

# hematology/oncology at Dayton Children's



# the six C's that trump cancer at Dayton Children's



## compassion

Many families hear the news that their child has cancer for the first time in the emergency department. Three-year-old Alex Lacy broke his arm riding his bike near his home in Sidney. A local hospital splinted it, but when he started to run a fever a day later and the pain got worse the day after that, his mom called Dayton Children's emergency department. "I knew I couldn't get medical advice over the phone but I just needed reassurance. The woman on the phone, Marcy, encouraged me to listen to my mother's intuition and bring Alex in. Even if it was nothing, she knew I would feel better."

Once in the ED, the doctor noticed how pale Alex looked and ran some tests. The doctor and Marcy returned to tell Melissa that Alex had leukemia. "Marcy walked me through calling my husband and getting

my mom to watch our other children. She stayed with me every minute until my husband arrived. I was never alone and I needed that. Everyone that night was compassionate, understanding, and went above and beyond," says Melissa.

## connection

While all parents who hear this news need that immediate support, at Dayton Children's they get much more. Dayton Children's is part of a giant network that stretches around the world and encompasses the greatest minds, the best treatments and the latest research in childhood cancer delivered right to their bedside.

Dayton Children's is one of just nine children's hospitals in the country that is accredited by the American College of Surgeons Commission on Cancer which recognizes cancer care programs for their commitment to

providing the most well-rounded and highest quality care.

Dayton Children's is also a member of the Children's Oncology Group (COG), the world's childhood cancer experts. This connection means a child treated at Dayton Children's gets the exact same treatment that they would get anywhere. They have access to nearly 100 active clinical trials at any given time from more than 200 leading children's hospitals, universities and cancer centers across the globe.

"You are not just seeing your doctor here at Dayton Children's," says Ayman EL-Sheikh, MD, division chief of hematology/oncology. "We talk with other experts on your particular type of cancer to get additional opinions. When you get a plan of treatment, you can know for sure that is the same plan you would get anywhere else in the country. There are so many cancers, in so many forms – but through the COG you have access to treatments for them all without leaving the comfort of home."

## community

Bringing all that expertise home to Dayton is incredibly important because cancer treatment is a marathon, not a sprint. Treatment can last years. Chemotherapy, appointments and inpatient stays are constant and ongoing. If a child spikes a temperature, parents have to be at the emergency department within the hour.

This schedule makes it challenging for parents trying to continue to work and take care of other children. Staying close to home allows parents to take advantage of their support system already in place.

For the Lucas family, the closeness was incredibly important. Each round of chemo involved a hospital stay of about five days for Gavin, followed by a week of recovery at home. The drugs caused dramatic side effects that included severe constipation, bone pain, mouth sores, frequent nosebleeds and vomiting.

Mom and Dad, Kelly and Sean, spent as much time with Gavin as they could, "tag teaming" so

that someone could be home with their three other children. Sean's co-workers took turns filling in for him at the fire station when needed. One parent volunteer became a substitute teacher so that she could be on call just for Kelly who was a teacher at Northmont High School.

"We had so much support we actually had to turn people down who offered to bring us food or clean our house!" says Sean. "That's something that we would not have had if we had to go outside our community for Gavin's cancer care – it would have been so much harder."

Staying in his community helped keep things as normal for Gavin as possible. All four of his grandparents were able to visit frequently, as were his aunts and uncles, siblings, cousins and family friends. Being able to visit with friends and family and even go back to school whenever possible helps stave off depression that can come with a cancer diagnosis.

The Children's Oncology Group (COG), a National Cancer Institute supported clinical trials group, is the world's largest organization devoted exclusively to childhood and adolescent cancer research.

- Unites more than 9,000 experts in childhood cancer at more than 200 leading children's hospitals, universities, and cancer centers across the world
- More than 90 percent of 14,000 children and adolescents diagnosed with cancer each year in the U.S. are cared for at member institutions.
- Nearly 100 active clinical trials open at any given time, including front-line treatment, and new and emerging treatments

The Children's Oncology Group research has turned children's cancer from a virtually incurable disease 50 years ago to one with a combined 5-year survival rate of 80 percent today.

When a child is diagnosed with cancer, it's a terrifying time for the family. The good news is that all the care and support they need is right in their own backyard. Each year adds new programs and services at Dayton Children's and in 2018, was no different. While cancer may be referred to as the big C, parents can trust there are a few other Cs that have a lot more power at Dayton Children's.

## Commission on Cancer

Dayton Children's is accredited by the American College of Surgeons and is one of only nine approved pediatric cancer programs in the country by its Commission on Cancer. This recognizes cancer care programs for their commitment to:

- Quality care close to home
- Comprehensive care
- A team approach
- Information and education
- Patient-centered services
- Options for genetic assessment and counseling, and palliative care services
- Care monitoring and quality improvement
- Treatment planning based on evidence-based national treatment guidelines
- Clinical trials and new treatment options
- Follow-up care including a survivorship care plan
- Patient tracking through the cancer data system





**collaboration**

Because staying close to home is such a critical part of cancer treatment, Dayton Children's collaborates to bring even more services close to home. A brand new partnership with Nationwide Children's Hospital in Columbus will allow Dayton Children's to expand into new territory and partner on bone marrow transplants, physician services, nursing education opportunities and a research collaborative that will offer even more clinical trial opportunities.

