

#MOONSHOT4KIDS

H. Res. 114

The National DIPG
Awareness Resolution

"The Little Bill That Could"



DIPG ADVOCACY GROUP

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November 12, 2020

To the Honorable Members of the United States House of Representatives:

We are deeply grateful for your attention as it is not commonly known that brain tumors lead in childhood cancer prevalence, and deaths. DIPG, the second most common type of pediatric brain tumor and the deadliest, is the #1 cause of childhood mortality due to brain tumors, and singularly represents a significant portion of the annual childhood cancer death toll. H. Res. 114, the DIPG Awareness Resolution, shines needed light in a place in our society which has remained in darkness for decades, as DIPG exemplifies in a powerful way the marginalization of our children by the current medical research investment culture, and the message we consistently hear as parents that our children's lives don't represent a significant enough investment incentive.

DIPG Advocacy Group is a coalition of childhood cancer advocates and pediatric brain cancer foundations formed expressly for the purpose of supporting the National DIPG Awareness Resolution in US Congress. After 5 years of bringing stories of constituents to Capitol Hill, 3 introductions of the resolution and 2000 more lives lost of innocent children to DIPG alone, we are humbly asking for your support considering the prolific nature of this killer, the cruelty of the deaths these children endure, and the fact that the only challenge to the scheduling of this resolution is the recognition of the urgency of the situation, that it represents a legitimate exception to the ban on "commemorative" resolutions due to frivolous overuse a quarter of a century ago. Here we refer to the current legislative protocol, "A resolution of bereavement, or condemnation, or which calls on others to take a particular action, is eligible to be scheduled for consideration."^[1]

You may not have previously heard of DIPG because these children, mostly between the ages of 5 and 9 years old, are fighting for their lives and most all of them die; their parents are typically too devastated to conceive of hopeful advocacy. The unspoken experience is exceedingly cruel and horrifying, both for the children who must imagine their approaching death in full cognitive awareness as their bodies decline, as for their loved ones who witness it in total helplessness because, as we so often hear, "the numbers aren't great enough for investors," in the wealthiest country in the world. However unintended, the terrible message we take from this is that our children's lives and suffering don't matter. With H. Res. 114 we are asking our Members of Congress for help to sound the alarm and draw attention to an urgent, unmet need in our society today for those who cannot speak out.

Out of sight and out of mind, DIPG has seen no significant change in standard treatment protocol *since 1962*, when Neil Armstrong's two-year-old daughter Karen died of it. Nor are the common signs and symptoms of childhood brain cancer commonly recognized or swiftly diagnosed; clinicians are often met with strong resistance from insurance companies for use of the definitive diagnostic tool, the MRI. Too many childhood brain tumors, many treatable, are discovered too late or at autopsy. In 2020, families are still told at diagnosis to, "Go make memories," and are left to their own devices to find a pathway forward with experimental treatments.

Despite increased appropriations for NIH and NCI, there is still insufficient awareness of the urgent financial need in childhood cancer research, specifically brain cancer—the most prevalent and deadliest subtype, which sits on the cutting edge of several frontiers of science today. At the #Moonshot4Kids Congressional Briefing in Rayburn on 2/13/2020, Dr. Adam Resnick (CHOP), leading scientist for the Children's Brain Tumor Network (CBTN) spoke authoritatively to the fact that exposing DIPG and the value of pediatric brain cancer research more publicly creates opportunities for systemic change in the way we share data, conduct research and fund new clinical trials for treatments. More than 36 organizations, including the Pediatric Neuro-Oncology Consortium (PNO), CBTN, National Brain Tumor Society, the Oncology Nursing Society, St. Baldrick's Foundation, and the Alliance for Childhood Cancer, have all lent their endorsements to H. Res. 114.

[1] The Office of Majority Leader Steny Hoyer, <https://www.majorityleader.gov/content/116th-congress-legislative-protocols>

The increased national awareness, education, and recognition which H. Res. 114 would help generate for childhood brain tumors could save lives today. These children might be given treatment access priority during a pandemic when a few weeks delay can mean missing a life-saving opportunity. Rather than detracting from the pandemic, H. Res. 114 supports the call to accommodate our most vulnerable citizens in most urgent need of help. And finally, the recognition would also serve to help more quickly attract financial and scientific support from around the world, as 95% of pediatric neuro-oncology research funding is provided by parent-led foundations which struggle to make promising clinical trials available and accessible. Today's most promising, largely unknown clinical trial for DIPG is said to possibly allow 6 patients this year, while a DIPG terminal prognosis with standard treatment is 9 months.

