

In Support of the Senate Awareness Resolution for DIPG

DIPG ADVOCACY GROUP



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

April 12, 2019

DIPG Advocacy Group is a nationwide association of childhood cancer advocates and parent-led foundations representing constituents in your state asking for your support of the DIPG Awareness Resolution, tentatively planned for Senate introduction in May by Senator Marco Rubio (R-FL) with Senator Jack Reed (D-RI). With growing support through the 114th and 115th Congresses, and an introduction in the House of Representatives on Feb. 8, 2019 by Jackie Speier (D-CA-14) and David Joyce (R-OH-14) amid 17 original cosponsors (now 30), this Resolution is a manifestation of the desire for more public accountability regarding pediatric cancer which is grossly underfunded in our medical research system. In 2018, thirty-one states have joined in recognizing May 17 (community consensus) as DIPG Awareness Day with more to follow. Why DIPG; why is it important?

In a powerful way, DIPG exemplifies the marginalization of pediatric cancers and subsequent chronic lack of adequate research funding for them, from both public and private funding sources. *Diffuse intrinsic pontine glioma* is responsible for the majority of childhood deaths due to brain cancer which is the leading disease-related cause of death in children in the US, yet neither terminal prognosis nor standard treatment for DIPG have changed since 1962 when Neil Armstrong's daughter died of it. I lost my 3 year old son Jack to DIPG in 2012, and I made it my mission to change what I heard about the value of my son's life with regard to our current US medical research industry: "the numbers aren't great enough for investors." Yet, as with the rather cool reception of the brilliantly crafted movie "First Man", no one likes to think about kids dying from cancer, or grieving parents; it's an uphill battle for awareness, and bereaved parents are burdened with the task of funding the research.

Not only would the designated day (May 17) in Brain Tumor Awareness Month help our foundations raise more funds for research, but it would draw attention to an issue for which parents have been asking for national conversation repeatedly over recent years to no avail: the general inadequacy of our medical research system to address the urgent needs of children with cancer. Amid proposed budget cuts to NCI, the significance of President's Childhood Cancer Initiative is doubtful; without greater public awareness, advocates will continue to fight for allocations for childhood cancer legislation which ought to be a matter of course without question.

Thank you for your consideration in support of this simple Resolution which has the potential to bring healing to our community through acknowledgement, support for new and recent childhood cancer initiatives and legislation, and greater transparency with regard to United States priorities in medical research. Parents have been repeatedly dismissed in our demands for a national conversation about the lack of funding for pediatric cancer research, especially with respect to our government resources. For decades these children have suffered horrible deaths, and their families, unspoken tragedy; it's time to shed light on this place of darkness in our society, that our children, too, might have hope for a cure. Please help make 2019 a Godsend year for the childhood cancer community, and support DIPG Awareness Day.

In honor of Karen Armstrong, **this is our #Moonshot4kids.**

Respectfully yours,

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For Senate Preview – Not Final Version

Text for 2019 Senate DIPG Awareness Resolution is not yet finalized, but it's based upon the following:

116TH CONGRESS 1ST SESSION *—one page version*

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.



31 STATES: MAY 17TH IS DIPG AWARENESS DAY

Governors in the States of Alabama, Arkansas, Arizona, Florida, Georgia, Hawaii, Idaho, Illinois, Indiana, Iowa, Kansas, Kentucky, Louisiana, Maryland, Massachusetts, Michigan, Mississippi, Missouri, Nebraska, Nevada, New Jersey, Ohio, North Carolina, Pennsylvania, Rhode Island, South Carolina, Tennessee, Texas, Virginia, Washington, and Wisconsin issued Proclamations establishing DIPG Awareness Day as May 17, 2018. In California, Mississippi, Nebraska, and Rhode Island, DIPG Awareness Day was established through the legislature. Four additional states still have requests under consideration. California was the first state to have a DIPG Awareness Resolution in 2014.*



53 cosponsors and counting...

The 115th Congress H. Res. 69 gained 53 cosponsors and 116th Congress H. Res. 114 had 19 at the Introduction, with pledges for more. 2019 is the 50th Anniversary of the Moonwalk, and the Senate is preparing a similar Resolution for a vote in May 2019.

CONFERRING EXPERTS OF H. RES. 114

Conferring experts 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 H.Res.114. Both scientists have laboratories dedicated to research in pediatric neuro-oncology with an emphasis on DIPG, diffuse intrinsic pontine glioma.

Supportive Research Institutions and Foundations



THE CURE STARTS NOW®



The Cure Starts Now Foundation, National Brain Tumor Society, Pediatric Brain Tumor Foundation, The Alliance for Childhood Cancer, **Oncology Nursing Society**, National Children's Cancer Consortium (NC3), **Julia Barbara Foundation**, **Michael Mosier Defeat DIPG Foundation**, Aiden's Avengers, ChadTough Foundation, The Children's Cause for Cancer Advocacy, Coalition Against Childhood Cancer, Lily LaRue Foundation
Jack's Angels 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 Tissue Consortium