

Re: #Moonshot4Kids  
H. Res. 114  
The National DIPG  
Awareness Resolution



## DIPG ADVOCACY GROUP

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Aug. 14, 2020

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

As we began the year 2020, over 1600 more children had died from DIPG since the first introduction of the National DIPG Awareness Resolution in January of 2016. DIPG represents a significant portion (approx. 15%) of the annual 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 August 11, 2020, there are 141.

DIPG represents the hidden, untold story of childhood cancer, in a society informed mainly by commercials asserting that 80% of children survive cancer due to our success with certain types of leukemia. DIPG is not the success story which industry would like to promote, as it points to our failure in accommodating the most urgent needs of our most vulnerable populations; all childhood cancers are marginalized as rare and receive inadequate attention into cures. Our success in translating hopeful adult leukemia research into successful treatments for children does not represent an increase in investment into childhood cancer research, which many erroneously assert with those quoted statistics. The fact is, very little has changed for most children with cancer and their families.

Thus we are requesting your attention to the matter of pediatric brain cancer and DIPG due to the enormous suffering largely unseen and unheard in our society today. The urgent, unmet needs of children with DIPG have been systematically overlooked 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.

DIPG exemplifies in a powerful way the challenges in treating pediatric cancer in general, and the daily tragedies which ensue from the general lack of solutions our current medical research industry has for deadly pediatric disease. DIPG is inoperable with a less than 1% long-term survival-rate post 5 years, and is the 2nd most common pediatric brain cancer--the leading cause of cancer-related childhood mortality in the US. DIPG has seen no significant change in the standard treatment protocol nor prognosis of the worst variety since Neil Armstrong's 2 year-old daughter Karen died of it in 1962. Brain cancer leads in childhood cancer incidence, and childhood cancer deaths; this is not commonly understood public knowledge.

You may not have previously heard of DIPG because these children, mostly between the ages of 5 and 9 years old, are fighting for their lives and most all of them die; their parents are typically too devastated to conceive of hopeful advocacy. H. Res. 114 is a plea to Congress for help; it creates awareness for doctors to know there are clinical trials worth trying as we seek to move hopeful treatments forward. These children might be given treatment access priority during a pandemic when a few weeks delay can mean missing a life-saving opportunity. Awareness gives parents crucial knowledge at diagnosis concerning experimental research *when a matter of days can mean life or death*. Indeed, clinicians would be alerted to the common signs of brain cancer, increasing the chances of early detection, life-extension, and survival. Rather than detracting from **COVID-19**, H. Res. 114 supports the call to accommodate our most vulnerable citizens in most urgent need of help. The virus will come and go; DIPG will continue to kill our children with annual consistency.

Our nation's leading experts in pediatric neuro-oncology have attested the importance of DIPG awareness and research not only for its obvious humanitarian considerations, but its relevance to our current frontiers of scientific research and genomic data-sharing. At the recent #Moonshot4Kids Congressional Briefing in Rayburn on 2/13/2020, Dr. Adam Resnick (CHOP), leading scientist for CBTTTC spoke authoritatively to the fact that exposing DIPG and the value of pediatric brain cancer research opens new opportunities for systemic change in the way we share data, conduct research and fund new clinical trials for treatments. For reference, a link to a synopsis of the #Moonshot4Kids Briefing

follows below. More than 36 organizations, including PNOG, CBTTC, National Brain Tumor Society, St. Baldrick's Foundation, and the Alliance for Childhood Cancer membership, have lent their endorsements to H. Res. 114.

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

H. Res. 114 represents a significant opportunity for needed communication between the American people and their representatives in Congress, such that issues of urgent concern for our children, otherwise unknown, be addressed and recognized by Congress and so the greater public. It also provides a unifying measure by which America might lead in a humanitarian effort for children with cancer. We pray that the wisdom of Representatives Jackie Speier (CA-14) and David Joyce (OH-14) in their introduction of this Resolution and the 141 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 at least. And although the Resolution designates a day of awareness for DIPG, it fulfills the Majority Leader's current legislative protocol, "A resolution of bereavement, or condemnation, or which calls on others to take a particular action, is eligible to be scheduled for consideration." We believe our children with brain cancer, the leading disease-related cause of childhood mortality in our country, are worthy of this consideration.

