

## DIPG Advocacy Group Asks for Your Support in May 2025:

### Senate DIPG/Pediatric Brain Cancer Awareness Resolution

*Led by Senator Jack Reed (D-RI)*



May 10, 2022

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

Thank you for taking a moment during Brain Tumor Awareness Month to learn about its significance for children and in American family life. We appreciate the continued leadership of the US Senate in drawing attention to childhood brain cancer, as most do not realize in 2025 that brain tumors lead in childhood cancer incidence and childhood cancer deaths, and that brain and CNS (central nervous system) tumors are the number 1 cause of disease-related death in children in the United States. If you are a new Senator, thank you for taking a moment to learn a little more about the importance of this issue.

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, in the wealthiest country in the world. But sadly, this is what we as parents invariably come to learn. This was the original motivation for the US House and Senate DIPG Awareness Resolutions.

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 powers-that-be with an awareness day, thus potentially saving lives with greater awareness of signs and symptoms of brain tumors for which there are helpful treatments if caught in time. For DIPG, there's been no change in the standard of care or terminal prognosis since Neil Armstrong's 2-year-old daughter died of it in 1962, yet, with the technology of the day, we sent men to the moon and brought them home safely. The missing element here is obvious: acknowledgement; public awareness. Our efforts here in the United States have been echoed and reciprocated in other countries, not shy of declaring an awareness day for children who urgently need our help. Help us this year to set a precedent for the acknowledgement of the urgent, unmet medical needs of children, and our desire to do better for them. We humbly ask you to support this resolution immediately, for the day in question will arrive shortly, May 17, 2025!

Please contact Jill Boland with Senator Reed's office: Jill Boland, [jill\\_boland@reed.senate.gov](mailto:jill_boland@reed.senate.gov).

Thank you for your consideration and support. In gratitude we will remain  
Respectfully yours,

A handwritten signature in black ink, appearing to read "Janet Demeter".

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.*

118TH CONGRESS  
2D SESSION

# S. RES. 691

Expressing support for the designation of May 17, 2024, 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.

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IN THE SENATE OF THE UNITED STATES

MAY 15, 2024

Mr. RUBIO (for himself, Mr. REED, Mr. BRAUN, Mr. CASEY, Mrs. HYDE-SMITH, and Mrs. FISCHER) submitted the following resolution; which was considered and agreed to

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## RESOLUTION

Expressing support for the designation of May 17, 2024, 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 300 children in the United States each year;

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

Whereas DIPG tumors are 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 approximately 11 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 10 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 meaningfully improved during the past 50 years: Now, therefore, be it

1       *Resolved*, That the Senate—

2               (1) supports designating May 17, 2024, as  
3       “DIPG Pediatric Brain Cancer Awareness Day”;

4               (2) supports efforts—

5                       (A) to better understand diffuse intrinsic  
6               pontine glioma (referred to in this resolution as  
7       “DIPG”) tumors;

8                       (B) to develop effective treatments for  
9       DIPG tumors; and

10                      (C) to provide comprehensive care for chil-  
11       dren with DIPG tumors and their families; and

12               (3) encourages all individuals in the United  
13       States to become more informed about—

14                      (A) DIPG tumors;

- 1 (B) pediatric brain cancer in general; and
- 2 (C) challenges relating to research on pedi-
- 3 atric cancers and ways to advance that re-
- 4 search.

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

By 2020, 34 states have upheld May 17<sup>th</sup> 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 114<sup>th</sup> Congress in January of 2016 as H. Res. 586, again in the 115<sup>th</sup> Congress in January of 2017 as H. Res. 69, and in the 116<sup>th</sup> 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 117<sup>th</sup> Congress, H. Res. 404 which gained 220 cosponsors...It was introduced to the 118<sup>th</sup> 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 2<sup>nd</sup> 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