

hematology/oncology annual report 2015-2016



dayton
children's



cancer care

Our cancer program is one of only 10 freestanding pediatric programs in the country approved by the American College of Surgeons Commission on Cancer. To earn this accreditation, a cancer program must meet or exceed standards in 34 categories of quality and patient-centered care.

Our cancer program also:

- Maintains a survival rate of more than 80 percent for all childhood cancers combined—higher than the national average
- Follows nationally approved care protocols developed by the Children's Oncology Group—the most current, state-of-the-art cancer treatments available
- Is committed to continuous quality improvement: clinical teams meet regularly to find ways of improving treatment protocols, care coordination and support services
- Participates in extensive clinical research to improve care
- Established one of the country's first long-term follow-up programs for childhood cancer survivors

blood diseases

Dayton Children's provides exceptional care for children with sickle cell disease, hemophilia and other blood disorders. Our pediatric hematologists/oncologists, nurses, social workers and other care professionals provide strong support for families to help them manage their child's condition at home.

One of the greatest strengths of our program is the personal relationships that develop between our team and the families we serve. We consider it a privilege to care for children for many years, watching them grow up and learn how to manage their condition effectively.

Every day at Dayton Children's, the hematology/oncology team surrounds children and their families with love, helping them endure difficult moments and celebrate victories in the midst of a cancer or blood disease diagnosis. This annual report gives a glimpse of the care we provided for our patients in the last year, highlighting five key areas:

- Clinical programs
- Collaboration
- Innovation
- Research
- Community outreach

Last year our team cared for 6,616 patients with cancer and blood diseases, providing compassionate, comprehensive therapies, education and support every step of the way.

why Dayton Children's is magnet recognized

The team at ANCC specifically highlighted five outstanding programs and outcomes that stood out in documentation and our site visit:

how nurses support academic practicum experiences and serve as preceptors, instructors, adjunct faculty or faculty.

ANCC mentioned how impressed they were that our nursing division assists Wright-Patterson Air Force Base with its combat readiness program, allowing nurses who are preparing for deployment to gain experience in caring for critically-ill children.

The structure(s) and process(es) used to identify and allocate resources for affiliations with schools of nursing, consortiums or community outreach programs. ANCC highlighted the many outreach and education efforts provided to local first responders. Dayton Children's solely provides the pediatric-specific emergency equipment needed for pediatric resuscitation in the field, dramatically improving outcomes of injured children.

how nurse leaders value, encourage, recognize/reward and implement innovation.

ANCC specifically called attention to our top workplace achievements, healthy hospital initiative and OHA safety awards. They also highlighted our emergency department call back program, which made 27,842 phone calls to patients last year alone.

recognition of nursing.

The ANCC called attention to ways that nurse leaders at Dayton Children's support nurses in their engagement and outreach at the local, state and national levels. They mentioned our advance practice nurses and clinical nurse specialists are well respected by physician partners.

culture of safety.

Magnet specifically mention how safety is infused in our culture and pointed out specific programs such as the daily safety brief, error prevention training and the number of days since our last central line bloodstream infection in the IMCU (950 days!)

magnet designation

Dayton Children's received Magnet designation in 2013, the highest and most prestigious distinction a health care organization can receive for nursing excellence and high-quality patient care. Developed by the American Nurses Credentialing Center, Magnet designation is the ultimate credential for high-quality nursing.

Dayton Children's is one of only 31 pediatric Magnet hospitals nationwide and one of 26 Magnet hospitals in Ohio. The 393 Magnet-designated organizations represent less than 7 percent of all U.S. health care organizations. Magnet hospitals have lower patient mortality, fewer medical complications, improved patient and employee safety, and higher patient and staff satisfaction.





Our care team is always seeking ways to strengthen clinical services, treatment protocols and support services for patients with cancer and blood diseases. This report highlights four clinical areas: Langerhans cell histiocytosis, antibiotic therapy for fever and neutropenia, the Hemostasis and Thrombosis Center and the West Central Ohio Comprehensive Sickle Cell Center.

LCH overview

Langerhans cell histiocytosis (LCH) is a term used to describe a group of clinical disorders characterized by presence of CD1a+/ CD207+ dendritic cells. The spectrum of presentation is variable and ranges from a minor, persistent skin rash to focal destructive bone lesions or extensive, disseminated disease that can wreak havoc in a young child and be potentially fatal. LCH commonly occurs in children at a rate of 5 per million, but any age group can be affected including adults (LCH in Children, 2016). It is widely believed to be underdiagnosed due to patients being asymptomatic or having symptoms that are mistaken for injury or other conditions.

clinical features

LCH occurs in both sexes and is most often seen between the ages 1-3 years, but no age is exempt. As indicated earlier, the clinical presentation at diagnosis is heterogeneous and signs and symptoms often depend on the organ or tissues involved. It may present as an isolated, single bone lesion or affect multiple organ systems with a plethora of systemic complaints.

A few cases are completely asymptomatic and are detected accidentally on routine x-ray examinations done for other problems. In other patients, common presenting complaints may include a persistent eczematous rash, enlarged lymph nodes, bone aches and pains, localized swelling, recurrent middle ear infection with drainage and constitutional complaints such as failure to thrive, weight loss and fever. Those cases with involvement of brain may also present with features of diabetes such as frequent urination and increased thirst.

