hematology/oncology at Dayton Children's

dayton children's

a historic year

Ayman El-Sheikh, MD

Ayman El-Sheikh, MD, medical director of hematology/oncology at Dayton Children's, reflects on the program's significant accomplishments in the last year—and shares what he loves most about his job.

Now that the new Mills Family Comprehensive Cancer and Blood Disorders Center is up and running, what are your impressions regarding how it benefits patients and staff?

The integrated care setting—having the outpatient clinic, infusion center and inpatient unit all in one place—enhances our ability to provide consistent, high-quality care across the continuum. Our staff are cross-trained so that they can provide care in every setting and communicate with one another easily about each patient's status and needs. Patients see the same friendly faces every time they come to the hospital, whether it is for an infusion, clinic appointment or inpatient stay.

Aside from the big news about the new center, what are some other highlights from the past year?

Part of my decision to come to Dayton Children's two years ago was the hospital's commitment to one day offer autologous stem cell transplant. In the last year we have been preparing for this exciting advancement, and expect to launch the program in mid-2018. This will be a huge benefit to families, who currently must travel to Columbus or Cincinnati for this treatment. Eventually, we would like to offer allogenic stem cell transplant, as well.

Another development is that we have been able to expand our infusion service to offer weekend hours. This is an added convenience for families, and allows the care team to do certain infusions as a same day procedure rather than admitting patients.

How would you characterize the center's cancer research?

In July, reviewers from the Children's Oncology Group (COG) came to Dayton Children's to conduct a thorough review of our center and found no major deficiencies—the equivalent of passing with flying colors. This achievement is notable, in that only 10-20 percent of pediatric oncology programs earn it after the initial review.

COG reviews occur every three years, and being a COG-accredited program means that we can offer our patients the same cutting-edge clinical protocols and research studies that are available at institutions like Boston Children's and Children's Hospital of Philadelphia. The cumulative effect of so many centers working together has led to a dramatic increase in pediatric cancer survivorship over the past 50 years.

Being part of COG provides opportunities to partner with research scientists from around the world to better understand the cause of certain cancers and find more effective cures for kids. We have about 85 open clinical trials at Dayton Children's, and try to find a study for every patient and family who is interested.

What's the best part of your job?

What I enjoy most is the opportunity to care for patients over the course of many years. In the acute phase of illness, patients might spend weeks and weeks in the hospital and have many outpatient visits. I become part of their family—I know their siblings, what their favorite toys are and how they are doing in school. Later on, when they are in remission, I get to see them in our long-term follow-up clinic. Watching them grow up and be successful and happy gives me hope. I still receive Christmas cards from patients I treated years ago—one is in his residency and planning to become a pediatric oncologist. What more can you ask for?

successful children's oncology group review affirms strength of clinical research program

The Children's Oncology Group (COG) includes more than 200 pediatric cancer programs worldwide, each one following strict standards for clinical research. Every three years, members submit to a thorough review process that includes a site visit. In July 2017, the cancer team at Dayton Children's welcomed two COG reviewers, and the program passed with flying colors.

"Accreditation is essential, and the requirements are stringent," says Nancy Bangert, RN, clinical research coordinator for the cancer program. "A physician and nurse from COG come for the day and review 10 charts chosen at random, looking to make sure that the patient's research protocol was followed and documented accurately. The visit also includes meeting with the pharmacy team to monitor the investigational drug distribution process. The reviewers also evaluate our Institutional Research Board processes. Adhering to national protocols ensures that the results of every research study are valid."

More than 80 Phase 2 and 3 clinical research trials are taking place at Dayton Children's, most of them sponsored by COG and others by the National Cancer Institute and pharmaceutical companies. All patients—including those newly diagnosed, high-risk or relapsed—are evaluated to see whether they are eligible for a research study. If so, the family is presented with the opportunity to participate. If they choose not to, the physician will follow the most current therapy validated through COG studies.

