

The Opportunity to Help A Truly Voiceless and Vulnerable Population Where Others Cannot.

Merits of H. Res. 404, The National DIPG Awareness Resolution

September 4, 2022

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



Thank you for taking a few minutes to consider the issue of childhood brain cancer, the leading cause of cancer-related death in children in the United States. For the greater American Public and the United States Congress, children with cancer, their families, and torturous suffering is largely an unknown tragedy. To alert, educate, and end obscurity for the lack of adequate research investment for childhood cancers, H. Res. 404 uses the powerful example of diffuse intrinsic pontine glioma (DIPG), the second most commonly diagnosed brain tumor in children and the deadliest, as an Ambassador for childhood cancer as such.

Where we have made great strides in treating childhood leukemia mainly due to robust investment in adult research with successful translation into therapies for children, it is assumed that, as a society, we invest in childhood cancer research amid a budget of increased billions at NIH, comforting St. Jude's commercials, and touted leukemia statistics. Sadly, brain cancer takes more children's lives than any other sub-type. On its own, DIPG is responsible for a significant portion of the annual childhood cancer death toll, yet there has been no change in the standard treatment protocol or terminal prognosis since Neil Armstrong's daughter Karen died of it in 1962. Out of sight and mind, the deaths and suffering continue unabated.

How can this be, in the wealthiest country in the world with the greatest technology? The medical research investment culture prioritizes investor and institutional goals before the needs of our children. Parents typically hear, "it's one of those sad, rare orphan things," and no one will invest in their child's cancer. This is an unacceptable reality in a country which possesses the resources and the technology to save these kids. With H. Res. 404, we are asking you to lend your unique power to draw attention to a truly voiceless population where we parents remain helpless to save them, or to reduce their suffering as they die.

Here are but a few reasons why your support truly matters: we know that with greater knowledge of the signs and symptoms of brain cancer, of which even some pediatricians are unaware, many lives will be extended and some saved; research funding will increase, and access to knowledge of possible experimental treatment options will improve for families of the newly diagnosed when a matter of time for a decision can mean life or death. Needed improvements in research infrastructure and data-sharing will speed discovery and access to effective therapies not just for children, but for all patients.

Most importantly, awareness is the missing link to speeding a cure; despite much touted progress made in childhood cancer legislation over the last decade, even with the STAR Act, the Gabriella Miller Kids First Research Act and the Creating Hope Act, *virtually nothing has changed* for children with DIPG and other childhood cancers. We are hopeful that the awareness generated by H. Res. 404 will ensure less compromise and delay for such important legislation. Our children continue to fight a death sentence completely unarmed in an invisible war. Tragically yet predictably, 2600 more children have been lost to DIPG alone since the first introduction of the resolution in 2016. We need H. Res. 404 to succeed now, this Congress, while we have the chance to show a solid House majority of support. For a downtrodden and bereaved population, many unable to speak to their experience and very few advocacy operatives, this is quite a feat in our 7th year; its repeatability, uncertain.

Please consider joining Congresswoman Dingell (D-MI-12), Congressman Joyce (R-OH-14), and Congressman McCaul (R-TX-10), Chairman of the Childhood Cancer Caucus, to support H. Res. 404 which recognizes the urgent, unmet medical needs of children 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. To support, have your staff contact Meg Makarewicz with Congresswoman Dingell's office, meg.makarewicz@mail.house.gov, or Will Mascaro with Congressman David Joyce's office, will.mascaro@mail.house.gov. Thank you for your time and kind consideration.

Respectfully yours,

DIPG Advocacy Group

Janet Demeter, Organizer and Founder

Paul Miller, Co-Founder

Marcelo Ramalho-Ortigao PhD

Science and Medical Advisor



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

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

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. PIN- GREE, 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 post diagnosis 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, 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 215 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 and 2022, the U.S. Senate unanimously passes S. Res. 223, S. Res. 587, S. Res. 231, and S. Res. 642 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 4 passages of unanimous consent as is customary in that chamber to recognize one specific day of a given year.

CONFERRING EXPERTS OF THE NATIONAL DIPG AWARENESS RESOLUTION

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, 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