

THE NATIONAL DIPG AWARENESS RESOLUTION

H.Res.69 #Hope4Kids

H.Res.69 supports greater research funding consideration for PEDIATRIC and HIGH-RISK cancers.

BECAUSE **NO** PARENT SHOULD DISCOVER there are no solutions for their child because,

“The numbers aren’t great enough for investors.”

Unfortunately, this is the experience that children with DIPG and their families face. This is not unique to diffuse intrinsic pontine glioma, the deadliest pediatric brain tumor; **most pediatric cancers are marginalized as rare** and receive little to no research funding.

Parents hear: “There is nothing more we can do”, and the family must witness the death of their child in utter helplessness with the sometimes quick, sometimes slow, agonizing terror of not knowing when, or how, or what exactly it will be like.

IT’S TIME FOR THIS UNACCEPTABLE REALITY TO CHANGE.

Call or write your Representative in Congress today!

Support DIPG Awareness Day, May 17

In over 50 years there has been no change in standard treatment nor prognosis for DIPG, which is true of most childhood cancers, even though pediatric cancer is the #1 disease-related killer of children in the US.



In 2017, 21 States have observed DIPG Awareness Day, May 17; support the National Movement!

Our children can’t wait so long for a cure.

H.Res.69 confronts the chronic lack of funding for pediatric research, and the urgent need for cures, now.

#Hope4Kids www.HRes69.org

(1-page version)

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.*