The DIPG Awareness Resolution can bring hope and a sense of support to afflicted children in America fighting for their lives, and their families desperate for a cure, right now. 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](http://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  
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*"People can't care if they're not aware."  
--Aimee Dickie of Scranton, PA in 2009, forever 12*



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 US Congress.

*"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 17<sup>TH</sup> 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, & 2020, THE U.S. SENATE PASSES S. RES. 223, S. RES. 587 ACKNOWLEDGING MAY 17 AS NATIONAL DIPG PEDIATRIC BRAIN CANCER AWARENESS DAY!**



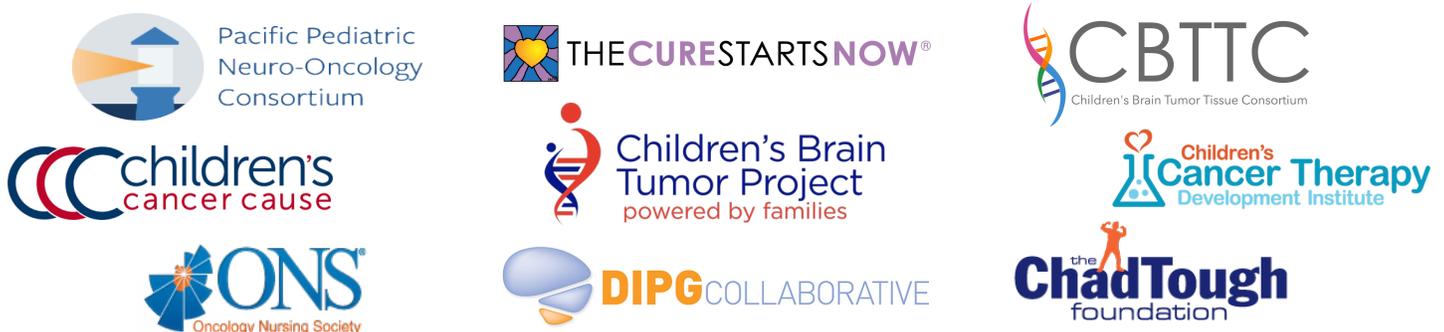
*In the House of Representatives, H. Res. 114 was introduced 2/8/2019 with 17 original cosponsors, 141 cosponsors as of 8/11/2020:*

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-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], 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], Suozi, 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], Riggleman, 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], Spano, Ross [R-FL15], Long, Billy [R-MO-7], Spano, Ross [R-FL-15], Barr, Andy [R-KY-6], Bilirakis, Gus M. [R-FL-12], Connolly, Gerald E. [D-VA-11], Biggs, Andy [R-AZ-5], Mucarsel-Powell, Debbie [D-FL-26], Walorski, Jackie [R-IN-2], Posey, Bill [R-FL-8] Lawson, Al [D-FL5], Shalala, Donna [D-FL27], Engel, Eliot [D-NY16], Taylor, Van [R-TX3], Deutch, Theodore [D-FL22], Diaz-Balart, Mario [R-FL25], Gomez, Jimmy [D-CA34], Garcia, Mike [R-CA25], Mullin, Markwayne [R-OK2], Clark, Katherine [D-MA5], Crist, Charlie [D-FL13], Hudson, Richard [R-NC8], Roby, Martha [R-AL2], Davis, Danny [D-IL7], Davis, Susan [D-CA53], Timmons, William [R-SC4], Levin, Andy [D-MI9], Luetkemeyer, Blaine [R-MO3], McCollum, Betty [D-MN4], Blumenauer, Earl [D-OR3], Hartzler, Vicky [R-MO4], Johnson, Mike [R-LA4], O'Halleran, Tom [D-AZ1], Gianforte, Greg [R-MT0], Gosar, Paul [R-AZ4], Murphy, Stephanie [D-FL7], Palazzo, Steven [R-MS4], Tipton, Scott [R-CO3], García, Jesús [D-IL4], Kilmer, Derek [D-WA6], Wilson, Frederica [D-FL24]

### 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. OVER 1000 CHILDHOOD CANCER ADVOCATES HAVE ENDORSED H. RES. 114*

### SUPPORTIVE RESEARCH INSTITUTIONS AND FOUNDATIONS



**Members, 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;

Smashing Walnuts Foundation, The Kortney Rose Foundation, 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, 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 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.*

