

Moonshot4Kids Childhood Brain Cancer Briefing for House Health Subcommittee of Energy and Commerce, the House Leadership Team, and the Biden Administration | October 2022

PART ONE: Voices Lost to the Front Line: Doctors, Families, Patients

H. Res. 404, Making an Invisible Population Visible

The first hour and 19 minutes constitutes the full briefing for the purpose of establishing the importance of awareness in accelerating cures, the urgency of childhood brain cancer, the unseen, horrific suffering and deaths in our community, and thus the worthiness of H. Res. 404 for scheduling consideration.

Despite impressive progress in research infrastructure and legislation, NOTHING has changed for children with DIPG and other childhood cancers. We possess all the tools, dedicated professionals, and a committed community. Awareness and more funding will save lives sooner.

PART TWO: The Components of Success Aligned: Parent-Driven Research; Consortia, Philanthropy, and Government Partnerships

The next hour fills in the gaps of the realities faced by pioneering parent-led foundations The Cure Starts Now and Carson Leslie Foundation, and also the National Brain Tumor Society; State Leadership in Texas with CPRIT, the DIPG Registry, Connect, CCDI, NIH programs with Dr. Brigitte Widemann contributing.

Featured Presentation: NKORE Biotherapeutics

Tracy Ryan, CCO presents ‘Saving Sophie’ and the entrepreneurial feats attained with Cannkids and NKORE Biotherapeutics. Tracy, from the diagnosis of her daughter Sophie, has been determined to find a cure for cancer; this leap forward with Dr. Anahid Jewett (UCLA) and Natural Killer Cell therapy originates from “outside the box” of the pharmaceutical and regulatory toolkit.

Cancer Moonshot Team Introduction: Jack’s Angels reports from the original charge from Vice President Biden’s 2016 Cancer Moonshot Initiative and OSTP Team, to create a Cancer Moonshot Summit locally, in Santa Clarita, CA in June of 2016, bringing the charge full circle to the 2022 Briefing.

Program of Testimony (full program, with time stamps)

<https://dipgadvocacy.org/wp-content/uploads/2022/10/Program-of-Testimony.pdf>

Youtube:

Moonshot4Kids Cong/Adm Briefing, full program: <https://youtu.be/Bydyh8OmEF8>

Part One: <https://youtu.be/EcPmFYpaVAE>

Part Two: <https://youtu.be/Y4dSld80ytc>

NKORE: (Featured Presentation) <https://youtu.be/tO3il7jojHk>

Cancer Moonshot Team Introduction: <https://youtu.be/WGXC8BtSZmQ>

Google Drive:

Full Briefing:

<https://drive.google.com/file/d/1idPpfHGHYilysJy73Wu1Kk4zWz-c0G6w/view?usp=sharing>

PART ONE:

https://drive.google.com/file/d/1wRUREKkkjYIkFDAAjgEgx_5iwEX6R7h/view?usp=sharing

PART TWO:

https://drive.google.com/file/d/1E_HQglWgTEeEqk4C-w_qDB_lzoQaajg5/view?usp=sharing

NKORE: Featured Presentation

<https://drive.google.com/file/d/1OLJgd99BeY4UcIl2Jg44aiG0xnVguA00/view?usp=sharing>

Cancer Moonshot Team Intro:

https://drive.google.com/file/d/17OR0WGQl9_0yFpdRpb15lcmzc50sNEo/view?usp=sharing

More Resources:

www.dipgadvocacy.org

Letter To Congress:

https://dipgadvocacy.org/wp-content/uploads/2022/09/0-Sept26_22Congress.pdf

Letter to House Leadership:

https://dipgadvocacy.org/wp-content/uploads/2022/10/0-Sept3Leadership_PRINT.pdf

H. Res. 404 Press Summary:

https://dipgadvocacy.org/wp-content/uploads/2022/09/117thC-922_Press-Summary_H.Res_.404.pdf

Bereavement Exception Protocol: (House Rules)

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

“A resolution of bereavement, or condemnation, or which calls on others to take a particular action, is eligible to be scheduled for consideration.”

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