

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



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

Sept. 3, 2022

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

Nancy Pelosi (CA-12), *Speaker of the House*

H-232 The Capitol,

Katherine Clark (MA-5), *Assistant Speaker of the House*

H-132 The Capitol,

Steny Hoyer (MD-5), *House Majority Leader*

H-107 The Capitol,

Kevin McCarthy (CA-23), *House Minority Leader*

H-204 The Capitol,

James Clyburn (SC-6), *Majority Whip*

H-232 The Capitol,

Steve Scalise (LA-1), *Minority Whip*

H-184 The Capitol,

Washington, D.C. 20515-0001:

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 their horrific suffering continue to be an invisible tragedy. To alert, educate, and end obscurity for lack of adequate research investment support for our children, 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; the resolution has been introduced four times.

While we have made great strides in treating childhood leukemia due mainly to robust investment in adult research with successful translation into pediatric therapies, brain cancer takes more children's lives in America than any other cancer subtype; on its own, DIPG is responsible for a significant portion of the annual childhood cancer death toll. And 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.

How can this be, in the wealthiest country in the world with the greatest technology? With a medical research investment culture which systematically prioritizes numbers and profits before the needs of our children, parents typically hear that it's just, "one of those sad things", that no one will invest in their child's cancer. With H. Res. 404 we are asking you to lend your unique power to draw attention to this issue as we parents remain helpless to save our children or reduce their suffering as they die. We are asking for your help. Here are some of the reasons why we believe your consideration matters:

From our experience we know that with greater awareness and knowledge of the signs and symptoms of brain cancer, of which even some pediatricians are unaware, many lives will be extended and some saved. Funding for research will increase, and greater access to knowledge of possible experimental treatments will improve for families of the newly diagnosed when a matter of days, even hours, can mean life or death. Increased federal support for the improvements in research infrastructure and data-sharing required for developing effective therapies for children will speed the discovery process; due to an explosion of parent investment over the last decade we are extremely close to finding a cure but lack needed funding.

Roughly 2600 more children have been lost to DIPG alone since the first introduction of the resolution in 2016. We realize that a "commemorative" resolution like H. Res. 404 is not usually considered; here is where we plead for your attention to the original context for the restriction in the 1990s of excessive overuse, and to the exception protocol* in the House Rules for bereavement and called-for action which was originally used for the Patriot's Day resolution. For our children, this devastating fact remains: despite the progress in childhood cancer legislation over the last decade, **virtually nothing has changed** experientially for children with DIPG, brain cancer and many other childhood cancers. Our children continue to fight a death sentence completely unarmed in an invisible war. They continue to die torturously while we possess the technology and the willing physician-researchers to save them; this is an unacceptable reality. We need awareness; we need H. Res. 404 to succeed now, this Congress.

"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>

The ultimate recognition of the House of Representatives will set an important precedent for unification and leadership in caring for children in our society today. Please note that in the 116th Congress, 215 of 219 signatures were officially registered for the DIPG Awareness Resolution. Today, were we to have all of our previous supporters back on board now, we would already have achieved a solid House majority of nearly 240 cosponsors.

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, which is in no danger of easy repetition; and a pre-vote 290 count is unlikely with the long-standing lack of awareness and small number of advocacy operatives. We personally request this consideration as a sacred duty to you as citizens, to our deceased children as parents, and to our fellow citizens representing thousands of devastated families. You do have the power to affect this tragedy in a meaningful way, for our children and a system of medical research investment and care that is more in alignment with our values as Americans. Please help us; please allow scheduling for H. Res. 404. Thank you for your kind consideration.

Respectfully yours,

Janet Demeter, Jack's mom



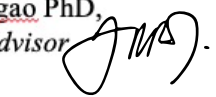
DIPG Advocacy Group

Janet Demeter, *Organizer and Founder*

Paul Miller, *Co-Founder*

Marcelo Ramalho-Ortigao PhD,

Science and Medical Advisor



c/o Jack's Angels Inc

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~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