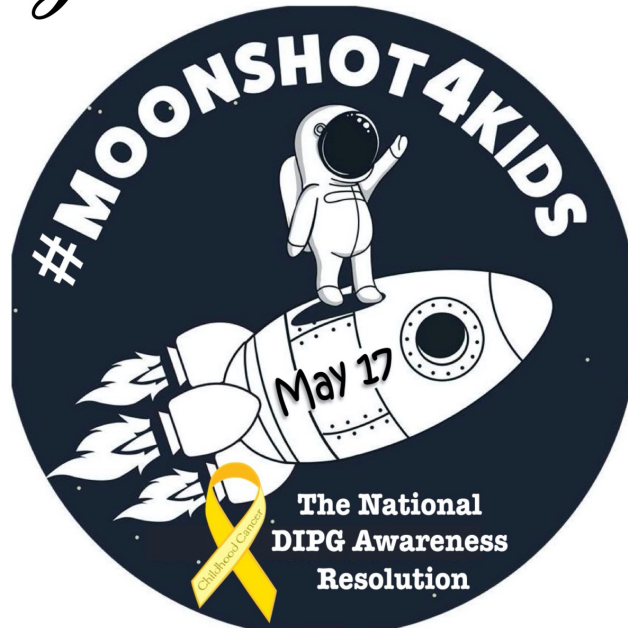


DIPG ADVOCACY GROUP

Presents a Compilation of Expert Testimony,

*spanning 2 Moonshot4Kids Childhood Brain Cancer Briefings, 2-13-2020 and 5-17-2022,
Specially Prepared for the **Health Subcommittee** of Energy and Commerce,
and the **House Leadership Team**, and for the benefit of the **Cancer Moonshot Initiative**.*
<https://youtu.be/Bydyh8OmEF8>

Congressional / OSTP



2022

DIPG/Pediatric Brain Cancer

BRIEFING

117th Congress ~ H. Res. 404

...In Collaboration of the Offices of Congresswoman Debbie Dingell (D-MI-12), Congressman David Joyce (R-OH-14), and Congressman Michael McCaul (R-TX-10);, with special thanks to Congresswoman Jackie Speier (D-CA-14) for her support for our initial briefing on February 13, 2020, and for her strong leadership throughout the 116th Congress for DIPG Awareness...

...On the Importance of Recognizing DIPG and Childhood Brain Cancer, the Leading Cause of Cancer-Related Deaths in Children, to Accelerate Cures for this Vulnerable Population in Urgent Need as Described and Commemorated in the DIPG Awareness Resolution, H. Res. 404, in this 117th Congress.



PART ONE

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

Introduction: Moonshot4Kids Congressional/OSTP Briefing
H. Res. 404: Asking our Reps to Help Attract a Cure for a Death Sentence

00:00:27

Janet Demeter, A founder of DIPG Advocacy Group

Jack's Angels, Santa Clarita CA, for DIPG Awareness and Childhood Cancer Advocacy
Jack's mom. (Jack Demeter 08-30-2008 – 07-30-2012)

i. DIPG/DMG Basic Science

"So close, but yet so far."

*--translatable research and the promise of novel therapies,
with current outcomes remaining unchanged*

00:09:13

Michelle Monje Deisseroth, MD PhD

Stanford University, Palo Alto, CA

Adam Green, MD

00:13:04

University of Colorado School of Medicine (Anschutz Campus)

Mark M. Souweidaine, M.D., F.A.C.S., F.A.A.P.

00:17:11

*New York-Presbyterian/Weill Cornell Medical Center and
Memorial Sloan Kettering Cancer Center*

Javad Nazarian, Ph.D, M.Sc -

00:23:46

*PNOC, Children's University Hospital, Zurich,
DIPG Centre of Excellence; Children's National Hospital, Washington, DC*

The Reality

00:25:35

Cassie Diaz: "So I plead with you, to help us spread awareness to this disease
as not enough people know about it...because our kids deserve a future;
they don't deserve a death sentence."

ii. Industry and Consortia, A Crossroads of Interests

00:28:47

Dr. Charles Keller

Scientific Director, Children's Cancer Therapy Development Institute (cc-TDI)
NCI/COG Soft Tissue Sarcoma (STS) Committee

*The "Valley of Death," the Commercial and Humanitarian Aspects of Research
and the Challenge of Funding Pediatric Drug Development, Lack of Awareness
H. Res. 404 as a needed mechanism for change complementary to current legislation*

00:35:24

DAY ONE BIO

*A Pediatric Focus: Burden of making the case for investment,
Academic collaboration; the challenge of drug approval/use off the shelf*

Samuel Blackman, MD PhD

and Mark Kieran, MD PhD

00:41:08

Adam Resnick, PhD –

Children's Hospital of Philadelphia, Children's Oncology Group (COG)
Lead Scientist, CBTN, PNOC; Principal Investigator, CCDI
Children's Brain Tumor Network, Pacific Pediatric Neuro-Oncology Consortium
National Cancer Institute /Children's Cancer Data Initiative

iii. The Voices of Survivors, Families, Patients

00:48:22

Jace Ward, Pre-Law Student, Patient (2-13-2020)

“Awareness is the catalyst for a cure. Please give us just one day a year...for all the years of lives lost to this horrible tumor.”

