#MOONSHOT4KIDS

DIPG ADVOCACY GROUP

Janet Demeter (CA) jacksangels1@gmail.com
818-400-2724, Organizer
Elizabeth Psar, (TN, US SE) juliabarbaradipg@gmail.com.
865-765-9655, co-Founder
Paul Miller, (CO, US W) stopkidscancer@gmail.com.
720-989-5047, co-Founder
Katherine Bader (MO, OK) kbader1966@gmail.com
573-826-7491, Secretary

H. Res. 114
The National DIPG
Awareness Resolution
" The Little Bill That Could "

October 19, 2020

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

We are grateful for your attention to this matter as it is not commonly known that brain tumors lead in childhood cancer incidence, 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 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 urgent need for our children to be accommodated rather than marginalized by the medical research investment culture.

DIPG represents the hidden, untold story of childhood cancer, in a society informed mainly by commercials asserting that 80% of children survive due to our success with certain types of leukemia. DIPG is not the success story which industry would like to promote, as it points to our failure in accommodating the most urgent needs of our most vulnerable populations; all childhood cancers are marginalized as rare and receive inadequate attention into cures. Our success in translating hopeful adult leukemia research into successful treatments for children does not represent an increase in investment into childhood cancer research, which many erroneously assume with those quoted statistics. The fact is, very little has changed for most children with cancer and their families.

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. 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. Also, the experience of DIPG is exceedingly cruel, both for the children who must walk bravely toward their death in full cognitive awareness as their bodies decline, and for their loved ones who witness this tragedy in utter helplessness because, as we so often hear, "the numbers aren't great enough for investors," in the wealthiest country in the world.

Out of sight and out of mind, DIPG has seen no significant change in the standard treatment protocol nor terminal prognosis ***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; even knowledgeable doctors 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 at autopsy. Too many families in 2020 are still told at diagnosis of DIPG to simply, "Go make memories," and are left to their own devices to find a pathway forward with experimental treatments.

Despite the appropriations made for NIH and NCI, there is still insufficient awareness as to the urgency of the need for support for the largely underfunded research in pediatric neuro-oncology, which sits on the cutting edge of several frontiers of science today. At the recent #Moonshot4Kids Congressional Briefing in Rayburn on 2/13/2020, Dr. Adam Resnick (CHOP), leading scientist for CBTTC spoke authoritatively to the fact that exposing DIPG and the value of pediatric brain cancer research opens new opportunities for systemic change in the way we share data, conduct research and fund new clinical trials for treatments. More than 36 organizations, including PNOC, CBTTC, National Brain Tumor Society, the Oncology Nursing Society, St. Baldrick's Foundation, and the Alliance for Childhood Cancer, have lent their endorsements to H. Res. 114.

The increased national awareness and education, which H. Res. 114 would help generate, 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 COVID-19, H. Res. 114 supports the call to accommodate our most vulnerable citizens in most urgent need of help. And finally, the recognition created by H. Res. 114 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.

Please consider that you are our closest representation in the federal government and we are asking for your help, not for any one person or organization's glory, but for the innocent children afflicted with this death sentence. After 3 introductions of this Resolution and by the end of 2020, another 2000 children will have perished to DIPG alone since it was first introduced in 2016. With your signature added to the substantial list of cosponsors, you have the power to attach hope to DIPG and all underserved childhood cancers, the #1 disease-related killer of America's children, and help ensure due process for H. Res. 114. Please give us hope that our democracy works and that our voices, representing countless others who will never speak, matter; that our children's lives matter. Thank you.

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

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
www.DIPGadvocacy.org
Moonshot4Kids@gmail.com
818-400-2724

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

National DIPG
May 17
Awareness Day
#Moonshot4Kids

Congressional correspondence:
Rep. Jackie Speier(CA-14)
Yana Mayayeva, LD, 202-225-3531
Yana.Mayayeva@mail.house.gov

DIPG ADVOCACY GROUP
Lend a hand ...share a heart!

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

116TH CONGRESS 1ST SESSION *–one page version*

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. CÁRDENAS) 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 aver- age of male and female life expectancy from that median age, 300 × 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, 178 cosponsors as of 10/16/2020:

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], Meeks, 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], Suozzi, 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], Riggleman, 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], Long, Billy [R-MO-7], Spano, Ross [R-FL-15], Barr, Andy [R-KY-6], Bilirakis, Gus M. [R-FL-12], Connolly, Gerald E. [D-VA-11], Biggs, Andy [R-AZ-5], Mucarsel-Powell, Debbie [D-FL-26], Walorski, Jackie [R-IN-2], Posey, Bill [R-FL-8] 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], García, Jesús [D-IL4], Kilmer, Derek [D-WA6], Wilson, Frederica [D-FL24], Latta, Robert [R-OH5], Holding, George [R-NC2], Finkenauer, 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], Houlahan, 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], Spanberger, Abigail [D-VA7]

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

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."

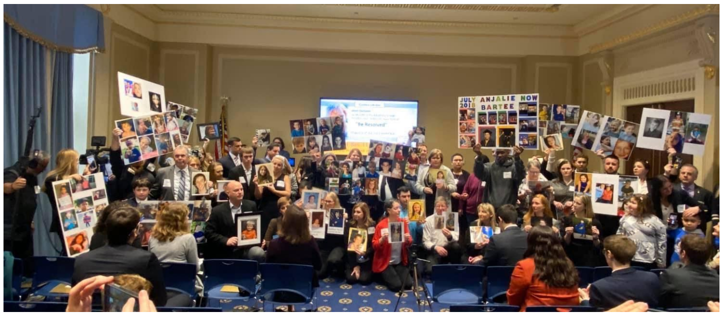
Elizabeth Psar (Julia Barbara Foundation, Knoxville TN)
"We can save lives today with this Awareness Resolution. Please decide that these children facing certain and probable death are a strong enough case for an Awareness Day."

