# 2$^{nd}$ Hearing Request Letter, DIPG Advocacy Group

## For DIPG, Pediatric Brain Cancer, the Value of the Research and the Importance of H. Res. 114, the DIPG Awareness Resolution

**The Honorable Frank Pallone(NJ-9) Jr**.,
Chairman, Committee on Energy & Commerce
2107 Rayburn H. O. B., Washington DC, 20515

**The Honorable Anna Eshoo(CA-18)**, Chairman
Subcommittee on Health
202 Cannon H. O. B., Washington DC, 20515

**The Honorable Greg Walden(OR-2)**, Ranking
Member, Committee on Energy & Commerce
2185 Rayburn H. O. B., Washington DC, 20515

**The Honorable Michael Burgess, MD,** Ranking
Member, Subcommittee on Health
2336 Rayburn H. O. B., Washington DC, 20515

December 11, 2019

Dear Chairman Pallone, Ranking Member Walden, Chairman Eshoo, and Ranking Member Burgess,

Roughly 1200 more children have died of DIPG since the DIPG Awareness Resolution was first introduced to Congress in January of 2016, with no attention in Committee since; we are contacting you to request a hearing for Jace Ward of Wamego, KS, a 20-year-old pre-law student, who was diagnosed with DIPG on May 17 of 2019. Most children diagnosed are very young and do not survive a year past diagnosis, with treatment; we hope you will appreciate this unique opportunity to shed light on a tragic issue which has remained in obscurity for decades. DIPG is the deadliest of all pediatric cancers and must be stopped, exemplifying the larger problem of pediatric brain cancer in the US today.

The DIPG Advocacy Group is an unincorporated association of pediatric brain cancer foundations and individual childhood cancer advocates formed for the purpose of supporting the DIPG Awareness Resolution, now eight months past its third introduction in Congress, to this Committee, as H. Res. 114, by Jackie Speier (CA-14) and David Joyce(Oh-14) amid 17 cosponsors, currently at 68.

## BACKGROUND ON DIPG

DIPG, *diffuse intrinsic pontine glioma*, is a highly aggressive, inoperable brain tumor in the pons area of the brainstem, with a median survival time of 9 months post diagnosis, and long-term survival rate of less than 1%. Most sufferers are impacted without warning from age 5-9 on average, though children from birth to adult may be diagnosed.

Brain Cancer is the number one killer of all cancers in children. In turn, pediatric cancer takes the lives of more children annually than any other disease. DIPG, the worst of them all, is a horrific killer stealing first the child's use of his or her arms and legs, facial expression, eye sight, hearing, swallowing, speech and finally respiration and heartbeat, while they retain full cognitive awareness of their decline, to the witness of their loved ones in utter helplessness to save them. Over 300 children a year are diagnosed with DIPG. In this decade alone, 3000 children, or an average of 210,000 years of life will be lost to DIPG in the United States. H. Res. 114 suggests that the mortality rate and the years of life lost for a given cancer type receive greater consideration in the research grant process with private and public funding sources.

Standardized treatment has not changed since the 1960's when Neil Armstrong's daughter died of DIPG. We call the DIPG Awareness Resolution our #Moonshot4Kids; how is it that we can bring a man to the moon and back safely, and still only six weeks radiation and palliative care are standardly recommended for newly diagnosed DIPG victims? Hope is on the horizon as discoveries recently have been made, due to the concerted efforts in research funding by parent-led foundations, concerning the most aggressive DIPG mutation in 80% of DIPG tumors. This is good news, as leading neuro oncologists* have long held that if we can find a cure and methodology to deliver it for DIPG, its applications on delivery, immunology and research sharing will drive faster cures for all brain cancers and other deadly cancers.

Government exposure and action is urgently needed to facilitate more timely cures for this vulnerable population. The marketplace of privately funded Research and Development by pharmaceutics finds "the numbers aren't great enough for pharmaceutical investors to warrant strategies for DIPG." Thus, if we rely on the market to dictate cures, even in the wealthiest country in the world, DIPG will continue to torture our children indefinitely. With awareness, we can do better to direct research and bring a cure.

