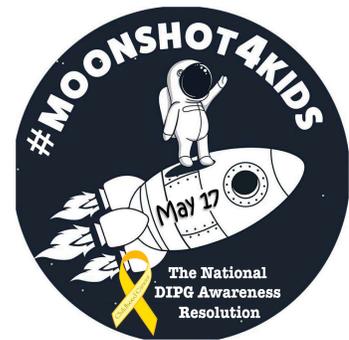


DIPG Advocacy Group Thanks the U.S. Senate
for supporting the 2019, 2020, 2021 Introductions

Senate DIPG/Pediatric Brain Cancer Awareness Resolution



April 30, 2021

To the Honorable Members of the United States Senate, and Staff:

DIPG Advocacy Group and its Affiliates would like to thank you for supporting this resolution in 2019, 2020, and we are hopeful for your support this May 2021. Senator Rubio is leading again with Senator Reed, Senator Braun, and others with the introduction on or before May 17. We need the continued leadership of the Senate for this issue as most do not realize in 2021 that brain tumors lead in childhood cancer incidence, and childhood cancer deaths, and that brain and CNS (central nervous system) tumors are the leading cause of disease-related death in children in the United States.

DIPG, diffuse intrinsic pontine glioma, serves as a powerful ambassador for childhood brain cancer in this resolution. It is the second most common type of brain tumor in children and is responsible for the majority of childhood brain cancer deaths annually, representing on its own a significant portion of the annual childhood cancer death toll. The deaths are as tragic as they are torturous. We maintain that our children and their families deserve better than to hear that there are no solutions for them because they don't represent an adequate investment incentive for pharmaceutical interests.

Equally important is the power to attract a cure more quickly for those afflicted with DIPG, a literal death sentence, by alerting the greater public and the global powers-that-be with an awareness day. There has been no change in standard DIPG treatment protocol or terminal prognosis since Neil Armstrong's precious 2-year-old daughter died of it in 1962.

Our gratitude for your support for the Resolution cannot be adequately expressed, as the denial of consideration from House Leadership as to the importance of this issue and tragedy in American life has been discouraging, with regard to the widely popular House Resolution, to be introduced by Debbie Dingell (MI-12), David Joyce (OH-14), Mike Garcia (CA-25) and others on May 17. Recognition and awareness is crucial to accelerating cures for our children. On behalf of the thousands of American families in recent years who have tragically witnessed the death of a beloved child afflicted with DIPG in all helplessness to save them, we thank you for this opportunity to raise awareness to the urgency of their need for solutions, and to recognize the preciousness and importance of the lives of America's children.

We hope you will consider joining Senator Rubio, Senator Reed, Senator Braun and others in supporting the introduction of the Resolution as cosponsors. Please contact have your staff contact Megan Axelrod and Jaime Varela at Senator Rubio's office to be added. (Megan_Axelrod@rubio.senate.gov. Jaime_Varela@rubio.senate.gov)
Thank you for your leadership! In gratitude we remain

Respectfully yours,

Janet Demeter, Elizabeth Psar, Paul Miller, Katherine Bader

DIPG Advocacy Group Administrators

Contact: admin@dipgadvocacy.org
818-400-2724



~Overwhelming Support for the National DIPG Awareness Resolution in the USA~

In 2019, 32 STATES uphold May 17th AS DIPG Awareness Day

The states of Alabama, Arizona, California*, Colorado, Florida, Georgia, Hawaii, Indiana, Illinois**, Iowa, Kansas, Kentucky, Louisiana**, Maryland, Massachusetts, Michigan, Mississippi, Missouri, Nebraska, Nevada, New Jersey, North Carolina, Ohio**, Pennsylvania, Rhode Island, South Carolina, Tennessee, Texas**, Virginia, Washington, and Wisconsin issued Proclamations establishing DIPG Awareness Day as May 17, 2019. Despite Covid-19, **Oregon and Idaho** joined this list in 2020.** More states still have requests under consideration. California was the first state to have a DIPG Awareness Resolution in 2014. * Established through the legislature. **Permanently established



In the House of Representatives:

The DIPG Awareness Resolution was first introduced to the 114th Congress in January of 2016 as H. Res. 586, again in the 115th Congress in January of 2017 as H. Res. 69, and in the 116th Congress as H. Res. 114, which finished out the session with 217 cosponsors. Although it has never been given consideration for a floor vote, childhood cancer advocates maintain the urgency and importance of recognizing childhood brain cancer as the #1 killer by disease of children in the United States, and DIPG, diffuse intrinsic pontine glioma—the 2nd most common type with its victims having a less than 1% chance of growing to adulthood. Outcomes have not changed significantly for this deadly disease in 50 years, nor have our treatment methods. DIPG represents and exemplifies a world of suffering largely unseen and unheard by the general population, and on its own represents a significant portion of the annual childhood cancer death toll.

Congresswoman Debbie Dingell (D-MI-12) leads with **Congressman David Joyce (R-OH-14)** to introduce the DIPG Awareness Resolution in the 117th Congress on May 17, 2021. Inquiries regarding the introduction and support of the resolution may be addressed to Legislative Assistant Timothy Huebner at Rep. Dingell's office: timothy.huebner@mail.house.gov, 202-225-4071

In 2019, & 2020, the U.S. Senate unanimously passes S. Res. 223, S. Res. 587, recognizing May 17 as National DIPG Awareness Day, and the importance of awareness for childhood brain cancer in the USA.

