

# Great EXPECTATIONS

The new Advanced Fetal Care Center will provide integrated care to children with congenital anomalies

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MUSC Children's Hospital has a long history of treating congenital heart anomalies, serving as the anchor hospital for the Children's Heart Program of South Carolina and providing all procedures and catheterizations for children with cardiac issues throughout the state. It offers the only pediatric cardiac intensive care unit in the state staffed by pediatric cardiologists and nurses specializing in the care of children with congenital heart disease.

As impressive as these achievements are, plans to open a new Children's Hospital and Women's Pavilion in 2019 have inspired clinicians who diagnose and treat congenital heart and other anomalies to think even bigger and envision a fully integrated model of care that bridges prenatal and postnatal life and provides a life plan for children once counted lucky if they survived the first few weeks after birth.

## The Advanced Fetal Care Center

The Advanced Fetal Care Center, which will be located in the new hospital, will provide a space where all MUSC Children's Hospital specialists involved in the prenatal and postnatal care of these children—the maternal fetal medicine (MFM) specialists who manage high-risk pregnancies, the neonatologists who stabilize the child

after birth, the pediatric subspecialists who can definitively diagnose anomalies, and pediatric surgeons who can operate to correct abnormalities—will be able to meet with the family as a team to discuss the diagnosis, its implications for the child's life, and possible treatment options. A coordinator will help organize subspecialty care and act as a patient liaison. Ultrasound and fetal magnetic resonance imaging (MRI) will be available on the same floor.

According to **Sinai C. Zyblewski, M.D.**, Director of Fetal Cardiology and one of the champions of the new center, it “will serve as a portal of entry into a lifetime continuum of specialized care at MUSC Health for children born with congenital anomalies.”

## The Importance of Prenatal Diagnosis

Most of us cannot—or do not wish to—imagine the brutal shock a mother feels when she is told that her baby has a congenital anomaly. Each year, 2% to 3% of expectant or new mothers receive this news. How well they cope with it and how poised they are for the fight ahead depends in part on how and when the news is delivered.

**Dr. Sinai Zyblewski is one of the pediatric cardiologists working with MFM specialists to improve prenatal detection of heart defects.**



VIDEO: Dr. Sinai Zyblewski and Dr. Jill Mauldin discuss the new Advanced Fetal Care Center in the online edition.





**Jill G. Mauldin, M.D.**, an MFM specialist and Medical Director of MUSC Health Women's Care, and Zyblewski are both firm believers that prenatal diagnosis of these anomalies provides the families time to come to terms with the news and to understand the treatment plan for their child. They also believe that the close collaboration between MFM specialists throughout the state and pediatric subspecialists leads to both a higher rate of prenatal detection and better care for children as they transition from prenatal to postnatal life. Perhaps as a result of the seamless, integrated care, children with congenital anomalies who are diagnosed prenatally are healthier at the time of surgery than those diagnosed after birth. In February at the 18th Annual Update on Pediatric and Congenital Cardiovascular Disease, **Catherine W. Sechrist, M.D.**, a pediatrician at MUSC Children's Hospital, Zyblewski, and colleagues reported that significantly fewer infants with a prenatal diagnosis of single-ventricle cardiac defects required ventilator support before cardiac surgery than did those diagnosed after birth (46% vs 71%).

Consider two scenarios.

In the first, a congenital heart defect, among the most common of congenital anomalies, is not diagnosed until after birth, as is true

**If there is concern for a congenital anomaly, an MFM specialist such as Dr. Jill Mauldin (right) is consulted to interpret level 2 ultrasound results.**

of almost half (47%) of these cases in South Carolina. The orderly course of events the mother expected—the birth of a healthy infant, the time spent holding and bonding with her child, the joyous arrival home—shatters into almost incomprehensible fragments. The worried looks on the faces of the health care providers. The ache of separation when the child is airlifted to the nearest neonatal intensive care unit. Days spent wondering what could have gone wrong. The news that the child is being airlifted again for subspecialty care. The long drive to rejoin the baby. Finally, a diagnosis. The struggle to follow medical terms and understand the details of the procedures that will be needed. Wondering if the baby has a future.

"It is not uncommon to receive a baby who has already been on two flights in the first 48 hours of life and the mom is still in a different hospital recovering from having given birth," says Zyblewski.

South Carolina's MFM specialists and pediatric cardiologists are determined to offer patients a second scenario. They encourage community obstetricians who see a cause for concern on a routine 20-week ultrasound to refer the patient to a regional MFM specialist for diagnosis and management. The regional MFM specialist manages the pregnancy, usually in collaboration with a local pediatric cardiologist, enabling the mother to receive care close to home. Then, at the beginning of the third trimester, a prenatal consultation is requested at MUSC Children's Hospital, where the baby will be delivered.

Eighteen months ago, Zyblewski and other pediatric cardiologists began joining MFM specialists such as Mauldin for these prenatal consultations. Together, they obtain and interpret a focused ultrasound of the heart to confirm the diagnosis, and a genetic counselor, such as **Sally M. Shields, RN, CGC**, helps parents understand its implications and serves as a social support for the family. The team meets the mother and family to formulate a birth plan, choose an induction date, and discuss the subspecialty care that will be needed after birth. On the day of delivery, the appropriate team is in place to meet the needs of both mother and child, who are never separated.

