

# H. RES. 114 #MOONSHOT4KIDS

## DIPG ADVOCACY GROUP



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*To the Honorable Members of the US House of Representatives, and Staff: June 17, 2019*

DIPG Advocacy Group is a nationwide association of childhood cancer advocates and parent-led foundations representing constituents in your state and district, writing to you in support of the DIPG Awareness Resolution, H. Res. 114, introduced on Feb. 8, 2019 by Representative Jackie Speier (D-CA-14) and David Joyce (R-OH-14) amid 17 original cosponsors (now 42). This Resolution represents, in part, the desire for accountability regarding pediatric cancer research which has been underfunded, historically, in the medical research industry. The first DIPG Awareness Resolution was in 2014 in California; in 2018 and 2019, over 30 more states have recognized May 17 (community consensus) as DIPG Awareness Day. Why single out DIPG; why is it important?

DIPG exemplifies in a powerful way the marginalization of and chronic lack of adequate research funding for most pediatric cancers, from both the government and private sector. *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. To this day it is not unusual for parents to hear there are no solutions for their child because, "the numbers aren't great enough for investors." Due to the utter lack of hope for children with DIPG at diagnosis, and the torturous experience of watching ones child die in utter helplessness, DIPG parents have been uniquely driven childhood cancer activists, foundation leaders, and research fundraisers. 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 have been 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 facilitate a ***national conversation*** for an issue which parents have asked for 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 considering cosponsoring this simple Resolution bringing leadership and hope to a global problem. Advocates have been repeatedly dismissed in vying for a national conversation about the lack of funding for pediatric cancer, especially brain cancer and DIPG for which we have no solutions. For decades these families have suffered 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 2020 a Godsend year for the childhood cancer community, and support DIPG Awareness Day. In honor of Karen Armstrong, **This is our #Moonshot4kids.**

*--For your convenience, we've included a link to the description of the 114th Congress Republican House Rules Convention Protocol 7 of Rule 28, regarding the cases where resolutions designating a specific day qualify for scheduling a vote with suspension of rules: <http://bit.ly/p7-rule28> (case sensitive)*

Respectfully yours,

Janet Demeter, Elizabeth Psar  
**DIPG Advocacy Group Leaders**  
(contact info at page-top)  
[www.dipgadvocacy.org](http://www.dipgadvocacy.org)



RESOLUTION TEXT  
[www.bit.ly/hres114-txt](http://www.bit.ly/hres114-txt)

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## IN 2019, 32 STATES UPHOLD MAY 17<sup>TH</sup> AS DIPG AWARENESS DAY

*Governors in the States of Alabama, Arizona, California\*, Colorado, Florida, Georgia, Hawaii, Indiana, Illinois\*\*, Indiana, Iowa, Kansas, Kentucky, Louisiana\*\*, Maryland, Massachusetts, Michigan, Mississippi, Missouri, Nebraska, Nevada, New Jersey, North Carolina, Ohio\*\*, Pennsylvania, Rhode Island, South Carolina, Tennessee, Texas\*\*, Virginia, Washington, and Wisconsin issued Proclamations establishing DIPG Awareness Day as May 17, 2019. 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 2019, THE U.S. SENATE PASSES S. RES. 223 ACKNOWLEDGING MAY 17 AS NATIONAL DIPG PEDIATRIC BRAIN CANCER AWARENESS DAY!

DIPG ADVOCACY GROUP



**H. Res. 114 was introduced 2/8/2019 with 17 original cosponsors, 43 cosponsors as of 6/17/2019:**

Brownley, Julia [D-CA26], Butterfield, George "G.K." [D-NC1], Cárdenas, Tony [D-CA29], Cohen, Steve [D-TN9] Dingell, Debbie [D-MI12], Fitzpatrick, Brian [R-PA1], Gabbard, Tulsi [D-HI2], Joyce, David [R-OH14], Kelly, Mike [R-PA16], Langevin, James "Jim" [D-RI2], McCaul, Michael [R-TX10], Raskin, Jamie [D-MD8], Schiff, Adam [D-CA28], Smith, Christopher "Chris" [R-NJ4], Soto, Darren [D-FL9], Stivers, Steve [R-OH15], Vela, Filemon [D-TX34], Higgins, Brian [D-NY26], Lipinski, Daniel [D-IL3], Lynch, Stephen [D-MA8], Tonko, Paul [D-NY20], Boyle, Brendan [D-PA2], Gallego, Ruben [D-AZ7], Napolitano, Grace [D-CA32], Rush, Bobby [D-IL1], Hill, Katie [D-CA25], Collins, Chris [R-NY27], McMorris Rodgers, Cathy [R-WA5], Waters, Maxine [D-CA43], Cisneros, Gilbert [D-CA39], Moulton, Seth [D-MA6], Flores, Bill [R-TX17], Meeks, Gregory [D-NY5], Wilson, Joe [R-SC2], Duncan, Jeff [R-SC3], Crow, Jason [D-CO6], Pappas, Chris [D-NH1], Calvert, Ken [R-CA42], Watkins, Steven [R-KS2], Johnson, Henry "Hank" [D-GA4], Norman, Ralph [R-SC5], Sherman, Brad [D-CA30], Grijalva, Raúl [D-AZ3]

### 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

## **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.