For Henry Springer's mom, Emily, that collaboration matters. Henry is 2 years old and battling a rare brain tumor. Emily and her husband, Matt, took Henry to Nationwide to have his stem cells collected.

"Henry calls it the big, big, big 'o'pital," says Emily. "It's reassuring that the two hospitals are working so closely together to make it a seamless experience for us. Our doctors and nurses at Dayton Children's arranged everything so we felt supported every step of the way.

"It's always comforting to come back to Dayton Children's. We pull into the parking garage here and Henry says we're home!" says Emily. "They know us at the front desk. We also love how Dayton Children's is set up, with all cancer care on one floor so no matter what you are there for, you can always find your nurse or doctor to ask a question."

**comfort**

Cancer is a traumatic diagnosis for the entire family. For kids, though, their most important job is still just being a kid. They shouldn't have to give up toys, games and make-believe, just because they have cancer. That's where child life specialists come in. These are specially trained to engage and distract children while they are going through difficult procedures or during a long hospital stay.

"Play is important because it promotes normal growth and development," says Rita Falkenbach, hematology/oncology child life specialist. "We play games, we use all sorts of

distraction devices – from bubbles to Playdoh to iPads. We find out what the child likes and go to great lengths to create special moments. We've held proms, we've had Skype kindergarten graduation ceremonies, we've turned little red wagons into mock fire trucks, we've staged Nerf gun wars – you name it, we will do it! It totally changes the way kids and families view the hospital experience."

For mom and dad, there are other amenities that help them keep life on track. One of those is the nurse navigator. Families meet with her during one of the first visits and she acts as their guide to the long process ahead. She will help them schedule appointments, find services and be a resource for any questions they may have, day or night.

Dayton Children's also offers a concierge for families. Imagine your child is not feeling well after



Amanda York, Dayton Children's concierge (on right)

a treatment and you don't want to leave her alone but your husband is working, the other kids are at school and your dog will tear up the house if you don't get home to walk him. No problem – contact the concierge who will find someone to walk your dog.

**commitment**

In the end, it's really all about commitment – to the child, to the family, to beating the cancer and returning everyone to their normal life.

"The good news is most children will beat their cancer," says Dr. EL-Sheikh. "So we are also caring for the adult they will become. We embed a psychologist into the program to protect their mental health. We have a fertility program to protect their ability to have children. We also have a new partnership with the Maple Tree Cancer Alliance to develop customized exercise programs for our kids."

Dayton Children's was one of the first hospitals in the country to offer a long-term follow up program for children who have survived pediatric cancer. In the last eight years, the number of former cancer patients served



Kelly Walker, Dayton Children's dietitian, with Ava

by the program has more than doubled to nearly 250, a reflection of Dayton Children's high cure rates.

Long term follow-up is crucial for these kids because they have a higher risk of developing another cancer or other issues. For Mariah McIntyre, she beat anaplastic large cell lymphoma in 2014. Only 500 kids younger than 20 years old are diagnosed with this non-Hodgkin lymphoma each year. Because they were following her closely, doctors just discovered she had cancer again.

She now has her team at Dayton Children's back by her side and catching cancer early can make all the difference.

The staff never stop looking for ways to help each child have the best experience possible with the brightest outcome. For example, the dietitian Kelly Walker knew that 60 percent of pediatric oncology patients suffered from malnutrition, so she started a program focused on nutrition standards. For 3-year-old Ava Gunn who had surgery,

chemotherapy and a bone marrow transplant, her little body was able to tolerate all that therapy better because of her improved nutrition. "Her mom was so happy because Ava was strong and energetic the whole time," says Kelly. "Ava just finished her last round of chemo and is doing great!"

"We're part of the Dayton Children's family now and they are a part of my family," says Ava's mom, Amanda. "They aren't just taking care of Ava, they are taking care of all of us."



**Ayman El-Sheikh, MD**

Dr. Ayman El-Sheikh is chief of the hematology/oncology division at Dayton Children's Hospital. He brings together a team of pediatric specialists, nurses, social workers, child life specialists and any other specialist that is needed to ensure that children battling cancer or blood disorders get the personalized care

plan they need. Dr. El-Sheikh is also a member of the Scientific Committee for The Children's Brain Tumor Tissue Consortium (CBTTC). His special interests include blood and marrow transplants, solid tumor treatment, education and research.

Dr. El-Sheikh joined Dayton Children's in 2015 from the University of Iowa Children's Hospital in Iowa City, where he was the

director of the pediatric blood and marrow transplant program, the institutional principal investigator for the Children's Oncology Group (COG) and the medical director of the inpatient ward. He was also a clinical assistant professor of pediatric hematology/oncology at Carver College of Medicine at the University of Iowa, as well as on the admissions committee. Along with English, Dr. EL-Sheikh also speaks Arabic.

# cancer in kids

## Alex

- Loving preschool and already planning his next trip to Disney
- Cancers of the bone marrow and blood
- Top types are ALL and AML



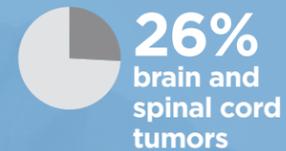
## Gavin

- Volunteers at Dayton Children's, plans to pursue a career in the medical field
- Includes osteosarcoma and Ewing sarcoma
- Most common in teens



## Jules

- Celebrated being cancer free with silly string and a happy dance
- Most start in the lower parts of brain
- Treatments can include surgery, chemo, radiation



## Colin

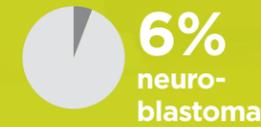
- Just started first year of college
- Cancer of the eye
- Usually found in 2-year-olds



kids are not just little adults - they get different types of cancers. The most common cancers of children are:

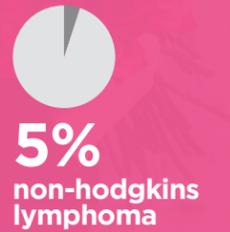
## Scarlett

- From headbands to nail polish, this pint sized powerhouse always rocks her look
- Develops in babies and young kid
- Starts in early forms of nerve cells before birth



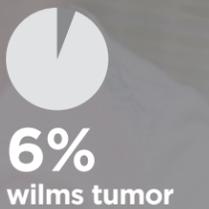
## Mariah

- Back at Dayton Children's after a relapse, tackling it head-on with fuchsia fringe
- Starts in immune system cells, like lymph nodes or the tonsils
- Determined by the presence of a specific type of abnormal cell



## Charlotte

- Beat cancer. Twice.
- Starts in the kidneys
- Most often found in 3 or 4-year-olds



## Sarah

- Officially in remission after a bone marrow transplant using her own stem cells
- Starts in immune system cells, like lymph nodes or the tonsils
- Very different treatment than non-Hodgkin



## Meghan

- 13 years cancer-free after a belly tumor.
- Had chemo, radiation and even trips to a hyperbaric chamber!



# powerful partnerships



## Collaborative with Nationwide Children’s Hospital will share knowledge and enhances services.

Dayton Children’s Hospital and Nationwide Children’s Hospital have announced a cancer, blood disorder and bone marrow transplant collaborative that will allow Dayton Children’s to expand into new territory and partner on bone marrow transplants, physician services, nursing education opportunities and a research collaborative that will offer even more clinical trial opportunities.

“Our collaboration with Nationwide Children’s Hospital will provide more advanced services than ever before at Dayton Children’s and make life a little easier for our patients and families,” says Ayman El-Sheikh, division chief of hematology/

oncology at Dayton Children’s Hospital. “The comfort and support system of home cannot be overstated for a family who is enduring a several-year treatment span for cancer in their child.

Dayton Children’s has a long tradition of quality cancer care. The overall survival rate for children treated at Dayton Children’s is higher than the national average. Dayton Children’s was one of the first hospitals in the country to offer a long-term follow up program for children who have survived pediatric cancer. In the last eight years, the number of former cancer patients in the program has more than doubled, a reflection of those high cure rates.

In addition, Dayton Children’s is a member of the Children’s Oncology Group (COG). This connection means a child treated at Dayton Children’s gets the exact same advanced treatment protocols that they would get at any of the 200 member children’s hospitals and cancer centers anywhere in the world.

Nationwide Children’s Hospital’s is uniquely positioned to assist Dayton Children’s with this additional service. Its hematology/oncology/bone marrow transplant services is ranked fifth in the 2018-19 U.S. News & World Report standings. The No. 5 ranking is the highest among all Nationwide Children’s

service lines. Additionally, the hematology/oncology/BMT program at Nationwide Children’s has the highest overall outcomes score as recognized by U.S. News & World Report and has earned the highest possible score in patient survival following a bone marrow transplant as noted by the national publication.

“The alliance with Dayton Children’s Hospital is an example of Nationwide Children’s vision to share learnings and discoveries that will provide best outcomes for children everywhere,” said Timothy Cripe, MD, PhD, division chief of hematology, oncology and bone marrow transplant at Nationwide Children’s

Hospital. “Like-minded hospital initiatives, such as the NEXT Consortium, impact children in the U.S. and around the world, all with the goal that any new cancer treatments developed at Nationwide Children’s is shared with institutions globally.”

This initiative is part of the Ohio Pediatric Care Alliance. Formed in October 2013, the Alliance formalized the long-standing partnership between Dayton

Children’s and Nationwide Children’s and allowed the two independent children’s hospitals to share resources, avoid duplication and better utilize limited pediatric specialists.

“The Alliance provides a structure for working collaboratively on initiatives that further the shared mission of both hospitals—to provide high quality, cost-effective, accessible care to all children,” says Deborah

Feldman, president and CEO, Dayton Children’s.

Three other initiatives currently operate under this umbrella: a joint outpatient specialty care center and a pediatric practice in Springfield, collaborative on heart services quality initiatives as well as a Lima clinic, and shared services in urology.

