DIPG Advocacy Group Letter to Congress, H. Res. 114 Text, and Evidence of National Support

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

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Monday, Dec. 16th, 2019

To the Honorable Members of the US House of Representatives, and Staff:

The DIPG Advocacy Group is an unincorporated association of pediatric brain cancer foundations and individual childhood cancer advocates formed for the sole purpose of supporting the DIPG Awareness Resolution, introduced to this Congress on Feb. 8, 2019, as H. Res. 114 by Jackie Speier (CA-14) and David Joyce (OH-14) amid 17 cosponsors. Roughly another 1200 more children have died from DIPG alone since the bill's first introduction in January of 2016. DIPG is the deadliest of all pediatric cancers and must be stopped. Respectfully, we ask your support in joining the Senate and many state and local governments in recognizing the importance of awareness for pediatric brain cancer through the passage of the DIPG Awareness Resolution. We are deeply grateful for your attention and consideration of H. Res. 114 in honor of children in your district and across the United States.

Brain cancer is the leading disease-related cause of death in children in the US. DIPG, diffuse intrinsic pontine glioma, is the 2nd most common pediatric brain cancer, the deadliest, and is responsible for the majority of pediatric brain cancer mortalities annually in the United States. It is inoperable and is highly resistant to chemotherapy. Most die within a year of diagnosis with treatment, and the long-term survival rate is less than 1%. H. Res. 114, also called our #Moonshot4Kids, suggests that pediatric and high mortality-rate cancers have greater consideration for research grants with government resources. There has been no change in the standard treatment for DIPG, radiation therapy and palliative care, since Neil Armstrong's daughter died of it in 1962. Clearly, we can and should do better for our children.

Our nation's leading experts in pediatric neuro-oncology have produced a joint statement, attached and signed for your convenience, attesting to the importance of DIPG awareness and research not only for its obvious humanitarian considerations, but to the relevance and benefits to our current frontiers of scientific research and genomic data-sharing.

Although difficult, we are requesting your attention to the indescribable human suffering that has gone unnoticed in obscurity for decades, 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 have no recourse but to 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.

We feel it is imperative that our Representatives in Congress hear this message. Now in our 4th year of sharing information about the Resolution, office to office in the halls of the House Office Buildings, our success has been marginal with regard to the Membership actually consuming the information. Most who do receive it are supportive and sign-on, but some staff members do not transmit the information even when it includes constituent requests for support. Some assert that the House no longer "does awareness days," despite the 114th Congress' clearly noted Protocol 7 of Rule 28 from the Rules Conference which permits consideration in cases of bereavement and urgency such as this.

We represent the bereaved, thousands of children who have died in recent years, and those fighting for their lives right now in real-time; it's improbable for us to attain the status of the larger cancer lobbies with boots on the ground. With wings in the air, H. Res. 114 is our plea to our Representatives in Congress for help.

To this end, we have also placed requests with House Leadership and Energy and Commerce Committee Leadership for a hearing of the testimony of Jace Ward from Wamego KS, diagnosed with DIPG, and, availability allowing, one of our nation's respected oncology experts signed onto the Joint Statement enclosed, and others from our DIPG community specified on the request; please be aware of it, and we hope that you will support such a hearing.

This May 17, with House approval of H. Res. 114, our country would recognize National DIPG Awareness Day sanctioned by the House of Representatives and the Senate, which approved May 17, 2019 as National DIPG Pediatric Brain Cancer Awareness Day in S. Res. 223. Through the awareness day activities, we will expose DIPG and catapult opportunities for sharing of data, private and public funding for research and clinical trials for treatment. It is no coincidence that breast cancer and leukemia deaths are on a steady decline after enjoying decades of national attention. In 2014, California was the first state to pass a DIPG Awareness Resolution through the legislature; in 2019, 32 of 50 states recognized a May 17th DIPG Awareness Day, demonstrating a growing national desire for this recognition.

This House Resolution is meant to shine a light on a very dark place where ignoring childhood deaths by cancer has been made acceptable, due to the marginalization of pediatric cancers which all have small patient populations and inadequate investment into research for cures. It creates awareness for oncologists to know there are clinical trials worth trying as we seek to move DIPG treatment forward. Awareness teaches parents and oncologists to consult pediatric brain cancer centers of excellence for the latest options; it gives parents of patients more knowledge from the date of diagnosis concerning experimental research. It exposes the helpless, financially draining path of families caring for DIPG children. It provides hope, that one day the next child will not hear "you have DIPG" as their death sentence. Finally, it challenges researchers to know the name DIPG and direct resources toward its cure.

A final note in consideration on the importance of the House of Representatives to our democracy as we know it:

The Awareness Resolution represents a significant opportunity for needed communication between the American People and their Representatives in Congress, such that issues of urgent concern, otherwise unknown, be addressed and recognized by Congress, and so the greater public. We sincerely hope that the wisdom of Representatives Jackie Speier (CA-14) and David Joyce (OH-14) in their introduction of this Resolution and the 68 other current cosponsors, the many research institutions, private sector supporters and endorsements of H. Res. 114, will help you to choose to give this measure a full hearing.

We heartily thank you for your consideration of H. Res. 114, which brings hope to afflicted children fighting for their lives, and their families, around the world. Help us lead and be a beacon of hope in the United States for pediatric brain cancer. In honor of so many of our children who have faced untimely death with no hope at all, and for all children facing a death sentence today whether from DIPG or other deadly cancer, let this be our **#Moonshot4kids**.

In gratitude we remain
Respectfully yours,

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

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#Moonshot4Kids
The DIPG AwarenesS
May 17
Resolution H. Res. 114
2020

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

-Jack's Angels Prayer