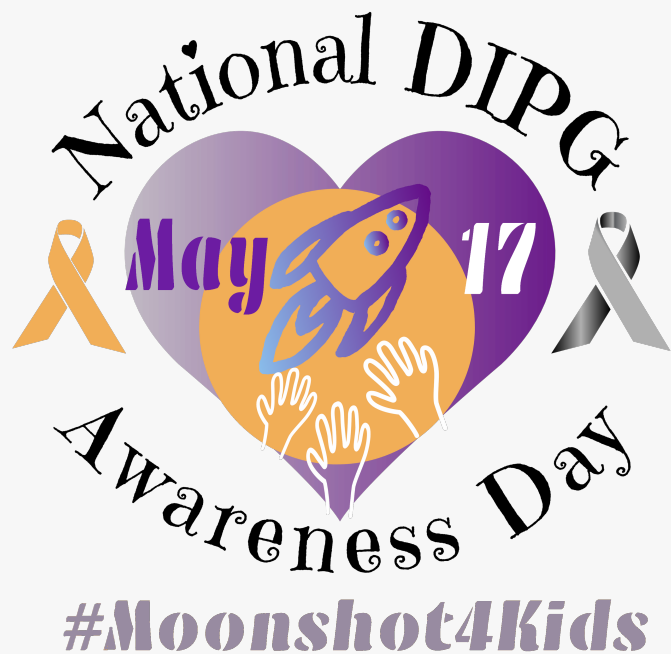


Senator Rubio Applauds the Passage of his Resolution to Designate May 17 as DIPG #PediatricBrainCancer Awareness Day

Brain/CNS tumors are the leading disease-related cause of childhood death in the United States, and represent the hidden, untold tragedy of childhood cancer.

SANTA CLARITA, CA, USA, May 20, 2020 /EINPresswire.com/ -- This evening, Senator Rubio's office sent news to Janet Demeter, Organizer for the DIPG Advocacy Group and founder of Jack's Angels, a childhood brain cancer foundation in Agua Dulce, CA, that a Senate vote had taken place and had unanimously passed the 2020 DIPG Pediatric Brain Cancer Awareness Resolution. May has been traditionally Brain Tumor Awareness Month from the time of Senator Ted Kennedy's passing and the work of brain cancer advocates, particularly the National Brain Tumor Society. This year, Jack's Angels Foundation and the Office of Congresswoman Jackie Speier (CA-14) hosted the #Moonshot4Kids Congressional Briefing in Washington DC on Feb. 13, 2020, "[DIPG, Pediatric Brain Cancer, and the Importance of H. Res. 114.](#)" In the House of Representatives, the DIPG Awareness Resolution (H. Res. 114) with similar language raises awareness to the deadly statistics of pediatric brain cancer and the inadequacy of the medical research system and investment culture to address the urgent, unmet needs of our nation's children afflicted with deadly



#Moonshot4Kids



Feb. 13 #Moonshot4Kids Congressional Briefing, Washington DC

pediatric disease. The briefing was a powerful opportunity for scientists at NIH to converse with those from [PNOC](#), Pacific Pediatric Neuro-oncology Consortium, and the [CBTTC](#), Children's Brain Tumor Tissue Consortium, America's leading scientific organizations for pediatric neuro-oncology research and treatment.

DIPG Advocacy Group had been anticipating this news from Senator Rubio's office after pushing for a vote on the 2020 Resolution, as in March the Senator's office had been less optimistic about getting the resolution on the Senate agenda amid the current COVID-19 pandemic. The Senate passed the resolution originally in 2019, which was a huge win for the childhood brain cancer community after 3 introductions of the House Resolution without gaining the attention of House leadership. The House Resolution was first introduced by Congressman Steve Knight in 2016, and in his absence Congresswoman Jackie Speier (D-CA-14) championed its re-introduction in 2019 with David Joyce (R-OH-14).