Studies have shown that bone involvement in LCH is the most common problem and occurs in approximately 78 percent of patients and affected bones include the skull, pelvic/hip bone, upper leg and ribs. Skin rashes or nodules are seen in as many as 50 percent of patients. Lung lesions are seen in 20 to 40 percent of patients, while 30 percent of patients have lymph node involvement (LCH in Children, 2016).

Children with widespread disease often have enlargement of other internal organs such as liver and spleen.

diagnosis of LCH

Once the diagnosis is suspected, these patients undergo an extensive evaluation to determine the extent of disease. The studies done include blood work to determine their counts and liver and kidney functions, x-rays of bones, urine studies and sophisticated imaging studies including CT scans, MRI studies and even PET scans, if necessary.

Selected cases may also need bone marrow evaluations to complete their evaluation. A biopsy of the involved organ or tissue is often necessary and final diagnosis rests on the demonstration of classical Langerhans cells that are CD1a+/CD207+.

Risk stratification is often done on the completion of all the above studies and patients are categorized into “low risk” or “high risk” based on site and extent of lesions. Patients with involvement of “risk organs” such as bone marrow, liver or spleen tend to have more severe disease, need more intensive therapy and are at higher risk for recurrence or relapse.

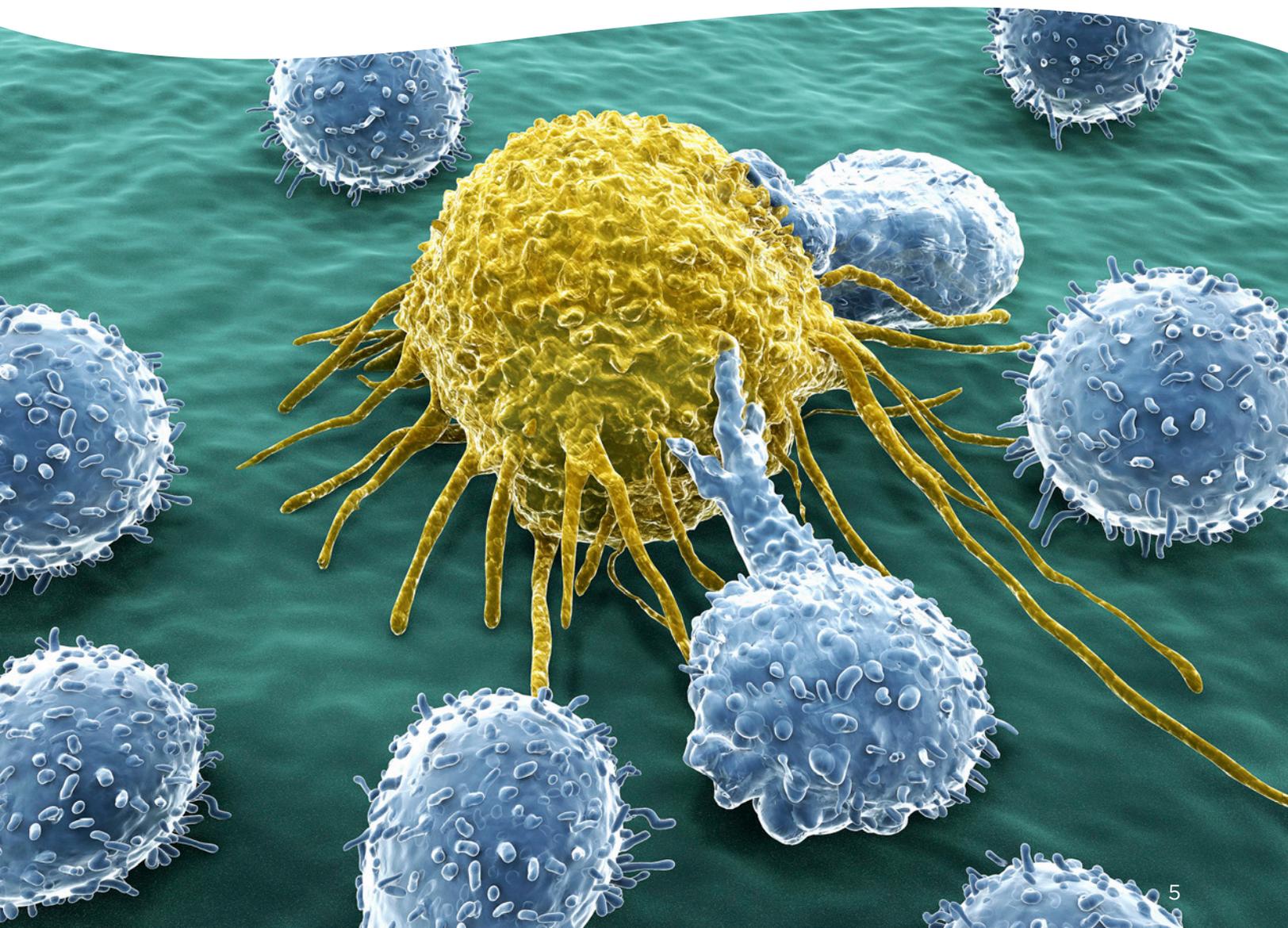
The response to the initial six to 12 weeks of therapy is important in predicting risk of progression and outcome; those who respond well tend to have a better outcome whereas those who do not tend to have a higher risk of progression and increased mortality from this disease.