## THE TIME IS NOW TO EXPOSE DIPG

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 with 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 May 17th in this way, 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.

This House Resolution is made 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.

For four years, advocates supporting the DIPG Awareness Resolution have visited congressional offices in the halls of the House Office Buildings on Capitol Hill. More often than not, staff members receive the information and our appointment with varied receptivity. Some staffers assert that the House no longer "does awareness days," despite the 114th Congress clearly stated Protocol 7 of Rule 28 from the Rules Conference which permits consideration in cases of bereavement and urgency such as this. We will never attain the stature of larger cancer lobbies and advocacy groups with ample numbers of boots on the ground. With wings in the air, we represent the bereaved, the thousands of children who have died, and those currently struggling to stay alive.

During our September 2019 visit, we saw the impact Jace Ward, a 20-year-old victim of DIPG, had in focusing staff members close to him in age on the effects of DIPG on his life, in real-time. This sobering realization was also impactful as he continued on to speak to the NIH at a Symposium regarding patient access to genomic data, an event having broad influence and support from private sector companies, government researchers and policy makers who were hopeful to hear of our planned Hearing Request.

*It is an extremely rare opportunity to hear from a DIPG sufferer.* Most children are diagnosed with DIPG between the ages of 5 and 9 years old, and last an average of 9 months post diagnosis with treatment. Most families are far too shocked and terrified to consider hopeful advocacy. Jace was diagnosed seven months ago; his life expectancy ends one day before his 21st birthday on February 17, 2020. Upon hearing the diagnosis, Jace simply stated *"I'm not afraid to die, I'm afraid I won't have long enough to make an impact before I die."* To the NIH Symposium Jace stated, *"While we wait even one year deciding if awareness, shared data and research funding is important enough, 300 children are tortured by DIPG before dying. While we wait, DIPG won't wait. It won't wait to take my mobility, my sight, my speech and my life. DIPG won't wait!"* Therefore, we firmly believe Congress should hear firsthand from Jace and the urgent need for cures to DIPG as he is determined to beat the odds.

## REQUEST FOR COMMITTEE HEARING - PURPOSE

DIPG Advocacy Group requests a Committee Hearing regarding the importance of the DIPG Awareness Resolution and addressing pediatric brain cancer in our society today. By hearing we are prepared to present:

i) the voice of the Jace Ward and parents of children who suffer indescribable pain every year as DIPG steals the mobility, sight, hearing, voice and eventually life of its victims; DIPG victims walk in utter helplessness to their deaths as their bodies decline but their cognitive ability remains intact, and is squarely in tune with the lack of care available to them;

ii) a testament to this opportunity our democracy provides with the Awareness Resolution, as we ask for the help of our Representatives in Congress to raise greater public awareness to this issue of urgency with a nationally recognized day of awareness for DIPG as the most deadly killer of all pediatric brain tumors, and as a call to action; that researchers, prospective sufferers, philanthropists and the NCI would be resolved to updating the now unconscionable sixty-year-old standardized treatment of radiation which does little to aid sufferers or extend the short 9 month life expectancy;

iii) the awareness raised with the passage of this Resolution will support current and future legislation benefiting childhood cancer research and medical research in general; that the goals and modest appropriations for STAR, RACE, Kids First, and 21st Century Cures would move forward through process more expeditiously and the reauthorizations met with less resistance; and

iv) the opinion of leading physicians and researchers* who will state that curing DIPG will lead to methods, medications, immunology and strategies that will invariably result in cures for other types of pediatric and adult cancers;

*v) the need for future bills to give greater consideration of funding efforts to pediatric and high-mortality rate diseases such as DIPG, as suggested in H. Res. 114.*

## PROSPECTIVE HEARING PARTICIPANTS:

● Jace Ward (in active treatment for DIPG), Lisa Ward (mother), Brooke Ward (sister), Wamego KS,

* A panel of pediatric neuro oncologist and DIPG researchers who have devoted their professional lives to researching and ultimately curing this disease. We feel their perspective is paramount to the discussion.

