

What's In A Day? The DIPG Community Takes a Stand for All Children's Lives with H. Res. 114, #Moonshot4Kids.

Would the Speaker of the House stand against acknowledging the urgent, unmet needs of children? It's hard to contemplate, but this is what we may be up against.

SANTA CLARITA, CA, USA, October 17, 2020 /EINPresswire.com/ -- The descriptions herein have required use of the first person for a detailed explanation and include partiality.

The National DIPG Awareness

Resolution, aka #Moonshot4Kids and the #LittleBillThatCould, is approaching its sunset marked by the end of this 116th Congress, in December of 2020. What's at stake? Tens of thousands of children lost to DIPG in the last 4 decades in our country alone; hundreds of kids fighting for

their lives, right now, facing a cruel and torturous death while their loved ones watch-on in complete helplessness. The rest of society hums along unaware; the medical research investment culture in place does not prioritize the vulnerable and the dying for medical research, and no one knows. The resolution is meant to alert Congress, the public, and the world at large to the urgent, unmet needs of children with cancer with the powerful example of DIPG, diffuse intrinsic pontine glioma: one of the most prevalent, and the deadliest, of pediatric brain tumors.

When people think about children with cancer they think,

"leukemia," and "80% cancer survival rate" due to popular advertisements soliciting charity donations and touting industry success in cancer treatments. Forty years ago, leukemia was a death sentence; we targeted it. We called it out by name. Thank God today, we have treatments for some types. But the 80% number is due largely to adult leukemia research successfully

★ **DIPG ADVOCACY GROUP PRESENTS:** ★

TUES. NOV. 17, 2020 AT NOON
The National DIPG Awareness Resolution

#HouseVOTE!
#Moonshot4Kids
#LittleBillThatCould
#ChildrensLivesMATTER

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MOONSHOT4KIDS 2020
H. Res. 114
RARE cancers neglected

The Little Bill That Could

National DIPG Awareness Day
May 17
#Moonshot4Kids

PROTEST
US CAPITOL
WEST LAWN
HOUSE LEADERSHIP:
"Please allow a vote on H. Res. 114"

Nov. 17 2020 event at the US Capitol

translated to therapies for children for these certain types. It does not represent, as many erroneously assume, any great uptick in our investment into pediatric cancer research.

Why DIPG?

DIPG and pediatric brain cancer more representatively exemplify the lack of solutions for most childhood deadly diseases. All childhood cancer types are marginalized as rare and receive inadequate funding for research into cures. Brain and CNS tumors are the most prevalent form of cancer in children, and the deadliest; this is not commonly known, and DIPG Advocacy Group is trying to change that. DIPG is the 2nd most common pediatric brain tumor and the #1 cause of deaths in children due to brain tumors, arguably responsible for the majority of annual pediatric brain tumor deaths in our country. Yet the same standard treatment protocol, and terminal prognosis exist today as did in 1962 when astronaut Neil Armstrong's 2-year-old daughter Karen died of it. We're told to "go make memories and enjoy what time you have with your child" because "the numbers aren't great enough for investors" in the wealthiest country in the world.

The National DIPG Awareness Resolution was first introduced on January 13, 2016, the day after the Cancer Moonshot Initiative was announced. It's designation in the 114th Congress was H. Res. 586, H. Res. 69 in the 115th Congress, and was introduced Feb. 8, 2019 as H. Res. 114, by Jackie Speier (D-CA-14) and David Joyce (R-OH-14).



Paul Miller, Janet Demeter, William Psar, and Elizabeth Psar in front of Cannon House Office Building



Congresswoman Jackie Speier (D-CA-14)

Simple House Resolutions, designated H. Res. rather than H. R., do not require a signature by the

President or approval of the Senate. A House Resolution is not law, nor does it authorize funds, but is a general agreement, “hear, hear!” among our 435 Members of the House of Representatives, our closest source of representation in our Federal Government. Little did I know that, in the 1990s, there had been a ban placed on so-called “commemorative” resolutions, those that included a commemorative period of time attached, due to excessive overuse and special interest involvement decades ago.

