November Update: Lomustine Access Survey + Advocacy Victory

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Quick Survey: Lomustine Access Issues

National Brain Tumor Society (NBTS) is concerned about patient access to the common chemotherapy drug Gleostine (also known as lomustine or CCNU), which is manufactured by the company NextSource. Many patients are having difficulty accessing this treatment because of a decision by NextSource to withdraw Gleostine from the Medicare program. NBTS is spearheading efforts to restore access to this critical treatment for brain tumor patients across the country.

If you are experiencing challenges accessing or paying for this drug, we want to hear from you. Please fill out a short questionnaire (expected completion time: 3-5 minutes). We encourage you to contact us at advocacy@braintumor.org with any questions.

COMPLETE THE SURVEY

Advocacy in Action: Federal Support for Pediatric Cancer Research
On November 4, the Children’s Brain Tumor Network announced that it had received a grant from the Childhood Cancer Data Initiative (CCDI) at the National Cancer Institute (NCI) to support analysis of thousands of pediatric brain tumor samples. This data will be shared with researchers alongside data collected through other NCI initiatives, such as the Gabriella Miller Kids First Pediatric Research Program, to help accelerate research and treatment development efforts.

Milestones like this are only made possible because of the involvement of people like you. Through the efforts of the brain tumor community at events like Head to the Hill and in-district meetings, we ensure that legislators and other key decision-makers are well aware of the urgent, unmet needs of brain tumor patients across the country. That translates into concrete victories such as this one, and will ultimately drive future discoveries to conquer and cure brain tumors - once and for all.

**Action Alert: Tell Congress to Act on Telehealth**

Since the coronavirus pandemic began and was declared a Public Health Emergency (PHE) by the federal government, patients have begun using telehealth services at dramatically higher rates. We have heard from many of
you about how loosening restrictions on who can use telehealth has created benefits, like reduced travel time and improved continuity of care, that make it easier to manage your experience.

However, when the PHE eventually ends, restrictions on telehealth that prevented access to this type of care before the pandemic will snap back into place. Several pieces of legislation, such as the Telehealth Modernization Act that we advocated for at this year’s Head to the Hill, would eliminate these restrictions permanently so patients can continue to receive health care services at home. Congress needs to act before the end of the year to pass telehealth legislation and protect patients’ access to care through the end of the pandemic and beyond.

Contact your legislators now and tell them to take action to protect access to telehealth by the end of the year!

TAKE ACTION

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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