



**Community & Government Relations Update
October 2020
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Advocate In-District Meetings Continue



We are so grateful to all of our Head to the Hill 2020 participants who signed up to attend virtual in-district meetings with their members of Congress this fall. To date, we have held 30 meetings, with approximately 48 in the process of being scheduled. In total, we expect advocates to participate in more than 78 meetings in 28 states. You are truly making a difference!

It's been an honor to participate in and/or get your feedback from these meetings, hear your stories, and see the impact your advocacy has on your elected officials and their staff. If you have already participated in a meeting, please share your experience through our [feedback form](#). Your feedback is important to help us understand how your member of Congress feels about medical research funding so that we can follow up appropriately.

Our advocates are building relationships with Congressional staff which will help them to advocate more effectively in the future. We look forward to more successful meetings in the coming weeks!



Creating Hope Reauthorization Act

Last month, we asked you to [take action](#) to ask Congress to extend the pediatric rare disease priority voucher review program created under the Creating Hope Act. Priority review vouchers are an incentive for biopharmaceutical companies to develop drugs for rare pediatric diseases, including brain tumors. The goal of these vouchers is to develop new treatment options specifically for rare diseases in children.

The program has already been extremely successful. Since 2014, when the first voucher was issued, 22 new drugs for rare diseases in kids have been approved, including two drugs for childhood cancers.

We are pleased to report the program was reauthorized before the original sunset date of September 30, 2020. [The House of Representatives passed the Creating Hope Reauthorization Act](#) and extended the pediatric voucher program for four years, while the Senate passed a continuing resolution to fund the US government, which included a short term reauthorization of the pediatric voucher program.

While we will need to work with the Senate to make sure they pass the Creating Hope Reauthorization Act by the new expiration date, December 11, 2020, to reauthorize the pediatric voucher program for a longer period, we are pleased with the progress that's been made and are grateful for your advocacy. Stay tuned for more chances to take action in the coming months.

Fiscal Year 2021 Appropriations Update

A stopgap spending bill was passed by Congress and signed by the President at the end of September which extends current government funding levels until December 11, 2020. Called a continuing resolution, or CR, this bill allows the government to continue operating, even though a new budget was not put in place by the beginning of the new fiscal year on October 1.

Congress will now have about two months to either finalize a Fiscal Year 2021 appropriations package, or pass another continuing resolution to continue current spending levels into 2021, potentially until after the new Congress begins. As you know, we advocate annually for an increase in medical research funding, and therefore support a full Fiscal Year 2021 budget passing as soon as possible. We will continue to advocate with Congress.

PROJECT HOPE: A CCAM WEBINAR



DR. W.K. ALFRED YUNG



DAVID ARONS



DR. MARIELLA FILBIN



PROJECT HOPE

High-Grade Glioma-Omics in Pediatric and AYA

[HTTP://BIT.LY/ABOUTCCAM](http://bit.ly/aboutccam)

Project HOPE: A CCAM Webinar

Project HOPE (High-Grade Glioma-Omics in Pediatric and Adolescent and Young Adult Cancer), is a transformative research project optimizing single-cell sequencing to learn more about tumor growth and progression. The project is funded by the National Cancer Institute (NCI), following the direct advocacy from NBTS and coalition partners like the Pediatric Brain Tumor Foundation.

During Childhood Cancer Awareness Month (CCAM), NBTS sponsored [a webinar](#) to update the community on this exciting project. During this webinar, Dr. Mariella Filbin, Co-Director, Pediatric Neuro-Oncology Program, Dana-Farber Boston Children's Cancer and Blood Disorder Center; Dr. W.K. Alfred Yung, Professor, Department of Neuro-Oncology, UT MD Anderson Cancer Center; and David Arons, CEO of NBTS, shared key details about this initiative and how it impacts the brain tumor community.

[WATCH NOW](#)

2020 Childhood Cancer Summit

2020 VIRTUAL CHILDHOOD CANCER SUMMIT

Each September during Childhood Cancer Awareness Month (CCAM), the Congressional Childhood Cancer Caucus hosts a summit to raise awareness about pediatric cancer and reflect on the progress made each year, including live-saving new research and treatments. Normally held on Capitol Hill, the Summit was virtual in 2020, allowing advocates across the country to participate and learn more.

[Click here](#) to watch the 11th Annual Childhood Cancer Summit and hear from the leaders of the Congressional Childhood Cancer Caucus, which includes Representatives Michael McCaul (TX-10), G.K. Butterfield (NC-01), Jackie Speier (CA-14), and Mike Kelly (PA-16).

[WATCH NOW](#)

Medical Grade Masks Available



Thanks to a donation from Karyopharm Therapeutics, free medical grade masks are available for our brain tumor community. If you would like to receive a shipment of masks, please contact Rachael Kittleson at patientnavigator@braintumor.org.

[REQUEST MASKS](#)

Meditation Mondays and Brain Tumor Support Conversations



Mental health and well-being has never been more important for our patients and their caregivers. NBTS is pleased to offer [Meditation Mondays](#) and [Brain Tumor Support Conversations](#) to provide support and an opportunity to connect with members of our community. Meditation Mondays are held the second Monday of each month. Our next session is November 9th at 7pm/EST. You can also [view previous sessions](#) that were recorded

anytime throughout the month. Brain Tumor Support Conversations are offered on the third Sunday of each month. Our next session is October 19th at 7pm/EST. We hope you will join us!

[QUESTIONS?](#)

[CONTACT US](#)

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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