

Regarding Vague Reference Objections to Awareness Days

“We don’t do those anymore.” Great; now what?

(DIPG Advocacy Group House Rules Research File 2019: www.DIPGadvocacy.org)

Since the first iteration of the DIPG Awareness Resolution (114th Congress H. Res. 586), we have occasionally experienced the disheartening “push-back” from certain legislative offices regarding an assumed abolishment of awareness days, which is not an altogether correct assumption. Apparently the designation of awareness days had become rather frivolous and was rightly limited by the 114th Congress, yet was not abolished entirely as many assume without further inquiry.

Though somewhat surprised at having come so far with this work as to help write legislative text in support of our cause with Congressman Knight’s office in September of 2015, and with conferring experts approval on data and statistics, only to have our project be declared null and void by the occasional critical legislative assistant, this was certainly depressing but not effective in deterring our mission. Finally after some digging during the 2nd iteration of the Resolution (115th Congress H. Res. 69), I found this account of the Republican Convention on House Rules, the actual Rule in question, and also the Protocol of that Rule which unequivocally qualifies our Resolution for suspension of rules, and for a vote to be scheduled under that process.

As an advocate, the idea of educating legislative staff, or at least making a sound and persuasive argument as to why this Resolution ought to have serious consideration, even though it’s verified by the rules themselves, has been a daunting proposition. First we fight for the idea that the urgent needs of children and the dying ought to have greater consideration, which many of us feel is self-evident, but then, as outsiders to Congress, we’ve had to fight to prove that the Resolution is viable. We strongly believe that indeed it is more than viable, as We The People are asking for Congress help in raising critical awareness to a much larger problem; if ever there were a need for an awareness day, DIPG is a worthy candidate. We are grateful for the wisdom and compassion of Representatives Speier and Joyce.

Rather than to make it more important than other diseases, DIPG exemplifies in a powerful way the marginalization and chronic lack of support for research funding for the deadliest pediatric cancers, the tried and true killers of our children with certain regularity, in the Resolution. Clearly our human values of prioritizing the dying and children, as they are in the Emergency Room, are not represented in the larger research industry. Since the 2015 #Morethan4 movement of parent emails to NCI, demanding answers to the small percentage of the annual research budget allocated to pediatric cancer as a whole, we parents have been told to be quiet, basically, that no one wants to work with “angry parents.” **We would like transparency and a national conversation**, not just promises of consideration, or a reproach to outrage. For those of us who have had to watch-on helplessly as our children die because “they aren’t worth the investment”, we’ll fight with our own lives to see our values one day represented in the system.

Protocol 7 of Rule 28

Taken from Congressional Research Service, “Sense Of” Resolutions and Provisions, name redacted, Analyst on Congress and the Legislative process, May 2016

“...As adopted in the 114th Congress (2015-2016), the rules of the House Republican Conference include language that limits the use of the suspension of the rules procedure for certain types of honorific or commemorative legislation. This rule could effectively preclude the consideration of some “sense of” legislation in the House. Specifically, Conference **Rule 28** states that the Republican leader “shall not schedule, or request to have scheduled, any bill or resolution for consideration under suspension of the Rules which ... 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 for such purposes.” **The rule may be waived by a majority of the elected House leadership. The House Republican leadership has also announced several “Legislative Protocols,” one of which is intended to clarify the application of Conference Rule 28:**

Protocol 7 states that a “resolution of bereavement, or condemnation, or which calls on others (such as a foreign government) to take a particular action [emphasis added], but which does not otherwise violate the provisions of Rule 28 is eligible to be scheduled under suspension of the Rules...”

Link to full document: bit.ly/p7-rule28 (case-sensitive)