Fetal Concerns Center



We are able to give families hope that we can improve the health and outcome for their babies; things that were truly not available 15 years ago.

- Emilie Lamberg Jones, RN, BSW

### Fetal Concerns Center

The Fetal Concerns Center at Children's Hospital of Wisconsin provides a comprehensive team approach – incorporating the referring physician, patient family, maternal fetal medicine specialist, nurse care coordinator, neonatologist and pediatric care specialists – when caring for women and their fetuses.

The Fetal Concerns Center is the only program of its type in Wisconsin and one of only a small number across the country. For more than 15 years, the center has served the special needs of women and families, coordinating services for more



than 500 families across the United States each year. The center operates in close collaboration with Froedtert & The Medical College of Wisconsin to deliver high-quality, comprehensive fetal care.

Our team of physicians specializes in the diagnosis, treatment, and comprehensive care coordination for women with high-risk pregnancies. In addition to prenatal care coordination and management, the Fetal Concerns Center team also performs fetal interventions for various conditions, such as spina bifida and twin-to-twin transfusion syndrome.

### Top-ranked care

- Children's ranked among the nation's best in ten specialties, including cardiology and neonatology, in U.S. News & World Report's 2016-17 Best Children's Hospitals report.
- Froedtert & The Medical College of Wisconsin is ranked nationally in four specialties and is a top-ranked adult hospital in Wisconsin.
- Children's has earned the highly coveted Magnet Recognition Program<sup>®</sup> status multiple times from the American Nurses Credentialing Center (ANCC) for sustained superiority in nursing care.
- The Fetal Concerns Center is a member of the North American Fetal Therapy Network (NAFTNet).











### We stand apart from the rest

#### Regional leader in fetal interventions

The only program of its type in Wisconsin, and one of the few that exist throughout the nation, we are leading the way in the diagnosis and treatment of conditions before and after a baby's birth. Our services begin early in pregnancy, and we have the ability to perform surgical procedures on fetuses before delivery. Our team of experts can diagnose congenital defects in the fetus, offer counseling, recommend and perform fetal interventions when indicated, and coordinate medical care for mother and baby.

#### Complete, coordinated care from start to finish

Our dedicated nurse care coordinators work directly with patients as their main point of contact to guide them through the prenatal experience. In addition, Froedtert's Birth Center is located inside Children's to reduce the time it takes to get fragile newborns the care they need in the neonatal intensive care unit (NICU) after delivery. Research shows outcomes improve when the delivery room and NICU are close together. This also offers families the added benefit of care for both mother and baby under one roof.

#### Expert care for multiples and fetal heart care

Our comprehensive program provides testing, diagnoses, and treatments for a wide variety of conditions, specializing in care for multiples and fetal heart care. In fact, the Fetal Concerns Center is one of a few perinatal centers in the country and the only one in Wisconsin specializing in complex complications with multiples. In addition, our fetal heart program utilizes the most advanced ultrasound techniques to assess heart problems before birth.

#### • Experience and expertise

Our interdisciplinary team includes various subspecialists with a wide variety of experience. This allows us to provide the best possible care for patients specific to their conditions and needs. Our physicians have also conducted a wide variety of nationally published research, and our neonatology program is ranked among the nation's best.

## The full spectrum of prenatal care for high-risk pregnancies

The Fetal Concerns Center provides a complete range of exceptional care for both women with high-risk pregnancies and their fetuses. Our team of experts coordinates care for all fetal conditions and concerns, ranging from initial screenings to highly complex treatments.



#### Services

- Fetal diagnosis of birth defects
- Maternal and fetal testing
- Prenatal counseling
- Multi-fetal pregnancy management
- Fetal Heart Program
- Fetal interventions and surgery
- Neonatal management
- Palliative care

### Common conditions we diagnose and treat

- Amniotic band syndrome
- Anencephaly
- Bladder outlet obstruction
- Bowel obstruction
- Cleft lip or palate
- Clubfoot
- Congenital anomalies in twins
- Congenital diaphragmatic hernia
- Congenital heart disease
- Congenital pulmonary airway malformation (CPAM)
- DiGeorge and/or velocardiofacial syndrome
- Encephalocele

- Gastroschisis
- Genetic disorders
- Hydrocephalus
- Hydrops fetalis/erythroblastosis fetalis
- Micrognathia and Pierre Robin sequence
- Multicystic dysplastic kidney
- Omphalocele
- Pyelectasis/hydronephrosis
- Rhabdomyomas/tuberous sclerosis
- Sacrococcygeal teratoma (SCT)
- Selective intrauterine growth restriction (sIUGR)
- Spina bifida (myelomeningocele)
- Tracheal esophageal fistula and esophageal atresia
- Twin reversed arterial perfusion (TRAP) sequence
- Twin-to-twin transfusion syndrome (TTTS)

### In-utero interventions for a wide range of conditions

- Open fetal myelomeningocele repair (fMMC) for spina bifida
- Open fetal surgery for CPAM
- Open fetal surgery for SCT
- TTTS treatment
- Fetal cardiac interventions
- TRAP sequence treatment
- