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Historic Separation of the Mata Conjoined Twins

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Elysse Mata gently kisses her daughters, Knatalye Hope and Adeline Faith Mata, before the conjoined twins are christened.
When the world knocks at your door, answer boldly

Mark A. Wallace | President and Chief Executive Officer

Texas Children’s is no stranger to audacious moves.

When I came to Texas Children’s Hospital in 1989, I had big hopes for what was then a small, yet promising organization. We were, primarily, a regional hospital. We had just over 200 beds and one building that was about 350,000 square feet. And we had about 1,400 employees. But we also had a vision that was much bigger than our humble beginnings would suggest.

In the mid-1990s Texas Children’s debuted Texas Children’s Pediatric Associates, the nation’s largest primary care network, and Texas Children’s Health Plan, the first pediatric HMO in the U.S. We followed those first significant steps in the 1990s with a number of advancements within our clinical programs, and we recruited some of the world’s most gifted physicians and scientists.

We’ve also had extraordinary expansion of our facilities. In the last two decades, Texas Children’s has added more than 10 million square feet of space to the main hospital campus and in several community expansions, like Texas Children’s Hospital West Campus and Texas Children’s Hospital The Woodlands, set to open in 2017. This growth represents a dedicated and consistent investment in the future of pediatric health care and in the local, regional and national communities. As health care has evolved, Texas Children’s has changed exponentially in size and clinical programs to meet the complex needs of the babies, children and women in our care.

We now have a workforce of 13,000 staff and employees and provide care during more than 3.6 million patient encounters each year. We are an international referral center for families worldwide seeking hope and advanced, comprehensive diagnoses, treatment and care.

That’s why we must make bold, assertive moves, like building our new Special Isolation Unit. This state-of-the-art space has been designed and equipped with the most advanced approaches to bioccontainment and care for children with highly contagious infectious diseases.

Our investment in our programs and facilities is also an investment in our mission. It means that we can continue to be the court of last resort for so many, like the Mata conjoined twins, for whom we began care while they were still in their mother’s womb.

The demand is ever increasing, and we are responding as we always have — strategically and decisively. So now, we’re expanding right in the heart of the world’s largest medical center — the Texas Medical Center — to grow the facilities and services of the Texas Children’s Hospital main campus.

We’ve embarked on a nearly $1 billion expansion — and launched our $475 million Promise Campaign — to reinvest in the programs needed by the most critically ill patients, primarily in the critical care units, operating rooms, Heart Center, Emergency Center, and in many of the diagnostic and therapeutic services offered by the hospital.

Our 19-floor, 640,000-square-foot expansion will house 130 beds for pediatric and cardiovascular intensive care, new operating rooms with advanced technology, and a new facility for Texas Children’s Heart Center. Our expansion also includes the renovation of our Emergency Center.

We feel a moral responsibility to the patients and families who come to Texas Children’s doorstep, and our physical and programmatic growth helps us advance our 60-plus-year mission of creating a healthier future for children throughout our global community.

We are driven to ensure we have the quality, capacity and staff to accommodate every patient who needs to come here. It means we can continue to deliver on our promise to make Texas Children’s one of the best places possible to give and receive care.

READ MORE FROM MARK A. WALLACE ON HIS BLOG AT ONTHEMARK.ORG.
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IN BRIEF

The Center for Vaccine Development awarded grant to develop therapeutic vaccine for Chagas disease

The Sabin Vaccine Institute and Texas Children’s Hospital Center for Vaccine Development, also known as the Sabin Product Development Partnership (Sabin PDP), received a grant of $1.8 million from the Robert J. Kleberg, Jr. and Helen C. Kleberg Foundation. The Sabin PDP is a major research component of the National School of Tropical Medicine at Baylor College of Medicine.

The grant will fund accelerated development of the first therapeutic vaccine for Chagas disease in humans in a development program under the direction of Peter Hotez, MD, PhD, Texas Children’s Hospital endowed chair in Tropical Medicine.

“Chagas has become a serious health issue, especially for the population of South Texas,” Bottazzi said. “Thanks to the support and confidence of the Robert J. Kleberg, Jr. and Helen C. Kleberg Foundation, we will be able to speed the research and development needed to create a vaccine for Chagas.”

Chagas disease is considered one of the five neglected parasitic infections in the United States, with tens of thousands of cases in Texas alone. The disease is caused by parasitic microorganisms known as trypanosomes that can destroy heart tissue leading to a condition called Chagasic cardiomyopathy. Insect vectors — triatomines, or blood sucking bugs, which are widespread throughout Texas — transmit the trypanosome parasite.

Of those infected by Chagas, 20 to 30 percent will develop Chagasic cardiomyopathy, which can cause heart failure and sudden death. In addition, a large number of pregnant women also are infected with Chagas disease, causing thousands of cases of congenital infection.

Chagas disease is also a veterinary problem in Texas, especially among dogs in South Texas. The successful development and testing of a therapeutic vaccine will be instrumental in improving thousands of lives and will save Texans hundreds of millions of dollars in health care costs.

Dormans sets sights high for Orthopedics Department

Chief of Orthopedics John Dormans, MD, has joined the team, along with two clinical fellows and one research fellow. This summer, Dormans anticipates hiring as many as eight new orthopedic surgeons at the Texas Children’s main campus and corresponding support for Texas Children’s Hospital The Woodlands and Texas Children’s Hospital West Campus. A more robust staff will allow the Orthopedics Department to accommodate the requests it currently gets from patients and families across the region, throughout the U.S. and across the globe. It also will position the department for tremendous growth in both its general practice and subspecialty areas.

A key element to the department’s growth is gaining more access to existing clinical space and operating rooms on the hospital’s main campus. Completion of Texas Children’s Hospital The Woodlands in 2017 and the new inpatient care tower currently under construction will help.

Another aspect of operations Dormans is focusing on is technology and getting the latest and greatest tools to aid his staff in doing the best they can to help the patients who seek expertise from his department. One such piece of equipment recently acquired is a device called an EOS system that allows the department to provide state-of-the-art low X-ray dose imaging for patients with scoliosis and leg length issues.

Ultimately, Dormans said he wants Texas Children’s to be the place to go to find answers for all pediatric musculoskeletal problems. With more than 20 physicians and advanced practice providers treating everything from minor fractures to complex disorders, the department is on the right track.

“’There are a lot of exciting things coming to fruition and many more to come,’ Dormans said. ‘The sky is the limit.’"
State selects Texas Children’s Health Plan to provide better health care coverage, access for children with special needs

On October 1, the Texas Health and Human Services Commission announced Texas Children’s Health Plan had been selected as a health plan provider in the state’s STAR Kids program. STAR Kids is a managed care program that provides health coverage to children and youth with special health care needs.

The STAR Kids program will go into effect November 1, 2016, and will provide benefits such as prescription drugs, hospital care, primary and specialty care, preventive care, personal care services, private duty nursing and durable medical equipment and supplies.

“Selection of the Health Plan for this program is a tremendous capacity, our ability and our passion for children in Texas,” said Christopher Born, president of Texas Children’s Health Plan. “STAR Kids will advance our efforts to extend care to the special needs patient population with a new and improved paradigm, creating a better model of care. This is a great day for children in Texas.”

Children and youth age 20 or younger who receive Supplemental Security Income Medicaid, are enrolled in the Medically Dependent Children Program, or receive services through 1915(c) waiver programs will receive a variety of services through the STAR Kids program. Children, youth and their families will choose among a handful of STAR Kids health plans with the option to pick one that best suits their needs.

The state’s selection of Texas Children’s Health Plan for STAR Kids is expected to bring about 40,000 new members into the Health Plan. In anticipation, more than 400 new employees will be hired to manage the additional cases.

“Our case managers will help these members through the process and through the system, removing barriers,” said Kristen Cover, marketing director of Texas Children’s Health Plan. “The families will have experienced care managers — many of whom will be nurses — to assist them and be a support system for the whole family. The parents will no longer be alone in managing their children’s cases.”

Texas Children’s Health Plan was founded in 1996 by Texas Children’s Hospital. The Health Plan was the nation’s first health maintenance organization (HMO) created just for children, and it covers kids, teens, pregnant women and adults. There are now nearly 400,000 members in Texas Children’s Health Plan.

Fernando Stein, MD, has been elected president of the American Academy of Pediatrics (AAP). This is the first time in the AAP’s 85-year history that a pediatrician from Texas has been elected to this post.

As president of the AAP, Stein will represent all pediatricians and subspecialists across the country and ultimately serve as Texas Children’s voice on national issues impacting pediatrics and the health and safety of the millions of patients and families we serve.

“Dr. Stein brings enormous vision, wisdom and experience to the presidency of the American Academy of Pediatrics,” said Texas Children’s Physician-in-Chief Mark W. Kline, MD. “The Texas Children’s family could not be prouder or more pleased to have one of its own in a leadership role for this great organization.”