Yet legislators and legislative counsel still conceived and introduced them, due to a variety of unmet, unseen needs in our society today seeking a voice. The only exception made since the 1990s was for the Patriot’s Day Resolution in 2016, due to a legislative protocol (Protocol 7 of Rule 28 in the 115th Congress) [\[1\]](#) which stated that, “A resolution of bereavement, or condemnation, or which calls on others to take a particular action, is eligible to be scheduled for consideration.” This protocol is still in place today on Majority Leader Steny Hoyer’s website. [\[2\]](#)

A Brief History

In our first year of advocating for the National DIPG Awareness Resolution, which was introduced by Congressman Steve Knight (CA-25) and Congresswoman Debbie Dingell (MI-12) in 2016, we discovered that in some offices, roughly 1 out of 15, staff would not even consider bringing the information about DIPG, and



Senator Rubio (R-FL), champion for the 2020 Senate DIPG Pediatric Brain Cancer Awareness Resolution



Pediatric Brain Cancer Awareness is important, as brain cancer leads in childhood cancer incidence, and deaths.

constituent families, to their bosses because, “We don’t do those.” “What on Earth...,” I thought, “have we been hopefully galavanting to Washington for, on our own time and energy, bringing families’ stories of their precious children, working legitimately with legislative counsel, and then this? Is that it?”

I had inadvertently stumbled upon the world of spoken and unspoken House Rules and politics which only seemed to show its head every so often to civilians working in advocacy. I would go back to the legislative aide who drafted the Resolution and he seemed hopeful that if we were persistent and simply got more awareness and support generated that we could eventually be successful. There was never a cut and dry answer or opinion, and increasingly along the way I heard about the “unspoken” rules--politics!--which appear to be the only excuse, in present-time, to a pathway forward to a House Vote for this resolution, which I will explain further along.

We were encouraged to “build a nationwide” coalition, a seemingly impossible task, as the experience of DIPG does not lend itself to hopeful advocacy, and to just keep getting more Members of Congress signed on. During the 115th Congress we worked with the Chairman of the Energy and Commerce Committee’s office, National Brain Tumor Society, Pediatric Brain Tumor society, and other key lawmakers’ offices to produce language that would be more representative of our cause and more acceptable to Congress. We consolidated as a community decidedly upon May 17th as the designated awareness day for DIPG and pediatric brain cancer for the 115th Congress introduction.

Speak, Madame Speaker!

Moreover, we conferred, in the 114th, and 115th Congress, with then Minority Leader Nancy Pelosi’s office about a pathway forward, an exception for the urgency of the needs of our children dying a torturous death. The word was, “we’ll be in a better position to be helpful when we’re in the Majority.” And yet, in this 116th Congress, we were bitterly disappointed to be handed down to lower-level staff and dismissed upon every attempt to meet with the Speaker, bringing CA-12 constituent expert scientists of a constituent, a constituent premier scientific consortium, and experts from around the world, for the CA-12 Congresswoman, rare survivors to speak to the importance of the Resolution for them, and yet staff would not allow it--not even 3 minutes of her time.

Though we were devastated, we were, and remain, 100% resolved. We produced the #Moonshot4Kids Congressional Briefing, “DIPG, Pediatric Brain Cancer, and the Importance of H. Res. 114” in Rayburn House Office Building in Washington DC in February of 2020, only to be rejected by the same staffer (aka “The Ice Queen” to a privileged few), with CA-12 dignitaries assembled to have 5 minutes with the Speaker only to be told that we needed to ask Committee Leadership for a path forward, which the current rules clearly deny. It rests with House Leadership to schedule a House vote, or to allow one. Truth be told, the House makes up it’s rules for each Congress and can amend or change them for any reason, at any time, process and time allowing.

This is a living democracy. So now, it is up to us to make this conflict as public as possible, with as strong of a stance as possible against the refusal to recognize innocent children fighting for their lives, and a voiceless, bereaved community of parents of angels. Disappointingly, that is the apparent attitude of the Office of the Speaker of the House of Representatives toward children with DIPG, and the marginalization of children with deadly disease. Our advocacy group suspends any judgement of the Speaker in her own right for the opportunity to learn of her actual disposition.

