

## **TACKLING CANCER**

HOW THE MARKEY CANCER CENTER TEAM PUT UK FOOTBALL PLAYER JOSH PASCHAL'S DISEASE ON THE SIDELINES

"YOU WON'T WALK OUT OF THIS HOSPITAL WITHOUT A NEW SET OF LUNGS" MANAGING DIABETES IN YOUNG CHILDREN



### INSIDE



#### A SPARK FOR LIFE

Living with cystic fibrosis requires courage, but when the disease devastated her lungs, Breanna Jessie of Olive Hill got a second chance at life thanks to the experts at UK HealthCare.

### WRESTLING WITH DIABETES

Diabetes is challenging to manage at any age, but especially so for the very young. The Barnstable Brown Diabetes Center is helping 9-year-old Kara and 5-year-old Max Middleton live life as normally as possible. For them, diabetes is not a barrier to anything.

#### **CALLING A BLITZ ON CANCER**

When UK Football player Josh Paschal was diagnosed with an aggressive melanoma, the multidisciplinary team at the Markey Cancer Center ensured the 19-year-old benefited from significant treatment advances. In the future, Josh will view cancer as only one chapter in a life full of promise.

**UPDATE FROM OUR 2018 ISSUE** 15

We check in with Patrick, Jade and John to see how they are doing in the year since we featured their experiences as UK HealthCare patients.

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On the cover: UK Football player Josh Paschal (center) with his father Clayton Paschal (left), and mother LaTauna Paschal (right).



### MY KENTUCKY HOME

I came home to Kentucky two years ago compelled by the opportunity to make a lasting contribution to the health of my home state. While I was listening and learning, the opportunities began to inspire me.

I have come to believe that the University of Kentucky and UK HealthCare have the potential to affect the overall health of our state and its system of care.

As the university for Kentucky, we have the potential – and I would say the duty – to play a leadership role in building a health system that meets Kentucky's present and future needs.

It will not be easy. Our state's needs are great – Kentucky residents are at high risk for major chronic and life-threatening diseases. Moreover, we face large challenges in lowering that risk profile.

If UK HealthCare is to advance its potential as an academic health system of the future, we must:

- Become a data-driven, highvalue health system that delivers high-quality, safe, patient-centered, efficient, and team-led care.
- Grow strategically, employing innovative partnerships to deliver the right care in the right setting at the right time.
- Align our resources within and without to meet our unique mission in education, research and clinical care.

I am not alone in this quest. Around me are colleagues like those in this issue who have dedicated their careers to serving Kentuckians and their health care needs.

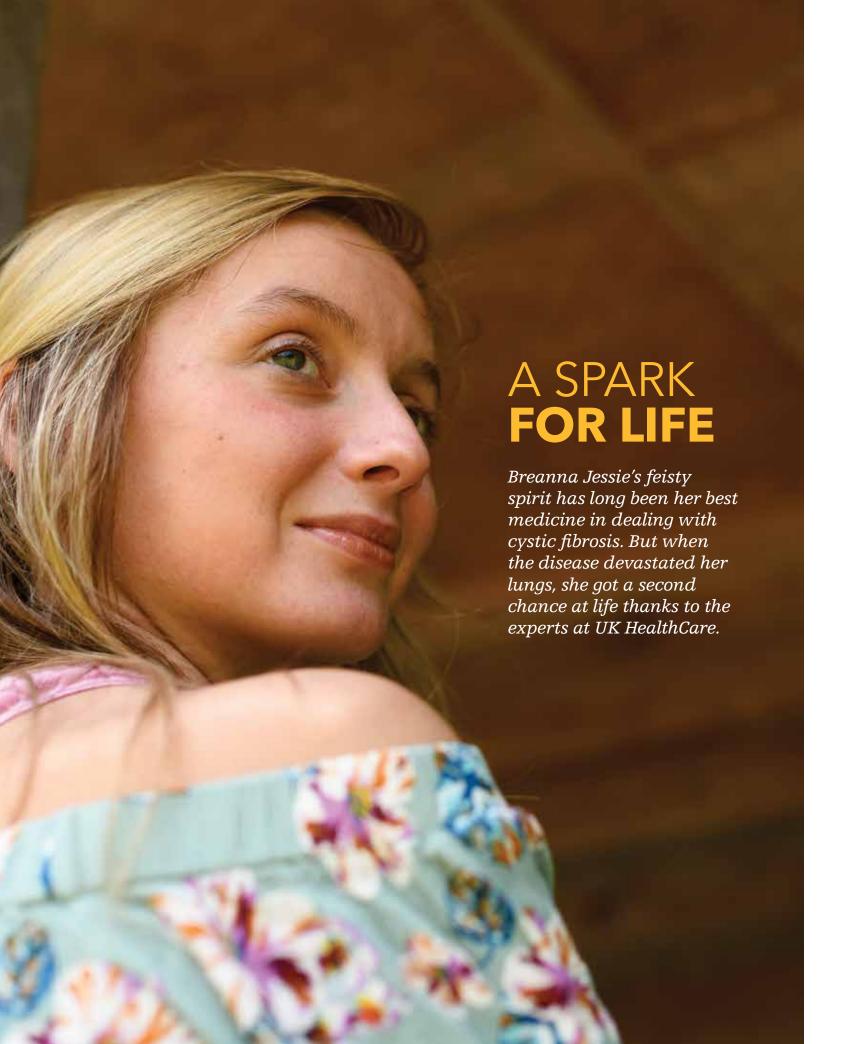
Together, we have a vision for Kentucky. Access to advanced, specialty health care is part of it. Beyond that, we want to improve health and wellbeing. Already we are adjusting to a new reality and taking firm steps to prepare for the future.

As you read about UK HealthCare specialists and staff who are making a difference today, know that we intend to build on that strong foundation for an academic health system of the future. Our future.

Excited about the possibilities,

Mark F. Newman, MD

Executive VP for Health Affairs UK HealthCare/University of Kentucky



A firecracker. A spitfire. That is how Breanna Jessie's care team members at UK HealthCare consistently describe this one-of-a-kind 20-year-old young woman who has battled cystic fibrosis (CF) her whole life. Diagnosed at the age of 3, Breanna has always drawn on her trademark high energy and gutsy determination in facing CF's increasing impairment of her respiratory and digestive systems.

Never were they needed more than when the calendar rolled over into 2018 and CF pushed Breanna's lungs to their limit. Over the next intense and precarious four months, Breanna's care team rallied their patient's feisty spirit and their own significant expertise – particularly in the leading-edge ECMO heart-lung bypass treatment – to keep Breanna alive and healthy enough to qualify for a double-lung transplant.

#### A childhood with CF

Cystic fibrosis is a rare genetic disease that affects around 30,000 patients in the U.S., according to the Cystic Fibrosis Foundation. It causes a patient's mucus to be thick and sticky, clogging airways and raising the risk of respiratory infections. The mucus also affects the release of digestive enzymes from the pancreas, blocking the absorption of important nutrients by the body.

