

## Summary: The DIPG Awareness Resolution

“Expressing support for the designation of the 17th day in May as “DIPG Awareness Day” to raise awareness for childhood brain cancer, and to 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, childhood 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. As such the resolution is meant to increase public awareness for childhood brain cancer, DIPG, and expedite research into cures.

The DIPG Awareness Resolution began as a simple House Resolution\* requiring only a House vote to pass; it is not a law. It is apolitical with no direct funding authorization. It does, however, suggest that for any given cancer type, that the years of human life lost associated with 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. To date, a similar resolution has twice been introduced in the Senate.

### History

The DIPG Awareness Resolution has its origins in the 2014 California Legislature, with the first 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’s journey, Janet Demeter worked with her Congressman to change the Resolution, which was reintroduced in January of 2017 to the 115th Congress as H. Res. 69, to designate May 17 as part of its language for greater solidarity and awareness of the project in the childhood cancer community and to help ensure its success. It finished out the 115th Congress with over 50 cosponsors, and then in the 116th Congress (H. Res. 114) gained the support of nearly half the House with 217 cosponsors, again without regards from House Leadership for a floor vote. As of April 1, 2021, the community awaits the 117th Congress introduction with Congresswoman Debbie Dingell (D-MI-12), and Congressman David Joyce (R-OH-14), leading.

### **\*In the Senate: DIPG Pediatric Brain Cancer Awareness Resolution**

Upon the formation of the DIPG Advocacy Group in the fall of 2017, founders Janet Demeter, Elizabeth Psar (Knoxville, TN) and Paul Miller (Littleton, CO) began to pursue a Senate resolution with advocates Wendy Fachon (Greenwich, RI) and Kirsten Finley (Ormond Beach, FL), as Senators Rubio (FL) and Reed (RI) were the original leading sponsors. The process being much more favorable to success in the Senate, a 2019 and 2020 version have passed and there are plans for the 2021 version. The process involves a unanimous “hotlined” vote and must be repeated yearly, as the language of Senate Resolutions of the commemorative variety recognize one day only, per year.

### **House Rules**

DIPG Advocacy Group, numerous childhood cancer organizations, advocates, clinicians and research scientists support the recognition of childhood brain cancer with the DIPG Awareness Resolution as a matter of urgency and human suffering which could be helped with this simple action by the House of Representatives. As generally “commemorative” resolutions were restricted in the 1990’s due to excessive overuse for non-essential interests of the People’s House, there does exist within the House Rule on commemoratives an exception protocol for bereavement and urgency. Advocates insist that the number one cause of disease-related death of children in the United States, underfunded for research, indeed ought to merit the simple consideration of House Leadership for time on the floor of the People’s House. DIPG Advocacy Group will continue asserting this claim as a voice for children who never have the chance to speak out, and for their devastated families and communities. Finding solutions for this torturous death sentence which is DIPG is veritably, with regard for this merciless suffering largely unseen, and unheard, a “Moonshot for kids”. #Moonshot4Kids.