

#Moonshot4Kids Letter to Congress, H. Res. 114 Text, and Evidence of National Support

DIPG ADVOCACY GROUP



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

March 12, 2020

As we begin the 2020 decade, roughly another 1600 more children have died from DIPG alone since the first introduction of the DIPG Awareness Resolution in January of 2016; DIPG represents a significant portion of the childhood cancer death toll. The Resolution was introduced to this Congress on Feb. 8, 2019, as H. Res. 114 by Jackie Speier (CA-14) and David Joyce (OH-14) amid 17 cosponsors; as of March 10, there are 101.

Although difficult, we are requesting your attention to the indescribable human suffering that has gone unnoticed in obscurity for decades, both for the children who must walk bravely toward their death in full cognitive awareness as their bodies decline, and for their loved ones who have no recourse but to witness this tragedy in utter helplessness because, as we so often hear, “the numbers aren’t great enough for investors,” in the wealthiest country in the world.

Despite its consistent death toll as the leading cause of disease-related childhood mortality in the US, pediatric brain cancer, of which DIPG (diffuse intrinsic pontine glioma) is the 2nd most common type and the deadliest, has seen no significant change in the standard treatment protocol nor prognosis of the worst variety since Neil Armstrong’s daughter died of it in 1962. It is inoperable with a less than 1% long-term survival-rate. DIPG exemplifies in a powerful way the challenges in treating pediatric cancer and the daily tragedies which ensue from the general lack of solutions our current medical research industry has for deadly pediatric disease.

Our nation’s leading experts in pediatric neuro-oncology have produced a joint statement, attached and signed for your convenience, attesting to the importance of DIPG awareness and research not only for its obvious humanitarian considerations, but to the relevance and benefits to our current frontiers of scientific research and genomic data-sharing. From the #Moonshot4Kids Congressional Briefing on 2/13/2020 in Rayburn, their statements of support for this resolution and pediatric brain cancer research are also included. Within a month of briefing conversations with NIH, PNOC and CBTTTC have created a novel, multi-institutional NCI/NIH SPORE grant proposal for pediatric brain cancer research.

Now in our 4th year of sharing the information about pediatric brain cancer, our success has been marginal with respect to the Members actually receiving it. We respectfully submit that in a representative democracy, consistent requests for consideration are worthy of at the very least a hearing, and that determination of the House Rules ought to consider the urgency of the requests—especially those representing our children, our most under-represented, vulnerable, and precious population. We hope that this letter, through staff, reaches the addressee.

H. Res. 114 is a plea to our Representatives in Congress for help; it is meant to shine a light on a very dark place where ignoring childhood deaths by cancer has been made acceptable, due to the marginalization of pediatric cancers which all have small patient populations and inadequate investment into research for cures. It creates awareness for doctors to know there are clinical trials worth trying as we seek to move hopeful treatments forward. Awareness gives parents of patients more knowledge at diagnosis concerning experimental research *when a matter of days can mean life or death*. Indeed, clinicians will be alerted to the common signs of brain cancer, increasing the chances of detection and survival; with greater awareness, we could save lives now.

Moreover with a simple signature of support you are providing the awesome power of hope, that one day the next child will not hear “you have DIPG” as their death sentence; those children fighting for their lives right now will know that we are fighting for them. We would challenge the world to know the name DIPG, to be aware of the deadly killer of children, pediatric brain cancer, and inspire the collaboration of resources toward its cure.

In 2019, thirty-two states recognized a May 17th DIPG Awareness Day, demonstrating a clear national desire for this recognition since the first DIPG Awareness Resolution in 2014 in the Great State of California. Exposing DIPG and the value of the research it represents opens opportunities for data-sharing, private and public funding for research and new clinical trials for treatment. It is no coincidence that breast cancer and leukemia deaths are on a steady decline after enjoying decades of national attention.