Soon after Breanna turned 3, her parents, Dave and Debra, noticed she was having difficulty breathing and digesting food. They made the wintry 85-mile drive west from their home in the small rural town of Olive Hill to Lexington for a consult at Kentucky Children's Hospital. Jamshed Kanga, MD, chief of pediatric pulmonology,

"I think that is what keeps these CF patients going. They are the most stubborn kids in the world. They have this will to live that keeps them going."

JAMSHED KANGA, MD

administered a sweat test. It detected high levels of chloride – a hallmark of cystic fibrosis. Shortly after, Debra gave birth to twin boys – Hunter and David – who were soon diagnosed with CF as well. "It was very heartbreaking for the family," said Dr. Kanga. "Within a three-month period, they had three children with a CF diagnosis."

Breanna's earliest memories of living with CF are of having to stay inside most of the time to avoid pollen and other environmental triggers for her coughing spells. "I learned a lot of board games at a young age," she said. Twice a day, every day, Breanna had to sit still for an hour for vest therapy, otherwise known as highfrequency chest wall oscillation. She would put on an inflatable vest under her clothes and attach it, via two hoses, to a machine. The machine vibrated the vest at a high frequency to thin out and loosen mucus in her chest, which she would then cough up. "I'd just sit there and shake," she said.

She also took daily doses of digestive enzymes to help her body better absorb the nutrients in her food. "Keeping on weight was the most important thing," she said. "If my weight was up, then my breathing was up, too. I could eat anything I wanted just to gain weight."



(Top) Breanna, critically ill in intensive care, was visited by brothers Hunter (left) and David (right). Both also have cystic fibrosis.

(Opposite page) Breanna Jessie of Olive Hill is embracing health - a new feeling.



(from left)
Pediatric pulmonologist Jamshed
Kanga, MD, has managed CF in
Breanna and her twin brothers for
most of their lives.

Respiratory therapist Anne Fitzpatrick was both caregiver and companion during Breanna's sickest days. They remain friends.

During her sickest hours, Michael Anstead, MD, made several key decisions to stabilize Breanna's breathing, including putting her on a ventilator and then finally ECMO.

Physical therapist Kathryn Gaines had the job of getting Breanna up and moving - she had to be physically strong enough to qualify for the transplant wait list.

### A SPARK FOR LIFE

Her health stayed relatively stable until the end of eighth grade, when she was hospitalized with the flu. She lost half of her right lung, and her blood-oxygen saturation dropped from 90 percent to 75 percent or lower. During high school, she developed pseudomonas, a bacterial infection that can be debilitating to the lungs. Breanna bristled at having to be hospitalized more often.

"She has never been a patient who would lie down and just do everything the doctor told her to do," said Kanga. "She would ask, 'Why?' or say, 'This doesn't work with my routine.' She has always had some rebelliousness in her. I think that is what keeps these CF patients going. They are the most stubborn kids in the world. They have this will to live that keeps them going."

Despite her hospitalizations,
Breanna was determined to make the
most of high school. She participated
in Future Farmers of America (FFA),
took engineering classes, attended
the homecoming dance and even
made the dance team.

"She came to the clinic one day and I told her, "You're sick. Your lung function is way down," said Kanga. "She said, 'I'm just fine. Let me show you what I did yesterday.' And she showed me one of her routines from a dance competition. She was going 100 miles an hour. You wouldn't know there was anything wrong with her. But she had such bad lung function that we took her straight from the clinic to the hospital."

At the end of her junior year, Breanna's condition took a serious turn. "We had to keep sizing down my prom dress because I was losing so much weight," she said. Two days after prom, she collapsed at a local festival. By the time she arrived at Kentucky Children's Hospital, she was coughing up a large amount of blood. Abnormal blood vessels become enlarged in the damaged area of lung in cystic fibrosis and can develop dangerous bleeding. These vessels had to be blocked off by the interventional radiology team to prevent her from bleeding to death. She slowly recovered after the procedure, but

it seemed to be the start of a more rapid decline in her health.

"My lung function just kept

going down, down, down after that," Breanna said. "All I wanted was to be able to graduate from high school." She did, on time. But soon afterward, she entered a tailspin as her condition progressed to end-stage lung disease. She started skipping breathing treatments as she tried to keep up with college classes and help take care of her brothers. At the boys' 16th birthday party, on December 29, 2017, Breanna was too exhausted to walk; her blood-oxygen saturation level was barely 50 percent. She was rushed to UK Albert B. Chandler Hospital, where she would remain for the next four months.

### Rallying the resources and can-do spirit

The top priority of the care team in the pulmonary intensive care unit (ICU) was to stabilize Breanna's breathing. "She was in a lot of respiratory distress," said Michael Anstead, MD, FCCP, medical director of the Center for Lung Transplant and director of the Adult Cystic Fibrosis Center.

"Over several days, even though she received antibiotics and steroids, her condition got worse, so we placed her on a ventilator." She also had a tracheostomy, a procedure that puts a tube through a hole in the patient's neck so that the ventilator can pump air directly into the windpipe.

Breanna's lungs were too stiff to respond well enough on the ventilator, so she soon was also put on ECMO (extracorporeal membrane oxygenation). This heart-lung bypass treatment uses a catheter to move blood out of the body and into an external pump. The blood circulates through an artificial lung to be scrubbed of carbon dioxide and "recharged" with oxygen and then is sent back into the patient's bloodstream.

ECMO requires aroundthe-clock support from a highly coordinated team, ranging from specialized nurses to physicians to respiratory, physical and occupational therapists. "It can be a

## "E" IS FOR **ECMO EXCELLENCE**

UK HealthCare is one of fewer than 100 ECMO Centers of Excellence in the world. This designation, issued by the Extracorporeal Life Support Organization (ELSO), recognizes programs that demonstrate high-quality standards, advanced education of all staff members and a commitment to exceptional patient care.

With the designation of excellence in neonatal, pediatric and adult ECMO care, UK HealthCare is one of a few centers offering a comprehensive program in extracorporeal life support (ECLS), committed to the needs of patients of all ages in respiratory failure.

ECMO stands for extracorporeal membrane oxygenation. The machine does the work of a patient's lungs.



#### A SPARK FOR LIFE

lifesaving treatment," Dr. Anstead said. (See sidebar.)

It also can have its complications. "ECMO can chew up a patient's blood cells, and so they often need blood transfusions," Anstead explained. "Because of those transfusions, Breanna's body started making antibodies that would have caused complications for a transplant." In early February, she was taken off ECMO to give her body time to purge the antibodies.

Breanna's memories are fuzzy of her first six weeks in the ICU. She remembers "coming to," as she puts it, on February 14 – Valentine's Day. She received a flood of texts from friends, family, even high school coaches sharing messages of love and support. "It was overwhelming to know how many people cared," she said.

