

A Request for Scheduling Consideration for H. Res. 404

117th Congress Legislative Protocols, #1 (Commemoratives)

Congressman Steny Hoyer (D-MD-5), House Majority Leader
1705 Longworth House Office Building
Washington, DC 20515

November 8, 2022



To the Honorable Steny Hoyer, Majority Leader for the U. S. House of Representatives:

We would like to thank the Leadership of the House of Representatives for considering proposals that would make a difference for children and families living with pediatric cancer. As you know, the DIPG Awareness Resolution has been introduced in 4 successive Congresses, enabling a small group of advocates to bring constituent stories from around the country to as many of the 435 offices in the House of Representatives as we could, to educate about the realities of childhood brain cancer, DIPG, and the urgent need for greater childhood cancer awareness. In our very first year, 2016, we came to discover there was an issue with commemoratives and the House Rules; and so, with research into the original cause for the restrictions on commemoratives which had been excessively overused in the 1960s through the 1990s, we persisted for reasons of urgency to acknowledge these children who are fighting completely unaided in an invisible war against a deadly foe. They are a voiceless population in urgent need of help, with 2800 more lost to the DIPG tumor alone since the first introduction of the Resolution in 2016.

In support of the efforts of the Honorable Debbie Dingell (D-MI-12), the Honorable David Joyce (R-OH-14), and the Honorable Michael McCaul (R-TX-10), Founder of the Childhood Cancer Caucus, DIPG Advocacy Group and the undersigned would like to formally request your consideration of H. Res. 404, the DIPG Awareness Resolution, for scheduling for a vote in the House of Representatives, with respect to the 117th Congress Legislative Protocols(1) concerning commemoratives: “A resolution of bereavement, or condemnation, or which calls on others to take a particular action, is eligible to be scheduled.”

Respecting the original 104th Congress (1995) rule VII clause 5 restriction on commemoratives due to excessive overuse at the time, and with respectful regard to the importance of floor-time in the House of Representatives, we submit that H. Res. 404 may, by your Leadership’s discretion, be considered as an exceptional, rare situation warranting national recognition. The deadly DIPG is responsible for the majority of childhood brain cancer deaths annually, a significant portion of the annual childhood cancer death toll—a fact of which most are shocked to learn because they’ve never heard of it. The four introductions alone, with cosponsor numbers 18 for one year in the 114th Congress, 53, for two years in the 115th Congress; 215, for two years in the 116th Congress, and currently 215(11/8/22), expected to surpass 218 by Dec. 1, 2022, are exceptional among other such resolutions.

We respectfully submit that, considering the small number of advocacy operatives sharing information, the show of support signifies an exceptional resolution with no parallel example of this magnitude, and also the uniqueness of this moment and opportunity. We hope that the following points will sufficiently demonstrate the exceptional nature of this resolution and the importance of acknowledging the needs of a voiceless population facing a merciless killer, where typically their families are told to “go make memories.”

The Problem

Pediatric brain cancer is one of the leading causes of death in children in the United States, of which most are largely unaware; it is also one of the least-funded areas of cancer research by the federal government. Despite celebrated progress in childhood cancer legislation with The Creating Hope Act, The RACE Act, and the

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

Childhood Cancer STAR Act, and despite promising government programs like Gabriella Miller Kids First designed to benefit pediatric research, literally nothing has changed for children afflicted with DIPG and many childhood cancer types. Amid the national narratives of St. Jude's commercials and the billions we pour into NIH, the general idea conveyed is that we invest in our children. The reality, when it strikes close to home, is tragically and disappointingly opposed; this is the first disillusionment that most families experience with a pediatric cancer diagnosis, and always, with DIPG.

There has been no change in the standard treatment protocol or prognosis for DIPG since Neil Armstrong's daughter Karen died of it in 1962, yet we put men on the moon and brought them home with the technology of the day. Why? Because we were all-in; we had national resolve. We created a vaccine in less than a year for Covid. If no one knows, nothing changes quickly enough to help these children who continue to endure these horrific deaths in obscurity, while we parents watch in complete helplessness. This is where Congress, our closest representation in the Federal Government, has the power to help us. DIPG represents an urgent, and much larger, unmet need of a voiceless population amid misleading national narratives about childhood cancer survival, and the resulting inflated assumptions about investment into pediatric research.

The Solution: Acknowledgment and National Awareness for Effective Change

An awareness day will alert the nation not only to the existence of a monster like DIPG, and the fact that we possess the resources to deter it, but to the fact that childhood cancers have been systematically neglected for research investment, no matter how unintentionally. It would serve to educate the public about childhood brain cancer, as even some pediatricians are unaware of the subtle subset of neurological symptoms which accompany most brain tumors; as such we discover too many of them at autopsy. As the late, great Jace Ward testifies in the Moonshot4Kids childhood brain cancer briefing, (00:48:22), time and time again awareness is the proven catalyst for accelerating cures. We can, and we must do better for our children, now.

Increased awareness is urgent, as parent-led foundations have been shouldering over the last decade 95% of research funding for childhood brain cancer and for clinical trials, and it is needed to support ongoing progress with data-sharing and research infrastructure development between consortia and government partners to better accommodate the unmet needs of children. Unlike 60 years ago, today we have the technology and the resources to address childhood brain cancers. Pediatric neuro-oncology is a crucial field of discovery on intersecting frontiers of our medical knowledge about cancer and the brain. We are so very close to a cure, but so far in awareness and funding; awareness is the missing catalyst to the flow of adequate funding and the production of effective therapies for children.

