Congenital diaphragmatic hernia (CDH) is a complex disease that affects approximately 1,000 babies born each year in the United States. A disease where a hole in the fetal diaphragm – the muscle separating the abdomen and the chest – can lead to underdevelopment of the lungs and potentially life-threatening breathing difficulties after birth, CDH requires specialized expertise to improve patient outcomes.

Physicians affiliated with Children’s Memorial Hermann Hospital and McGovern Medical School at UTHealth have a long history of dedication to caring for babies with CDH and continue utilizing innovative methods and advanced research to offer alternative treatment options, enhance patient care and optimize outcomes.

In addition to establishing one of the first organized programs for pediatric extracorporeal membrane oxygenation (ECMO) in Texas and earning the ECMO Center of Excellence–Gold Level designation from the Extracorporeal Life Support Organization (ELSO), Children’s Memorial Hermann Hospital is home to an integrated CDH team of affiliated specialists. The team includes affiliated maternal-fetal medicine specialists, neonatologists, pediatric surgeons, pediatric anesthesiologists and pediatric specialists, who provide seamless care from prenatal diagnosis to delivery through childhood, with a smooth transition into adolescent specialty care. This treatment approach has translated to higher-than-expected risk-stratified survival, as well as one of the highest rates of surgical repair in the world.
Leaders in Innovation: CDH Care

Impacting CDH Patient Care Globally

The affiliated team continues to impact the current state of CDH patient care globally. Physicians affiliated with The Fetal Center at Children’s Memorial Hermann Hospital are at the forefront of prenatal treatment for CDH, participating in an international research trial to provide leading-edge techniques for the treatment of severe CDH in babies still in the womb. The physician team from the division of General and Thoracic Pediatric Surgery at McGovern Medical School continues to be a leader in the comprehensive care of CDH from postnatal surgery to long-term follow-up, conducting research to optimize postnatal treatment and care for CDH patients.

In addition, the affiliated team members coordinated the founding of the CDH Study Group, an international consortium of centers that track long-term outcomes of CDH patients to gain knowledge on the effects of the disease and CDH procedures. The affiliated physicians have played a major role in the continued advancement of CDH care, having cumulatively published more medical journal articles on CDH in the past 20 years than most centers in the United States, providing education on CDH by teaching courses locally and giving lectures throughout the country, and furthering research by gathering data to track long-term outcomes.

Advanced Techniques in the Prenatal Period

Anthony Johnson, D.O., Co-director of The Fetal Center, Professor of Obstetrics, Gynecology and Reproductive Sciences, and Professor of Pediatric Surgery at McGovern Medical School, spearheaded a consortium through the North American Fetal Therapy Network (NAFTNET) to bring an innovative treatment option from Europe to the United States as part of an international clinical trial to improve care for CDH patients. Dr. Johnson is working to advance utilization of this treatment – fetoscopic endoluminal tracheal occlusion (FETO) intervention – versus conventional care for severe CDH in the U.S.

FETO intervention, a minimally invasive procedure performed during pregnancy, involves placing a balloon in the baby’s airway, causing a backup of fluid produced by the lungs. As the fluid builds, lung growth and development is promoted. Based on early results of preliminary studies, the fetoscopic balloon device for FETO intervention has shown promise as an additional therapy to improve outcomes in babies with the most severe forms of CDH. Further studies are needed to confirm the early results.

Through Dr. Johnson’s efforts, The Fetal Center at Children’s Memorial Hermann Hospital is one of only eight U.S. fetal centers granted FDA approval and institutional approval to offer the FETO intervention procedure. The affiliated team has recently completed the trial’s feasibility study, aimed to demonstrate The Fetal Center’s ability to safely insert and remove the FETO device in severe CDH fetuses.

Following the completion of the feasibility study, The Fetal Center has been approved to join the Severe Arm of the Tracheal Occlusion to Accelerate Lung Growth (TOTAL) Trial, led by Jan Deprest, M.D., Ph.D., Professor of Obstetrics and Gynecology at the University Hospitals Leuven in Belgium. The TOTAL Trial – the international, multicenter randomized controlled trial – is evaluating survival and morbidity in fetuses with severe CDH detected prior to 29 weeks gestation.