Breanna's brothers, Hunter and David, were relieved to see her fully awake. "Hunter asked me, 'Are you going to be okay?'" she remembered. "I told him, 'It's all going to be okay, I promise.' I made a pinkie promise with him that it would be okay."

Anstead had a frank discussion with Breanna about her prognosis. "He told me, 'You won't walk out of this hospital without a new set of lungs," she recalled. He also told her that if she wanted to be on the lung transplant list, she needed to walk. Research shows that transplant patients who can walk 300 feet prior to their surgery have much better outcomes.

Breanna was skin and bones with no muscle tone. Enter physical therapist **Kathryn Gaines, PT, DPT.** It was her job to get Breanna up and moving, one step at time,

"I heard this little voice in my head that said, 'Tell them you're going to be okay – that you're not going anywhere. That's what I did. I told my dad, 'It's going to be okay. I can hold on a little bit longer.'"

**BREANNA JESSIE** 

along the ICU hallways and toward her goal of a lung transplant.

"Every time I went to get her, she'd say, 'I am not going to do it,'" Gaines said. "But she would rally herself and make herself do it." Breanna would crank up the Carrie Underwood song "The Champion" on her phone and force herself to walk a little farther with each session. A chart in Breanna's room documented how many feet she covered each time. "She could see she was making progress," Gaines said. "It was possible; she could do it." She did. And she was put on the transplant list.

On days when Breanna's internal motivation was lacking, Gaines provided some external motivation. "She loves food, so we would bribe her with food," she said with a laugh. The care team learned that her favorites — including Reese's ice cream, chicken fingers and fries, and Mountain Dew — could quickly get Breanna's attention and cooperation.

Another member of Breanna's team who took care to the next level was respiratory therapist **Anne Fitzpatrick, RRT.** "She was always there by my side," Breanna said.

Fitzpatrick monitored
Breanna's ventilator settings. She
provided nebulization treatments
to break apart the mucus. And
when mucus plugged Breanna's
airways, Fitzpatrick "blocked" her,
squeezing a bag valve to manually
force air into her lungs.

"She would work with my breath instead of against it," Breanna explained. "If something wasn't quite right, she'd adjust and it would be perfect."

As a frequent presence in Breanna's room, Fitzpatrick soon became a comforting companion as well, especially during those times when Breanna's family members could not be with her. "I'd keep her company, even on my days off," Fitzpatrick said. "I knew it gave her a calmness she needed."

### "I can hold on a little bit longer."

It was a calm amidst the storm. With each passing week, the care team did their best to keep Breanna strong in body and spirit. One day Fitzpatrick wheeled Breanna outside for a respite from her hospital room. "I wanted her to feel the sunshine one more time in case she didn't make it," Fitzpatrick said. But the sun did not cooperate, and the cool and windy weather quickly drove them back inside.

Breanna's respite from ECMO was over as well. "Her lungs were at the point of failing," Fitzpatrick said. "Her  $\mathrm{CO}_2$  levels got so high that the pressure was causing migraines and making her eyes bulge. She had to go back on ECMO a second time, which is unheard of."

The following week, on April 11, the news came that Breanna

had been waiting for: She had been matched with a donor, a 25-year-old male. "I couldn't believe it," she said. But after preliminary surgery prep, she waited...and waited. Then she was told that the surgeons had rejected the lungs. The transplant was canceled.

"It happens fairly often,"
Anstead explained. "In this case,
some of the blood vessels were
damaged and there would have been
trouble sewing in the donor lungs.
We had to turn down the match."

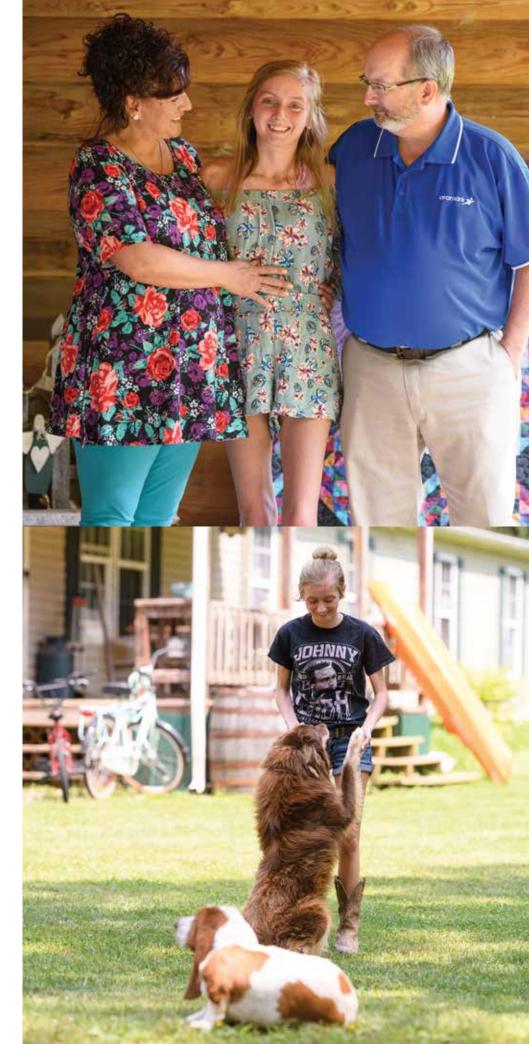
Breanna's family members cried around her bedside. "I heard this little voice in my head that said, 'Tell them you're going to be okay – that you're not going anywhere,'" Breanna said. "That's what I did. I told my dad, 'It's going to be okay. I can hold on a little bit longer.'"

That is all it took – a little bit longer. Two days later, on April 13, Breanna was matched with another donor: a young woman her age and her build with healthy lungs. "This was the perfect set of lungs for someone in Breanna's situation," Anstead said.

This time, Breanna gave herself permission to cry, too. "I was so happy," she said. "My mom and my aunt and I watched through the window as the helicopter flew over." She was quickly wheeled to the operating suite, where the transplant team began the eighthour surgery.

(top) Breanna at home in Olive Hill with parents Debra Jessie and Dave Jessie.

(bottom) Playing with dogs at her grandmother's house, Breanna's newfound health allows her feisty side to come roaring back.





Breanna with a sternum support pillow, signed by her care team, used after transplant of a healthy set of lungs donated by a young woman her age.

## HONORING THE GIFT OF LIFE

Organ donations are the gift of life. When 4-year-old Marco Shemwell died after he was hit by a driver outside a UK football game in September 2018, his parents donated their son's organs, giving several others the gift of life.

In a touching display of love, support and respect, friends, family members and UK medical staff lined the hallway of Kentucky Children's Hospital in an "honor walk" as Marco's parents escorted their son from the ICU to the operating suite.

