

A Medical
Home for
Adolescents
and Young
Adults with
Cancer

Our team consists of more than 30 doctors specializing in cancers that affect newborns to young adults.

According to the National Cancer Institute (NCI), 70,000 Americans ages 15 to 39 are diagnosed with cancer each year. NCI also reports that adolescents and young adults (AYAs) are much more likely to be diagnosed with cancer than children under age 15.¹ Over the past 30 years, cancer survival has not been improving for teens and young adults as fast as it has been for children and older adults. In fact, the rates have hardly improved at all.² These findings obviously point to a need to focus on the unique medical needs of the adolescent and young adult patient population and to develop more effective treatment.

Research shows that, for certain kinds of cancer, teens and young adults have dramatic improvements in long-term survival when they are treated on pediatric treatment protocols. For example, teens and young adults with acute lymphoblastic leukemia (one of the most common AYA cancers) have a 25 percent improvement in survival when they are treated on pediatric treatment regimens.

Seattle Children's Cancer and Blood Disorder Center ranks as one of the top pediatric cancer centers in the nation, according to *U.S. News & World Report*. Our team consists of more than 30 doctors specializing in cancers that affect newborns to young adults. These physicians co-lead a multidisciplinary team of pediatric oncologists, hematologists, surgeons, radiation oncologists, social workers, child-life specialists, clinical dietitians, pharmacists, pain management specialists, and professionals from many other disciplines to provide the best care possible. Under the care of this team, our patients experience better outcomes than the national average (see Table 1, page 31). It's important for patients to know that, depending on their diagnosis, the location of their treatment matters and pediatric protocols can dramatically improve their outcome.

Expanding Our Program

Seattle Children's, which serves a multi-state region, including Washington, Alaska, Idaho, and Montana, treats more newly-diagnosed young cancer patients than any other institution in the region. Teens and young adults comprise a significant population of patients receiving cancer treatment at Seattle Children's, where about one-fourth of the patients are currently age 15 and

older. When a lack of available beds resulted in patients being turned away, the hospital made the decision to expand to accommodate a growing patient demand.

In April 2013 the hospital opened its newly expanded facility, known as Building Hope. The new facility houses:

- The Cancer Center, with 48 new private rooms for child, adolescent, and young adult cancer patients, providing the comfort and privacy families need
- An Emergency Department
- A Critical Care Unit, with 32 new private rooms.

With this expansion, Seattle Children's became the first hospital in the United States to open an inpatient cancer unit exclusively for adolescents and young adults. The 16-bed unit is located on the top floor of Building Hope. Within one month of Building Hope's April 2013 opening, all of the new 80 beds were filled, including those in the AYA cancer unit.

Building Hope is the first phase of a four-phase approach to expanding Seattle Children's. We began the design process in 2010, with a goal of creating a patient-focused facility. From the beginning, we incorporated patients, families, and staff members in our planning advisory board to help create an environment that would support the physical, emotional, and psychological aspects of healing from the people who knew best.

The primary goal of the advisory board was to discuss ways to improve the hospital for patients and families. A secondary goal was to make our staff more efficient. To create an open and collaborative forum, we adopted a motto of "no idea is a bad idea" for the advisory board meetings.

The advisory board offered diverse perspectives and ideas on how to make Seattle Children's the best place for healing. This brainstorming led to insights into how to improve the physical space in Building Hope, as well as how to improve our services to better accommodate patients and families. For example, one parent thought it would be important for a child to have a visual assessment as soon as he or she entered the emergency department. Another suggested quiet areas where families could talk privately with hospital staff and process the events of the day.

Special consideration was given to the AYA unit's physical



Building Hope expansion



Artwork in AYA Unit

features and environment. For example, providing these patients with some control over their rooms was important given that they have little control of much else when undergoing treatment. Some of the unique features of our AYA inpatient cancer unit are listed in the box on page 33.

Meeting the Unique Needs of AYAs

Our AYA cancer unit is designed to address the particular needs of adolescents and young adults—ages 14 to 21 (and up to age 30 for certain diagnoses)—who often fall between the cracks in the healthcare system. The unit also houses the hospital’s AYA oncology program, which focuses on the unique needs and treatment challenges of this age group and has a special emphasis on offering psychosocial support.