Only about 15 percent of children being treated for cancer at Dayton Children's end up participating in a research study. This is largely due to the fact that inclusion criteria is highly specific. Recognizing the critical importance of clinical research, the Dayton Children's cancer team is participating in COG's "Project EveryChild," whose goal is to increase research efforts for all 200+ types of pediatric cancer. In the initial phase of this study, COG will store biopsied tissue from research participants. Information on the effectiveness of each child's therapy will be maintained securely in COG's data center, allowing scientists to link genomic findings to outcomes data. The study will produce a single biological classification protocol for COG studies.

research by the numbers

- **84 open studies**
- **53 actively accruing studies**
- **16 long-term follow-up studies**

about childhood Hodgkin Lymphoma

overview

Childhood Hodgkin lymphoma (HL) is a disease in which cancer cells form in the lymph system. One unique characteristic is that the malignant cell, the Reed-Sternberg cell, represents only a small proportion of cells constituting the bulk of the tumor.

The two types of Hodgkin lymphoma are classical Hodgkin lymphoma and nodular lymphocyte-predominant Hodgkin lymphoma. Hodgkin lymphoma is somewhat rare in the pediatric population, although it does comprise approximately 40 percent of all lymphomas that present during childhood. In fact, HL is the most common malignancy in adolescents and young adults. Among this population, HL is most common in patients ages 15 to 19. The cure rate has steadily improved over the years, particularly with the introduction of combined radiation and multi-agent chemotherapy.

common signs

Most patients with childhood Hodgkin disease present with painless, swollen lymph nodes near the clavicle, neck, chest, underarm or groin that are not responsive to antibiotic therapy. Other, "B symptoms" include:

- Unexplained fever
- Unintended weight loss
- Night sweats
- Fatigue
- Itchy skin

risk factors

Risk factors for childhood Hodgkin lymphoma include:

- Previous infection by mononucleosis or Epstein-Barr virus
- A weakened immune system
- Exposure to certain other diseases of the immune system
- A family history of Hodgkin lymphoma (about 5 percent of cases have a family link)

diagnosing and staging

Hodgkin lymphoma may be mistaken for histoplasmosis, disorders of the lymphatic system, mononucleosis, Epstein-Barr virus infection, or other types of cancer, such as acute lymphoblastic leukemia and non-Hodgkin lymphoma. Tests and procedures used to diagnose HL may include:

- A physical exam and medical history
- Blood tests
- Imaging tests, including X-ray, computed tomography and positron emission tomography
- Bone marrow biopsy
- Lymph node biopsy
- Immunophenotyping to diagnose the specific type of lymphoma

treatment

Five types of standard treatment are used to treat HL, including:

- Chemotherapy
- Radiation therapy, including proton radiation therapy
- Surgery
- High-dose chemotherapy with stem cell transplant