The "honor walk," the first ever for UK HealthCare, generated such a tremendous outpouring of positive feedback that the Organ Donation and Transplantation Action Committee (ODTAC) has crafted a formal policy for offering honor walks to patients and their families on an ongoing basis.

"We've assembled the policy carefully so that we respect families and staff, protect everyone's privacy, and allow the honor walk to happen in a way that isn't disruptive to regular hospital operations," said **Andrew Bernard, MD**, chief of trauma and acute surgery.

"It is a show of honor, a show of gratitude, and a show of respect for the families who make this generous gift of life," said Dr. Bernard.

#### A SPARK FOR LIFE

### "I have things to do now."

Breanna was expected to sleep for two days after surgery; instead she woke up within hours. "The doctor came in and said, 'What in the world? How are you awake already?'" she recalled. "I told them, 'I'm not tired. I don't need to sleep.' They told me that in order to get out of the recovery room I had to walk. So I did; I walked half of the hallway with my dad."

Her appetite quickly came roaring back. "The day after she got her lungs, she ate a whole plate of chicken, mashed potatoes, and mac and cheese," Fitzpatrick said with a laugh. "I don't know if she chewed it or swallowed it whole. Her whole body was hungry again."

After her transplant, Breanna's care team added new members:

Maher Baz, MD, medical director of lung transplant, would now be her primary physician. And

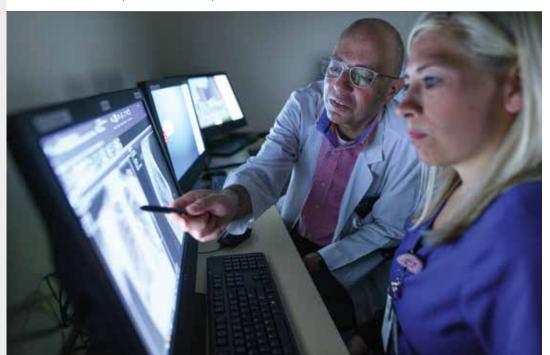
Rachael Serafini, BSN, became her lung transplant coordinator, her first point of contact for all questions and care going forward. They quickly became acquainted with Breanna's feisty side.

"She was on the go after her transplant, ready for the next phase," said Dr. Baz. "She'd say, 'I need to get back on my feet, learn my meds, learn how to take care of myself. I have things to do now.'"

About a week after the surgery, she was taken off the ventilator for the first time in four months. She took her first breath on her own with her new lungs. "It was amazing," she said. "I love country music, but I could never finish a song without getting out of breath. So I sang a whole song, all the way to the end. That was life changing." The song: Carrie Underwood's "The Champion."

She was strong enough to transition to a nearby hotel on May

As a transplant patient, director Maher Baz, MD, (left) is now Breanna's primary physician and Rachael Serafini, BSN, is her point of contact for questions and care.





Breanna at her favorite pizza spot in Olive Hill. The whole community has always rallied behind her and is now delighted by her newfound health.

2 for her last month of medical supervision. Friends came to visit and lift her spirits, especially through some challenges. She contracted MRSA, a drug-resistant infection that is always a concern but especially so for a recent transplant patient. She also suffered a seizure a week before she was to be discharged. But true to form, she persevered, and she was sent home just two days behind schedule, on June 1 – 154 days after she arrived. The next day, she cheered on a close friend at his high school graduation, just as she had promised she would.

Breanna will never have a completely clean bill of health. Her cystic fibrosis continues to affect her digestive system and pancreas. She has developed diabetes, common for CF patients, and now needs to watch what she eats – a tough lifestyle change for someone who has always eaten

"I can play basketball. I can run with my friend's little girls and keep up with them. I can be outside and be around animals and not have to worry anymore. I can get out and live."

**BREANNA JESSIE** 

whatever she wanted in order to gain weight.

She has been hospitalized a few times for rejection and infection. Each time she pushed to be released as soon as possible. "You just have to lay out the bigger picture for her," Serafini said. "The last thing she wants is to go back in the hospital. But if we tell her about the positive results that await if she gives us five days to straighten her out, she can do that."

This spring, Breanna reached the one-year anniversary of her transplant, a major milestone. "She is doing great," said Fitzpatrick, who remains a close friend of Breanna's. "She's a firecracker who won't let anything stop her."

From now on, Breanna's checkups will be fewer and farther between. That is just fine with her because she has people to see and things to do to make up for all those lost years. "I can play basketball," she said. "I can run with my friend's little girls and keep up with them. I can be outside and be around animals and not have to worry anymore. I can get out and live."



FOR MORE PATIENT STORIES, VISIT: UKHEALTHCARE.ORG/DIFFERENCE

For more information about organ transplant, contact UK HealthCare at 859-257-1000, toll free at 800-333-8874, or visit ukhealthcare.uky.edu.

# WINNING THE WRESTLING MATCH WITH **TYPE 1 DIABETES**

At 5 years of age, Max Middleton is 40 pounds of pure childhood enthusiasm, with a zest for life and a passion for WWE wrestling. In corner two, his arch nemesis, Type 1 diabetes.

Big sister and sidekick, Kara, 9, has been fighting alongside Max since she was diagnosed with Type 1 at age 5.

One of their biggest fans, Dad, JC, is also their coach, mentoring them from his own life experience with Type 1 diabetes, diagnosed at age 29.

Mom, Lisa, manages it all, ensuring that everyone has what they need to win a good, clean fight.

In truth, the Middleton family is like any other: school, work, sports and family trips. The only

"One of the hard things can be that they are so normal and do everything normally. It's easy to forget that it's actually a serious disease and you really have to be careful."

LISA MIDDLETON

difference is that Max, Kara, and JC have to take extra breaks for snacks or a dose of insulin.

"At our house, it's almost like I'm the unusual one," said Lisa, who is the only one who does not have diabetes in her family. "But one of the hard things can be that they are so normal and do everything normally. It's easy to forget that it's actually a serious disease and you really have to be careful. A lot of that is the behind-the-scenes work on our end."

### **Achieving 'normal' with diabetes**

Most people see a 5-year-old boy playing with his WWE action figures or hitting a grounder at a tee-ball game. They see a 9-year-old girl serving the volleyball or practicing equitation in her horseback riding lessons. They see a software engineer finishing a 40-mile bike ride, or they see a family taking pictures with Mickey at Disney World.

What most people do not see is the constant mindfulness of carbohydrate ratios and insulin

Wearing insulin pumps and continuous glucose monitors frees both Kara, 9, and Max, 5, Middleton to pursue the activities they love.





# KY DERBY GALA RAISES \$15 MILLION FOR DIABETES CARE, RESEARCH

The UK Barnstable Brown Diabetes Center is able to provide the highest-quality care and make cutting-edge research discoveries thanks to the generosity of Patricia Barnstable Brown, Priscilla Barnstable and their mother, Wilma. Together, they pledged the initial funding for the center in memory of Patricia's husband, David, who passed away from diabetes-related complications in 2003.

