



## DIPG ADVOCACY GROUP

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## H.Res.69 The National DIPG Awareness Resolution

*Diffuse intrinsic pontine glioma, a pediatric brain cancer*

*To the Honorable Member of the United States House of Representatives, and staff,*

Brain tumors are the leading cause of death in children with cancer; DIPG is the 2<sup>nd</sup> most common pediatric brain tumor and is responsible for the majority of brain cancer deaths in children annually. Despite its terminal prognosis and median survival time of 9 months post-diagnosis, there has been no change in standard treatment protocol nor terminal prognosis for DIPG—*diffuse intrinsic pontine glioma*—in over 50 years of clinical observation. Sadly, parents must be resigned to witnessing the death of their beloved children in utter helplessness, not knowing exactly when, how, or ultimately why, they will die. The devastation of this experience cannot be understated, and there is a strong movement across the US for a DIPG Awareness Day in May, Brain Tumor Awareness Month, and greater consideration for these children's lives, as written in H.Res.69.

***Parents have been expected to accept that there are no solutions for their children because their numbers don't warrant the investment; now we parents are asking our Representatives in Congress for help.***

The DIPG Awareness Resolution acknowledges the inadequacy of the medical research system to address the needs of our children with brain cancer, and the national desire for greater consideration for their lives. DIPG exemplifies the marginalization of childhood cancers, which permits the industry's indifference to suffering in favor of numbers to continue indefinitely. You are our greatest hope for change. A DIPG Awareness Day represents something that our families *never have* from day one: HOPE, hope that we are actively seeking solutions for them because their lives matter, and the urgently needed research will benefit many.

**Support across the United States is significant.** In 2017, 22 States had Awareness Resolutions for DIPG, with 32 States in 2018 with 4 pending, demonstrating an undeniable national desire for a DIPG Awareness Resolution.

Thank you for your consideration, as this was written by parents, for these children and their families, with Congressman Steve Knight (R-CA-25) in the spirit of national awareness, acknowledgement and conversation toward solutions to funding urgently needed research for children facing certain death. **H.Res.69** offers a practical avenue to do just that, by starting the conversation about the issue and welcoming collaboration for effective solutions and promising ideas. The Awareness Day will help families continue raising funds for research, a burden which parent-led foundations have carried alone for the most part, and effectively supported some of the most promising research in the field.

The text is brief and to the point for your consideration. Please consider it and contact the legislative assistants below for further inquiry. On behalf of our national community, we thank you with all of our hearts.

Very Truly Yours,

Janet Demeter

**DIPG Advocacy Group, Organizer**

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Representative Steve Knight (R-CA-25)

Molly Fishman, [molly.fishman@mail.house.gov](mailto:molly.fishman@mail.house.gov) 225-3531

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!

*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.*

### Cosponsors as of May 16, 2018

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] 5/19/17
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)

**National DIPG Awareness DAY!**   
**May 17**  
Make **PEDIATRIC** and **HIGH-RISK** cancers  
**Research Funding Priorities!**  
Please support:  
**H.Res.69**  
[www.HRes69.org](http://www.HRes69.org)  
Logos: NATIONAL CHILDREN'S CANCER CONSORTIUM, CANNONBALLS, ONS the Oncology Nursing Society, the Chad Tough foundation, children's cause cancer advocacy, Jack's Angels, Lily LaRue Foundation.  
"Because every child is a life, not a number."

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

### 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**

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

## *The Power of HOPE in the Darkest Hour*



*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, 1/15/2018*

### **“Lighten our Darkness...”**

#### ***There 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 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.

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?*

**There has been resistance in the House to considering DIPG Awareness Day due to the 114<sup>th</sup> Congress Republican Conference Rule #28. However, Protocol 7 of that Rule states that matters of bereavement, or condemnable situations requiring remedial action, domestic or foreign, are clearly exempt from the ban on awareness days celebrating or commemorating an individual or group.** The worthiness of any cause may be debatable, but we, in all certainty of the devastation of our own experience, are confident 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.

**Please support the DIPG Awareness Resolution, H. Res. 69**

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