

H.Res.69: Written for YOU

*H.Res.69 is the only childhood cancer bill that directly asks that **pediatric and high-risk cancers** have greater consideration in our medical research system.*

THE NATIONAL DIPG AWARENESS RESOLUTION

(To help advocate, visit: www.HRes69.org)

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; **all 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.

In over 50 years, little has changed in standard treatment protocol nor the **terminal prognosis** for DIPG.

Less than 4% of our tax dollars purposed for cancer research any given year are designated to pediatric cancer, and a much smaller percentage of private sector investments benefit research to save our children’s lives.

WE DESERVE ACKNOWLEDGEMENT!

4% is **NOT** enough!

H.Res.69 is the **ONLY BILL** to address this directly.

#MoreThan4 #HRes69 #SaveLivesFirst

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

Mr. KNIGHT 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 as a singular designation has been represented by less than 4 percent of the National Cancer Institute budget in any given year: 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 the National Cancer Institute and other research funders to elevate their consideration of mortality rate of a type of cancer as well as the life years lost as significant factors considered during the grant application process.



Jack's Angels Foundation