biology of LCH

For a long time, there was an incomplete understanding of this disease and controversy as to whether this was an inflammatory disorder as opposed to a proliferative neoplasm. Recent evidence backed by genetic studies suggest that the LCH cell is indeed a myeloid precursor cell (a “blood cell”) and LCH is a result of excessive and uncontrolled proliferation of these cells, very much like a malignancy.

A characteristic genetic mutation in an important protein called BRAF, which is commonly present in LCH cells and is now believed to play an important role in the development of this disease.

The BRAF protein is a key enzyme that controls cell survival, proliferation, differentiation and motility (Nichols & Arceci, 2010) and a mutation in this enzyme causes deregulation of all these processes leading to development of LCH. This BRAF mutation (called BRAF V600E) is present in approximately 50 percent of patients with LCH and has also been detected in many other malignant diseases, including melanoma, hairy cell leukemia, papillary thyroid carcinoma and colorectal cancer. (Gandolfi, 2015).





treatment

The treatment of LCH has advanced largely due to cooperative clinical trials conducted by The Histiocyte Society over the last several decades. These trials are commonly referred to as the LCH trials and there have been a succession of these over the last 30 years.

Treatment for LCH is often tailored to the needs of the patient and depends on the nature and extent of disease. Patients with localized disease (e.g., in bones) can be treated with local surgery and/or steroid injections into these lesions.

Those with multiple lesions in bones and other tissues may warrant systemic chemotherapy and the drugs commonly used include vinblastine, steroids, 6-mercaptopurine and methotrexate. The duration of therapy typically ranges from six to 12 months.

Radiation may also be used in selected cases, but carries the small risk of inducing second cancers and is usually avoided in young children. Patients with severe, disseminated disease, especially infants, are treated with above-mentioned chemotherapy for at least a year.

The response to chemotherapy in the first six to 12 weeks is often a good indicator of future outcome and prognosis and is often used to plan additional therapy.

Patients with persistent or resistant disease may require intensification of therapy that is very similar to that used to treat myeloid leukemia. These drugs, which include cytarabine,

cladribine and clofarabine, have been quite effective in treating such cases and are often used as second-line agents in the treatment of LCH.

The recent identification of the BRAF V600E mutation in LCH has opened up the exciting new field of targeted therapy.

A new group of drugs called BRAF inhibitors are being used to treat LCH and other cancers that are positive for this mutation. Vemurafenib is one such drug that has been used successfully to treat cases of refractory LCH as in Caleb's case.

However, the long term toxicity of these new drugs still remains unknown and more clinical studies need to be done to ensure the safety of these agents in children.

References

Allen, E.A. et al: How I treat Langerhans cell histiocytosis. *Blood*, 2015; 126(1):26-33.

Gandolfi, L. A. (2015). Multisystemic and multiresistant Langerhans Cell

Histiocytosis: A case treated with BRAF inhibitor. *Journal of the National Comprehensive Cancer Network*, 715-718.

LCH in Children. (2016, August 5). Retrieved from Histiocytosis Association: <http://www.histio.org/lchinchildren>

Nichols, K. E., & Arceci, R. J. (2010, September 16). BRAF, a piece of the LCH puzzle. Retrieved from *Blood Journal*: www.bloodjournal.org

a long journey to healing

experimental therapy is a game-changer for young boy with LCH

Sarah Hodge spent two long years trying to find out what was wrong with her son, Caleb. Doctors diagnosed him with chronic ear infections and severe dermatitis; one commented on his distended belly, another on his huge intake of fluids. But no one could tell Sarah what was really wrong with Caleb, or why he wasn't getting any better.

"Doctors kept brushing off my concerns and saying there was nothing wrong," Sarah remembers. "What worried me most was that Caleb had a huge scab on his head. The dermatologist just prescribed ointment, but the scab kept growing."

Fighting feelings of despair and frustration, Sarah and her husband decided to move from their home in North Carolina to Dayton—closer to family and, they hoped, more specialized pediatric care for their son, who was now four years old. It was a decision that may have saved Caleb's life.

A definitive diagnosis

Shortly after the move, Sarah made an appointment with Dayton Children's pediatrician Nancy Hesz, MD. After examining Caleb, Dr. Hesz was concerned about the scab, especially since it was covering a lump. She ordered an X-ray to gather more information. "An hour later, Dr. Hesz called me and said the X-ray showed lesions all over Caleb's skull, and that we needed to go the Dayton Children's for tests right away," Sarah says.

The lesions were a red flag that something serious was happening inside Caleb's brain. Magnetic resonance imaging revealed two more tumors: one on his pituitary gland and the other on his brain stem. Further testing revealed that Caleb had Langerhans cell histiocytosis, a disease in which certain white blood cells, called Langerhans cells, grow out of control. LCH could account for virtually every symptom Caleb had experienced in the last two years.

