

For Immediate Release:

**'Action Days' coming for Kids on Cancer's Death Row: HRes586 "Chad and Jack's DIPG Resolution"**

*April 2, 2016 Santa Clarita, CA*—The significant rise in awareness for the devastating lack of funding for research into causes and cures for pediatric cancer asks for change, and makes the need for it obvious, in (R-CA-25) Congressman Steve Knight's H.Res.586. The Awareness Resolution calls for elevated consideration for low-survival-rate cancers and years of life lost in the research grant process with the National Cancer Institute. Currently, only 4% of the NCI budget for research targets pediatric cancer, the leading cause of death in children in the United States after accidents and injuries. The very deadliest of those cancers are brain tumors, specifically **DIPG**--diffuse intrinsic pontine glioma—literally Cancer's Death Row for children, which has seen no change in prognosis since Neil Armstrong's daughter died of it in 1962.

"This is nothing new," states Janet Demeter of Jack's Angels Foundation in Santa Clarita, CA, "I was motivated to do something about it because the experience we had with our son Jack was so horrific, not just in the terminal diagnosis, but for the obvious lack of research activity there is for these children. Families regularly hear that there is nothing to save their child because the numbers aren't great enough for investors, meaning their lives have little value in our medical research system the way it currently operates."

Written by Congressman Steve Knight with Jack's Angels in collaboration with Dr. Michelle Monje, conferring DIPG expert at Stanford University, HRes.586 is unofficially titled "Chad and Jack's DIPG Resolution" in honor of Chad Carr of Ann Harbor MI, and Jack Demeter of Santa Clarita, CA. "Action Days" to call local and Washington Congressional Offices in support of H.Res.586 are set for April 7 and 20, respectively.

With growing awareness in social media, parents are learning that DIPG is not so rare as excuses attempt to justify, and are banding together for support. Demeter explains, "after Jack died I learned that DIPG is responsible for most of the brain tumor deaths in children, so, how many have to die until their lives are worth saving?" DIPG mostly affects young children between 5 and 10 years old; they remain fully aware of their demise until respiration is affected and death ensues, the families powerless to change it. HRes.586 designates the 4th week of May "National DIPG Awareness Week" for the thousands of departed heroes who have bravely faced death with little fanfare, and for those children currently fighting for their lives on Cancer's Death Row.

Jack's Angels is taking action with activist-running for H.Res. 586, planning a 200-miler with childhood cancer activist-runner Everett Smith, of Redlands, CA, April 20-24, wearing angel wings with ribbons for the many beloved children deceased to DIPG. "I'm asking our Governor Jerry Brown to consider a Proclamation for DIPG Awareness, as Maryland's Governor is doing so for May 17 (due to the work of Michael Mosier Foundation, Washington DC), of course with the ultimate goal that our President and Vice President will recognize our children with DIPG." The run will be featured on "Childhood Cancer Talk Radio" on TogiNet.com Thursday, April 21 at 1pm PST, with guests from across the country who are also activist runners for children with cancer.

The "Run for HRes586" begins April 20<sup>th</sup> in Bakersfield, CA, to honor newly founded N8 Pediatric Brain Tumor Foundation with Nicholas and Tracy Street; it passes through Santa Clarita, home of Jack's Angels,

and finishes April 24<sup>th</sup> in Huntington Beach, CA, home of McKenna Claire Foundation, Kristine Wetzel Executive Director; those who inspired these groups all died of DIPG.

Jack's Angels main fundraising event of the year, **"RELAY FOR JACK!"**, May 28 at Vasquez Rocks Natural Area in Agua Dulce, raises funds for a specific research project for **DIPG** called **"Jack's 12 Pebbles"** with the Children's Cancer Therapy Development Institute (Beaverton, OR) a non-profit biotech company dedicated to making all forms of childhood cancer survivable. Very little funding for pediatric cancer comes from the private sector, including the biggest cancer charities which give 2% at best to pediatric cancer research, despite their use of children in advertising. "We wanted to create an event that would have a *direct impact on research for DIPG and pediatric cancer*, and where kids helping kids could be featured." The relay accommodates ultra-distance runners, walkers, and children alike, with a variety of family activities at Vasquez Rocks County Park, including an archeological dig, arts and crafts, nature hikes and wildlife education.

For more information about HRes586 Action Days, visit [www.HRes586.com](http://www.HRes586.com); registration and sponsorship for "Relay for Jack!" May 28, and "Jack's 12 Pebbles" research project, visit [www.RelayforJack.org](http://www.RelayforJack.org) . Follow Janet Demeter and Jack's Angels on facebook and twitter to watch the activism run April 20-24, or visit [www.RunforDIPG.org](http://www.RunforDIPG.org). For all other inquiries visit Jack's Angels Foundation at [www.jacksangels.org](http://www.jacksangels.org); 661-977-3125, or email [jacksangels1@gmail.com](mailto:jacksangels1@gmail.com).

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