



DIPG ADVOCACY GROUP

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H.Res.69 ---Senate Awareness Bill Proposal *National DIPG Awareness Resolution*

To the Honorable Member of the United States Senate, and staff,

The Resolution text on the following page is brief for your consideration of a comparable Senate Awareness Resolution. Roughly 800 more children have died in the US since the Resolution was first introduced in the House in January 2016, hence our sense of urgency. We feel our cause would be better represented in the Senate, as the movement in the states is strong, while our bereaved community is more difficult to organize at the level of congressional districts. Due to the efforts of the Michael Mosier Defeat DIPG Foundation in Bethesda, MD and its affiliates across the country, 22 states passed a DIPG Awareness Resolution in 2017, with more poised for 2018.

Brain cancer is the leading cause of death in children with cancer, and DIPG is responsible for the majority of pediatric brain cancer deaths each year, yet there has been no change in standard treatment protocol nor terminal prognosis for diffuse intrinsic pontine glioma (DIPG) 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. With treatment, the median survival time is 9 months post diagnosis.

Parents of children with DIPG 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 represents the acknowledgment of the loopholes through which our children are lost in our medical research system, and the desire for greater consideration for the lives of our children facing certain death. 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, that they have a certain value deserving of recognition and support from the U.S. Government.

Thank you for your consideration, as this was written by parents, for these children and their families, with Congressman Steve Knight (R-CA-25), who as CA State Senator was involved with the first Awareness Resolution for DIPG in California in 2014. We feel there ought to be acknowledgement and conversation about funding urgently needed research for children facing certain death. **H.Res.69** does this and furthermore provides crucial support for the bereaved community charged with the responsibility of generating most of all research funding for DIPG currently, with the Awareness Day May 17 during Brain Cancer Awareness Month.

Thank you for considering it. On behalf of our community nationwide, thank you from our hearts to yours.

Very Truly Yours,

Janet Demeter

DIPG Advocacy Group, Organizer

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Molly Fishman, molly.fishman@mail.house.gov 225-3531

Representative Jackie Speier (D-CA-14)

Conferring experts on H.Res.69:

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.*

Cosponsors as of May 14, 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)

National DIPG Awareness Day! 
May 17
Make PEDIATRIC and HIGH-RISK cancers Research Funding Priorities!
Please support: H.Res.69
www.HRes69.org

Logos: NATIONAL CHILDREN'S CANCER CONSORTIUM (NC3), CANNONBALLS FOR KAYNE, ONS the Oncology Nursing Society, the ChadTough foundation, Jack's Angels, children's cause cancer advocacy, Defeat DIPG, 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**

Governors in the States of Arizona, Connecticut, Georgia, Illinois, Iowa, Kansas, Kentucky, Maryland, Massachusetts, Michigan, Mississippi, Nebraska, Nevada, Pennsylvania, Virginia, Washington, and Wisconsin issued Proclamations establishing DIPG Awareness Day as May 17, 2017. In Louisiana, Tennessee, California and Texas, DIPG Awareness Day was **established through the legislature**. Additional states still have requests under consideration for 2018. **In 2014, California was the first state to have a DIPG Awareness Resolution in the State Legislature.**

"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. The cause is unknown.

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?*

Without awareness it's not possible; without our voices being heard, no one will know...until someone close to you is affected by deadly pediatric cancer. Six months after my son had died, my neighbor lost her niece to DIPG; I watch new children being diagnosed daily, and the children I've followed, die. They are the ones for whom I'm appealing to you right now. They'll never get to tell their stories; their parents may be too devastated, hopes dashed far too many times. A few of us speak out for our own emotional survivals sake. But I can tell you this: the idea of an Awareness Day May 17 for these families brings hope to parents like Jo Sandoval, upper right, where little else has; 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...”