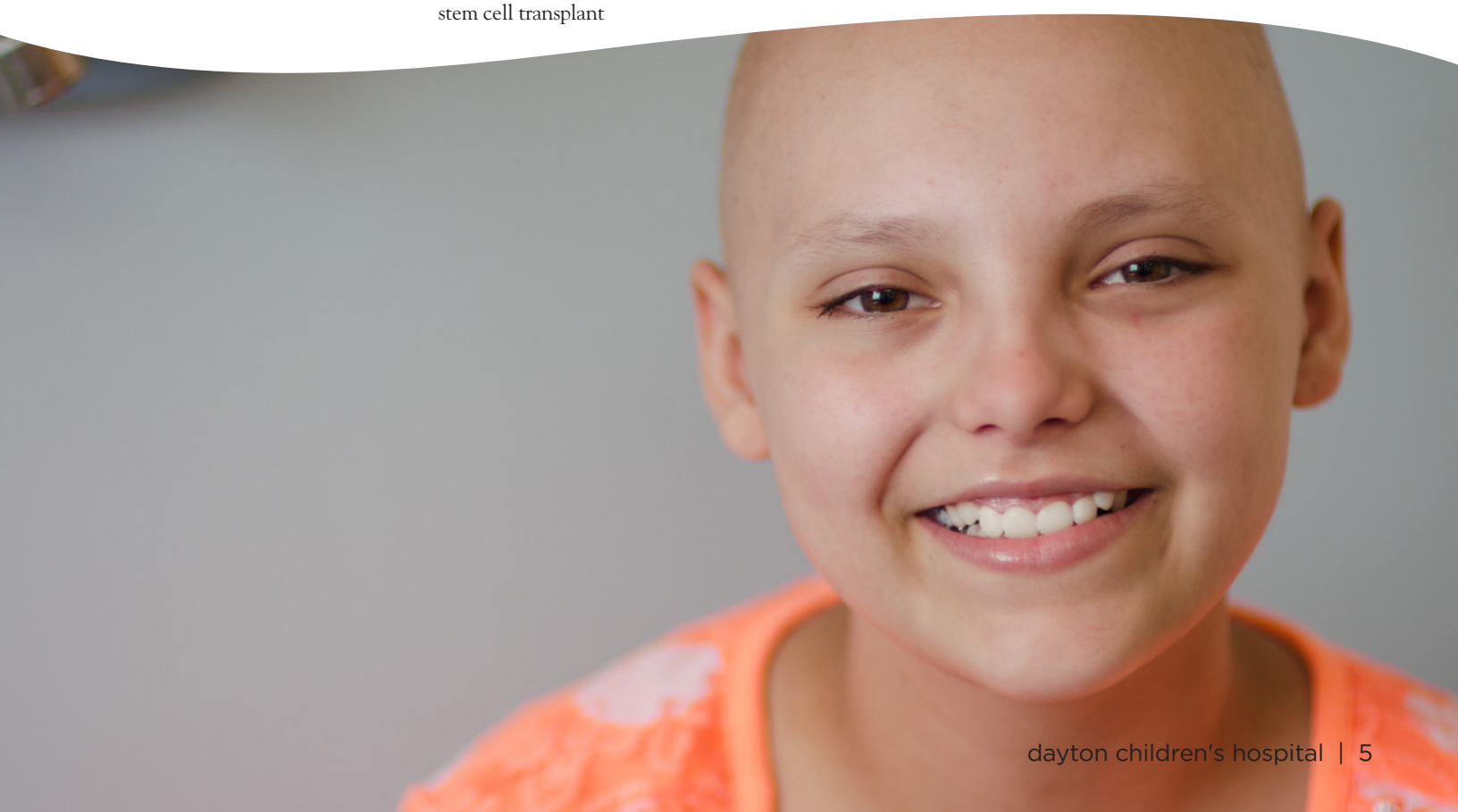
prognosis

Prognosis depends on the type and stage of the cancer, size of the tumor and the presence of B symptoms, which may be associated with advanced disease and an adverse prognosis.

In developed countries, the five-year overall survival rate for Hodgkin lymphoma of all stages is usually greater than 80 percent. Patients with stage I or II disease have overall survival rates greater than 90 percent whereas those with stage III or IV disease have overall survival rates of 70 percent The survival rate in children and adolescents with Hodgkin lymphoma is similar to adult patients.

long-term prognosis

Children who survive Hodgkin lymphoma sometimes experience late effects due to long-term toxicities. Depending on the therapeutic modality, this may include the risk of cardiac disease, lung toxicity, infertility, infection and secondary cancers. Long-term surveillance is essential.



a long road to remission

Sarah pictured with Bev Farris, RN, her favorite nurse when she was inpatient at Dayton Children's.

Many words can be used to describe people who are going through cancer therapy. Words like tired. Nauseated. Scared. Sarah Krizner was all of those things, but in the words of her mom, Cathy, she was one more: Brave.

It was Sarah herself who discovered the lump in her neck, on the last day of a family vacation in Florida in March 2015. Cathy was immediately concerned. Worrisome ultrasound results back in Dayton led to a next-day appointment with Mukund Dole, MD, a pediatric oncologist at Dayton Children's. Dr. Dole diagnosed Sarah with II-A Hodgkin lymphoma after a biopsy confirmed the presence of cancer cells in two lymph nodes. Sarah was only 12 years old.

