

# 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**

*117<sup>th</sup> 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 116<sup>th</sup> 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 117<sup>th</sup> 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*

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#### *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.”

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#### 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

**E N D P A R T T W O**

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*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 Immunotherapeutic”  
*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*