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 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.*



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 neurologic 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

M. Monje

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

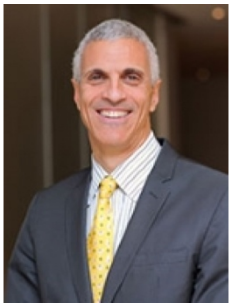
Maryam Fouladi, MD, MSc, FRCP
Marjory J. Johnson Chair of Brain Tumor Translational Research
Professor of Clinical Pediatrics Medical
Director, Brain Tumor Center Chair,
CONNECT Collaborative
Chair, COG CNS Committee
Division of Oncology
Cancer and Blood Diseases Institute
Cincinnati Children’s Hospital Medical Center

Javad Nazarian

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
University Children's Hospital, Zurich Switzerland

Marc M. Souweidane, MD, FACS, FAAP
Vice Chair and Professor, Department of Neurological Surgery
Director of Pediatric Neurosurgery
Weill Cornell Medical College and Memorial Sloan-Kettering Cancer Center
New York, New York
(212)-746-2363

Weill Cornell Medicine
Department of Neurological Surgery
525 East 68th Street, Box 99
New York, NY 10065
T 212-746-2363
F 212-746-7729
weillcornellbrainandspine.org



Alliance for Childhood Cancer

April 15, 2019

The Honorable Frank Pallone, Jr.
Chairman
Committee on Energy & Commerce
2107 Rayburn House Office Building
Washington, DC 20515

The Honorable Greg Walden
Ranking Member
Committee on Energy & Commerce
2185 Rayburn House Office Building
Washington, DC 20515

Dear Chairman Pallone and Ranking Member Walden,

The undersigned childhood cancer organizations are members of the Alliance for Childhood Cancer, consisting of patient advocacy groups, healthcare professionals and scientific organizations, representing millions of Americans who care deeply about childhood cancer. We write in support of House Resolution 114, which would designate May 17th as “DIPG Awareness Day” to raise awareness and encourage research into cures for diffuse intrinsic pontine glioma (DIPG) and pediatric cancers in general.

Diffuse Intrinsic Pontine Glioma is the leading cause of childhood brain tumor deaths. Every year, 200-400 children in the U.S. will be diagnosed with DIPG, and most of them will only survive nine months, or about as long as the typical school year. There is currently no consistent standard of care for these kids, and few treatments.

The House resolution designating a DIPG Awareness Day would help spread awareness about this deadly disease, and support researchers in their efforts to find new therapies to treat DIPG. In addition, the resolution proposes that private and public research funding “elevate the consideration of the mortality rate of a type of cancer” to ensure that research is funded to find treatments for those with the most challenging diseases.

While all childhood cancer is devastating, DIPG is a particularly terrible disease that leaves children and their families with limited options and limited time. We urge you to pass this resolution to honor those children whose lives have been lost, and to encourage additional research to give hope for children diagnosed in the future.

Sincerely,

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

CC: Members of Congress

2318 Mill Road Alexandria, VA 22314/ alliance@asco.org/ www.allianceforchildhoodcancer.org

St. Baldrick's
FOUNDATION
Conquer Childhood Cancers

May 26, 2020

The Honorable Jackie Speier United States House of Representatives 2465 Rayburn House Office Building Washington, DC 20515	The Honorable David Joyce United States House of Representatives 1124 Longworth House Office Building Washington, DC 20515

Dear Representative Speier and Representative Joyce:

On behalf of the childhood cancer community, the St. Baldrick's Foundation is proud to support H. Res. 114, which would designate May 17 as "DIPG Awareness Day" to raise awareness and encourage research for diffuse intrinsic pontine glioma (DIPG) and pediatric cancers in general.

The St. Baldrick's Foundation is a volunteer and donor powered charity committed to supporting the most promising research to find cures for childhood cancers and give survivors long and healthy lives. We are the largest non-government funder of childhood cancer research grants, and we have funded over $286 million in research grants to date.

Worldwide, a child is diagnosed with cancer every 2 minutes. Cancer is the leading disease-related cause of death in the U.S. for children and adolescents ages 1-19, and 1 in 264 children and adolescents will develop cancer before the age of 20. We have made significant advances to develop better treatments for the most common forms of childhood cancer, but for many other types, progress is limited, and for too many children there is no available cure. Each year, approximately 250 kids in the U.S. are diagnosed with diffuse intrinsic pontine glioma (DIPG), an aggressive pediatric brain cancer. Treatment options for DIPG are currently very limited, and nearly all DIPG patients die within two years of a diagnosis. Supporting research and raising awareness are critical to developing treatments for this devastating disease.

Thank you again for your leadership on this important issue. We look forward to working with you to move this resolution forward. Please contact Sarah Milberg, Director of Government Relations and Advocacy, at sarah.milberg@stbaldricks.org or 626.792.8247 ext. 265 with any questions about this legislation or any issue impacting the childhood cancer community.

Sincerely,

Kathleen Ruddy
Chief Executive Officer
St. Baldrick's Foundation