

President Barack Obama
The White House
1600 Pennsylvania Avenue NW
Washington DC, 20500



Tuesday, September 15, 2015

Dear President Obama,

I cannot thank you enough for your kind replies to my previous letters about DIPG children and the desire for more effective action to be taken to help them. I appreciate your support for more funding to be designated to the NIH; we need much more. Yet this is an important but partial solution to the problem of funding for research for children with the deadliest of diseases that have been neglected by our system for decades, specifically those with DIPG and other pediatric brain tumors—the leading cause of cancer-related death in children.

Since the NCI is, in its unique way as a Federal Agency, beholden first and foremost to the President of the United States, it follows that priorities set by the President would in whatever way most practical be observed. I strongly contend that the children of our country afflicted with the most deadly cancers, specifically DIPG with a 0% survival rate and regularity of incidence, must needs be given status as a National Priority. For decades now, with a steady stream of incidence, children have been diagnosed with the experience of being told there are no effective therapies developed to save their lives. The families learn quickly that they are, in effect, just a number. We learn that the relatively small, though constant and terminal, number of patients each year somehow justifies this. Now that there are nearly 10,000 or more dead after over 35 years, and most of the terminal cases of pediatric cancer in the news are DIPG, can something more be done? Since DIPG is responsible for the majority of brain tumor deaths in children each year, it is hardly insignificant.

I would like to see a National Day for DIPG, along with many other parents. No one will “just say it”; in the news it’s referred to as just one more case of some rare and tragic disease that baffles our scientists as some sporadic and random anomaly, thus impossible to figure out. If our children’s lives are not a priority, then yes, this is so. However, if we can put a man on the moon in the 1960s, we can make progress with pediatric brain cancer. Karen Armstrong died of DIPG, as you may well know, Neil Armstrong’s daughter. Lauren Hill, the basketball player, honored at the ESPYs but the monster she fought was never mentioned. AJ Peterson who died this year also, son of former Chicago Bear’s linebacker—DIPG never mentioned in the news. This disease that tortures the child with full consciousness as he/she loses all his bodily functions as the family watches on in terror, helpless as their child disappears from this world, must be addressed; it is time. I’m asking for your support.

Please consider a National Day for DIPG, and to make some sort of provision with the NCI such that our children with cancers of steady incidence and 0% survival rate are prioritized for research. The Gabriella Miller Kids First Act—of course she also had DIPG—provides a mere 12M to all of childhood disease research. Three billion went to help refugees at our border last year, without second thought. Why can’t we prioritize our children? To many of us it seems that the political world is completely driven by

profits for big corporations while children are left to die. It seems that way because this is what we experience. DIPG makes a case for more funding for the NIH, because we are unable to address the situation our most gravely afflicted citizens: our children. Awareness for DIPG, one of our most deadly pediatric cancers, makes a case for more funding for all medical research.

I have written to you before about this and I have appreciated so much your kindness, sympathy, and condolences for the loss of my son, Jack. But President Obama, why have you never mentioned DIPG, despite the fact it has been the focus of my writing? I am always motivated by the love of my son, but I only do what I'm doing for the host of other families and DIPG diagnosed children I now have to watch experience the same horror that we did, and the pain that never goes away or diminishes with time. I have to believe that our numbers are significant, that our lives count too. I have contacted my representatives about this, asking for their support in these requests that I'm making to you, I'm sure by this point quite redundantly. I apologize for this, personally, but I must do it for the children dying right now, for those to come, and for the families who must simply watch and wait in fear.

No one should have to helplessly watch their child disappear from our world forever, and no child should have to experience, in full awareness, losing all bodily functions until they die. Not without a better fight from all of us.

Thank you so much, with all of my heart, for your time and consideration.

Sincerely yours,



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