Seeking Member Support for the Recognition of Children Fighting Brain Cancer:

H. Res. 404, The National DIPG Awareness Resolution

May 3, 2022

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

Thank you for taking a moment to consider this issue amidst the extreme urgencies of the day, particularly the war in Ukraine. H. Res. 404 brings needed public awareness to a long-fought invisible war, killing our children. The DIPG Awareness Resolution was first introduced in 2016 to draw attention to the urgent, unmet needs of children with brain cancer, the leading cause of cancer-related childhood mortality in the United States. The devastation of DIPG, *diffuse intrinsic pontine glioma*, a literal death sentence, is a powerful example of what our children and their families are expected to endure amid a medical research investment culture which does not prioritize children or the dying.

Cancer is the #1 cause of disease-related death in children in our country, yet childhood cancer remains poorly funded for research into cures. As such, DIPG Advocacy Group is committed to achieving Congressional recognition for DIPG as an ambassador for childhood cancer. As most don't realize that there is this real-life monster DIPG that kills most every child it attacks, H. Res. 404 is a unique opportunity for our Members of Congress to intervene for this unseen and voiceless population in urgent need of help where we parents remain helpless to save them or reduce their terrible suffering.

Here are a few lesser-known childhood brain cancer facts which are crucial to stronger national attention and support for childhood cancer research:

1. Brain tumors lead in childhood cancer incidence and deaths; DIPG is the 2nd most common, not rare, brain tumor in children, and is responsible for the majority of pediatric brain tumor deaths annually, a significant portion of the annual childhood cancer death toll. 2400 more children have been lost to DIPG alone since the resolution was first introduced.

2. The standard treatment protocol for DIPG is the same today as when Neil Armstrong's daughter died of it in 1962.
3. Parents routinely discover there are no solutions for their children because they aren't considered an "adequate investment incentive" in the wealthiest country in the world. Medical research investment for children is one area where our priorities as Americans are completely upside-down.

Why DIPG? The general public and Congress both need a concrete example of what our families endure, as the current narratives in national media sugar-coat the idea of childhood cancer. The horrific nature of the experience of DIPG and the multitude of deaths which continue out of sight, and out of mind, are an unseen national tragedy; this is truly a voiceless population. The families are most often too devastated to speak out, much less conceive of hopeful advocacy; we are asking for your help in lending your unique ability to bring national awareness to the suffering of these children, and, to set a precedent of caring for and acknowledgement of the value of our children's lives, in US Congress. 2500 more children have been lost to just this one tumor since the first introduction of the resolution on 1/13/2016.

With increased awareness for childhood brain cancer, we are confident that lives could be extended or saved with greater knowledge of the signs and symptoms, of which most parents, caregivers and many pediatricians are not educated. With awareness and education there would be less resistance from insurance companies to approving the definitive diagnostic tool (MRI), more financial support for research into cures, and accessible knowledge of possible experimental treatments for families of the newly diagnosed when a matter of days, even hours, can mean life or death.

We hope that you will join Congresswoman Dingell (D-MI-12), Congressman Joyce (R-OH-14) and the growing number of cosponsors of H. Res. 404 in recognizing the importance of children fighting this horrific death sentence in America and around the World. The public awareness generated by the ultimate recognition of the House of Representatives* will help save lives and set an important precedent for leadership in caring for our children as a society.

Finally, this acknowledgement would also allow the possibility for important, authorizing legislation** for research into

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*** H. R. 623, H. R. 2210, H. R. 5377, H. R. 5416, increased support for NIH, for recalcitrant cancers, for Cures II, allocations for the Childhood Cancer STAR Act are all crucial for pediatric disease research and treatment access.*

cures, access to treatment, and caring for the unique needs of survivors of childhood disease to be met with expedience, rather than resistance and excessive compromise. For more information, please contact Timothy Huebner with Congresswoman Dingell's office for more information, or to support with your signature:

Timothy.Huebner@mail.house.gov, 202-225-4071. On the Republican side, contact Will Mascaro with Congressman David Joyce's office (OH-14), will.mascaro@mail.house.gov, 202-225-5731. Thank you for your kind consideration.

Respectfully yours,

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https://DIPGadvocacy.org

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

Janet Demeter, *Organizer;* President, Jack's Angels, Agua Dulce, CA
Paul Miller, *co-Founder*, Childhood Cancer Advocate, Littleton, CO
Marcelo Ramalho-Ortigao PhD, Science and Medical Advisor, Fort Collins, CO

*On Commemoratives:

We submit that our request for the consideration of H. Res. 404 under the current exception protocol under House Rule XII, clause 5, related to the prohibition on scheduling legislation that is commemorative in nature, is legitimate with respect for the need to conserve floor-time in the People's House for matters of import to the American People.

