

Public Sharing of Pediatric Brain Cancer Presentation Prepared for House Health Subcommittee Supporting H. Res. 404

Urgently seeking the attention of House and Committee Leadership, DIPG Advocacy Group also makes its case to the public with its 3-year compilation of testimony

LOS ANGELES, CALIFORNIA, UNITED STATES, October 7, 2022 /EINPresswire.com/ -- DIPG Advocacy Group, the national advocacy arm of Jack's Angels, a childhood brain cancer charity in Agua Dulce, CA is making public a specially prepared presentation on childhood brain cancer for the House Health Subcommittee of Energy and Commerce and the House of Representatives Leadership Team, creating a private and now public hearing of this information as they make the case for a vote for H. Res. 404, the DIPG Awareness Resolution. Premiering on Youtube publicly tomorrow evening, Saturday, October 8 at 8pm Eastern time, is a compilation of testimonials from physician-researchers, industry leaders, parent-led foundations and families including selections from the group's first Congressional

Congressional OSTP

The National DIPG Awareness Resolution

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DIPG/Pediatric Brain Cancer

BRIEFING

117th Congress ~ H. Res. 404

2022 Banner for the May 17 Congressional and Cancer Moonshot Team Briefing

Briefing in Washington, D.C. Feb. 13, 2020 immediately before the pandemic shutdown, the Moonshot4Kids Congressional/OSTP Cancer Moonshot briefing on May 17, 2022, and key testimony from childhood cancer advocates across the United States in support of accelerating a cure for DIPG, which is a currently a death sentence.

Essentially, the group is directly requesting that the Committee to which the resolution has been introduced, and House Leadership, allow a pathway to a vote for this bill after 4 Congresses, 7 years, and 2600 more children lost to this one tumor alone. With the attention brought to DIPG, and the fact that childhood cancer research has been systematically neglected, the aim is to accelerate a cure where nothing has changed in standard treatment for DIPG since Neil Armstrong's daughter died of the disease in 1962. "The deaths are prolific, as well as torturous,"

states Janet Demeter, founder of DIPG Advocacy Group, "DIPG alone is responsible for a significant portion of the annual childhood cancer death toll." The only controversy surrounding consideration for this resolution appears to be internal House politics. House Leadership has the power to amend, change, or create new rules with each Congress; however, the only other such exception made for a commemorative resolution was for Patriot's Day. Demeter puts forth a populist perspective, asserting, "We The People insist that saving the lives of our children is not only a worthy exception to the restrictive rule on commemoratives, but a qualified one as well. We are not asking for any rules to be broken, or recklessly disregarded," referring to the exception protocol(1) in the House Rules for bereavement and required action.

Presenters Keith Desserich of <u>The Cure</u> <u>Starts Now</u>, Gerald McDougall, and Ripley Martin, Board Chairman and



The effects of steroid use on pediatric brain tumor patients can be devastating



Breakthrough Natural Killer Cell Cancer Treatment Presentation by NKORE Biotherapeutics

Director, respectively for the <u>Carson Leslie Foundation</u> (Dallas TX), as well as Michelle M. Le Beau, PhD, CSO, Cancer Prevention & Research Institute of Texas (CPRIT), give accounts of their trailblazing activity in creating and funding new research infrastructure and data registries to serve pediatric brain cancer research. Notable expert presenters include Dr. Michelle Monje

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(Stanford University, Palo Alto, CA), 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), Javad Nazarian (PNOC, Children's University Hospital, Zurich, DIPG Centre of Excellence, and Children's National Hospital, Washington, DC), Willou Parsonsullu MD, Phud, Texas Children's Cancer and Hematology Center, Baylor College of Medicine (Houston TX), Brigitte C. Widemannu, M.D. Chief, Pediatric Oncology Branch,

National Cancer Institute (NCI) and Special Advisor to the NCI Director for Childhood Cancer;

Lindsey Hoffman Phoenix Children's Medical Group, Hematology/Oncology, and Director of THE DIPG REGISTRY; Samuel Blackman, MD Ph\(\text{D}\)D, co-founder and Chief Medical Officer, Day One Biopharmaceuticals, and Dr. Charles Keller, Scientific Director of the Children's Cancer Therapy Development Institute. DIPG families presented at both of the 2022 and 2020 briefings; tragically Ryan Agnew's 6-yr-old daughter Aspen just recently passed away. Her memorial is to be held in Sandy Utah on Sunday, Oct. 9. Xavier Tan, (July 3, 2022) and Ella Breese (Sept. 15), whose families also presented at the 2022 briefing, also passed away.

"The Cancer Moonshot portion of this," adds Demeter, "is the amazing breakthrough cancer discovery presentation by NKORE Biotherapeutics, inspired by the love of a young child with brain cancer." Los Angeles based entrepreneur and supermom Tracy Ryan, a founder and the Chief Communications Officer for NKORE, shares the ongoing, epic story of "Saving Sophie", a childhood brain cancer charity with a focus on saving her daughter Sophie, and physician-researcher Dr. Anahid Jewett (UCLA, CSO NKORE) shares her recent breakthrough, "Novel Strategies to Treat and Prevent Aggressive Lethal Cancers Using Super-Charged Natural Killer Cell Immunotherapeutic."

"We are hopeful that with breakthrough non-toxic scientific discoveries finding the light of day, and testimony shared by the world's experts in pediatric neuro-oncology, industry, philanthropy, patient and parent leaders, that H. Res. 404 recognizing the urgent, unmet needs of America's children will ultimately be deemed worthy of a few minutes of consideration on the floor of the People's House, this Congress. There has never been a time in the last seven years where something else on the Hill was not deemed more important than the suffering and deaths of these children. We need this now," concludes Demeter. For more information about H. Res. 404 and how to support it, visit dipgadvocacy.org.

(1) "A resolution of bereavement, or condemnation, or which calls on others to take a particular action, is eligible to be scheduled for consideration."

https://www.majorityleader.gov/content/117th-congress-legislative-protocols

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