DIPG ADVOCACY GROUP
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July 31, 2020

To The Leadership of the House of Representatives,

The Honorable Nancy Pelosi, Speaker of the House (CA-12),
The Honorable Steny Hoyer, Majority Leader (MD-5),
The Honorable Kevin McCarthy, Minority Leader (CA-23),
The Honorable James Clyburn, Majority Whip (SC-6), and
The Honorable Steve Scalise, Minority Whip (LA-1):

DIPG Advocacy Group and the undersigned are asking for your attention to H. Res. 114, the DIPG Awareness Resolution, and thus to the leading cancer-related cause of childhood mortality in the United States: pediatric brain cancer. After 4 years have passed and a third introduction, little has changed for these children. As we clearly outline below, little has changed for them in decades. By the end of this session of Congress and roughly 2000 more deaths from DIPG alone, we request that with a significant showing of bipartisan support for this Resolution you would allow giving it due consideration for a House vote by suspension of rules. From your unique position, we are calling upon your leadership to help raise greater national awareness to this hidden tragedy in American life, that the appropriate resources and creativity would be alerted to this urgent, unmet need in our society today.

Amid a barrage of commercials asserting that 80% of children survive cancer due to our success with certain types of leukemia, **DIPG represents the hidden, untold story of childhood cancer**. Brain cancers lead in childhood cancer incidence and lead in childhood cancer deaths. DIPG, diffuse intrinsic pontine glioma, is the 2nd most common pediatric brain tumor and the leading cause of death in children afflicted with brain cancer, representing a significant portion of the annual childhood cancer death toll. There has been no change in its standard treatment protocol, nor its prognosis, since Neil Armstrong's daughter Karen died of it in 1962. You may not have heard of DIPG because most all of the children die and the families too devastated to be inclined to hopeful advocacy. The few of us who can speak out, speak for countless others who cannot. We are asking for your help.

DIPG is not the success story people want to hear, but until we have more awareness of this tragedy and failure, frankly, of the medical research investment culture to recognize the urgent, unmet needs of children with cancer, solutions for them will remain elusive; modest allocations for childhood cancer legislation will continue to be a fight for our advocates where there should be little question of merit. Parents will continue to hear that there are no solutions for their children with DIPG, as they helplessly witness their decline and death, because "the numbers aren't great enough for investors" in the wealthiest country in the world. By simply allowing this Resolution to move forward, you have the power to bring hope and to affect change, to help bring needed attention and resources to our scientists who need more support for this crucial, and valuable, research* which now is funded almost entirely by parents who have already paid the ultimate price.

As Covid-19 exposes weaknesses in our system of health care, so pediatric brain cancer exposes the failure of our medical research system to address needs of our most vulnerable population--our children. In the past four years (114th, 115th, 116th Congress) of our bringing this message to Washington, there has ***never been a convenient time*** to consider the needs of children with DIPG brain cancer, and the terrible reality of their situation: while retaining full cognitive awareness, the children lose control of their bodies--with some in great pain and neurological duress--as with tumor progression eventually respiration ceases. They are aware of their impending doom as their parents struggle to reckon with it, failing to provide solutions or feel adequate in guiding them to their end, though they try with all their might. This cruel experience has continued unchecked for decades in obscurity and darkness; from diagnosis onward, these children and their families have no hope. “Go make memories,” parents routinely hear. It would be tragic still if this movement for awareness for DIPG and childhood cancer were to become another casualty of the pandemic when all we are asking for our children, our most vulnerable citizens, is a day of recognition for their struggle and greater awareness to this urgent, unmet need in our society; a motion which would only support, and not detract from other humanitarian measures crucial to national interest in this time.

The argument has been made many times by Congressional staff that Members do not consider resolutions concerning a specific disease. For minimizing case load, this makes practical sense. With respect to sounding the alarm to an unseen killer of our children, it makes no sense whatsoever. We feel the importance of the wise discernment of our lawmakers concerning the case for exceptions to be made, is obvious. We are reporting to you that after nearly 5 years of bringing this story to Congress that there has not been a single instance of having a Member’s direct attention when that Member has not supported the National DIPG Awareness Resolution. And, in each and every case, each Member had no idea that brain cancer is the #1 cancer-related cause of death in children in the this country; that DIPG, the 2nd most common type, is responsible for the majority of pediatric brain cancer deaths, and that cancer is by far the #1 killer of our children by disease.

