

September, 2018

# I N T R O D U C T I O N

## H. Res. 69

### The National DIPG Awareness Resolution

*Diffuse intrinsic pontine glioma, a pediatric brain cancer*  
*An Ambassador for Childhood Cancer Awareness*



*Previous Administrations have refused a national conversation about the lack of adequate research funding for childhood cancer, and Congress has consistently failed to commit appropriate funds to pediatric research.*

**Now we Parents are asking our Members and Leaders in the US House of Representatives for help.**

*DIPG is responsible for the majority of brain tumor deaths each year in children, and exemplifies in a powerful way the marginalization and suffering so many children with cancer and their families face every day:*

*Sadly, DIPG parents must be resigned to witnessing the death of their children in complete helplessness, not knowing exactly when, how, or ultimately why, they will die. They discover there are no solutions for them because, "the numbers aren't great enough for investors," in one of the wealthiest countries in the world.*

*DIPG is responsible for the majority of pediatric brain tumor deaths annually;  
brain cancer is the #1 disease-related cause of death in children in the United States.*

**An unrelenting killer of our children, DIPG is hardly irrelevant.**

*There is a strong movement across the USA with **31 State Proclamations in 2018** for a DIPG Awareness Day on May 17, and for greater consideration for children with cancer as written in H. Res. 69.*

*We beg of you to please consider the information included herein of our request for a House Vote on H.Res.69 before the end of this Session of Congress.*



*Thank you,*

**DIPG ADVOCACY GROUP**



*So that one day, no parent must hear there are no solutions for their child because, "the numbers aren't great enough for investors..."*

# DIPG ADVOCACY GROUP

Concerned Citizens across the United States and around the World

Support for awareness and research for diffuse intrinsic pontine glioma, a pediatric brain cancer

[www.HRes69.org](http://www.HRes69.org)



to the Honorable Members of the United States House of Representatives, and Staff:

H.Res.69 represents a movement, born of intense grief, for greater national awareness of the lack of research funding for DIPG, deadly pediatric disease, and of the resulting human suffering which continues with no end in sight. The commonly heard excuse is that only a small population is affected in any given year. *Their lives matter.* Cancer kills more children than any other disease each year in the USA, as you may know. Unfortunately, we must fight tooth and nail for scarce recognition of this fact in one of the wealthiest countries in the world which boasts the most advanced technologies.

The DIPG Awareness Resolution was authored by Congressman Steve Knight (R-CA-25) in the hopeful spirit of national awareness, acknowledgement and conversation regarding more timely solutions for children with cancer, specifically DIPG, *who invariably face certain death.* The median survival time, with treatment, is 9 months. An Awareness Day will help families raise funds for research, a burden which parent-led foundations have carried virtually alone and have effectively supported some of the most pioneering and valuable research in neuroscience and oncology.

***H.Res.69 simply asks that years of life lost and the mortality rate for any given type of cancer receive greater consideration for research grants both with public and private funding, and brings attention to the tens of thousands of children who have bravely walked toward their death without enough of a fight from us. The standard treatment protocol of radiation and palliative care are the same today for DIPG as when Neil Armstrong's daughter died of it in 1962. Clearly greater awareness to this relentless human suffering is needed.***

**You are our greatest hope for change!** Greater national awareness for this issue will also help continuing efforts to fund the *Childhood Cancer STAR Act*, the *Gabriella Miller Kids First Research Act*, and other important legislation for pediatric cancer. The failure to procure allocations for previous legislation, such as the *Caroline Pryce Walker Conquer Childhood Cancer Act of 2008*, and its reauthorization in 2013, is still strong in the minds of many advocates, who are working hard, as I write, to raise national support for this hurdle of allocations for STAR. Time is not a luxury these children can afford.

Support for a DIPG Awareness Day across the United States is significant. In 2018, 31 States had DIPG Awareness Proclamations, and Awareness Day May 17, demonstrating an undeniable national desire for support; Protocol 7 of Rule 28 of the 114th Congress House Republican Conference clearly supports the legitimacy of a House Vote in this case, if you happen to be of the mind of those who say, "we don't do those anymore."

