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Taking Neonatal Care to a Higher Level

The Neonatal Intensive Care Unit (NICU) at Children’s Mercy is officially the region’s only Level IV Neonatal Center, providing the highest level of neonatal care for the most complex and critically ill newborn infants.


A Level III facility can address the needs of most premature babies, according to Howard Kilbride, MD, Neonatology Division Director. What distinguishes a Level IV facility is having a full range of pediatric medical and surgical subspecialists and pediatric anesthesiologists available at the site of the neonatal intensive care. Level IV units have the capability of providing subspecialty and surgical support for all newborn conditions, including cardiovascular surgery.

“What makes us a Level IV center is the ability to handle fetal anomalies,” says Dr. Kilbride. “We offer unique services at Children’s Mercy for both term and preterm babies who have complications which require surgical and pediatric subspecialty care.

“Our goal is to help the community do the best job at caring for newborns in the safest, most appropriate locations; for the subset of newborns who need the highest level specialty care, that means bringing them here to provide that service.”

Transport Brings NICU to the Bedside

Since transporting the first tiny patient in 1971, the Children’s Mercy’s Critical Care Transport program has grown to one of the largest in the country performing nearly 4,500 transports — about one-fifth of them neonates — in the past year.

That experience is a huge factor in a moving environment where the patients are critically ill and the resources for care are limited.

“Transport is a very complex environment. That’s why our team members only do transports and all our team members have at least three years of neonatal/pediatrics critical care experience,” says Sherry McCool, RRT-NPS, MHA, CMTE, Transport Director. “Our dedicated transport teams are very skilled and efficient at delivering care, anticipating what could potentially happen, and adapting to the situation.”

The transport team’s goal is to bring the Children’s Mercy NICU to the patient, stabilizing the patient at the referral hospital. Bringing a more stabilized pediatric patient back to Children’s Mercy reduces mortality and morbidity in the long run, according to McCool.

The transport program’s experienced team is capable of safely transporting extremely premature babies, newborns with heart defects and other congenital anomalies, and any other critically ill baby.

“These babies require very specialized care,” says Emily McNellis, MD, Director of Neonatal Transport Medicine for Children’s Mercy. “Our teams have the high-level skills to perform procedures a typical ambulance can’t provide. We bring a lot of experience and skill to the patient’s bedside.”
NICHD STUDIES TARGET HIGH-RISK POPULATIONS

The NICHD Neonatal Research Network centers perform clinical research to seek ways to improve the outcomes of both term and preterm high-risk infants. The Children’s Mercy-Truman-UMKC Center is one of 18 NIH-funded Neonatal Research Network centers in the nation.

Led by William Truog, MD, Director of the Center for Infant Pulmonary Disorders and Sosland Chair in Neonatal Research at Children’s Mercy and Professor and Associate Chair of the Department of Pediatrics at the UMKC School of Medicine, Children’s Mercy is currently involved in several important interventional studies in conjunction with other institutions within the NICHD Network. Each of these studies could have lasting implications for high-risk populations.

Two studies concern babies who have suffered birth asphyxia just before or after delivery, which puts them at high risk for brain injury, cerebral palsy or other debilitating conditions. About a decade ago it was found that providing therapeutic cooling for these babies resulted in more positive long-term outcomes.

One study is looking at the potential benefits of cooling for longer periods (five days vs. three days), or at lower temperatures (32º C vs. 33.5º C). This study was already under way when Children’s Mercy joined the network in 2011.

Another similar study is attempting to determine whether there are additional benefits in starting the cooling therapy between 6 and 24 hours after birth.

“This is a prime example of a study that wouldn’t be possible without such an expansive network of participating institutions, as the test pool consists solely of babies who for some reason couldn’t begin being cooled within the first six hours,” Dr. Truog says.

A recently begun study is measuring the benefits of using hydrocortisone on babies born before 30 weeks. For years, hydrocortisone took a back seat to dexamethasone, until problems with that drug were discovered after children were evaluated at the age of two. Children’s Mercy is active in getting babies enrolled in this study of the benefits of hydrocortisone in infants’ third and fourth weeks of life, with the goal of diminishing or reducing lung injuries due to prematurity.