As a critical care physician at Texas Children’s and a faculty member in the Department of Pediatrics at Baylor College of Medicine for more than 30 years, Stein has dedicated his career to the care of children surviving critical illness and technological dependency. He has been extremely active in global advocacy for children in impoverished regions of the world and in the integrated management of childhood illness.

Stein is one of the founding members of the AAP Section on Critical Care and serves on several AAP subcommittees, where he has been recognized for his extraordinary service and commitment to children.

“I am honored for this privilege to serve the AAP in this capacity,” Stein said. “I have a deep understanding and appreciation for the shareholders of this organization, and my message to shareholder members and colleagues is one of a clear commitment to them, to our traditions of scientific inquiry, altruism and to challenge the status quo.”
IMPROVE THE CARE and the
RANKINGS FOLLOW

U.S. News’ Best Children’s Hospitals rankings help raise national level of pediatric health care

By Ina G. Fried

It’s one of parents’ worst fears — their child has a complex or life-threatening illness. How do they decide where to go for the comprehensive care their child needs?

Over the years, the U.S. News & World Report Best Children’s Hospitals rankings have helped thousands of parents identify top sources of care for children with the most difficult medical problems. And Texas Children’s Hospital has consistently been among them.

On the 2015–16 Best Children’s Hospitals Honor Roll, which recognizes pediatric centers that are highly ranked in multiple specialties, Texas Children’s, working closely with academic partner Baylor College of Medicine, ranked no. 4 in the nation for the fifth consecutive year. It is the only children’s hospital in Texas on the Honor Roll.

“We’re rightfully proud of the great work that Texas Children’s does day in and day out on behalf of sick children and their families, but we know we have room for improvement,” said Texas Children’s Physician-in-Chief Mark W. Kline, MD. “To the degree that the U.S. News survey can help us develop a blueprint for being the world’s best and highest quality pediatric health care institution, we are pursuing that.”

In a process that has become increasingly rigorous and data driven, the U.S. News rankings enable hospitals to look in the mirror and scrutinize themselves.

“Do we like the reflection? Are we as good as we think we are?” asked Angelo P. Giardino, MD, PhD, senior vice president and chief quality officer at Texas Children’s. “In many cases, we are, and we’re thrilled because we are a really great children’s hospital. But there are opportunities where we look in the mirror and we say, ‘We could really do that better’.”

RANKINGS EVOLVE

Beginning in 1990, as part of the Best Hospitals list, the pediatric rankings were 100 percent reputational for more than 15 years, based entirely on a survey of pediatricians and pediatric specialists across the country, asking them to identify the best children’s hospitals.

When U.S. News decided to rank pediatric hospitals separately from adult hospitals, the publication faced a challenging absence of data. While adult hospital rankings were drawn from Medicare data, no comparable data were available. As a result, rankings in six specialties, working closely with academic partner Baylor College of Medicine, ranked no. 1 in the nation for the fifth consecutive year. It is the only children’s hospital in Texas on the Honor Roll.

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The 2015–16 Honor Roll required a hospital to rank in the top 10 percent in three or more specialties. Only 12 pediatric hospitals qualified among 184 surveyed nationwide. Texas Children’s has appeared on every Honor Roll. In 2015, Texas Children’s ranked no. 2 in three specialties: cardiology/heart surgery, neurology/neurosurgery and pulmonology. Texas Children’s ranked among the top five hospitals in six specialties and in the top 30 hospitals in 10 specialties.

“The original purpose of the Best Hospitals rankings was to inform patients and families and help them make decisions,” said Health Rankings Editor Avery Comarow, who has directed the Best Hospitals projects since their beginnings. “I now recognize that we don’t necessarily have to just reflect performance. We can also drive it by incorporating metrics that reflect that goal. Every year, our contractor, RTI International, meets with medical experts to evolve the methodology in ways that not only reflect what children’s hospitals are doing, but ways in which they could and should be doing better.”

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QUALITY FRAMEWORK

Today, the U.S. News Best Children’s Hospitals rankings use a well-accepted framework for evaluating the quality of health care:

- **Structure:** hospital resources related to patient care, such as the ratio of nurses to patients, specialized clinics and programs, and certification by external organizations.

- **Process:** compliance with best practices in diagnosis, treatment, prevention and patient education. As a part of the process, reputation now counts as 16.7 percent of the overall score, down from the original 100 percent.

- **Outcomes:** factors such as rates of survival, infection, mobility and cure. The increasing emphasis on quality measures had strong support from the late Bernardine Healy, MD, a former director of the National Institutes of Health, who was health editor of U.S. News before her death in 2011.

“Her expertise and perspective were invaluable,” Comarow said. “She had such a strong sense of the things that were important to patients and families. She brought that same standpoint to the medical staff.”

“Any outcome is a partnership of care to children and families,” Giardino said. “If you look at the hospitals on the Honor Roll, we’re all delivering great care to children and families.” Giardino added. “Everybody’s working hard to get better. So the bar keeps moving higher. And that’s the whole point.”

TEAM EFFORT

“The evolution into quality led us to bring all the chiefs of medical and surgical services to the table,” said Mary Jo Andre, RN, senior vice president and chief nursing officer and former senior vice president of Quality and Safety. “The more that quality and best practices were built into the survey, the more accountability of the survey shifted from an administrative standpoint to the medical staff.”

To help build physician engagement, Giardino and Thomas Luerssen, MD, chief quality officer – surgery, were appointed quality officers for Pediatrics and Surgery, respectively, in 2013. The next year, Giardino was named to his present position as chief quality officer of Texas Children’s, and Eric Williams, MD, succeeded him as quality officer for Pediatrics. They work closely with teams of physician section chiefs, practice administrators and data specialists.

Although only 10 clinical areas are ranked, a total of about 20 different services contribute to the survey, such as Radiology, Emergency Services, Intensive Care, Social Work and Nutrition. For example, nursing certification, attention to safe practices and increasing specialty roles of nurses appear in each section of the survey. Texas Children’s receives points for safety because of the hospital’s Magnet certification by the American Nurses Credentialing Center.

“Any outcome is a partnership of nursing and physician,” Andre said. “The question directly related to nursing is about staffing. Seeing how we compared to the rest of the country has been a good thing for nursing, because it’s driven us to have higher standards as well.”

More than 100 people at Texas Children’s contribute to the survey each year, submitting more than 1,500 survey elements in all. Texas Children’s is represented in four of the working groups that RTI consults each year in continuing to refine the methodology. Involvement in quality improvement at Texas Children’s is even more far-reaching. More than 400 staff members have been trained in Advanced Quality Improvement.

“Quality improvement, which Texas Children’s is passionate about, extends everywhere,” said Charles D. Fraser, Jr., MD, chief of Congenital Heart Surgery and surgeon-in-chief at Texas Children’s. “Quality starts immediately when the patient or family arrives here. Everyone is important, whether you’re in housekeeping or food services, the cardiac intensive care unit or are an administrative executive. Everyone is responsible for quality.”

GAP ANALYSIS

Texas Children’s analytics team provides data to each section chief with a detailed analysis of the gaps between the section and comparable data from top-ranked peer institutions in the Best Children’s Hospitals rankings. The service chiefs and their clinical and administrative teams review the data closely and objectively, identifying gaps and opportunities to improve quality, access or outcomes.

For example, in Texas Children’s Diabetes and Endocrinology section, gap analysis revealed several opportunities for improvement that are being addressed. To help deal with limited patient access, four new pediatric endocrinologists have been hired. To reduce disease complications, timely alerts now appear on physicians’ computers, reminding them to schedule their patients for tests for thyroid problems, kidney complications and early signs of diabetic retinopathy, which is associated with blindness.

“The U.S. News rankings are a wonderful opportunity to shine a light on potential problem areas and to allow us to make the care that we deliver better, more effective and more patient centered,” said Jake Kushner, MD, chief of Diabetes and Endocrinology at Texas Children’s.

The rankings not only help identify gaps where improvements are needed, but also provide data to build the case for needed changes.

“Many of the service chiefs and practitioners have said, ‘We’ve been wanting this — this process, this equipment, this type of clinic — for years, and here it is in the survey,’” said Terri Brown, assistant director of Clinical Outcomes and Data. “So they are able to leverage the survey to help achieve what they already know to be good ideas.”

As the Best Children’s Hospitals survey focuses more and more on ways to improve outcomes, the transparency and accountability of the published rankings is helping to improve children’s health care nationally.

“If you look at the hospitals on the Honor Roll, we’re all delivering great care to children and families,” Giardino said. “Everybody’s working hard to get better. So the bar keeps moving higher. And that’s the whole point.”
Spacious rooms equipped with the latest scientific and technological approaches to biocontainment are just one of the features of Texas Children’s new Special Isolation Unit. The eight-bed unit, housed at Texas Children’s Hospital West Campus, is designed for children with highly contagious infectious diseases and is part of an 18-bed expansion of the hospital’s Acute Care Unit.