When her parents broke the news to her, Sarah remembers thinking the worst—that she was going to die. But Dr. Dole believed her initial prognosis was good. The course of care would include four rounds of chemotherapy over 16 weeks, and Dr. Dole was optimistic that life would be back to normal by October.

the cancer spreads

But cancer sometimes has a way of surprising even the most experienced doctors. Soon after her final chemotherapy infusion in July, Sarah was inexplicably anxious. "We had a check-up in about a week's time, but I called Dr. Dole to tell him that Sarah was convinced the cancer hadn't gone away," says Scott, her dad. "He said, 'that's good enough for me, bring her in today.' Tests confirmed that the cancer had spread to more lymph nodes throughout her torso. It was awful—worse than finding out she had cancer in the first place. It was such a helpless feeling as her father... a daddy is supposed to protect his little girl, and there was nothing I could do."

Sarah's cancer was now considered to be persistent IV-A Hodgkin lymphoma. Her survival would depend on a successful autologous stem cell transplant at Cincinnati Children's Hospital Medical Center. Preparation involved three inpatient rounds of chemotherapy at Dayton Children's, followed by a stem cell harvest in mid-December. Through it all, Sarah tried to live her life, spending time with friends and earning straight A's. When her hair fell out (twice), she simply soldiered on, with no thought of wearing a hat or wig. During inpatient stays and visits to the clinic at Dayton Children's, care team members did their best to keep her spirits up. One favorite memory is of the day Dr. Dole and fellow pediatric oncologist Jordan Wright, MD, danced into her clinic infusion room wearing sombreros and shaking maracas, for no other reason than to make her smile.

another setback

Everything was on target for the transplant to happen on January 11, 2016, until a positron emission tomography scan revealed that too much cancer remained in Sarah's body for the transplant to proceed. Finally, after four more rounds of chemo using powerful doses of gemcitabine and brentuximab, Sarah was admitted to Cincinnati Children's for the transplant, which took place on March 18. It would be another two weeks before doctors would know whether the cells had engrafted.

Meanwhile, Sarah suffered severe effects from her final round of chemotherapy. "It seemed like the chemo was burning her from the inside out," says Scott. "Sarah's skin was extremely itchy, she had blistering on her elbows and heels, and the lining of her mouth just sloughed off. She couldn't take anything by mouth, and she had horrible nausea and diarrhea. Thankfully, she really doesn't remember most of it—but it was very difficult for us to see her endure those effects."

Through these long, stressful days in the hospital, the Krizners relied on the support of family and friends, and their church home in Vandalia. Although Sarah could have only a few visitors, she received hundreds of cards, which Scott strung up to brighten her hospital room. "So many people from all over the country were praying for Sarah, and we felt that support," says Cathy. Scott adds, "We reminded ourselves over and over that children are a gift from God, and we had to be willing to let her go."

signs of life

Finally, after days of uncertainty, Easter Sunday brought good news. Sarah's absolute neutrophil count, barely measurable five days earlier, had climbed to above 1,700—a strong indication that engraftment was taking place. By the end of the day, Sarah was able to walk the halls for the first time in weeks. The effects of chemo would continue to take their toll over the next several days, but Sarah had turned the corner. Almost one month to the day after being admitted to Cincinnati Children's, Sarah returned home.

"It felt weird being home after all that time, and I remember just wanting life to be normal again," Sarah remembers. "My class trip to Washington, DC, was a month away, and I really wanted to go. Dr. Dole said it would be okay, and he even pushed back my follow-up radiation therapy so I could make it."

After three weeks of radiation therapy that summer, she started maintenance treatment with a new targeted agent called Brentuximab, specifically developed for treatment of Hodgkin's lymphoma. She continued this therapy for one year post stem cell transplant.

