Press Summary

The DIPG Awareness Resolution **H. RES. 416** (118th Congress)

“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…

…encourages all people of the United States 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…

…encourages public and private sources of research funding to elevate their consideration of the mortality rate of a type of cancer, as well as the life-years lost, as significant factors to be considered during the grant application process.”

General Description

DIPG exemplifies in a powerful way the challenges in treating pediatric brain 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 DIPG Awareness Resolution is meant to increase public awareness for childhood brain cancer, DIPG, and expedite research funding into cures for pediatric cancers in general. It’s not generally known that childhood brain cancer leads in childhood cancer incidence and disease-related deaths, and that monsters like DIPG exist and have no solutions; DIPG mortalities represent a significant portion of the annual childhood cancer death toll, DIPG is the second most commonly diagnosed brain tumor in children, and the disease has seen no change in standard treatment or prognosis since Neil Armstrong’s daughter died of it in 1962. Out of sight and mind, nothing changes: families witness their childrens’ demise in utter helplessness to save them or to reduce their suffering as they die.

The DIPG Awareness Resolution was first introduced to the US House of Representatives (114th Congress) in 2016, by Congressman Steve Knight (CA-25) and Congresswoman Debbie Dingell (MI-12). 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 for decades. To date, a similar resolution has been introduced five times in the Senate, passing with unanimous consent in 2019, 2020, 2021, 2022 and 2023, with leading sponsors Senator Marco Rubio (R-FL) and Senator Jack Reed (D-RI).

History

The DIPG Awareness Resolution has its origins in the 2014 California Legislature, with the first state 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 currently a CA-State Senator. Steve Knight, CA-State Senator 2012- 2014, was elected in Nov. 2014 for the 25th Congressional District of California. In September of 2015, 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 US Congress on January 13, 2016, also designating the final week of May. The co-lead for H. Res. 586 was Debbie Dingell (D-MI-12), in honor of Chad Carr in Ann Harbor, MI, and the work of the ChadTough Foundation. Exclusive to the first introduction, the original resolution was referred to as “Chad and Jack’s DIPG Awareness Resolution,” honoring Chad Carr and Jack Demeter of Agua Dulce, CA, and the work of Jack’s Angels, respectively.

In 2016, the Michael Mosier Defeat DIPG Foundation in Bethesda, MD (now merged with ChadTough Defeat DIPG Foundation) began a campaign to encourage as many states as possible to commemorate DIPG children on the

17th day of May, as the inspirational Michael Mosier, a record-breaker in 2015 for raising funds with Team Big Hero 6 for the National Brain Tumor Society's event "Race for Hope"occurring annually on the first weekend of May, Brain Tumor Awareness Month, tragically lost his life to DIPG on May 17 2015. Having followed Michael's journey, Janet Demeter worked with her Congressman to change the date designation of the national Resolution, which was reintroduced in January of 2017 to the 115th Congress as H. Res. 69 designating May 17 for greater solidarity and awareness of the project in the childhood cancer community and to help ensure its success. To date, over 34 states have recognized DIPG Awareness Day, May 17th, either by gubernatorial proclamation or by the state legislature.

Subsequently H. Res. 69 finished the 115th Congress with 53 cosponsors, and then in the 116th Congress, H. Res. 114, the resolution gained the support of nearly half the House with 215 signatures recorded, and again without regards from House Leadership for a floor vote. On May 17, 2021 the resolution was introduced for a fourth time, with Congresswoman Debbie Dingell (D-MI-12), and Congressman David Joyce (R-OH-14) leading in the 117th Congress. The resolution achieved an unprecedented House Majority (219) of signatures for floor consideration, which it was ultimately denied despite hopeful steps and multiple constituent requests for conversation.

House Rules History for "Commemoratives"

It is important to note that "commemorative" resolutions were restricted in the 1990's due to excessive overuse at the time, taking valuable floor-time away from matters of import to the People's House of Representatives. However, an exception protocol was added to this rule in 2016 for matters of bereavement and/or requiring certain remedial action, to make way for the Patriot's Day Resolution. DIPG Advocacy Group's directive throughout the 114th-117th Congresses (and continues to date) was to represent an urgent unmet need of the American people demanding greater exposure; children suffering and dying from cancer mainly due to lack of investment into cures, exemplified by the horrific yet not uncommon experience of DIPG, indeed ought to merit the simple consideration of House Leadership for time on the floor of the People's House. We maintained that, as brain cancer leads in childhood cancer incidence and childhood cancer deaths in America, this rule from another time, place, and circumstance ought to be reviewed for relevance, and given consideration with the exception protocol, "A resolution of bereavement, or condemnation, or which calls on others to take a particular action, is eligible to be scheduled for consideration." *

We reached an impasse in December of 2022 when we were indirectly told by Congressional staff that this consideration would never be given and that we could 'take comfort' in knowing the resolution could be introduced for symbolic and educational purposes to support legislation bringing more appropriate funding to the pediatric space, and to affirm the popular establishment of DIPG Awareness Day in the United States and in support of contributing efforts around the world. Indeed, it has helped support greater funding for many successful pediatric cancer funding bills. However, for DIPG as with many other childhood cancers and deadly diseases, nothing has changed in outcomes for our children despite this celebrated legislative progress. Our final work is to procure a direct and clear conversation with House Leadership, something we have sought from the beginning, to review the rules and their context in the 1990s in light of the urgent unmet needs of our children and the lack of support for them. On behalf of the thousands of families who have lost their children to this monster since we began advocating for them, with many of them sacrificing time and energy while their children were still alive, we cannot give up on hopes for 20 minutes of time on the House Floor and a House Vote. If no one knows, nothing will change quickly enough for them; we continue to maintain that the support of our elected government officials is urgently needed, and crucial for expedient change.

*In the Senate: DIPG Pediatric Brain Cancer Awareness Resolution

The resistance to consideration for the DIPG Awareness Resolution in the House to be scheduled for a vote inspired the quest for a Senate Resolution. DIPG Advocacy Group, the advocacy arm of Jack's Angels (Janet Demeter Agua Dulce, CA and Paul Miller, Littleton CO, co-founders), with one more important yet anonymous contributor, was officially founded in the fall of 2017 for this purpose. The group 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 for four consecutive Senate resolutions. The process being much more favorable to success in the Senate, the 2019, 2020, 2021, 2022 and 2023 resolutions passed with unanimous consent, with similar though more abbreviated language, and designating May 17th as National DIPG/Pediatric Brain Cancer Awareness Day. The process involves a unanimous "hotlined" vote and must be repeated yearly, as the commemorative language of Senate Resolutions recognize one specific date or period of time.

Jack's Angels pursues the educational and awareness raising benefits of the resolutions for pediatric brain cancer, to attract a cure more quickly to save lives and reduce unnecessary suffering. Our motto, "every child is a life not a number" speaks to the deeply rooted resistance in our society today to acknowledging that childhood cancers are, technically, neglected diseases in the wealthiest country in the world. For the thousands of children who never have had the chance to live, and equally for their devastated families and communities, finding effective treatments for this torturous death sentence which is DIPG and the children who continue to suffer this tragedy unseen and unheard, will veritably constitute a "Moonshot for kids" fulfilled. #Moonshot4Kids.

**https://www.majorityleader.gov/schedule/floor-protocols.htm*

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