

The DIPG Awareness Resolution: H. Res. 114



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Reps Speier, Joyce Introduce Bipartisan Resolution to Fight Deadly Pediatric Cancer

Washington, DC –Today, Reps. Jackie Speier (D-San Francisco/San Mateo) and David P. Joyce (R-Cleveland), along with 16 of their colleagues, introduced a bipartisan resolution to raise awareness of and advocate for increased research funding for diffuse intrinsic pontine gliomas (DIPG) – a highly aggressive and difficult to treat pediatric cancer brain tumor. H. Res. 114 would recognize May 17th as National DIPG Awareness Day and call for expanded research for treatments and care for children with this deadly disease.

“DIPG is a death sentence for children today, but it doesn’t have to be. By investing in research and raising awareness we have the power to thwart this terminal scourge,” Rep. Speier said. “Our youngest and most vulnerable patients, and their families, deserve our full support. This resolution is an important first step in securing the support, attention, and resources needed to develop better treatment options and find a cure.”

“Sadly, cancer continues to be one of the leading causes of death for children,” Rep. Joyce said. “I’m proud to join Congresswoman Speier in introducing this bipartisan resolution to increase awareness of one of the deadliest forms of pediatric cancer and call for increased funding for the research needed to fight it. We must continue to work together on behalf of every child, parent and family affected by this devastating disease until no child has to hear the heartbreaking words ‘you have cancer’ ever again.”

Each year, some 200 to 400 children – typically between the ages of 5 to 9 years old – are diagnosed with DIPG. Less than one percent of its victims live more than five years after diagnosis and the median survival time is only nine months. Despite being responsible for the most pediatric brain tumor deaths each year, DIPG has not garnered significant attention from the media, researchers, or the government. As a result, parents are regularly told there is little that can be done for their children.

But there is hope. Recent studies, supported in part by the National Cancer Institute, have identified potential therapeutic targets for DIPG brain tumors. This type of research buttresses the development of drugs that could help to slow tumor growth.

The resolution was first proposed by Janet Demeter, a California resident, who lost her son Jack to DIPG in [2012], and later established the Jack’s Angels Foundation in his memory. Since then, Demeter and the DIPG Advocacy group have succeeded [with their partners, the Michael Mosier Defeat DIPG Foundation in Bethesda, MD,] in getting 31 states to establish DIPG Awareness Day resolutions and continue to work tirelessly to make sure that the children and families affected by this deadly disease receive the national recognition they deserve.

As a Co-Chair of the Childhood Cancer Caucus and Co-Chair of the Biomedical Research Caucus, Rep. Speier has a long history of supporting critical investments in medical research at the National Institutes of Health (NIH) and the Department of Defense (DoD). The Congresswoman also remains committed to working with her colleagues on both sides of the aisle and the foundation to make DIPG Awareness Day a reality.

[-2 edits provided by Jack’s Angels Foundation

-- DIPG Advocacy Group Introductory Letter to Congress and Resolution Text: www.bit.ly/hres-114 --