

February 5, 2024

The Honorable Anna G. Eshoo U.S. House of Representatives 272 Cannon House Office Building Washington, DC 20515

The Honorable Kim Schrier U.S. House of Representatives 1110 Longworth House Office Building Washington, DC 20515 The Honorable Diana DeGette U.S. House of Representatives 2111 Rayburn House Office Building Washington, DC 20515

Dear Representative Eshoo, Representative DeGette, and Representative Schrier:

The undersigned childhood cancer organizations are members of the Alliance for Childhood Cancer, consisting of patient advocacy groups, health care professionals, and scientific organizations representing Americans who care deeply about childhood cancer. We are writing to offer our endorsement of H.R. 6963, the Pediatric Cancer Drug Supply Act of 2024, and hope to see this policy included in a more comprehensive approach to addressing drug shortages. Thank you for your leadership in addressing ongoing childhood cancer drug shortages.

Approximately 1 in 263 children in the U.S. are diagnosed with cancer before their 20th birthday. Unfortunately, cancer remains the most common cause of death by disease among children in the United States. While the childhood cancer community has been experiencing oncology drug shortages for more than a decade, today's shortages are the worst we've seen. These shortages are caused by a multitude of factors, including quality issues, manufacturer business decisions, disruptions to raw ingredients and excipient supplies, and natural disasters and other emergencies that take place in countries that house critical drug manufacturing facilities. Exacerbating these issues is a fragile economic model that does not encourage the development of resiliency or manufacturing upgrades that could otherwise mitigate some of these factors.

Drug shortages significantly impact children with cancer and the health care professionals who care for them. Unfortunately, shortages of life-saving and live-extending drugs in childhood cancer care, many of which are also used in adult care, often do not have alternative treatments. As a result, some providers are forced to prioritize some patients over others, delaying treatment for children and disrupting clinical trials.

In our own survey conducted in 2023, more than half of the childhood cancer patients, survivors, caregivers, and/or family members reported that a life-saving drug experienced a shortage or became unavailable during treatment. Further, nearly 20% of this same cohort reported delays in



treatment due to the unavailability of a necessary drug. Pediatric cancer drugs were among the drugs in shortage during the 2010-2011 shortages spike, and from 2010 to 2020, eight of the 10 most frequently used drugs to treat acute lymphoblastic leukemia – the most common childhood cancer – were at some point temporarily unavailable.

The Pediatric Cancer Drug Supply Act of 2024 is a step toward mitigating shortages of life-saving and life-extending childhood cancer drugs by creating a pilot program to establish and maintain a 6-month reserve of essential childhood cancer chemotherapy drugs. By creating a reserve of critical pediatric chemotherapeutic drugs, we can ensure children can continue to have access to the medications they need during an acute, unexpected disruption to the supply chain while broader and longer-term policies are being enacted that would address underlying causes of these recurrent shortages.

Thank you for your leadership on behalf of children with cancer. The Alliance for Childhood Cancer welcomes the opportunity to further discuss the unique challenges of childhood cancer drug development and research. We look forward to working with you as the Pediatric Cancer Drug Supply Act of 2024 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 mlink@stanford.edu.

Sincerely,

## The Alliance for Childhood Cancer

American Association for Cancer Research

American Cancer Society Cancer Action Network

American Childhood Cancer Organization

American Society of Pediatric Hematology/Oncology

Andrew McDonough B+ Foundation

Association for Clinical Oncology

Association of Pediatric Hematology-Oncology Nurses

Association of Pediatric Oncology Social Workers

Children's Brain Tumor Foundation

Children's Cancer Cause

Children's Oncology Group

Dana-Farber Cancer Institute



Leukemia & Lymphoma Society

Mattie Miracle Cancer Foundation

MIB Agents

National Brain Tumor Society

Pediatric Brain Tumor Foundation

Rally Foundation for Childhood Cancer Research

St. Baldrick's Foundation

St. Jude Children's Research Hospital