"I think when school started, I finally felt more like myself," Sarah says. "Looking back, if I could give advice to other kids going through cancer treatment, I'd tell them to try really hard not to overthink it. Count on your friends and family to get you through. And also you might want to find your favorite artist, because sometimes all you are going to feel like doing is listen to music."

Sarah's last maintenance chemo infusion was in September 2017, and she is officially in remission. Now in the 10th grade, she continues to excel in school, serve on the yearbook team and play piano. "One thing I told Sarah when she was sick that I also told myself is try to be strong and set a good example for other kids who may get cancer," Cathy says. "I will never forget the first day she walked onto the school bus with a bald head—I had tears in my eyes, but she never faltered. She really was brave throughout the whole experience, and inspired a lot of people."

In 2018, Dayton Children's will begin offering autologous stem cell transplants, so that patients like Sarah can receive this advanced therapy close to home.

hemostasis and thrombosis center

advancing care for children with bleeding and clotting disorders

The Dayton Children's Hemostasis and Thrombosis Center provides expert care for children diagnosed with hemophilia, other bleeding disorders and clotting disorders. Our care team includes a pediatric hematologist, coagulation resource nurses, research nurse coordinator, social worker, physical therapist, genetic counselor and data manager. The team coordinates services with patients and families to provide comprehensive care and cutting-edge research.

Personalized care is a hallmark of our program, and in the last year our team has been working to address the unique needs of a growing immigrant population. "These patients face many challenges, which can include problems communicating in a language that is new to them, the effect of inadequate care in their home country and difficulty paying for care," says Melissa Sears, MSW, LISW-S, medical social worker. "To help achieve the best outcomes possible for these patients, our team coordinates resources that are available from the hospital, community agencies, pharmaceutical companies and insurance companies. Social work plays a big role in identifying ways to help advocate and empower patients as they navigate these systems."

In addition, the hemophilia team works closely with Southwestern Ohio Hemophilia Foundation (SWOHF), a non-profit organization whose goal is to improve the quality of life for those affected with hemophilia, Von Willebrand disease and other bleeding and clotting disorders. As part of this collaboration, the team participates in the annual Family Fest, a medical alert program, summer camp and additional educational programs.

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research to advance scientific discovery

The center also participates in research to better understand hemophilia and develop more effective therapies for people with bleeding disorders.

One of our current clinical trials is evaluating the use of a hemophilia factor replacement drug in preventing and treating bleeds in previously untreated patients. Since hemophilia is a rare disorder and many new patients are treated with factor during the diagnosis period, finding patients to enroll in a previously untreated patients study is challenging. Clinical trials involving previously untreated patients are conducted after trials have been successfully and safely completed with adult and child participants.

In recent years, some hemophilia products have been developed that have a half-life that has been extended by various methods, such as glyco-PEGylation and FC fusion. The extended half-life products allow patients to achieve higher factor levels for a longer period of time with fewer infusions. In theory, the need for fewer infusions should improve adherence to treatment regimens. We have been participating in a trial using glyco-PEGylation for more than four years.

At the beginning of the year, a Phase 1 clinical trial was opened to investigate the possibility of delivering factor replacement therapy subcutaneously rather than intravenously. One of our patients was the first in the United States to participate in this innovative Phase 1 study.

Another new study, recently approved by the hospital's Institutional Review Board, looks at immune tolerance induction (ITI). ITI is the treatment for people with hemophilia who develop inhibitors, antibodies that work against the factor and make it ineffective. Consequently, patients with inhibitors have an increase in morbidity and mortality. Between 20 and 30 percent of people with hemophilia develop inhibitors.

In addition to clinical trials, the Dayton Children's Hemostasis and Thrombosis Center participates in numerous registries and health surveillance initiatives to further scientific discovery.

My Life, Our Future is a national initiative whose goal is to genotype as many people with hemophilia as possible in the United States. The study has expanded and now offers genetic testing to hemophilia carriers and other family members who are unsure if they are a silent carrier of hemophilia. Community Counts gathers and shares information about common health issues, medical complications and other specific challenges that affect people with bleeding disorders. Community Counts also offers inhibitor screening to patients.

