

Request for Your Personal Support, Scheduling Consideration for H. Res. 404

RE: Regarding the Letter Sent to Majority Leader Hoyer with no response, 117 Congress Legislative Protocols, #1 (Commemoratives) dated November 11, 2022

December 6, 2022

To the Honorable 219 co-sponsors of H. RES. 404, your esteemed and most helpful staff,

First and foremost, thank you for the opportunity to communicate with your offices regarding this urgent resolution designating May 17 for DIPG/childhood brain cancer. Over the past seven years, there has never been a convenient time to consider children dying of DIPG, especially now amidst the midterm elections and the coming 118th Congress. We did not initiate this under a presumption of failure, sacrificing time, life energy and resources with our families after losing a child to the success of this resolution. We believe with all our hearts it meets the standards of the exception protocol(1) in the books, and has an unparalleled House Majority of pre-vote support for a resolution of its kind, for a community with very few advocacy operatives.

We need your help in encouraging the Majority Leader to schedule 5 minutes for merits of the resolution to be heard, for these tens of thousands of children lost, of life-years lost annually, for their families, and for the benefit of medical research. He and/or his staff have repeatedly denied requests for the Congressman to meet with constituent families on this issue, while their children were alive. To some of us, this is a travesty of the duty of representation. We may not have this opportunity next Congress, something we have heard we would have, 4 times, and with 3000 more souls lost to DIPG alone by 2023, fighting an invisible war against a powerful and prolific killer, unprotected.

Thanks to the investment and collaboration of parents with researchers, we are so close in knowledge, yet so far away in awareness and funding, from a cure—a fact upon which noted experts* have repeatedly concurred for your knowledge and benefit in our Congressional briefings. **Indeed, the world is watching**—believe you me, our international DIPG community has put a great amount of hope in this as they are making similar efforts—also with great resistance, as the unthinkable scope of terrible suffering continues, unabated and unseen. This simple gesture of acknowledgement from the House of Representatives would shine a national spotlight on the issue, and could literally save lives.

Finally, the resolution is a unifying measure with a practical healing potential amid divisive political posturing both in Washington and among the American People. It is within reason to believe that such a touchstone of humanity in service of our young people may support our lawmakers in the difficult decisions moving forward into 2023, together.

Please help us get a response, somehow on the record for these children and the seven years of effort in having them recognized, at the very least. In heartfelt gratitude, and undying hope for a miracle in the 117th Congress, we will remain,

Very truly yours,

Three handwritten signatures in black ink, appearing to be initials or names, positioned at the bottom of the letter.

DIPG Advocacy Group

Janet Demeter, Founder (Agua Dulce, CA)

Paul Miller, Co-Founder (Littleton, CO)

Marcelo Ortigao PhD, Medical and Science Advisor (Ft. Collins, CO)

*For reference: [program with presenter time-stamps](#) Moonshot4Kids Congressional/OSTP Childhood Brain Cancer Briefing:

<https://dipgadvocacy.org/wp-content/uploads/2022/10/Program-of-Testimony-1.pdf>

(1) <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.”