*Please support this avenue in our democracy for the People to petition their Representatives in Congress for help.*

**Please co-sponsor and support a House Vote for H. Res. 69!** The text is brief and to the point for your consideration; for further inquiry, the staff members listed below would be happy to accommodate you. On behalf of our national community, we thank you with all of our hearts, and our host of angels thanks you.

Very Truly Yours,

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Representative Jackie Speier (D-CA-14)



*Conferring experts for statistics included in the text of H.Res.69, and statements of fact:  
Dr. Michelle Monje Deissiroth, Stanford University; Dr. Adam Green, University of Colorado at Denver*

*So that one day, no parent must hear there are no solutions for their child because, "the numbers aren't great enough for investors..."*

# 115TH CONGRESS

## 1ST SESSION H. RES. 69

“Expressing support for designation of the 17th day in May as “DIPG Awareness Day” to raise awareness and encourage the research into cures for diffuse intrinsic pontine glioma (DIPG) and pediatric cancers in general.”

### IN THE HOUSE OF REPRESENTATIVES

JANUARY 30, 2017

Mr. KNIGHT (for himself, Ms. SPEIER, Ms. ESHOO, Mr. MCCAUL, Mr. CARDENAS, Mr. MURPHY of Pennsylvania, Mrs. COMSTOCK, Mrs. DINGELL, Mr. DELANEY, Ms. BROWNLEY of California, and Mr. SOTO) submitted the following resolution; which was referred to the Committee on Energy and Commerce

## RESOLUTION

Expressing support for designation of the 17th day in May as “DIPG Awareness Day” to raise awareness and encourage the 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 25,000 years of person life lost (calculated as the number of children diagnosed by average of male and female life expectancy from that median age,  $300 \times 80 = 25,000$  years of person life lost annually);

Whereas prognosis has not improved for children with DIPG in over 40 years; and

\*Whereas government funding for research for pediatric cancer is not commensurate with 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) And 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.

*\*These lines have been edited slightly from the original for the approval of the Energy and Commerce Committee and those parties concerned with pediatric brain cancer research.*

## 31 STATES AND COUNTING: May 17<sup>th</sup>, 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, 2017. 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 an Awareness Resolution in 2014.**

*\*These states have a permanent May 17<sup>th</sup> DIPG Awareness Day and do not have to renew in 2019.*



<https://www.govtrack.us/congress/bills/115/hres69/summary>



### Cosponsors

1. Brownley, Julia [D-CA26] 1/30/17
2. Cárdenas, Tony [D-CA29] 1/30/17
3. Comstock, Barbara [R-VA10] 1/30/17
4. Delaney, John [D-MD6] 1/30/17
5. Dingell, Debbie [D-MI12] 1/30/17
6. Eshoo, Anna [D-CA18] 1/30/17
7. McCaul, Michael [R-TX10] 1/30/17
8. Murphy, Tim [R-PA18] 1/30/17
9. Soto, Darren [D-FL9] 1/30/17
10. Speier, Jackie [D-CA14] 1/30/17
11. Tonko, Paul [D-NY20] 1/30/17
12. Hurd, Will [R-TX23] 3/9/17
13. Smith, Lamar [R-TX21] 3/9/17
14. Kennedy, Joseph [D-MA4] 3/20/17
15. Chaffetz, Jason [R-UT3] 4/20/17
16. Duncan, John [R-TN2] 5/1/17
17. Rush, Bobby [D-IL1] 5/1/17
18. Costello, Ryan [R-PA6] 5/3/17
19. Ryan, Tim [D-OH13] 5/17/17
20. McCollum, Betty [D-MN4] 5/19/18
21. Clark, Katherine [D-MA5] 6/12/17
22. Moulton, Seth [D-MA6] 6/12/17
23. Higgins, Brian [D-NY26] 9/5/17
24. Matsui, Doris [D-CA6] 12/7/17
25. Perry, Scott [R-PA4] 12/7/17
26. Rosen, Jacky [D-NV3] 12/13/17
27. Duncan Hunter [R-CA50] 3/14/18
28. Andy Barr [R-KY-06] 3/19/18
29. Adam Schiff [D-CA-28] 4/12/18
30. Donovan, Daniel [R-NY11] (4/24/18)
31. Fitzpatrick, Brian [R-PA8] (4/24/18)
32. Gabbard, Tulsi [D-HI2] (4/24/18)
33. Tsongas, Niki [D-MA3] (4/24/18)
34. Collins, Chris [R-NY27] (4/27/18)
35. Engel, Eliot [D-NY16] (5/8/18)
36. Jenkins, Evan [R-WV3] (5/15/18)
37. Barletta, Lou [R-PA11] (5/16/18)
38. Lofgren, Zoe [D-CA19] (5/22/2018)
39. Grijalva, Raúl [D-AZ3] (6/13/2018)
40. Lipinski, Daniel [D-IL3] (6/26/2018)
41. Vela, Filemon [D-TX34] (7/2/2018)



