

DIPG ADVOCACY GROUP

Janet Demeter, Organizer
Elizabeth Psar, Co-Founder
Paul Miller, Co-Founder
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dipgadvocacy.org

November 17, 2020

Re: Consideration for Scheduling Eligibility for H. Res. 114; *the subject-worthiness of children afflicted with the deadliest cancer known to humankind, as reasonable cause for exception*

To The Leadership of the U. S. House of Representatives,

The Honorable Nancy Pelosi, Speaker of the House (CA-12),
The Honorable Steny Hoyer, Majority Leader (MD-5),
The Honorable Kevin McCarthy, Minority Leader (CA-23),
The Honorable James Clyburn, Majority Whip (SC-6), and
The Honorable Steve Scalise, Minority Whip (LA-1):



As we approach the end of 2020, the 116th Congress, and our 5th year of advocating for the National DIPG Awareness Resolution designated H. Res. 114, nearly 2000 more innocent children have endured a horrific, terrifying death since its first introduction. Our fledgling group of bereaved parents have managed to alert nearly ½ of the Membership of the House of Representatives to the deadly prevalence, not rarity, in the childhood cancer space of brain tumors like DIPG. Brain cancer is the #1 cause of death in children with cancer, and DIPG is responsible for the majority of brain tumor deaths in children, representing on its own a significant portion of the annual childhood cancer death toll. We desperately need help. There is nowhere in the world you can go to save your child from DIPG.

The main reason we need you to allow consideration for H. Res. 114, is the incredible cruelty of the deaths these children endure, and for the families who must witness this tragedy in complete helplessness. 95% of the funding for research is provided by parents, because, as we are so often told, our children don't represent a worthy investment incentive. In the wealthiest country in the world, we discover that our children's lives and the suffering that they endure simply don't matter to the system in place. This is an unacceptable reality in our Great Country. Also, many childhood brain tumors are diagnosed late or at autopsy due to lack of awareness of their signs and symptoms; respected doctors are often met with resistance from insurance companies for the appropriate diagnostics. With greater awareness, we could help save lives today.

Children with cancer have been falling through the cracks of a profit-dominated medical research investment culture for decades. Change is slowly coming to the field but it is embarrassingly inadequate in the most technologically advanced country in the world. And why is that? People do not know that our research system does not prioritize children or the dying. With the DIPG Awareness Resolution, we are asking for your help in sounding the alarm, attracting financial and scientific resources to the field until we can find more impactful legislative pathways. It suggests that we do prioritize children and the dying, and that, "Federal funding for research for pediatric cancer should be increased to address the level of unmet medical need for this vulnerable population." We call H. Res. 114 our Moonshot4Kids, as there's been no change in the standard treatment or prognosis for DIPG since 1962, when tragically, Neil Armstrong's 2-year-old daughter Karen succumbed to the disease.

One of our greatest champions, and an original cosponsor of H. Res. 114, Congressman G. K. Butterfield (NC-1), recently fought long and hard in the Energy and Commerce Committee to ensure that The Creating Hope Act at least had four more years, as it didn't get permanent installation. The modest allocations in the STAR Act so hard fought, omitted GAO oversight, the fact that the Creating Hope Act of 2019 couldn't be fully implemented; these would be unthinkable if there were greater awareness of the urgent, unmet needs of America's children with cancer. By singling out DIPG in an awareness resolution we are using its horrifying powers for good, as it is

difficult to raise awareness for a problem without a concrete example for the average person to inspect. The larger problem of inadequate treatments for children with cancer is powerfully illustrated by DIPG in H. Res. 114.

Finally, whether or not these children represent a great enough cause for exception to the restrictions on commemorative resolutions is seemingly the greatest challenge to gaining the recognition of House leadership, with whom a decision would ultimately rest. The back-and-forth direction we have received from your staff to go, “ask Committee Leadership,” and then vice versa, knowing all-the-while the futility of this exercise, is an unacceptable way of handling this issue concerning hundreds of innocent children in the United States currently facing a horrific death. The current legislative protocol[1] for allowing an exception, were it officially consulted, would within any reasonable interpretation allow a pathway forward for H. Res. 114 to be considered for scheduling.