Finally, H. Res. 404 was originally conceived to draw attention to the fact that our children are underserved in the medical research investment culture, where parents routinely discover that their children are not considered a worthy investment incentive, and where their suffering remains literally unknown. DIPG children remain fully cognizant as their bodies become increasingly paralyzed until their organs fail, aware of their approaching death, unable to express themselves. It is indescribably terrifying for them. Where we parents are powerless, and our doctors are powerless, our representatives in Congress are in a position to shed needed national light on their predicament with H. Res. 404.

We believe H. Res. 404 represents an important unifying influence at this time in our democracy, both with seemingly impossible divisions between political parties, and with cynicism among the electorate who doubt their representation amid super-PACs and special interests. The process of working with our Members of Congress to help these suffering and dying children has been an encouraging and hopeful process of

(2) <http://hres404briefing.us> || Links to program, video content: *Congressional/OSTP childhood brain cancer briefings 2020, 2022, and selected submissions from families around the US and the world*

partnership, fostering more immediate support of important childhood cancer legislation such as Gabriella Miller Kids First 2.0 and the STAR Act allocations.

Thank you for your time considering this issue of urgency affecting our most vulnerable citizens. We hope that you know not only how much we appreciate the care which you consistently support in service of our children, but in the unique power you possess to accelerate effective therapies, now, with H. Res. 404. Scheduling a vote will not only make history for childhood cancer, but take the global lead in acknowledging the need for, and inspiring, greater action towards a cure.

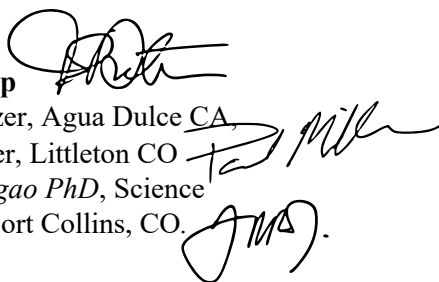
In gratitude for your consideration, we remain
Respectfully yours,

DIPG Advocacy Group

Janet Demeter, Organizer, Agua Dulce CA

Paul Miller, Co-Founder, Littleton CO

*Marcelo Ramalho-Ortigao PhD, Science
and Medical Advisor, Fort Collins, CO.*



DIPG Advocacy Group is the national advocacy arm of Jack's Angels, partnering with childhood cancer organizations and individual advocates to support the DIPG Awareness Resolution in the United States Congress.

Partial list of supporters of the DIPG Awareness Resolution 2016 onward:

Oncology Nursing Society (ONS), The Children's Brain Tumor Project, Children's Cancer Therapy Development Institute (cc-TDI), Children's Brain Tumor Network (CBTN), Pacific Pediatric Neuro-Oncology Consortium (PNOC), Cincinnati Children's Hospital;

2019-2020 Sign-on Letter for pediatric neuro-oncologists

Dr. Adam Green

University of Colorado, Denver, Children's Hospital Colorado

Javad Nazarian, PhD

The George Washington University School of Medicine and Health Sciences; Children's National Medical Center, Washington, DC.; DIPG Research Institute, University Children's Hospital, Zurich Switzerland

Dr. Charles Keller, Scientific Director, Children's Cancer Therapy Development Institute

Sabine Mueller, MD, PhD, MAS

Adjunct Associate Professor, UCSF, PNOC lead scientists

Director, DIPG Centre of Expertise, University Children's Hospital Zurich, Switzerland

Michelle Monje, MD, PhD, Associate Professor of Neurology; and by courtesy, of Pediatrics, Pathology, Neurosurgery and Psychiatry, Stanford University

Mark Souweidane, MD, FACS, FAAP, Director of Pediatric Neurosurgery, Weill-Cornell Medical College and Memorial Sloan-Kettering Cancer Center, New York, NY

Maryam Fouladi, MD, MSc, FRCP; COG, CNS Committee, CONNECT DIPG Collaborative Chair, Brain Tumor Center Chair, Cincinnati Children's Hospital Medical Center

Jack's Angels Inc, Smashing Walnuts Foundation, The Kortney Rose Foundation, Michael Mosier Defeat DIPG Foundation, Aiden's Avengers, The ChadTough Foundation, Lily LaRue Foundation, The Cure Starts Now Foundation, McKenna Claire Foundation, MUSELLA Foundation for Brain Tumor Research, 4AydenStrong Foundation, All In To Win Foundation, Julia Barbara Foundation, Cannonballs for Kayne Foundation

Members, The Alliance for Childhood Cancer, 4/15/2019:

Children's Oncology Group

Rally Foundation for Childhood Cancer Research Children's Brain Tumor Foundation

Children's Cause for Cancer Advocacy

The Andrew McDonough B+ Foundation

Association of Pediatric Hematology/Oncology Nurses National Brain Tumor Society

American Society of Pediatric Hematology/Oncology American Childhood Cancer Organization

CureSearch for Children's Cancer

St. Baldrick's Foundation

Association of Pediatric Oncology Social Workers American Cancer Society/Cancer Action Network

A further list of individual advocates, caregivers and organizations is being compiled November 10 – 17, to be submitted to the Office of the House Majority Leader Steny Hoyer on Friday, November 18.