Depending on the hearing date, the availability in person will include *professionals who set forth their joint statement attached to this letter* for your convenience.

- Elizabeth Psar (bereaved parent), William Psar (son--age 8), Co-Founder DIPG Advocacy Group, Julia Barbara Foundation, Knoxville, TN

- Janet Demeter (bereaved parent), Jack's Angels Foundation, DIPG Advocacy Group Founder, Agua Dulce, CA

- Ellyn Miller (bereaved parent), Gabriella Miller Kids First Research Act, Smashing Walnuts Foundation, Leesburg, VA

- Jenny Mosier (bereaved parent), Michael Mosier Defeat DIPG Foundation, May 17 "DIPG Across the Map" program creator, Bethesda, MD

- Jonathan Agin (bereaved parent), Patient Advocate, National Cancer Institute Brain Malignancy Steering Committee, Executive Director, MaxCure Foundation, HR 2720, The Alexis Agin Identity Theft Protection Act of 2013

- Paul Miller (concerned citizen), Event Coordinator for St. Baldrick's Foundation Denver CO, founder of "DIPG Awareness for Family and Friends" group on Facebook, Co-Founder DIPG Advocacy Group, Littleton, CO

*Others have expressed a desire to participate from Florida, Texas, New York, New Jersey, Pennsylvania, Oklahoma, Oregon, and Missouri; consideration of this would be contingent of course on hearing approval.

Our group is scheduled to be in Washington D.C. the week of January 13, 2020. Considering Jace Ward's prognosis, we respectfully suggest that a hearing be scheduled before March 1, 2020. We humbly thank the Leadership and Members of the Energy and Commerce Committee for your attention to this matter.

Sincerely yours,

Lisa Ward and Janet Demeter,
DIPG Advocacy Group Organizer
Moonshot4Kids@gmail.com
www.Moonshot4Kids.org

National DIPG
May 17
Awareness Day
#Moonshot4Kids

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stopkidscancer@gmail.com 720-989-5047
Lisa Ward, Patient Advocate, Wamego KS, 66547
jwtoughertogether@gmail.com 620-669-7811

October 9, 2019

Dear Honorable Members of the United States House of Representatives:

We are writing in regard to H. Res. 114, the National DIPG Awareness Resolution. DIPG is diffuse intrinsic pontine glioma, an aggressive brain tumor that mostly affects children. Brain tumors are now the most common cause of death for in childhood cancer, and DIPG is the deadliest of childhood brain tumors, with a zero percent cure rate. We are physician-scientists who have dedicated our careers to understanding this disease and improving outcomes for these unfortunate patients and their families. We ask for your support of this bill to make the American people aware of this unacceptable situation so that they will help us in our effort.

Pediatric cancer research as a whole has been one of the great successes of medicine in the last 70 years. Our field has taken a diverse set of incurable diseases and, through basic research leading to cooperative clinical trials, turned the tide so that we are now able to cure more than 80% of children with cancer overall. Along the way, discoveries in children have benefited adult cancer in enormous ways, including the advent of chemotherapy, which was first used for childhood leukemia. Unfortunately, the 80% figure belies a darker reality underneath, as in many childhood cancer subtypes, the vast majority of children still die of their disease. DIPG represents the most striking and tragic example of this continued challenge and represents the ultimate challenge in childhood cancer: an inoperable tumor with unique biology that is resistant to chemotherapy and is located in an area of the brain crucial for the most basic neurologic functions. If we can innovate to find a treatment for DIPG, it is likely to benefit not only these patients but other adults and children too whose cancers share some of these challenges.

We believe that your support of this bill will draw attention to the trail of lost children, devastated families, and broken communities left by this disease so that we can increase the research support needed to finally deliver hope to DIPG patients. We have the biological understanding of this tumor now, but we know that translating this knowledge to cures is the hardest and most expensive part. With your help, though, we can accomplish our goal and turn DIPG from an unimaginable tragedy to another success story for childhood cancer research. Thank you for your consideration of our letter.

