United States Senate

WASHINGTON, DC 20510

April 15, 2019

The Honorable Roy Blunt Chairman Subcommittee on Labor-HHS-Education Appropriations Committee United States Senate Washington, DC 20510 The Honorable Patty Murray Ranking Member Subcommittee on Labor-HHS-Education Appropriations Committee United States Senate Washington, DC 20510

Dear Chairman Blunt and Ranking Member Murray:

As you begin work on the Fiscal Year (FY) 2020 Labor, Health and Human Services, and Education Appropriations bill, we write to thank you for providing full funding for the childhood cancer programs established in the Childhood Cancer Survivorship, Treatment, Access, and Research (STAR) Act in FY2019, and we ask that you continue to provide funding for these programs at \$30 million in FY2020.

While some progress has been made in pediatric cancer research – leading to a decline in childhood cancer deaths by almost 70 percent over the last four decades – cancer is still the leading cause of death by disease past infancy among children in the United States, according to the National Cancer Institute (NCI). And while survival rates for some forms of childhood cancer like leukemia have increased to greater than 85 percent, the median survival rate for other childhood cancers such as diffuse intrinsic pontine glioma is less than one year.

With the goal of raising overall survivorship rates, the Childhood Cancer STAR Act authorized key research initiatives, such as biorepositories at the National Institutes of Health (NIH) and surveillance at the Centers for Disease Control and Prevention (CDC), while focusing on some of the least-studied and understood childhood cancers.

Further, childhood cancer survivors continue to face significant health issues requiring specialized follow-up care for the rest of their lives. As many as two-thirds of childhood cancer survivors will develop a serious or life threatening condition, such as secondary cancers and organ damage. 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, we ask that you also fully fund the Childhood Cancer STAR Act provisions to develop best practices for the treatment of late effects of childhood cancers, to improve collaboration among providers so that doctors are better able to care for this population as they age, and to create innovative models of care for childhood cancer survivors.

We greatly appreciate your support for funding in FY2019 to implement the Childhood Cancer STAR Act and look forward to working with you to ensure that these efforts continue in FY2020.

Sincerely,

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FY20 Childhood Cancer STAR Act funding

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