

ACS CAN and Childhood Cancer



As the advocacy partner of the American Cancer Society, childhood cancer advocacy is a high priority for ACS CAN. Our staff works closely with the childhood cancer community in our efforts to develop strategies around public policy advocacy. We believe real progress in reducing the incidence of and mortality from childhood cancer will come as a result of policy change that incentivizes and supports research and the development of new therapies.

Childhood Cancer Facts:

- Cancer is the leading cause of disease-related death among children ages 1-19, and more than 15,000 children will be diagnosed with cancer in 2018.
- A majority of childhood cancer survivors experience serious side effects or late effects as a result of currently available cancer-fighting treatments. This can cause significant and potentially life-threatening chronic conditions that can last a lifetime among the nearly 380,000 survivors of childhood cancer and their families living in the US today.
- Additional scientific discovery is essential to drive advances against the childhood cancers that have seen little or no progress and remain deadly, and to deliver more effective and less toxic cancer treatments to improve quality of life so these children and adolescents can both survive AND thrive

ACS CAN Childhood Cancer Accomplishments:

- In 2014, the American Cancer Society prepared a special section on childhood cancer in its annual Cancer Facts and Figures publication, which highlighted the burden of disease across the childhood and adolescent communities. It also provided data that showed that childhood cancer is not just a single disease and that progress made in some areas has not been felt in many others.
- ACS CAN worked in partnership with the Alliance for Childhood Cancer, a coalition of organizations advocating on childhood issues, on a Congressional briefing focused on childhood cancer issues in April 2014. We remain very involved in the Alliance's annual lobby day as sponsors and participants, and bring in several of our own volunteers to participate in the event.
- The American Cancer Society hosted a workshop in March 2015 with the National Cancer Policy Forum that examined recent trends in comprehensive cancer care for pediatric cancer patients and their families and consider potential policy actions to improve care and outcomes.
- Through the combined efforts of ACS CAN, the Alliance for Childhood Cancer, and the childhood cancer community, two childhood cancer bills were recently passed by Congress and signed into law. The Childhood Cancer STAR Act, which was signed into law June 2018, will help advance pediatric cancer research, increase transparency and expertise for pediatric cancer research at the NIH, and expand research into the long-term side effects of childhood cancer and its treatments. The RACE Act, which was signed into law August 2017, requires companies that are developing cancer drugs for adults to study them in pediatric cancers as well.
- In 2016, ACS CAN spearheaded the development of a landscape report, Translating Discovery into Cures for Children with Cancer, that identifies areas of need and opportunity for childhood cancers. This landscape survey includes information regarding incidence and mortality of pediatric cancers, the number of pediatric clinical trials in progress, an examination of drugs with pediatric label information, major themes in pediatric cancer research, and an explanation the logistical, economic and regulatory features unique to pediatric cancer. ACS CAN and the Alliance for Childhood Cancer held a congressional briefing on this hearing in September 2016.

ACS CAN is committed to fighting for policies that will improve how we care for children diagnosed with cancer.