

DIPG ADVOCACY GROUP



Janet Demeter (CA) jacksangels1@gmail.com 661-977-3125
Elizabeth Psar, (TN, US SE) juliabarbaradipg@gmail.com 865-765-9655
Paul Miller, (CO, US W) stopkidscancer@gmail.com 720-989-5047
Vicki Thomas, (NY-NJ Metro) thomasvictoria075@gmail.com 732-773-5564
Walter and Michele Cramer (NJ, US NE) wrcramer6@yahoo.com 732-682-3613
Kirsten Finley (FL, US MidW, SE) cannonballsforkayne@gmail.com 859-991-1084

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

Feb 14, 2019

DIPG Advocacy Group is a nationwide association of childhood cancer advocates and parent-led foundations representing constituents in your state and district, writing to you in support of the DIPG Awareness Resolution, H. Res. 114. Introduced on Feb. 8, 2019 by Representative Jackie Speier (D-CA-14) and David Joyce (R-OH-14) amid another 17 original cosponsors, this Resolution is a manifestation of the public desire for more accountability regarding pediatric cancer which is grossly underfunded in our medical research system. The first DIPG Awareness Resolution was in 2014 in California; in 2018, thirty more states have joined in recognizing May 17 (community consensus) as DIPG Awareness Day. Why single out DIPG; why is it important?

DIPG exemplifies in a powerful way the marginalization of and chronic lack of adequate research funding for pediatric cancers, from both the government and private sector. *Diffuse intrinsic pontine glioma* is responsible for the majority of childhood deaths due to brain cancer which is the leading disease-related cause of death in children in the US, yet, neither terminal prognosis nor standard treatment for DIPG have changed since 1962 when Neil Armstrong's daughter died of it. I lost my 3 year old son Jack to DIPG in 2012, and I made it my mission to change what I heard about the value of my son's life with regard to our current US medical research industry, "the numbers aren't great enough for investors." Yet, as with the rather cool reception of the brilliantly crafted movie "First Man", no one likes to think about kids dying from cancer, or grieving parents; it's an uphill battle for awareness, and bereaved parents are burdened with the task of funding the research.

Not only would the designated day (May 17) in Brain Tumor Awareness Month help our foundations raise more funds for research, but it would draw attention to an issue for which parents have been asking for national conversation repeatedly over recent years to no avail: the general inadequacy of our medical research system to address the urgent needs of children with deadly pediatric cancers.

*For your convenience, we've included the description of the 114th Congress Republican House Rules Convention Protocol 7 of Rule 28, regarding the cases where resolutions designating a specific day qualify for scheduling a vote with suspension of rules.**

Thank you for considering cosponsoring this simple Resolution which could trigger so much healing and support in our national community, and also bring leadership and hope to a global problem. In recent years, advocates have been rebuked in vying for a national conversation about the lack of funding for pediatric cancer, especially brain cancer and DIPG for which we have no solutions. For decades these children have suffered horrible deaths, and their families, unspoken tragedy; it's time to shed light on this place of darkness in our society, that we might all embrace the reality of a cure for cancer. Please help make 2019 a Godsend year for the childhood cancer community, and support DIPG Awareness Day. **This is our #Moonshot4kids.**

Respectfully yours,

Janet Demeter, President
Jack's Angels Foundation
818-400-2724 direct
jacksangels1@gmail.com
www.dipgadvocacy.org



**on flipside of H. Res. 114 text*

H. Res. 114 correspondence:
Max Endicott, 202-225-3531
Legislative Assistant, Rep. Jackie Speier
Max.Endicott@mail.house.gov



31 STATES: MAY 17TH IS DIPG AWARENESS DAY

Governors in the States of Alabama, Arkansas, Arizona, Florida, Georgia, Hawaii, Idaho, Illinois, Indiana, Iowa, Kansas, Kentucky, Louisiana, Maryland, Massachusetts, Michigan, Mississippi, Missouri, Nebraska, Nevada, New Jersey, Ohio, North Carolina, Pennsylvania, Rhode Island, South Carolina, Tennessee, Texas, Virginia, Washington, and Wisconsin issued Proclamations establishing DIPG Awareness Day as May 17, 2018. In California, Mississippi, Nebraska, and Rhode Island, DIPG Awareness Day was established **through the legislature**. Four additional states still have requests under consideration. California was the first state to have a DIPG Awareness Resolution in 2014.*



53 cosponsors and counting...