### H.Res.69 SUPPORTERS



**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.69. Both scientists have laboratories dedicated to research in pediatric neuro-oncology with an emphasis on DIPG, diffuse intrinsic pontine glioma.

National Brain Tumor Society (*supplied edits*), Pediatric Brain Tumor Foundation (*approved edits*), The Alliance for Childhood Cancer, **Oncology Nursing Society, National Children's Cancer Consortium (NC3), Julia Barbara Foundation, Aimee's Army, 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**



*"So that one day, no parent must hear there are no solutions for their child because, "the numbers aren't great enough for investors..."*

## Please support a House Vote for H. Res. 69

Support for a DIPG Awareness Day across the United States is significant. In 2018, 31 States had DIPG Awareness Proclamations, and Awareness Day May 17, demonstrating an undeniable national desire for support.

**Protocol 7 of Rule 28 of the 114th Congress House Republican Conference** clearly supports the legitimacy of a House Vote in this case, if you happen to be of the mind of those who say, “we don’t do those anymore.”

**Please support this avenue in our democracy for the People to petition their Representatives in Congress for help.**

The common fate of DIPG came 1 month post diagnosis for Braylynn in Florida; she died 1/15/2018



Jo Sandoval and Katelyn, facing the worst, have hope in H.Res.69—that some day, DIPG children will have a chance.  
-Los Angeles, CA, February, 2018

*“Lighten our Darkness...”*

*Here are few options*

...when your child is diagnosed with DIPG, and *none* of them contain a survival prognosis; the only hope one can develop is that, through experiment—if the child even qualifies, this experience may be part of finding a solution for those yet to be diagnosed. Or, parents can spend hundreds of thousands of dollars, if they can raise the money, to take their child out of the country for the latest promising treatment on foreign soil, taking the gamble that it will extend their life.

I lost my son Jack to DIPG in 2012, and our story is no different from the stories of your constituents. If I could tell you if there were *one determining factor* in the whole equation of the DIPG experience which I would like to see change, it would be that one day, no one will hear that there are no solutions for their child because they’re not considered, by some unknown entity, to be worth the research investment.

*It’s a hard pill to swallow; even after 50+ years of clinical knowledge, there are no solutions for your child because his or her life, for all practical purposes, doesn’t matter.*

DIPG is responsible for the majority of childhood deaths due to brain tumors, the leading cause of death in kids with cancer. 350+ deaths a year...if there were a human killer on the loose doing that, we’d invest whatever resources it took to bring him to justice. *Wouldn’t we?*

The worthiness of any cause may be debatable, but we, in all certainty of the devastation of our own experience, are confident in valuing our children’s lives in submitting to you this: *the idea of an Awareness Day May 17 for these families brings hope to parents like Jo Sandoval, upper right, where nothing else can, as they watch their children die. It brings hope for a future where children like Katelyn get a bigger fight for their lives from us.* Sadly, she was buried in March, 2018.

**#HouseVote #Hope4Kids #KidsMatter #littlebillthatcould #HRes69**

*“So that one day, no parent must hear there are no solutions for their child because, “the numbers aren’t great enough for investors...”*