

DIPG ADVOCACY GROUP

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June 18, 2020

To The Leadership of the 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):

DIPG Advocacy Group and the undersigned organizations are asking for your attention to H. Res. 114, the DIPG Awareness Resolution, and thus to the leading disease-related cause of childhood mortality in the United States: pediatric brain cancer. After 4 years have passed and a third introduction, little has changed for these children. As we clearly outline below, little has changed for them in decades. By the end of this session of Congress and roughly 2000 more deaths from DIPG alone, we request that with a significant showing of bipartisan support for this Resolution you would allow giving it due consideration for a House vote by suspension of rules. From your unique position, we are calling upon your moral integrity as leaders of the House of Representatives, that body designated with the most direct source of representation for the American People by our US Constitution, to help us to raise greater national awareness to this hidden tragedy in American life, that the appropriate resources and creativity would be alerted to this urgent, unmet need in our society today.

Amid a barrage of commercials asserting that 80% of children survive cancer due to our success with certain types of leukemia, **DIPG is truly the hidden, untold story of childhood cancer.** Brain cancers lead in childhood cancer incidence and lead in childhood cancer deaths. DIPG, diffuse intrinsic pontine glioma, is the 2nd most common pediatric brain tumor and the leading cause of death in children afflicted with brain cancer, represents a significant portion of the annual childhood cancer death toll. There has been no change in its standard treatment protocol, nor its prognosis, since Neil Armstrong's daughter Karen died of it in 1962. You may not have heard of DIPG because most all of the children die and the families are devastated and not prone to hopeful advocacy. The few of us who can speak out, speak for countless others who cannot. We are asking for your help.

DIPG is not the success story people want to hear, but until we have more awareness of this tragedy in our society today, solutions for children with brain cancer will remain elusive; modest allocations for childhood cancer legislation will continue to be a fight for our advocates where there should be little question. Parents will continue to hear that there are no solutions for their children, as they helplessly witness their decline and death, because "the numbers aren't great enough for investors" in the wealthiest country in the world. By simply allowing this Resolution to move forward, you have the power to bring hope and to affect change, to help bring needed attention and resources to our scientists who need more support for this crucial, and valuable, research which now is funded almost entirely by parents who have already paid the ultimate price.

As Covid-19 exposes weaknesses in our system of health care, so pediatric brain cancer exposes the failure of our medical research investment system to address the urgent, unmet needs of our most vulnerable population--our children. In the past four years (114, 115, 116 Congress) of our bringing this message to Washington, there has **never been a convenient time** to consider the needs of children with DIPG brain cancer, and the terrible reality of their situation: while retaining full cognitive awareness, DIPG children lose control of their bodies--with some in great pain and neurological duress--as with tumor progression eventually respiration ceases. They are aware of their impending doom as their parents struggle to reckon with it, failing to provide solutions or feel adequate in guiding them to their end, though they try with all their might. This cruel experience has continued unchecked for decades, in obscurity and darkness; from diagnosis these children and their families have no hope. "Go make memories," parents routinely hear. It would be tragic still if this movement for awareness for childhood brain

cancer were to become another casualty of the pandemic when all we are asking for our children is a day of recognition, and greater awareness to this urgent, unmet need in our society today of our most vulnerable citizens, a motion which would only support, and not detract from other measures important to national interest in this time.

With national recognition and with the awesome power of the House of Representatives, there is hope of alerting needed resources, of inspiring the ingenuity and creativity of the world to help find solutions for our children facing certain or probable death. "Commemorative days" designated by the House were banned presumably due to overuse. H. Res. 114 is a clear case meeting the criteria used for previous exceptions made (115C, Protocol 7, Rule 28), and the humanitarian benefit is unquestionable; we submit to you that the original reasons for, and context of this ban with respect to this resolution, ought to be reviewed. We ask you in all earnestness, in making your decision whether to allow consideration for a vote, to please put the potential benefit to our children in the balance with this question: what possible harm could it bring? Please ask yourselves, as ones who truly value America's children, "which has more import to our citizens"--not to the current politics of the House, but to the American People it was consecrated to represent?

Thank you for your consideration for our children with DIPG, brain cancer and deadly disease neglected by the system in place. You do possess the power to bring hope to pediatric brain cancer with a simple nod of allowing. In a bipartisan way, 119 Members of the House of Representatives have signed on to H. Res. 114. Please allow our "Moonshot4Kids" a chance to bring hope and much needed attention to a dire situation, this Congress; we humbly ask. Thank you.

In gratitude we remain
Respectfully yours,

DIPG ADVOCACY GROUP

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#Moonshot4Kids



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The undersigned:

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,
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

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

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, & 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, 119 cosponsors as of 6/11/2020:



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], 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], 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]

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