Since then, their annual Derby Eve Gala has raised nearly \$15 million to continue supporting the health services and clinical research at Barnstable Brown.



The Barnstable Brown family's annual Derby Eve Gala has raised nearly \$15 million for diabetes care and research. Here with the 2018 check are (from left) Lisa Tannock, MD, Mark F. Newman, MD, Wilma Barnstable, Patricia Barnstable Brown and John Fowlkes, MD.



Diabetes educator Angela Hepner (left) and nurse practitioner Deb Howard follow Kara and Max closely to adjust insulin doses or manage the disease through an illness.

#### WINNING THE WRESTLING MATCH WITH TYPE 1 DIABETES

dosages, circumventing the dangers that can come with a common stomach bug, or monitoring the normal but frequent blood-sugar fluctuations children can experience.

"We're sometimes up every half hour to an hour to keep an eye on the kids overnight," Lisa said. "They never do the same thing either; one might be high and need insulin and one might be low and need food. JC is super supportive, and he and I alternate getting up every night to check on the kids and dose them if they need it. Neither of us has slept more than a couple of nights in a row in almost four years."

### **Barnstable Brown team offers critical support**

Whether Lisa and JC have a concern about abnormal blood sugars, one of the kids gets sick, or they just need comfort, the team at the UK Barnstable Brown Diabetes Center is there to support them.

"Our health care team has been critical," Lisa said. "They respond to emails immediately, they are available for any issue, and both Angela and Deb always reassure us that we're doing a good job."

Every three months, Max and Kara see **Deb Howard**, **APRN**,

MLDE, CDE, and diabetes educator Angela Hepner, MEd, MLDE, CDTC, CDE, LD, RDN.

"We download their pumps and their glucose monitors to see how the last three months have been going and then make insulin dose changes if we need to based on the data or their growth," Howard said.

In between visits, Hepner is there for whatever the Middletons might need. "I spend a lot of time on email or the phone adjusting blood sugar doses or managing the disease through an illness," she said. "Sometimes it's a matter of dealing with insurance companies and trying to make sure they have everything they need or are not having to pay for duplicate or triplicate of things when one would do for all of them."

The overarching goal is to help the Middleton family feel empowered to live life as normally as possible and not let diabetes be a barrier to anything.

"Angela and Deb are really important for handling those things that I just can't fix on my own," Lisa said. "It seemed like at one point or another, both my kids' insulin dosage requirements skyrocketed overnight. I was

nervous and thought something was wrong, but Angela and Deb said it was normal and expected, and they showed us how to fix it. They really have become like our extended family."

### Don't let diabetes take anything away

JC learned long ago that managing Type 1 diabetes means much more than carbohydrate calculations and timing of insulin dosages. It is about perseverance and a positive mindset.

"Don't give up, because if you do, that's the first step to letting diabetes win," he said. "Don't let diabetes take something away from you. For me that was cycling. I can go for a 30- to 40-mile ride and come back and all my stress is gone."

Cycling is also integral to keeping JC's blood sugars balanced. He and Lisa have raised their kids to understand the importance of and enjoy staying active. Kara has horseback riding and volleyball. For Max, it is basketball and playing with his WWE wrestlers.

"He has channeled this into a positive," JC said of Max. "He is constantly trying to 'fight' "Our health care team has been critical," Lisa said. "They respond to emails immediately, they are available for any issue, and both Angela and Deb always reassure us that we're doing a good job."

LISA MIDDLETON

with me, his sister or one of his wrestling dolls, and jumping off the furniture. If you didn't know he was diabetic, you would never guess it."

The Middletons' positivity, dedication to a healthy lifestyle and determination to live life on their terms are all part of taking responsibility for their Type 1 diabetes, which is essential, JC said.

### Embrace technology, empower yourself

Technology makes it a lot easier to handle the responsibility of diabetes. For the first six months after Max's diagnosis, regular finger sticks monitored his blood sugar and needle injections delivered the insulin his pancreas is unable to produce. It added a

lot of hardship to managing the disease in a 20-month-old child who was unable to understand what was happening.

Today, both kids use an insulin pump and a Dexcom continuous glucose monitor. The Dexcom records their blood sugar levels every five minutes and sends an alert to Lisa and JC's cellphones if those levels are off-balance.

"My children got the pumps first, and I saw that they were able to continue to do everything and didn't have to carry with them a bag that's got insulin, syringes and alcohol swabs – all of this extra stuff that I was packing with me all of the time," JC said of the decision to use an insulin pump himself. "With a pump, it's all self-contained; it gave me back so much freedom."

Insulin pumps mimic the pancreas by delivering a continuous low dose (basal rate) or a shortacting higher dose of insulin as needed through a catheter under the skin. Dosages are easy to adjust in order to accommodate the kids' varying activity level, behavior changes and food intake. JC, Kara and Max rotate their pumps to a new position every three days,

# UK HEALTHCARE NATIONALLY RANKED IN DIABETES CARE

In 2018, U.S. News & World
Report ranked UK HealthCare
among the Top 50 diabetes
and endocrinology programs
in the nation. Patients from
across Kentucky come to the
UK Barnstable Brown Diabetes
Center for the

comprehensive care they need to manage their disease, including consultation with expert diabetes specialists, coordination of care for diabetes complications, screening and management, and patient education plans.

More than 20 providers and nearly 15 diabetes educators are dedicated to relieving Kentucky of its status as the state with the fifth-highest incidence of diabetes nationwide. In 2017, 15.3 percent of the adult population, nearly 600,000 people, were living with the disease, up from just 6 percent in 2000. Additionally, as many as one in three adults in Kentucky may have pre-diabetes.

A leader in diabetes prevention, education, research and care, Barnstable Brown helps more than 7,500 adult patients and 2,500 pediatric patients each year. The state-of-the-art clinic space houses an on-site pharmacy, ophthalmology and optometry services, laboratory testing, ultrasound, and radiology.



WINNING THE WRESTLING MATCH WITH TYPE 1 DIABETES

Brown Diabetes Center. He and sister Kara (background) visit the center every three months.

significantly decreasing the number of uncomfortable needle sticks.

"The pump isn't for everybody; some people do very well on the injections," Hepner said. "But for some of our younger kids or really small body-type kids, we just can't get the dosing otherwise. With the pump, we can dose in hundredths of a unit rather than half- or whole-unit increments, so that makes a big difference in being able to meet their needs."

### The kids are OK

Hepner and Howard have supported the Middletons from the day Max was diagnosed at Kentucky Children's Hospital, offering guidance through the initial learning curve, answering every question, assuaging every fear and filling in the gaps when motivation runs low. They have helped JC, Lisa, Max and Kara navigate every down and celebrate every up.