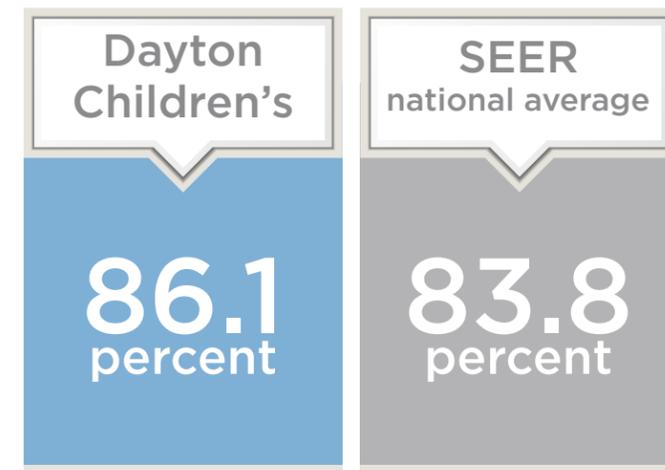
“One of the most important ways pediatric hospitals achieve

best outcomes for children is by learning from each other,” says Steve Allen, CEO, MD, Nationwide Children’s Hospital. “Our relationship with Dayton Children’s has proven for years that families are best served when we work together, and this expansion of the alliance will allow even more of Ohio’s youngest residents to benefit.”

## survival and satisfaction

### survival

The most important question families ask when they learn their child has cancer is ‘can they beat it?’ They overwhelming positive answer is ‘yes!’ Thanks to amazing advances, on average the survival rate for all cancers is 83.8 percent, according to the National Cancer Institute Surveillance, Epidemiology and End Results (SEER) Program. At Dayton Children’s, the average is even higher - 86.1 percent.



(SEER = National Cancer Institute Surveillance, Epidemiology and End Results Program)

### satisfaction

Dayton Children’s is proud to say that patient satisfaction scores in hematology and oncology are a perfect ten. In surveys given to patient families, 100 percent of families responded that the provider explained things well and that they would recommend the service. That’s high praise when you spend as much time in the hospital as cancer patients do!





## what is sickle cell disease?

- An incurable disease that affects hemoglobin, a protein in the red blood cells.
- Causes red blood cells to change from disc shaped to crescent shaped. These cells may stick to vessel walls or burst apart, creating blockages and preventing oxygen from reaching nearby tissues.
- Causes organ damage and attacks of sudden, severe pain, called pain crises. These can come without warning, although triggers may include infection, physical exertion and stress.

The first thing you notice about Fanta Keita is her dazzling smile. And Fanta smiles a lot, whether she's hanging out with friends, cheering on the Trotwood-Madison High School football team or getting new acrylic nails at her favorite salon.

But some days it's harder for Fanta to smile, laugh or even get out of bed. She often suffers from pain in her abdomen and back due to a condition called sickle cell disease. Sometimes she can manage with over-the-counter medication; other times, taking opioids is the only way to find relief. Fanta misses a lot of school because of the pain, and sometimes has to be hospitalized to get them under control.

### a special bond

Living with sickle cell can be very stressful for children and their families, because the disease causes so much pain and requires daily care. When Fanta is really hurting, she becomes very quiet and withdraws from whatever is going on around her. That's when she relies most on her mom, Cheri. Cheri has been bringing her to the Sickle Cell Center at Dayton Children's since Fanta was about three months old. Mom and daughter share a special bond that has been forged through the heartache of dealing with this disease.

Fanta has missed a lot of school due to pain. Her eighth grade year was the worst for school absences, but it also taught her something about herself. "I had really good grades going into eighth grade, and I knew if I worked hard I could be valedictorian," she says. "I was missing so much school that year that people were counting me out—they didn't expect me to

do it. So I just worked that much harder. I'd pick up on the new material I'd missed by studying for hours at a time at night and on weekends."

A week before graduation, Fanta was thrilled to learn she had been named valedictorian. She decided to keep it a secret for a few days as she worked on the speech she would need to make at graduation. When the speech was ready, she sat down with Cheri and shared her surprise. "My mom had been stressed out that week, but once I told her about valedictorian, she could do nothing but cry out of joy," Fanta says. "Seeing her so emotional from my news made me feel overjoyed. It made the achievement ten times better.

### a drive to succeed

Now a junior at Trotwood-Madison High School, Fanta takes honors classes, loves reading and writing, and is a member of the National Honors Society. Close friends know what she has to deal with on a day to day basis, but some people—even teachers—just don't get it. "I had a gym teacher who wanted to flunk me because I couldn't do some of the activities in class," Fanta says. "I'm like, really? Are you kidding? But he just didn't understand."

The one place Fanta and Cheri can always count on finding understanding and support is Dayton Children's. "The nurses in the Sickle Cell Center are amazing, especially Teresa Berter," Cheri says. "She is always helping us behind the scenes. If I'm having trouble with my health insurance, I call Teresa. If I need my Family and Medical Leave Act papers renewed for work, I call Teresa. She even came to Fanta's school for a face to face with the gym teacher. I can't even imagine Teresa's workload, but she never misses a beat."