“It’s a state-of-the-art isolation unit designed and staffed to provide the highest quality care and treatment for infants and children with serious or life-threatening infectious diseases of public health significance, with the greatest possible margin of safety,” said Texas Children’s Physician-in-Chief Mark W. Kline, MD. “We believe this will be an indispensable resource to our local community, Texas and the nation.”

Texas Children’s Special Isolation Unit is the only one of its kind in Texas and the southwest region, and it is among only a few in the United States designated just for children. The unit is fully equipped to care for any infant or child with a serious communicable disease, with all of the measures available to assure safety of the health care team, other patients and their families. Each of the patient rooms has an anteroom, where doctors and nurses don personal protective equipment. Caregivers exit the patient room through a separate door and enter a third room, where they remove the protective equipment. Nurses can observe the patient and care team through large glass windows.

A skilled special response team participated in extensive training, including simulation exercises, to prepare for the opening of Texas Children’s Special Isolation Unit.

**Types of Highly Contagious Pathogens**

- **Ebola, Marburg and Lassa fevers** are hemorrhagic viruses that affect multiple organ systems and spread through contact with blood, tissues, excretion and secretion.

- **Avian Influenza** and other pandemic flus originate with non-humans then evolve to spread from human to human. People have little to no immunity to these viruses.

- **MERS, SARS and RSV** are respiratory illnesses that affect the lungs and breathing tubes, causing severe acute respiratory illness that can lead to multi-organ failure and death.

- **Smallpox and Monkeypox** are viruses that cause raised bumps on the face and body. There are no specific treatments, and the only form of prevention is the smallpox vaccine.

- **Measles** is a viral disease that can lead to pneumonia, encephalitis and death. It is spread through coughing and sneezing and is highly contagious to those who are not vaccinated.
The unit has its own biosafety Level 3 laboratory, which allows for safe, on-site, rapid identification of usual and unusual pathogens. There’s also a separate medical waste room, where carts of used clothing and equipment can be disposed of or cleansed inside 6-foot autoclaves. Other features of the unit include:

- Negative pressure rooms and isolated air handling.
- High-protocol workflows designed around a “clean-to-dirty” workflow.
- Observation windows into patient rooms to limit staff exposure.
- Specialized technology and communication devices to communicate as a team.
- Staff locker room where caretakers can shower before and after each shift.
- Child life play room for patient siblings and young visitors.

Children treated within the Special Isolation Unit receive specialized care from a team of highly trained nurses and physicians. At least six members of the team, called the Special Response Team, are assigned to each child in the unit, with one team member acting as a family liaison. The children can use mobile tablet devices to talk with their families via video chat. In addition, to make the unit’s patients feel as comfortable as possible, a special doll is being developed that will wear a mini version of the personal protective equipment the doctors and nurses wear.

The decision to build a special isolation unit came last year when an unprecedented Ebola outbreak in West Africa began to reach other countries. A handful of cases were diagnosed in the U.S. in fall 2014. Texas Children’s immediately responded with a plan for a more robust approach to handling emerging infections, and shortly after, began the build-out of the unit and selected and trained a special response team to staff it.

The Special Isolation Unit is part of a new 18-bed acute care unit. When the isolation unit is not activated, its eight beds are used for acute care patients. The Special Isolation Unit is led by Medical Director Gordon Schutze, MD, and Associate Directors Judith Campbell, MD, and Amy Arrington, MD. Sondra Morris, RN, leads the team’s nursing staff. The unit’s Special Response Team comprises physicians, nurses, medical technologists and environmental service technicians who have been trained in infection control, hospital epidemiology and management of infectious diseases in the critical care setting.

“I could not be more impressed with Texas Children’s desire to run toward issues of critical importance to the health and wellbeing of the children of Texas and our nation,” said Brett Giroir, MD, director of the Texas Task Force on Infectious Disease Preparedness and Response and chief executive officer of Texas A&M Health Science Center.

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Elysse Mata kisses her daughters, Knatalye and Adeline Mata, during the first few weeks after the girls were born conjoined from the chest to the pelvis.

Surgeons allowed the girls to grow and gain strength for 10 months before spending more than 26 hours separating them.

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THE JOURNAL OF TEXAS CHILDREN’S HOSPITAL

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Advanced technology has made successful separation surgeries more common than they once were. The medical challenges and risks, however, remain significant. And in many cases, the decision to attempt the separation of conjoined twins can pose profound ethical questions as well. Texas Children’s addressed the Mata twins’ case both clinically and ethically through the hospital’s medical ethics review process.

While the chances of having conjoined twins are rare—one in every 200,000 live births—the overall survival rate for these babies is only 25 percent. About 40 to 60 percent of conjoined twins are stillborn, and another 35 percent die shortly after birth due to serious health anomalies. The separation of conjoined twins can be risky, depending on how the twins are connected. The greater the number of vital organs the babies share, the more difficult the odds for a positive outcome. Approximately 250 successful separations in which one or both twins have survived have been recorded worldwide, according to the American Pediatric Surgical Association. The number is small because the decision to attempt separation is not taken lightly.

Since Texas Children’s opened its doors in 1954, multiple sets of conjoined twins have been referred to the hospital for consideration. However, in many of these cases, separation was not medically possible.

Surgeons at Texas Children’s Hospital have performed three successful separation surgeries. The first pioneering procedure occurred February 16, 1965, when a team of surgeons separated 9-week-old conjoined twins Kimberly and Karen Webber. The Webber twins were connected at the liver and pericardium—the membrane enclosing the heart. On June 9, 1992, Texas Children’s surgeons successfully separated Tiesha and Iesha Turner, who were 1 year old and shared a sternum, liver, entwined intestines and fused organs. The Mata twins’ surgery was the third successful separation surgery performed at Texas Children’s. On February 17, 2015, 10-month-old Knatalye Hope and Adeline Faith Mata were detached during a marathon 26-hour operation. The girls were born connected from the chest to the pelvis, sharing a chest wall, pericardial sac, diaphragm, liver, intestinal tract, urinary system and reproductive organs.

W
The rarity of separation surgeries in cases of conjoined twins not only reflects the medical complexity of the surgeries, but also the ethical questions raised by medical procedures that have terribly uncertain outcomes.

Lead surgeon Oluyinka Olutoye, MD, a pediatric surgeon and co-director of Texas Children’s Fetal Center, has participated in four conjoined twins’ separation surgeries, one at Texas Children’s Hospital and three at the Children’s Hospital of Philadelphia. He emphasized that the potential for success depends on many factors, the most important being where the twins are connected and which structures they share.

Olutoye, also professor of Surgery at Baylor College of Medicine, recalls a time in his medical training when he and his surgical colleagues were presented with a complex case involving conjoined twins who were supported by the heart of one twin.

“One baby had a thriving heart, while the other twin didn’t have a heart at all and was being fed by blood vessels from the healthier twin,” Olutoye said. “We knew that if we separated them, the one without a functioning heart would not survive. But, at the same time, if we did not separate them, the heart would not be able to support both babies as they grew older.”

The decision was wrenching. But the family and their medical team elected to proceed with the separation surgery.

As Texas Children’s Hospital’s medical ethicist, Laurence McCullough, MD, consults on patient cases in which treatment decisions are unclear or morally difficult. Every Thursday morning, he and a multidisciplinary team of physicians, surgeons, counselors and social workers huddle in a large conference room at the hospital to discuss the ethical implications of new and ongoing patient cases — one of which was the Mata twins’ case.

“My role in this process is to ensure all ethical dimensions of each case are clearly identified so our medical staff can provide guidance to the families,” said McCullough, a professor of Medicine and Medical Ethics at Baylor College of Medicine. “We have a thorough process for identifying ethical challenges and putting plans in place to manage them and determine whether surgery is ethically permissible in certain cases.”

When determining whether to proceed with surgery for conjoined twins, McCullough said some cases are not clear-cut. One ethical approach might call on the principle of double effect, in which the attempted separation could result in irreversible harm or death to one twin while improving the quality of life for the other twin. According to this principle, it is sometimes permissible to cause harm as a side effect (double effect) of bringing about a good result — as long as the two outcomes are causally independent. Another ethical perspective is that saving one life may be better than losing two.

In the case of the Mata twins, the double effect principle did not apply. Knatalye and Adeline had enough separate functioning body parts to enable them to sustain lives apart from each other. In this case, then, the medical challenges were paramount.

“We knew that one twin was going to be more challenging than the other based on the anatomy and what their structure was like,” Olutoye said. “While they didn’t share equal parts, we had to determine if they had enough parts to survive and function. It became more of an issue of how could we medically accomplish this so both babies survive.”

Throughout the entire process, from the initial diagnosis in utero to the day of separation, lead surgeon Darrell Cass, MD, and others involved in the care of the Mata twins held regular meetings with the family to keep them informed — ethically essential in medical decision-making.