Until now, there was no medical home for this age group since cancer programs are typically divided into pediatric and adult care where teens and young adults are a distinct minority. Thus, adolescents and young adults often feel isolated when they are battling cancer because they do not have contact with people their own age that they can relate to. Peer interactions are especially important for teens and young adults because they look to one another to see what milestones they should be reaching. Healthy peers are viewed as moving forward very fast as they head toward adulthood. If cancer treatment causes patients to miss months of school, or key events like graduation and going to college, patients may feel like their whole world has moved on without them.

Creating an AYA unit in Building Hope was a top priority so that we could not only offer an age-appropriate care environment, but also so that patients could benefit from the support of their peers during one of the most challenging times in their lives. Just knowing that they aren’t alone and are on a similar path as others their age can be very valuable.

Tailored Treatment & Programming

Seattle Children’s has one of the leading AYA cancer programs in the country. Our program offers a multidisciplinary team that includes experts in many specialties that have a specific

focus on caring for this population, such as our dedicated AYA psychologist and AYA child-life specialist.

Seattle Children’s pediatric oncology and hematology experts are both scientists and physicians, who place as much emphasis on diagnosis and care planning as they do on developing new treatments. Our cutting-edge research makes the newest protocols available to patients from infancy through young adulthood. We also offer patients greater access to groundbreaking clinical trials, such as the cellular immunotherapy Phase I cancer trial currently taking place at Seattle Children’s Research Institute.

We have done a lot of work to create innovative programs, as well as teen- and young-adult-focused educational materials and tools designed to help patients meet their treatment goals while also improving their quality of life.

From educational and supportive tools like the “Good Times and Bald Times” video series, to a Healing Arts Program that provides psychosocial support by helping patients share their stories through creative arts, these programs help to improve a patient’s treatment experience.

Seattle Children’s Healing Arts Program has been particularly beneficial to patients. The arts can be a powerful tool in helping patients and families through challenging circumstances. This program gives patients a voice in telling their stories through photography, film, music, and writing. Some of the patient-created works that have come out of the program include:

- Chris Rumble’s music video “Stronger,” which went viral last year and caught the attention of singer Kelly Clarkson
- “The Cat Immersion Project” starring Maga Barzallo Sockemtickem
- “The Hidden Shadows of Cancer” featuring Ruby Smith’s photography
- “Haunting A Head” starring Jenna Gibson
- “Sara Takes Her Leap into the Bone Marrow Sea” by Sara Mirabdolbaghi.

We understand missing school can also be a major issue for children, teens, and young adults while they are undergoing

(continued on page 32)

