

To Congress, from Colleagues, Experts, Philanthropists, Parents, Patients

from Congressional Briefing 2/13/2020, 11am, 2168 Rayburn H.O.B.

“DIPG, Pediatric Brain Cancer, and the Importance of H. Res. 114”

Congresswoman Jackie Speier (D-CA-14)

“DIPG is a death sentence for children today, but it doesn’t have to be; this resolution is an important first step in securing the resources needed to develop better treatment options and find a cure.”*

Dr. Sabine Mueller (UCSF, Children’s University Hospital Zurich)

“As a community we have to continue to work together and advocate for families and children affected by this terrible disease – it always starts with awareness and this is why this resolution is so critical...I am hoping for your support for this so that there will be a day in the near future when I can say to families, ‘This used to be incurable...but we now have effective therapies.’”

Dr. Adam Resnick (CHOP)

“DIPG represents the beachhead from which our community can innovate on the required infrastructure, technologies and resources that will drive bold and much needed change in how discovery and impact can be newly empowered and coordinated across all pediatric cancer patient communities, academic institutions, companies, clinicians and investigators, bringing an end to the suffering of pediatric cancer patients and their families... But we need more hands in the fight, and awareness to the urgency of this need is the key to timely progress.”

Dr. Charles Keller (Children’s Cancer Therapy Development Institute)

“By drawing attention to...the urgent need for solutions for children with brain cancer, and DIPG, H. Res. 114 is a straightforward mechanism to stimulating conversation, innovation, and potential new cures.”

Josh Allen, Ph.D. (Oncoceutics)

“I call upon you to increase support for federally funded basic, translational, and clinical research for DIPG, as suggested by House Resolution 114. This will be critical... in doing everything that we can to help these patients live longer and better lives.”

Dr. Malcolm Smith (NCI/NIH)**

“For those who have lost a child to DIPG, I know that the discoveries we are supporting today are coming too late. Please know that my colleagues and I within NIH and those working throughout the country understand the urgency... to keep pushing this field forward as fast as we can.”

David Arons, JD (NBTS)

“If there were a stronger word than urgent, it should be applied to finding a cure to DIPG... We urge Congress to pass the DIPG Resolution, and elevate DIPG on the congressional priority list.”

Jace Ward (Pre-Law, Kansas State University, DIPG Patient)

“I can’t promise I’ll be back here next year. Which is exactly why I respectfully ask you to co-sponsor House Res. 114 before you leave for the weekend. DIPG won’t wait until this is convenient, DIPG won’t wait until we are ready. While we have been “waiting” to take a solid stand, DIPG has been taking the sight, the hearing, the speech, the ability to swallow and eventually the breath of thousands of kids across this country.”

Dr. Michelle Monje (Stanford University)

“Progress forward has come only from a collaborative effort...by those who have seen this disease...and could not turn away from this urgent, unmet need. How much larger the effort would be, how much quicker we would find effective therapies if more people were aware, and more people and resources joined us in this fight.”

Jenny Mosier (Michael Mosier Defeat DIPG Foundation, Bethesda MD)

“H. Res. 114 alone cannot stop this disease. But recognition by our federal government matters. By raising awareness of this disease, we will build a coalition of supporters who are rallying for our children. Official government recognition of the need for attention and funding for this disease is meaningful as we all work to increase the resources available for researchers.”

Elizabeth Psar (Julia Barbara Foundation, Knoxville TN)

“We can save lives today with this Awareness Resolution. Please decide that these children facing certain and probable death are a strong enough case for an Awareness Day.”

Jill Morin (Luke’s Posse, Denver CO)

“Are we the country where people just look the other way? These are our children. Please recognize the urgent need for help and support H. Res. 114; that is something you CAN do to help. Thank you.”

Janet Demeter, DIPG Advocacy Group (Jack’s Angels, Agua Dulce, CA)

“H. Res. 114 is a plea to our Representatives in Congress for help; it challenges the world to be aware of this deadly killer of children and know DIPG by name, and to inspire the collaboration of resources toward its cure. With a simple signature, you have the power to do something to help. We hope with all our hearts and minds, that you do.”

*Feb. 8, 2019, official press release for H. Res. 114

***As a federal employee, Dr. Smith is not able to take a position on H.Res. 114. He provided here an update on research supported by the National Cancer Institute and the National Institutes of Health to advance much needed progress for children with DIPG and their families.*

