

For Immediate Release September 20, 2019 Contact: Jess Kean, Communications Director jkean@childrenscause.org

CHILDHOOD CANCER NONPROFIT MARKS 20 YEARS

WASHINGTON, DC – A DC-based nonprofit organization that serves as a policy advocate for children with cancer, survivors, and their families is celebrating its 20th year and marking the occasion with a name change. The Children's Cause for Cancer Advocacy is now Children's Cancer Cause.

Susan L. Weiner, PhD, founded the Children's Cancer Cause in 1999 to give voice to the concerns of childhood cancer patients, survivors and their families and empower them to take on leadership roles in pediatric cancer advocacy.

"In 1999, families' and survivors' urgency and perspectives on the need for new treatments and the struggles of survivors seemed to be absent in national cancer policy debates," said Dr. Weiner.

"We've come so far. We've worked to give those affected by childhood cancer the knowledge and skills to become informed, responsible advocates," she said. "Working closely with partners on Capitol Hill, in federal agencies and other childhood cancer organizations, we've achieved legislative victories in improving how new therapies are developed and how survivors are cared for."

Recent legislative victories include passage of the *RACE for Children Act* in 2017, followed by the *Childhood Cancer STAR Act* in 2018. The RACE Act authorizes FDA to require pediatric testing of adult cancer drugs, accelerating the development of new treatments for children. The STAR Act authorizes \$30 million annually from 2019-2023 for programs and research to combat childhood cancer through the National Institutes of Health and the Centers for Disease Control and Prevention.

As Children's Cancer Cause looks ahead to 2020 and beyond, the organization remains steadfast in its mission to serve as the voice of children with cancer to policymakers in Washington.

Despite the progress of the last 20 years, there is still much work to be done. The era of precision medicine has opened up new doors to better, less toxic therapies but has also created new challenges around access and coverage issues. More children are surviving cancer than ever before but far too many of the nation's 500,000 childhood cancer survivors are left to battle life-long side effects.

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Children's Cancer Cause, formerly known as the Children's Cause for Cancer Advocacy, is the leading national advocacy organization working to achieve access to less toxic and more effective pediatric cancer therapies; to expand resources for research and specialized care; and to address the unique needs and challenges of childhood cancer survivors and their families. Children's Cancer Cause leads efforts to ensure that these needs and perspectives of children with cancer are integrated into the highest deliberations on health care and cancer policy at the federal level.