

For Immediate Release  
Jack's Angels Foundation  
Santa Clarita, CA

## May 17 is DIPG Awareness Day—A National Movement

*May 14, 2017, Santa Clarita, CA*—Over half of the states in the USA have had advocates working hard this year at getting a declaration of some kind for DIPG Awareness Day, May 17 for 2017 in support of a DIPG Awareness Day. H.Res.69, the National DIPG Awareness Resolution introduced by Congressman Steve Knight January 30 2017, currently awaits a vote in the House of Representatives. It waited for a vote all year last year as H.Res.586, while roughly 300 more children died of the disease in the US<sup>1</sup>. With a simple House vote, H.Res. 69 acknowledges the children who walk so bravely toward their death in full awareness, the suffering of their families, and the urgent need for greater pediatric cancer research funding. DIPG (diffuse intrinsic pontine glioma) exemplifies in a powerful way the marginalization of every childhood cancer, demonstrating that even with its prevalence—taking more lives than any other brain tumor, and brain cancer being the leading cause of death in kids with cancer—there has been no change in standard treatment protocol nor terminal prognosis for the disease in over 50 years.

Thanks to Jenny Mosier, Executive Director of the Michael Mosier Defeat DIPG Foundation in Bethesda, MD, a movement was initiated in October 2016 called “DIPG Across the Map”, an effort to get as many States as possible to declare a DIPG Awareness Day May 17, as Michael perished to the disease on May 17, 2015. ([www.defeatDIPG.org](http://www.defeatDIPG.org)) So far in 2017, 16 States have made the Declaration and there are some 10 more pending. “We are hoping this movement, California included, will lend support for the National Resolution,” says Janet Demeter, president of Jack's Angels Foundation in Agua Dulce, CA, an instigator of H.Res.69, which, in following suit with the “DIPG Across the Map” movement designates May 17<sup>th</sup> also for a cohesive effort for DIPG. “It's going to happen, whether in-time, or retroactively, May 17<sup>th</sup> is DIPG Awareness Day.” Demeter is planning a special celebration in Santa Clarita on the date, which may include a Proclamation from the City Council.

It is the reality endured by these children and their families each year that was the original motivation for the *DIPG Awareness movement*. “On top of a terminal prognosis there is the discovery that your child's life doesn't matter to our medical research system, because ‘the numbers aren't great enough for investors’; I live for the day when no one has to hear that,” explains Demeter. It was her meeting with then CA-State Assemblyman Scott Wilk, moved by her story, who wrote the original California Resolution in 2014 for DIPG Awareness Week. Congressman Steve Knight was State Senator at the time, and Jack's Angels began working with the Congressman in late 2015, during his first term to help create the National Resolution first introduced in January 2016(H.Res.586), re-introduced to the 115<sup>th</sup> Congress January 30<sup>th</sup> 2017 as H.Res.69. DIPG experts Sabine Mueller of UCSF, Michelle Monje of Stanford University, and Adam Green of UC Denver have all been contributors to the DIPG Awareness Resolutions.

“As I joined the childhood cancer advocacy community in 2014, I realized that the experience of marginalization wasn't isolated to DIPG, but was a common to many childhood cancers.” Little Jack

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<sup>1</sup> <https://www.defeatdipg.org/dipg-facts/overview/what-is-the-prognosis-for-a-child-diagnosed-with-dipg/>

Demeter's (8/30/08 – 7/30/12) life was cut short by the disease in 2012, at which time his mother, Janet Demeter, vowed to be a force for change. "We were told it was so rare it was like being struck by lightning, which only served to excuse the lack of solutions and research activity for this disease of which we had never heard, but we learned was well-known by clinicians. After Jack's death, I discovered it was the 2<sup>nd</sup> most common pediatric brain tumor, and responsible for the majority of pediatric brain cancer deaths each year. If brain cancer is the leading cause of death in kids with cancer, it's hardly irrelevant, no matter how you define 'rare'."

Cancer remains the leading cause of disease-related mortality in children in the United States.<sup>2</sup>

Parents have been expected to accept that the 4% of the NCI research budget<sup>3</sup>, and just 2% of ACS and LLS budgets for pediatric cancer research are generous numbers considering the patient population of children in hospitals is proportional to them, but it begs for questions as to how research is prioritized and who makes the decisions. H.Res.69 simply asks that pediatric and high mortality rate cancers have greater consideration for research funding as currently, they are not priorities. Parents have been demanding a conversation about the 4% since 2014 only to hear "no". There has been no public conversation, no statement, and no official update into pediatric funding percentages from the National Cancer Institute since 2013. Most parents of children with DIPG are far too emotionally devastated from their experience to take immediately to advocacy or activism. Demeter passionately underlines, "H.Res.69 was written for these parents, and for the children who will never have a voice in our world."

Demeter's activism began by running with angel wings covered with hundreds of ribbons for DIPG children; she would go to Washington that way, wearing them to the Summits for the Congressional Caucus for Childhood Cancer (2014-16) and White House Briefings (2015-16) to represent them. "The further we as advocates get from the death of our child, the easier it is to be placated into accepting that 4% is actually generous, that we needn't speak out about it...this is dangerous political correctness. Yes, we must work with the powers that be, but are not serving them nor those we represent by supporting political complacency. We must always be thinking of the child whose life was just snuffed out—the mother devastated by losing her beautiful daughter, once so full of life and hope—than to accept a system which values commerce certainly, but does not adequately reflect the values of the People it serves."

For more information about H.Res.69, visit [www.hres69.org](http://www.hres69.org).

*This article was written in honor of Julia Barocio and her mother, Sonia Gonzalez, of West Covina, CA. Julia died of DIPG on May 4, 2017. She was an avid softball player at her high school, and wanted to play Softball for UCLA.*

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<sup>2</sup> American Childhood Cancer Organization, <http://www.acco.org/us-childhood-cancer-statistics/>

<sup>3</sup> "An Analysis of the National Cancer Institute's Investment in Pediatric Cancer Research," NCI September, 2013, <https://www.cancer.gov/types/childhood-cancers/research/pediatric-analysis.pdf>