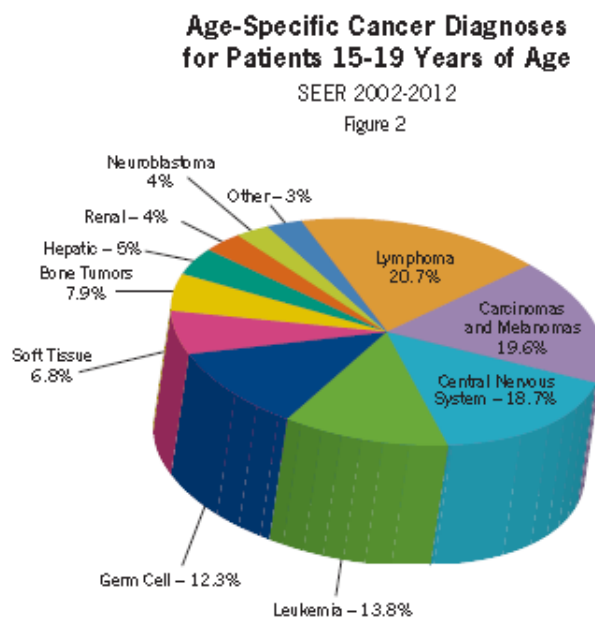
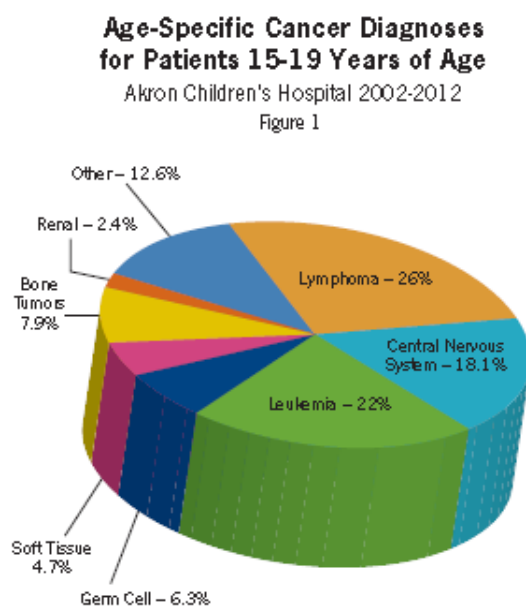


Adolescent and Young Adult Hematology-Oncology

Pediatricians have always known that children have unique needs and are not simply “little adults.” This is also true of our adolescent and young adult (AYA) hematology-oncology patients who fall between childhood and adulthood. For them, adolescence can be a frightening, challenging, complicated and wonderful time of life, both inside the hospital and out. In the U.S. and Canada, cancer diagnosed between 15 and 29 years of age is nearly three times more common than cancer during the first 15 years of life. Diagnoses in this age group account for 2 percent of all invasive cancers, compared to cancers diagnosed before age 15, which account for 0.75 percent. In 2009, 68,400 adolescents and young adults age 12 to 39 were diagnosed with cancer. This was nearly six times the number of cases diagnosed in children age 0 to 14 years.

The distribution of cancer types changes dramatically from age 15 to 30, such that the pattern at the youngest age does not resemble that at the oldest. Overall, the incidence of cancer in this age group has increased steadily during the past quarter century. Hodgkin’s lymphoma, melanoma, testicular cancer, female genital tract malignancies, thyroid cancer, soft-tissue sarcomas, non-Hodgkin lymphoma, leukemia, brain and spinal cord tumors, breast cancer, bone sarcomas, and non-gonadal germ cell tumors account for 95 percent of the cancers in this age group. From 2002 through 2012, the most common diagnoses in the 15 to 19 years age group seen at Akron Children’s Hospital were lymphoma (26 percent), leukemia (22 percent) and central nervous system tumors (18.1 percent). (Figure 1) These incidences are in accordance with national data during the same time period. (Figure 2)



Incidence and Survival

Cancer is the leading cause of disease-related death in the AYA population. For females, it’s the most common disease related cause. For males, it’s second only to heart disease. Only accidents, suicide and homicide claim more lives than cancer. Over the past several decades, there has been tremendous improvement in outcomes for pediatric cancers. Some diseases once considered fatal, like acute lymphoblastic leukemia, are now regularly cured. Unfortunately, improved survival rates among the

AYA group has been less robust, with little change over the past 30 years. In fact, at the beginning of the last quarter century, cancer in 15 to 39 year olds had a more favorable prognosis than at younger ages. Today, the opposite is true.

Incidence rates of cancer in adolescents and young adults vary by race and ethnicity. Both incidence and five-year survival rates are highest among Caucasians. American Indian/Alaska natives have the lowest cancer rates, but they have poorer survival rates than Caucasians. African-Americans have intermediate incidence rates and the lowest survival rates.

Much remains to be learned regarding these differences and the poorer outcomes of AYA patients in general. As a field, we strive to explain biological differences in cancer within this age group. Factors that may account for the lack of improved outcomes among AYA patients include:

- Delayed diagnosis of primary cancers
- Poor understanding of the biology and causes of cancers in this population
- Inadequate access to clinical trials and low participation rates
- Inadequate treatment practices and settings
- Unique psychosocial and supportive care needs

At Akron Children's, the overall five-year survival in the AYA group from 2002-2008 is statistically similar to the nationally reported rate of 85 percent. (Figure 3) Some variation may be due to variations in specific cancer types. Overall, this reflects the excellent standard of care we provide.

Our dedicated team of hematologists-oncologists and ancillary staff are experts in treating AYA patients. All of our team members, including those from child life, psychology, psychiatry and physical therapy, are geared toward the needs of this group. As a member institution of the Children's Oncology Group, we can offer access to national, multi-center clinical trials. We work with physicians at local institutions, such as Akron General Medical Center and Summa Health System, to ensure our patients receive the most age-appropriate, evidence-based therapies.

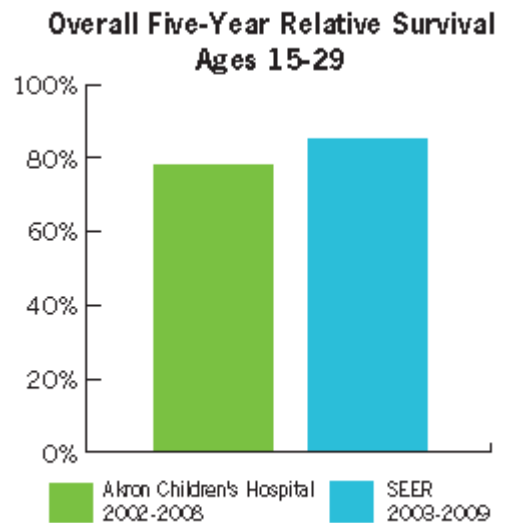


Figure 3

We apply this comprehensive approach toward AYA patients through all our programs, including those for non-malignant diseases such as hemophilia and sickle cell. This includes special support groups targeted to the AYA population for each disease. Our sickle cell program offers assistance with educational and vocational challenges. We recently opened a chronic pain clinic in collaboration with our Department of Palliative Care that provides AYA-specific services, including medication management and coordination with schools and employers. All our patients with chronic disease receive structured counseling beginning in their early teen years and continuing until they transition to adult providers.

At Akron Children's, we also strive to meet the unique medical and complex psychosocial needs of our AYA patients at the time of diagnosis and treatment, as well as after treatment when chronic and delayed sequelae may arise. In the long-term, we expect this targeted care will lead to improved outcomes within our AYA population. Meanwhile, each day we hope to help them not just survive, but to thrive and enjoy this wonderful and exciting time of life.