### thankful hearts

Thankfulness — for Dayton Children's, for God's care, for supportive family members and each other—is a common theme in the Keita household. Cheri says she's made it a point to instill that quality in her children, and remind them that they have everything they need to overcome whatever lies ahead. Fanta has taken those lessons to heart. "When friends or teachers find out I have sickle cell, they are so surprised, because I am a really positive person," she says. "I am just not someone who is going to be sad all the time and feel sorry for myself about the circumstances that have been handed to me. My mom says



Dan Evans, MD, division chief of pulmonology (on right)

sickle cell doesn't own me, and she's right. I'm just going to keep on living my life."

### additional services

In 2018, Dayton Children's added a pulmonologist to the clinical care team for sickle cell patients. Dan Evans, MD, chief, division

of pulmonology, regularly attends clinic for sickle cell patients. This is important because sickle shaped cells don't carry oxygen as well as regular shaped cells. A pulmonologist is able to measure oxygen levels and provide tools and treatments to help a child maximize each breath they take.



## Mukund Dole, MD

Dr. Mukund G. Dole has been an integral part of the pediatric hematology/oncology program since 1997 and currently serves as an associate professor at WSU Boonshoft and the program director of the West

Central Ohio Comprehensive Sickle Cell Center in Dayton. He pioneered the development of transitional care for adolescent and young adult sickle cell patients and helped develop the first Adult Sickle Cell program in the area.

Dr. Dole obtained his medical degree from the University of Bombay and received his

General Pediatrics training at Children's Hospital of Louisiana and LSU Medical Center, New Orleans, LA. He completed his fellowship in Pediatric Hematology-Oncology at the University of Michigan, Ann Arbor, MI. He is board certified in both General Pediatrics and Pediatric Hematology-Oncology



Going above and beyond at Dayton Children's requires a commitment to continuous improvement. Great ideas normally come from employees on the front lines—including doctors and nurses, food service workers, schedulers, social workers, and anyone else who interacts with patients and families, but need the right format to grow into a successful, committed program.

Which is why Dayton Children's offers the Intermediate Quality Improvement Course (IQIC, pronounced "I Quick.") This intensive, nine-month course empowers leaders to provide exceptional clinical care and the best possible patient experience.

Every spring, Dayton Children's employees are invited to submit IQIC project proposals. After a rigorous selection process, a team of evaluators chooses up to 20 proposals. Instructors teach valuable QI and leadership skills, participants apply those skills to their selected project, and coaches provide support.

The course combines principles from several successful quality improvement (QI) programs and is customized for Dayton Children's. In the last two years, 75 percent of Dayton Children's IQIC projects resulted in statistically significant improvement, which is better than results you see at many large academic medical centers that sponsor QI programs.

**case study:** Identification and treatment of malnutrition in pediatric oncology

**project leader:** Kelly Walker, MS, RD, CSO, LD

**existing problem:** Children diagnosed with cancer often are malnourished at the time of diagnosis, or may develop malnutrition due to treatment side effects. Early intervention is important to improve their nutritional status. Prior to the IQIC project, Dayton Children's did not have nutrition standards of care for children diagnosed with cancer and malnutrition.

**goal achieved:** The percentage of patients with improved nutrition increased from 49 percent in May 2017 to 80 percent by May 2018 (initial project focused on 20 patients with solid tumors).

**key interventions:**

- Established standards of care for mild, moderate and severe malnutrition
- Utilized indicators developed by the Academy of Nutrition and Dietetics to diagnose the degree of malnutrition
- Incorporated measures of muscle mass/fat mass as a part of nutritional assessment
- Educated residents about how to identify and treat malnutrition
- Talked with families about the importance of nutrition to encourage participation in the treatment plan

**observations from project leader:**

"When you do an IQIC project, you are continually looking for ways to improve what you are doing, collecting data and tracking your progress. Every time we added an intervention, we saw improvement in patient outcomes."

## new additions

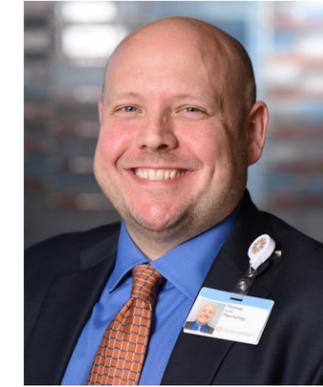
### neuro-oncologist



Lionel Chow, MD, joined Dayton Children's in October 2018 as a new oncologist with expertise in neuro-oncology, the management of brain tumors. He will focus on further developing the neuro-oncology program, adding a strong research component, and coordinating the care between neurosurgeons and oncology services to find the best treatments for each child. He comes to us from Cincinnati Children's Hospital Medical Center. He earned his medical degree at McGill University in Montreal, Canada, completed his residency at the Hospital for Sick Children in Toronto, Canada, and completed a fellowship both there and at St. Jude Children's Research Hospital in Memphis, Tennessee.

### neuro-psychologists

Dayton Children's added two new neuropsychologists in 2018 with special interests in hematology and oncology. Cancer treatments can impact a child's brain development, especially those who have brain tumors removed, which make up approximately one-third of the cancer patients at Dayton Children's. Neuropsychologists identify a child's cognitive strengths and weaknesses, finding ways to overcome any deficits that treatment created to help them be successful at home, school and in the community.