As such, we respectfully request that children with cancer and other deadly disease neglected for research be considered a matter of import to the House of Representatives.

https://www.majorityleader.gov/content/117th-congress-legislative-protocols

1) Commemoratives

Purpose

This protocol is meant to provide further guidance on House Rule XII, clause 5, related to the prohibition on scheduling legislation that is commemorative in nature.

Protocol

The Majority Leader shall not schedule any bill or resolution for consideration that expresses appreciation, commends, congratulates, celebrates, recognizes the accomplishments of, or celebrates the anniversary of, an entity, event, group, individual, institution, team or government program; or acknowledges or recognizes a period of time.

A resolution of bereavement, or condemnation, or which calls on others to take a particular action, is eligible to be scheduled for consideration.

Other documents in this pdf:
Endorsements for the National DIPG Awareness Resolution
H. Res. 404 Text

Jack's Angels
jacksangels.org

National DIPG
May 17
Awareness Day
#Moonshot4Kids

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 the United States Congress.

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

Jack's Angels Prayer

117TH CONGRESS 1ST SESSION

H. RES. 404

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

MAY 17, 2021

Mrs. DINGELL (for herself, Mr. JOYCE of Ohio, Mr. BUTTERFIELD, Mr. CLEAVER, Ms. SPEIER, Mr. BLUMENAUER, Mr. COHEN, Ms. WILLIAMS of Georgia, Mr. LEVIN of Michigan, Ms. DEAN, Mr. DEUTCH, Ms. PIN- GREE, Mr. LAMALFA, Ms. SALAZAR, Mr. CONNOLLY, Mr. VELA, Mr. RUTHERFORD, Mrs. WALORSKI, Mr. LAMB, Mr. RUSH, Mr. LONG, and Mr. WALTZ) 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 cer-tain 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 ex- pectancy, 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 annu- ally);

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 sys-tem in designating sufficient research funding for pediatric cancers;

(3) supports expanded research to better understand DIPG, develop effective treatments, and pro- vide comprehensive care for children with DIPG and their families; and

(4) encourages public and private sources of re- search 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.

~Overwhelming Support for the National DIPG Awareness Resolution in the USA~

National DIPG
May 17
Awareness Day
#Moonshot4Kids

In 2019, 32 STATES uphold May 17th AS DIPG Awareness Day

The states of Alabama, Arizona, California, Colorado, Florida, Georgia, Hawaii, Indiana, Illinois**, 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. Despite Covid-19,* ***Oregon and Idaho** joined this list in 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 217 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 the U.S. Senate unanimously passes S. Res. 223, S. Res. 587, S. Res. 231 recognizing 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 this resolution, which has received 3 passages of Unanimous Consent from the United States Senate.

CONFERRING EXPERTS OF THE NATIONAL DIPG AWARENESS RESOLUTION

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 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

ChadTough Defeat DIPG Foundation
Children's Brain Tumor Project powered by families
ONS Oncology Nursing Society
Pacific Pediatric Neuro-Oncology Consortium
Children's Brain Tumor Network Until every child is cured
children's cancer cause
National Brain Tumor Society
Smashing Walnuts Cracking The Cure for Childhood Brain Cancer
St. Baldrick's FOUNDATION Conquer Childhood Cancers
Cannonballs for Kayne.org
Jack's Angels jacksangels.org
CLF CARSON LESLIE FOUNDATION helping kids fight cancer
Support Childhood Brain Cancer Awareness The Kortney Rose Foundation
MUSELLA FOUNDATION FOR BRAIN TUMOR RESEARCH & INFORMATION, INC
#cureMEdullo powered by Carson Leslie Foundation
DIPG COLLABORATIVE
PCRF Pediatric Cancer Research Foundation
#warriorjace Live.Like.Jace. Warrior Jace Foundation Jace Kinley Thompson
Children's Cancer Therapy Development Institute
Lily LaRue Foundation
THE CURE STARTS NOW®

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*

Philanthropic and Scientific Organizations and Institutions: Smashing Walnuts Foundation, The Kortney Rose Foundation, Oncology Nursing Society, Michael Mosier Defeat DIPG Foundation, Aiden's Avengers, ChadTough Foundation, 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

DIPG Advocacy Group | dipgadvocacy.org | Janet Demeter, Organizer | 818-400-2724 | jacksangels1@gmail.com | Jack's Angels Inc | Santa Clarita, CA