We The People are asking for an exception for children fighting DIPG/brain cancer, from the leadership of the House of Representatives, consecrated to serve our interests, not special interests. We do this with optimism and belief in our representative democracy, as we lend our voice to countless lives gone, and countless parents grieving. At a time of political unrest and cynicism, we submit to you that your attention to our plea is affirming and reassuring of our ideals as Americans. Thank you for hearing our plea. God bless you, God bless our children, and God bless the United States of America.

Very truly yours,



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#Moonshot4Kids



[1] “A resolution of bereavement, or condemnation, or which calls on others to take a particular action, is eligible to be scheduled for consideration.” <https://www.majorityleader.gov/content/116th-congress-legislative-protocols>



Jack's Angels Prayer: "May Light and Hope one day replace Darkness and Despair for DIPG children and their families"



1,389 childhood cancer advocates
and organizations signed onto the
July 31 letter, online at
dipgadvocacy.org.

Supportive research organizations and foundations:

Smashing Walnuts Foundation,
The Kortney Rose Foundation,
Pediatric Brain Tumor Foundation
The Alliance for Childhood Cancer,
Oncology Nursing Society,
Julia Barbara Foundation,
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;

Supporters of H. Res. 114:

Support Letter, The Alliance for Childhood Cancer, 4/19/2019:

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

Joint Statement of Experts signed October 8, 2019

Dr. Maryam Fouladi, Professor of Clinical Pediatrics Medical
Director, Brain Tumor Center Chair, CONNECT Collaborative,
Cincinnati Children's Hospital
Dr. Charles Keller, Scientific Director, Children's Cancer Therapy
Development Institute
Dr. Sabine Mueller, PNO leading scientist, UCSF adjunct,
Children's Hospital Zurich, DIPG Centre of Excellence
Dr. Mark Souweidane, Director of Pediatric Neurosurgery,
Weill Cornell Medical College and Sloan-Kettering Memorial
Cancer Center, New York NY
Dr. Michelle Monje, Associate Professor of Neurology
and by courtesy, of Pediatrics, Pathology, Neurosurgery and
Psychiatry, Stanford University
Javad Nazarian, PhD
Associate Professor of Pediatrics,
The George Washington University,
School of Medicine and Health Sciences
Children's National Medical Center, Washington, DC. Head,
DIPG Research Institute
University Children's Hospital, Zurich Switzerland
Dr. Adam Green, Assistant Professor of Pediatrics University of
Colorado School of Medicine, Attending Physician in Neuro-
Oncology, Children's Hospital Colorado

The Children's Brain Tumor Project ,
Children's Cancer Therapy Development Institute,
Children's Brain Tumor Tissue Consortium,
MUSELLA Foundation for Brain Tumor Research,
Pacific Pediatric Neuro-Oncology Consortium,
McKenna Claire Foundation,
Childhood Cancer Talk Radio
4AydenStrong Foundation
Cannonballs for Kayne Foundation
#GoldTogether, The American Cancer Society
Children's Hospital of Philadelphia
Luke's Posse: DIPG Ends Now!
Students Supporting Brain Tumor Research
Why Not Devin Foundation to End DIPG
Ava's Army
PB&J Charity Spreading the Love
Colors for a Cause and teamdrakequibodeaux
The Max Cure Foundation
National Brain Tumor Society
Pediatric Brain Tumor Foundation
Salutation
Levi Harden Defeat DIPG Foundation
Emma Loves Dogs
TaterTough
Childhood Cancer Awareness Group of Coffee County
The Kortney Rose Foundation
Austin Strong Foundation
Brooke's Blossoming Hope for Childhood Cancer Foundation
Our Amazing Fighters
Warriorenguerrand.com
Gabiella's Smile Foundation
Fox Chapel Middle/ Hernando Cty. FL
Gamers for Children's Health

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.

To Congress, from Colleagues, Experts, Philanthropists, Parents, Patients

from Congressional Briefing 2/13/2020, 11am, 2168 Rayburn H.O.B.