“We made sure we set the right expectations for the Mata family from the start,” said Cass, a pediatric surgeon, co-director of Texas Children’s Fetal Center, and associate professor of Surgery, Pediatrics and Obstetrics and Gynecology at Baylor. “We explained all of the steps that must be taken before any surgical intervention could take place to ensure the best possible outcomes for both girls.”
When Elysse and John Eric Mata decided to start a family, they never imagined they would have twins. So when they learned that their girls were conjoined — a phenomenon that occurs in only one of 200,000 live births — their astonishment was twofold.

“We were shocked,” Elysse Mata said. “We also were scared.”

But they did what any concerned parents would do. They found a medical home offering world-class care for complex maternal-fetal conditions. After choosing Texas Children’s Hospital and getting to know the team of experts who would spend the next 18 months shepherding them through the birth and separation of their daughters, many of the couple’s fears subsided.

Extensive prenatal imaging and multidisciplinary consultation at Texas Children’s Fetal Center revealed the girls were connected from the chest to the pelvis — sharing a chest wall, pericardial sac, diaphragm, liver, intestinal tract, urinary system and reproductive organs.

“The girls had a thoraco-omphalo-ischiopagus connection, which is very complex,” said Darrell Cass, MD, pediatric surgeon, co-director of Texas Children’s Fetal Center and associate professor of Surgery, Pediatrics and Obstetrics and Gynecology at Baylor College of Medicine. “Their anatomy was as complicated as it could be and still be separable.”

After weeks of careful monitoring, Knatalye Hope and Adeline Faith Mata were born at Texas Children’s Pavilion for Women on April 11, 2014, at 31 weeks gestation via Caesarean section. But their eventual separation would require extensive preparation from numerous specialists.

Before undertaking the complex task, Cass and the multidisciplinary care team allowed the twins to grow and gain strength for more than 10 months. During that time, the twins received specialized care, including a five-hour surgery at Texas Children’s main campus to place custom-made tissue expanders into their chest and abdomen area. Several times a week, fluid was added allowing the girls’ skin to gradually stretch. This new skin would be used to provide coverage once the babies were separated.

“When the babies are connected at the chest, the belly and the pelvis, and you separate the babies, that whole area doesn’t have enough skin to close,” Cass said. “Larry Hollier, MD, chief of Plastic Surgery at Texas Children’s and chief of the Division of Plastic Surgery at Baylor College of Medicine. “So we needed enough good tissue with a reasonable blood supply to cover all of that. The only way we could really do this was by creating it before surgery with tissue expanders.”

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PREPARING FOR THE BEST:

TEXAS CHILDREN’S GIVES CONJOINED TWINS HOPE FOR A BETTER LIFE

BY KIMBERLY VETTER

When their lives were instantly changed by learning they were expecting conjoined twin daughters, Elysse and John Eric Mata traveled to Houston for the world-class care at Texas Children’s Hospital. The 10 months leading up to the girls’ separation presented a series of firsts for nearly everyone involved, as well as meticulous planning and preparation to help ensure a successful surgery.

Video: Learn more about the Mata twins’ tissue expansion procedure.

JOURNAL.TEXASCHILDRENS.ORG/ISSUE3/TISSUEEXPANSION
To keep pressure off the tissue expanders and to help the girls continue to develop normally, nurses Jennifer Pitlik and Jennifer McGinnis and physical therapist Frank McCormick worked with experts from the Hanger Clinic — specialists in orthotics and prosthetics — to create a device that would safely keep the twins upright for a large portion of each day.

Together, they developed a U-shaped device that supported the girls’ backs, bottoms and heads. The device’s headrests were removable to allow for more movement, and the main portion of the device was equipped with liners that could be taken out as the girls grew. The twins were suspended from a Hoyer, typically used to lift immobile patients from one place to another. The staff began to refer to the device as “the swing.”

“The girls loved it,” McGinnis said. “They pushed off with their feet, so they were able to swing and move around, and since they were both upright, they were able to make eye contact with other people.”

Meanwhile, the rest of the girls’ care team spent hours planning for and simulating the separation surgery, even creating an intricate 3-D model of the twins’ anatomy. With help from MedCad, a Dallas printing company, Texas Children’s chief of Radiology Research Imaging, Rajesh Krishnamurthy, MD, created the model using a computerized image data set of the twins and a 3-D printer. The detailed model included a detachable liver, which was especially helpful in the planning of the pelvic portion of the surgery — a part of the procedure that would be challenging because the blood supply for each of the girls’ pelvic organs was shared.

“Three-dimensional modeling is a visual representation of the complexity that surgeons might encounter during a procedure,” Krishnamurthy said. “It’s a very powerful tool when you are trying to develop unique solutions to challenging situations, such as the Matas’.”

As the date of the separation surgery got closer, the comprehensive team of surgeons, physicians, nurses and support staff assigned to the Mata case continued to prepare for the big day. The lead surgeons met and thoroughly examined every aspect of their procedure, the simulation staff prepared the team for potential complications, and critical care nurses readied the pediatric intensive care unit for the girls post-surgery.

By the time the surgery was scheduled, everyone, including the Mata family, felt satisfied with the care team’s preparations and optimistic about the surgery’s outcome.

“I have an extreme amount of faith in the team at Texas Children’s,” Elysse said prior to her daughters’ surgery. “I know God put us here for a reason.”
"WE HAVE THE TEAM AND THE MOST COMPLEX EXPERTISE TO HANDLE MEDICAL CONDITIONS."

Charles D. Fraser, Jr., MD, Surgeon-in-Chief
The surgery that would separate the Mata twins was an intricate production, involving 12 surgeons, nine nurses and countless support staff. Together they performed an exceptionally complex series of surgical procedures, meticulously choreographed to ensure that each step of the process would lead to and support the steps to come. Throughout the separation process, the Mata family stood by, waiting and praying for good news.
February 17, 2015, 

Elysse Mata sat holding her babies tightly, crying and kissing them as she said goodbye. It was her last chance to spend time with them before they underwent a historic surgery at Texas Children’s Hospital that would offer them the chance of separate lives.

“We’ve been waiting for this moment for a year,” Elysse said. “Ever since we found out the twins were conjoined, we’ve been praying and hoping this day would come.”

Elysse’s husband, John Eric Mata, and their then-5-year-old son, Azariah, were also near, kissing the girls’ foreheads and holding their tiny hands while they anxiously awaited the start of the procedure. A group of extended family and friends joined the Matas in an emotional prayer led by Texas Children’s Hospital Chaplain Kristen Springmeyer.

“God of all people and places, we come before you today to offer you Knatalye Hope and Adeline Faith Mata, known by their family simply as Hope and Faith,” Springmeyer said. “We pray for the staff that will be caring for them, for their holy hands as they begin their separation.”

**SURGICAL OVERVIEW**

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**2.17.2015**

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**Lead surgeon Darrell Cass, MD, entered the room, gave the family a hug, and with the help of supporting operating room staff, escorted the girls to Texas Children’s Operating Room 12. Members of the twins’ care team from the neonatal intensive care unit (NICU), who had been by their sides for 10 months, lined the hallways in an emotional show of support.**

Just after 7 a.m., Knatalye and Adeline were wheeled into the operating room where a team of more than 40 clinicians from seven pediatric specialties began the surgical procedures to separate the twins.

**8:34 p.m.**

Urologists and pediatric gynecologists assist in separating the twins’ bladders and uteruses.

**11:12 p.m.**

The historic milestone of separation occurs, and each girl is moved to her own operating table and then into separate rooms.

**12:30 a.m.**

Orthopedic surgeons make an incision into the girls’ pelvic bones and place a metal frame outside the bones, bringing them closer together and aiding the closure process.

**2:30 a.m.**

One lead pediatric surgeon works with a team to close Adeline and another starts closing Knatalye.

**6:49 a.m.**

Knatalye is wheeled into the pediatric intensive care unit (PICU) where her parents and relatives see her, alone, for the first time.

**8:55 a.m.**

Adeline is taken to a room next to her sister in the PICU. Family, friends and some of the surgeons embrace in a hard-earned, emotional hug.

**H O P E , F A I T H A N D E X P E R T I S E : B Y K I M B E R L Y V E T T E R**
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BY KIMBERLY VETTER

2.17.2015

Video: See behind-the-scenes highlights of the Mata twins’ surgery.

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Members of the Mata family pray before surgeons embark on a lengthy surgery to separate conjoined twins Knatalye and Adeline Mata.

Elysse and John Eric Mata, with family members, say their last goodbye to daughters, Knatalye and Adeline, before the conjoined twins are wheeled off to a monumental surgery that will make them two.
Texas Children’s clinicians began preparing the Mata twins for surgery at 7:43 a.m. on February 17, 2015. The team didn’t stop working for another 26 hours.
Two of several surgeons who performed the separation of the Mata twins work intently during the complex procedure.

One of two lead surgeons scrub in before walking into the operating room where conjoined twins, Knatalye and Adeline, await separation.

Texas Children’s orthopedic surgeons discuss how they will close the pelvic and hip bones on each of the Mata twins after separation.