For more information about the clinical trials, please visit ClinicalTrials.gov.

sickle cell support for children

sickle cell program offers comprehensive support for children, families and physicians

Last year, seven babies in our region were diagnosed with sickle cell disease through the state of Ohio's newborn screening test. But an additional 417 were found to have the sickle cell trait or some other type of hemoglobin disorder. The West Central Ohio Comprehensive Sickle Cell Center at Dayton Children's offers extensive support and resources for all of these babies and their families.

Regardless of what diagnosis newborn testing reveals, immediate intervention is essential. Children with sickle cell disease should begin prophylactic antibiotic therapy in the first months of life, and their families need to begin learning about what their child's long-term needs may be. "The West Central Ohio Comprehensive Sickle Cell Center at Dayton Children's provides care coordination and disease management to help children with sickle cell disease live as normal lives as possible," says Cynthia Moon, sickle cell project director and newborn screening coordinator at Dayton Children's. "Therapies for sickle cell disease continue to evolve, and researchers are finding new ways to increase fetal hemoglobin, improve pain management and treat side effects such as hydroxurea."

When a child has sickle cell trait or another hemoglobin disorder and not sickle cell disease itself, intervention is different, but still important. "Symptoms such as mild pain, fatigue and shortness of breath are associated with these diagnoses, and parents need to know what to look for," Cynthia says. "They also need to know the genetic implications of their child's test results. We offer genetic testing for parents who are unaware of their own sickle cell status, and genetic counseling to help them understand how it could affect any children—or grandchildren—they may have in the future."

recommendations for providers

The state of Ohio notifies Moon any time a child in the West Ohio region has an abnormal hemoglobin result after a newborn screening. The primary care physician is notified as well, and has a choice. He or she can provide the confirmatory testing and follow-up education, or can refer the family to Dayton Children's instead. If a provider chooses to perform these services rather than refer patients to Dayton Children's, it is important to follow these steps:

- **COMMUNICATE** the newborn screening results to the infant's parents or legal guardians.
- **OBTAIN** a family history including race and ethnicity information.
- **OFFER** genetic testing to family members who do not have documentation of previous hemoglobin testing. Avoid paternity issues by initially only testing the mother when performing family studies.
- **CONFIRM** the initial newborn screening result within one month of age in a hematology or reference laboratory that reports pediatric reference ranges.
- **INFORM** the family of the confirmatory test results—**especially if the hemoglobin trait results are abnormal**.
- **PROVIDE** and **DOCUMENT** hemoglobin counseling services.
- **SEND** documentation of the **FINAL DIAGNOSIS** to the Regional Sickle Cell Program for case closure. The report should confirm test results/laboratory reports, consults and treatment information (if applicable).

"Even if a primary care doctor chooses to provide follow-up testing and education, I still reach out to the family by sending them information about whatever hemoglobinopathy their baby has and the availability of genetic testing and counseling at Dayton Children's," Cynthia says. "By serving as a resource to families and physicians, I can help these children receive the best care possible."

For assistance with newborn screening follow-up, such as confirmatory testing, diagnostic evaluation or hemoglobin counseling services, please contact Cynthia Moon at 937-641-5014. If you do not receive a newborn screening report on an infant identified in your practice, contact the Ohio Department of Health Public Health Laboratory at 1-888-ODH-LABS.

siblings with sickle cell disease focus on living life to the fullest

Even when Antonio Copher and his sister, Sydnei, aren't on stage, people love cheering them on. Maybe it's because, despite having sickle cell disease, these kids are excited about their future and are working toward big goals.

Antonio, 14, is active in choir and plays piano, and hopes to work for a technology company some day or have a career in music. Sydnei, 13, loves dance, theatre and playing the violin, and wants to be an anesthesiologist. Both children were diagnosed with sickle cell disease through the Ohio Newborn Screening Program, and have received care through the Dayton Children's sickle cell program ever since. Their parents—Antonio Sr. and Synthia—have always taught them how to take ownership of their treatment and learn how to cope with their condition.

