



National Brain Tumor Society Public Policy and Advocacy Update Vol. 8, No. 5

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Brain Tumor Advocates Create Change at Head to the Hill

Every May, advocates from across the country "Head to the Hill" to advocate directly with Congress on Capitol Hill on behalf of the entire brain tumor community. National Brain Tumor Society trains volunteers on our legislative "asks," provides opportunities for connection between attendees - patients, care-partners, family members, friends, and healthcare providers - and organizes the meetings with members of Congress and their staff. For a full recap of this year's record-breaking Head to the Hill (most advocates in attendance & meetings with Congress than ever before), read [this blog](#) and this [news release](#).

Head to the Hill creates *actual, measurable change for brain tumor patients and their families*. For example, the *Palliative Care & Hospice Education and Training Act* has seen **30 new co-sponsors** in the three weeks since Head to the Hill. In addition, it provides a unique, memorable, positive experience for people affected by brain tumors. 2019 Head to the Hill attendee Jim Graul of Colorado wrote that the event was "One of the best experiences of my life. After going through 2.5 years of taking care of my wife, and another 2.5 years of dealing with my 'new' life, this was a much needed positive direction I needed to take. See you next year!"

Head to the Hill Scholarship Fund

We are beyond excited to share a new scholarship fund for Head to the Hill. Attending this event can be "life-changing," "powerful," "inspirational," and "impactful." It can also be financially impossible for some members of our community, due in large part to high medical (and other) costs associated with brain tumor treatment. [Please consider making a donation today](#), so Head to the Hill can continue to be accessible to volunteers regardless of their financial situation. NBTS is proud to offer travel scholarships each year, and this fund will create the opportunity for more patients, care partners, and their loved ones to experience Head to the Hill in the future.

May Brain Tumor Awareness (ACTION) Month

We're wrapping up Brain Tumor Awareness Month (BTAM), but we're not wrapping up taking action and creating positive change for the brain tumor community. Several states proclaimed May 2019 as Brain Tumor Awareness Month, thanks to the efforts of advocates across the country - thank you! Members of the brain tumor community joined together to create change in a variety of ways - read more about a successful Brain Tumor Awareness (ACTION) Month [here](#).

Glioblastoma Awareness Day Resolution introduced in Senate

National Brain Tumor Society (NBTS) is proud to announce its endorsement of a bipartisan resolution introduced on May 16, 2019, by U.S. Senator Lindsey Graham (R-SC), with the support of Senators Mitch McConnell (R-KY), Elizabeth Warren (D-MA), Kyrsten Sinema (D-AZ), and Martha McSally (R-AZ), to raise public awareness for glioblastoma, a highly aggressive and deadly form of brain cancer that takes thousands of lives every year. [Read more here](#).

Call to Action: PCHETA

Back in February, we introduced you to a piece of legislation that we're actively advocating for this Congressional Session. The Palliative Care & Hospice Education and Training Act (PCHETA) ([H.R. 647](#), Engel and Reed) is a bill that's been introduced in the US House of Representatives (originally

introduced during the 115th Congress) that will positively impact brain tumor patients and their families, if passed.

Despite the benefits reported by patients, many U.S. hospitals lack palliative care programs that include the interdisciplinary care teams necessary to provide comprehensive, high-quality palliative care. Additionally, palliative care is a relatively new medical specialty, and patients and their families are not always educated on the benefits of accessing palliative care.

How can you help? [Contact your member of Congress now and ask them to support PCHETA](#) to ensure that patients and providers understand the benefits of palliative care, and that an adequate, appropriately trained workforce is available to provide the pain and symptom management, intensive communication, and level of care coordination required by patients facing a serious and complex chronic illness.

Studies have shown that palliative care improves quality of life, enhances patient and family satisfaction with care, and controls costs for the rapidly expanding population of individuals with serious illness or multiple chronic conditions.

In addition to taking the action linked above, save Monday, June 17 in your calendar for an Online Day of Action to raise awareness about PCHETA. We'll share sample social media posts that you can post on Twitter and Facebook on June 17.

National Brain Tumor Society unrelentingly invests in, mobilizes, and unites our community to discover a cure, deliver effective treatments, and advocate for patients and care partners. Our vision is to conquer and cure brain tumors - once and for all.

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