

H. RES. 416: An Opportunity for Unity and Effectiveness in Accelerating Cures for Childhood Brain Cancer, the Leading Cause of Cancer-Related Deaths in Children in the USA

“With H. Res. 416, we are asking you to lend your unique power and platform, the People’s House of Representatives, to draw attention to a truly voiceless population where we parents remain helpless to save them or to reduce their suffering as they die.”

July 22, 2024

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

Thank you for taking a moment to consider the **DIPG Awareness Resolution** representing the issue of childhood brain cancer, the leading cause of cancer-related deaths in children in the United States. For the American Public and the United States Congress, the unmet medical needs of children with cancer is still largely an unknown tragedy. To alert, educate, and end obscurity for the lack of adequate research investment for childhood cancers, **H. Res. 416** uses the powerful example of diffuse intrinsic pontine glioma (DIPG), the second most commonly diagnosed brain tumor in children and the deadliest, as an exemplar and an ambassador for childhood cancer.

Childhood cancers literally fit the criteria of the World Health Organization’s standard for what is considered a neglected disease, a disease which receives disproportionately little research investment despite the urgent, unmet medical needs of the afflicted. Amid notable legislative successes such as Creating Hope, Kids First, and RACE, literally nothing has changed for a child diagnosed with DIPG since Neil Armstrong’s 2-year-old daughter died of it in 1962. Parents typically hear today, “the numbers aren’t great enough for investors,” and to, “go make memories.” This is an unacceptable reality in a country which possesses everything necessary to save these kids. With H. Res. 416, we are asking you to lend your unique power and platform, the People’s House of Representatives, to draw attention to a truly voiceless population where we parents remain helpless to save them or to reduce their suffering as they die. After five introductions to Congress including the achievement of a House Majority of cosponsors in the 117th(H.RES.404), an unprecedented display of support for a resolution of its kind, the DIPG Awareness Resolution has not been granted suspension of rules consideration in light of its qualifications.*

It’s a veritable catch-22: out of sight and mind, the deaths and the terrible suffering continue unabated, numbering roughly 3200 from DIPG alone since the first introduction in 2016, the year that the Patriot’s Day Resolution* was passed. Truly, the missing catalyst has been public awareness and visibility on the national stage, something that the House of Representatives has the power to do for the American People—a concept of hope for the true representation of our interests and love of country which inspired the creation of this resolution for our children.

Please consider joining Congresswoman Dingell (D-MI-06), Congressman Joyce (R-OH-14), and Congressman McCaul (R-TX-10), Chairman of the Childhood Cancer Caucus, to support H. Res. 416 which recognizes the urgent, unmet medical needs of children with cancer in America. The ultimate recognition of the House of Representatives will help save lives and set an important precedent for unification and leadership in caring for children in our society today, and for a brighter future. Thank you for your kind consideration; we will remain hopeful for your support!

Respectfully yours,

DIPG Advocacy Group

Janet Demeter, *Organizer and Founder* (Dunsmuir, CA)*

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#NeverForgetOurChildren

* “A resolution of bereavement, or condemnation, or which calls on others...to take a particular action, but which does not otherwise violate the provisions of Rule 29 is eligible to be scheduled under suspension of the Rules.” –(see *Commemorative Resolutions*)

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

H. RES. 416

“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, 2023

Mrs. DINGELL (for herself, Mr. JOYCE of Ohio, Mr. MCCAUL, Ms. NORTON, Ms. MACE, Ms. PORTER, Mr. DOGGETT, Mr. QUIGLEY, Ms. GARCIA of Texas, Mrs. TRAHAN, Ms. ROSS, Mr. NORCROSS, Ms. PINGREE, Ms. KUSTER, Mr. COHEN, Mrs. CHERFILUS-MCCORMICK, Ms. WILLIAMS of Georgia, Mr. MCGOVERN, Mr. CARSON, and Mr. MOYLAN) submitted the following resolution; which was referred to the Committee on Energy and Commerce

R E S O L U T I O N

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

Resolved, That the House of Representatives—

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

(2) 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;

(3) supports expanded research to better understand DIPG, develop effective treatments, and provide comprehensive care for children with DIPG and their families; and

(4) 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.

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

By 2020, 34 states have upheld May 17th as DIPG Awareness Day

The states of Alabama, Arizona, California*, Colorado, Florida, Georgia, Hawaii, Idaho**, Indiana, Illinois**, Iowa, Kansas, Kentucky, Louisiana**, Maryland, Massachusetts, Michigan, Mississippi, Missouri, Nebraska, Nevada, New Jersey, North Carolina, Ohio**, Oregon, Pennsylvania, Rhode Island, South Carolina, Tennessee, Texas**, Virginia, Washington, and Wisconsin issued Proclamations establishing DIPG Awareness Day as May 17, by 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, in the 115th Congress in January of 2017 as H. Res. 69, in the 116th Congress as H. Res. 114, and H. Res. 404 in the 117th Congress which finished out the session with 220 pre-vote signatures of support though never given suspension of rules consideration for actual floor discussion. Outcomes and treatment options have not changed significantly for this deadly disease in 60 years. 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-6) lead with **Congressman Michael McCaul (TX-10)** and **Congressman David Joyce (R-OH-14)** and 17 more original cosponsors to introduce the DIPG Awareness Resolution in the 118th Congress on May 17, 2023. To support, and for more information, inquiries may be addressed to the Legislative staff of the lead sponsor Representative Debbie Dingell (D-MI-12), and/or the leading cosponsor, Representative David Joyce (R-OH-14).

In 2019, 2020, 2021, 2022, 2023 and 2024 the U.S. Senate unanimously passed the DIPG/Pediatric Brain Cancer Awareness Resolution to recognize 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 the Senate version of the resolution, which has received 5 passages of unanimous consent as is customary in that chamber to recognize one specific day of any given year.

CONFERRING EXPERTS OF THE NATIONAL DIPG AWARENESS RESOLUTION

Dr. Adam Green of the University of Colorado, Denver and **Dr. Michelle Monje** of Stanford University were consulted for resolution statistics and facts. Both scientists have established 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, National Brain Tumor Society

Philanthropic and Scientific Organizations and Institutions: Smashing Walnuts Foundation, The Kortney Rose Foundation, Oncology Nursing Society, ChadTough Defeat DIPG Foundation, Aiden's Avengers, 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, the Carson Leslie Foundation and #CureMEdullo Project