Today, Antonio and Sydnei attend East Dayton Christian School and continue to stay active, eat right, and pay close attention to what their bodies tell them. "You have to fight through the worst days to get to the best days," Sydnei says. Adds Antonio, "I don't think of myself as being different. Things happen for a reason, and you should work to prepare yourself for the future."

nurse navigator program

cancer program adds nurse navigator to improve patient experience

A child's cancer diagnosis has a way of turning an entire family's life upside down. Suddenly and without warning, parents and patients are plunged into a world of chemotherapy infusions, blood tests, surgical procedures, cancer education and endless appointments, all with the added strain of an uncertain outcome. Overwhelmed families often report being unaware of resources available to them, confused about next steps in the treatment plan and unsure about whom to call for help.

To address this problem, two Dayton Children's nurses launched a quality improvement project to determine whether nurse navigation could help. Their work led to the creation of a new oncology nurse navigator position at the Comprehensive Center for Cancer and Blood Disorders. The nurse navigator study was also reviewed in the Comprehensive Cancer Care Committee as a resource for patients.

Amy Staup, BSN, RN, CPON, the cancer and blood diseases center's quality improvement coordinator, and Erin Black, BSN, RN-BC, CPEN, a nurse in the emergency department, designed the quality improvement project as part of their participation in the hospital's Evidence-Based Practice Scholar Program. After studying current research on the effectiveness of nurse navigation in the pediatric oncology setting, they ran a three-month trial to test its effectiveness at Dayton Children's. This involved providing nurse navigation to a small group of patients.

Based on responses to pre- and post-trial surveys, nurse navigation improved patient satisfaction, overall experience and coordination of care. Specifically, families reported increased understanding about their child's diagnosis and treatment, greater awareness of the resources available to them and a better sense of who to call with questions.

After presenting the study results in January 2017 to physicians and some key nursing leaders, Staup assisted with developing a job description. Nancy Bangert, who has worked for many years as oncology clinical research coordinator at Dayton Children's, was hired for the position in May. "Nancy begins developing a relationship with families during the earliest days of their child's diagnosis and becomes a trusted resource throughout their experience with us," says Staup.

"Among her many responsibilities are coordinating the child's care, answering questions and recognizing when additional services such as psychosocial counseling or social work are needed."

Having a nurse navigator allows oncology nurse practitioners and doctors to focus on and develop their own areas of expertise in the clinical setting. It also improves efficiency and cost savings by reducing no-shows and cancellations, and can improve follow up through close care coordination. "Most importantly, nurse navigation provides a sense of security and peace of mind when families need it most," Staup says. "Our families know Nancy will be with them every step of the way."

offering hope for children with treatment-resistant tumors

Whole genome sequencing is giving patients new hope for a cure when standard cancer therapies fail. The testing is available primarily to patients who have recurrent or treatment-resistant cancers, and can help physicians determine the best treatment options for the patient based on the cancer's genetic profile.

In order to provide this high-tech service, Dayton Children's partners with Foundation Medicine, a Cambridge, Massachusetts company that offers genetic testing and a validated comprehensive genomic profile for solid tumors and leukemia. "We send a pathology specimen to Foundation Medicine, and their assessment identifies any genetic abnormalities that the cancer cells possess," says Nancy Bangert, RN, BSN, nurse navigator. "If a specific therapy is known to be effective against that genetic defect, the report will share that information as well. The physician may be able to tailor the cancer treatment by targeting the unique DNA mutations that allow cancer to grow and spread."

Some insurance plans cover the testing, but financial assistance is always available if needed. "As researchers discover more about cancer genomics and molecular profiling and their correlation to treatment efficacy, the value of this technology will only increase," Bangert says. "Some day, we may be offering genetic profiling to children who have been newly diagnosed with cancer. This could potentially help us identify sooner in the treatment process which therapy offers the greatest potential for success."

proton therapy partnership

proton therapy is one of the most precise and advanced forms of radiation therapy available in the world today.