The collaboration between MFM specialists and pediatric cardiologists at these prenatal consultations has proven so fruitful that plans are under way to open an intermediary Advanced Fetal Care Center in summer 2015 in the current MUSC Children's Hospital. There, families can meet with a team whose members include an MFM specialist such as Mauldin or **Eugene Y. Chang, M.D.**, a neonatologist, any needed pediatric subspecialist, a pediatric surgeon, a pediatric radiologist, and a nursing representative to discuss treatment options for their child. Although the space in the new Children's Hospital and Women's Pavilion will offer the ideal setting



for these team consultations, Mauldin and Zyblewski are already working to integrate currently available Women's Care and pediatric subspecialty services, to strengthen referral patterns and processes, and to improve the patient experience.

### More Subspecialties to Come Aboard

The vision for the Advanced Fetal Care Center is that it will serve as a regional center for children with congenital anomalies and their families and that it will offer truly integrated prenatal and postnatal care through close collaboration between MFM specialists and the full spectrum of pediatric subspecialists. In addition to pediatric cardiology, a number of other subspecialties, including neonatology, urology, neurosurgery, general pediatric surgery, and otolaryngology, already offer prenatal consultations. According to **André V. Hebra, M.D.**, Chief of Pediatric Surgery, "the ideal consult enables the pediatric surgeon to educate parents about strategies related to the best delivery approach as well as the potential outcomes and treatment options for their infant while providing parents with the time to ask questions and express their values and concerns." In the opinion of pediatric neurosurgeon **Ramin Eskandari, M.D.**, "Families who receive a prenatal consultation do a better job of coping than those who learn about the anomaly after birth."

Currently, pediatric cardiology is the only subspecialty to conduct prenatal consultations jointly with an MFM specialist. That model will eventually expand to all other subspecialties in the new Advanced Fetal Care Center, where the family will meet with all providers at once. This is convenient for the family, but it also offers them the combined experience of all team members, a centralized treatment plan, and a consistency of message that avoids the miscommunication and confusion that can result from fragmented care.

"It's rewarding to me as a provider to do the multidisciplinary consults—the patients hear all the different perspectives at once and get their questions answered better," says Mauldin.

In addition to pediatric cardiology, the first subspecialties to begin participating in these multidisciplinary teams at the Advanced Fetal Care Center in its intermediary location will be pediatric urology, general pediatric surgery, and pediatric neurosurgery. Common anomalies evaluated and treated include hydronephrosis, posterior urethral valve, and renal anomalies (urology); abdominal wall defects (gastroschisis and omphalocele), diaphragmatic hernia, cystic lung lesions, and pulmonary sequestration (general pediatric surgery); and hydrocephalus and myelomeningocele (pediatric neurosurgery).

### Improved Imaging Modalities

Among imaging technologies, ultrasound is the workhorse for prenatal diagnosis and, in recent years, the quality and resolution of imaging obtained with it have improved dramatically. However, when additional information is needed, the greater anatomic detail provided by fetal MRI can be useful in making, and sometimes changing, a diagnosis. According to **Meryle J. Eklund, M.D.**, a pediatric radiologist specializing in fetal MRI, "It is an amazing tool that really provides a window into the womb as the baby is developing. It takes out some of the guesswork with fetal diagnosis and it's an additional piece of information that helps fit the puzzle together."

At times, fetal MRI reveals that what was thought to be a potentially lethal anomaly is much less severe than expected. For example, in a recent case, fetal MRI revealed that a fetus who had been diagnosed earlier at an outside institution as having a large chest mass and who was thought to have a poor prognosis in fact had a much less severe and more treatable abnormality. In another recent case, a fetus diagnosed as having a potentially life-altering midline spinal tumor using ultrasound was found instead to have an easily correctable renal anomaly. "The fetal MRI changed the family's expectations, from thinking there was a diagnosis of cancer with all sorts of negative effects to understanding that there was only a kidney anomaly requiring a small overnight-stay surgery," says **Andrew A. Stec, M.D.**, Director of Pediatric Urology.

Even when fetal MRI reveals that the situation is worse than what was originally thought—for example, when a misdiagnosed case of hydronephrosis turns out to be a bladder outlet obstruction—the greater insight into the anomaly ensures that the appropriate treatment plan is in place and that the parents are not blindsided by an unexpected diagnosis after birth.

### Setting Expectations High

Advances in imaging and surgical techniques and better integrated care mean that the bar has been set higher for those who treat congenital anomalies. These clinicians are no longer satisfied with survival of these infants. According to Zyblewski, "For a long time we have invested a lot of time and energy into survival but, in this day and age, it is about so much more than survival—it's about optimizing quality of life, giving these children the best chance for being able to complete school successfully, and optimizing their opportunity to grow into adults who are independent and can function." Ensuring prenatal detection of congenital anomalies and providing integrated, multidisciplinary care for both mother and child at the new Advanced Fetal Care Center are the first steps to meeting these great expectations.