One of nine operating room nurses prepares surgical tools used during the separation of conjoined twins Knatalye and Adeline Mata.
Knatalye and Adeline Mata’s grandmother, Marie Blanco, hugs Edward Buchanan, MD, and their father, John Eric Mata, embraces Oluyinka Olutoye, MD, following the marathon surgery that separated the girls.
On February 17, 2015, a team of more than 40 clinicians from at least seven specialties spent 26 hours performing an operation that would separate conjoined twins, Knatalye and Adeline Mata. Here are the pediatric subspecialty teams that executed the historic separation surgery.

**A THOROUGHLY OUTFITTED ARMAMENTARIUM**

**PLASTIC SURGERY**
Three plastic surgeons, including Texas Children’s Chief of Plastic Surgery Larry Hollier, MD, and plastic surgeons Edward Buchanan, MD, and David Khechoyan, MD, made the initial incisions into the twins and sewed the girls’ final stitches. During the first few minutes of the procedure, the team took two custom-made tissue expanders out of the girls’ abdomens. The expanders, placed months earlier, stretched the girls’ skin, allowing the surgeons to close them more easily at the end of the procedure.

**ANESTHESIOLOGY**
Led by Helena Hippard-Karlberg, MD, a team of five anesthesiologists prepared the Mata twins for surgery by inducing and intubating them, establishing IV access, placing arterial lines in both girls and anesthetizing them. During the lengthy procedure, at least one member of the anesthesiology team was in the operating room at all times, monitoring the twins’ vital signs, including their blood pressure, heart rhythm, temperature, level of consciousness and amount of oxygen in the blood. The anesthesiology team also worked with the after-care team to keep the twins comfortable post-surgery.

**CONGENITAL HEART SURGERY**
Dean McKenzie, MD, represented Congenital Heart Surgery during the procedure, separating the girls’ pericardial sac, which lines the heart. Each twin was born with her own heart, but they shared a pericardial sac. McKenzie separated that sac, giving each twin one of her own. He also repaired Adeline’s heart defect, patent ductus arteriosus, and helped close the girls’ chests.

**OPERATING ROOM STAFF**
A team of nine registered nurses and two certified surgical technologists maintained a sterile field throughout the more-than-26-hour procedure and assisted surgeons with their instruments.

**PEDIATRIC SURGERY**
Darrell Cass, MD, and Oluyinka Olutoye, MD, orchestrated the entire procedure and were present from beginning to end, taking part in all aspects of the operation. After the actual separation, Cass continued to operate on Knatalye, and Olutoye focused on Adeline.

**PEDIATRIC UROLOGY AND PEDIATRIC GYNECOLOGY**
Three urologists and two pediatric gynecologists were in the operating room, working together on the girls’ pelvic region. Although each girl had her own pelvic organs—bladder, uterus and ovaries—each of those organs received blood supply from the other girl. Chief of Pediatric Gynecology Jennifer Dietrich, MD, and urologist Chester Koh, MD, led the team that helped preserve all of the girls’ pelvic organs.

**PEDIATRIC ORTHOPEDICS**
Orthopedic surgeons William Phillips, MD, and Scott Rosenfeld, MD, helped separate and reconstruct the girls’ pelvic bones, giving them the chance to walk.

**TRANSPLANT SERVICES**
John Goos, MD, helped separate the girls’ livers, which were fused together.

**OPERATING ROOM STAFF**
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Just before 10 a.m., some 26 hours after the surgery began, it was complete. The family saw their girls, apart for the first time, in adjacent rooms in the pediatric intensive care unit (PICU), where they would be cared for by a team including both their NICU primary nurses and their new PICU nurses.

Elysse said she and her family were extremely grateful for the team that separated her babies, and the countless hours they put into understanding the girls’ conditions and how best to treat them.

Cass and several other surgeons, including plastic surgeon Ed Buchanan, MD, met the family in Adeline’s room to share in the family’s joy and relief. They gave the family a summary of the monumental procedure and explained what they should expect in the next few days.

“Thank you for your trust,” Cass said to the Mata family. “We are going to keep doing everything we can to get them through this. So far, so good.”

Hollier said that to the best of his knowledge the Mata separation surgery is the first time a case with this many connections at the chest, abdomen and pelvis has ever been done successfully.

“It could not have gone better,” he said. “It was phenomenal teamwork and great preparation on the part of the institution.”

By late morning Wednesday, February 19, Elysse and John Eric were again with their babies, watching over the girls in their two separate beds. It was a moment they had been awaiting for more than a year. And it marked the beginning of a promising new chapter, thanks to the compassionate expertise of Texas Children’s physicians, nurses, and countless staff and employees.

“We love them,” Elysse said of the girls’ medical team. “They mean the world to us, and they will forever hold a special place in our hearts.”

Surgeon-in-Chief Charles D. Fraser, Jr., MD, said the separation surgery is another example of the dedication and depth of skill that the professionals in the Department of Surgery bring to their patients.

“I am proud to work with this tremendous team,” he said. “Their planning and hard work have given Knatalye and Adeline a chance to lead separate lives.”

The initial separation was not the end of the marathon surgery. Separate for the first time, the twins were taken to different operating rooms where teams of surgeons continued to work on the girls’ critical organs. Pediatric gynecologists and pediatric urologists spent hours on the girls’ reproductive systems. Orthopedic surgeons reconstructed the girls’ pelvic bones.

A DREAM REALIZED
Formerly conjoined twins Knatalye and Adeline Mata spent the first few months recovering at Texas Children’s Hospital, even celebrating their first birthday with a family party in a hospital conference room. Post-separation, both girls underwent additional surgeries, including the removal of metal rods in their pelvises and shunts in their bladders that were inserted during separation. Each twin required a gastrostomy, which includes a button and special tube to help regulate and deliver food and medicines until a child can chew and swallow. Adeline also needed a tracheostomy to help her breathing and lung development.

Throughout their recovery, the girls received physical and occupational therapy to aid in their development, learning to grasp objects and to sit on their own. But Elyse Mata, the girls’ mother, described the joy of seeing her daughters “light up” when they had the opportunity to play and interact with one another during therapy together.

The girls, whose recovery is described by lead surgeon and Texas Children’s Fetal Center Co-director Darrell Cass, MD, as “remarkable,” soon grew stronger and Knatalye was discharged on May 8 — just three months after the complex separation surgery. Adeline followed on June 9, joining her sister, her 6-year-old brother Azariah and her mother in a temporary apartment donated to the family by a local church.

Though both girls were discharged, the family stayed in Houston for another month for outpatient clinic appointments at the hospital that were part of the girls’ follow-up care.

“It hasn’t really sunk in yet,” said Elyse in the first few days after both girls were discharged. “Once we get home, I’m pretty sure it’s going to feel amazing.”
CONTINUING CARE

Eager to return home, the family got the news that the girls could travel to Lubbock just in time for Independence Day. Their homecoming, though a joyful milestone for the family, also came with challenges. Because Adeline had a tracheostomy and continues to receive support from a ventilator, the Mata family has a home nurse who helps care for her. Both girls also receive physical, occupational and speech therapy services at home.

The sisters will return to Texas Children’s every couple of months for follow-up appointments with specialists who will monitor their progress, growth and development. They may also require additional surgeries in the future.

Even with the challenges of adjusting to life at home, the Mata family is thankful to have some normalcy back in their lives.

“It was a long road to get to where we are,” Elyse said. “But it was well worth the wait for our girls to be able to come home happy and healthy, with the ability to lead independent lives.”

Cass is already peering far down the road. Successful separation was one milestone, but the reward, he said, will be in the quality of life the girls are afforded in years to come.

“When I first met the Mata family and learned of the diagnosis, I was optimistic we would have a positive outcome,” Cass said. “It is with great joy that we watched them leave the hospital, and I look forward to the day Elyse shares with me pictures of these beautiful girls walking into kindergarten together.”
Knatalye and Adeline Mata are all smiles at their checkup, almost a year post-surgery.

The Matas pose for a family portrait just before Adeline is discharged from the hospital. The family is doing well and is now home near Lubbock.

Oluyinka Olutosoye, MD, tells Knatalye goodbye shortly after she is discharged from the hospital.
AT THEIR SIDE

THE ROLE OF NURSING IN THE MATA TWINS’ MEDICAL JOURNEY

By Hasti Taghi
Texas Children’s nurses were the backbone of the twins’ care team, and they played an integral role in the girls’ growth, development and healing, from inside the womb to post-separation.

When operating room nurse Audra Rushing finally sat down after a 30-hour shift, tears flowed unexpectedly. Overcome with emotion, she couldn’t help but flash back to the moment just a few hours earlier when she stood between the two beds of twin sisters Knatalye and Adeline Mata as they finally lay separately for the first time.
"It was like seeing a baby being born for the first time," Rushing said of the twins’ separation. "Throughout the surgery, there was no time to stop and think about how monumental this was. Once it was all over, there was just that feeling in my heart like, 'this is why I do what I do.'"

