

Moonshot4Kids Congressional/OSTP Briefing and Reception Support DIPG Awareness Resolution for Childhood Brain Cancer

A forum of research experts, families, industry leaders and philanthropists make the case for Congressional acknowledgement of DIPG and childhood brain cancer.

WASHINGTON, DC, UNITED STATES, May 27, 2022 /EINPresswire.com/ -- The Moonshot4Kids Congressional/OSTP [Briefing on Tuesday, May 17 at 9 am](#) in the Rayburn House Office Building was hosted by DIPG Advocacy Group, [The Cure Starts Now](#), and the [Carson Leslie Foundation](#), with respective leadership giving testimony to the urgent, unmet needs of children with brain cancer, a largely unknown, unseen population in the United States. Brain cancer is the leading cause of disease-related death in children in the USA, and is one of the most poorly funded areas of cancer research considering the population's consistent death toll. Janet Demeter, organizer of the event and DIPG Advocacy Group, scheduled it to coincide with the agreed-upon date within the childhood cancer community to recognize the deadliest cancer known to humankind which kills most of its victims within a year, and nearly all of its victims within 3 years of diagnosis: DIPG, diffuse intrinsic pontine glioma, an ambassador for deadly childhood cancers categorically neglected for research funding.



Congressional / OSTP

#MOONSHOT4KIDS

May 17

The National DIPG Awareness Resolution

2022

DIPG/Pediatric Brain Cancer

BRIEFING

117th Congress ~ H. Res. 404

Moonshot4Kids Congressional / OSTP Briefing 2022



Presenting Sponsor

H. Res. 404, the DIPG Awareness Resolution, is now in its 7th year in Congress after 4 introductions. The resolution asks that pediatric and high-mortality rate cancers have greater consideration for research grants with public and private funding sources, and that federal funding be increased for pediatric cancer research, drawing direct attention to the challenges of the medical research investment culture to address the needs of children.

"Without that awareness," asserts Demeter, "change, support for

pediatric cancer legislation, and actual cures for children are painfully slow and hard fought. As every expert has attested, we are so close to finding a cure, but it's too far out of reach due to a research and regulatory infrastructure which is not responsive to the needs of children and those suffering from rare diseases, which is 90% of cancer diagnoses."

“

We are hopeful that ultimately House Leadership will allow consideration for a vote for H. Res. 404, recognizing the urgent, unmet needs of America's children.”

Janet Demeter

Keith Desserich of The Cure Starts Now, Gerald McDougall, Board Chairman and Ripley Martin, Director of the Carson Leslie Foundation (Dallas TX), as well as Michelle M. Le Beau, PhD, CSO, Cancer Prevention & Research Institute of Texas (CPRIT), gave detailed accounts of their trailblazing activity in creating and funding new research infrastructure and data registries to serve pediatric brain cancer research. Notable expert presenters included Dr. Michelle Monje (Stanford University, Palo Alto, CA), who attested to the utter lack of the aforementioned infrastructure until

recent years; Dr. Adam Green (Children's Hospital Colorado, University of Colorado School of Medicine), Dr. Adam Resnick, Children's Hospital Philadelphia (Scientific Chair for CBTN, PNOC, CCDI), Will Parsons MD, PhD, Texas Children's Cancer and Hematology Center, Baylor College of Medicine (Houston TX), Brigitte C. Widemann, M.D. Chief, Pediatric Oncology Branch, National Cancer Institute (NCI) and Special Advisor to the NCI Director for Childhood Cancer; Samuel Blackman, MD PhD, co-founder and Chief Medical Officer, Day One Biopharmaceuticals, and the briefing was completed by Ryan Agnew (Sandy, UT) whose 6-yr-old daughter Aspen is currently fighting DIPG for her life.

Due in part to temporary road closures on Capitol Hill, the briefing began late and was cut short. Actress, Author, and brain tumor survivor Grace Wethor (Los Angeles, CA), leader of the new DIPG/DMG Brain Tumor Board Lisa Ward (Wamego, KS), entrepreneur/brain tumor parent Tracy



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Ryan, CCO of NKore Biotherapeutics (Los Angeles, CA), Javad Nazarian Ph.D, M.S., PNO, Children's University Hospital, Zurich, Children's National Hospital, Washington, DC, Mark Souweidane M.D., F.A.C.S., F.A.A.P. New York-Presbyterian/Weill Cornell Medical Center, and parents Philip Tan (San Diego CA) and Marcelo Ortigao (Ft Collins, CO) were among those valued presenters unable to complete the morning's lineup of testimony. However the synopsis of the briefing with their recorded testimonies will be presented first to the Health Subcommittee of Energy and Commerce, the House Leadership, and will be shared with the entire Congress throughout June and July. Dr. Danielle Carnival EOP, OSTP was present for the Administration, with DIPG Advocacy Group's hope for greater acknowledgement of the #1 cancer-related killer in children with the Cancer Moonshot Initiative. "There's literally been no change in the standard treatment protocol for DIPG since Neil Armstrong's daughter died of it in 1962, and parents are in the same position as they were back then--saddled with finding the answers and watching our kids die in complete helplessness," notes Demeter.

Tracy Ryan and Dr. Anahid Jewett, Chief Scientific Officer of NKore Biotherapeutics, were among those slated to present at the briefing who had given presentations at the Moonshot4Kids Reception event the evening prior, on Monday, May 16 at the London Room, Marriott Hotel at Metro Center. The reception was a welcome to briefing presenters and a forum of gratitude to Members of Congress and the Senate for their support for the DIPG Awareness Resolution, the Archangel of Hope Awards. Several Members were represented by Congressional staff, but Congressman Michael McCaul (R-TX-10) was able to personally attend the reception and witness enthusiastically the first public presentation of breakthrough scientific discovery by NKore, "Novel Strategies to Treat and Prevent Aggressive Lethal Cancers Using Super-Charged Natural Killer Cell Immunotherapy". Congressman McCaul had been honored at the event for his continued crucial service to the childhood cancer community as Chairman of the Childhood Cancer Caucus, and specifically for the DIPG Awareness Resolution as a consistent supporter since the first introduction in 2016, giving voice to an invisible population in urgent need of help.

Congresswoman Debbie Dingell (D-MI-12) and Congressman David Joyce (R-OH-14) were among those honored as the current leading sponsor and co-sponsor, respectively, of H. Res. 404, the DIPG Awareness Resolution. Senator Marco Rubio (R-FL) and Senator Jack Reed (D-RI), the lead sponsors for the Senate DIPG/Pediatric Brain Cancer Awareness Resolution, were also honored, and delivered the message that evening through staff that the 2022 Senate Resolution had just been hotlined for a vote earlier that day.

"We are hopeful that with this testimony shared by the world's experts, patient and parent leaders, that ultimately House Leadership will allow consideration for a vote for H. Res. 404, recognizing the urgent, unmet needs of America's children," concludes Demeter. For more information about H. Res. 404 and how to support it, visit dipgadvocacy.org.

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