Brainstem Glioma & Diffuse Intrinsic Pontine Glioma

Brainstem gliomas (BSGs) affect 200-300 children in the United States each year. Diffuse intrinsic pontine gliomas (DIPGs) are the most common form of BSGs (approximately 80% of pediatric brainstem gliomas).

Children's National Medical Center IRB# 4932: "Molecular Analysis of Samples from Patients with Diffuse Intrinsic Pontine Glioma and Brainstem Glioma" is an ongoing clinical study protocol to increase our understanding of these types of tumors. This study is important because DIPGs and BSGs are among the least understood pediatric cancers. As part of the study, specimens [blood, urine, cerebrospinal fluid (CSF) or tumor] are collected and are analyzed to understand tumor biology with the goal of developing better treatments.

Potential Benefits

There are no direct benefits to participants of this study, but participating may help in developing treatments for this cancer. Participants in this study will help us to learn about brain tumors. By looking at tumor cell DNA, RNA, and proteins, we can better understand how these tumors form and grow. These markers can also tell us about the behavior and make-up of the tumor, and can help us improve diagnosis and develop targeted treatments. Participation in this study is voluntary, and if you do decide to participate, you can withdraw at any time.

What do participants have to do?

This is a study of tissue samples related to DIPG and BSG. Participation requires a sample of blood, urine, CSF, or tumor tissue from a biopsy.

Donating samples during the course of your child's treatment

If your child's doctor determines that during the course of treatment your child needs a procedure to obtain blood, urine, CSF or tumor tissue, a portion of this sample may be donated to our research laboratory for further study. Samples collected during the course of your child's treatment are collected for medical reasons, and a portion of that may also be used for research purposes.

Donating samples postmortem

If a child succumbs to his or her tumor, parents or legal guardians may decide to donate samples (blood, CSF, and/or tumor tissue) for study upon the child's passing. This is a precious and invaluable gift that can help other families by providing scientists a way to investigate the tumor and develop new and better treatments.

Risks

As the study seeks permission to use samples already collected as part of medical care, there are no additional procedures or risks required to participate. Specimens will be given to us only if the physician requires blood, urine, CSF, or if a biopsy is conducted for the patient's diagnosis and/or treatment.

Participation in this study does not require any additional evaluations, hospitalizations, doctor visits, procedures, or treatments for the patient. Participation in this study will not affect the treatment, course, or prognosis of the patient's disease.

There will be no additional expenses on the participant's part. However, if any occur, our study will cover the costs.

If you have any additional questions, please contact Dr. Javad Nazarian, study Principal Investigator or Jennifer Perez, the study coordinator.

FOR MORE INFORMATION:

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Resources for Families

- http://clinicaltrials.gov
  CNMC DIPG Study. Clinical Trial Identification Number: NCT01106794
- http://www.kidsvcancer.org/
  Changing the landscape of pediatric cancer research

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