We had, with this “House-Runaround,” more formally organized and turned to the Senate in late 2017 for a Resolution in that Chamber for which we found champions in Senator Rubio (R-FL) and Senator Reed (D-RI). Though we were too late to get a 2018 introduction we managed to get a successful “DIPG / Pediatric Brain Cancer Awareness Resolution” in 2019 and 2020, and we are poised to repeat this 2021. And so, why is the House Resolution so important?

Again, our Representatives are our closest point of having a voice in our Federal Government and when they stand together on an issue it is enormously helpful and resounding. H. Res. 114 has served as a platform from which we have been able to speak out for so many who will never, ever have a voice; it continues to serve as an avenue of communication concerning the marginalization of childhood cancer and childhood disease, which are not prioritized in any way by the system in place. Now is the time to assert that the values of our children, of saving lives, be somewhere inserted in the research funding process of our tax-payer dollars.

Indeed, the most important language in [House Resolution 114](#) for DIPG awareness is that “federal funding for pediatric cancer should be increased to address the level of unmet medical need for this vulnerable population”, and that “years of life lost” and “mortality rates” should have “elevated consideration” in the research grant process. In other words, it asserts that our #ChildrensLivesMATTER.

Political Semantics

Within the last month, bringing to the attention of certain lawmakers offices the protocol allowing a pathway for a “resolution of bereavement, or condemnation, or which calls on others to take a particular action,” brought only more disappointment. I was told that it wasn’t the “right kind” of bereavement, or the “right kind” of action, which is unspecified in the protocol. This is just another way of saying “the protocol’s there but only for one exception ever made,” which is ridiculous, as all political stonewallings are. It’s high time to put people before politics, especially our children; we can stand together on that. Both Democrats and Republicans are capable of political distemper...and simply need to be reminded for whom they are working.

It must be noted that an overwhelming number of our lawmakers are supportive of the “Little Bill That Could.” Our most important strategy has always been to inform as many offices as possible about pediatric brain cancer, the #1 killer of our kids with cancer, and to get the most amount of cosponsors signed on in the resolution; we are shooting for a House Majority before December 2020 to help support our position. Adopting the “I think I can” mindset is the reason

the bill has been introduced three times, in its fifth year of advocacy, and the reason we are pushing the point. Why? There has never been any good argument against it. The immense good that can and will come to pediatric cancer research, the hope to children fighting for their lives, and the promise of more timely cures for those yet to be diagnosed, with the success of the Resolution has no equal in argument. By the end of 2020, another 2000 children will have perished to DIPG alone since the first introduction of the Resolution in January of 2016. It is high time.

"With Awareness we can save lives today," asserts Elizabeth Psar, co-founder of DIPG Advocacy Group and Executive Director of Julia Barbara Foundation in Knoxville, TN. "People don't think 'brain tumors' with childhood cancer, though it's the most prevalent type. The symptoms are being overlooked, diagnostics resisted by insurance companies, and too many pediatric brain tumors are discovered at autopsy. We need this Resolution now; not in 5 years, not next session of Congress, but now. There's simply no excuse, except its the big scary elephant in the living room nobody wants to talk about because it exposes our failures. We're better than that; we've got to be."

What's in a day? Awareness! Acknowledgement! The summoning of help from around the world to the most exciting space in cancer research, with dedicated scientists poised with efficacious and powerful new scientific tools, simply needing more funding and collaboration. A world of Hope and caring where there has never been such. We can't take away the insufferable pain of countless thousands, but we can give them acknowledgement, and honored purpose--fulfilment, until they can see their loved ones again in the next world. That's bereavement, and that is certain action. This is the age of necessarily re-defining our terms according to our values.

The protest, led by DIPG Advocacy Group, of House Leadership's dismissal of H. Res. 114 and the acknowledgement of our children with the deadliest pediatric cancer will be held on Tuesday, Nov. 17th at 12pm EST at the US Capitol lower front lawn. Updates can be found on this beginning Monday, October 19 at www.dipgadvocacy.org. The hashtags #HouseVote, #Moonshot4Kids, and #ChildrensLivesMATTER will be used for this event.

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