

For Immediate Release

200 Mile Activist Run for HRes586 Makes History for DIPG, Childhood Cancer Awareness, and the State of California

April 19, 2016 Santa Clarita, CA—Ultra-distance runner and activist for children with cancer Everett Smith of Redlands, CA and Janet Demeter of Jack's Angels in Agua Dulce, CA team up to promote "Action Days" for HRes586 in support of children currently afflicted with DIPG and their families. Beginning in Bakersfield, CA at Juliet Thorner Elementary School to honor Nathan Street and N8 pediatric brain tumor foundation, the 200-mile epic run passes through Lancaster, Agua Dulce—home of Jack's Angels, Newhall, through the Fernando Valley using the Topanga Route to Malibu, hugging the coastline to finish in Huntington Beach in honor of the McKenna Claire pediatric brain tumor foundation, at Mama's Restaurant on 39. The children Nate, Jack, and McKenna Claire who inspired the honored foundations all perished to DIPG, diffuse intrinsic pontine glioma. HRes586 designates the 4th week in May, Brain Tumor Awareness Month, to be National DIPG Awareness Week.

"It's literally cancer's death-row for children," says Janet Demeter, President of Jack's Angels Foundation about DIPG, "there have been no solutions for these children since Neil Armstrong's daughter died of it in 1962." Brainstem gliomas are the leading cause of death in children with cancer, and DIPG is responsible for roughly 80% of those mortalities; it is perhaps the deadliest pediatric cancer. "I call DIPG the 'Great Embarrassment' to our medical research system," says Demeter, "which has for decades neglected these children due to the projected idea that it won't be immediately profitable to invest in the research. And so, for a long time, families have been hearing there are no solutions because their children's lives basically don't matter to the system, even with our tax-dollars for cancer research with NCI." Action Days for HRes586, April 20 through May are the collaboration of Jack's Angels Foundation, Michael Mosier Defeat DIPG Foundation, and the Children's Cause Cancer Advocacy both in Washington, DC.

Authored by Congressman Steve Knight (R-CA-25) and co-sponsored by Representative Jackie Speier (D-CA-14) HRes586 asks for more consideration for low-survival-rate cancers and years of life lost in the research grant process with the National Cancer Institute (NCI). Currently, only 4% of NCI's research budget is designated towards pediatric research. "This has been a big issue nationally with the Childhood Cancer Community; the experience of DIPG exemplifies the effect of this neglect for pediatric research in a powerful way. These children must bravely face their death in full awareness of what's happening to them with their families watching on helplessly; to allow this neglect to continue would be unconscionable." Demeter and Smith hope to raise awareness for HRes586 so that all may encourage their friends and family across the United States to learn about it, and take action to support National DIPG Awareness Week by going to www.HRes586.com.

HRes586 has its beginnings in California, and in Santa Clarita, with CA State Assemblyman Scott Wilk's Resolution for DIPG, designating the 4th week in May 2014 as DIPG Awareness Week in California. Then State Senator Steve Knight was aware of the advocacy work of Jack's Angels and was very receptive as the new Congressman for the 25th District of California to this national ambition for DIPG Awareness. Knight joined the Congressional Caucus for Childhood Cancer and endorsed the STAR Act legislation, also pending in the House of Representatives, last September 2015. At that time his office began working with Jack's Angels and conferring DIPG expert Michelle Monje of Stanford, University on the writing of

HRes586, unofficially titled “Chad and Jack’s DIPG Resolution,” for Chad Carr of Ann Harbor, MI and Jack Demeter of Agua Dulce, CA, respectively, to honor the many thousands of brave children departed to DIPG with little to no fanfare.

Congressman Steve Knight, Everett Smith and other activist runners “Tattoo Tom” Mitchell, Becky Moss Mudd, Brian Jones and John McKay will be featured on the April 21 edition of Childhood Cancer Talk Radio, hosted by Demeter on TogiNet.com at 1pm Pacific, 4pm Eastern time. Billy Malone, candidate for Los Angeles County Supervisor 5th District, will be joining the Run for HRes586 with his own 300 mile “Walk in Your Shoes” through Santa Clarita on April 22 when the Run passes through. For maps and schedules for each day of the Run for HRes586, or to support the run, visit www.runforDIPG.org, or visit Jack’s Angels main website at www.jacksangels.org for this and information on the pioneering “Relay for Jack”, May 28 at Vasquez Rocks County Park in Agua Dulce, CA supporting an innovative research project for DIPG.

Volunteer Staff

Jack’s Angels Foundation
32520 Wagon Wheel Rd.
Santa Clarita, CA 91390
661-977-3125
Jacksangels1@gmail.com
www.jacksangels.org