

# ADOLESCENT & YOUNG ADULT CANCER

## ELIMINATING BARRIERS TO SURVIVE & THRIVE

# RESEARCH & CLINICAL TRIALS

## "THEY DON'T KNOW"

Ask an adolescent or young adult what their doctor said about their chance of survival and you will likely hear: "They don't know". Unfortunately, providers must frequently make care and treatment decisions using research, data, and therapies solely based on experiences of pediatric or older adult patients.

## INCREASED RISK FOR...

In addition, adolescent and young adult cancer survivors are not only at risk for a recurrence of their original cancer, but the 70,000 American diagnosed between 15 and 39 years of age are also at higher risk for developing new diseases due to previous treatments and screenings.



- Radiation treatment and imaging is one of the most important risk factors for secondary cancers and these cancers often do not arise until 10 to 20 years after initial exposure.



- Studies suggest that age at diagnosis is directly linked to risk of death from heart disease. Six percent of adolescent and young adult cancer patients die from heart disease before the age of 50 compared to just one percent of the general population.

## WE ARE INVISIBLE.

There are a number of reasons why providers struggle to answer questions about prognosis, survivability, and long-term risk:



- The National Cancer Institute (NCI) and Centers for Disease Control (CDC) have no formal way to coordinate efforts to study adolescents and young adults with cancer.



- Adolescents and young adults are least likely to be enrolled in clinical trials; and



- Most adolescents and young adults are referred to local community hospitals which means less access to tumor sample and data collection programs that researchers need to conduct studies.

## FEDERAL ADVOCACY PLAN

These are just a few of the problems researchers and providers face when understanding cancer trends and identifying treatment and protocols specific to 15-39 year old patients. Critical Mass supports federal policies that:

- Adds a dedicated adolescent and young adult program to the National Clinical Trials Network;
- Establishes a CDC Federal Advisory Committee for Adolescent and Young Adult Cancers;
- Expands the definition of cancer disparity to include 15 to 39-year-olds within existing programs such as the NCI's Community Oncology Research Program; and
- Incentivizes research to include annotated data for adolescents and young adults.

**IT'S TIME TO TRANSFORM THE CARE AND TREATMENT OF ADOLESCENTS AND YOUNG ADULTS IMPACTED BY CANCER.**

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SOURCES - Bleyer A, O'Leary M, Barr R, Ries LAC (eds). Cancer Epidemiology in Older Adolescents and Young Adults 15 to 29 Years of Age, Including SEER Incidence and Survival 1975-2000. National Cancer Institute, NIH Pub. No. 06-5767, Bethesda, MD 2006. de Moor JS, Alfano CM, Breen N, Kent EE, Rowland J. Applying evidence from economic evaluations to translate cancer survivorship research into care. J Cancer Surviv 2015 Sep;9(3):560-6. Kent EE, Breen N, Lewis DR, de Moor JS, Smith AW, Seibel NL. US trends in survival disparities among adolescents and young adults with non-Hodgkin lymphoma. Cancer Causes Control 2015 Aug;26(8):1153-62. Potosky AL, Harlan LC, Albritton K, Cross RD, Friedman DL, Hamilton AS, Kato I, Keegan TH, Keel G, Schwartz SM, Seibel NL, Shinoharorian M, West MM, Wu XC, AYA HOPE Study Collaborative Group. Use of appropriate initial treatment among adolescents and young adults with cancer. J Natl Cancer Inst 2016 Nov;108(11). Smith AW, Bellizzi KM, Keegan TH, Zebreck B, Chen VW, Neale AV, Hamilton AS, Shinoharorian M, Lynch CF. Health-related quality of life of adolescent and young adult patients with cancer in the United States: the Adolescent and Young Adult Health Outcomes and Patient Experience study. J Clin Oncol 2013 Jun 10;31(7):1235-45.