“DIPG, Pediatric Brain Cancer, and the Importance of H. Res. 114”

Congresswoman Jackie Speier (D-CA-14)

“DIPG is a death sentence for children today, but it doesn’t have to be; this resolution is an important first step in securing the resources needed to develop better treatment options and find a cure.”*

Dr. Sabine Mueller (UCSF, Children’s University Hospital Zurich)

“As a community we have to continue to work together and advocate for families and children affected by this terrible disease – it always starts with awareness and this is why this resolution is so critical...I am hoping for your support for this so that there will be a day in the near future when I can say to families, ‘This used to be incurable...but we now have effective therapies.’”

Dr. Adam Resnick (CHOP)

“DIPG represents the beachhead from which our community can innovate on the required infrastructure, technologies and resources that will drive bold and much needed change in how discovery and impact can be newly empowered and coordinated across all pediatric cancer patient communities, academic institutions, companies, clinicians and investigators, bringing an end to the suffering of pediatric cancer patients and their families... But we need more hands in the fight, and awareness to the urgency of this need is the key to timely progress.”

Dr. Charles Keller (Children’s Cancer Therapy Development Institute)

“By drawing attention to...the urgent need for solutions for children with brain cancer, and DIPG, H. Res. 114 is a straightforward mechanism to stimulating conversation, innovation, and potential new cures.”

Josh Allen, Ph.D. (Oncoceutics)

“I call upon you to increase support for federally funded basic, translational, and clinical research for DIPG, as suggested by House Resolution 114. This will be critical... in doing everything that we can to help these patients live longer and better lives.”

Dr. Malcolm Smith (NCI/NIH)**

“For those who have lost a child to DIPG, I know that the discoveries we are supporting today are coming too late. Please know that my colleagues and I within NIH and those working throughout the country understand the urgency... to keep pushing this field forward as fast as we can.”

David Arons, JD (NBTS)

“If there were a stronger word than urgent, it should be applied to finding a cure to DIPG... We urge Congress to pass the DIPG Resolution, and elevate DIPG on the congressional priority list.”

Complete briefing synopsis with transcripts, and video access:
<https://dipgadvocacy.org/congressional-briefing>

Jace Ward (Pre-Law, Kansas State University, DIPG Patient)

“I can’t promise I’ll be back here next year. Which is exactly why I respectfully ask you to co-sponsor House Res. 114 before you leave for the weekend. DIPG won’t wait until this is convenient, DIPG won’t wait until we are ready. While we have been “waiting” to take a solid stand, DIPG has been taking the sight, the hearing, the speech, the ability to swallow and eventually the breath of thousands of kids across this country.”

Dr. Michelle Monje (Stanford University)

“Progress forward has come only from a collaborative effort...by those who have seen this disease...and could not turn away from this urgent, unmet need. How much larger the effort would be, how much quicker we would find effective therapies if more people were aware, and more people and resources joined us in this fight.”

Jenny Mosier (Michael Mosier Defeat DIPG Foundation, Bethesda MD)

“H. Res. 114 alone cannot stop this disease. But recognition by our federal government matters. By raising awareness of this disease, we will build a coalition of supporters who are rallying for our children. Official government recognition of the need for attention and funding for this disease is meaningful as we all work to increase the resources available for researchers.”

Elizabeth Psar (Julia Barbara Foundation, Knoxville TN)

“We can save lives today with this Awareness Resolution. Please decide that these children facing certain and probable death are a strong enough case for an Awareness Day.”

Jill Morin (Luke’s Posse, Denver CO)

“Are we the country where people just look the other way? These are our children. Please recognize the urgent need for help and support H. Res. 114; that is something you CAN do to help. Thank you.”

Janet Demeter, DIPG Advocacy Group (Jack’s Angels, Agua Dulce, CA)

“H. Res. 114 is a plea to our Representatives in Congress for help; it challenges the world to be aware of this deadly killer of children and know DIPG by name, and to inspire the collaboration of resources toward its cure. With a simple signature, you have the power to attach ‘hope’ to pediatric brain cancer; you have the power to help! We hope with all our hearts and minds that you do.”

*Feb. 8, 2019, official press release for H. Res. 114

***As a federal employee, Dr. Smith is not able to take a position on H.Res. 114. He provided here an update on research supported by the National Cancer Institute and the National Institutes of Health to advance much needed progress for children with DIPG and their families.*



Briefing synopsis of transcripts, outlines, and video record can be found at <https://dipgadvocacy.org/congressional-briefing/>