



## Community & Government Relations Update Vol. 10, No. 1

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### 2020 Government Relations Impact Report

With our advocacy work already underway in 2021, we wanted to take a moment to pause and celebrate our impact in 2020.

The following is only a brief snapshot of the work we've been able to accomplish together over the past year. We are continuously grateful to you, our brain tumor advocates, for your contributions, efforts, and support, especially during a year full of unexpected challenges. You took action, shared your stories, participated in virtual meetings and events, and worked tirelessly to make sure the voices of our community were heard.

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### Legislative Victories

Every year, NBTS sets a legislative agenda that supports the vision of our organization: to conquer and cure brain tumors, once and for all. Advocates like you push our priorities forward by emailing your members of Congress, sharing our action alerts on social media, and participating in virtual meetings.

Thanks to your efforts, elected officials understand the urgent needs of the brain tumor community. We're pleased to highlight several of NBTS's legislative priorities that were included in the 2020 omnibus spending bill passed by Congress, demonstrating monumental progress in our advocacy work.

- **Our Priority:** Increase funding to the National Institutes of Health (NIH) and National Cancer Institute (NCI).
- **Result:** \$42.934 billion provided to the NIH for FY21, a \$1.25 billion increase over FY20 and \$6.559 billion to NCI, a \$119.5 million increase.

- **Our Priority:** Appropriate \$120 million in funding for the Peer Reviewed Cancer Research Program (PRCRP) at the Department of Defense, and with brain cancer and pediatric brain tumors included as topics eligible for funding.
- **Result:** \$115 million provided to PRCRP for FY21, a \$5 million increase over FY20. Brain cancer, pediatric brain tumors, and pediatric, adolescent, and young adult cancers were once again included as eligible priority research topics.
  
- **Our Priority:** Fund the Childhood Cancer STAR Act.
- **Result:** \$30 million provided by Congress to fully fund the Childhood Cancer STAR Act for a third consecutive year.
  
- **Our Priority:** Provide funding to continue the Childhood Cancer Data Initiative, which will establish more efficient ways to share and use childhood cancer data in research efforts.
- **Result:** \$50 million provided by Congress to fully fund the Childhood Cancer Data Initiative for a second consecutive year.
  
- **Our Priority:** Break down barriers to clinical trial enrollment by enacting H.R. 913, the Clinical Treatment Act, which ensures coverage of routine medical costs associated with clinical trial participation for Medicaid recipients.
- **Result:** The Clinical Treatment Act was included among few other Medicaid provisions in the 2020 omnibus spending package.
  
- **Our Priority:** Pass the Creating Hope Reauthorization Act, which would extend the Pediatric Priority Review Voucher program at the FDA.
- **Result:** The Creating Hope Reauthorization Act was included in the omnibus bill passed by Congress at the end of 2020, which will allow incentives for pharmaceutical companies to research and create life-changing and life-saving treatments for rare diseases in children, including brain tumors, to continue.

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## Glioblastoma (GBM) Awareness Day



Your support of the second annual Glioblastoma Awareness Day helped us raise the national consciousness about everyone's stake in finding a cure for this devastating tumor type.

- The Glioblastoma Awareness Day (GBM) Resolution was passed in the Senate, and a House resolution was introduced for the first time in 2020.
- Our GBM Awareness Day program included speakers from Congressional sponsors of the GBM Awareness Day Resolution, brain tumor patients, care partners, researchers, and clinicians, and National Cancer Institute (NCI) and Food and Drug Administration (FDA) leadership.
- Over 15,000 people watched our live-streamed program, spreading greater awareness of glioblastoma to a larger audience.
- NBTS advocates sent over 2,000 messages to their members of Congress in support of the GBM Awareness Day resolution and medical research funding for GBM.
- Thanks to the awareness raised, for the first time, Congress urged the National Cancer Institute to support pre-clinical and early phase glioblastoma clinical trials necessary to rapidly evaluate potential treatments in the Fiscal Year 2021 appropriations bill.

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## Head to the Hill

Head to the Hill is a pivotal opportunity for members of Congress to hear directly from you, their constituents and brain tumor advocates. Every year, your stories put a face to the statistics and show policymakers the human impact of brain tumors. Despite having to convert to a completely virtual platform in less than six weeks due to the COVID-19 pandemic, your advocacy made Head to the Hill 2020 a success.

- Over 600 brain tumor patients, caregivers, medical professionals, and industry partners registered to join Head to the Hill in 2020 — our largest event to date.
- You helped spread the word: more than 1,500 advocates from all 50 states sent over 5,000 messages to Congress emphasizing the importance of medical research funding for the brain tumor community.

- NBTS In-District Meetings Program, a follow up to the success of Head to the Hill, resulted in 50 virtual meetings with members of U.S. House of Representatives and Senate leadership – the largest number of meetings we have ever coordinated in districts across the country.

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## Thank you!

Your advocacy made an impact in 2020, and we look forward to working together to make positive change for the brain tumor community in 2021.

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## Save the Date!

### Virtual Head to the Hill

### Tuesday, May 4, 2021

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Questions? Contact us at [advocacy@braintumor.org](mailto:advocacy@braintumor.org).

### Make a Gift

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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