Senator Marco Rubio (R-FL) and **Senator Jack Reed (D-RI)** have led with this Resolution amid our attempt to raise greater awareness in the House of Representatives, encouraging much of the progress made to date in the House for childhood brain cancer awareness. Senator Bob Casey (D-PA), Senator Cindy Hyde-Smith (R-MI), and Senator Michael Braun (R-IN) have also supported the introduction of this resolution. For inquiries regarding the upcoming Senate introduction and vote hotline before May 17, 2021, please contact Jaime Varela and Megan Axelrod (Senator Rubio): Jaime_Varela@rubio.senate.gov, Megan_Axelrod@rubio.senate.gov, 202-224-3041

CONFERRING EXPERTS OF THE NATIONAL DIPG AWARENESS RESOLUTION

Conferring experts **Dr. Michelle Monje** of Stanford University and **Dr. Adam Green** of the University of Colorado, Denver confirmed the facts and statistics in the text of the resolution. Both scientists have laboratories dedicated to research in pediatric neuro-oncology with an emphasis on DIPG, diffuse intrinsic pontine glioma. **OVER 1300 CHILDHOOD CANCER ADVOCATES and ORGANIZATIONS HAVE ENDORSED THE DIPG AWARENESS RESOLUTION.**

SUPPORTIVE RESEARCH INSTITUTIONS AND FOUNDATIONS



Alliance for Childhood Cancer Organizations support the DIPG Awareness Resolution: Children's Oncology Group, Rally Foundation for Childhood Cancer Research, Children's Brain Tumor Foundation, Children's Cause for Cancer Advocacy, The Andrew McDonough B+ Foundation, Association of Pediatric Hematology/Oncology Nurses, National Brain Tumor Society, American Society of Pediatric Hematology/Oncology, American Childhood Cancer Organization, CureSearch for Children's Cancer, St. Baldrick's Foundation, Association of Pediatric Oncology Social Workers, American Cancer Society/Cancer Action Network

Philanthropic and Scientific Organizations and Institutions: Smashing Walnuts Foundation, The Kortney Rose Foundation, Oncology Nursing Society, Julia Barbara Foundation, Michael Mosier Defeat DIPG Foundation, Aiden's Avengers, ChadTough Foundation, Coalition Against Childhood Cancer, Lily LaRue Foundation, Cincinnati Children's Hospital, The Cure Starts Now Foundation, Jack's Angels Foundation, McKenna Claire Foundation, TogiNet Radio, Childhood Cancer Talk Radio, 4AydenStrong Foundation, Cannonballs for Kayne Foundation, The Children's Brain Tumor Project, Children's Cancer Therapy Development Institute, Children's Brain Tumor Network, MUSELLA Foundation for Brain Tumor Research

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.

116TH CONGRESS
2D SESSION

S. RES. _____

Expressing support for the designation of May 17, 2020, as “DIPG Pediatric Brain Cancer Awareness Day” to raise awareness of and encourage research on diffuse intrinsic pontine glioma tumors and pediatric cancers in general.

IN THE SENATE OF THE UNITED STATES

Mr. RUBIO (for himself, Mr. REED, Mrs. HYDE-SMITH, and Mr. CASEY) submitted the following resolution; which was referred to the Committee on _____

RESOLUTION

Expressing support for the designation of May 17, 2020, as “DIPG Pediatric Brain Cancer Awareness Day” to raise awareness of and encourage research on diffuse intrinsic pontine glioma tumors and pediatric cancers in general.

Whereas diffuse intrinsic pontine glioma (referred to in this preamble as “DIPG”) tumors regularly affect 200 to 400 children in the United States each year;

Whereas brain tumors are the leading cause of cancer-related death among children;

Whereas, during childhood, DIPG tumors are—

- (1) the second most common type of malignant brain tumor; and

(2) the leading cause of pediatric brain cancer deaths;

Whereas, with respect to a child who is diagnosed with a DIPG tumor and receives treatment for a DIPG tumor, the median amount of time that the child survives after diagnosis is only 9 months;

Whereas, with respect to an individual who is diagnosed with a DIPG tumor, the rate of survival 5 years after diagnosis is approximately 2 percent;

Whereas the average age at which a child is diagnosed with a DIPG tumor is between 5 and 9 years, resulting in a life expectancy approximately 70 years shorter than the average life expectancy in the United States; and

Whereas the prognosis for children diagnosed with DIPG tumors has not improved over the past 40 years: Now, therefore, be it

1 *Resolved*, That the Senate—

2 (1) supports—

3 (A) designating May 17, 2020, as “DIPG
4 Pediatric Brain Cancer Awareness Day”; and

5 (B) efforts to—

6 (i) better understand diffuse intrinsic
7 pontine glioma tumors;

8 (ii) develop effective treatments for
9 diffuse intrinsic pontine glioma tumors;

10 and

1 (iii) provide comprehensive care for
2 children with diffuse intrinsic pontine
3 glioma tumors and their families; and

4 (2) encourages all individuals in the United
5 States to become more informed about—

6 (A) diffuse intrinsic pontine glioma tu-
7 mors;

8 (B) pediatric brain cancer in general; and

9 (C) challenges relating to research on pedi-
10 atric cancers and ways to advance such re-
11 search.