The affiliated team continues the founding of the Severe Arm of the TOTAL Trial in the U.S. Dr. Johnson and the fetal surgeons affiliated with Children’s Memorial Hermann Hospital and McGovern Medical School, with extensive experience in fetoscopic intervention (having performed more than 800 fetoscopic cases), have worked with Professor Deprest in Belgium and in Houston to bring the FETO technique to The Fetal Center. In collaboration with Professor Deprest, Dr. Johnson is leading the Severe Arm of the TOTAL Trial in the U.S.

Exclusion criteria are:

- Additional life-threatening anatomic or genetic anomalies
- Multi-fetal pregnancy
- History of latex allergy
- Shortened cervix (less than 15 millimeters)
- Preterm labor or uterine anomaly strongly predisposing to preterm labor

Patients must meet specific criteria to be eligible for participation in the Severe Arm of the TOTAL Trial.

Inclusion criteria are:

- Isolated left CDH
- Normal fetal karyotype
- Gestational age between 27° to 29° weeks
- Severe CDH as defined by an observed-to-expected lung-to-head ratio of < 25% on fetal ultrasound
- Liver herniation into the fetal chest

Mothers must be between the ages of 18 and 50 with a singleton pregnancy and be willing to live within 30 minutes of Children’s Memorial Hermann Hospital while participating in the trial. The trial examines this group of severe CDH patients to determine whether tracheal occlusion will improve the overall outcome as compared to conventional care for severe CDH.

The balloon is placed at 27° to 29° weeks gestation and is removed between 34° and 34° weeks gestation due to the risk of rupture of the membranes and premature labor. Comprehensive evaluation is essential to determine whether patient is a candidate for prenatal repair.

To contact The Fetal Center regarding the Severe Arm of the TOTAL Trial, call 832.325.7288.
Leaders in Innovation: CDH Care

Postnatal Care – Approaching Every CDH Patient as a Potential Survivor

Kevin P. Lally, M.D., M.S., Surgeon-in-Chief at Children’s Memorial Hermann Hospital as well as Chair and Professor of Pediatric Surgery at McGovern Medical School, has taken a progressive approach to the care and treatment of patients with CDH for over 20 years. As head of the affiliated pediatric surgery team, he leads the postnatal side of the comprehensive CDH care approach provided at Children’s Memorial Hermann Hospital. Dr. Lally’s years of work, research and expertise have resulted in major contributions to the advancement of CDH patient care across the globe.

Under Dr. Lally’s leadership, the affiliated pediatric surgery team continues to make progress in the management of CDH with optimized mechanical ventilation strategies, pharmacotherapy and other therapeutic modalities, including extracorporeal membrane oxygenation (ECMO) – a treatment used for newborns and children who are critically ill with respiratory failure. Children’s Memorial Hermann Hospital is one of only two hospitals in Houston offering pediatric ECMO and has been recognized as a Designated Center of Excellence by the Extracorporeal Life Support Organization (ELSO) since the inception of the award in 2006. ELSO recognizes ECMO programs worldwide that distinguish themselves by having processes, procedures and systems in place that promote excellence and exceptional care in extracorporeal membrane oxygenation.

By utilizing these strategies and building upon established practices from their extensive experience in CDH patient care, the affiliated physicians at Children’s Memorial Hermann Hospital take a very aggressive approach to the management of CDH. The affiliated team is one of a handful of pediatric surgery teams in the country that operate on 93 percent of all postnatal patients, repairing the hole in the diaphragm surgically to give each child a chance of survival.

Research – Home to the International CDH Study Group

Overall worldwide survival of infants diagnosed with CDH has increased from about 55 percent to close to 70 percent in the last 30 years. Unfortunately, CDH remains a challenge for physicians, surgeons and scientists. Although the defect can be corrected with surgery, the arrest in prenatal development of the lungs results in unacceptably high rates of neonatal mortality and long-term complications for children born with CDH.

