

DIPG Advocacy Group Strategy and Goals for H. Res. 404

DIPG Awareness Resolution in the 117th Congress (Jan. 2021 - Jan. 2023)

July 9, 2021

To our Leaders in the Childhood Cancer Awareness Movement, the Childhood Brain Cancer Community, Friends and Allies in Research and Awareness for the urgent unmet needs of our children in the USA:

We have an opportunity to set a precedent for children everywhere fighting DIPG, childhood cancer, and deadly “rare” disease. As many of you may or may not know, the House of Representatives restricted the use of commemorative resolutions in the 1990s due to “excessive overuse” at that time, to conserve important floor-time for discussion of issues of import to the American People. In 2016, to allow for the Patriot’s Day Resolution, an exception protocol was added to the restrictive rule to allow consideration for scheduling for resolutions of bereavement and/or matters requiring certain remedial action. As you may also know, the House Leadership has allowed the introduction of hundreds, thousands of resolutions of this kind to support education on a variety of issues. At the same time it’s been standard procedure for many offices to not consider signing such resolutions as they would never have the chance for a vote, and/or because disease-specific legislation of any kind is generally avoided. Many of us have never felt this was right.

Being that there are so few avenues of communication and meaningful dialogue between the People and our Representatives in Congress, this particular avenue of a resolution intended to raise awareness to the urgent, unmet needs of voiceless and downtrodden populations is absolutely essential at this time in our democracy. DIPG Advocacy Group is committed to seeing the DIPG Awareness Resolution succeed in the House against all odds. Last session, we gained 215 recorded signatures (yes, there were several left unrecorded) comprising nearly half of the House Membership. This unprecedented show of support encourages us to pursue the super-majority (290), which would force the issue of consideration--simple consideration for scheduling of a House Vote.

This is our STRATEGY:

1. **Zoom meetings with Congressional Staff**--one of the blessings of the pandemic.
2. **Ask the community to share “statements of support” (SOS)** with our group, that we may have support voiced from all 435 districts, or as close to that number as possible, to share stories and support of our childhood brain cancer and childhood cancer families with those Members and their staff.
3. Ask other childhood cancer advocacy and brain cancer advocacy organizations with a national reach to **help us gather support from the public** to the offices of the Members of Congress.
4. **Reach out to children’s advocacy groups** of all kinds to share our mission and ask for their support, endorsement for H. Res. 404, etc..
5. CONTACT admin@dipgadvocacy.org (818-400-2724) for more information or to get involved

These are our GOALS:

Plan A.

1. To attain the signatures of all previous supporters by Oct. 1 (215+)
2. To attain the signatures of another 85 Members (totalling 300) before Jan 1 2022.
Thereby giving us 5 months to rally House Leadership to schedule:
3. A strongly supported House Vote for H. Res. 404 on or before May 17, 2022

Plan B.

(I'd like to just say "there is no Plan B", but I'd rather err on the side of being magnanimous)

1. Having worked hard for Plan A, we will still have until Dec. 31 2022 to achieve the House Vote to have a chance at an historic passage of a commemorative resolution for our children, and to attract a cure more quickly. We'd just prefer it happen for May 17, 2022 for all the advocates who have fought so hard. For Michael, and Chad, and Julia, and Jace, and my little Jack--and the thousands of children who have inspired us!--May 17 2022 is our goal. But even if we get a house vote before the end of the 117th Congress, May 17th will be officially DIPG Awareness Day every year! We win!

Here is our Strategic Timeline:

1. **July - September --gain back all previous, plus more. 2. Fall - Jan. 1 2022, attain 300 to enable us to rally House Leadership 1/22 - 5/22 to schedule H. Res. 404 for a VOTE!!!**
 - July--weeks 7/12-16, 7/19-23, focus on meetings with previous supporters
 - August weeks 8/16-20, 8/23-27, begin targeting other half of House, by state, committee, caucuses, and continue sending letters to previous supporters not signed on yet with the timeline.
 - September: 9/13 - 17 (tele-meetings), 9/20-24 (meetings on the Hill), Curefest Activities 9/28-10/1 (tele-meetings)
 - October: zoom-meetings weeks of 10/11, 10/18, 10/25
 - November: zoom weeks of: 11/1,11/8,11/15
 - December: zoom weeks of: 12/6, 12/13 House, and Senate prep for 2022

This is not a national holiday mind you, but a day of recognition, awareness, education, and honoring the brave children who faced their death without enough of a fight from us. It will encourage those currently fighting, underlining the fact that we care and are helping generate more support. It will serve as a time to draw attention to our researchers, the urgent need for greater research investment, and hopefully will create some healthy competition to find a cure! In short, we will have succeeded in bringing attention and needed light to a subject matter and experience that has seen mostly darkness over the last 50+ years. Most importantly, it will raise awareness about the prevalence of childhood brain cancer, the fact that this is the leading cause of cancer related deaths in children, and also alert the

public, physicians, caregivers, teachers and parents to the subtle subset of neurological symptoms accompanying most childhood brain tumors. We could save lives today with greater awareness and quicker diagnostics.

Furthermore, I really do hope it encourages more invisible people needing help to be seen, more diseases to attract the research attention they need, and to elevate our science and also respect for our researchers who have tirelessly devoted their lives to saving our children. If there truly is such a “floodgate” of such issues before Congress being avoided, now is the time to open it, not hold it shut.

Finally: In every meeting, DIPG Advocacy Group endorses all current childhood cancer legislation and all legislation that supports children. But to be specific, we are especially promoting the Gabriella Miller Kids First Research Act 2.0 (H. R. 623) , and the Fairness to Kids With Cancer Act of 2021 (H. R. 2210), in spirit of the idea that these are “no-brainers” after talking about H. Res. 404. Kids First must be funded, and the Fairness Act sets a very important precedent for supporting children with cancer. As Mina Carroll says, “We Must Do Better!”

Helpful references:

[DIPG Advocacy Group Letter to Congress with Endorsements and Resolution Text](#)

Bitlink: bit.ly/L721_404

[H.Res.404 Press Summary](#)

DIPG Advocacy Group website: www.DIPGadvocacy.org

POINTS OF STRATEGY CONTACT:

Would you like to register with our community, endorse the resolution, or offer a Statement Of Support (SOS)? Contact us at admin@dipgadvocacy.org.