

About Pediatric Cancer, Brain Tumors, and **DIPG** (Diffuse Intrinsic Pontine Glioma)

After accidents and injury, cancer is the leading cause of death in children, and brain tumors are the leading cause of cancer-related death. DIPG accounts for 80% of pediatric brain tumor deaths, and roughly 12% of pediatric brain tumor incidence, out of some 170+ varieties. DIPG is the most devastating of pediatric malignancies; almost all children with this disease die within 2 years of diagnosis. Median survival time is 9 months; without treatment, they have weeks.*



- *Because the tumor is in the **pons** area of the brainstem, and diffuse in nature, surgical removal is not possible.*
- *No chemotherapy to date has affected the terminal prognosis.*
- *Radiation can provide short-term relief.*
- *Long-term survival rate is less than 1%.*
- *The causes are unknown.*
- *Little progress has been made in 30 years.*
- *Genomic testing of samples for research is urgently needed.*

*Statistical Sources:

<http://www.acco.org> AMERICAN CHILDHOOD CANCER ORGANIZATION; <http://www.curesearch.org> CureSearch; <http://www.stjudes.org> St. Judes Research Center; Pediatric Brain Tumor Foundation <http://pbtbf.us>
The Lyla Nsouli Foundation for DIPG Research, www.lylansoulifoundation.org

Our Mission: Hope for Survival. DIPG affects approximately 300 children a year in the US, and like all childhood cancers, is marginalized as “rare”, and thus undeserving of research investment, no matter what the frequency of incidence or number of cumulative deaths. Our children are not coming first, they’re coming dead-last: *only 4% of the National Cancer Institute’s budget for research goes to pediatric cancers as a whole, reported 2/14/2014.* We believe that no parent should ever hear that there are no solutions for their child because his/her life is insignificant to research investors.

We remain committed to the fund for DIPG research, in Jack’s honor, at Children’s Hospital Los Angeles, and to the idea that DIPG research invariably benefits all of neuro-oncology and represents an important contribution to advances in medicine. As a support organization we are committed to affecting change in the experience of a family receiving a DIPG diagnosis for their beloved child, that there be active research and hope for survival.

<http://www.jacksangels.org>