Rushing was chosen as the lead operating room (OR) nurse for the Mata twins’ separation surgery, which took more than 24 hours to complete. Months before the girls’ separation surgery, Rushing’s job was to ensure all of the logistics were ironed out — a significant challenge, since she had never been involved in a case where two patients were in the same OR, requiring two of every monitor and every piece of equipment. With more than seven medical specialties represented, the needs and preparations were great.

Nurses from the antepartum unit, neonatal intensive care unit (NICU) and pediatric intensive care unit (PICU) helped plan the details of every procedure and developed solutions and therapies to keep the girls comfortable as they grew into new milestones, playing crucial roles in Knatalye and Adeline Mata’s successful separation and recovery.

"The attention to detail in this case doesn’t compare to anything I’ve experienced in my career."

— Audra Rushing
Preparing for delivery

Before the twins were even born, specialized nursing care began for their mother, Elysse Mata, who was monitored around the clock for several weeks in the Texas Children’s Pavilion for Women antepartum unit — a dedicated care area designed for expectant mothers who are on bed rest or require monitoring for complex pregnancies. Nurses there, like Stephanie Pruitt, help ensure the safety of the mothers and their unborn babies and also comfort the mothers during their extended hospitalizations until delivery.

As the conjoined twins’ arrival came nearer, the family’s story began to receive international attention, and the hospital staff felt the eyes of the world on them.

“It was definitely an exciting case because it’s something few people experience during their nursing careers,” Pruitt said. “But I treat all of my patients like they are high profile, so Elysse was just another patient who needed my absolute best care and attention.”

Pruitt was part of the team that ensured Mata was able to reach a safe gestational age before her twins were delivered and transferred to Texas Children’s NICU, the largest in the country.

“It was definitely an exciting case because it’s something few people experience during their nursing careers.” — Stephanie Pruitt
The first 10 months

The first days in the NICU can be a complex, emotionally charged time for any family, and the Matas were no different. Thankfully, NICU nurses are specially trained to handle these cases with care and compassion.

"I walked into their rooms for the first time when Knatalye and Addie were just 6 days old," nurse Jennifer Pitlik, one of the girls’ primary NICU nurses, said. "The Matas really made us feel like an extension of their family, and we encouraged them to parent their hospitalized babies."

For 10 months, NICU nurses cared for the girls as they grew into healthy toddlers, strong enough to endure their difficult separation surgery. For Alex Luton, a clinical nurse specialist in the NICU, overseeing the team that managed the girls’ care was inspiring.

"There was a clear multidisciplinary partnership on every aspect of care," Luton said. "Nurses, therapists and physicians worked together constantly to make decisions about the girls’ care, whether it was the logistics of how we would keep the girls comfortable on one bed, or what we could do to give the girls some mobility at an age when most babies would begin to roll or crawl."

Before the girls’ surgery to place tissue expanders on their chest and abdomen in preparation for their separation, Chief of Plastic Surgery Larry Hollier, MD, said nurses asked crucial questions about the twins’ comfort and development.

"In one of the planning meetings, we were mired in all the technical details of the expander surgery, and two of the nurses who care for these children every day
asked us, “Just out of curiosity, how are they going to relax? How are they going to sleep? How do we position them?”” Hollier said. “These were important questions to ask. It’s all those details that make an integrated system like ours so effective in complex cases.”

During the surgery preparation process, nurses coordinated with physical therapists to design a special bed and a positioning swing for increased mobility as the girls grew. And at 10 months after their birth, it was finally time for Knatalye’s and Adeline’s big day. More than a dozen nurses who’d cared for them during that time came from various units to stand with the family, lining the halls as the twins were wheeled off to surgery.

“It was my day off, but I came in to be with the family and other staff as we went through the emotions of this historic day for all of us,” NICU nurse Hawa Samson-Metzger said.
Separation and recovery

Once in the operating room, the girls were under the care of a nine-person nursing team. Accompanied by one of the lead surgeons, Rushing was there to give the family the good news after approximately 20 hours: the girls were finally separated.

"It was really emotional for me to deliver the news," Rushing said. "When we started the surgery, we knew the chance of loss was very real, and each time we hit a big milestone, we felt relief."

About 26 hours after the first incision was made, the team wheeled the girls into the PICU, where their NICU nurses waited to greet the family and ease the transition of care.

For Elysse Mata, whose little girls are now home, the bond with the nurses is something she hopes to someday share with the twins.

"Our nurses are like my friends — they’re really family,” she said. "They’re the girls’ aunts. I hope one day the girls will be back to meet every single one of them.”
Our nurses are like my friends — they’re really family.

— Elysse Mata
THE DEBILITATING FOE

It happens again. Another flare-up. The symptoms are humiliating: crippling abdominal pain, bloody stools and mortifying dashes to the bathroom. This isn’t a 24-hour stomach bug. Instead, it’s the unpleasant reality for patients with ulcerative colitis (UC).

Casey Cook, 17, and Jonathan Tybur, 19, know this reality all too well. Four years ago, they were diagnosed with this devastating bowel condition that inflames the inner lining of the large intestine or colon.

This two-word diagnosis — ulcerative colitis — turned their lives upside down. While most teens their age enjoy the simple pleasures in life — swimming, traveling and hanging out with friends — these outings can be filled with anxiety due to the disease’s unpredictable nature.

“You never know when an attack will happen,” Tybur said. “It usually strikes without warning.”

Ulcerative colitis progresses slowly, and the symptoms may not be easily detected until the inflammation is severe. Most patients experience rapid weight loss, swollen joints, tainted stool, sharp abdominal pain, and violent and frequent episodes of diarrhea.

“When I was diagnosed, I remember feeling this stabbing pain in my stomach that made me double over,” Cook said. “By the time I went to the hospital, my entire colon was inflamed with ulcers.”

Patients with UC have medical and surgical treatment options. The medical treatments include anti-inflammatory steroids and other powerful immunosuppressant/immune-modulator drugs. The surgical option is essentially the removal of the colon. The disease is more aggressive in children than adults, with up to 40 percent of children requiring colon removal within 10 years of diagnosis, according to studies in the past decade.

Cook’s and Tybur’s treatment regime included a powerful combination of steroids and immunosuppressant medications. While it controlled the
symptoms, it produced side effects, and some of the medications were known to increase the potential risk for certain types of cancers.

“I would get very irritable, very bipolar, and I had problems with infection because my immune system was altered,” recalled Tybur.

The treatments drained Cook’s energy.

“I felt tired all the time, extremely hungry and depressed,” he said.

FINDING A BALANCE

Texas Children’s is among very few hospitals across the nation exploring fecal bacteriotherapy, or fecal microbiota transplantation (FMT), a nonconventional treatment that transplants stool from healthy donors into the colon of UC patients in an attempt to restore a healthy, diverse bacterial population in the gut.

“We believe it is beneficial to have a more diverse, complex community of bacteria and microorganisms in our intestinal tract because it is a denominator of good health,” said Richard Kellermayer, MD, a pediatric gastroenterologist and clinical initiator of the investigative Intestinal Microbiome Transplantation program at Texas Children’s.

While the cause of UC is unknown, researchers believe that an imbalance of the bacterial community in the colon may cause the immune system to overreact, triggering the chronic intestinal inflammation. In theory, restoring the colonies of helpful bacteria through FMT may induce a healthier microbial community that could reset the patient’s immune system and stop the chronic inflammation, resulting in long-term remission.

“Patients who have used fecal bacteriotherapy to treat antibiotic-induced Clostridium difficile intestinal infections have seen up to a 90–95 percent success rate,” Kellermayer said. “We are exploring this therapeutic treatment alternative for UC patients so they don’t have to endure the severe side effects of immunotherapy.”

PUTTING GUT MICROBES TO THE TEST

Kellermayer is the lead investigator of an ongoing, Phase I study at Texas Children’s that examines the safety and tolerance of fecal bacteriotherapy in 10 immunotherapy-dependent patients with UC.

Unlike most clinical trials that have used a maximum of five fecal transplants, this study uses 37 fecal enema treatments over the course of one year. The lab-prepared stool samples are supplied by healthy, anonymous donors who have undergone a meticulous screening process.

Donor provides multiple stool specimens during a one-month window immediately after passing the health screening.

Saline-diluted stool is pressed and filtered in a stomacher to create a cleaner specimen. This is performed within four hours of specimen delivery.

Stool is resuspended in glycerol to maintain viability of the bacterial cells before they are frozen.

Sterile saline is added to frozen stool and warmed to body temperature at time of transplant.

Bacterial DNA is extracted from stool specimen. Next-generation sequencing technology identifies and compares the composition of microorganisms in the donor and patient stool samples to monitor change in patient’s microbiome.
“I LOVE TO COOK,” COOK SAID. “I’VE RECENTLY COME UP WITH MY OWN FLAVORED RUM CAKES, WHICH I’VE BEEN SELLING LIKE CRAZY.”

