

Seeking Member Support for the Recognition of Children Fighting Brain Cancer:

H. Res. 404, The National DIPG Awareness Resolution

July 8, 2021



To the Honorable Members of the United States House of Representatives, and Staff:

DIPG Advocacy Group is committed to achieving Congressional recognition for those lost to, and those currently facing out of public view and without adequate support, a merciless and indefatigable killer of American children. After California's first state-level resolution addressing DIPG and childhood brain cancer in the United States in 2014, our community is unified in this effort with 34 states having recognized May 17th, three US Senate Resolutions have passed by unanimous consent, and after a near House majority supported it in the 116th Congress, an historic 4th introduction of the House Resolution occurred on May 17, 2021. Out of public view, this deadly childhood brain cancer has seen no change in its death sentence for decades.

In H. Res. 404, DIPG, *diffuse intrinsic pontine glioma*, serves as a powerful ambassador for childhood brain cancer--the leading cause of cancer-related death in children. DIPG is the second most common type of brain tumor in children and is the #1 cause of childhood brain cancer deaths annually. 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. As parents, this continues to be our experience as we watch them die in complete helplessness to save them. This experience is not limited to DIPG, which, as such, exemplifies the larger problem of inadequate financial support for the entire childhood cancer research space, with roughly 3.8 – 7% of the NCI budget so allocated on any given year over the past decade.

Of utmost importance is the centerpiece of the Resolution, 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 nor terminal prognosis since Neil Armstrong's daughter died of it in 1962. As such, we believe that the subject-matter of this resolution is worthy of the simple consideration of House Leadership under the exception protocol* for the restrictions placed on commemorative resolutions in the 1990s. Considering the context of excessive overuse at the time, the restrictions were duly applied to conserve floor-time in the House of Representatives for matters of import to the American People. We maintain that the DIPG Awareness Resolution is respectful of both the House Rules and America's most vulnerable citizens in urgent need of visibility.

Furthermore, as brain cancer is generally an unseen, unknown prolific killer of children, we are confident that lives could be saved immediately with greater public awareness of the signs and symptoms. Increasing awareness and education about childhood brain cancer will help dispel the resistance from insurance companies to approving the definitive diagnostic tool (MRI), support research into cures, and facilitate access to knowledge of possible experimental treatments for families of the newly diagnosed when a matter of days, even hours, can mean life or death.

We hope that you will join Congresswoman Dingell (D-MI-12), Congressman Joyce (R-OH-14) and the twenty-more original cosponsors in recognizing the importance of the DIPG Awareness Resolution for children fighting this horrific death sentence in America, and around the world. The greater public awareness generated by the recognition of the House of Representatives would help save lives and set an important precedent for leadership in caring for children as a society. Please contact Timothy Huebner with Congresswoman Dingell's office for more information, and to support with your signature:

Timothy.Huebner@mail.house.gov, 202-225-4071. Thank you for your kind consideration. In gratitude we will remain,

Respectfully yours,

DIPG Advocacy Group Administrators

Janet Demeter, *Organizer*; President, Jack's Angels, Agua Dulce, CA

Katherine Bader, *Director of Community Relations*, Rhineland, MO

Elizabeth Psar, *co-Founder*; President, Julia Barbara Foundation, Knoxville, TN

Paul Miller, *co-Founder*, Childhood Cancer Advocate, Littleton, CO

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DIPG Advocacy Group is a coalition of childhood brain cancer organizations and individual childhood cancer advocates supporting pediatric brain cancer awareness and the DIPG Awareness Resolution in the United States Congress.

* <https://www.majorityleader.gov/content/117th-congress-legislative-protocols>

1) Commemoratives

Purpose

This protocol is meant to provide further guidance on House Rule XII, clause 5, related to the prohibition on scheduling legislation that is commemorative in nature.

Protocol

The Majority Leader shall not schedule any bill or resolution for consideration that expresses appreciation, commends, congratulates, celebrates, recognizes the accomplishments of, or celebrates the anniversary of, an entity, event, group, individual, institution, team or government program; or acknowledges or recognizes a period of time.

***A resolution of bereavement, or condemnation, or which calls on others to take a particular action, is eligible to be scheduled for consideration.**

Other documents in this pdf:

Endorsements for the National DIPG Awareness Resolution
H. Res. 404 Text



"May hope and light replace darkness and despair for DIPG children and their families."

Jack's Angels Prayer

~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) lead with **Congressman David Joyce (R-OH-14)** and 20 more original cosponsors to introduce the DIPG Awareness Resolution in the 117th Congress on May 17, 2021. To support, and for more information, inquiries may be addressed to Legislative Assistant Timothy Huebner at Rep. Dingell's office: timothy.huebner@mail.house.gov, 202-225-4071.

In 2019, 2020, & 2021 the U.S. Senate unanimously passes S. Res. 223, S. Res. 587, S. Res. 231 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 in the Senate 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), Senator Roger Marshall (R-KS), Senator Dianne Feinstein (D-CA) and Senator Deb Fischer (R-NE) have cosponsored this resolution, which has received 3 passages of Unanimous Consent from the United States Senate.

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

117TH CONGRESS
1ST SESSION

H. RES. 404

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.

IN THE HOUSE OF REPRESENTATIVES

MAY 17, 2021

Mrs. DINGELL (for herself, Mr. JOYCE of Ohio, Mr. BUTTERFIELD, Mr. CLEAVER, Ms. SPEIER, Mr. BLUMENAUER, Mr. COHEN, Ms. WILLIAMS of Georgia, Mr. LEVIN of Michigan, Ms. DEAN, Mr. DEUTCH, Ms. PINGREE, Mr. LAMALFA, Ms. SALAZAR, Mr. CONNOLLY, Mr. VELA, Mr. RUTHERFORD, Mrs. WALORSKI, Mr. LAMB, Mr. RUSH, Mr. LONG, and Mr. WALTZ) submitted the following resolution; which was referred to the Committee on Energy and Commerce

RESOLUTION

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.

Whereas diffuse intrinsic pontine glioma (DIPG) affects 200 to 400 children in the United States each year with certain regularity;

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

Whereas DIPG is the second most common malignant brain tumor of childhood;

Whereas DIPG is the leading cause of childhood death due to brain tumors;

Whereas the median survival time is only 9 months postdiagnosis with treatment;

Whereas 5-year survival is less than 1 percent;

Whereas, given the age at diagnosis and the average life expectancy, the number of life years lost annually because of DIPG is approximately 24,000 years of person life lost (calculated as the number of children diagnosed by average of male and female life expectancy from that median age, $300 \times 80 = 24,000$ years of person life lost annually);

Whereas prognosis has not improved for children with DIPG in over 40 years; and

Whereas Federal funding for research for pediatric cancer should be increased to address the level of unmet medical need for this vulnerable population: Now, therefore, be it

1 *Resolved*, That the House of Representatives—

2 (1) supports the designation of “DIPG Awareness Day”;

3 (2) encourages all people of the United States
4 to become more informed about diffuse intrinsic
5 pontine glioma (DIPG) pediatric brain cancer, and
6 the current challenges to the medical research system
7 in designating sufficient research funding for
8 pediatric cancers;

1 (3) supports expanded research to better under-
2 stand DIPG, develop effective treatments, and pro-
3 vide comprehensive care for children with DIPG and
4 their families; and

5 (4) encourages public and private sources of re-
6 search funding to elevate their consideration of the
7 mortality rate of a type of cancer, as well as the life-
8 years lost, as significant factors to be considered
9 during the grant application process.

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