

#MOONSHOT4KIDS

H. Res. 114

The National DIPG
Awareness Resolution
"The Little Bill That Could"



DIPG ADVOCACY GROUP

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To the Honorable Members of the United States House of Representatives:

We are deeply grateful for your attention as it is not commonly known that brain tumors lead in childhood cancer prevalence, and deaths. DIPG, the second most common type of pediatric brain tumor and the deadliest, is the #1 cause of childhood mortality due to brain tumors, and singularly represents a significant portion of the annual childhood cancer death toll. H. Res. 114, the DIPG Awareness Resolution, shines needed light in a place in our society which has remained in darkness for decades, as DIPG exemplifies in a powerful way the marginalization of our children by the current medical research investment culture, and the message we consistently hear as parents that there's no cure for our children because their lives don't represent a significant enough investment incentive.

DIPG Advocacy Group is a coalition of childhood cancer advocates and pediatric brain cancer foundations formed expressly for the purpose of supporting the National DIPG Awareness Resolution in US Congress. After 5 years of bringing stories of constituents to Capitol Hill, 3 introductions of the resolution and 2000 more lives lost of innocent children to DIPG alone, we are humbly asking for your support considering the prolific nature of this killer, the cruelty of the deaths these children must endure, as their parents witness in complete helplessness to save them. We need 218 signatures because the only challenge to the scheduling of this resolution with House Leadership is the recognition of the urgency of the situation, that it represents a legitimate exception* to the ban on "commemorative" resolutions due to frivolous overuse a quarter of a century ago.

You may not have previously heard of DIPG because these children, mostly between the ages of 5 and 9 years old, are fighting for their lives and most all of them die; their parents are typically too devastated to conceive of hopeful advocacy. The unspoken experience is exceedingly cruel and horrifying, both for the children who must imagine their approaching death in full cognitive awareness as they become imprisoned in their increasingly paralyzed bodies, as for their loved ones who witness it in total helplessness because, as we so often hear, "the numbers aren't great enough for investors," in the wealthiest country in the world. However unintended, the terrible message we take from this is that our children's lives and suffering don't matter. With H. Res. 114 we are asking our Members of Congress for help to sound the alarm and draw attention to an urgent, unmet need in our society today for those who cannot speak out.

Out of sight and out of mind, DIPG has seen no significant change in standard treatment protocol **since 1962**, when Neil Armstrong's two-year-old daughter Karen died of it. Nor are the common signs and symptoms of childhood brain cancer commonly recognized or swiftly diagnosed; clinicians are often met with strong resistance from insurance companies for use of the definitive diagnostic tool, the MRI. Too many childhood brain tumors, many treatable, are discovered too late or at autopsy. In 2020, families are still told at diagnosis to, "Go make memories," and are left to their own devices to find a pathway forward with experimental treatments.

Despite increased appropriations for NIH and NCI, there is still insufficient awareness of the urgent financial need in childhood cancer research, specifically brain cancer—the most prevalent and deadliest subtype, which sits on the cutting edge of several frontiers of science today. At the #Moonshot4Kids Congressional Briefing in Rayburn on 2/13/2020, Dr. Adam Resnick (CHOP), leading scientist for the Children's Brain Tumor Network (CBTN) spoke authoritatively to the fact that exposing DIPG and the value of pediatric brain cancer research more publicly creates opportunities for systemic change in the way we share data, conduct research and fund new clinical trials for treatments. More than 36 organizations, including the Pediatric Neuro-Oncology Consortium (PNOC), CBTN, National Brain Tumor Society, the Oncology Nursing Society, St. Baldrick's Foundation, and the Alliance for Childhood Cancer, have all lent their endorsements to H. Res. 114.

[1] The Office of Majority Leader Steny Hoyer, <https://www.majorityleader.gov/content/116th-congress-legislative-protocols>

The increased national awareness, education, and recognition which H. Res. 114 would help generate for childhood brain tumors could save lives today. These children might be given treatment access priority during a pandemic when a few weeks delay can mean missing a life-saving opportunity. Rather than detracting from the pandemic, H. Res. 114 supports the call to accommodate our most vulnerable citizens in most urgent need of help. And finally, the recognition would also serve to help more quickly attract financial and scientific support from around the world, as 95% of pediatric neuro-oncology research funding is provided by parent-led foundations which struggle to make promising clinical trials available and accessible. Today's most promising, largely unknown clinical trial for DIPG is said to possibly allow 6 patients this year, while a DIPG terminal prognosis with standard treatment is 9 months.

We thank you for your support if you are already one of the nearly 190 signatories of H. Res. 114; you are our closest representation in federal government and we need your support in asserting that a pathway does exist for this resolution with House leadership according to the current protocol[1] in place, for the deadliest pediatric cancer. If you have not signed yet, with your supportive signature you have the power to attach hope to DIPG and all underserved childhood cancers, the #1 disease-related killer of America's children, and let House leadership know it's the right thing to do to help where an opportunity such as this exists, and that our children represent a worthy exception to a rule from a different time and circumstance. And if the Session ends and the resolution must be reintroduced, we hope that you might remember this challenge for the recognition of these children fighting for their lives and support its expedition. Please give us hope that our voices, representing countless others who will never speak, matter; that our children's lives matter.

In gratitude, we remain
Respectfully yours,



DIPG Advocacy Group Co-Founders

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*Link to 2-13-2020 Briefing Synopsis: bit.ly/MS4K-synopsis (case sensitive)

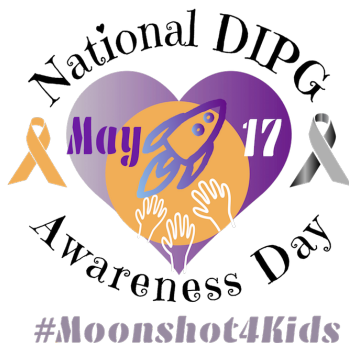
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"People can't care if they're not aware."

--Aimee Dickie of Scranton, PA in 2009, forever 12

DIPG Advocacy Group is a coalition of childhood brain cancer organizations and individual childhood cancer advocates supporting pediatric brain cancer awareness and the DIPG Awareness Resolution in US Congress.

"May hope and light replace darkness and despair for DIPG children and their families."

-Jack's Angels Prayer

H. RES. 114

“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 FEBRUARY 8, 2019

Ms. SPEIER (for herself, Mr. JOYCE of Ohio, Mrs. DINGELL, Mr. STIVERS, Mr. RASKIN, Mr. SCHIFF, Mr. VELA, Mr. FITZPATRICK, Mr. SMITH of New Jersey, Ms. GABBARD, Mr. COHEN, Mr. MCCAUL, Mr. LANGEVIN, Ms. BROWNLEY of California, Mr. BUTTERFIELD, Mr. KELLY of Pennsylvania, Mr. SOTO, and Mr. CÁRDENAS) 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 age 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.