A final note in consideration on the importance of the House of Representatives to our democracy as we know it:

The Awareness Resolution represents a significant opportunity for needed communication between the American People and their Representatives in Congress, such that issues of urgent concern, otherwise unknown, be addressed and recognized by Congress and so the greater public; it provides a unifying measure by which America may lead in a world humanitarian effort. We pray that the wisdom of Representatives Jackie Speier (CA-14) and David Joyce (OH-14) in their introduction of this Resolution and the 101 current cosponsors, the many research institutions, private sector supporters and endorsements of H. Res. 114, will help you to choose to give this measure a full hearing.

Thank you for your consideration of H. Res. 114, which brings hope to afflicted children fighting for their lives, and their families, around the world. Help us lead and be a beacon of hope in the United States for pediatric brain cancer. In honor of so many of our children who have faced untimely death with no hope at all, and for all children facing a death sentence today whether from DIPG or other deadly disease, let this be our **#Moonshot4kids**.

Link to 2-13-2020 Briefing Synopsis: bit.ly/MS4K-synopsis (case sensitive)

In gratitude we remain
Respectfully yours,

DIPG Advocacy Group Leadership

Janet Demeter, Agua Dulce CA, Jack's Angels Inc

Elizabeth Psar, Knoxville TN, Julia Barbara Foundation

Paul Miller, Littleton CO, Childhood Cancer Advocate

Lisa Ward, Wamego, KS, Patient Advocate

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#Moonshot4Kids



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

-Jack's Angels Prayer

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. CARDENAS) 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 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.



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!



H. Res. 114 was introduced 2/8/2019 with 17 original cosponsors, 101 cosponsors as of 3/10/2020:

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-R12], 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], Blunt Rochester, Lisa [D-DE0], Hern, Kevin [R-OK1] (joined Sep 10, 2019), Axne, Cynthia [D-IA3], Cleaver, Emanuel [D-MO5], DelBene, Suzan [D-WA1], Foster, Bill [D-IL11], Perlmutter, Ed [D-CO7], Schrader, Kurt [D-OR5], Van Drew, Jefferson [D-NJ2], Waltz, Michael [R-FL6], Bonamici, Suzanne [D-OR1], Burchett, Tim [R-TN2] Matsui, Doris [D-CA6], Trahan, Lori [D-MA3], Gooden, Lance [R-TX5], DeGette, Diana [D-CO1], Schweikert, David [R-AZ6], Davids, Sharice [D-KS3], Kim, Andy [D-NJ3], Castor, Kathy [D-FL14], Walberg, Tim [R-MI7], Mast, Brian [R-FL18], DeFazio, Peter [D-OR4], Rutherford, John [R-FL4], Ryan, Tim [D-OH13], Velázquez, Nydia [D-NY7], Watson Coleman, Bonnie [D-NJ12], Williams, Roger [R-TX25], Correa, Luis [D-CA46], Hurd, Will [R-TX23], Scanlon, Mary [D-PA5], Suozzi, Thomas [D-NY3], Wittman, Robert [R-VA1], Comer, James [R-KY1], Trone, David [D-MD6], Hastings, Alcee [D-FL20], Kennedy, Joseph [D-MA4] Kirkpatrick, Ann [D-AZ2], Kuster, Ann [D-NH2], Rigglesman, Denver [R-VA5], Thompson, Glenn [R-PA15], Meuser, Daniel [R-PA9], Pingree, Chellie [D-ME1], Reschenthaler, Guy [R-PA14] Himes, James [D-CT4] Kildee, Daniel [D-MI5], Luria, Elaine [D-VA2], Sherrill, Mikie [D-NJ11], Wexton, Jennifer [D-VA10], Lamb, Conor [D-PA17], Murphy, Gregory [R-NC3], Beatty, Joyce [D-OH3], Lofgren, Zoe [D-CA19] Cunningham, Joe [D-SC1]

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



National Brain Tumor Society, **Smashing Walnuts Foundation**, The Kortney Rose Foundation, 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, Cincinnati Children's Hospital, The Cure Starts Now 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, MUSELLA Foundation for Brain Tumor Research

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.”

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.*

