

CCC Support Letter 10-2021

National DIPG Awareness Resolution H. Res. 404

"I'm writing in support of the National DIPG Awareness Resolution, which designates May 17th as DIPG Awareness Day and encourages citizens to become more informed about diffuse intrinsic pontine glioma (DIPG), pediatric brain cancer, and the current challenges to the medical research system in designating sufficient research funding for pediatric cancers in general.

This resolution suggests that pediatric and high mortality-rate cancers have elevated consideration for research into cures with both public and private funding sources. This is the fourth iteration of this resolution, which gained 215 House signatures last session and unanimously passed the Senate in 2019, 2020, and 2021. We are hopeful to gain the support of the House of Representatives in taking a stand for these children, helping us to attract a cure more quickly and to shine a spotlight on a population which has suffered in obscurity for decades. There has been no change in the standard treatment protocol for DIPG since Neil Armstrong's daughter Karen died of it in 1962.

Parents of children diagnosed with DIPG are told there are no solutions for their child and then must witness in utter helplessness their child die a horrible death. DIPG is the second most common type of brain tumor in children and is responsible for the majority of childhood brain cancer deaths annually. But out of sight, out of mind, no one knows how urgently our children need help.

No parent should hear there are no solutions for their child because they don't represent an adequate investment incentive, but this is not uncommon today in the childhood cancer world.

I hope that I can count on your support. Your consideration means a great deal to families of children with brain cancer, the leading cause of cancer related death in children, and to those families and communities who have lost a child to DIPG across this great country. Thank you."