We thank you for your support if you are already one of the nearly 190 signatories of H. Res. 114; you are our closest representation in federal government and we need your support in asserting that a pathway does exist for this resolution with House leadership according to the current protocol in place, for the deadliest pediatric cancer. At a difficult time passing authorizing legislation, this is something which could be done bringing an immense good to our community. If you have not signed yet, with your supportive signature you have the power to attach hope to DIPG and all underserved childhood cancers, the #1 disease-related killer of America's children, and let House leadership know it's the right thing to do to help where an opportunity such as this exists, and that our children represent a worthy exception to a rule from a different time and circumstance. And if the Session ends and the resolution must be reintroduced, we hope that you might remember this challenge for the recognition of these children fighting for their lives and support its expedition. Please give us hope that our voices, representing countless others who will never speak, matter; that our children's lives matter. Thank you; we remain in your debt.

Respectfully yours,

DIPG Advocacy Group Co-Founders

Janet Demeter, Agua Dulce CA, Jack's Angels Inc
Elizabeth Psar, Knoxville TN, Julia Barbara Foundation
Paul Miller, Littleton CO, Childhood Cancer Advocate

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*Link to 2-13-2020 Briefing Synopsis:
bit.ly/MS4K-synopsis (case sensitive)

Congressional correspondence:
Rep. Jackie Speier (CA-14)
 Emily Small, Legislative Assistant
 202-225-3531
 Emily.Small@mail.house.gov



"People can't care if they're not aware."
 --Aimee Dickie of Scranton, PA in 2009, forever 12

DIPG Advocacy Group is a coalition of childhood brain cancer organizations and individual childhood cancer advocates supporting pediatric brain cancer awareness and the DIPG Awareness Resolution in US Congress.

"May hope and light replace darkness and despair for DIPG children and their families."

-Jack's Angels Prayer

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.”

IN THE HOUSE OF REPRESENTATIVES

FEBRUARY 8, 2019

Ms. SPEIER (for herself, Mr. JOYCE of Ohio, Mrs. DINGELL, Mr. STIVERS, Mr. RASKIN, Mr. SCHIFF, Mr. VELA, Mr. FITZPATRICK, Mr. SMITH of New Jersey, Ms. GABBARD, Mr. COHEN, Mr. MCCAUL, Mr. LANGEVIN, Ms. BROWNLEY of California, Mr. BUTTERFIELD, Mr. KELLY of Pennsylvania, Mr. SOTO, and Mr. CARDENAS) submitted the following resolution; which was referred to the Committee on Energy and Commerce

RESOLUTION

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.

Whereas diffuse intrinsic pontine glioma (DIPG) affects 200 to 400 children in the United States each year with certain regularity;

Whereas brain tumors are the leading cause of cancer-related death in children;

Whereas DIPG is the second most common malignant brain tumor of childhood;

Whereas DIPG is the leading cause of childhood death due to brain tumors;

Whereas the median survival time is only 9 months post diagnosis with treatment;

Whereas 5-year survival is less than 1 percent;

Whereas given the age at diagnosis and the average life expectancy, the number of life years lost annually because of DIPG is approximately 24,000 years of person life lost (calculated as the number of children diagnosed by average of male and female life expectancy from that median age, $300 \times 80 = 24,000$ years of person life lost annually);

Whereas prognosis has not improved for children with DIPG in over 40 years; and

Whereas Federal funding for research for pediatric cancer should be increased to address the level of unmet medical need for this vulnerable population: Now, therefore, be it

Resolved, That the House of Representatives—

(1) supports the designation of “DIPG Awareness Day”;

(2) encourages all people of the United States to become more informed about diffuse intrinsic pontine glioma (DIPG) pediatric brain cancer, and the current challenges to the medical research system in designating sufficient research funding for pediatric cancers;

(3) supports expanded research to better understand DIPG, develop effective treatments, and provide comprehensive care for children with DIPG and their families; and

(4) encourages public and private sources of research funding to elevate their consideration of the mortality rate of a type of cancer, as well as the life-years lost, as significant factors to be considered during the grant application process.



