

Supporting H. Res. 114, the DIPG Awareness Resolution

April 12, 2019

To the Honorable Speaker of the House of Representatives, to the House Majority Leader, House Minority Leader, and to the Honorable House Majority and Minority Whips:

Thank you for considering this and the attached information being distributed among all members of the House of Representatives. Your position of leadership and consideration of support for this Resolution is crucial to a three-year struggle for its recognition and movement out of the Energy and Commerce Committee, that decades of hidden suffering might find the light of day. Those of us who are committed to advocating for children with brain cancer, the leading cause of death in children with cancer, and DIPG, the deadliest of all, we are speaking for those parents who cannot; we speak for our children who will never have the opportunity, because they no longer walk the earth with us.

Our request for your support of H. Res. 114 in no way diminishes our appreciation for STAR, Race, Creating Hope, and Gabriella Miller Kids First, for which members of our DIPG Advocacy Group have actively advocated along with the larger childhood cancer groups. Still, the fight for allocations for instated laws and re-approvals continues; the experiential status quo remains unchanged for us. The auspicious SOTU announcement for childhood cancer and the Presidential Initiative gives absolutely no guarantees amid the proposed budget cuts to the NCI, potentially rendering it insignificant.

The missing ingredient is *greater public awareness* to the chronic lack of adequate research funding for pediatric cancers, most of which are deadly, marginalized as rare, and devoid of solutions. H. Res. 114 is a plea to Congress for help; our population is downtrodden, bereaved, yet determined to fight for those children yet to be diagnosed to have the chance to go to school, find love; to live to, and through, adulthood. In other words, they ought to have the same Constitutional rights of Life, Liberty, and the Pursuit of Happiness.

There is no transparency with regard to the decision-making concerning research funding with our tax-dollars devoted to cancer research. It is apparent to our experience that the urgency of certain death, and years of life potentially lost, are nowhere in the equation. Routinely, parents hear they must “go make your child comfortable and make memories”...why? Because, “the numbers aren’t great enough for investors,” we hear, in the richest and most technologically advanced country in the world. Adequate support for research into cures for pediatric cancer should be a no-brainer.

Out of sight and out of mind, the suffering and the tragedy continues, exemplified in a most horrific way by the experience of DIPG, which, out of the blue, robs the child of the use of their body until finally respiration ceases, while they retain full cognitive awareness of what’s happening to them.

We appreciate your considering the importance of public awareness, H. Res. 114, and designated day May 17, with a renewed spirit of democratic intention. Where parent-led foundations are saddled with the burden of funding the research, and we don’t expect this to change overnight, this awareness would

help immensely and also alert the larger philanthropic community. In 2018, thirty-one states had a DIPG Awareness Day May 17, with more poised for this year.

We deeply appreciate your consideration on behalf of the children we are losing daily to DIPG, and, with your assistance, the possibility for hope you might bring to those currently fighting for their lives.

Thank you for your service to the American People, and God bless you.

Respectfully yours,

Janet Demeter
jacksangels1@gmail.com
818-400-2724



DIPG Advocacy Group
www.dipgadvocacy.org

Janet Demeter, Organizer (CA), Paul Miller (CO, US West), Elizabeth Psar (TN US South) Vicki Thomas (NY, NJ Metro), Walter and Michele Cramer (NJ US-NE), Kirsten Finley (FL, SC, LA), Bill Kohler (PA), Robin Dodd (KY, MT);
stopkidscancer@gmail.com, ekspar@gmail.com, thomasvictoria0725@gmail.com, wrcramer6@yahoo.com,
kirsten@cannonballsforkayne.org, bill@4aydenstrong.com, robin.dodd@uky.edu

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