The 115th Congress H. Res. 69 gained 53 cosponsors and 116th Congress H. Res. 114 had 19 at the Introduction, with pledges for more. 2019 is the 50th Anniversary of the Moonwalk, and the Senate is preparing a similar Resolution for a vote in May 2019.

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®



The Cure Starts Now Foundation, National Brain Tumor Society, 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

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.

Regarding Vague Reference Objections to Awareness Days

“We don’t do those anymore.” Great; now what?

Since the first iteration of the DIPG Awareness Resolution (114th Congress H. Res. 586), we have occasionally experienced the disheartening “push-back” from certain legislative offices regarding an assumed abolishment of awareness days, which is not an altogether correct assumption. Apparently the designation of awareness days had become rather frivolous and was rightly limited by the 114th Congress, yet was not abolished entirely as many assume without further inquiry.

Though somewhat surprised at having come so far with this work as to help write legislative text in support of our cause with Congressman Knight’s office in September of 2015, and with conferring experts approval on data and statistics, only to have our project be declared null and void by the occasional critical legislative assistant, this was certainly depressing but not effective in deterring our mission. Finally after some digging during the 2nd iteration of the Resolution (115th Congress H. Res. 69), I found this account of the Republican Convention on House Rules, the actual Rule in question, and also the Protocol of that Rule which unequivocally qualifies our Resolution for suspension of rules, and for a vote to be scheduled under that process.

As an advocate, the idea of educating legislative staff, or at least making a sound and persuasive argument as to why this Resolution ought to have serious consideration, even though it’s verified by the rules themselves, has been a daunting proposition. First we fight for the idea that the urgent needs of children and the dying ought to have greater consideration, which many of us feel is self-evident, but then, as outsiders to Congress, we’ve had to fight to prove that the Resolution is viable. We strongly believe that indeed it is more than viable, as We The People are asking for Congress help in raising critical awareness to a much larger problem; if ever there were a need for an awareness day, DIPG is a worthy candidate. We are grateful for the wisdom and compassion of Representatives Speier and Joyce.

Rather than to make it more important than other diseases, DIPG exemplifies in a powerful way the marginalization and chronic lack of support for research funding for the deadliest pediatric cancers, the tried and true killers of our children with certain regularity, in the Resolution. Clearly our human values of prioritizing the dying and children, as they are in the Emergency Room, are not represented in the larger research industry. Since the 2015 #Morethan4 movement of parent emails to NCI, demanding answers to the small percentage of the annual research budget allocated to pediatric cancer as a whole, we parents have been told to be quiet, basically, that no one wants to work with “angry parents.” **We would like transparency and a national conversation**, not just promises of consideration, or a reproach to outrage. For those of us who have had to watch-on helplessly as our children die because “they aren’t worth the investment”, we’ll fight with our own lives to see our values one day represented in the system.

Protocol 7 of Rule 28

*Taken from Congressional Research Service, “Sense Of” Resolutions and Provisions, name redacted,
Analyst on Congress and the Legislative process, May 2016*

“...As adopted in the 114th Congress (2015-2016), the rules of the House Republican Conference include language that limits the use of the suspension of the rules procedure for certain types of honorific or commemorative legislation. This rule could effectively preclude the consideration of some “sense of” legislation in the House. Specifically, Conference **Rule 28** states that the Republican leader “shall not schedule, or request to have scheduled, any bill or resolution for consideration under suspension of the Rules which ... expresses appreciation, commends, congratulates, celebrates, recognizes the accomplishments of, or celebrates the anniversary of, an entity, event, group, individual, institution, team or government program; or acknowledges or recognizes a period of time for such purposes.” **The rule may be waived by a majority of the elected House leadership. The House Republican leadership has also announced several “Legislative Protocols,” one of which is intended to clarify the application of Conference Rule 28:**

Protocol 7 states that a “resolution of bereavement, or condemnation, or which calls on others (such as a foreign government) to take a particular action [emphasis added], but which does not otherwise violate the provisions of Rule 28 is eligible to be scheduled under suspension of the Rules...”

Link to full document: bit.ly/p7-rule28 (case-sensitive)