Florida Advocate Bonnie Woodworth with her daughter Tatum, who perished to DIPG

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Janet Demeter

Ms. Demeter explains, “the experience of DIPG doesn't lend itself to hopeful advocacy. When you are told at diagnosis that your child is going to die and there's nothing you can do about it, and then you must witness their death in complete helplessness--not just to save them, but to adequately comfort them as their death approaches, you don't just feel like running out and asking the world to help and to care. I was told there were no solutions for my son because his life had no value to research investors. That's a fine how-do-you-do in the wealthiest country in the world with the “best” technology. It's an unacceptable reality and I won't stop insisting that our children matter

until this changes.”

Upon hearing the news that this year, because of COVID-19 the Resolution might be shelved, Florida advocates in the group brought their voices together to let the Senator's office know that this would not sit with them. “As the virus exposes challenges in our health care system, DIPG and pediatric brain cancer expose the fact that our children have been falling through the cracks of the medical research system for decades without enough of a fight from us. If no one knows,

no one cares; most all these children die, and their families are too devastated to speak out. The few of us assembled represent thousands more who cannot speak out," Demeter explains. DIPG Advocacy Group just completed (4/27 - 5/1) a "virtual advocacy trip" to Capitol Hill with Congressional Offices on zoom; Florida advocates Ana-Mari Carr (Miami, FL), Bonnie Woodworth (Brandon, FL), Christina Wascher (Miami, FL), Kelly Fenzel (St. Augustine, FL), and Kirsten Finley (Ormond Beach, FL) were essential to the success of the trip as well as Senator Rubio's crucial support for the Senate Resolution.



Senator Rubio (R-FL), champion for the 2020 Senate DIPG Pediatric Brain Cancer Awareness Resolution

California was the first state in 2014 to recognize the importance of DIPG awareness, thanks to then Assemblyman Scott Wilk now CA State Senator.

When Steve Knight became Congressman for CA-25 in 2015, Jack's Angels worked with his office on the first national Resolution. Janet Demeter with Jack's Angels, Elizabeth Psar with Julia Barbara Foundation (Knoxville TN), and Paul Miller, childhood cancer advocate from Littleton CO, together as DIPG Advocacy Group turned to the Senate beginning in late 2017 to find champions for a Senate resolution, as it was difficult for the then 3-person group to get the message to all 435 offices of the House of Representatives. Demeter explains, "No one's heard of DIPG, so the going is slow, and it's hard to represent constituents to staff who will then actually transmit the information to the Members." Senator Rubio (R-FL) and Senator Reed (D-RI) became the Senate champions for the cause, with Wendy Fachon of East Greenwich, RI, as the lead advocate in honor of her son Neil Fachon for Rhode Island with Senator Reed.

DIPG, diffuse intrinsic pontine glioma, is the 2nd most common pediatric brain tumor. Brain cancer leads in childhood cancer incidence and deaths. DIPG causes more children to die each year than any other brain cancer, and represents a significant portion of the annual childhood cancer death toll. Amid a barrage of commercials asserting that 80% of children survive cancer due to our success with certain types of leukemia, DIPG is truly the hidden, untold story of childhood cancer. "It's not the success story people want to hear, but until we have more awareness of this fact among our representatives in Congress, and the greater public, solutions for children with brain cancer will remain elusive; modest allocations for childhood cancer legislation will continue to be a fight for our advocates where there should be no question. We are deeply grateful for the leadership Senator Rubio and Senator Reed in addressing this urgent

unmet needs of children in our society today.”

The group’s next goal is to have House leadership allow a floor vote on the House Resolution H. Res. 114 before the end of this session of Congress, designating May 17 as DIPG Awareness Day in perpetuity. Because of the partnering in this effort for May 17th with the Michael Mosier Defeat DIPG Foundation in Bethesda MD, 32 States in 2019 recognized the day, 31 the year prior, and now 20 this year have recognized it amid the Covid-19 crisis.

For more information about DIPG Advocacy Group and H. Res. 114, visit dipgadvocacy.org.

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