Thanks to more accurate prenatal diagnosis and the work of the international CDH Study Group – led by physicians affiliated with Children’s Memorial Hermann Hospital and McGovern Medical School – the global survival rate of infants born with CDH is steadily rising. Coordinated by Dr. Lally and members from multiple specialties and centers, the CDH Study Group is a coalition of centers from around the world that track CDH patient outcomes in an international database – the CDH Registry. Based on risk-adjusted data, Children’s Memorial Hermann Hospital’s outcomes are in the top 10 percent or higher worldwide.

In the past 20 years since the CDH Study Group was founded, the voluntary collaborative has gathered data on more than 10,000 babies with CDH. The registry now represents centers in 15 countries. Information from this registry has been used in more than 47 CDH Study Group reports. These projects evaluate diagnostic and prognostic variables such as preductal oxygen saturation, defect size/anomaly association and pulmonary hypertension.

Investigators at Children’s Memorial Hermann Hospital are also engaged in promising research using extracellular vesicles, small membrane particles released from mesenchymal stem cells, to help manage pulmonary hypertension and reduce the mortality rate of CDH. While their research remains in the early stages, their aim is to translate innovative therapies to the clinical setting as quickly as possible.

Leaders in Innovation: CDH Care

Comprehensive Long-term Care

Matthew Harting, M.D., M.S., pediatric surgeon affiliated with Children’s Memorial Hermann Hospital and Assistant Professor of Pediatric Surgery at McGovern Medical School, leads the Comprehensive Center for CDH Care – a long-term multidisciplinary clinic for CDH patients. This specialized clinic provides optimal care for CDH patients from postnatal treatment at infancy through follow-up care during childhood, with a seamless transition of care to adolescence and adult subspecialists – a unique service that offers care for the long term, making this clinic one of only a few of its kind in the country.

Under Dr. Harting’s direction, the Comprehensive Center for CDH Care is staffed by a team of specialists from all associated medical disciplines, providing patients with a one-stop-shop approach that allows families to see all pediatric specialists relevant to their case, in a single visit under one roof.

In addition to offering convenience to patients and families, this approach allows physicians to optimize patient care, collect data and understand the challenges faced by families of children with CDH in ways that were previously impossible.

Most children who survive severe CDH have long-term pulmonary problems. While the pediatric specialists affiliated with The Fetal Center can assess how much pulmonary hypoplasia infants are likely to have at birth, there are critical aspects of patient survival related to the lung vasculature that are difficult to measure and predict.

To that end, specialists at the Comprehensive Center for CDH Care track a range of outcomes across various subsets of its patient population, creating a rich source of long-term data that enables the affiliated team to identify the best interventions for each case. Data collected can be tied to decisions about future research, enabling the physician researchers to positively impact patient outcomes throughout the timeline of patient care.

Continuing Efforts to Advance Care for CDH Patients

The affiliated physicians at Children’s Memorial Hermann Hospital and McGovern Medical School are internationally recognized leaders in providing state-of-the-art fetal care, neonatal critical care and minimally invasive surgical repair of CDH. The care they provide is based on data collected and new insights gained through the international CDH Study Group and Registry. These specialists will continue working to advance care for CDH patients around the world and bring hope to families faced with a CDH diagnosis.

For more information about our long-term approach to CDH care, visit: childrens.memorialhermann.org/cdh
“We saved our daughter for our wedding anniversary,” Courtney says as she reflects on the impactful events she and her husband, Robert, have experienced together. They both remember the feeling of pure joy in January 2016 when finding out they were pregnant with their second child – a baby girl – after three years of trying. Their happiness soon gave way to worry, though, when Courtney’s obstetrician said her ultrasound scan results suggested the baby’s stomach was in the wrong place – an indication of congenital diaphragmatic hernia (CDH).