"Diabetes is a lot of work, and there are times it's not fun and it's frustrating, but the good news is your child can be healthy and normal," Hepner said. "You just have a few extra steps to make that happen. Kids are resilient. If you give it all you've got, they're going to be OK." Kara is OK. "I can still do everything other kids can do even though I have Type 1," she said. "I have really nice friends at school. I love sports like volleyball, soccer and horseback riding. I like watching Netflix. I like playing with my brother."

Max is certainly OK, too. "Miss Deb and Miss Angela are super nice," he said. "I like that they work there [at Barnstable Brown]. I can run around and play with my guys [WWE action figures]. I like that we eat sugar and defeat sugar. When I'm high, I dose. When my Dexcom beeps, I'm too low, so I eat. When I crash, I eat lots and lots of candy."

The Middletons, Hepner and Howard work as a team toward one goal: healthy, happy children who feel confident that they can live their lives to the fullest, and that no matter how many rounds they go up against diabetes, they always come out the champions. MAD



FOR MORE PATIENT STORIES, VISIT: UKHEALTHCARE.ORG/DIFFERENCE
For more information about diabetes care, contact UK HealthCare at 859-257-1000, toll free at 800-333-8874, or visit ukhealthcare.uky.edu.

## **HOW ARE THEY DOING?**

We checked in with patients featured in the 2018 issue.



#### **PATRICK GOODING**

Berea, Kentucky

Patrick Gooding was the first patient at UK HealthCare to be treated with implanted nerve stimulators. During a 2016 procedure, two stimulators were placed on his spinal cord to help dull nerve pain. All was well until December of 2018. While undergoing a full shoulder replacement, one of the implants suppressing his pain was damaged and guit functioning. Patrick writes, "When it was brought to the attention of neurosurgeon Dr. Steven Grupke, he wasted no time in securing a new device and working to schedule surgery within three weeks." The replacement of the damaged stimulator went as planned, and the use of spinal cord stimulation continues to be life changing for Patrick. "I have spoken with many individuals concerning my positive experience. I tell people who are experiencing nerve pain to never lose hope."

#### **JADE WATTS**

Harrodsburg, Kentucky

In 2016 Jade Watts was diagnosed with infant botulism, a rare condition that affects approximately 100 children each year. She was six months old at the time. After her care at Kentucky Children's Hospital, she has recovered fully. Today, Jade is busy keeping up with her big sisters and preparing to become a big sister herself. Her mom writes, "She adds innumerable laughs and indescribable joy to our family. Jade is as happy and healthy as any 2-year-old little girl could be. She has made a full recovery."



#### JOHN MCLARNEY, MD

Lexington, Kentucky

Dr. McLarney suffered an acute heart attack in 2016 while working at UK Chandler Hospital. He credits the work of John Gurley, MD, and the whole team in the cardiac catheterization lab, who were able to stabilize him after he went into ventricular fibrillation. "I am still so thankful the heart attack happened at work. They are the reason I am here today." Since then he has been staying active and eating healthier. McLarney still works full-time as medical director of the preoperative clinic and is a course director for a fourth-year medical student class. "My faith and perspective grew and changed that day, and I have been trying to live that out ever since."

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### CALLING AN ALL-OUT BLITZ ON SKIN CANCER



### **Melanoma brings Paschal to Markey**

Sharon Martin, RN, remembers the first time she saw the 6'3", 284-pound Paschal at Markey. "Here was this huge young man wearing a UK sweatshirt. When he told me he played football, it hit me. I said, 'You're defensive line. You're the Josh who's number 4.' " The oncology nurse nicknamed Giggles for her ability to make patients laugh is a Kentucky Wildcat season ticket holder. She and Josh have talked sports ever since.

Josh said Markey staff, from the greeters at the front door to nurses like Martin, have helped him remain upbeat through his cancer treatment because of their compassion and positive attitudes. Just as important has been his support team of family, friends and teammates, and his faith in God.

The college student's cancer journey began in July 2018 when he noticed a small spot on the bottom of his right foot. He thought it was a blood blister. The football team's athletic trainer immediately sent him to a dermatologist.

Biopsy results were not good. Josh had a rare and aggressive form of skin cancer, acral lentiginous melanoma (ALM). Two days after the July 16 diagnosis, he was in surgery.

"It was a shock," Josh said.

He had appeared in all 13 football games his freshman year, receiving accolades for his outstanding play.

A 19-year-old sophomore, he was in the best physical shape of his life.

Now he would be sidelined.

"I kept thinking this can't be real," he said. "Nobody talked about skin cancer when I was little. I thought it was something I didn't have to worry about because I'm African American." "Fortunately, Josh, his trainer and his family all focused on the problem and took quick action," said **B. Mark Evers, MD**, director of the Markey Cancer Center, who performed Josh's surgeries and worked with a team of other specialists to develop a treatment plan.

While ALM accounts for just 2 to 3% of all melanoma cases, its incidence is higher in people of color, particularly in blacks, according to research published in the *Journal of the American Medical Association*. It appears most often in areas unaffected by sun exposure, such as the soles of the feet, palms of the hands and under the nails.

Possibly, because of the misconception that those with dark skin cannot get skin cancer, African Americans have the highest melanoma death rate of any racial group even though Caucasians are 20 times more likely to receive a melanoma diagnosis.

### Faith, family provide support

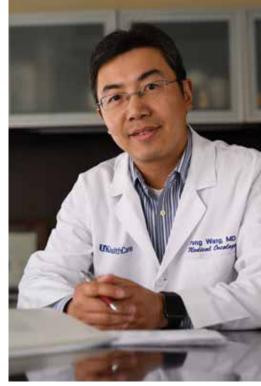
Armed with a notebook full of questions, LaTauna Paschal, Josh's mother, flew to Kentucky with her husband and other family members from their hometown of Olney, Maryland, before the first surgery.

"When you get a diagnosis like that, you're numb," she said. "But

(opposite) No. 4 Josh Paschal, a defensive lineman, played in three UK Football games in 2018 after being diagnosed with a malignant melanoma that summer.

B. Mark Evers, MD, (top) and Peng Wang, MD, (bottom) were the surgical and medical oncologists who directed Paschal's treatment team.







## **LEADING CANCER CARE**IN THE COMMONWEALTH

Patients diagnosed with cancer want the most advanced and best care. That includes the newest technology, access to clinical trials, physician experts and a compassionate team that will support them every step of the way. That place is UK Markey Cancer Center. But don't take our word for it. Industry authorities have taken notice and recognized Markey for providing outstanding care.



• Markey is the only National Cancer Institute (NCI)-designated center in Kentucky and one of only a handful in the U.S. As an NCI facility, Markey Cancer Center is recognized for delivering leading-edge cancer treatment and having a robust research program, offering clinical trials to patients that aren't readily available elsewhere. To receive the

designation, a cancer program undergoes a rigorous review and site-visit process that assesses everything from the level of scientific excellence to safety protocols to community outreach.

• Markey is designated as one of the Top 50 Cancer Centers in the nation by U.S. News & World Report.



