



## Tissue Donation for DIPG Research: An Act of Courage and Defiance

DIPG tumor tissue is a gift from your family to our TGen family to give hope and answers to future families facing this diagnosis. With this gift, our scientists can conduct multiple studies to help increase our knowledge of DIPG. Advanced planning can decrease the logistical concerns and soften the emotional impact of this incredibly difficult decision.

**Your child's legacy will help future DIPG patients. They will not be forgotten.**

### Frequently Asked Questions (FAQs)

#### **What is the purpose of this tissue donation?**

Deep genomic analysis of the patient's tumor compared against their normal tissue will be performed. As additional cases are studied, a better understanding of the molecular subtypes of DIPG will emerge and inform strategies for tailoring treatments to best match interventions with an individual patient's disease. Additionally, tumor cell lines will be developed. These serve as patient-derived models of DIPG which allow testing of new drugs, drug combinations, and the opportunity to link genetic events with optimal anticancer care.

#### **How is the tissue donation coordinated?**

TGen will coordinate the logistics for tissue collection and shipment to alleviate concerns for your family. Advanced planning for tissue donation ensures that all contingencies will be accommodated and the wishes of the family are honored. We will work with the hospital, hospice, or funeral home personnel to ensure that timely and respectful best-practices are utilized for the tissue donation.

#### **How soon must the donation process be completed after my child passes?**

It is extremely important that these samples be collected as soon as possible, ideally within three hours. Planning in advance for tissue donation can ensure that the proper preparations are in place for successful collection. TGen will work to ensure that this process puts as little burden on you and your family as possible.

#### **Does tissue donation slow down the memorial or funeral service?**

Tissue donation does not typically impede the family's plans for memorial or funeral services. TGen will work to coordinate the tissue donation so that it fits within the timeline of events during this time of family grieving.

#### **How are the expenses of the research covered?**

Generous donors support the ongoing work to "Move the Needle" against DIPG. In many instances, the availability of tumor tissue specimens establishes unique opportunities for peer-reviewed grant awards that also support the research. TGen will cover all expenses related to your loved one's tissue donation. Participating in this study will not include any additional costs for you.

#### **Will I be able to find out the results from any research on the tissue?**

Circumstances permitting, we may be able to return research results to families of participants.

#### **How do I enroll?**

Please visit [www.tgen.org/dipg](http://www.tgen.org/dipg) and click "To View the Tissue Donation Study Release Form and Enroll." If you choose to enroll after viewing the release form, you can do so using the DocuSign links on the page. You will then be contacted by the Clinical Research Coordinator.

**For more information, please contact the Clinical Research Coordinator at [DIPG@tgen.org](mailto:DIPG@tgen.org) or 602-343-8653.**