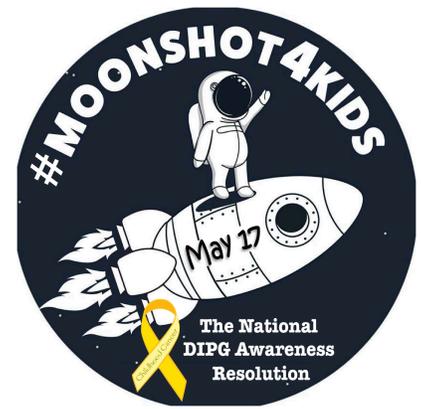


Seeking Your Support for the Recognition of Children Fighting Brain Cancer, in May: The National DIPG Awareness Resolution



April 28, 2021

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

On the eve of Brain Tumor Awareness Month, our childhood brain cancer community deeply appreciates your consideration for supporting the introduction of the DIPG Awareness Resolution in the 117th Congress. After California's first state-level resolution addressing DIPG and childhood brain cancer in the United States in 2014, our community is unified in our efforts and 34 states have to date recognized May 17th to help raise national awareness of the urgent need for solutions for our children afflicted with brain cancer.

With this national resolution, now in its fourth iteration after gaining 215 signatures last session, we are asking for your help in drawing attention to an urgent, unmet need in our society today affecting our most vulnerable and precious population, America's children. Most do not know that brain and CNS (Central Nervous System) tumors are the number one disease-related cause of childhood mortality in the US, nor are they aware of the inadequacy of childhood cancer research funding relative to the urgent need for cures. The resolution, along with raising awareness to the statistics and facts about DIPG and childhood brain cancer, in its language asks that pediatric and high mortality rate cancers be given greater consideration with public and private research funding sources, or quite simply, that urgency of need (children, the dying) should be a priority for funding into research.

DIPG, *diffuse intrinsic pontine glioma*, serves as a powerful ambassador for childhood brain cancer in this resolution. It is the second most common type of brain tumor in children and is responsible for the majority of childhood brain cancer deaths annually. The deaths are as tragic as they are torturous. We maintain that our children and their families deserve better than to hear that there are no solutions for them because they don't represent an adequate investment incentive for pharmaceutical interests.

Equally important is the power to attract a cure more quickly for those afflicted with DIPG, a literal death sentence, by alerting the greater public and the global powers-that-be with an awareness day. There has been no change in standard DIPG treatment protocol or terminal prognosis since Neil Armstrong's precious 2-year-old daughter died of it in 1962. For this reason, we maintain with unwavering commitment that this resolution is worthy of House Leadership consideration for a floor vote under the exception protocol* for the restrictions on "commemorative" resolutions. Considering the context of the origin of this prohibition in the 1990s, which was to conserve floor-time in the People's House of Representatives for matters of import, we affirm that a request for consideration for the DIPG Awareness Resolution is respectful of both the House Rules and America's most vulnerable citizens in need.

Furthermore, as brain cancer is generally an unseen, unknown prolific killer of children, we are confident that lives could be saved immediately with greater public awareness of the signs and symptoms, and with increased education about childhood brain cancer, which would in-turn improve access to proper diagnostics (MRI) and support for research into cures.

Thank you for your generous consideration; we hope that you will join Congresswoman Dingell (D-MI-12), Congressman Joyce (R-OH-14), Congressman Garcia (R-CA-25) and others in recognizing the importance of the introduction of the National DIPG Awareness Resolution in the 117th Congress. Please contact Timothy Huebner with Congresswoman Dingell's office to sign in support for the House introduction scheduled for Monday, May 17th, 2021: Timothy.Huebner@mail.house.gov 202-225-4071. In gratitude, we remain,

Respectfully yours,

DIPG Advocacy Group

Janet Demeter, *Group Organizer*, Agua Dulce, CA
Katherine Bader, *Director of Community Relations*, Rhineland, MO
Elizabeth Psar, *Julia Barbara Foundation*, Knoxville, TN
Paul Miller, *Childhood Cancer Advocate*, Littleton, CO

DIPGadvocacy.org

Admin@dipgadvocacy.org

Contact: 818-400-2724

c/o Jack's Angels Inc
32520 Wagon Wheel Rd.
Agua Dulce, CA 91390



DIPG ADVOCACY GROUP



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.

* <https://www.majorityleader.gov/content/117th-congress-legislative-protocols>

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.

Other documents in this pdf:

Endorsements for the National DIPG Awareness Resolution
Press Summary and Brief History
Resolution Draft



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

-Jack's Angels Prayer