- UK Chandler Hospital, home of the Markey
  Cancer Center, was again named one of
  the nation's 100 Hospitals and Health Systems with Great
  Oncology Programs by Becker's Hospital Review in 2018.
  The list acknowledges hospitals that are innovators in cancer
  treatment and research, investing in the growth of their
  oncology programs.
- UK HealthCare, the health system that includes the Markey Cancer Center, received the 2018 Rising Star Award from Vizient, the nation's largest health care performance-improvement company. The award is based on exemplary performance in safety, mortality, clinical effectiveness, efficiency, patient centeredness and equity of care.



• UK HealthCare has Magnet status - the highest institutional honor for nursing excellence from the American Nurses Credentialing Center's Magnet Recognition Program.

### ALL-OUT BLITZ ON SKIN CANCER

before I could ask a single question, Dr. Evers and the entire team answered and explained everything."

After surgery, tests showed some cancer cells remained at the edge of the tissue that was removed. To get "clean margins," Josh had a second surgery on August 1.

"You think about Josh being a football player with a possible pro career ahead of him," Evers said. "But if you start to cut corners, you're missing the big picture of dealing with the cancer. Everyone was on board with going back to the operating room."

### Leading-edge cancer care

Afterward, with no signs of cancer remaining, a plastic surgeon joined Evers on August 24 and performed a skin graft, taking skin from Josh's calf to repair and replace the tissue on the sole of his foot.

As the only National Cancer Institute-designated cancer center in Kentucky, Markey offers the most technologically advanced and sophisticated care available. (See Leading Cancer Care in the Commonwealth sidebar for more details.)

Five days after his skin graft, Josh began immunotherapy, which boosts the body's own immune system to fight disease. Once a month he receives an infusion of the drug Opdivo. Approved by the FDA in 2018 for certain patients with melanoma, Opdivo significantly lowers the risk of recurrence. His last infusion takes place in September.

"Immunotherapy has completely changed the treatment of melanoma," said **Peng Wang, MD**, the Markey



(Left) Josh Paschal in a photo taken for UK Football. At the time of diagnosis, he was in the best physical shape of his life. Cancer "was a shock," he said. (Right) "Every time I come in," said Josh, "There is joy in the room. It really lifts me up." Here Markey nurse Leila Scandrani, RN, monitors the immunotherapy Josh receives that boosts his immune system to fight the cancer.

medical oncologist leading Josh's post-surgical treatment. "Ten years ago it was a sad situation. We had no medications to offer. Now we have multiple options and sometimes have to debate which one to choose first."

To guide the decision-making process, Josh's case was brought to Markey's Melanoma Tumor Board, which consists of medical, surgical and radiation oncologists, as well as pathologists. It meets every other week, bringing the best minds together to discuss how to care for individual patients.

"I'd never heard of immunotherapy," Josh admitted.

"It was a shock. I kept thinking this can't be real. Nobody talked about skin cancer when I was little. I thought it was something I didn't have to worry about because I'm African American."

JOSH PASCHAL

Throughout his treatment, he experienced only a few side effects and occasionally missed classes for appointments. The honors athlete, majoring in family sciences, maintained a cumulative GPA of 3.469 and earned a 3.5 last semester.

"Every time I come in," said Josh, "I'm surrounded by positive people. There is joy in the room. It really lifts me up."

His mother agrees. "I can't imagine Josh being treated anywhere else. They made us feel like family. Dr. Evers gave us his cell number and told us to call at any time." It's something he does for all of his patients.

The Markey culture is to do everything possible to make patients and their families feel comfortable, said **Deb O'Nan, RN**, who cared for Josh during his immunotherapy treatment. "We love our patients and we do what we can to reassure them. We work to make this a warm environment. And I always let them know that I may

not have the answers, but I know how to find them."

For Leila Scandrani, RN, seeing a young, active patient like Josh hits home. "That could be my brother, my family," she said. "Josh is always kind, humble and appreciative. Most of our patients are. It's the little things we can do, like explaining the plan for their treatment that day, talking to them about their interests, pulling the shades if the room is too bright, that make a difference."

#### **Back to the game**

Throughout his treatment, Josh continued to work out and went through intensive rehabilitation.
The entire Markey team was thrilled when he returned to the game on November 17, 2018, where he made a tackle that contributed to the team's win against Middle Tennessee.

"I was yelling and screaming and jumping," Martin said. "And when he came in the next time and I told him I saw that hit, he just grinned."



The Paschals live in Maryland, but mom LaTauna and father Clayton have been at their son's side through diagnosis, surgery and treatment. "I can't imagine Josh being treated anywhere else," said LaTauna.

### ALL-OUT BLITZ ON SKIN CANCER

Josh also played in the last regular season game and in the Citrus Bowl win against Penn State. The Wildcats ended the season 10-3, their best record since 1977.

The football player invited Evers to join his family at UK's annual CATSPY Awards, where UK athletes are recognized for their achievements. Josh won the Heart of a Wildcat award.

"It was very special," said
Evers, another season ticket holder.
"With any cancer diagnosis, we
remain hyper vigilant. But with his
support, his strong faith, his hard
work, and the help of our amazing
group at Markey, cancer is just
going to be one chapter in the book
of Josh Paschal." MAD



### FOR MORE PATIENT STORIES, VISIT: UKHEALTHCARE.ORG/DIFFERENCE

For more information about cancer services, contact UK HealthCare at 859-257-1000, toll free at 800-333-8874, or visit ukhealthcare.uky.edu.

### **OUTPATIENT CANCER SERVICES EXPAND**

A new collaboration between UK HealthCare and Lexington Clinic is expanding outpatient access to exceptional cancer care. It's a significant step in the effort to remove Kentucky from its rank as the nation's leader in cancer deaths.

The partnership includes medical oncology and infusion services at UK Markey Cancer Center at Lexington Clinic, 1221 South Broadway. In addition, radiation therapy, medical oncology and infusion services coordinated with the UK Markey Cancer Center are offered at the clinic in Richmond, 858 Eastern Bypass.

The affiliation between two organizations that both have had a long commitment to improving the health of the community also brings enhanced specialty pharmacy and support services to cancer patients and survivors.

Cancer patients already being seen at Lexington Clinic will continue to see their physicians there. However, if it is determined that additional cancer services, more advanced care or clinical trials would be







of benefit, they may need to visit the UK campus. If so, their medical oncologist will still oversee their care and be part of the treatment team. **For more information**, call **859-258-4673**.



Radiologist Michael Winkler, MD, demonstrates the Mixing Cup application he co-created to help patients easily see and understand their medical problem.

### **SMART ART**

## PUTTING MEDICAL 3D ANIMATIONS IN PATIENTS' HANDS

Smartphones can pull up weather maps, full-length movies and GIFs galore. Why not 3D animations of medical images? It was a problem in need of a practical yet elegant solution – a problem custom-made for the unique expertise of UK radiologist **Michael Winkler, MD**, of the Gill Heart & Vascular Institute.