Caleb underwent three different treatment regimens at Dayton Children's over the next year, but none were effective in shrinking the tumors. So in the summer of 2015 his doctor, hematology/oncology specialist Jordan Wright, MD, decided to take a different approach. "Dr. Wright felt that Caleb might be able to qualify for a clinical research study at Cincinnati Children's for kids with LCH who have a mutated version of the gene BRAF," Sarah says. "The study is testing a new drug called dabrafenib, which is used on adults with melanoma who have the same genetic mutation. I was really hopeful that this new drug would make a difference."

From despair to hope

When tests at Cincinnati Children's revealed that Caleb's tumors were not big enough for him to qualify, Sarah was devastated. "Dr. Wright said he wasn't giving up, and that he could prescribe the drug for Caleb without having him participate in the study," Sarah says. "By

early 2016, Caleb was able to get started on dabrafenib."

Since then, the news has been all good for Caleb. His tumors are shrinking, and the skin on his scalp has healed over. Although he does experience some mild side effects from the therapy, including fatigue and a little nausea, he doesn't let that stop him. In fact, Sarah describes Caleb as a happy, normal kid—something she couldn't have imagined saying two years ago.

The Hodges return to the hematology/oncology clinic at Dayton Children's every month for follow-up care. It's a place Sarah describes as friendly and familiar. "I don't even think of Dayton Children's as a hospital because the care he receives is so personalized—the doctors and nurses really go above and beyond for kids and families," Sarah says. "I wouldn't take Caleb anywhere else. For as long as Dr. Wright has cared for my son, he has advocated for him, and I couldn't be more thankful for him and the rest of the team."





▷ Amy Staup, BSN, RN, clinical resource nurse, led an initiative in response to an article published in the *Journal of Clinical Oncology* that provided guidelines for managing fever in children with cancer.

quality improvement initiative brings antibiotic use in line with best practices

When a child who has cancer and is on chemotherapy develops a fever, antibiotic therapy can be lifesaving and essential. But with so many antibiotics to choose from, which one is best?

That question was the focus of a quality improvement initiative that began at Dayton Children's in 2013. The initiative was in response to an article published in the *Journal of Clinical Oncology* that provided guidelines for managing fever in children with cancer. Those guidelines were based on the latest research and evidence, and encouraged oncologists to consider multiple factors before choosing which antibiotic to prescribe.

An important factor used to determine therapy is neutropenia. Neutropenia is a condition where the absolute neutrophil count (ANC) is low. Children with a low ANC are considered very high risk for infections that can be deadly. These children need an aggressive antibiotic right away. On the other hand, if the ANC is normal, these patients are considered low risk and can be treated with a less aggressive antibiotic medication.

The choice of antibiotic is also determined by the bacteria that causes the infection. This is important, because

inappropriate antibiotic use can lead to antibiotic resistance, and resistance makes future infections harder to treat.

A multidisciplinary team at Dayton Children's worked together for several months to incorporate the new fever and neutropenia guidelines that were best suited for our hospital. The team included a pharmacist, the medical director for infectious disease and multiple physicians and nurses from the emergency department and hematology/oncology program. Their work involved creating new clinical practice guidelines, educating care providers about the new standard of care and educating parents about fever management.

The team focused on reducing the use of a strong antibiotic called meropenem. "We want to reserve meropenem for very sick patients, which means not using it until we absolutely have to," says Amy Staup, BSN, RN, clinical resource nurse. "So when a patient does not have a resistant pathogen causing an infection, we typically prescribe alternative antibiotics that are just as effective as meropenem. The new guidelines have allowed us to reduce our use of meropenem for inpatients by 82 percent."

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, cutting-edge research and involvement in clinical trials.

The Dayton Children's Hemostasis and Thrombosis Center is participating in two ground-breaking research initiatives: Community Counts and My Life, Our Future.

- **Community Counts** is a public monitoring program funded by the Centers for Disease Control's Division of Blood Disorders. The aim of this study is to gather and share information about common health issues, medical complications and other specific challenges that affect

people with bleeding disorders. Researchers use the data 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 organization offers a free genotyping test to help patients understand the genetic cause of their condition. The organization uses test results to aid in research and future treatment development.

The hemophilia team also works closely with the Southwestern Ohio Hemophilia Foundation (SWOHF). SWOHF is 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, we participate in the annual family retreat Family Fest, a medical alert program, summer camp and additional educational programs.





Marcus Harrison

Looking at 15-year-old Marcus Harrison, you would never know he suffers from hemophilia, until he tells you what he wants to be when he grows up — a doctor who treats kids with the same disease that he has.

“It’s a good thing he loves math and science since he wants to be a doctor,” shares Juanita, Marcus’ mother. “I know it’s odd, but his back-up plan is to be a preacher or an artist when he grows up, and he’s always drawing cartoon characters.”

Hemophilia is a disease that prevents blood from clotting properly, so a person who has it bleeds more than someone without hemophilia. It’s a genetic disorder, passed from parent to child in the womb. Hemophilia mostly affects boys versus girls.