Thomas Duda, PhD, joined Dayton Children's because in his words he found "it provides state-of-the art treatment and services while maintaining a community-focused and family-like atmosphere." He received his doctoral degree at the University of Windsor and completed his internship and fellowship at Baylor College of Medicine at Texas Children's Hospital in Houston.



Thea Quinton, PhD, joined Dayton Children's because she says "everyone who works here is caring, passionate, and works hard on behalf of the children we serve." She received her doctoral degree at the University of Texas, served her residency at Kennedy Krieger Institute/Johns Hopkins School of Medicine in Baltimore, Maryland, and completed her fellowship in pediatric neuropsychology at Cincinnati Children's Hospital Medical Center.



# no challenge too great for the hemophilia team



Ayham Dawoud is living proof that the hemophilia team at Dayton Children's won't let anything stand in the way of providing patients with the best possible care. Even patients who are here on a travel visa, can't speak English and don't have health insurance.

Ayham came to Dayton from the Middle East last year with his mother, Jaklin. The 5-year-old was born with hemophilia, a rare and incurable condition that prevents blood from clotting properly. For people with this disease, a simple injury can cause excessive bleeding outside the body and inside the joints. Ayham had not received proper care in his home country, putting him at high risk for bleeding episodes. One of his ankles had become a frequent site for internal bleeding, which caused him to walk with a limp.

"Our hemophilia patients usually see Dr. Jordan Wright, but since Dr. Ayman El-Sheikh, our medical director for hematology/oncology, speaks Arabic we decided to make an exception for the first visit," says Sandy Hibner, BSN, RN, hemophilia resource

nurse. "It made such a difference to the family that they could communicate with Dr. El-Sheikh in their native language."

## the high cost of drug therapy

Blood tests showed that Ayham has a severe form of hemophilia that resists standard treatment. Caring for him would require a different type of drug therapy, which typically costs as much as \$700,000 a year. Compounding the problem was the fact the family had come to the United States on tourist visas, making Ayham ineligible for government assistance.

Despite these obstacles, the hemophilia team moved forward with Ayham's care. "We are never going to turn a patient away,

no matter where they are from or what kind of insurance they have," says Dr. Wright, who is the director of the hemophilia program. "There was no doubt we would get Ayham treatment, but we had to think outside the box."

Dr. Wright found a research study that would allow Ayham to receive one of the medications free (the drug typically costs about \$3,000 a day). Although it is experimental, this medication has been shown to help patients with the same severe form of the disease that Ayham has. He was the first patient in the U.S. to participate in the study—Dr. Wright initiated it at Dayton Children's specifically for Ayham's care.

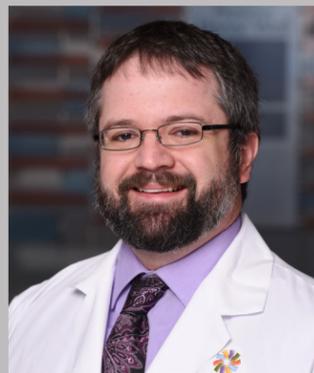
## true heroes

Another major challenge was to find insurance coverage for Ayham's other needs—everything from physical therapy and child life to medical imaging and additional drug therapy. Sandy and social worker Christie Blankenship worked tirelessly to find assistance, which came from Ohio's Children with Medical Handicaps program, the hospital's patient assistance fund, Southwestern Ohio Hemophilia Foundation and other sources. Meanwhile, Sandy spent hours each week making sure that Ayham was following the research study protocol and documenting his progress.

## a new life for Ayham

Today, Ayham's condition has improved significantly. He is able to communicate in English and is excited about going to kindergarten. Jaklin has found a job as a seamstress, and a lawyer is trying to obtain immigrant visas for the family.

"Our team is working on a long-term treatment strategy for Ayham, just in case the experimental drug is not effective," Dr. Wright says. "Thirty or 40 years ago, hemophilia treatment was extremely limited. Patients were disfigured by bleeds, and wheelchair bound as young adults. Today, with the right treatment, patients can live normal lives."



## Jordan Wright, MD

Jordan M. Wright, MD, is a physician in the hematology/oncology department, an assistant professor at WSU Boonshoft School of Medicine and the hemophilia

program director. Dr. Wright came to Dayton Children's from Cincinnati Children's Hospital Medical Center in 2015. He completed a fellowship in pediatric hematology/oncology and earned a master's in clinical and translational research at the University of

Cincinnati. Dr. Wright served his pediatric residency and internship in the University of Alabama at Birmingham's program at Children's of Alabama. He earned his doctorate at the Medical College of Georgia in Augusta.



# this is how we will find a cure for brain cancer



Unique initiative creates living biobank and shares research with worldwide brain tumor consortium.

“I will never forget looking at that image – something inside of Blake that should never be inside a child,” says Amberly Barr. In July 2016, she was staring at a black and white MRI scan of the inside of her 10-year-old son’s head where a very rare, softball-sized tumor had grown in the space of just a few months. She brought him to Dayton Children’s emergency department when he collapsed after breakfast one morning, following weeks of headaches and blurred vision.

Blake wasn’t all that worried, just upset he couldn’t make it to the swimming pool as he had planned that day. But Amberly was worried, and with good reason.