Children’s Mercy also is testing one of two different kinds of surgery for premature babies who have developed intestinal problems, including necrotizing enterocolitis, an uncommon but devastating condition. There aren’t many subjects for this study, which requires two years to determine which procedure produces the better outcome.

“The network sponsors this study for babies who develop a need for intervention, and families allow the initial operation to be picked by chance, to best determine which approach produces a better overall outcome,” Dr. Truog says.
Since opening in March 2011, the Elizabeth J. Ferrell Fetal Health Center at Children’s Mercy Hospitals and Clinics has had more than 150 births and provided more than 300 integrated consultations.

Those numbers exceeded expectations, and will undoubtedly increase now that the center is operating in a new 12,000-square foot unit as of August 2012.

As one of the only programs to deliver babies within a pediatric hospital, the Fetal Health Center’s expanded, permanent space — which has doubled in size and includes two operating rooms, a resuscitation room and four labor-and-delivery rooms — allows the integrated team of experts on staff to accommodate both mother and newborn with state-of-the-art care before, during and after delivery.

“As our pediatric resources focus more on fetal anomalies, we have the opportunity to add services and technologies not currently available in our region,” says Howard Kilbride, MD, Division Director of Neonatology and Vice Chair of Perinatal Services at Children’s Mercy. “Just in the past year, we’ve increased our MRI capabilities dramatically. We’ve more than doubled our fetal cardiology assessment services, and we’re constantly meeting in multidisciplinary, collaborative ways to assess how best to apply our expertise.

“We’re positioned to not only expand what we’ve done,” Dr. Kilbride continues, “we’re in a position to open frontiers.”

“Our Fetal Health Center is a natural step in providing Level IV neonatology services,” Dr. Kilbride said. “After identifying babies prenatally who are going to need the most advanced services, it just makes a lot more sense to have them delivered in a place where we have top-level services readily available, rather than to have them separated from their mothers to be transferred here after birth.”

The center is also directly connected — via a private, covered bridge — to Truman Medical Center for rapid transfer of the mother in the rare emergency situation. In addition to the special delivery services, the Fetal Health Center offers prenatal care for selected high-risk newborns.

Developed and offered in collaboration with the University of Missouri-Kansas City School of Medicine, the Fetal Health Center provides the region’s most advanced care for selected high-risk newborns. The integrated center focuses on healthy moms with fetuses who have complex congenital malformations who will benefit from advanced diagnostics and/or the availability of a comprehensive spectrum of pediatric specialists during the newborn period.
As the Fetal Health Center grows, so does the need for additional services to meet the needs of the critically ill newborns delivered at Children’s Mercy. It’s estimated that nearly one out of 100 infants (.08 percent) is born with heart problems. Not all of these need immediate care, but for those who do, it’s life-saving, according to Tara Swanson, MD, cardiologist. The need for that care has spurred the development of a Ward Family Heart Center Fetal Cardiac Program.

The Fetal Cardiac Program is focused on early diagnosis so care can begin immediately. Of the more than 150 babies delivered by the hospital’s Fetal Health Center, 27 percent have been diagnosed with heart conditions.

The Fetal Cardiac Program offers fetal echo, consultations, and a full spectrum of cardiology and cardiovascular surgery services before and after birth.

“AS CARDIOLOGISTS, WE WANT TO DO A GREAT JOB CARING FOR THE PATIENT AND FAMILY FROM THE MOMENT THE FETUS IS DIAGNOSED UNTIL THE CHILD IS AN ADULT.”

Tara Swanson, MD
Director, Fetal Cardiac Program at Children’s Mercy; Assistant Professor of Pediatrics, UMKC School of Medicine
A team of Children’s Mercy Hospitals and Clinics investigators led by Stephen Kingsmore, MB, ChB, BAO, DSc, FRcPath, Director of the Center for Pediatric Genomic Medicine, has pioneered the use of groundbreaking next generation genome sequencing to rapidly diagnose critically ill infants.

As reported in the October issue of Science Translational Medicine, the team describes STAT-Seq® as a whole genome sequencing test — from blood sample to returning results to a physician — that delivers results in about 50 hours. Currently, testing even a single gene takes six weeks or more. Reducing test speed may reduce infant morbidity and mortality.

