

## H. Res. 114 Summary for Press

“Expressing support for the designation of the 17th day in May as “DIPG Awareness Day” to raise awareness and encourage research into cures for diffuse intrinsic pontine glioma (DIPG) and pediatric cancers in general.”

### **General Description**

Despite its consistent death toll as the leading cause of disease-related childhood mortality in the US, pediatric brain cancer, of which DIPG (diffuse intrinsic pontine glioma) is the 2nd most common type and the deadliest, has seen no significant change in the standard treatment protocol nor prognosis of the worst variety since Neil Armstrong’s daughter died of it in 1962. DIPG exemplifies in a powerful way the challenges in treating pediatric cancer and the daily tragedies which ensue from the general lack of solutions our medical research industry has for deadly pediatric disease.

The DIPG Awareness Resolution (H. Res. 114) is a simple House Resolution requiring only a House vote to pass; it is not a law. It is apolitical with no funds allocated. It does, however, suggest that for any given cancer type, that the years of life lost associated it as well as the mortality rate be given elevated consideration in the research grant process with public and private funding sources. It shines a national spotlight on an issue of human suffering which has remained in obscurity and imposed irrelevance for decades.

### **History**

The DIPG Awareness Resolution has its origins in the 2014 California Legislature, with the first DIPG Resolution designating the last week in May, Brain Tumor Awareness Month, as “DIPG Awareness Week.” It was introduced by CA State Assemblyman Scott Wilk, who is the current State Senator; the State Senator at the time, Steve Knight, went on to become Congressman for the 25th District of California in 2015. That fall, his constituent Janet Demeter with the foundation Jack’s Angels, instrumental to the 2014 California Resolution, worked with his office to introduce the first DIPG Awareness Resolution to the 114th Congress on January 13, 2016, H. Res. 586, also designating the final week of May. Subsequently, the Michael Mosier Defeat DIPG Foundation, having formed in 2015 upon the death of Michael Mosier on May 17 of that year, began a campaign to encourage as many states as possible to commemorate DIPG children on the 17th day of May. Having followed Michael Mosier’s journey, Janet Demeter worked with her Congressman to change the Resolution, which was re-introduced in January of 2017 to the 115th Congress as H. Res. 69, also designating that day as part of its language, to encourage solidarity and awareness of the project in the greater childhood cancer community and to help ensure its success. It finished out the 115th Congress with over 50 cosponsors with no suspension of rules vote, and so was re-introduced in February of 2019 by Congresswoman Jackie Speier and Congressman David Joyce amid 16 other cosponsors. As of February 26, 2020 the tally is 98.

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