



## National Brain Tumor Society Public Policy and Advocacy Update Vol. 8, No. 6

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### **Brain Tumor Advocates Attend PCHETA Lobby Day**

On June 20th, 100 volunteer advocates from more than 40 different organizations (including medical professional groups and pediatric, disease-specific, and palliative care organizations) gathered in Washington, DC to advocate for the Palliative Care & Hospice Education and Training Act (PCHETA) (H.R 647). The advocates had a great opportunity to hear directly from staff in all the sponsors' offices, including House of Representatives sponsors Eliot Engel (NY-16) and Tom Reed (NY-23) and Senate sponsors Shelley Moore Capito (WV) and Tammy Baldwin (WI).

Since June 20, we've seen 8 new co-sponsors to this bill, bringing the total number of co-sponsors to 237 (out of 435 House of Representatives members). We expect the Senate to introduce a companion bill in the coming days and will request it pass by voice vote, without deliberation.

Special thanks to advocates Ashley Finch Hermsen, Kenny Hermsen, and Meghan Whaley for participating in this event and advocating for PCHETA on behalf of the brain tumor community.

Recently, we've provided some background about this bill, and if you haven't already, please [click here to find out more and TAKE ACTION](#) by contacting your member of Congress and asking them to support PCHETA. If passed, PCHETA would ensure that patients and providers understand the benefits of palliative care, and that an adequate, appropriately trained workforce is available to provide pain and symptom management, intensive communication, and the level of care coordination required by patients facing a serious and complex chronic illness.

### **Rally for Medical Research**

As part of our legislative agenda each year, we advocate for increased medical research funding through the National Institutes of Health (NIH). We advocate for these increases throughout the year and at [Head to the Hill](#). The Rally for Medical Research Hill Day, hosted by the American Association for Cancer Research and taking place this year on Thursday, September 19, is another annual advocacy event that brings together patients, family members, and medical providers across various diseases and medical fields to serve as one united voice for increased funding for the NIH.

National Brain Tumor Society advocates are welcome and encouraged to join with our partners from other organizations in attending this event. This is a great opportunity for you to take your advocacy to the next level. Let us know if you're interested in representing the brain tumor community by attending this Washington, DC-based advocacy event. Email [advocacy@braintumor.org](mailto:advocacy@braintumor.org) for more information or [visit the "Rally Hill Day" website](#) for additional information.

### **Brain Tumor Awareness + ACTION**

May 2019 was officially recognized as National Brain Tumor Awareness Month by the United States Senate when they passed Senate Resolution 258, marking the third straight year that the Senate has taken this step! We would like to thank Senator Steve Daines (MT) for once again championing this effort and Senators Susan Collins (ME), Chris Van Hollen (MD), Ed Markey (MA) and Elizabeth Warren (MA) who stepped up for the brain tumor community to co-sponsor this resolution. We are grateful for their support.

Further, as you likely know, July 17, 2019 will be recognized as Glioblastoma Awareness Day, thanks to a separate Senate Resolution (S.Res. 245) passed earlier this month ([read the full story here](#)). As our CEO has said, "We ask all of America to join us in commemorating July 17 as Glioblastoma Awareness Day by paying tribute to those that have been taken by this disease, as well as the patients and families still coping with a diagnosis, and by uniting in a day of action and support to advance research and care so we can conquer and cure this disease once and for all." Please keep an eye out for special ways you can be involved as we honor patients, survivors, care partners and act to #DefeatGBM on #GBMDay on the 17th.

#### **Medicare Coverage of Tumor Treatment Field Therapy**

On Thursday, June 20, a meeting was held to hear public comments regarding a recent decision on Medicare coverage of Tumor Treatment Field Therapy (TTFT). As you may know, there is currently one FDA approved device available to glioblastoma (GBM) patients that uses TTFT. However, despite FDA approval, the cost of using the device has not previously been covered for Medicare patients. National Brain Tumor Society, along with patients, physicians and other brain tumor advocacy organizations, testified at the meeting and [submitted written testimony](#) to support coverage of this FDA approved treatment. It is the National Brain Tumor Society's position that glioblastoma patients, the group for which tumor treating fields was approved by the FDA for, should have affordable access to this treatment especially since it is now part of the standard of care for GBM. Medicare policy should help enable access.

A special thank you to Maryland advocate Jennifer Sebor for attending the meeting on behalf of her fellow patients around the country and officially representing NBTS. A final decision on coverage of the device is expected in the coming months.

#### **Support NBTS Programs at Events this Summer**

If you are involved in advocacy and are interested in expanding your support of the brain tumor community and National Brain Tumor Society programs, please consider attending or volunteering at an event in your area.

If you're interested in joining in on the fundraising by participating in a race or endurance event, check out [Gray Nation Endurance](#):

- October 6, 2019: [Medtronic Twin Cities Marathon/10-Miler](#)
  - [Join our Gray Nation charity team - accepting applications now](#)
- Ongoing Opportunity: [Your Own Race](#)
  - Select a race or endurance activity of your choice. Fundraise and train as an individual or get a team together to celebrate a survivor, pay tribute to a family or friend, and to create a deeper impact in the brain tumor community.
  - Fill out our [Gray Nation Interest Form](#)!

Here is a list of the events benefiting NBTS this summer through our [Community Fundraising Program](#):

- [10th Annual Mary E. Smith Brain Tumor Awareness 5K/10K Fun Run/Walk](#) on July 6, 2019 in Country Club Hills, IL
- [Madison Brain Tumor 5k](#) on July 13, 2019 in Madison, WI
- [Blake Strong Fest](#) on July 20, 2019 in Indianapolis, IN
- [Frank R. Williams Golf Tournament](#) on July 26, 2019 in Upper Marlboro, MD
- [Bob Burns Memorial 5k](#) on July 28, 2019 in Augusta, ME
- [Shelby's "Brewerfest" and Wine Tasting](#) on August 11, 2019 in San Jose, CA

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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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