

**Testimony for the House Committee on Appropriations  
Subcommittee on Labor, Health & Human Services, Education  
and Related Agencies**

**Kathleen Ruddy, Chief Executive Officer of the St. Baldrick's Foundation**

**May 19, 2021**

The St. Baldrick's Foundation is very pleased to have the opportunity to provide this testimony to the House Appropriations Committee in support of funding for childhood cancer research programs in Fiscal Year 2022. Specifically, we hope that Congress will once again this year provide \$30 million to fully fund the programs created by the Childhood Cancer STAR Act and provide an additional \$50 million once again to fund the Childhood Cancer Data Initiative.

The St. Baldrick's Foundation is a volunteer and donor powered charity committed to supporting the most promising research to find cures for childhood cancers and give survivors long and healthy lives. We are the largest non-government funder of childhood cancer research grants, and we have funded over \$306 million in research grants to date.

Worldwide, a child is diagnosed with cancer every 2 minutes. Cancer is the leading disease-related cause of death in the U.S. for children and adolescents ages 1-19, and 1 in 264 children and adolescents will develop cancer before the age of 20. We have made significant advances to develop better treatments for the most common forms of childhood cancer, but for many other types, progress is limited, and for too many children 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.

## **Impact of COVID-19 on Childhood Cancer Research Funding**

Thanks to greater awareness and advocacy, the National Cancer Institute has nearly doubled its investment in childhood cancer research in recent years, but childhood cancer research, unfortunately, has not been spared by COVID-19. The COVID-19 pandemic has caused severe disruptions to the medical research ecosystem, including childhood cancer research. Many laboratories have been forced to minimize operations, delay research already underway, and postpone planned projects. Clinical trials play a pivotal role in advancing childhood cancer care and treatment. Because the effects of clinical trials and drug development can take years to realize, the pandemic's disruptions to childhood cancer research will be felt for years to come.

Further, research for many diseases is principally funded by sources other than government, such as philanthropies, academia, and industry sources. Childhood cancer research, however, uniquely depends on the federal government as its primary source of funding. About 60% of all funding for drug development in adult cancers comes from pharmaceutical companies, but for kids, almost none. Many cancer charities are exclusively focused on adult cancers. There is a big funding gap to be filled, and the childhood cancer community is counting on the federal government to keep its commitment to support necessary research.

The St. Baldrick's Foundation has also felt the effects of the COVID-19 pandemic. Due to the pandemic's effect on St. Baldrick's fundraising efforts, donations to St. Baldrick's dropped 35% last year, causing a shortfall of almost \$13 million in our grants for childhood cancer research in 2020. Since St. Baldrick's is the largest maker of these grants aside from the U.S. government, this has been a big hit not only to St. Baldrick's, but to the broader childhood cancer

research community. Cancer does not stop for a pandemic, and kids facing cancer need help now.

### **Childhood Cancer Research Funding Requests for Fiscal Year 2022**

Last year, we were so thankful that Congress provided \$30 million for the childhood cancer programs established in the Childhood Cancer Survivorship, Treatment, Access, and Research (STAR) Act – the most comprehensive childhood cancer bill in history. **For the coming year, we ask that you continue to provide funding for the programs created by the Childhood Cancer STAR Act at \$30 million.**

The STAR Act includes key research initiatives focused on some of the least studied and understood childhood cancers by expanding and enhancing biorepositories, which the National Institutes of Health (NIH) is currently working to develop. Moreover, the STAR Act expands childhood cancer surveillance at the Centers for Disease Control and Prevention (CDC) to better identify and track incidences of child, adolescent, and young adult cancer.

Further, childhood cancer survivors continue to face significant health issues requiring specialized follow-up care for the rest of their lives. As a result, childhood cancer survivors often need advanced follow-up care long after battling cancer and we need to ensure that health care professionals are equipped to provide that care into adolescence and adulthood. As such, the STAR Act allows for the development of best practices for the treatment of late effects of childhood cancers, improved collaboration among providers so that doctors are better able to care for this population as they age, and the creation of innovative models of care for childhood cancer survivors.

The long-term economic costs to properly treat survivors of childhood cancers is staggering – underscoring the need for more effective initial treatment. This is why the STAR

Act works hand-in-hand with the Childhood Cancer Data Initiative (CCDI), for which Congress provided \$50 million last year. CCDI expands the breadth and quality of patient data and makes the data more accessible and easier for researchers to use to fast-track advances for children with cancer. **We ask that Congress once again fund the Childhood Cancer Data Initiative to establish more efficient ways to share and use childhood cancer data.**

The St. Baldrick's Foundation appreciates the leadership and support of the Subcommittee in funding childhood cancer research. We are ready to work with you in any way we can to continue to help children and their families who are fighting cancer.