

Attention Members of the US House of Representatives, 119th Congress

Friday May 16th Introduction
The 2025 DIPG Awareness Resolution
for Childhood Brain Cancer Awareness



May 12, 2025

To Members of the US House of Representatives in the 119th Congress, and Staff:

I'm Janet Demeter, founder of Jack's Angels, a small charity devoted to raising awareness nationwide to the unmet medical needs of children fighting brain cancer. Since 2016, we have worked with constituents to alert most Congressional District Offices about the DIPG Awareness Resolution for childhood brain cancer. Whether you are a previous supporter of the DIPG Awareness Resolution (which attained 220 cosponsors in the 117thC) or have never contemplated its text, we would like you to consider its populist spirit and beginnings: an effort of bereaved parents to alert the public and Congress to the suffering and deaths of our children for whom nothing has significantly changed in over 60 years, because as we invariably learn, "the numbers aren't great enough for investors" in the wealthiest country in the world.

If you are just now coming to this issue, or if you've pondered it before, we need you; the unmet medical needs of children with cancer is still largely an unknown tragedy in our country today. To alert, educate, and end obscurity for childhood brain cancer, the leading cancer-related cause of death in children nationwide, the DIPG Awareness Resolution uses the example of diffuse intrinsic pontine glioma (DIPG). DIPG is the second most commonly diagnosed brain tumor in children and the leading cause of childhood brain cancer deaths. The resolution proposes to designate May 17, 2025 as DIPG Awareness Day, to raise national awareness for these children who have long fought an invisible war against a merciless killer. DIPG is literally a death-sentence.

In our childhood brain cancer communities across the country, we are indebted to Congresswoman Dingell (D-MI-6) and her colleague Congressman David Joyce (R-OH-14) for their commitment to these children and their families with the effort to ensure this upcoming 6th introduction. Please consider joining them as original cosponsors as we work to assemble a significant show of support for children with brain cancer who are fighting an invisible war indeed. In the 12 years we've worked to raise awareness for this issue, experts invariably agree that pediatric brain cancer research benefits all oncology research and represents important advances in medicine, our understanding of the brain, and biological science; and yet, parents continue to learn that research into childhood brain cancer lacks "investment incentive" for pharmaceutical companies to explain the lack of solutions for their children. We deeply appreciate your consideration; the ultimate recognition of the House of Representatives will help to accelerate a cure and set an important precedent for leadership in caring for children in our society today.

Please reach out to William Seabrook (william.seabrook@mail.house.gov) at Rep. Debbie Dingell's office for more information; thank you. (Also included in this document: Resolution text, Endorsements document)

In gratitude we will remain

Respectfully yours,

Janet Demeter, Founder
DIPG Advocacy Group
Paul Miller, Co-Founder, Littleton, CO
Marcelo Ramalho-Ortigao, PhD,
Science and Medical Advisor,
Ft. Collins CO



Because every child is a life, not a number.

.....
(Original Signature of Member)

119TH CONGRESS
1ST SESSION

H. RES. _____

Expressing support for the designation of May 17, 2025, 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

Mrs. DINGELL submitted the following resolution; which was referred to the Committee on _____

RESOLUTION

Expressing support for the designation of May 17, 2025, 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 of an individual with DIPG is only 9 months postdiagnosis with treatment;

Whereas 5-year survival of an individual with DIPG 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 Aware-
3 ness Day”;

4 (2) encourages all people of the United States
5 to become more informed about diffuse intrinsic
6 pontine glioma (DIPG) pediatric brain cancer, and
7 the current challenges to the medical research sys-
8 tem in designating sufficient research funding for
9 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.

~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. **Rep. Debbie Dingell** (D-MI-6) lead with **Rep. David Joyce** (R-OH-14) and 20 more original cosponsors to introduce the DIPG Awareness Resolution in the 117th Congress, H. Res. 404 which gained 220 cosponsors...It was introduced to the 118th Congress May 17, 2023. 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 commonly-diagnosed and the leading cause of childhood brain cancer deaths. Outcomes have not changed significantly for this disease in 60 years, nor has the standard of care. 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.

In successive years 2019-2024, the U.S. Senate unanimously passed the DIPG Pediatric Brain Cancer Awareness Resolution, to recognize May 17 as National DIPG Pediatric Brain Cancer 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), Senator Deb Fischer (R-NE) and Senator Roger Marshall (R-KS) have cosponsored this resolution, which has received 6 passages of Unanimous Consent from the United States Senate.

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

Philanthropic and Scientific Organizations and Institutions: Smashing Walnuts Foundation, The Kortney Rose Foundation, Oncology Nursing Society, 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, the Carson Leslie Foundation and #CureMEDullo Project