## Congress of the United States

Washington, DC 20515

September 25, 2025

The Honorable Robert F. Kennedy, Jr. Secretary
U.S. Department of Health and Human Services
200 Independence Avenue, S.W.
Washington, DC 20201

The Honorable Douglas R. Lowy, M.D. Principal Deputy Director National Cancer Institute 31 Center Drive, Building 31 Bethesda, MD 20814

Dear Secretary Kennedy and Dr. Lowy:

We are deeply concerned by the National Cancer Institute's decision to terminate funding for the Pediatric Brain Tumor Consortium (PBTC) and transition the PBTC's functions over to the Pediatric Early Phase Clinical Trials Network (PEP-CTN). This decision could undermine critical research offering hope to children and families facing heartbreaking diagnoses. I urge you to reverse this decision and provide clarity on this decision to researchers, families, and most importantly, patients who will be affected by this change.

As you know, brain and spinal cord tumors are the most common types of solid tumor found in children, accounting for about one in five cancers in all patients under the age of fifteen. Voluntary clinical trials are an indispensable practice for medical professionals to evaluate the safety and effectiveness of new treatments. For many patients and families, these trials represent the only option after conventional treatments fail.

The PBTC is an association of academic centers and children's hospitals, including the Memorial Sloan Kettering Cancer Center in New York, dedicated to trials of novel treatments for pediatric brain cancer. Since 1999, the PBTC has made use of Federal dollars to develop lifesaving therapies to treat some of the deadliest pediatric brain cancers.

Last month, the PBTC was informed that it would receive no Federal funding beyond March 2026. Terminal patients on waiting lists for these trials will no longer be able to enroll in these critical trials, and those currently enrolled may lose access to the trials for a period of time as studies are put on hold due to lack of funding.

We understand the Administration intends to transition the PBTC to PEP-CTN, but the PEP-CTN's mission is far too broad and will result in the de-prioritization of pediatric brain cancer trials, in favor of other pediatric cancer trials. A specialized center focused solely on pediatric brain cancer is essential to the success of brain tumor research in the future. Additionally, we have concerns that some patients may be lost in the fold during this transition, and that crucial time will be lost as well. For patients on PBTC trials, every second counts.

This decision is devastating for patients, for researchers, and for so many affected by pediatric brain cancer. We cannot afford to take this step backward, and we stand ready to work on a bipartisan basis in Congress to ensure that this research continues in full and that the United States continues to support research, innovation and medical breakthroughs.

We urge you to reconsider this harmful decision, and we look forward to your response.

Regards,

Laura A. Gillen Member of Congress Kirsten Gillibrand United States Senator

Kirsten Gillibrand

Michael V. Lawler Member of Congress