IN 2019, 32 STATES UPHOLD MAY 17TH AS DIPG AWARENESS DAY

Governors in the States of Alabama, Arizona, California*, Colorado, Florida, Georgia, Hawaii, Indiana, Illinois**, Indiana, Iowa, Kansas, Kentucky, Louisiana**, Maryland, Massachusetts, Michigan, Mississippi, Missouri, Nebraska, Nevada, New Jersey, North Carolina, Ohio**, Pennsylvania, Rhode Island, South Carolina, Tennessee, Texas**, Virginia, Washington, and Wisconsin issued Proclamations establishing DIPG Awareness Day as May 17, 2019. More states still have requests under consideration. California was the first state to have a DIPG Awareness Resolution in 2014.

* Established through the legislature. **Permanently established

IN 2019, & 2020, THE U.S. SENATE PASSES S. RES. 223, S. RES. 587 ACKNOWLEDGING MAY 17 AS NATIONAL DIPG PEDIATRIC BRAIN CANCER AWARENESS DAY!



In the House of Representatives, H. Res. 114 was introduced 2/8/2019 with 17 original cosponsors, 186 cosponsors as of 11/09/2020:

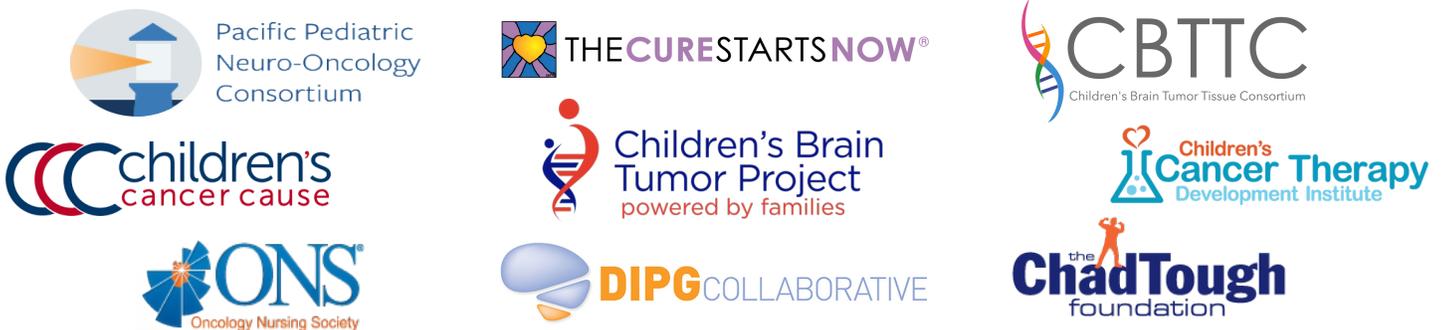


Brownley, Julia [D-CA26], Butterfield, George "G.K." [D-NC1], Cárdenas, Tony [D-CA29], Cohen, Steve [D-TN9] Dingell, Debbie [D-MI12], Fitzpatrick, Brian [R-PA1], Gabbard, Tulsi [D-HI2], Joyce, David [R-OH14], Kelly, Mike [R-PA16], Langevin, James "Jim" [D-RI2], McCaul, Michael [R-TX10], Raskin, Jamie [D-MD8], Schiff, Adam [D-CA28], Smith, Christopher "Chris" [R-NJ4], Soto, Darren [D-FL9], Stivers, Steve [R-OH15], Vela, Filemon [D-TX34], Higgins, Brian [D-NY26], Lipinski, Daniel [D-IL3], Lynch, Stephen [D-MA8], Tonko, Paul [D-NY20], Boyle, Brendan [D-PA2], Gallego, Ruben [D-AZ7], Napolitano, Grace [D-CA32], Rush, Bobby [D-IL1], Hill, Katie [D-CA25], Collins, Chris [R-NY27], McMorris Rodgers, Cathy [R-WA5], Waters, Maxine [D-CA43], Cisneros, Gilbert [D-CA39], Moulton, Seth [D-MA6], Flores, Bill [R-TX17], Meeke, Gregory [D-NY5], Wilson, Joe [R-SC2], Duncan, Jeff [R-SC3], Crow, Jason [D-CO6], Pappas, Chris [D-NH1], Calvert, Ken [R-CA42], Watkins, Steven [R-KS2], Johnson, Henry "Hank" [D-GA4], Norman, Ralph [R-SC5], Sherman, Brad [D-CA30], Grijalva, Raúl [D-AZ3], Bergman, Jack [R-MI1], Neguse, Joe [D-CO2], King, Peter "Pete" [R-NY2], Marshall, Roger [R-KS1], Blunt Rochester, Lisa [D-DE0], Hern, Kevin [R-OK1] (joined Sep 10, 2019), Axne, Cynthia [D-IA3], Cleaver, Emanuel [D-MO5], DelBene, Suzan [D-WA1], Foster, Bill [D-IL11], Perlmutter, Ed [D-CO7], Schrader, Kurt [D-OR5], Van Drew, Jefferson [D-NJ2], Waltz, Michael [R-FL6], Bonamici, Suzanne [D-OR1], Burchett, Tim [R-TN2] Matsui, Doris [D-CA6], Trahan, Lori [D-MA3], Gooden, Lance [R-TX5], DeGette, Diana [D-CO1], Schweikert, David [R-AZ6], Davids, Sharice [D-KS3], Kim, Andy [D-NJ3], Castor, Kathy [D-FL14], Walberg, Tim [R-MI7], Mast, Brian [R-FL18], DeFazio, Peter [D-OR4], Rutherford, John [R-FL4], Ryan, Tim [D-OH13], Velázquez, Nydia [D-NY7], Watson Coleman, Bonnie [D-NJ12], Williams, Roger [R-TX25], Correa, Luis [D-CA46], Hurd, Will [R-TX23], Scanlon, Mary [D-PA5], Suozi, Thomas [D-NY3], Wittman, Robert [R-VA1], Comer, James [R-KY1], Trone, David [D-MD6], Hastings, Alcee [D-FL20], Kennedy, Joseph [D-MA4] Kirkpatrick, Ann [D-AZ2], Kuster, Ann [D-NH2], Rigglesman, Denver [R-VA5], Thompson, Glenn [R-PA15], Meuser, Daniel [R-PA9], Pingree, Chellie [D-ME1], Reschenthaler, Guy [R-PA14] Himes, James [D-CT4] Kildee, Daniel [D-MI5], Luria, Elaine [D-VA2], Sherrill, Mikie [D-NJ11], Wexton, Jennifer [D-VA10], Lamb, Conor [D-PA17], Murphy, Gregory [R-NC3], Beatty, Joyce [D-OH3], Lofgren, Zoe [D-CA19] Cunningham, Joe [D-SC1], Spano, Ross [R-FL15], Spano, Ross [R-FL15], Barr, Andy [R-KY6], Bilirakis, Gus M. [R-FL12], Connolly, Gerald E. [D-VA11], Biggs, Andy [R-AZ5], Mucarsel-Powell, Debbie [D-FL26], Walorski, Jackie [R-IN2], Posey, Bill [R-FL8] Lawson, Al [D-FL5], Shalala, Donna [D-FL27], Engel, Eliot [D-NY16], Taylor, Van [R-TX3], Deutch, Theodore [D-FL22], Diaz-Balart, Mario [R-FL25], Gomez, Jimmy [D-CA34], Garcia, Mike [R-CA25], Mullin, Markwayne [R-OK2], Clark, Katherine [D-MA5], Crist, Charlie [D-FL13], Hudson, Richard [R-NC8], Roby, Martha [R-AL2], Davis, Danny [D-IL7], Davis, Susan [D-CA53], Timmons, William [R-SC4], Levin, Andy [D-MI9], Luetkemeyer, Blaine [R-MO3], McCollum, Betty [D-MN4], Blumenauer, Earl [D-OR3], Hartzler, Vicky [R-MO4], Johnson, Mike [R-LA4], O'Halleran, Tom [D-AZ1], Gianforte, Greg [R-MT0], Gosar, Paul [R-AZ4], Murphy, Stephanie [D-FL7], Palazzo, Steven [R-MS4], Tipton, Scott [R-CO3], Garcia, Jesús [D-IL4], Kilmer, Derek [D-WA6], Wilson, Frederica [D-FL24], Latta, Robert [R-OH5], Holding, George [R-NC2], Finkenaue, Abby [D-IA1], Katko, John [R-NY24], Rose, Max [D-NY11], Babin, Brian [R-TX36], Clarke, Yvette [D-NY9] DeSaulnier, Mark [D-CA11], Fleischmann, Charles "Chuck" [R-TN3], Houlihan, Chrissy [D-PA6], Kustoff, David [R-TN8], Lowey, Nita [D-NY17], Morelle, Joseph [D-NY25]. Morelle, Joseph [D-NY25], Brindisi, Anthony [D-NY22], Lowenthal, Alan [D-CA47], McAdams, Ben [D-UT4], Stewart, Chris [R-UT2], Davis, Rodney [R-IL13], Sánchez, Linda [D-CA38], Wenstrup, Brad [R-OH2], Harder, Josh [D-CA10], Pocan, Mark [D-WI2], Cox, TJ [D-CA21], Curtis, John [R-UT3], Chu, Judy [D-CA27], Ocasio-Cortez, Alexandria [D-NY14], Payne, Donald [D-NJ10], Peterson, Collin [D-MN7], Castro, Joaquin [D-TX20], Gonzalez, Vicente [D-TX15], Higgins, Clay [R-LA3], Craig, Angie [D-MN2], Heck, Denny [D-WA10], Kaptur, Marcy [D-OH9], Stefanik, Elise [R-NY21], Spnberger, Abigail [D-VA7], Baird, James [R-IN4], Cole, Tom [R-OK4], Case, Ed [D-HI1], Porter, Katie [D-CA45], Quigley, Mike [D-IL5], Aderholt, Robert [R-AL4], Demings, Val [D-FL10], Lee, Barbara [D-CA13]