Courtney’s obstetrician, located in her hometown of San Antonio, referred her to a local high-risk pregnancy specialist to perform additional scans and confirm the diagnosis. After the testing, the high-risk pregnancy doctor informed Courtney that her baby was indeed suffering from the suspected condition and that the survival rate for CDH is very low.

CDH is a hole formed in the baby’s diaphragm in utero that causes the intestines and abdominal organs to migrate into the chest cavity, leading to compression and underdevelopment of the lungs. Although the hole in the diaphragm can be surgically corrected after birth, the underdevelopment of the lungs prenatally results in a high fatality rate or long-term complications for a surviving child. While its cause is unknown, CDH affects about 1,000 babies born each year.

“We were overwhelmed. I wanted to know if there was anything we could do to save our baby,” Courtney remembers. The high-risk pregnancy doctor told Courtney about a hospital in Houston taking part in an experimental study on fetal treatment for CDH. That day, Courtney called The Fetal Center at Children’s Memorial Hermann Hospital for an appointment.

The Fetal Center

Courtney and Robert traveled to Houston the next week to see Anthony Johnson, D.O., Co-Director of The Fetal Center and a high-risk pregnancy specialist at McGovern Medical School at UTHealth. Dr. Johnson and the affiliated team at The Fetal Center are participating in an experimental trial to treat babies diagnosed with severe CDH before birth through a minimally invasive procedure called fetoscopic endoluminal tracheal occlusion (FETO). FETO intervention, performed during pregnancy, involves placing a balloon in the unborn baby’s airway, causing a backup of fluid produced by the lungs. As the fluid builds, lung growth and development is promoted.

Outcomes for CDH babies have shown improvement when the FETO intervention procedure is coupled with the traditional treatment for CDH – surgery after birth to close the defect. According to Dr. Johnson, “The survival rate for severe CDH is less than 20 percent without fetal intervention based on international data, so it is important to pursue research and innovative procedures like FETO that can offer families hope through alternative treatment options.”

During her initial visit, Courtney underwent advanced scans and consulted with a number of affiliated specialists to discuss her options. Courtney met with the lead FETO nurse coordinator, Alex Patch, R.N., who helped walk her through the evaluation process. “Alex was extraordinary throughout the whole experience,” Courtney says. “I am so grateful for her support during this time when I had so many questions.”

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After a follow-up MRI scan showed that Courtney qualified for FETO intervention, Dr. Johnson sat down with Courtney and explained step-by-step the potential risks and outcomes for fetal and postnatal treatment of severe CDH. He made it clear that FETO intervention is not at all a guaranteed fix and stressed the importance of comprehensive care from pregnancy through delivery and after birth. “CDH is a complex disease,” Dr. Johnson says. “No matter where families choose to receive care, babies with severe CDH must be cared for by a hospital that has a multidisciplinary program with a commitment to all stages of care – prenatal, postnatal and long-term follow-up – and a research engine pursuing new avenues for treatment.”

Courtney remembers the impact this meeting had on her. “Other doctors had already told me that my baby was not going to live,” Courtney says. “I wanted someone to tell me they were going to try, and that is what Dr. Johnson and the team at The Fetal Center did for me. They did not sugarcoat anything and told me all of the risks up front, but they were also sympathetic to my situation.”

On July 7, 2016, Courtney underwent FETO intervention, performed by Dr. Johnson and the multidisciplinary team affiliated with The Fetal Center. The procedure went well, and the balloon was successfully inserted into the baby’s trachea. By chance, this was the same day as Courtney and Robert’s four-year wedding anniversary. Courtney remembers, “That was an awesome anniversary. After the procedure to save our baby girl was over, Alex and the other FETO nurses took the time to get Robert and me an extra-special dinner to eat together. We really appreciated that.”

The next step was a follow-up operation in August 2016 to remove the balloon from the baby’s airway. Courtney says, “My baby had her chin pointed down, so the doctors could not gain access to her trachea to get the balloon out.” Courtney had an emergent C-section shortly after, and the affiliated team removed the balloon at delivery.

