



December 10, 2024

The Honorable Susan Wild
U.S. House of Representatives
1027 Longworth House Office Building
Washington, DC 20515

The Honorable Brian Fitzpatrick
U.S. House of Representatives
271 Cannon House Office Building
Washington, DC 20515

The Honorable Lori Trahan
U.S. House of Representatives
2439 Rayburn House Office Building
Washington, DC 20515

The Honorable John Joyce
U.S. House of Representatives
152 Cannon House Office Building
Washington, DC 20515

Dear Representatives Wild, Fitzpatrick, Trahan, and Joyce:

The undersigned childhood cancer organizations are members of the Alliance for Childhood Cancer, which is composed of patient advocacy groups, healthcare professionals, and scientific organizations representing Americans who care deeply about childhood cancer. We are writing to endorse the Bolstering Research and Innovation Now (BRAIN) Act (H.R. 9113). Thank you for prioritizing the needs of the brain tumor community and introducing what we understand to be the first-ever bill that was crafted with the unique needs of the brain tumor community in mind.

Today, more than 1 million people in the United States are living with a brain tumor. Another 94,000 more will likely be diagnosed in 2024, in addition to hundreds of thousands of Americans diagnosed with metastatic brain cancer. Additionally, more than 5,200 children and adolescents (ages 0-19) will be diagnosed with a primary brain tumor in the U.S. this year alone. A single diagnosis comes with a serious impact on patients and their loved ones—from changes in brain function to decreased independence—and too often is life-threatening.

For malignant brain tumors, incidence and survival rates have remained stagnant for 45 years, despite major improvements made in the treatment of other cancers, with a five-year relative survival rate of only 35.7%. Only a few treatments have been approved for malignant brain tumors. None of these extend survival more than two years on average or are considered to be curative, and there has never been a drug developed and approved uniquely for pediatric brain tumor patients. Pediatric brain tumors are now the leading cause of cancer-related death among children and young adults ages 19 and younger.

In the past decade, the genomics and immunotherapy revolutions in cancer research have ushered in an era of groundbreaking new treatments and precision medicines for patients with many different forms of cancer. However, these advances have yet to demonstrate success in rare and recalcitrant cancers, such as malignant brain tumors.



The BRAIN Act would benefit patients with brain tumors and other rare and highly deadly cancers and is complementary to many existing laws and policies. At a high level, it will:

- Increase transparency of federally-funded biobank collections so that researchers are aware of others who possess samples that might be shared to enable important research.
- Sufficiently resource the National Cancer Institute's Glioblastoma Therapeutics Network, so that it can realize its promise of vetting treatments and completing innovative early-phase clinical trials.
- Enable team science to advance immunotherapy research (CAR-T) engineered to attack brain cancer cells.
- Direct the Centers for Disease Control to conduct a public education campaign around the importance of clinical trials and biomarker testing in cancer treatment.
- Expand funding to develop innovative systems of care models for brain tumor survivors.
- Direct FDA to issue guidance to ensure brain tumor and other rare and recalcitrant cancer patients access to clinical trials evaluating treatments for other diseases.

Despite the increased promise, the reality is that to realize additional meaningful progress against brain tumors – including pediatric brain tumors – more, better-funded, and collaborative research is required to advance innovative solutions for patients with these stubborn, hard-to-treat, and aggressive cancers. Additionally, the development of model systems of care and public education and awareness will be critical in generating progress for this area of urgent, unmet medical need.

We need breakthroughs — now. Pediatric patients with brain tumors and their loved ones are waiting for better treatments, a better quality of life, and cures. Patients, caregivers, researchers, government officials, and healthcare providers must work together to disrupt the status quo and invest in promising treatments and technology to achieve life-saving outcomes.

Thank you for your leadership on behalf of children with cancer. We look forward to working with you as the BRAIN Act moves through the legislative process. Should you have any questions or need additional information, please contact Rosalie Abbott, Co-Chair of the Alliance for Childhood Cancer, at Rosalie.abbott@stbaldricks.org, or Dr. Michael Link, Co-Chair of the Alliance for Childhood Cancer, at mink@stanford.edu.

Sincerely,

Alliance for Childhood Cancer

American Childhood Cancer Organization

American Society of Pediatric Hematology/Oncology

The Andrew McDonough B+ Foundation

Association of Pediatric Hematology/Oncology Nurses



Association of Pediatric Oncology Social Workers

Children's Brain Tumor Foundation

Children's Cancer Cause

Dana-Farber Cancer Institute

The Leukemia & Lymphoma Society

The Pediatric Brain Tumor Foundation

Rally Foundation for Childhood Cancer Research

St. Baldrick's Foundation