

October 9, 2019

Dear Honorable Members of the United States House of Representatives:

We are writing in regard to H. Res. 114, the National DIPG Awareness Resolution. DIPG is diffuse intrinsic pontine glioma, an aggressive brain tumor that mostly affects children. Brain tumors are now the most common cause of death for in childhood cancer, and DIPG is the deadliest of childhood brain tumors, with a zero percent cure rate. We are physician-scientists who have dedicated our careers to understanding this disease and improving outcomes for these unfortunate patients and their families. We ask for your support of this bill to make the American people aware of this unacceptable situation so that they will help us in our effort.

Pediatric cancer research as a whole has been one of the great successes of medicine in the last 70 years. Our field has taken a diverse set of incurable diseases and, through basic research leading to cooperative clinical trials, turned the tide so that we are now able to cure more than 80% of children with cancer overall. Along the way, discoveries in children have benefited adult cancer in enormous ways, including the advent of chemotherapy, which was first used for childhood leukemia. Unfortunately, the 80% figure belies a darker reality underneath, as in many childhood cancer subtypes, the vast majority of children still die of their disease. DIPG represents the most striking and tragic example of this continued challenge and represents the ultimate challenge in childhood cancer: an inoperable tumor with unique biology that is resistant to chemotherapy and is located in an area of the brain crucial for the most basic neurological functions. If we can innovate to find a treatment for DIPG, it is likely to benefit not only these patients but other adults and children too whose cancers share some of these challenges.

We believe that your support of this bill will draw attention to the trail of lost children, devastated families, and broken communities left by this disease so that we can increase the research support needed to finally deliver hope to DIPG patients. We have the biological understanding of this tumor now, but we know that translating this knowledge to cures is the hardest and most expensive part. With your help, though, we can accomplish our goal and turn DIPG from an unimaginable tragedy to another success story for childhood cancer research. Thank you for your consideration of our letter.

Sincerely



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because all children with DIPG deserve science-justified hope



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