

DIPG ADVOCACY GROUP

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To NCI/NIH Leadership:

I'm writing in support of the NIH Pediatric Brain Tumor SPORE grant proposal to be submitted by Dr. Resnick and Dr. Prados on behalf of PNOC and CBTTC multi-institutional research organizations. A grant of this kind would be crucial to the forward progress of identifying and developing viable treatment options for pediatric brain cancer, the leading cause of cancer-related death in children in the United States.

I lost my son Jack to DIPG in 2012. Upon his diagnosis, I did not know that brain cancer was the leading cause of cancer-related death in children, or that DIPG was the 2nd most common variety and responsible for the majority of deaths in children due to brain tumors. I did learn, however that the oncologists were certainly familiar with it, and were reticent to explain why they had no solutions for it; I was met with downward glances, shaky voices, and the words "rare" and "orphan" to explain this. The truth is that despite decades of clinical reference there's been no progress in this area of research which would produce a hopeful treatment, and the actual excuse presented to me was that "the numbers aren't great enough for investors," in the wealthiest country in the world.

That clear answer came from the husband of one of my best friends who works for a pharmaceutical company. This continues to be for me personally and all other parents I know an unacceptable reality. It is the reason for my advocacy for children with brain cancer. We must change the way research is conducted to accommodate our children afflicted with deadly disease. Period. And this necessitates multi-institutional, global collaboration to accommodate the smaller numbers of patients and expand data resources.

DIPG Advocacy Group, an association of pediatric brain cancer foundations, childhood cancer advocates and patient advocates was formed for the sole purpose of raising greater congressional and public awareness to the failure of our medical research system to address the urgent needs of children with cancer, specifically brain cancer, using the deadly example of DIPG, as described in House Resolution 114, the DIPG Awareness Resolution. On February 13, 2020, we hosted in collaboration with the Office of Congresswoman Jackie Speier (CA14), co-chair of the Childhood Cancer Caucus, a congressional briefing entitled "DIPG, Pediatric Brain Cancer, and the Importance of H. Res. 114." I believe the conversations between NCI/NIH and PNOC, CBTTC scientists helped facilitate the idea of this novel grant for pediatric brain cancer, and also the need for this research to be multi-institutional which is also unprecedented for this type of grant. Upon hearing of this possibility I was thrilled to say the least; the idea that the briefing information regarding the inadequacies of the current system to producing promising therapies for children was heard, and proactive solutions were being proposed, is music to the ears of so many parents in the pediatric brain cancer community.

As an advocate and a parent, I cannot adequately thank the leadership at NCI/NIH enough for doing what you can to accommodate this urgent need, and for our dedicated scientists at PNOC and CBTTC for working tirelessly to help our children with brain cancer who have been systematically overlooked

for decades for the fact that they simply have not had a voice. We deeply appreciate the responsiveness of NCI/NIH to help facilitate pediatric brain cancer research, and to recognize the urgency of the need for viable treatments for these children.

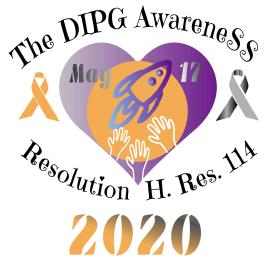
Thank you for keeping our hope alive. I pray that this grant may move forward and pave the way for greater innovation and collaboration in this space and facilitate actual cures for pediatric brain cancer and greater knowledge of its causes and conditions, advancing science for humankind.

To this end, I will remain

Respectfully yours,

Janet Demeter
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