Proton therapy can be used to treat 80-85 percent of children whose cancers require radiation therapy for treatment. However, it is not widely available—many families travel hundreds of miles for their child to receive this cutting-edge therapy. For children in the Dayton area, however, it is a different story. In 2016, Cincinnati Children's Hospital Medical Center opened its Proton Therapy Center, just 30 miles south of our main campus. Our clinical team works closely with the center's team to ensure seamless, well-coordinated care.

Certain types of cancer are better suited for proton therapy. In children and adolescents, these include Hodgkin lymphoma, pediatric brain tumors and soft tissue sarcomas.

Proton therapy:

- Delivers higher radiation doses with increased conformity and speed compared to scattering proton technology
- Sculpts doses to the complex shapes of tumors
- Treats tumors in difficult locations, such as those surrounded by critical, healthy tissue and organs
- Can often reduce the side effects common in traditional radiotherapy, due to sparing of healthy tissues

phase 1 research trials for children with rare, relapsed and recurrent cancers

For several years, Dayton Children's has been participating in the Advanced Cancer Therapies Network (ACTN), which gives patients with rare, relapsed and recurrent cancers access to Phase 1 clinical trials. The trials are conducted by Cincinnati Children's Hospital Medical Center often as part of a regional or national study. Recently, the program expanded to include non-therapeutic trials focusing on concerns such as parental stress and anxiety related to cancer treatment.

"Participation in this network gives our families more options," says Ayman El-Sheikh, MD, medical director of hematology/oncology at Dayton Children's. "Once children reach the maintenance phase they can receive their care close to home at Dayton Children's. This arrangement reduces treatment delays and provides additional avenues for treatment."

tumor registry

Dayton Children's maintains an extensive tumor registry that dates back to 1994, with data on 1,321 patients. Registry data items include: demographics (age, sex, race, place of residence), medical history (presenting symptoms, date of diagnosis, comorbidities), diagnostic findings (types, dates, staging, results of procedures) and treatment modalities (surgery, chemotherapy, hormonal therapy, radiation therapy and other therapy), recurrence and vital status. Data is reported monthly to the Ohio Cancer Incidence Surveillance System and annually to the National Cancer Database.

Quality cancer registry data can be utilized for planning, fundraising, treatment assessment and benchmarking.

The information presented below is based on our 2016 analytical cases, and includes cases that were diagnosed and/or initially treated at Dayton Children's. The International Classification of Childhood Cancer is based on tumor morphology and primary site, with an emphasis on morphology. In summary, 46 patients (19 females, 27 males) from 12 counties were cared for at Dayton Children's. One child had two reportable primary tumors for a total of 47 reportable tumors.

Registry data including incidence, outcomes, outmigration and in migration can be obtained via specialty reports through the hematology/oncology department's certified tumor registrar, Michele Keyes. Contact Michele at 937-641-3263 or keyesm@childrensdayton.org

county of residence	2016 analytic patients
Montgomery	18
Greene	7
Miami	6
Preble	3
Warren	3
Mercer	2
Butler	2
Clark	1
Van Wert	1
Wayne	1
Highland	1
Champaign	1
Grand Total	**46**

International Classification of Childhood Cancer Site Group	2016 Analytic Cases	Percentage of total 2016 Analytic Cases
Leukemias, Myeloproliferative diseases and Myelodysplastic Diseases	6	13%
Lymphomas and Reticuloendothelial Neoplasms	10	21%
CNS and Miscellaneous Intracranial and Intraspinal Neoplasms	12	25%
Neuroblastoma and Other Peripheral Nervous Cell Tumors	5	11%
Soft Tissue and Other Extraosseous Sarcomas	5	11%
Retinoblastoma	1	2%
Renal Tumors	1	2%
Hepatic Tumors	1	2%
Malignant Bone Tumors	5	11%
Germ cell tumors, trophoblastic tumors and neoplasms of gonads	1	2%
Grand Total	**47**	**100%**

dayton children's

above and beyond