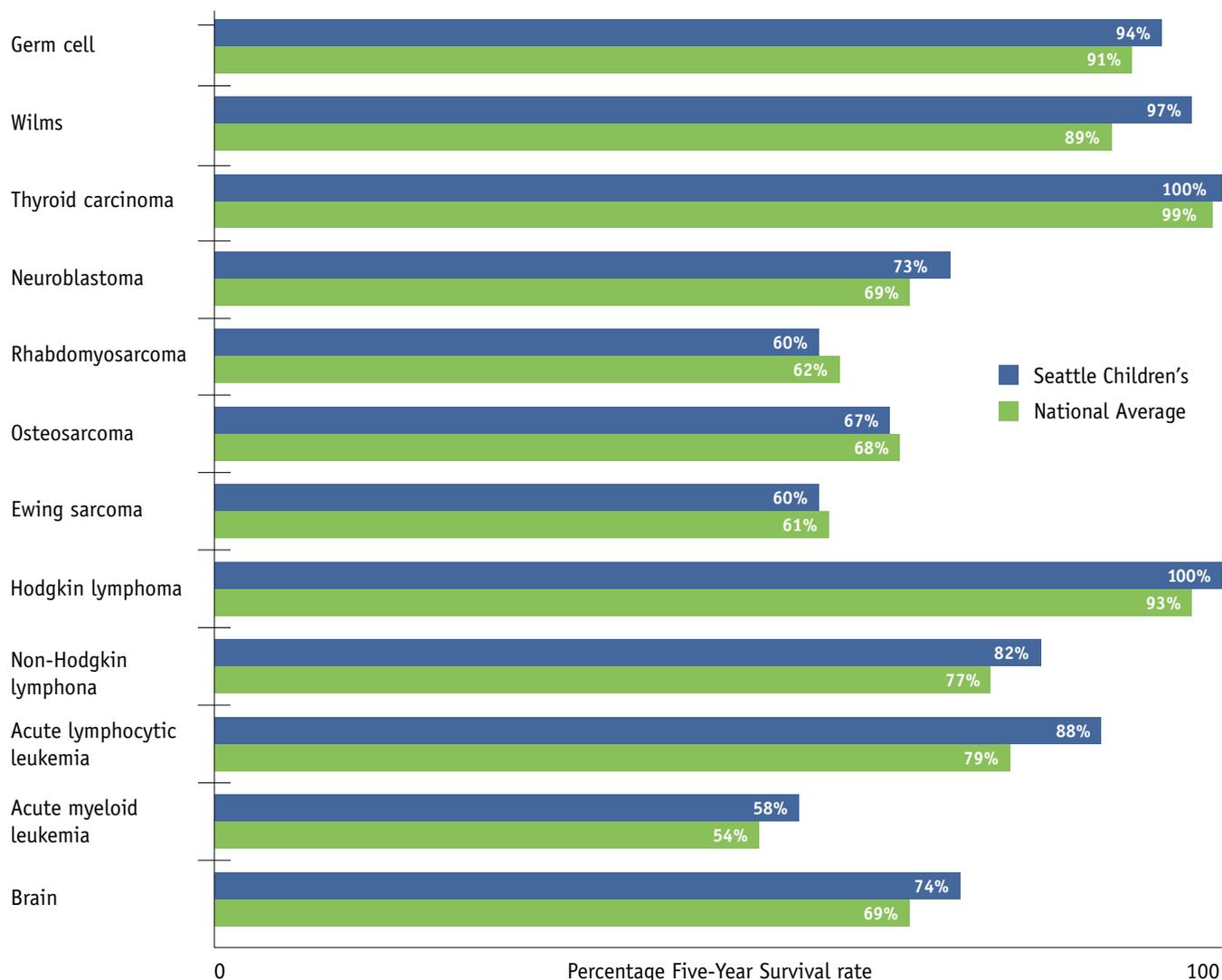


Soothing hallway in AYA Unit



AYA patient room

Table 1. Percentage of Children with Cancer between 1998 and 2005 Who Have Survived Cancer for at Least Five Years after Diagnosis*



*The blue bar shows the survival rates for Seattle Children's patients; the green bars show the national average survival rates.



AYA quiet room



Patient Lounge

cancer treatment. Because of this, we help patients continue with their education during treatment.

Another major area of focus in our AYA program is educating patients about fertility preservation. When a patient is first diagnosed as a teen, starting a family can be the furthest thing from their mind. But it's a crucial time to educate patients about how they can take steps to preserve their fertility, informing them of their options and connecting them with the necessary fertility preservation services that are available.

Becoming a Survivor

The word "remission" can be a breath of fresh air for patients and their families. However, young cancer survivors need to understand there are long-term risks to their overall health.

According to a 2006 study in *The New England Journal of Medicine*, about two-thirds of childhood survivors suffer from at least one chronic health condition and about one-third will experience another life-threatening condition.³

At Seattle Children's we understand that comprehensive, long-term support is crucial for cancer survivors to help prevent a relapse or other life-threatening illness. We've collaborated with the Fred Hutchinson Cancer Research Center in Seattle to create a Cancer Survivor Program that aims to keep survivors healthy throughout their lives by providing care and education about health risks.

This program is open to all survivors of childhood cancer who have completed treatment and have no signs of cancer, no matter where their treatment took place. Most survivors come to our survivorship clinic about two years after finishing therapy.

The program provides three types of services to childhood cancer survivors: education, clinical care, and research. Each survivor receives a notebook that describes the specific treatment they received, the health issues they should be aware of, and recommendations on how to stay healthy and improve their long-term outcomes. A personalized cancer treatment summary and long-term follow-up recommendations are also sent to the survivor's primary care provider.

In addition, this program helps ease the transition from pediatric to adult care and provides the opportunity to network with other cancer survivors and their families. Participants also have the option to take part in ongoing research studies about medical and psychosocial issues for long-term survivors.

Key Takeaways

While Seattle Children's was the first medical center to create a specific unit for AYAs, the concept of creating a medical home for adolescent and young adult patients is gaining interest in other parts of the country. At Seattle Children's, we have helped to pave the way for the creation of other AYA cancer units across the United States. We are excited to see other facilities follow in our footsteps and we hope that with an increased focus on this population, we can begin to move the needle on improving survival outcomes. 

Douglas S. Hawkins, MD, is the associate hematology/oncology division chief and the associate director of the Center for Clinical and Translational Research at Seattle Children's Hospital. He is also a professor at the University of Washington School of Medicine, the principal investigator for Children's Oncology Group (COG) at Children's and chair of the COG Soft Tissue Sarcoma Committee.

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