“Marcus had a bacterial infection at birth and spent a month in the hospital where he was born,” Juanita says. “Nurses had a difficult time finding his veins. When I went to visit him at night after I was discharged from the hospital, they had shaved his head and put the IV in his head, which was a complete shock.”

After Marcus was discharged, he needed to go for a follow-up visit to the pediatrician, who pricked his finger. It took a while for the bleeding to stop. Two hours later, the bleeding started again ... and then stopped again.

That night, Juanita left Marcus with his godmother while she went to play bingo with friends. “Marcus’ godmother called me

and said his finger started to bleed again and it wouldn’t stop,” Juanita said. “The sound of her voice made me understand that it was much worse than I had originally thought.”

Juanita left to pick him up and drove straight to the emergency department at Dayton Children’s. “When I arrived, his car seat was filled with blood, which was the scariest thing I’ve ever seen,” she shares. “The emergency department doctor immediately said Marcus might have hemophilia. We had no clue what hemophilia even was.”

Marcus was admitted that night for testing; later, Juanita was tested and learned she is a carrier of the disease. That’s when intense education started for the family on how to care for a child with a chronic illness. “With hindsight, my father was probably a hemophiliac and never was diagnosed, so I was grateful that I learned about Marcus’ disease right after he was born,” she shares.

Because Marcus was diagnosed as a baby, shots and medications are his every day normal. “He’s learning how to give himself his medication from his nurses at Dayton Children’s and a camp for kids with hemophilia,” she shares. “Spending so much time at Dayton Children’s has given him confidence to take care of himself and inspired him to hopefully have a similar career as his own physicians one day.”

west central ohio comprehensive sickle cell center

lifelong support for patients with sickle cell disease

Dayton Children's is the only facility in west central Ohio providing comprehensive care for infants, children and young adults with sickle cell disease, sickle cell trait, thalassemias and other hemoglobin variants.

Our program is called the West Central Ohio Comprehensive Sickle Cell Center, one of six programs that is funded by the Ohio Department of Health to provide care for children with sickle cell disease and support for their families. We serve patients and families from a 17-county area.

The center is staffed exclusively by Dayton Children's providers. Our team includes a pediatric hematologist/oncologist, sickle cell nurse coordinator, social worker, nutritionist, genetics counselor, newborn screening coordinator and outreach coordinator. These caring individuals serve patients and families in a compassionate, culturally sensitive and coordinated way to ensure the best quality of life possible.

When an infant is diagnosed with sickle cell disease, the whole family is affected. To provide support and encouragement, we offer many programs—including the new Parent-to-Parent Empowerment Group. Special events in 2015 included the Fifth Annual Sickle Cell Family Day; Seventh Annual Sickle Cell Walk, Run or Jog; and Sickle Cell back-to-school skating event.

Services for children and families include:

- Evaluation, diagnosis and treatment for patients from birth to age 22
- Care coordination and specialty resource referrals
- Hemoglobin counseling and testing
- Nutrition assessment and counseling
- Social work services and psychosocial assessment/intervention
- Participation in clinical research

- Patient/family support group (Dayton Sickle Cell Affected Families Association, Inc.)
- School intervention program
- Collaboration with other community organizations
- Professional education and outreach
- Special educational activities, such as Sickle Cell Sabbath/Sunday faith-based outreach campaign
- Patient assistance program

Programs for adults with sickle cell disease:

- Consultation and collaboration with adult health care providers as patients transition from pediatric care
- Free hemoglobin testing for those of child-bearing age
- Special events (Sickle Cell Family Day, Sickle Cell Walk Run or Jog.

We also coordinate the Ohio Newborn Screening Program for hemoglobinopathies. This program is in place to identify all infants born in Ohio with a hemoglobinopathy. Ohio began testing for hemoglobinopathies in March of 1990. Each year in Ohio, approximately 100 infants are diagnosed with some form of sickle cell disease. Infants who test positive for a hemoglobin disease will be referred to Dayton Children's for care coordination and disease management. The initial visit includes repeat testing to confirm the initial newborn screening result done at birth, hemoglobin counseling and education for parents and/or caregivers and initiation of penicillin prophylaxis at two months of age. After the initial visit, families are required to follow-up every few months for monitoring, disease management and continuing education.





A commitment to collaboration allows the hematology/oncology team to provide the most effective, timely and convenient care possible. That commitment is evident in the way we plan care, work with other local health care institutions and find new ways to reduce treatment delays.

Quality Item	2013	2014	2015	Increase % 2014/2015
Total # of Meetings	34	36	40	11%
Total Case Presentation	85	100	133	33%
Total Physician CE hours/Attendance	295	324	421	30%
Total Non Physician CE hours/Attendance	197	192	207	8%

toward a better tumor board

The cancer team continued to refine its tumor board format in 2015, and the benefits are clear. Compared to 2014, the group held more meetings, presented more cases and had higher physician participation.

