

A U.S. Congress United: Resolution Spotlights Childhood Brain Cancer, Establishes May 17 as DIPG Awareness Day

Five Introductions in both the House and Senate and a decade of childhood cancer advocacy have established May 17th as DIPG Awareness Day.

WASHINGTON, DC, UNITED STATES, May 17, 2023 /EINPresswire.com/ -- Just in time for the 118th Congress, Tuesday May 16 was the fifth introduction to the U.S. House of Representatives of the DIPG Awareness Resolution which draws attention to the unmet medical needs of children with brain cancer and establishes May 17 as DIPG Awareness Day. With now a [7-year track record](#) in the House of Representatives, the resolution attained an unprecedented 220 signatures last Congress to acknowledge DIPG and childhood brain

cancer—the leading cause of cancer-related deaths in children. “Most are unaware of the existence of monsters like DIPG— a literal death sentence,” says Janet Demeter (Dunsmuir, CA) President of Jack’s Angels, a 501(c)3 charitable organization devoted to raising awareness for DIPG and the need for greater research investment into childhood brain cancer. The charity was founded in Agua Dulce, CA, inspired by little Jack Demeter who succumbed to DIPG in 2012 at just 3 years, 11 months of age, and has been involved in promoting the resolution since 2014.

The bi-partisan team of lawmakers devoted to bringing attention to this largely unknown yet pervasive American tragedy, namely Rep. Debbie Dingell (D-MI-6), Rep. David Joyce (R-OH-14), and Rep. Michael McCaul (R-TX-10), are all well-acquainted with this issue due to the tireless efforts of their constituents to raise funds for research and to raise public awareness for childhood brain cancer. The Carr family of Ann Arbor, MI, founders of the ChadTough Foundation now the ChadTough Defeat DIPG Foundation and leaders in research development



and raising awareness; the Ronnebaum family of Cleveland, Ohio with The Cure Starts Now Foundation, founded by Keith and Brooke Desserich, have been fighting for “The Homerun Cure” since the late 2000s, and Texas’s powerful legacy of pediatric brain tumor support with the Carson Leslie Foundation, attendant upon the very first meetings of the Childhood Cancer Caucus in 2010. Equally important to note is the adoption of May 17th as the actual date supported by the community due to the efforts of the Michael Mosier Defeat DIPG Foundation, recently merged with ChadTough, to establish that date in as many states as possible beginning with their first Proclamation in the State of Maryland in 2016. The United States Senate, which has passed the DIPG/Pediatric Brain Cancer Awareness Resolution in four consecutive years 2019-2022, is expected to announce a similar commemoration once more in that chamber, an effort traditionally led by Senator Marco Rubio (R-FL) and Senator Jack Reed (D-RI).



Congresswoman Debbie Dingell (D-MI-12), Lead Sponsor the DIPG Awareness Resolution H. Res. 404

“DIPG is responsible for the most pediatric brain tumor deaths each year and consistently has one of the lowest survival rates. We must redouble our efforts to confront childhood cancer with the urgency it requires by supporting efforts that will spread awareness and spur new research endeavors that inspire new treatments and cures.

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Together, we can show these young children and their families that they are not alone in their fight,” comments Congresswoman Dingell, who co-lead the [original introduction](#) of the Resolution to the 114th Congress of the resolution on January 13, 2016, just one day after the original Cancer Moonshot Initiative was announced, for which the DIPG resolution has been consistently dubbed “moonshot4kids.”

“I’d never heard of DIPG; we were just told that there were no solutions for Jack because there weren’t enough of these children to matter to investors,” remarks Demeter

about her motivation to advocate for these children who typically die within a year of diagnosis. “Awareness is so important; their suffering has continued for decades out of sight and mind of the general public.” Marcelo Ortigao from Fort Collins, CO, Science and Medical Advisor to DIPG

Advocacy Group, lost his daughter Juliana to DIPG in 2019, comments, "DIPG is the deadliest pediatric tumor no one has heard about. Every year in the US, 400 kids are diagnosed with DIPG and odds are they will all die within 12 to 16 months. The DIPG Awareness Resolution has the power to start changing this picture. Resolutions provide clarity of goals: I fight for my daughter taken by DIPG, I fight for the DIPG Awareness Resolution."

Co-founder of DIPG Advocacy Group Paul Miller (Littleton, CO) is a long-time childhood cancer advocate who became a primary supporter of the

advocacy efforts for the DIPG Awareness resolution in 2016, for which the populist roots have never been an easy sell. "We are sorry, your child has a brain tumor...there is no cure... make as many memories as you can.. you may have a year at best.' The 1st man on the moon's daughter died from DIPG; I'm thinking he was told the same thing. Aren't we better than this," exclaims Miller, when asked to comment on the need for the resolution. Demeter's outlook on the introduction's effects is clearly positive; "with this powerful gesture we have hope for a cure to come more quickly, for more hands on deck, and our Members of Congress in actual agreement!"

DIPG Advocacy Group has just gotten word (4pm ET) that the Senate Resolution has been sent to be hotlined for a vote, led by Senator Marco Rubio (R-FL) and Senator Jack Reed (D-RI), along with a number of other original cosponsors; where the last 4 years have shown unanimous consent, their hopes are high for May 17, 2023!

Congresswoman Dingell's full press release can be [found here](#). For more information about the DIPG Awareness Resolution and its history, visit DIPGadvocacy.org.

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Juliana right before diagnosis, and months later.

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