



April 4, 2023

Dr. Monica M. Bertagnolli
Director
National Cancer Institute
9000 Rockville Pike
Bethesda, MD 20892

Dear Dr. Bertagnolli:

The undersigned childhood cancer organizations are members of the Alliance for Childhood Cancer, consisting of patient advocacy groups, healthcare professionals and scientific organizations, representing Americans who care deeply about childhood cancer. We write to offer our partnership in the development of the newly proposed Childhood Cancer – Data Integration for Research, Education, Care, and Clinical Trials (CC-DIRECT) program.

As you know, each year in the U.S. an estimated 16,000 children are diagnosed with cancer. Approximately 1 in 263 children in the U.S. are diagnosed with cancer before their 20th birthday. Overall, incidence rates from 2010 through 2019 have stabilized in children after increasing since 1975 but continued to rise in adolescents by 1% per year, although trends vary by cancer type. Unfortunately, cancer remains the most common cause of death by disease for children in America.

Together, we have made significant advances to develop better treatments for many forms of childhood cancer. However, for too many children, progress is limited and there is no available cure. Unfortunately, 1 in 5 children diagnosed with cancer in the U.S. will not survive, and for the ones who do, the battle is never over. By the age of 50, more than 99% of survivors have had a chronic health problem, and 96% have experienced a severe or life-threatening condition caused by the toxicity of the treatment that initially saved their life, including brain damage, loss of hearing and sight, heart disease, secondary cancers, learning disabilities, infertility and more.

CC-DIRECT brings clinical and patient navigation support to families facing childhood cancer from diagnosis through survivorship. Through supporting families seeking care information, enabling research participation, and creating standardized cancer health records, CC-DIRECT has the potential to transform the childhood cancer patient navigation landscape.

We are heartened to see the National Cancer Institute (NCI) is already collaborating with many community stakeholders to build CC-DIRECT, including members of the Alliance for Childhood Cancer. As this program continues to grow, we ask that the NCI continues to incorporate the perspectives of patients, survivors, family members, and caregivers into the development of the program. We also suggest that NCI review the landscape of existing navigation services provided



by the community to determine how best to integrate existing community services into CC-DIRECT. Additionally, we encourage openness and transparency about CC-DIRECT with the broader childhood cancer community, particularly as decisions are made about where CC-DIRECT will be placed within NCI and how the program will be funded. The Alliance for Childhood Cancer stands ready to partner with the NCI to achieve these goals.

Thank you for your work on behalf of children, adolescents, and young adults with cancer. The Alliance for Childhood Cancer looks forward to working together on this innovative endeavor. Please contact Sarah Milberg, Co-Chair of the Alliance for Childhood Cancer, at smilberg@allianceforchildhoodcancer.org or Dr. Michael Link, Co-Chair of the Alliance for Childhood Cancer, at mlink@stanford.edu for any additional information.

Sincerely,

The Alliance for Childhood Cancer

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

Leukemia & Lymphoma Society

Mattie Miracle Cancer Foundation

National Brain Tumor Society

Pediatric Brain Tumor Foundation

Rally Foundation for Childhood Cancer Research

Sarcoma Foundation of America

St. Baldrick's Foundation