Refinements since 2014 include:

- Presenting some cases multiple times over the course of treatment, such as at diagnosis and post-chemotherapy
- Allowing flexibility with the meeting agenda so that emergent cases can be presented
- Conferencing in physicians from Nationwide Children’s Hospital in Columbus

Tumor board participants include specialists from hematology/oncology, radiation oncology, radiology, pathology, surgery, nursing and other clinical areas; they represent Dayton Children’s, Nationwide Children’s and UC Health. Here is what some

participants have to say about the quality of the experience:

- “The changes are excellent. We not only review and update older cases, but we also get to cover cases on the fly—great format with a team approach!”
- Todd Boyd, MD,
Dayton Children’s
- “I really appreciate your efforts to make the tumor board available through audio/video conferencing. This has really helped us in radiation oncology to be able to contribute to the tumor board.”
- John Breneman, MD,
radiation oncology,
University of Cincinnati
- “The tumor board has been reborn in an excellent educational format that is equal to any tumor board at a top-notch academic oncology center.”
- Ayman El-Sheikh, MD,
hematology/oncology,
Dayton Children’s

convenient access to proton therapy

Proton therapy is a new kind of focused radiation therapy that destroys cancer cells while sparing healthy tissue. But it is so new that only a few medical centers offer it—the nearest facilities to Dayton are in Chicago and Philadelphia.

All that will change in late 2016, when Cincinnati Children's opens its new Proton Therapy Center in Liberty Township. Instead of traveling to distant cities and taking on the expense of an extended relocation, patients from Dayton Children's will be able to drive just 30 miles south of our main campus for outpatient treatment.

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
- Sculptures 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

The Cincinnati Proton Center is a joint venture of Cincinnati Children's and UC Health.

reducing the turnaround time for genetic testing

Dayton Children's patients with high-risk cancers can receive DNA sequencing results much faster than ever before, thanks to new funding from the Gala of Hope Foundation in Beavercreek, Ohio.

The testing is available to patients who have recurrent or treatment-resistant cancers, and can help physicians determine the best treatment options for the patient based on their unique DNA makeup. It has been available for many years, but may not be covered by private

insurance plans. In order to cover out-of-pocket costs, Dayton Children's had to offer the testing through a grant administered by Cincinnati Children's Hospital Medical Center. This involved sending the specimen to Cincinnati Children's first, rather than directly to the specialty genetic lab. The new arrangement shortens the wait time by as much as three weeks, a lifetime for families whose child has an aggressive form of cancer.





▷ Two nurses at Dayton Children’s—Jani Rice and Kari Roberts—began researching the idea for the fertility preservation program last year. Today, Dayton Children’s has an established program in partnership with Wright State Physicians.

cancer program begins offering fertility preservation consults

Dayton Children’s was one of the first hospitals in the country to establish a long-term follow-up program for children who have survived pediatric cancer. In 2016, as part of this program, we began offering fertility preservation consults.

Two nurses at Dayton Children’s—Jani Rice and Kari Roberts—began researching the idea for the program in 2015. They shared their findings with Ayman El-Sheikh, MD, medical director of hematology/oncology and Steven Lindheim, MD, an obstetrician/gynecologist at Wright State Physicians. The two physicians were enthusiastic, and led the process of establishing guidelines and referral procedures.

“The number of pediatric cancer survivors is growing rapidly as treatments become more effective,” says Dr. El-Sheikh. “However, many current therapies cause permanent damage to the ovaries or testes, significantly impacting quality of life. Fertility preservation options are often overlooked as parents and physicians focus on cancer treatment and the child’s immediate health. It is important to counsel patients who are at risk for infertility and initiate preservation management prior to beginning treatment.”

Egg retrieval/freezing is the primary fertility preservation option for girls who have already reached puberty. Researchers are studying a technique for younger girls that involves removing ovarian tissue, freezing it and re-implanting it when the patient is older. Boys ages 13 and over may

be candidates for sperm banking; the option of removing and replanting testicular tissue is still in the research phase.

Fertility preservation may be considered for patients who:

- Are undergoing a bone marrow transplant
- Have been diagnosed with a solid tumor, such as osteosarcoma or Ewing’s sarcoma
- Will undergo radiation therapy focused around the pelvic area, abdomen, spine or whole body.
- Will receive alkylating agents or heavy metal chemotherapies as part of a chemotherapy regimen
- Will undergo an oophorectomy (ovary removal surgery) as part of their cancer treatment
- Have been diagnosed with a testicular type of tumor

Dr. Lindheim meets with families who are interested in learning more, and can perform fertility preservation procedures in a timely fashion to minimize cancer therapy delays. Dr. Lindheim and the cancer team are working to secure funding that will help make the procedures more affordable, as they are not covered by insurance at this time.

“A cancer diagnosis can be devastating for families, but fertility preservation is a reminder that there is hope,” Rice says. “Our team helps parents and patients think beyond the next few months or years to a time when cancer is just a memory.”

protecting Hasti's future

When Hasti Hooshiari was diagnosed with Hodgkin lymphoma in March 2016, her parents were thinking about one thing: curing the disease as quickly as possible. So when the topic of fertility preservation came up during their first meeting with Dr. Ayman El-Sheikh and the cancer team at Dayton Children's, they were surprised.