Brain tumors are the second most common cancer found in children, and the leading cause of disease-related death for kids. Even so, little progress has been made in finding a cure. Doctors still can’t say what causes many of these tumors. Therapies to treat them haven’t changed much in decades. Many tumors don’t respond to chemotherapy and the other available treatments can have side effects that cause lifelong damage.

Work to change that has been slow. Researchers trying to understand brain tumors have a

very limited amount of material. Tumors can be removed from a child and frozen for research but they lose some critical information during that process. In addition, there is a finite amount of that tumor so very few researchers can get their hands on a sample to study.

“We decided to do something different at Dayton Children’s,” says Robert Lober, MD, PhD, neurosurgeon and brain tumor researcher at Dayton Children’s Hospital. “We decided to make a living biobank. The tumors that we remove from children are grown in a dish so that one tumor can be propagated into 100 or more tumors. That tumor can be shared with researchers all over the world, again and again.”

To start his tumor biobank here, Dr. Lober reached out to his former colleagues at Stanford University in California for a tumor sample he could try to grow. He was able to propagate samples here that other hospitals couldn’t get to grow. To expand the program, he asked families at Dayton Children’s if they would be willing to donate their child’s tumor to research. No one refused.

“It’s a terrifying thing for parents but kids are so resilient, so funny about it,” says Dr. Lober. “Often they name their tumor – my favorite so far has been ‘Growbot.’”

Blake was one of the first kids to donate his tumor to this effort.



“Donating it to science creates a sense of comfort that, even though Blake went through surgery and had the tumor removed, it doesn’t stop here,” says Amberly. “We are gaining understanding to prevent and stop childhood cancer and brain tumors. It helps soothe the fear and the uncertainty that we went through, and it creates hope for a whole bunch of families.”

The Gala of Hope Foundation, through generous donations from the community, provided the seed money to get this project started at Dayton Children’s. These funds were used to purchase special storage containers,

equipment and tools. The next step was to get the tumors in the hands of people who could use them.

That’s when Dayton Children’s joined the Children’s Brain Tumor Tissue Consortium, based at the Children’s Hospital of Philadelphia. It’s a group of just 16 primary member institutions around the world, from Beijing to San Francisco, from Australia to Italy who know that collaboration is the path to innovation. In September 2018, the group launched the Pediatric Brain Tumor Atlas, one of the world’s most comprehensive collections of childhood brain tumor data

now available to all researchers worldwide for free.

The initiative provides samples and previously unimaginable amounts of data about childhood brain tumors in one place. This will allow researchers to spend less time tracking down the data they need, and spend more time focused on discovery of treatments and trials.

“Not only do we provide a living tumor that researchers can continue get new pieces of to run trials again and again, technology has advanced to the point where we can provide the clinical data about the child it came from.