CONFERRING EXPERTS OF H. RES. 114

Conferring experts Dr. Michelle Monje of Stanford University and Dr. Adam Green of the University of Colorado, Denver confirmed the facts and statistics in the text of H.Res.114. Both scientists have laboratories dedicated to research in pediatric neuro-oncology with an emphasis on DIPG, diffuse intrinsic pontine glioma. **OVER 1000 CHILDHOOD CANCER ADVOCATES HAVE ENDORSED H. RES. 114**

SUPPORTIVE RESEARCH INSTITUTIONS AND FOUNDATIONS



Members, The Alliance for Childhood Cancer, 4/19/2019: 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;

Smashing Walnuts Foundation, The Kortney Rose Foundation, Oncology Nursing Society, Julia Barbara Foundation, Michael Mosier Defeat DIPG Foundation, Aiden's Avengers, ChadTough Foundation, Coalition Against Childhood Cancer, Lily LaRue Foundation, Cincinnati Children's Hospital, The Cure Starts Now Foundation, Jack's Angels Foundation, McKenna Claire Foundation, TogiNet Radio, *Childhood Cancer Talk Radio*, 4AydenStrong Foundation, Cannonballs for Kayne Foundation, The Children's Brain Tumor Project, Children's Cancer Therapy Development Institute, Children's Brain Tumor Tissue Consortium, MUSELLA Foundation for Brain Tumor Research

116th Congress Legislative Protocols

The following Legislative Protocols are proposed guidelines to help the Majority Leader's Office schedule and consider legislation on the House floor. While these aren't the sole determining factors in the introduction of legislation, a good-faith adherence to the protocols will be necessary for legislation to be scheduled.

1) Commemoratives

Purpose

This protocol is meant to provide further guidance on House Rule XII, clause 5, related to the prohibition on scheduling legislation that is commemorative in nature.

Protocol

The Majority Leader shall not schedule any bill or resolution for consideration that expresses appreciation, commends, congratulates, celebrates, recognizes the accomplishments of, or celebrates the anniversary of, an entity, event, group, individual, institution, team or government program; or acknowledges or recognizes a period of time.

A resolution of bereavement, or condemnation, or which calls on others to take a particular action, is eligible to be scheduled for consideration.

