

# A Moonshot for Kids: Congressional Briefing Scheduled for Childhood Brain Cancer Advocacy Group's Plea for Awareness

*Pediatric Brain Cancer Experts, Industry Leaders, Patients, and Families Convene in Washington DC for Congressional Briefing on H.Res.114 and Inaugural Summit.*

SANTA CLARITA, CA, UNITED STATES OF AMERICA, February 1, 2020 /EINPresswire.com/ -- DIPG Advocacy Group's long quest to attain acknowledgment from the US House of Representatives for the deadliest pediatric cancer, diffuse intrinsic pontine glioma, is reaching a literal summit for pediatric brain cancer awareness and research. An unincorporated association of childhood brain cancer foundations and individual childhood cancer advocates, DIPG Advocacy Group was formed to promote greater support in the childhood brain cancer community for the DIPG Awareness Resolution, which was first introduced to the US House of Representatives January 13, 2016, just one day after Vice President Biden's Cancer Moonshot Initiative was announced. From its beginnings as the first DIPG Awareness Resolution to pass a State Legislature in California in 2014 inspired by Jack's Angels Foundation's namesake James-William "Jack" Demeter of Agua Dulce, CA who perished to DIPG on July 30th, 2012, it was [re-introduced to the 116th Congress](#) on February 8th, 2019 by Representative Jackie Speier (D-CA-14) with leading cosponsor David Joyce (R-OH-14) as H. Res. 114. In her Feb. 8, 2019 press statement she notes, "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 support, attention, and resources needed to develop better treatment options and find a cure." As of 1/30/2020, 88 cosponsors have signed-on in support.

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*Representative Jackie Speier  
(D-CA-14)*

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DIPG CONGRESSIONAL BRIEFING AND STATE OF DIPG SUMMIT

**DIPG WON'T WAIT**

DIPG kills more kids than any other pediatric cancer annually. It's time WE change that. Join us in DC on Feb 13. Pass H. Res 114.

Jace Ward will speak at the #Moonshot4Kids Briefing and Summit 2/13/2020

Janet Demeter, President of Jack's Angels and Jack's mom, joined with childhood cancer advocate Paul Miller of Littleton CO, and Elizabeth Psar, President of Julia Barbara Foundation in Knoxville, TN as DIPG Advocacy Group to support [“the little bill that could”](#), in the summer of 2017. They continually bring stories from families around the country to their lawmakers offices in Washington, where

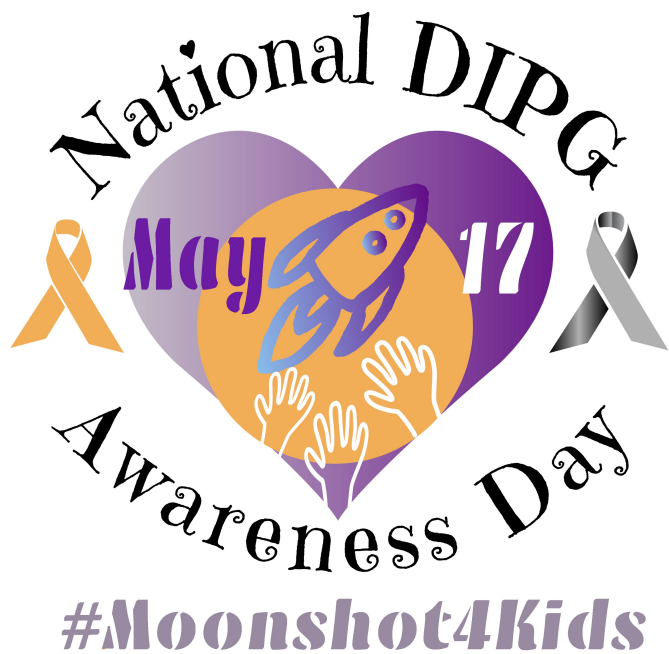
often constituent voices are lost to policy issues. "Even with noted exceptions for which the Resolution qualifies, such as bereavement and the urgent need for decisive action, some staffers simply do not transmit the requests for support of anything designating a day of awareness," notes Demeter, who is no stranger to rejection. "When you represent...families currently struggling to live with the horror of DIPG, your voice is no match against the other concerns of the day. No one wants to think about dying children, and few know that brain cancer is such a terrible killer of our children, which is the whole point of the resolution of course, so that people know."

In support of the DIPG Awareness Resolution, experts from around the world will [testify in a briefing to members of Congress](#) and their staff at 11am on Thursday, Feb. 13 in the Gold Room of the Rayburn House Office Building in Washington, DC. The panel includes Dr. Sabine Mueller, Director, DIPG Centre of Excellence, University Children's Hospital Zurich; Dr. Adam Resnick, Director of Data Driven Discovery in Biomedicine, Children's Hospital of Philadelphia (CHOP) Scientific Chair, Children's Brain Tumor Tissue Consortium (CBTTC), PNOG; Dr. Charles Keller, Scientific Director, Children's Cancer Therapy Development Institute (cc-TDI), Beaverton, OR NCI/COG Soft Tissue Sarcoma (STS) Committee; Josh Allen, Ph.D., Senior Vice President, Oncoceutics; 2016 Forbes "30 Under 30" and inventor of ONC201, and David Arons CEO, National Brain Tumor Society and Member, NCI Council of Research Advocates and Clinical Trials Advisory Committee.