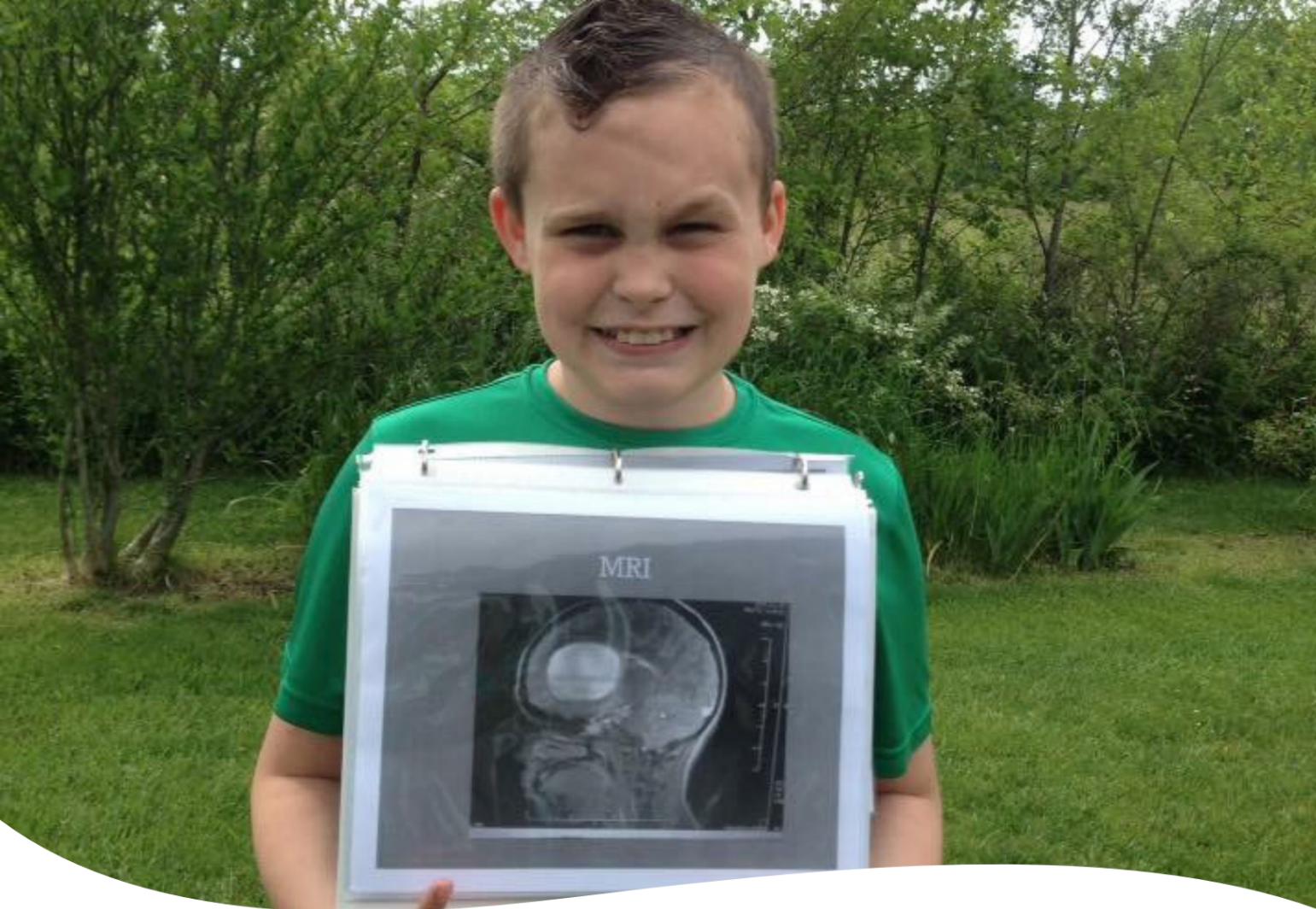


## Robert M. Lober, MD, PhD

Coming to Dayton Children’s from Lucile Packard Children’s Hospital in Palo Alto, California, Dr. Lober

completed a fellowship in pediatric neurosurgery and pediatric neuro-oncology, a rare combination for a pediatric surgeon. He served his residency at Stanford Hospitals and Clinics in California. He earned his

medical degree and a PhD in biomedical science at Georgia Regents University in Augusta, Georgia.



## meet Blake

Blake Barr is 12 years old from St. Paris in Champaign County. He loves fishing, video games, playing with his cat and hanging out with his grandpa. His mom made an appointment with the eye doctor when he started having headaches and blurred vision, but he would end up in the emergency department diagnosed with a brain tumor the size of a softball.

Laurence Kleiner, MD, removed the tumor in a more than seven-hour surgery, and Jordan Wright, MD, managed Blake's cancer care. Blake's tumor was anaplastic ependymoma stage 3 cancer, only 200 cases are seen every year in the U.S. in kids and adults. Dr. Wright connected Blake to Children's Hospital of Philadelphia for seven weeks of proton therapy to zap any remaining cancer tissue with targeted radiation.

Blake's medical team helped him focus on just being a kid



during it all. They knew he loved aquariums so they set up a narwal hunt for him one time when he was in the hospital. He received a wish through the Make-A-Wish Foundation and chose to go to Atlantis in the Bahamas to swim with the sharks.

He was declared cancer free in spring of 2017 and celebrated

with a big party at his grandma's house. He's back to enjoying his math and science classes at Graham Middle School where he recently shared his experience with the whole school. While Blake recovered amazingly well, his mom has noticed some changes in his emotions and mannerisms, which is common

after surgery on the brain. Dayton Children's doctors will continue to watch him closely. He will return every six months for an MRI and receive follow-up care from psychologists, physical and occupational therapists and ophthalmologists.

Previously that was just too much data to transfer – MRI scans, medical notes, other clinical and imaging features – but now cloud technology makes it possible to link massive amounts of data from the donor, giving researchers more information to work with.”

“The purpose of this is to allow the whole world to move forward by providing the tools that will expedite the work on curing cancer,” says Adam Mezoff, MD, chief medical officer and vice president of health care transformation at Dayton Children's. “This consortium not only increases the breadth and depth of what we are doing at Dayton Children's, but it shares the vision of providing these tumors to people who need them, without restricting them

in any way, which can sometimes happen. The collaboration is the key.”

The dataset available in the Pediatric Brain Tumor Atlas represents data collected from more than 1,000 subjects and 30 unique brain tumor types. That number will continue to grow. “We have about 20 tumors here at Dayton Children's that are part of this data set,” says Dr. Lober. “That is a huge boost because just growing them and banking them does nothing until you get them in the hands of the researchers who need them. This is how you are going to get a cure for brain cancer.

“A year or so ago, nothing like this existed. Collaboration with

institutions on a global stage, amazing advances in technology, the generosity, love and support from the people of Dayton who believe in and funded this mission and the families who want some good to come out of their child's struggle with a brain tumor – they all made this happen.”

“What a wonderful gift to a family to say, we know it's the right medicine. How come? Because we have taken that very tumor from your child's body and we have exposed to the medicine and we know that it works,” says Dr. Mezoff.

Amberly looks at her son, now on the verge of entering his teenage years, and knows that

he will play a part in that. “I don't think he knows what it means yet. He knows it's big, but he can't comprehend just how big,” she says, looking at Blake thoughtfully. “But I do. And I know he will one day. One day, he will look back and be able to say ‘I helped cure brain tumors in kids.’”

“It feels amazing that I survived something that not many other people can,” says Blake. “It will be even more amazing when we can figure out what's causing it. Then we can stop it.”



