New Report Reveals Gaps, Identifies Unique Barriers in Pediatric Cancer Research

Analysis Highlights the Importance of Safeguarding Long-term Health of Pediatric Cancer Survivors

Atlanta –September 8, 2016 – A first of its kind joint report today from the American Cancer Society and Alliance for Childhood Cancer compiles the latest information related to pediatric cancer, including statistics and trends, a current list of drugs used to treat pediatric cancers, ongoing pediatric cancer clinical trials, and research funding levels. The report, "Translating Discovery into Cures for Children with Cancer: Childhood Cancer Research Landscape Report" marks the first time that statistics and information about childhood cancers have been brought together with a critical analysis of challenges and opportunities related to pediatric cancer prevention and treatment.

The American Cancer Society estimates that in 2016, approximately 14,660 children (age 0-19) will be diagnosed with some form of pediatric cancer and 1,850 will die. As of 2013, each death from pediatric cancer takes an average of 69 years of life.

"The numbers here tell a compelling story," said Katherine Sharpe, senior vice president of patient and caregiver support for the American Cancer Society. "We have seen significant progress when it comes to developing effective treatments for a variety of pediatric cancer sites and ultimately saving lives. But when we expand our view to look at all pediatric cancers, as well as long term health and survival, it becomes clear that there are still areas of research where progress is urgently needed."

While much progress has been made in childhood cancer, the report highlights that progress has not been consistent for all cancer types. The 5-year survival rate for all cancers combined rose from 64 percent among children diagnosed from 1975-1979 to 84 percent for children diagnosed from 2005-2011. For neuroblastoma, 5-year survival is currently 78 percent. But for high-risk neuroblastoma, 5-year survival is only 40-50 percent, and the 5-year survival rate for some cancers like diffuse intrinsic pontine glioma (DIPG) is still essentially zero.

The report also details troubling statistics about the long-term health of pediatric cancer survivors, indicating high rates of late side effects, susceptibility to chronic conditions, and early death. More than two in three survivors of childhood cancer treated several decades ago developed chronic conditions and more than one in three survivors aged 35 or older have experienced health effects considered severe or life threatening, including death. This rate of severe events is over five times higher than the rate experienced by these survivors' siblings. In recent decades, treatments have been modified to reduce these risks, and the report shows evidence of improvement in late mortality associated with cancer and its treatment. Research into long-term and late effects among childhood cancer survivors is very important to address the needs of long-term survivors and identify risks associated with newer treatments.

The report features several key barriers specific to pediatric cancer research efforts. These include:

- Many pediatric cancers are unique to children and are different enough from adult cancers that they require separate research. This will require child-specific tumor banks and unique animal models for pediatric cancer drug testing.
- Market incentives don't entice industry investments in childhood cancer research and drug development to the same extent as adult cancer research, leaving a larger responsibility on government and philanthropies to make these investments. The National Cancer Institute (NCI) funds on average about $200 million per year specifically for pediatric cancer research and philanthropies cumulatively invest at a level that reaches about 50 percent of the NCI investment.
- The small number of children diagnosed with any given type of cancer can make conducting clinical trials more challenging, so careful coordination of research is critical to avoid competition for the same patients.

"Recognizing that progress is still needed in childhood cancer, this report aims to describe the process by which

childhood cancer drugs are developed," says Michael Link, M.D., co-chair of the Alliance for Childhood Cancer. “Describing the pediatric cancer research landscape and identifying barriers to progress allows us as a community to work collectively on ways to overcome these challenges.”

To view a full copy of the report, visit www.cancer.org/childrensreport.