Finally, another notable excuse for objection levied by Congressional staff has been, “Well, if we help you, then we have to do this for everyone.” And that’s exactly right. Is not your work to represent us and to decide, case by case, the merits of attention and exposure, and time, and appropriate action? With a simple nod of allowing, you have the power to bring hope to the hopeless. With national recognition and the awesome power of the House of Representatives, there is an immediate alerting of needed resources, of inspiring the ingenuity and creativity of the world to help find solutions for our children facing certain or probable death. Indeed, we could save lives today with greater awareness among clinicians, educators, and parents of the common signs of pediatric brain cancer, while too many children are diagnosed at autopsy.

Finally, “Commemorative days” designated by the House were banned presumably due to frivolous overuse. H. Res. 114 is a clear case meeting the criteria used for previous exceptions made (114th Congress Republican Rules Convention in May 2016, Protocol 7, Rule 28), and the humanitarian benefit is unquestionable; we submit to you that the original reasons for, and context of this ban with respect to this resolution, ought to be reviewed. We ask you in all earnestness, in making your decision whether to allow consideration for a vote, to please put the potential benefit to our children in the balance with this question: what possible harm could it bring? As leaders of the US House of Representatives, we are asking you to consider which has more import to the American People it was consecrated to represent.

In a bipartisan way, as of July 29th, 2020, 137 Members of the House of Representatives have signed on to H. Res. 114, with more yet to appear on the list. Please allow our “#Moonshot4Kids” a chance to bring hope and much needed attention to a dire situation, now, this Congress. We plead to you with our hearts and what remains of our dispositions after witnessing the devastation of DIPG and childhood cancer more times than we could ever count. As we ask for your help, we humbly thank you for your attention.

Respectfully yours,

DIPG Advocacy Group Founders:
Janet Demeter (Santa Clarita, CA)
Elizabeth Psar (Knoxville, TN)
Paul Miller (Littleton, CO)

* From the February 13, 2020 #Moonshot4Kids Congressional Briefing, The Gold Room, Rayburn House Office Building, the testimony of Dr. Adam Resnick (CHOP, lead scientist CBTTC):

> *“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.”*

#Moonshot4Kids

The DIPG Awareness
May 17
Resolution H. Res. 114

2020

Supporters of H. Res. 114:

Support Letter, 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

Joint Statement of Experts signed October 8, 2019
Dr. Maryam Fouladi, Professor of Clinical Pediatrics Medical Director, Brain Tumor Center Chair, CONNECT Collaborative, Cincinnati Children's Hospital
Dr. Charles Keller, Scientific Director, Children's Cancer Therapy Development Institute
Dr. Sabine Mueller, PNOC leading scientist, UCSF adjunct, Children's Hospital Zurich, DIPG Centre of Excellence
Dr. Mark Souweidane, Director of Pediatric Neurosurgery, Weill Cornell Medical College and Sloan-Kettering Memorial Cancer Center, New York NY
Dr. Michelle Monje, Associate Professor of Neurology and by courtesy, of Pediatrics, Pathology, Neurosurgery and Psychiatry, Stanford University
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
Dr. Adam Green, Assistant Professor of Pediatrics University of Colorado School of Medicine, Attending Physician in Neuro-Oncology, Children's Hospital Colorado

Supportive research organizations and foundations:
Smashing Walnuts Foundation,
The Kortney Rose Foundation,
Pediatric Brain Tumor Foundation
The Alliance for Childhood Cancer,
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;

The Children's Brain Tumor Project ,
Children's Cancer Therapy Development Institute,
Children's Brain Tumor Tissue Consortium,
MUSELLA Foundation for Brain Tumor Research,
Pacific Pediatric Neuro-Oncology Consortium,
McKenna Claire Foundation,
Childhood Cancer Talk Radio
4AydenStrong Foundation
Cannonballs for Kayne Foundation