

**The Leukemia & Lymphoma Society
HR 2019, the Kids First Research Act
Position Paper**

The Leukemia & Lymphoma Society (LLS) is the world's largest voluntary health agency dedicated to curing leukemia, lymphoma, Hodgkin's disease and myeloma, while improving the quality of life of patients and their families. Treating cancer involves accessing a complex and extensive set of health care services including chemotherapy and prescription drugs, among others. LLS is committed to ensuring access to and compliance with the most appropriate, evidence-based treatments for all blood cancer patients.

Pediatric Research Funding

Pediatric cancer is the leading cause of disease-related death for children, with approximately 13,500 children who will be diagnosed with cancer this year¹. While critical advances have been made in treatments for adult cancer, in 20 years the FDA has approved only two drugs for childhood cancer, and half of all chemotherapies used for children's cancers are over 25 years old².

The National Institutes of Health (NIH) is the foundation for national cancer research activities, and NIH funded research has been critical to developing scientific breakthroughs. In adult clinical research, 25 percent of research funding is from the NIH and 60 percent is from industry. In childhood cancer research, the NIH provides nearly all of the funding. Because only four percent of the NIH budget is dedicated to pediatric, adolescent, and young adult cancer research, sustained funding for researchers and health care professionals is crucial in the fight against pediatric cancers³.

LLS supports HR 2019, the Kids First Research Act, a bill which will increase funding for pediatric medical research activities administered through the Common Fund at National Institutes of Health (NIH). HR 2019 provides much needed funding for crucial research projects, at a time in our nation's progress in medical research. In cancer research in particular, we are yielding unprecedented examples of precision based medicine that are fundamentally altering the way in which we will categorize and treat cancers going forward. These funds will help advance the important projects funded by the NIH in areas of high unmet medical need. We urge Members to co-sponsor this legislation.

For more information on LLS' position, please contact Emily Shetty, Senior Director of Legislative Affairs at Emily.Shetty@lls.org.

To cosponsor HR 2019, the Kids First Research Act, please contact Scot Malvaney, Policy Director, in Rep. Harper's office at scot.mulvaney@mail.house.gov, or Tom Cheney, Legislative Assistant, in Rep. Welch's office at tom.cheney@mail.house.gov.

¹ American Childhood Cancer Organization. (n.d.). Childhood cancer statistics. 2013. Retrieved from <http://www.acco.org/information/aboutchildhoodcancer/childhoodcancerstatistics.aspx>

² People Against Childhood Cancer. (n.d.). *Childhood cancer facts and statistics*. Retrieved from <http://curechildhoodcancer.ning.com/page/facts-1>

³ Ibid