H. RES. 114 #MOONSHOT4KIDS

DIPG ADVOCACY GROUP
Lend a hand ...share a heart!

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To the Honorable Members of the US House of Representatives, and Staff: September 3, 2019

H. Res. 114, the National DIPG Awareness Resolution, represents the hope of parents across the United States that Congress will help us raise greater public awareness to the unmet needs of children with cancer. Using the case of DIPG, the 2nd most common pediatric brain cancer, it is remarkable that, although it is responsible for a significant portion of childhood cancer deaths annually, and brain cancer is #1 killer of children with cancer, it tragically remains one of the least-funded areas of cancer research. The first DIPG Awareness Resolution was in the California Legislature in 2014. In 2019, over 32 more states have recognized May 17 as DIPG Awareness Day. And so, why DIPG; why is it important?

DIPG, *diffuse intrinsic pontine glioma*, exemplifies in a powerful way the marginalization of and chronic lack of adequate research funding for pediatric cancers, on the part of the government and the private sector. Neither terminal prognosis nor standard treatment for DIPG have changed since 1962 when Neil Armstrong's daughter died of it. Despite the recent passage of the STAR Act (10 years after the signing of its failed precursor), the RACE Act, 21st Century Cures Act, and the Creating Hope Act, less than 4% of the National Cancer Institute budget for research has been designated for all childhood cancers combined *in any given year over the last decade*. The truth is, the experiential status quo has not changed for us. The battle for awareness continues, and bereaved parents must shoulder the burden of funding the research.

Not only would the designated awareness day, May 17, in Brain Tumor Awareness Month help parent-led foundations with fundraising, it would encourage national conversation for which parents have asked repeatedly over recent years for this issue: **the general inadequacy of the medical research system to provide viable treatments for children with cancer.** To this day it is not unusual for parents to hear that there are no solutions for their child with DIPG because, "the numbers aren't great enough for investors," in the wealthiest country in the world boasting the greatest technologies. DIPG children walk bravely toward their death as their bodies decline, in full awareness of what is happening to them in most cases, as their parents must witness this in utter helplessness.

Furthermore, amid new proposed budget cuts to NCI, the effectiveness of President's Childhood Cancer Initiative is uncertain at best. What is certain however, is that without greater public awareness, advocates will continue to fight over and over again for allocations for childhood cancer legislation which ought to be a matter of course without question—a "no-brainer." Yet, in reality, our "ask" has been dismissed by several lawmakers offices with excuses as to why Congress can't honor our request—constituent requests—to help raise public awareness to this problem.

We heartily thank you for your consideration of support for this House Resolution, which brings hope to afflicted children and their families everywhere. For decades, we 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 support H. Res. 114.
In honor of so many of our children who have faced untimely death with no hope, for all children facing a death sentence today whether from DIPG or other deadly cancer, let this be our #Moonshot4kids.

Respectfully yours,

Janet Demeter, Elizabeth Psar, Paul Miller
DIPG Advocacy Group Leaders
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#Moonshot4Kids
The DIPG Awareness
May 17
Resolution H. Res. 114
2020

RESOLUTION TEXT ONLINE
www.bit.ly/hres114-txt

H. Res. 114 correspondence:
Emily Small, 202-225-3531
Legislative Assistant, Rep. Jackie Speier
Emily.Small@mail.house.gov

April 15, 2019

The Honorable Frank Pallone, Jr.
Chairman
Committee on Energy & Commerce
2107 Rayburn House Office Building
Washington, DC 20515

The Honorable Greg Walden
Ranking Member
Committee on Energy & Commerce
2185 Rayburn House Office Building
Washington, DC 20515

Dear Chairman Pallone and Ranking Member Walden,

The undersigned childhood cancer organizations are members of the Alliance for Childhood Cancer, consisting of patient advocacy groups, healthcare professionals and scientific organizations, representing millions of Americans who care deeply about childhood cancer. We write in support of House Resolution 114, which would designate May 17th as "DIPG Awareness Day" to raise awareness and encourage research into cures for diffuse intrinsic pontine glioma (DIPG) and pediatric cancers in general.

Diffuse Intrinsic Pontine Glioma is the leading cause of childhood brain tumor deaths. Every year, 200-400 children in the U.S. will be diagnosed with DIPG, and most of them will only survive nine months, or about as long as the typical school year. There is currently no consistent standard of care for these kids, and few treatments.

The House resolution designating a DIPG Awareness Day would help spread awareness about this deadly disease, and support researchers in their efforts to find new therapies to treat DIPG. In addition, the resolution proposes that private and public research funding "elevate the consideration of the mortality rate of a type of cancer" to ensure that research is funded to find treatments for those with the most challenging diseases.

While all childhood cancer is devastating, DIPG is a particularly terrible disease that leaves children and their families with limited options and limited time. We urge you to pass this resolution to honor those children whose lives have been lost, and to encourage additional research to give hope for children diagnosed in the future.

Sincerely,

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

CC: Members of Congress

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 aver- age of male and female life expectancy from that median age, 300 × 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.

National DIPG
May 17
Awareness Day
#Moonshot4Kids

IN 2019, 32 STATES UPHOLD MAY 17TH 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
Lend a hand ...share a heart!

Jack's Angels
jacksangels.org

Fighting to Cure DIPG
The Julia Barbara Foundation

Cannonballs for Kayne

Michael Mosier Defeat DIPG Foundation

Lily LaRue Foundation

H. Res. 114 was introduced 2/8/2019 with 17 original cosponsors, 47 cosponsors as of 6/25/2019:

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], Bergman, Jack [R-MI1], Neguse, Joe [D-CO2], King, Peter “Pete” [R-NY2] , Marshall, Roger [R-KS1]

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

CBTTC
Children's Brain Tumor Tissue Consortium

DIPG COLLABORATIVE

Pacific Pediatric Neuro-Oncology Consortium

children's cause cancer advocacy
The Voice of Children with Cancer

Children's Brain Tumor Project
powered by families

Children's Cancer Therapy Development Institute

ONS
Oncology Nursing Society

THE CURE STARTS NOW®

the ChadTough foundation

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