

# 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**.*

*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*