Despite the volatile nature of UC, there’s one thing this disease did not strip away: Cook’s and Tybur’s freedom to pursue their passions.

As a high school athlete, Tybur was a competitive breaststroke swimmer and still is today. Before his diagnosis, he was competing at national level swim meets and was one of the top breaststrokers in the nation in his age group of 13- and 14-year-olds.

“When I was going through the treatments, I went from not even placing in the top eight at districts to being second in the state and winning a state medal in high school,” Tybur said.

As a college sophomore, Tybur hopes to add to his medal collection as he competes on the Texas A&M University swim team. He has now qualified for the 2016 Olympic trials in 100m and 200m breaststroke.

As for Cook, he is refining his culinary skills in the kitchen.

“I love to cook,” Cook said. “I’ve recently come up with my own flavored rum cakes, which I’ve been selling like crazy.”

To add to this milestone, Cook has been accepted into the coveted culinary program at his high school.

“It is really exciting to see him chase his dreams,” his mom Adrien Cook said. “I can see the life in his face again. The treatments have truly been a major life changer in our house.”
TOO DEEPLY ATTACHED

Growing trend toward C-section delivery contributes to rise in a serious complication

by Rosanne Moore and Anissa Orr

With the rise of Cesarean births and morbidly adherent placenta cases, Texas Children’s Pavilion for Women continues to attract a growing number of patients across the nation due to its successful treatment of this potentially fatal condition.
A mother is waiting to see her unborn baby appear in black and white on the screen beside the exam room bed. She’s anxious, and as she peers at the obstetrician, the look on the doctor’s face says it all. His concern is followed by, “You have placenta percreta.”

What does it mean, and what happens now? It’s a question more and more women find themselves facing as the rate of Cesarean births increases.

Morbidly adherent placenta is a rare but serious pregnancy complication in which the placenta and its blood vessels can attach to or grow deeply into the wall of the uterus, keeping the placenta from detaching after childbirth. In the case of placenta accreta, the placenta attaches to the innermost layers of uterine muscle. In cases of placenta increta, it deeply invades the muscle. With placenta percreta, the placenta penetrates the uterine wall entirely and can even invade nearby organs such as the bladder.

As the rate of Cesarean (C-section) deliveries increases, morbidly adherent placenta is becoming more common in pregnant women. Women who have had prior C-sections or other uterine surgeries are more at risk for these complications because the placenta can latch on to the surgical scar too firmly. Once rare — with only one in 4,027 pregnancies affected in the 1970s — morbidly adherent placenta now occurs in roughly one in 500 to 1,000 pregnancies. About 1 percent of women die from this condition due to massive hemorrhage.

CONVENIENCE VS. CAUTION

Texas Children’s Maternal-Fetal Medicine Specialist Karin Fox, MD, says the data raises serious questions about choosing a Cesarean delivery for convenience or preference rather than medical need. Leading organizations such as the Society for Maternal-Fetal Medicine and the American College of Obstetricians and Gynecologists are now advising physicians to take steps when possible to prevent the first Cesarean delivery.

“Cesarean delivery can be lifesaving for some women but must be medically indicated,” said Fox, a member of the multidisciplinary placenta accreta team at Texas Children’s Pavilion for Women. “Doctors should educate their patients on the benefits and risks of Cesarean delivery, including their risk factors for placenta accreta.”

Winchester recalls racing to the bathroom in the middle of the night. “I was bleeding everywhere,” Winchester said. “I thought I’d had a miscarriage.”

Winchester’s husband rushed his 35-weeks-pregnant wife to the emergency room, where doctors gave her three pints of blood before she was whisked away by air ambulance to Texas Children’s Pavilion for Women. When she arrived at 2:30 a.m., Winchester didn’t fully comprehend the seriousness of her medical condition until she was wheeled into the crowded operating room.

“I looked in the room, and there were people everywhere,” Winchester said. “I asked, ‘What’s going on?’ and the nurse said, ‘Baby, you are about to have a baby.’ I just cried.”

She recalls Fox cutting through the confusion to console her and explain what was going to happen next. Comforted, she digested the information, prayed and mentally prepared herself for the surgery.

Winchester, who had two previous Cesarean deliveries, had developed placenta percreta, and her placenta had invaded part of her bladder. Doctors noticed increased vascularity — a cluster of blood vessels that are unusually enlarged and susceptible to rupture during delivery — between her bladder and uterus. To reduce bleeding, her physicians made an incision high on Winchester’s uterus to avoid touching her placenta. Despite minimal bleeding during the actual delivery of her 6-pound 7-ounce baby girl, Brooklyn, Winchester began bleeding profusely from the numerous vessels that had fed her invasive placenta.

She lost copious amounts of blood during surgery that required a massive 25-pint blood transfusion. “I hardly had blood pumping through my veins,” and if I had gone to a hospital in my hometown of Alexandria, I would have died,” Winchester said. “Hospitals in smaller communities don’t carry the large volume of blood or provide the comprehensive care that I needed to survive.”

WORLD-RENOWNED EXPERTISE

Winchester credits her story of survival to the highly skilled, multidisciplinary team of physicians at Texas Children’s Pavilion for Women who meticulously prepared and planned for her emergency surgery.

“Our experience and success in treating even the most severe cases of morbidly adherent placenta continues to attract a growing number of patients from across the country,” said Texas Children’s Ob/Gyn-in-Chief Michael A. Belfort, MD, a world-renowned expert in morbidly adherent placenta and founder of the Morbidly Adherent Placenta Program at Baylor College of Medicine. “Our success is rooted in our ability to work as a team.”

Patients with morbidly adherent placenta receive care from a diverse group of specialists representing different areas of expertise, including maternal-fetal medicine, gynecologic oncology, anesthesiology, urology, neonatology, radiology, critical care medicine and blood bank services.
The doctors and nurses treated me like I was family. I still keep in contact with Dr. Fox and send her photos of Brooklyn, so she can see how fast she’s growing.

- KHADAJAH WINCHESTER

“Since it’s difficult to predict how severe the actual bleeding will be for each individual patient, our team works closely with the hospital’s blood bank to ensure an adequate supply of blood products is available for surgery, and to help manage transfusions,” Fox said.

“We rely on our anesthesiology team to administer blood and draw labs to ensure electrolytes remain stable, in addition to keeping the patient comfortable. Urologists are mobilized to provide expertise when the placenta imbeds itself into the urinary system.”

The approach that gynecologic oncology surgeons use to remove uterine cancer inspired the team’s technique for treating placenta percreta, since the abnormal placenta acts like a cancer invading the outside of where it is supposed to be growing.

“We take a wider approach when we perform a hysterectomy to reduce the potential for blood loss,” said Texas Children’s gynecologic oncologist and surgeon, Concepcion Diaz-Arrastia, MD. “We remove the uterus and cervix in a modified radical hysterectomy, along with a small amount of the tissue that attaches the uterus to the pelvis as if it were cancerous.”

Belfort and his extraordinary team have treated 82 patients with morbidly adherent placenta in the past three years at the Pavilion for Women.

**EARLY DIAGNOSIS, BETTER OUTCOMES**

Early diagnosis of morbidly adherent placenta prior to delivery is crucial to help ensure the best possible outcomes for mother and baby. Texas Children’s maternal-fetal medicine experts recommend that patients with risk factors for morbidly adherent placenta consult with specialists early — ideally by 24 to 28 weeks of pregnancy.

“An early referral gives us time to talk to patients before we admit them to the hospital, and we can review each step of their personalized treatment plan,” Fox said.

A typical treatment plan includes state-of-the-art imaging, including 2-D and 3-D ultrasound and, in some cases, magnetic resonance imaging (MRI) to confirm cases difficult to see without ultrasound. After diagnosis, women with morbidly adherent placenta can expect more frequent prenatal visits compared to routine pregnancies. They are then scheduled for a planned C-section delivery at 34 to 35 weeks to minimize potential blood loss.

These women are admitted to the hospital one week prior to their scheduled deliveries — earlier, if they have bleeding or contractions. Once admitted, patients meet the Pavilion for Women’s multidisciplinary team of specialists prior to surgery.

In general, Fox said the safest way to manage morbidly adherent placenta is to deliver the baby by a Cesarean section followed immediately by hysterectomy. In select cases in which the placenta is not low-lying and when a patient would prefer to retain her uterus, it may be possible to remove the part of the uterus where the placenta is attached and repair the remaining organ. This option is rare and must be determined on a case-by-case basis.

**A YEAR LATER**

Nearly a year and a half after her surgery, Winchester and her daughter, Brooklyn, are doing very well. Last summer, she, her husband and their children moved to Pearland — further from their hometown of Alexandria, but closer to Texas Children’s, where Brooklyn’s story began.

“I can’t thank Dr. Fox and the team enough for saving my life,” Winchester said. “The doctors and nurses treated me like I was family. I still keep in contact with Dr. Fox and send her photos of Brooklyn, so she can see how fast she’s growing.”

