Dear Advocate,

As you may have heard, the President announced an initiative to provide $500 million in funding over the course of 10 years to accelerate childhood cancer research during his State of the Union address. We were encouraged to hear this announcement and honored to also be included in a virtual meeting held last week by the Administration to discuss further details of the initiative.

During that meeting, Dr. Ned Sharpless, Director of the National Cancer Institute (NCI), announced that a major focus of the initiative will be on how to improve the collection and sharing of data to advance pediatric cancer research. Aggregating data to improve research on childhood cancers like brain tumors is critical, and we look forward to hearing more on this initiative in the coming months.

The new initiative complements the National Brain Tumor Society’s flagship research program focused on children, the Defeat Pediatric Brain Tumors Research Collaborative. Launched with the support of collaborating organizations including Rally Foundation for Childhood Cancer Research, St. Baldrick’s Foundation, and Students Supporting Brain Tumor Research, this initiative is working to find new treatments for DIPG and other pediatric high-grade gliomas. Funded labs from St. Jude Children’s Research Hospital, Montreal Children’s Hospital/McGill University Health Centre, and the German Cancer Research Center are sharing data to speed the research process. To learn more about this program, visit our website.

The driving force behind NCI’s childhood cancer data effort is clearly the efforts of many dedicated pediatric cancer research advocates, including all of you who participate in our NBTS Advocacy program. Your advocacy also led to the passage of the Childhood Cancer STAR Act that NBTS championed last year as part of the Alliance for Childhood Cancer. The new law will advance pediatric cancer research and child-focused cancer treatments, while also improving childhood cancer surveillance, as well as enabling the development of enhanced resources for survivors and those impacted by kids’ cancers. Implementation of the STAR Act will be an important part of the new data aggregation effort at the NCI.

Advocates across the country have spoken up for kids with cancer and our elected leaders have taken notice. We will continue to advocate for change and will update you as more information becomes available on the President’s initiative.

As always, thank you for your advocacy.

Lainey Titus Samant
Director of Advocacy