

Re: Chad and Jack's DIPG Resolution, HRes.586

Dear House Committee of Energy and Commerce Member

February 3, 2016

I'm writing to you in support of HRes586, which in essence encourages more consideration of low survival rate cancers and years of life lost in the research grant approval process with the National Cancer Institute, as well as other investors in cancer research. HRes586 also calls for the last week in May to be designated National DIPG Awareness Week, and is unofficially titled, "Chad and Jack's DIPG Resolution," for little Chad Carr of Michigan and Jack Demeter of California. Lauren Hill and AJ Peterson are other recognizable names of children who perished to DIPG last year. Neil Armstrong's daughter Karen died of DIPG in 1962.

Perhaps you have not heard of DIPG. Although it is classified as a "rare disease", it is singlehandedly responsible for roughly 80% of pediatric brain tumor deaths each year in the United States. Since brain tumors are the leading cause of cancer-related death in children, DIPG is hardly irrelevant. Its legacy of certain death and regular frequency of incidence for over 35 years exemplifies the fact that the leading cause of cancer-related death in children is one of the least-funded areas of cancer research. If any one group in these United States needed a Moonshot, it would be these kids and their families.

How does systematic neglect for research of pediatric brain tumors translate to a common experience? Parents are told that their numbers are not prolific enough to justify research investment to save these children. From this point of view there is little consideration of scientific merit, long-term benefits, finding a cure to cancer, and of course most obviously, the value of the life of a child.

Our hope with HRes586 is that it begins the conversation for more consideration for our children and their families with these most deadly cancers. If truly we wish to find a cure, committing to understanding these most aggressive and elusive varieties is key—to a greater understanding of biology, and advances in medicine in general. It's a long-term investment victory, creating new industry and jobs that scientific breakthroughs invariably bring.

Thousands of very young children have bravely faced certain death to DIPG, and there are currently hundreds facing their own personal death row today. Please help bring light to one of the darkest experiences a child and his or her family can have; please support this Moonshot for kids, HRes586!

Respectfully yours,