Currently, the Pavilion for Women’s Morbidly Adherent Placenta team is collaborating with other treatment centers to add to the growing body of research on this condition.

“There’s still a lot to be learned about morbidly adherent placenta,” Fox said. “Our goal is the safety and compassionate care of our mothers and babies. It is absolutely a team approach.”

As a mom of three boys under age 5, Lindsey Gillespie had the pregnancy routine down. So, when the tireless emergency room nurse from Dallas became pregnant with baby number four, she opted to have the gender-revealing ultrasound to determine whether to buy pink or blue baby clothes. Instead, the results planted seeds of worry: Gillespie’s obstetrician diagnosed her with morbidly adherent placenta.

While all three of her kids were C-section babies — a major risk factor for placenta accreta — Gillespie didn’t know anything about this pregnancy complication. She was told she’d need a hysterectomy after delivery, which “just devastated” her, she said, even though she wasn’t planning on having any more children.

But without the right treatment and specialized care, she could bleed to death. Her doctor had never treated a patient with placenta accreta and knew of few doctors who did in the Dallas/Fort Worth area Gillespie called home.

Weeks of frantic phone calls and Google searches finally led Gillespie to Texas Children’s Pavilion for Women, where she met with Ob/Gyn-in-Chief Michael A. Belfort, MD. Despite verification of placenta percreta, Gillespie’s delivery went smoothly and she gave birth to a healthy son, Gabriel, at just the right time — 34 weeks.

“We named him Gabriel because we wanted an angel on our side,” she said.

Following delivery, the team of Drs. Michael Belfort, Concepcion Diaz-Arrastia, Karin Fox and Alireza Shamshirsaz separated and removed Gillespie’s uterus and abnormal placenta, which had attached itself to the bladder and surrounding tissues. Remarkably, Gillespie did not need a blood transfusion and sailed through recovery. Today, she is living the active life of a working mother of four kids.
I n the past, if we were sick and sought medical care, we would see our family doctor during routine office hours or, if it was urgent, go to an emergency room. But over time, our expectations have changed. We now expect convenient care at convenient times.

Most after-hours clinics are staffed by non-pediatric mid-level providers, with a few offering care from non-pediatric physicians. From the standpoint of a child’s health care provider, this is precisely the problem. As pediatric care specialists, we frequently need to reiterate that children are not simply “little adults,” and the care they receive at these clinics is often unreasonable. We know that more than 50 pediatric primary care practices throughout the city and several urgent care locations.

Our Texas Children’s Pediatrics network comprises 53 practices spread throughout the Greater Houston area. Several of our practices provide after-hours care for established patients. In addition to these, several more of our practices offer acute care visit appointments into the early evening hours, and many of our practices offer Saturday morning hours.

Despite our efforts, the greater pediatric community has not been afforded this type of quality pediatric after-hours care. We have much work to do, and I am delighted that we’ve now opened Texas Children’s Urgent Care clinics throughout the Greater Houston area, so that we will be able to provide this type of quality pediatric care.

In 2014, the American Academy of Pediatrics issued a policy statement advising pediatricians to discourage the use of retail-based urgent care clinics for their pediatric patients, citing the delivery of less-than-optimal care and the loss of continuity of care. This recommendation presents a quandary for the pediatric community. Simply advising our families not to seek care at one of these clinics is unreasonable. We know that more and more of our families will continue to seek after-hours urgent care. But we also know that making ourselves available throughout the community will go a long way toward preventing families from getting sub-par pediatric care.

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Texas Children’s Hospital was built on a promise to provide the highest quality care to all who need it. After more than 60 years, our mission has not changed. With more than 3 million annual patient encounters, we are extending leading health care to more children and women than ever before.

But Texas Children’s is at an important moment in its history, when the hospital must grow to continue to provide the finest care available to the people of Houston, the region, the nation and beyond. To address current challenges and in order to anticipate patients’ needs — both now and in the future — we have launched Promise: The Campaign for Texas Children’s Hospital.

The Promise Campaign is a comprehensive $475 million endeavor that will focus on five key priorities.
At just 13 years old, Karla was diagnosed with a congenital heart defect. Her condition threatened not only her dream of graduating high school — it threatened her life. When medication did nothing to alleviate her symptoms, experts at Texas Children’s Hospital decided that surgery was her best option, and a pump was implanted in Karla’s heart to assist with the proper flow of blood.

Weeks later, Karla walked across the stage at her graduation with her family cheering her on. Texas Children’s Hospital had saved Karla’s life and helped turn her dream into a reality.

Texas Children’s Hospital treats the sickest children — just like Karla — with conditions so complex they simply can’t receive the world-class care they need at any other hospital. More and more families are coming to Texas Children’s for lifesaving care. For the sickest children, care at Texas Children’s means the difference between life and death.

But we have reached a critical point in the hospital’s history. Current facilities were built for a different time and are no longer large enough. Thirty years ago, they were state-of-the art. Equipment was smaller. Today, there is so much more technology and equipment, and it is larger and more complex. And too often, our facilities are so full that we are unable to accept transfers of patients who desperately need our help.

**Bottom line:** Texas Children’s has outgrown the space we currently have at the Texas Medical Center campus, and the time for expansion is now.
**THE CHALLENGE**

**Critical care**
The pediatric intensive care unit (PICU) and cardiovascular intensive care unit (CVICU) often operate beyond capacity. Rooms that once functioned very well can no longer comfortably accommodate patients, along with the equipment they require, nor can they give families the space and privacy they need and deserve.

**Surgical care**
Among the 1,200 pediatric surgeons in the United States, few have the expertise to perform the complex, specialized procedures for which Texas Children’s is known. Every year, we treat the most critically ill patients who require extremely complex surgery. We need larger operating rooms, and more of them, all equipped with the most up-to-date technology and equipment.

**Emergency care**
In the past two years alone, visits to the Emergency Center (EC) have increased by more than 25 percent. Texas Children’s receives 50 percent of all pediatric trauma-related 911 and EMS transports.

**OUR PROMISE**

Funds raised through the Promise Campaign will provide support for the construction of a new, 19-floor pediatric tower.

- We will build new and larger PICUs and CVICUs, moving them from their current location in the West Tower and significantly increasing the total number of critical care beds available. These rooms will be specially designed and configured so that parents can stay with their children overnight and so that all necessary equipment is easily accessible for caregivers.

- We will add more operating rooms (ORs) that are larger and more flexibly designed to accommodate patients who require the most complex procedures. These, too, will be moved from the West Tower.

- Relocating the PICUs, CVICUs and ORs will free up space in the West Tower, where the EC is located, to completely redesign the EC so that patients can be triaged and treated more quickly and efficiently.

At Texas Children’s, we are committed to taking care of every critically ill child who comes to us for help. The time to grow and expand is now.
THE CHALLENGE
When Bennett, who lives in The Woodlands, was diagnosed with adenoviral pneumonia, he had to be rushed more than 30 miles from his home for lifesaving treatment at Texas Children’s Hospital.
But what if the ambulance hadn’t arrived in time?
Some of the fastest-growing communities in the nation lie just north of Houston, with a combined population already exceeding 1.1 million. When dedicated, comprehensive pediatric health care is needed, no family should have to drive 30, 40 or 50 miles away.

OUR PROMISE
To meet the growing needs of a sprawling community, the Promise Campaign will support the construction of Texas Children’s Hospital The Woodlands, bringing world-class care where it’s needed most — close to home.

Texas Children’s Hospital The Woodlands will include:
• An outpatient tower opening in 2016 with specialty medical services, including cancer, cardiology, allergy/immunology/rheumatology, and diabetes/endocrinology.
• An inpatient tower that will open in 2017 with the only dedicated pediatric emergency center and PICU in the region.

LEADERSHIP OF TEXAS CHILDREN'S HOSPITAL

MICHELLE RILEY-BROWN
• Executive Vice President, Texas Children’s Hospital
• President, Texas Children’s Hospital The Woodlands
• President, Texas Children’s Hospital West Campus, 2012–2014
• Fellow, American College of Healthcare Executives
• BA, Tulane University
• MHA, Health Administration, Washington University School of Medicine in St. Louis
• Native of New Orleans, Louisiana

CHARLES HANKINS, MD
• Chief Medical Officer, Texas Children’s Hospital The Woodlands
• Chief Medical Officer, Texas Children’s Hospital West Campus, 2011–2014
• MD, University of Tennessee
• Fellowship in neonatology/perinatal medicine, Walter Reed Medical Center
• MBA, University of Tennessee
• Board Member, March of Dimes Board of Directors/Houston area
• Native of East Tennessee

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— Michelle Riley-Brown,
Executive Vice President, Texas Children’s Hospital
President, Texas Children’s Hospital The Woodlands
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Cover: Elyse Mata gently kisses her daughter, Knatalye Hope and Adeline Faith Mata, before the conjoined twins are christened.