Speed of diagnosis is most critical in acute care situations, as in a neonatal intensive care unit (NICU), where medical decision-making is made in hours not weeks. Using STAT-Seq, with consent from parents, the investigators diagnosed acutely ill infants from the hospital’s NICU. By casting a broad net over the entire set of about 3,500 genetic diseases, STAT-Seq demonstrates for the first time the potential for genome sequencing to influence therapeutic decisions in the immediate needs of NICU patients.

“Up to one third of babies admitted to a NICU in the United States have genetic diseases and more than 20 percent of infant deaths are caused by congenital malformations, deformations and chromosomal abnormalities caused by genetic illnesses,” says Dr. Kingsmore. “By obtaining an interpreted genome in about two days, physicians can make practical use of diagnostic results to tailor treatments to individual infants and children.”

 Genetic diseases affect about three percent of children and account for 15 percent of childhood hospitalizations. Treatments are currently available for more than 500 genetic diseases. In about 70 of these, such as infantile Pompe disease and Krabbe disease, initiation of therapy in newborns can help prevent disabilities and life-threatening illnesses.

**New Technology Developed at Children’s Mercy**

STAT-Seq uses Children’s Mercy-developed software that translates physician-entered clinical features of individual patients into a comprehensive set of relevant diseases.

This software, SSAGA (Symptom and Software-assisted Genome Analysis), substantially automates identification of the DNA variations that can explain the child’s condition and may provide diagnosis. SSAGA software and the use of an Illumina’s HiSeq 2500® system, which sequences an entire genome at high coverage in about 25 hours, allows results in about 50 hours. Children’s Mercy was the first hospital with access to the HiSeq2500 prototype, and is the first hospital to acquire the sequencer.

“For us, this isn’t research, but a new approach to medicine here at Children’s Mercy,” says Dr. Kingsmore. “The results of our work immediately impact diagnosis and treatment of a patient, not a sample.”

To inquire about referring a patient or sending a sample, please visit childrensmercy.org/pediatricgenomicmedicine or call Rawni Anderson at (816) 234-3686.
One in every 10 babies born in the United States is admitted to a newborn intensive care unit because of premature birth or other medical condition. To support families in what can be a frightening, confusing and overwhelming time, Children’s Mercy offers the NICU Parent to Parent Program.

Children’s Mercy is part of the nationwide, 116-member March of Dimes NICU Family Support Program, which provides education and supportive activities for families with critically ill newborns.

Laura Miller, Manager of the NICU Parent to Parent Program, is dedicated to supporting the emotional needs of families upon admission to the NICU, throughout the length of stay, and beyond discharge.


Miller coordinates a variety of family-centered educational and support activities, which include admission orientation; a family/staff advisory council; a parent chat group where families can share experiences, concerns and hopes; a milestone calendar session where scrapbook pages are created; the “Breathe Easy Group” for families whose children have tracheotomies; and many more.

“Families need to feel that they’re not alone,” Miller says. “My sole job is to support the emotional needs of the NICU families and work to improve their experience here.”

For more information on the Parent to Parent program, contact Miller at (816) 983-6918.

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Children’s Mercy Hospitals & Clinics — Kansas City
Josh and Julie Bowen know firsthand how important the Fetal Health Center is for families in the region.

During a routine prenatal ultrasound, Landon, the Bowens’ son, was diagnosed with transposition of the great arteries.

The Bowens then met with Timothy Bennett, MD, Medical Director of Fetal Health Services, for an integrated prenatal consultation that allowed pediatric and surgical subspecialists to collaboratively evaluate Landon’s problem.

After delivery, Landon was taken to the neonatal resuscitation room to be stabilized. Because this room is adjacent to the delivery room, Josh was able to be with both Landon and his wife. Landon then underwent a heart surgery procedure at 2 a.m. and, again, the Bowens were able to be present and keep abreast of Landon’s situation.

“It was definitely one of those moments that we realized how grateful we were to be at the Fetal Health Center and not somewhere else,” Josh said.