00:55:45

Jenny Mosier (2-13-2020)

“The recognition of our federal government matters.”

Founder, Michael Mosier Defeat DIPG Foundation,
currently the merged ChadTough Defeat DIPG Foundation

01:00:01

Nicole Puglisi

On living in the Shadow of DIPG

Student, long-term DIPG survivor

01:04:35

Grace Wethor,

The Importance of Being Visible

DIPG Patient, Actress, Author, Brain Tumor Survivor

01:05:42

Philip Tan, PhD

“The victims are not only suffering from this disease, but from neglect and indifference of the U.S. government and the health care industry.”

DMG parent (Xavier), Pharmaceutical Industry professional

01:08:47

Ryan Agnew

“She doesn’t have time; we need it yesterday...we need it now.”

DIPG parent (Aspen), on speeding a cure.

01:12:40

Ella Breese

Medulloblastoma Patient

01:14:26

Jace Ward in December of 2020

(DIPG is beginning to progress)

01:16:32

~ Parent and Grandparent Advocates ~

Lena Davis

Grandmother of Aldon Blom

Harrisville, PA

Tribute to Drake Joseph Quibodeaux

With his mother and little brother

Venton, LA

Margie Akehurst

Grandmother of Bailey Dodson

Broken Arrow, OK

Howard Salmon

Father of Liam Salmon

Redding, CA

1:19:11

End of Part One

PART TWO

The Components of Success Aligned:

Parent-Driven Research; Consortia, Philanthropy, and Government Partnerships

01:19:45

Congressman Michael McCaul (R-TX-10)
Chairman and Founder, Childhood Cancer Caucus
The Hope and Optimism of Adventurer Explorers for the Cure

A. The Investment of Parents Driving Needed Research

Trailblazing the pathway for the Homerun Cure and the DIPG Registry

01:24:59

Keith Desserich, Founder
THE CURE STARTS NOW

01:33:13

Lindsey M. Hoffman, DO
Phoenix Children's Medical Group,
*Hematology/Oncology, and Director of **THE DIPG REGISTRY***

B. The Investment of Parents Driving Needed Research Part II

CPRIT, The Cancer Prevention and Research Institute of Texas
Unparalleled State-Level Leadership

THE CARSON LESLIE FOUNDATION
Pediatric Brain Cancer and Childhood Cancer Investment
#CureMEdullo

01:39:17

Gerald McDougall, Board Chairman
Carson Leslie Foundation, Dallas TX

01:41:41

Ripley Martin, Director
Carson Leslie Foundation, Dallas, TX

01:45:56

Michelle M. Le Beau, PhD, CSO
Cancer Prevention & Research Institute of Texas (CPRIT)

C. NIH/NCI Steps Up for Childhood Cancer Research

01:48:40

Brigitte C. Widemann, M.D.
Chief, Pediatric Oncology Branch, National Cancer Institute (NCI)
and Special Advisor to the NCI Director for Childhood Cancer

01:54:41

Will Parsons MD, PhD
Texas Children's Cancer and Hematology Center,
Baylor College of Medicine (Houston TX)
Principal Investigator, **Pediatric MATCH Trial**

01:59:16

D. Philanthropic Partners
*Carson Leslie Foundation, The Cure Starts Now,
National Brain Tumor Society*

02:03:20

David Arons, JD, CEO
National Brain Tumor Society
“For pediatric brain tumors, the urgency to take action could not be more clear.”

02:08:23

E. THE REALITY
*Childhood brain cancers as neglected, rather than rare diseases
AND THE UNREALITY OF DIPG STATISTICS*

Marcelo Ramalho-Ortigao, PhD –
DIPG Advocacy Group and DIPG parent (Juliana)
Research expert in infectious and neglected diseases

02:11:50

DIPG/DMG DADS

02:14:47

David Turner
An Amazing Young Kentucky Advocate, with his Best Friend

02:15:13

Lori Samms Remembers Annabelle
Cambridge City, IN

02:15:27

Patricia Palman Remembers Josephine
Woodland Park, NJ; Jim Thorpe, PA

02:17:30

END PART TWO

Featured Presentation

NKORE Biotherapeutics Scientific Breakthrough Discovery for CANCER

With Tracy Ryan and Dr. Anahid Jewett

02:17:46

1. Tracy Ryan: Saving Sophie, the Journey
Entrepreneur Supermom On A Mission To Cure Cancer
“Weed the People” documentary, founding Cannakids, and founding NKORE

02:39:33

2. Dr. Anahid Jewett
“Novel Strategies to treat and prevent aggressive lethal cancers using super-charged
Natural Killer Cell Immunotherapy”
*Professor and Director of Tumor Immunology Laboratory
Division of Oral Biology and Medicine
The Jane and Jerry Weintraub Center for Reconstructive Biotechnology
Jonsson Comprehensive Cancer Center
UCLA School of Dentistry and Medicine
Chief Scientific Officer, NKORE Biotherapeutics*