From the website of Majority Leader Steny Hoyer:

<https://www.majorityleader.gov/content/116th-congress-legislative-protocols>

Due to "excessive overuse" in the 1990s, commemorative resolutions were restricted by House Rules and only one exception has been made for this in the 114th Congress, for Patriot's Day. In May of 2016, the Republican House Rules Conference first used the protocol, set apart in red above, to allow for it, introduced Sept. 9, 2016. The very same protocol is in effect today.

This is more completely explained in the **Congressional Research Service Report from October 2019:**

<https://fas.org/sgp/crs/misc/98-825.pdf>

Note:

We are not asking House Leadership to change to rules but rather to allow for an exception to be made for our children considering the urgency of their need for help. We have also been told that our families' bereavement isn't the "right kind", nor is the action called for in the Resolution the "right kind" of action. These are not specified in the Protocol and ought to be used with reasonable consideration per its public listing. The legitimate needs and requests of the People ought to be served by House rules rather than denied by the institution consecrated to represent them.

--DIPG Advocacy Group 11/2/2020

October 9, 2019

Dear Honorable Members of the United States House of Representatives:

We are writing in regard to H. Res. 114, the National DIPG Awareness Resolution. DIPG is diffuse intrinsic pontine glioma, an aggressive brain tumor that mostly affects children. Brain tumors are now the most common cause of death for in childhood cancer, and DIPG is the deadliest of childhood brain tumors, with a zero percent cure rate. We are physician-scientists who have dedicated our careers to understanding this disease and improving outcomes for these unfortunate patients and their families. We ask for your support of this bill to make the American people aware of this unacceptable situation so that they will help us in our effort.

Pediatric cancer research as a whole has been one of the great successes of medicine in the last 70 years. Our field has taken a diverse set of incurable diseases and, through basic research leading to cooperative clinical trials, turned the tide so that we are now able to cure more than 80% of children with cancer overall. Along the way, discoveries in children have benefited adult cancer in enormous ways, including the advent of chemotherapy, which was first used for childhood leukemia. Unfortunately, the 80% figure belies a darker reality underneath, as in many childhood cancer subtypes, the vast majority of children still die of their disease. DIPG represents the most striking and tragic example of this continued challenge and represents the ultimate challenge in childhood cancer: an inoperable tumor with unique biology that is resistant to chemotherapy and is located in an area of the brain crucial for the most basic neurological functions. If we can innovate to find a treatment for DIPG, it is likely to benefit not only these patients but other adults and children too whose cancers share some of these challenges.

We believe that your support of this bill will draw attention to the trail of lost children, devastated families, and broken communities left by this disease so that we can increase the research support needed to finally deliver hope to DIPG patients. We have the biological understanding of this tumor now, but we know that translating this knowledge to cures is the hardest and most expensive part. With your help, though, we can accomplish our goal and turn DIPG from an unimaginable tragedy to another success story for childhood cancer research. Thank you for your consideration of our letter.

Sincerely



Adam Green, MD
Assistant Professor of Pediatrics
University of Colorado School of Medicine
Attending Physician in Neuro-Oncology
Children's Hospital Colorado



Charles Keller, MD
Scientific Director
Children's Cancer Therapy Development Institute
www.cc-tdi.org

because all children with DIPG deserve science-justified hope



Sabine Mueller, MD, PhD, MAS

Adjunct Associate Professor, University of California San Francisco

PNOC lead (www.pnoc.us)

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



Maryam Fouladi, MD, MSc, FRCP

Marjory J. Johnson Chair of Brain Tumor Translational Research

Professor of Clinical Pediatrics Medical

Director, Brain Tumor Center Chair,

CONNECT Collaborative

Chair, COG CNS Committee

Division of Oncology

Cancer and Blood Diseases Institute

Cincinnati Children's Hospital Medical Center



Javad Nazarian, PhD

Associate Professor of Pediatrics,

The George Washington University,

School of Medicine and Health Sciences

Children's National Medical Center, Washington, DC.

Head, DIPG Research Institute

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weillcornellbrainandspine.org



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.”

Complete briefing synopsis with transcripts, and video access:
<https://dipgadvocacy.org/congressional-briefing>

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 attach ‘hope’ to pediatric brain cancer; you have the power 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.*