Most importantly, Jace Ward, a 20 year-old pre-law student from Kansas State University diagnosed with DIPG, will speak to the reality of the disease and his good fortune in having access to the hopeful treatment ONC 201. Learning of Jace's diagnosis and the predicament in the summer 2019 of the potential shut-down of production of the promising drug, the pediatric brain cancer community's support and collaboration was crucial to the re-opening of the clinical trial. "It's because of Jace's advocacy on behalf of other children and his desire to speak to the experience of DIPG that our group first started trying to find a way to get a



Jack Demeter, 8/30/2008 - 7/30/2012, Agua Dulce, CA



hearing before Congress, so that he can be the voice for DIPG," Demeter states unequivocally.

H. Res. 114, "Expressing support for the designation of the 17th day in May as "DIPG Awareness Day" to raise awareness and encourage research into cures for diffuse intrinsic pontine glioma (DIPG) and pediatric cancers in general," raises awareness to the statistics of DIPG, pediatric brain cancer, and asks for greater consideration for pediatric cancer research in general. Demeter explains, "We hope that DIPG can be an ambassador of sorts, a powerful example for the public to consider, representing the lack of options for deadly pediatric disease." Community consensus was reached for May 17th in collaboration with the Michael Mosier Defeat DIPG Foundation in Bethesda, MD, as 32 States in 2019 have, as a result of the "DIPG-Across-the-Map" project, declared through legislative resolution or gubernatorial proclamation a May 17th Awareness Day for DIPG. The US Senate has recognized it as well in 2019 with S. Res. 223, although passing it retroactively on May 23, 2019. Ironically, Jace was diagnosed on May 17, 2019.

Jace's mother, Lisa Ward, is a new admin to the DIPG Advocacy Group since September, 2019 and in taking on the job of organizing the briefing reception, discovered out of the intense community need for sharing vital information and overwhelming desire of the private sector, government agencies such as FDA and NCI, data management companies and top researchers to collaborate on solutions, the project has literally turned into "The State of DIPG" conference with the entire event entitled the Moonshot4Kids Congressional Briefing and Summit. The Summit will consist of a professional panel, DIPG families, childhood cancer advocates, and clinicians. This portion of the event will take place at 2pm on February 13, 2020 at the offices of Covington and Burling LLP in Washington DC, as a platform for community support and professional collaboration between the public and private sector.



*DIPG Families and Childhood Cancer Advocates, Please Join Us!*

#MOONSHOT4KIDS

## Congressional Briefing & Summit

Briefing:  
DIPG, Pediatric Brain Cancer & the Importance of H. Res. 114

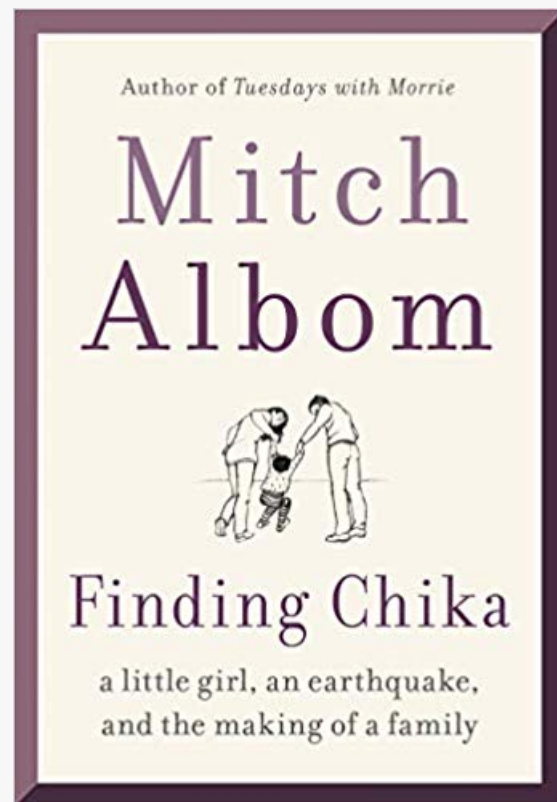
*and*

Summit to follow:  
"The State of DIPG"  
Courtesy of Covington and Burling, LLP

*Feb 13, 2020 WASHINGTON, DC*


For More Details, Registration and Hotel Information visit <http://dipgadvocacy.org/congressional-briefing/>

social media event info



Author of *Tuesdays with Morrie*

# Mitch Albom



## Finding Chika

a little girl, an earthquake,  
and the making of a family

You can find, "Finding Chika", by Mitch Albom, on Amazon

"Lisa Ward has helped facilitate the beginning of an inaugural event of hope for DIPG and pediatric brain cancer, through all the groups who have played a role in research and advocacy. It's free to attend, all-inclusive, and brings the top thinkers and leaders in research, data management, and treatment to the table," explains Demeter, "a literal dream-come-true."

Also of note to speak at the morning briefing will be Dr. Malcolm Smith, Associate Branch Chief, Pediatrics in the Clinical Investigations Branch [Cancer Therapy Evaluation Program, Division of Cancer Treatment and Diagnosis], National Cancer Institute. As a federal employee, Dr. Smith is not able to take a position on H.Res. 114. He will be providing 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, a certain highlight for health policy staff attendees.

In noted author Mitch Albom's most recent book, "Finding Chica," he illustrates his experience adopting a 7-year old girl who dies of DIPG. To lend his personal support as a DIPG parent to the briefing, he states frankly, "To be told 'there is no cure' is devastating to any patient. When told to kids as young as 3 or 4, it is beyond tragic. DIPG robs our future generations. If we do not dedicate serious funding and research to it right now, we are turning our backs on our most precious resource, our children."

For more information and for updates about the event including registration, visit [dipgadvocacy.org/congressional-briefing](http://dipgadvocacy.org/congressional-briefing).

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