Winkler majored in sculpture as an undergraduate before entering medical school. His highly aesthetic perspective informs his work as a radiologist. "Radiology is an artistic process," he explained. "You perceive and then transmit your observations in a form that you can share to enlighten others."

However, the file size of most medical images was too large to transmit by email or share on a handheld device. Winkler collaborated with computer engineering student Leon Lin to develop an innovative solution called Mixing Cup. This open-source application compresses and formats the images into small enough files to email and display sophisticated 3D animations easily on a handheld device. Patients can see their medical problems illustrated in stunning detail on a phone or tablet.

It is a giant leap forward from the hastily scratched diagrams many physicians draw to help explain a patient's condition.

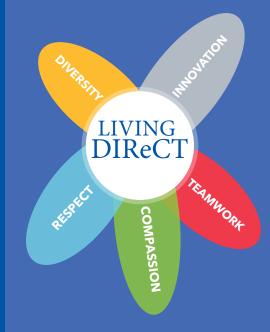
"When a patient sees something as polished as the Mixing Cup animations and is told, 'This is your body, and this is what we are going to do,' they'll recognize that this is obviously advanced technology and advanced care," Winkler said. "It will give them a feeling of security that the rest of their care will be just as professional."

### LIVING DIReCT

# DIVERSITY INNOVATION RESPECT COMPASSION TEAMWORK

The Mixing Cup app is a great example of the UK HealthCare LIVING DIReCT value - Innovation. Kudos to Dr. Winkler for seeing an opportunity to improve the clinician's ability to explain a patient's medical problem. His solution was both innovative and patient centered.

Is there a problem you might solve?



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# THE LATEST AT UK HEALTHCARE



### UK HEALTHCARE RECEIVES RISING STAR AWARD

Following the 2018 Vizient Quality and Accountability Study, UK HealthCare received the Rising Star Award in recognition of its significant improvements in year-over-year rankings. UK HealthCare ranks among the Top 25 performers in the national study.

The study identifies exemplary performance among 99 comprehensive academic medical centers in safety, mortality, clinical effectiveness, efficiency, equity of care and patient-centeredness.



### Meds to Beds program receives Gage Award honorable mention



The Gage Award recognizes achievements in quality improvement and population health. The

Meds to Beds program, which delivers discharge prescriptions to patients at no additional cost prior to discharge, has

demonstrated success in reducing all-cause readmission rates, as well as increasing patient compliance



and adherence to their prescription regimens. Visit ukhealthcare.uky.edu/pharmacy-services/patients to learn more.

### NEW SIMULATION CENTER OFFERS ADVANCED TRAINING OPPORTUNITIES

The UK HealthCare Simulation Center is a state-of-theart multidisciplinary training and research facility that enhances patient safety by educating students and providers with the most advanced simulation technology and experiential learning.

### Facilities include:

• Three patient rooms, an intensive care unit, an operating room and a flex room with high-fidelity patient simulators for complex clinical-scenario training.

- Debriefing rooms for private, psychologically safe reflection and self-critique.
- A multipurpose room for individual and team-based skills training and medical-exam practice.

For additional information, visit ukhealthcare. uky.edu/uk-healthcare-simulation-center or contact Jenny Sutton-Amr, administrative director, at ukhcsimcenter@uky.edu.





## EXPRESSIONS OF **GRATITUDE**

Each year we are humbled by the thousands of patients who choose UK HealthCare and Kentucky Children's Hospital for their medical care.

The important life-saving, life-changing work of our physicians, researchers and other health care professionals would not be possible without philanthropic support from our community. Heartfelt gifts given from generous individuals are essential to help our team conduct research, deliver world-class care to all patients, and train the next generation of future leaders in our field.

If you would like to express your gratitude for the great care you or a loved one received at UK HealthCare or Kentucky Children's Hospital, please visit **ukhealthcare.org/give** to make a gift to the area of health care that has made an impact on your life.

To learn more about opportunities to give back, or to make a gift via check or credit card, please call 859-323-6306.

### THE LATEST AT UK HEALTHCARE

### UK HealthCare expands outpatient care through Lexington Surgery Center



UK HealthCare has expanded outpatient care available to residents of the Bluegrass and is increasing surgical capacity through a joint venture for Lexington Surgery Center.

UK HealthCare, now the majority owner, entered the joint venture with Surgical Care Affiliates, LLC, earlier this year. SCA continues to manage the facility, which will soon move to a new facility at the Turfland development on Harrodsburg Road.

Moving routine surgical services and outpatient procedures to Lexington Surgery Center improves access and cost for patients, while opening up UK HealthCare's main-campus operating suites for more complex and advanced subspecialty procedures. Currently, UK specialists in pediatric ear, nose and throat; plastic surgery; ophthalmology; orthopaedics; pain management; oculoplastics; pediatric dentistry and gastroenterology are conducting surgeries for cataract removal, adenoidectomies, carpal tunnel procedures and more at Lexington Surgery Center.

### Provider ratings a valuable tool for patients

To help patients with their decision-making process, UK HealthCare publishes star ratings and reviews of its providers who care for patients in the clinic setting.

When people share their health care experiences, it can be a valuable tool to

help other patients feel more confident in choosing the right provider.

We survey patients using the Clinician and Group Consumer Assessment of Healthcare Providers and Systems (CG CAHPS) survey developed by the Agency for Healthcare Research and Quality (AHRQ) for these ratings.

The provider star ratings and reviews can be found on the UK HealthCare website at UKHealthCare.uky.edu and by clicking the link for "Find a Doctor."

## UK HEALTHCARE IS NO. 1 HOSPITAL IN KENTUCKY

For the third consecutive year, the 2018 U.S. News & World Report's Best Hospitals in America rankings named UK HealthCare the No. 1 Hospital in Kentucky and the Bluegrass Region.

Additionally, four major health care areas achieved Top 50 national rankings: diabetes and endocrinology; cancer; ear, nose and throat; and orthopaedics.

UK HealthCare also ranked as high-performing in five adult specialties: geriatrics, nephrology, neurology and neurosurgery, pulmonology, and urology. Six common adult procedures and conditions were rated as high-performing as well: heart bypass surgery, heart failure, colon cancer surgery, hip replacement, knee replacement and lung cancer surgery.





# WE ARE PROOF

# DELIVERING THE POWER OF ADVANCED MEDICINE

Our current advertising campaign - We are Proof - highlights stories of passion, perseverance, and courage told by UK HealthCare physicians, staff, patients and families. We prove the Power of Advanced Medicine every day.

### DO YOU HAVE A STORY TO TELL?

To share your story or to read more, visit proof.ukhealthcare.com.

Cancer nurse Rebecca Heichelbech has become like family to middle school choral teacher Damon Greene





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