Sincerely

Adam Green, MD
Assistant Professor of Pediatrics
University of Colorado School of Medicine
Attending Physician in Neuro-Oncology
Children’s Hospital Colorado

Charles Keller, MD
Scientific Director
Children’s Cancer Therapy Development Institute
www.cc-tdi.org
*because all children with DIPG deserve science-justified hope*

Sabine Mueller, MD, PhD, MAS

Adjunct Associate Professor, University of California San Francisco

PNOC lead (www.pnoc.us)

Director DIPG Centre of Expertise

University Children’s Hospital Zurich, Switzerland

M. Monje

Michelle Monje, MD, PhD
Associate Professor of Neurology
and by courtesy, of Pediatrics, Pathology, Neurosurgery and Psychiatry
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116TH CONGRESS 1ST SESSION *–one page version*

# 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 aver- age of male and female life expectancy from that median age, 300 × 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.

Alliance for
Childhood
Cancer

April 15, 2019

The Honorable Frank Pallone, Jr.
Chairman
Committee on Energy & Commerce
2107 Rayburn House Office Building
Washington, DC 20515

The Honorable Greg Walden
Ranking Member
Committee on Energy & Commerce
2185 Rayburn House Office Building
Washington, DC 20515

Dear Chairman Pallone and Ranking Member Walden,

The undersigned childhood cancer organizations are members of the Alliance for Childhood Cancer, consisting of patient advocacy groups, healthcare professionals and scientific organizations, representing millions of Americans who care deeply about childhood cancer. We write in support of House Resolution 114, which would designate May 17th as "DIPG Awareness Day" to raise awareness and encourage research into cures for diffuse intrinsic pontine glioma (DIPG) and pediatric cancers in general.

Diffuse Intrinsic Pontine Glioma is the leading cause of childhood brain tumor deaths. Every year, 200-400 children in the U.S. will be diagnosed with DIPG, and most of them will only survive nine months, or about as long as the typical school year. There is currently no consistent standard of care for these kids, and few treatments.

The House resolution designating a DIPG Awareness Day would help spread awareness about this deadly disease, and support researchers in their efforts to find new therapies to treat DIPG. In addition, the resolution proposes that private and public research funding "elevate the consideration of the mortality rate of a type of cancer" to ensure that research is funded to find treatments for those with the most challenging diseases.

While all childhood cancer is devastating, DIPG is a particularly terrible disease that leaves children and their families with limited options and limited time. We urge you to pass this resolution to honor those children whose lives have been lost, and to encourage additional research to give hope for children diagnosed in the future.

Sincerely,

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

CC: Members of Congress

National DIPG May 17 Awareness Day

#Moonshot4Kids

## 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!*

Jack's Angels jacksangels.org

Fighting to Cure DIPG — The Julia Barbara Foundation

Support Childhood & Brain Cancer Awareness — The Kortney Rose Foundation

DIPG Advocacy Group — Lend a hand ...share a heart!

Cannonballs ForKayne.org

Michael Mosier Defeat DIPG™ Foundation

Lily LaRue Foundation

### *H. Res. 114 was introduced 2/8/2019 with 17 original cosponsors, 68 cosponsors as of 11/13/2019:*

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], Castor, Kathy [D-FL14], Walberg, Tim [R-MI7]

### *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.*

Luke's Posse DIPG Ends Now!

THE CURE STARTS NOW®

## SUPPORTIVE RESEARCH INSTITUTIONS AND FOUNDATIONS

Pacific Pediatric Neuro-Oncology Consortium

DIPG COLLABORATIVE

CBTTC Children's Brain Tumor Tissue Consortium

children's cancer cause

Children's Brain Tumor Project powered by families

Children's Cancer Therapy Development Institute

ONS Oncology Nursing Society

MUSELLA FOUNDATION FOR BRAIN TUMOR RESEARCH & INFORMATION, INC

the ChadTough foundation

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, Cincinnati Children's Hospital, **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, DragonMaster Foundation