

DIPG Advocacy Group Letter to Congress, H. Res. 114 Text, and Evidence of National Support

DIPG ADVOCACY GROUP



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October 28, 2019

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

Respectfully, we ask your support in joining the Senate and many state and local governments in recognizing National DIPG Awareness Day on May 17, and the importance of pediatric brain cancer awareness, the leading disease-related cause of childhood mortality in the US, through the passage of H. Res. 114. To this end, the DIPG Advocacy Group is an unincorporated association of pediatric brain cancer foundations and individual childhood cancer advocates formed for the sole purpose of supporting the DIPG Awareness Resolution, now eight months past its third introduction in Congress, as H. Res. 114. Roughly another 1200 more children have died from DIPG alone since the bill's first introduction in January of 2016. DIPG is the deadliest of all pediatric cancers and must be stopped.

First and foremost, 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 often hear, "the numbers aren't great enough for investors," in the wealthiest country in the world.

DIPG, *diffuse intrinsic pontine glioma*, is the 2nd most common pediatric brain cancer, and is the deadliest, responsible for the majority of pediatric brain cancer mortalities annually in the United States. It is inoperable and is highly resistant to chemotherapy. Most die within a year of diagnosis, and the long-term survival rate is less than 1%. Brain cancer leads in pediatric cancer incidence and pediatric mortality due to cancer in the US, and is one of the least funded areas of cancer research. H. Res. 114, also called our **#Moonshot4Kids**, suggests that pediatric and high mortality-rate cancers have greater consideration for research grants with government resources. There has been no change in the standard treatment for DIPG, radiation therapy and palliative care, since Neil Armstrong's daughter died of it in 1962. Clearly, we can and should do better for our children.

We feel it is imperative that our Representatives in Congress hear this message. Now in our 4th year of sharing information about the Resolution, office to office in the halls of the House Office Buildings, our success has been marginal with regard to the Membership actually consuming the information. Most who do receive it are supportive and sign-on, but some staff members do not transmit the information even when it includes constituent requests for support. Some assert that the House no longer "does awareness days," despite the 114th Congress' clearly noted Protocol 7 of Rule 28 from the Rules Conference which permits consideration in cases of bereavement and urgency such as this. We represent the bereaved, thousands of children who have died in recent years, and those fighting for their lives right now in real-time; it's improbable for us to attain the status of the larger cancer lobbies with boots on the ground. With wings in the air, H. Res. 114 is our plea to our Representatives in Congress for help.

This May 17, with House approval of H. Res. 114, our country would recognize National DIPG Awareness Day sanctioned by the House of Representatives and the Senate, which approved May 17 as National DIPG Pediatric Brain Cancer Awareness Day this year in S. Res. 223. In 2014, California was the first state to pass a DIPG Awareness Resolution through the legislature; in 2019, 32 of 50 states recognized a May 17th DIPG Awareness Day, demonstrating a growing national desire for this recognition. Through the awareness day activities, we will expose DIPG and catapult opportunities for sharing of data, private and public funding for research and 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.

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.

This House Resolution 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 oncologists to know there are clinical trials worth trying as we seek to move DIPG treatment forward. Awareness teaches parents and oncologists to consult DIPG centers of excellence for latest options; it gives parents of patients more knowledge from the date of diagnosis concerning experimental research. It exposes the helpless, financially draining path of families caring for DIPG children. It provides hope, that one day the next child will not hear "you have DIPG" as their death sentence. Finally, it challenges researchers to know the name DIPG and direct resources toward its cure.

On a final note in consideration of the importance of the House of Representatives to our democracy as we know it: this movement for a day for DIPG began in part as an experiment. One citizen wondered if her voice really mattered in our democracy as she was told countless times as she grew up, took government classes, and considered the theoretical nature of the relationship between citizens and our representatives in Congress. The Awareness Resolution in the House of Representatives is significant opportunity to honor that communication, such that issues of urgent concern, otherwise unknown, be addressed by the public. We sincerely hope that the wisdom of Representatives Jackie Speier (CA-14) and David Joyce (OH-14) in their introduction of this Resolution and the 66 other 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.

We heartily 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 cancer, let this be our **#Moonshot4kids**.

"People can't care if they're not aware."
--Aimee Dickie of Scranton, PA in 2009, forever 12.

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

Lisa Ward, Wamego KS, patient advocate (son Jace Ward in active treatment)

Paul Miller, Littleton CO, Childhood Cancer 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. 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.



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, 66 cosponsors as of 10/22/2019:

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], 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]

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 Foundation, National Brain Tumor Society, 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 **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