“Aryah was holding her own without the assisted breathing machine, which is unheard of for a baby with her severe CDH diagnosis”

Baby Aryah

On August 21, Baby Aryah was born. Weighing only 4 pounds, 11 ounces, she went straight to the Level IV Neonatal Intensive Care Unit (NICU), was intubated and put on an oscillator to assist breathing. She spent less than 24 hours intubated since she was breathing on her own. “Aryah was holding her own without the assisted breathing machine, which is unheard of for a baby with her severe CDH diagnosis,” Courtney says.

To repair the hole in her diaphragm, Aryah underwent surgery at 4 days old. Mary T. Austin, M.D., a pediatric surgeon at McGovern Medical School, Dr. Johnson, and other members of the multidisciplinary team affiliated with The Fetal Center performed the surgery to reposition Aryah’s stomach, intestines, spleen and liver as well as repair the diaphragm. “Aryah surprised everybody with how well she did during and after the postnatal surgery,” says Dr. Johnson.

“Aryah came out with no issues at all, and they were able to extubate her at 9 days old. That’s when I got to hold her for the first time,” Courtney remembers. Aryah stayed in the NICU, receiving care from the nurses, who were “extremely comforting from the get-go and took care of anything our baby needed immediately,” says Courtney. At 11 days old, Aryah was able to get her first visit from her big brother, Rylyn, who was 5 at the time. On September 21, 2016, all four members of their family went home from Children’s Memorial Hermann Hospital. Baby Aryah only required medicine for acid reflux.
**Aryah's CDH Story: The First FETO Intervention Patient of The Fetal Center**

**First Birthday**

Baby Aryah turned one in August 2017 and is surpassing milestones most thought unimaginable. A month after celebrating Aryah’s first birthday, Courtney explains that her baby girl is more advanced than anyone expected. “With CDH, there’s a high risk of developmental delay, but Aryah is doing great,” Courtney says. “Our physical therapist told us Aryah would not be walking until she was a year and a half, but she is running and trying to climb stairs at 13 months.”

Courtney and Robert are overjoyed by Aryah and her miraculous development. “I owe everything to The Fetal Center team because we went from having no hope that our baby would survive to having her with us today. They have always treated us like we’re family. If I had to go through all of this again, I wouldn’t want to go anywhere else.”

**CDH Community**

To continue Aryah’s pediatric care, Courtney takes Aryah back to Children’s Memorial Hermann Hospital for regular checkups with the Comprehensive Center for CDH Care, led by Matthew Harting, M.D., a pediatric surgeon at McGovern Medical School. The Center is staffed by a team of pediatric CDH specialists from all associated medical disciplines who provide seamless care from prenatal treatment at infancy through follow-up care during childhood, with a smooth transition into adult specialty care – a unique service offering care for the long term.

“We love our team of doctors and nurses, and we visit Children’s Memorial Hermann Hospital every chance we get,” Courtney says. “I feel more reassured having the follow-up clinic care for Aryah because I worry that even great pediatricians don’t know the complexities of CDH. It is wonderful that a CDH-specialized team is following her progress.”

Recently, Courtney signed up with The Fetal Center as a support contact for other patients impacted by CDH. “I am here for anyone who finds themselves in a similar situation since I’ve been there firsthand. When I run into a CDH family now, I tell them to contact The Fetal Center at Children’s Memorial Hermann Hospital – they will take care of y’all.”

To learn more about the comprehensive CDH care provided by physicians affiliated with Children’s Memorial Hermann Hospital, visit: childrens.memorialhermann.org/cdh

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**Alexandra Patch, RN, Named The Fetal Center Practice Manager**

Alexandra Patch was recently named Practice Manager for The Fetal Center. Having joined The Fetal Center in February 2016, Alexandra has continually demonstrated exceptional nursing and management skills in her specialized role as the lead FETOP Program Nurse. Prior to joining The Fetal Center, Alexandra served as a dedicated nurse in the Cath Lab at CHI St. Luke’s Health in Houston and spent four years at Dartmouth-Hitchcock Medical Center in New Hampshire as a postoperatively care nurse for urology, gynecology, and surgical oncology patients. She graduated from the University of Vermont with a Bachelor’s Degree in Nursing.