"We were focused on cancer treatment, but the team helped Nasrin and I look ahead to Hasti's future," says Ali Hooshiari, Hasti's dad. "Fertility preservation seemed like a way to provide assurance that we had done everything we could to protect Hasti's ability to have children."

Dr. El-Sheikh assured the Hooshiaris that he would work closely with fertility specialist Dr. Stephen Lindheim at Wright State Physicians to minimize any delays in treatment. "Hasti was the first Dayton Children's patient to express interest in our fertility preservation program," Dr. El-Sheikh says. "Despite the urgency

to start chemotherapy and the magnitude of coordination of care between two different institutions, we were ready to put our fertility preservation protocol to the test."

Within just a few days, Hasti and her parents met with Dr. Lindheim. He explained what egg retrieval and freezing would involve, and answered their questions. Ali and Nasrin talked to Hasti about it afterward, allowing her to come to her own decision. It didn't take Hasti long to decide. "I wanted to be sure that I could have kids when the time comes," she says. "I felt like cancer shouldn't stop me from doing that."

Preparation involved going to Dr. Lindheim's office almost every day for two weeks for medication and blood work. Hasti's surgery took place in late March, and was followed by frequent follow-up ultrasound scans. "It was kind of hard at times," Hasti says. "But looking back, I am really glad I did it."

Less than a month of her initial diagnosis, Hasti's three rounds of chemotherapy began. She missed the rest of the school year, but worked with her teachers at Springboro Junior High School in Springboro, Ohio, to stay caught up. In the fall of 2016, she returned to school for her ninth grade year. Recent imaging tests reveal no signs of cancer.

"Now that my chemo is over I feel a lot better, and I know my life will keep getting better from here!" says Hasti, who recently turned 14. "I plan to be very successful. I hope to do really well in high school so I can get into an Ivy League School. I am thinking about becoming a doctor, and then maybe meeting someone and getting married and having two kids! And throughout my life I will travel around the world to places I've always wanted to go such as Greece, Spain, Brazil and France to name a few!"



▷ Hasti Hooshiari was the first patient at Dayton Children's to undergo fertility preservation when she was diagnosed with cancer.





The hematology/oncology department at Dayton Children's is expanding its participation in clinical research through new partnerships and long-standing collaborations.

new research partnership to help unlock the mysteries of the brain and spine

An innovative partnership between Dayton Children's, Wright State University and Premier Health Neuroscience Institute could help provide new treatments for cancer and neurological diseases such as epilepsy. Established in 2015, this partnership brings together scientists, physicians and Wright State's systems research engineers to create a unique synergy between biomedical research and

engineering. It is housed at the new Neuroscience Engineering Collaboration Center on Wright State University's campus.

Representing Dayton Children's in this partnership is Rob Lober, MD, PhD, who joined the hospital's neurosurgery department in August 2015. Dr. Lober splits his time between caring for patients at the hospital

and conducting pediatric research at Wright State. His research focuses on improving diagnosis and treatment with advanced imaging protocols. The recent addition of the 3T MRI at Dayton Children's, with twice the quality and clarity of most current scanners, will help him in this research, as will an \$800,000 PET/CT scanner at Wright State.

"We are pioneering the most advanced clinical neuroimaging technologies available in Ohio, including specialized vascular and spinal imaging techniques that are being developed through a joint collaboration with Stanford University," says Dr. Lober. "We are on the verge of many exciting medical discoveries that promise to improve the lives of patients in ways that we could not have previously imagined."

Dr. Lober is fellowship trained in pediatric neurosurgery and pediatric neuro-oncology, a rare combination for a pediatric surgeon. He earned his medical degree and a PhD in biomedical science at Georgia Regents University in Augusta, Georgia, and completed his residency at Stanford Hospitals and Clinics in Stanford, California, prior to joining Dayton Children's, he worked at Lucile Packard Children's Hospital in Palo Alto, California.

Dr. Lober's plans include creating a neuroimaging laboratory that will analyze the massive amounts

of data from the medical imaging scans of Dayton Children's patients, as well as experimental subjects, to guide protocols and better care for the next patients, including those with brain tumors and hydrocephalus.

fast track access to clinical cancer trials

Children from the Dayton region have rapid access to all Phase I and II clinical cancer trials at the Cincinnati Children's Cancer and Blood Diseases Institute, thanks to our participation in the Advanced Cancer Therapies Network (ACTN). Through this network, eligible patients start their clinical trial in Cincinnati. Once they 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. In 2015, one Dayton Children's patient was able to start participating in a clinical trial within two weeks of expressing interest.

Dayton Children's also participates in the Diffuse Intrinsic Pontine Glioma (DIPG) Registry, which was established to help researchers find more effective ways to treat this deadly cancer.

**dayton children's
tumor registry:
2015 data**

Dayton Children's maintains an extensive tumor registry that dates back to 1994 with data on 1,277 patients. We report data monthly to the Ohio Cancer Incidence Surveillance System and annually to the National Cancer Database.

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)
- Treatment modalities (surgery, chemotherapy, hormonal therapy, radiation therapy and other therapy)
- Recurrence
- Vital status

2015 analytical cases

The information presented in the following tables is based on our 2015 analytical cases. These cases were diagnosed or initially treated at Dayton Children's. In summary, 46 patients received care at Dayton Children's, including 21 females and 25 males, from 12 counties.

