumor and the more data we can collect and analyze, the better equipped we are to develop these personalized treatments.

Each donation allows us to gain a wealth of invaluable information through molecular, cellular, and genetic analysis of the tissue. It is this information that is so essential to creating a brighter future for the children and families that this disease so greatly affects. The desperate need for tissue samples led us to create the Legacy Donation Program, which gathers samples in what is called a rapid autopsy.

We realize the decision to donate your child's brain tissue from rapid autopsy is multifaceted and highly emotional, and requires reflection and preparation. We hope we can provide any information and guidance you may need in the process. Most important, we admire your strength in these difficult times. Together we will work toward changing the future of this devastating diagnosis.

Sincerely,
Dr. Mark Souweidane and Dr. Jeffrey Greenfield
Co-directors, Weill Cornell Children's Brain Tumor Project

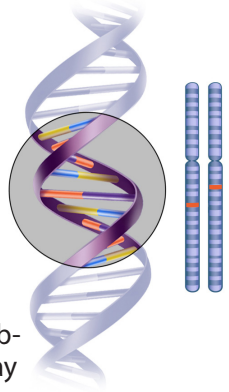
ABOUT LEGACY DONATIONS

THE STUDY

When a family makes a legacy donation, researchers are able to study a tumor in several different ways, including microscopic analysis and genomic sequencing. Each tumor can provide an astonishing amount of data, all of which can be invaluable to researchers.

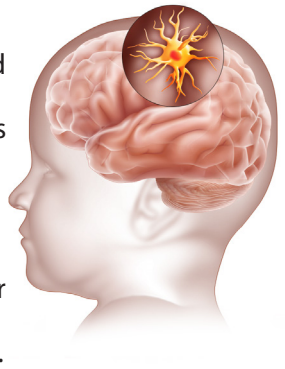
THE ANALYSIS

Study of the tumor tissue generates a wealth of information about that specific tumor, but it also identifies patterns and commonalities with other tumors. This allows scientists to determine subgroups of a tumor that may be vulnerable to known treatments, or lead them to developing new ones.



THE CLINICAL TRIALS

Using the information gleaned from the tissue samples, researchers can conduct clinical trials to test new drugs, new delivery systems, and other potential options for children diagnosed with a similar tumor.



THE GOAL

After thorough testing in the lab and in clinical trials, effective new treatments emerge for pediatric brain tumors, creating hope for families.

FREQUENTLY ASKED QUESTIONS

What is a rapid autopsy?

A rapid autopsy is a way to procure tumor tissue quickly from both primary and metastatic sites (when applicable) before the tissue quality has degraded. Such rapid procurement improves the quality of advanced tumor analysis and permits an abundance of information to be extracted from tissue.

How soon after death is the autopsy performed? How long does it take?

The goal is to begin the autopsy procedure within two to three hours of death, but it can be considered for up to 12 hours after death. Once started, the procedure will typically take two to four hours to complete.

Where is the procedure performed?

The autopsy is performed in a state-of-the-art autopsy facility within Weill Cornell Medical College. The procedure will involve attending pathology faculty, pathology residents, experienced autopsy technicians, and research tissue procurement personnel. If you do not live near our facility, we will help you coordinate this process with your local hospital, pathology department, and funeral home.

Will the autopsy interfere with funeral arrangements or having an open casket?

No. A well-planned brain autopsy will not delay or interfere with a family's funeral plans. You may have any sort of service or remembrance that you and your family wish. The autopsy is done discreetly and does not cause any change in the donor's outward appearance.

What if we register and later change our mind and do not wish to donate? What should we do?

You may withdraw from the donation program at any time. All you need to do is contact our office and inform us of your decision.

When should plans be made to ensure tissue donation occurs in a timely way?

While it may be overwhelming and emotional, it is important to try to begin making plans for tissue donation as soon as possible. Ensuring that all details are coordinated prior to death will prevent stress during a very difficult time.

How do I find more information about the legacy donation program?

Please contact our Neuro-oncology research team, which will help you with any questions and coordination.

Telephone: 212-746-2363
Email: neurosurgery-legacy@med.cornell.edu
Online: childrensbraintumorproject.org

"We were powerless to stop the tumor from eventually taking Allie's life. But, after her death, we knew we were not powerless to help find a cure. Donating Allie's tissue gives us hope that we will see improved outcomes and treatments for children with brain cancer." *-Kelly and Kyle Fisher*

THE IMPORTANCE OF TISSUE DONATION

- Precision medicine—the new science of matching a treatment plan individually to a specific patient—depends on collecting and analyzing huge amounts of data about different tumor types.
- At Weill Cornell, we are committed to sequencing the tumors of every brain tumor patient we can, both adult and pediatric. Each sequencing generates a tremendous amount of valuable data for study in the lab.
- The more rare a tumor is, the more difficult it is to collect enough samples to study and sequence, and draw meaningful conclusions to help future patients.
- Inoperable pediatric brain tumors are almost always of the rarest types—which means researchers have the least information about the tumors we most need to study.
- Pediatric tumors that are inoperable are often also not amenable to biopsy, making it even more difficult to collect adequate tissue samples for research.
- The current best hope for collecting meaningful data from pediatric brain tumor tissue is through the Legacy Donation Program.

ABOUT THE CHILDREN'S BRAIN TUMOR PROJECT

The Children's Brain Tumor Project is a research effort at the Weill Cornell Pediatric Brain and Spine Center, co-directed by Dr. Mark Souweidane and Dr. Jeffrey Greenfield. The Children's Brain Tumor Project has a single goal: to bring hope to the hundreds of patients and families each year who confront the heartbreaking diagnoses of rare and inoperable pediatric brain tumors.

Gliomatosis cerebri, DIPG, AT/RT, and thalamic gliomas are just a few examples of the devastating brain tumors that typically strike children, adolescents, and young adults. Because they are so rare, these inoperable tumors simply do not get the funding or attention that research scientists need to find a cure. The Weill Cornell Children's Brain Tumor Project takes a multi-pronged approach to the research:

- Genomic sequencing will offer physicians the ability to quickly identify a brain tumor's "fingerprints" at the molecular level, allowing for personalized tumor therapy.
- Alternative delivery methods will bring the right drugs for an individual patient right to the tumor site, bypassing the blood-brain barrier.
- Basic science research lays the foundation for translation into clinical trials, with the goal of bringing new treatment options from bench to bedside as quickly as possible.

The Children's Brain Tumor Project team conducts its research in the pediatric neuro-oncology laboratories at the Weill Cornell Brain and Spine Center, 525 East 68th Street, Box 99, New York, NY 10065.

For more information about the Children's Brain Tumor Project
or the
Legacy Donation Program,
visit
childrensbraintumorproject.org

Weill Cornell Medicine
Brain & Spine Center