

April 10, 2019

To the Honorable Representatives of California's 53 Districts, and Staff:

The DIPG Awareness movement for childhood brain cancer began in our Great State of California in 2014 with the first-ever DIPG Awareness Resolution, ACR151 led by then Assemblyman Scott Wilk (now State Senator), and then Senator Steve Knight, who later became Congressman of the 25th district for the 114th and 115th Congress. Because of collaboration with other advocates and foundations in recent years, thirty-one states declared May 17 as DIPG Awareness Day in 2018; we are asking for your California leadership on behalf of residents in your District by supporting H. Res. 114, introduced by Jackie Speier (CA-14) and David Joyce (OH-14) on Feb. 8 of 2019.

The Resolution asks simply that pediatric and high-mortality rate cancers receive greater consideration in the research grant process especially with government resources. 2019 is the 50th Anniversary of the Moonwalk; Neil Armstrong's daughter died of DIPG in 1962, yet today's standard treatment and terminal prognosis remain the same for this relentless killer. Clearly change is needed, as DIPG exemplifies in a powerful way this problem with pediatric cancer research being underfunded and the terrible reality that so many children and their families must face--in the most technologically advanced, and wealthy, nation in the world.

My son Jack was diagnosed with DIPG in October 2011 and died in July of 2012; there were no viable solutions for my son to the excuse that, "the numbers aren't great enough for investors." Clearly something was very wrong; I'd entered into a terrible world where "the system" definitively had no value for the lives of children, and the powers that be were resisting any kind of national discussion about it.

Legislation such as the STAR Act, and President Trump's Childhood Cancer Initiative are steps forward, but neither guarantee transparency or change. Considering the large cuts proposed to the NCI annual budget, the proposed Initiative by the President may make very little difference. The missing ingredient is public awareness and national conversation; procuring allocations for childhood cancer legislation wouldn't be so difficult. Foundations led by bereaved parents to fund research would be supported with the Awareness Day, May 17, and the greater philanthropic community. In 2018, 31 States including California celebrated this designation in solidarity, with more poised for 2019.

And so, we unapologetically fight for all of our children with the banner of the DIPG Awareness Resolution. Few will ever have the chance to speak out; most DIPG children perish within 9 months of diagnosis. The torturous nature of the experience cannot be understated.

We hope that Representatives of California Districts will consider cosponsoring H. Res. 114 and support a House vote; what might take 10 minutes on the floor could bring actual hope to thousands, and help begin the healing that only acknowledgement can bring. We dearly hope that you will consider supporting this important resolution for valuing the lives of those in most urgent need of our help; America's children with cancer. Let's lead as Californians.

Respectfully yours,

Janet Demeter, Organizer
DIPG Advocacy Group



DIPG ADVOCACY GROUP



Janet Demeter, (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, wcramer6@yahoo.com, kirsten@cannonballsforkayne.org, bill@4aydenstrong.com, robin.dodd@uky.edu