To contact Alex with clinically related questions, call 832.325.7288.

**Anthony Johnson, D.O., Leads Ultrasound Training Program in Ghana**

Dr. Anthony Johnson, serving as team leader of the International Society of Ultrasound in Obstetrics and Gynecology’s (ISUOG) training team for Phase II of the Ghana Outreach Program, traveled to the Ashanti region of Ghana to help improve maternal and child health by aiding the creation of a local ultrasound training program. The Ghana Outreach Program – a collaborative effort led by ISUOG, Women’s Health to Wealth and GE Healthcare – aims to reduce the number of maternal deaths by training local midwives, sonographers and OB/GYN practitioners in ultrasound so that they may become trainers. In his role as Chair of the ISUOG Outreach Committee, Dr. Johnson directs and organizes various outreach projects in the Middle East, Sub-Saharan Africa, Southeast Asia and Haiti.

**Mary Austin, M.D., Discusses Her Personal Journey with Spina Bifida**

Dr. Mary Austin, a pediatric surgeon at McGovern Medical School at UTHealth, serves as the main feature in a recent STAT article written by Charlotte Huff. In the article, Huff details Dr. Austin’s personal struggle with spina bifida and writes, “Dr. Mary Austin refrained from telling her patients about her own birth defect, for fear of swaying their decisions about treating their unborn children.”

To read the full STAT article on Dr. Austin, visit: childrens.memorialhermann.org/patient-stories/a-surgeon-s-secret

**Kenneth Moise, Jr., M.D., Recognized with 2016 Roy M. Pitkin Award**

Dr. Kenneth Moise, Co-Director of The Fetal Center and Professor of Obstetrics, Gynecology and Reproductive Sciences at McGovern Medical School, is an author of a research article cited as one of the most outstanding papers published in Obstetrics & Gynecology in 2016. He is the first author of the paper to be recognized with a 2016 Roy M. Pitkin Award, an award established in 1998 “to honor departments of obstetrics and gynecology that promote and demonstrate excellence in research.” The award is granted by the editors of Obstetrics & Gynecology who select the top articles that have been published within the past year in the journal. The winning article from the McGovern Medical School Department of Obstetrics, Gynecology and Reproductive Sciences is “Circulating Cell-Free DNA to Determine the Fetal RHD Status in All Three Trimesters of Pregnancy.”
News of Note

Patient Education Videos

Great Arteries

The Fetal Center offers families comprehensive, objective educational tools about fetal complications that may require intervention. The latest online patient education video series highlights select congenital heart defects, including:

- Coarctation of the aorta (CoA)
- Hypoplastic left heart syndrome (HLHS)
- Tetralogy of Fallot (ToF)
- Transposition of the great arteries (TGA)

To watch the videos, visit: childrens.memorialhermann.org/thefetalcenter/patient-education

Spina Bifida & TTTS Published Patient Outcomes

The Fetal Center values transparency in patient outcomes. Since 2011, the affiliated team has performed 400 cases of laser photocoagulation for the treatment of Twin-Twin Transfusion Syndrome (TTTS) with survival of both babies seen in 72 percent of cases.

For fetal spina bifida, The Fetal Center has evaluated more than 200 patients with outcomes mirroring those reported in the Management of Myelomeningocele Study (MOMS). In addition, physicians affiliated with The Fetal Center are the first in the world to utilize a patch made from cryopreserved human umbilical cord for fetal spina bifida repair.

To view The Fetal Center's outcomes data, visit: childrens.memorialhermann.org/thefetalcenter/outcomes

Contacts

Located within the UT Physicians Professional Building in the Texas Medical Center, The Fetal Center is affiliated with Children’s Memorial Hermann Hospital and the physicians at McGovern Medical School at UTHealth.

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Email: thefetalcenter@memorialhermann.org

To view The Fetal Center’s online resources, visit: childrens.memorialhermann.org/thefetalcenter