

Supporting H. Res. 114, the DIPG Awareness Resolution

DIPG ADVOCACY GROUP



Janet Demeter (CA) jacksangels1@gmail.com 661-977-3125
Elizabeth Psar, (TN, US SE) juliabarbaradipg@gmail.com 865-765-9655
Paul Miller, (CO, US W) stopkidscancer@gmail.com 720-989-5047
Vicki Thomas, (NY-NJ Metro) thomasvictoria075@gmail.com 732-773-5564
Walter and Michele Cramer (NJ, US NE) wrcramer6@yahoo.com 732-682-3613
Kirsten Finley (FL, US MidW, SE) cannonballsforkayne@gmail.com 859-991-1084

To the Honorable Members of the US Congress and Staff:

March 14, 2019

Introduced on Feb. 8, 2019 by Representative Jackie Speier (D-CA-14) and David Joyce (R-OH-14) amid 17 original cosponsors (now 28), H. Res. 114 is a manifestation of the public desire for more accountability regarding pediatric cancer which is grossly underfunded in our medical research system. A similar Resolution will be introduced in the Senate by Senators Marco Rubio (R-FL) and Jack Reed (D-RI) in early May. The first DIPG Awareness Resolution was in 2014 in California; in 2018, thirty more states have recognized May 17 (community consensus) as DIPG Awareness Day. Why single out DIPG; why is it important?

Parents who have lost children to cancer, and specifically to DIPG, have been asking for a national conversation about the fact that childhood cancer research has been chronically underfunded, but we have been rebuked at every opportunity. H. Res. 114 represents this populist movement for childhood cancer begun by DIPG parents who all, invariably, must watch their children die because “the numbers aren’t great enough for investors,” exemplifying in a powerful way the experience that most childhood cancer families have: there are no viable solutions for their children. ***We stand in solidarity in our belief that this is an unacceptable reality in the richest, most technologically advanced country in the world.***

We are grateful for the passage of the STAR Act; many of us advocated strongly for it over the years. We are also grateful for President Trump’s Initiative to give \$500M to the cause over the next 10 years, and his mention of childhood cancer in his State of the Union Address; how this will translate with the proposed NCI budget cuts is unknown. The obvious point is, without sufficient public discussion and identification of the problem, solutions are a long way off. The basic experience of childhood cancer will not change without awareness.

Not only would the designated day (May 17) in Brain Tumor Awareness Month help foundations raise more funds for research, *but it would draw attention to an issue for which parents have been asking for national conversation repeatedly over recent years to no avail:* the general inadequacy of our medical research system to address the urgent needs of children with deadly pediatric cancers.

For your convenience, we've included a link to the description of the 114th Congress Republican House Rules Convention Protocol 7 of Rule 28, regarding the cases where resolutions designating a specific day qualify for scheduling a vote with suspension of rules: <http://bit.ly/p7-rule28> (case sensitive)

Thank you for considering cosponsoring this simple Resolution which will bring hope to our national community and leadership to a global issue. For decades these children have suffered horrible deaths, and their families, unspoken tragedy; it’s time to shed light on this place of darkness in our society, that we might all embrace the reality of a cure for cancer.

Please help make 2019 a God-send year for the childhood cancer community, and support DIPG Awareness Day. **This is our #Moonshot4kids.**

Respectfully yours,

Janet Demeter, President
Jack’s Angels Foundation
818-400-2724 direct
jacksangels1@gmail.com
www.dipgadvocacy.org



RESOLUTION TEXT

www.bit.ly/hres114-txt

Contact:

Max Endicott, 202-225-3531

Legislative Assistant, Rep. Jackie Speier

Max.Endicott@mail.house.gov

In the Senate:

Ted.Sacasa@rubio.senate.gov

Jill.Boland@reed.senate.gov