Quality cancer registry data can be utilized for planning, fundraising, treatment assessment and benchmarking. Incidence, outcomes, outmigration and in migration can be obtained from registry data. To request specialty reports/queries, contact the hematology/oncology department's certified tumor registrar, Michele Keyes, at 937-641-3263 or keyesm@childrensdayton.org

County of Residence	2015 Analytic Patients
Montgomery	20
Greene	6
Miami	4
Mercer	3
Auglaize	2
Butler	2
Clark	2
Darke	2
Shelby	2
Allen	1
Highland	1
Preble	1
Grand Total	46

International Classification of Childhood Cancer* Site Group	2015 Analytic Cases	Percentage of total 2015 Analytic Cases
Leukemias, Myeloproliferative diseases, and Myelodysplastic Diseases	7	15%
Lymphomas and reticuloendothelial neoplasms	7	15%
CNS and miscellaneous intracranial and intraspinal neoplasms	13	28%
Neuroblastoma and other peripheral nervous cell tumors	5	11%
Soft tissue and other extraosseous sarcomas	5	11%
Renal tumors	1	2%
Hepatic tumors	2	4%
Malignant bone tumors	2	4%
Germ cell tumors, trophoblastic tumors and neoplasms of gonads	2	4%
Other malignant epithelial neoplasms	2	4%
Grand Total	46	100%

* The International Classification of Childhood Cancer is based on tumor morphology and primary site with an emphasis on morphology.





new tower to feature a fully integrated, kid-friendly cancer center

Dayton Children's is building a new, eight-story patient tower that will transform the way we care for the children of our region when it opens in 2017. A major element of the project involves creating the new Mills Family Comprehensive Cancer and Blood Disorders Center.

Benefits of the new Mills Family Comprehensive Cancer and Blood Disorders Center:

- **Integrated care.** Inpatient and outpatient care will be integrated to allow children to receive treatment in one central location and decrease infection risk by limiting the need for immune-compromised patients to visit other areas of the hospital. This approach will enable rooms to flex between inpatient and infusion to meet the needs of each child.
- **Additional conveniences in one location.** A pharmacy, procedure room and unit lab draw station in one location will help reduce wait times for families. Conveniences for families will be added, including a place for parents to exercise, work on their computer and spend the night in their child's room.
- **More space for families.** Larger rooms will comfortably accommodate parents and siblings, who may spend eight hours together in one room with a child who is undergoing treatment. In addition, there will be more space for procedures. This will eliminate the need to schedule a patient for surgery and move the patient and the patient family to another area of the hospital. Also, there will be more space for drawing blood and labs. This will eliminate the need to send the patient to the hospital's lab.
- **More space for care teams.** An integrated center will allow for increased knowledge sharing between nursing staff. Inpatient and outpatient nurses can be cross-trained and collaborate for additional skills development, improving the overall patient experience.
- **Easier access.** The new center will provide quicker access to all members of the care team including social workers, physical therapists and child life specialists.
- **Rooftop garden and dedicated play spaces.** The center will boast a rooftop garden and activity area for children and families to enjoy sunshine and fresh air as they relax together. Also, a space will be dedicated for patients with compromised immune systems.
- **On-demand technology.** New infrastructure will support interactive, on-demand technology for children and families.
- **A central reception area and "hubbed" nurses' stations.** A centralized, open and friendly reception area will allow both inpatient and outpatient families to check in easily with a receptionist. One nurse's station will be to manage patient charts and discuss patient care; another will have central monitoring to visualize a group of patient rooms at a glance.
- **Dedicated patient transport elevator.** Critically ill children will be transported on a separate, non-public elevator for faster, safer movement and direct access to the care center.
- **Larger corridors and hallways.** Larger hallways will make transporting patients easier.

expansion in springboro brings cancer clinic to southern suburbs

Dayton Children's is creating an ambulatory care destination center in Springboro, located about 16 miles south of our main campus. The project involves a major expansion of our existing outpatient care and urgent care centers, and new services will be implemented in phases. When complete in 2017, the 210,000-square-foot facility will include a speciality care center, emergency department and outpatient surgery center.

"This expansion in our south market is another significant milestone in Dayton Children's history and clearly demonstrates our commitment to providing the

best care for children and families in this region for generations to come," shares Debbie Feldman, president and CEO at Dayton Children's.

"While we are continuing our long-range campus renewal at the main campus to provide world-class inpatient care, the need for outpatient services continues to grow and more services are needed closer to home for families.

"This ambulatory destination center will serve as the gateway to Dayton Children's in the south market. The goal of this expansion is to be a magnet in

our south market, providing children in this area with easy access to subspecialists close to home."

As part of this expansion, Dayton Children's will offer a twice-monthly clinic for new and established hematology and oncology patients needing clinic visits, lab testing and radiology exams. All three of our hematology/oncology specialists—Dr. Ayman El Sheikh, Dr. Mukund Dole and Dr. Jordan Wright—will see patients there. The clinic will open in fall 2016.



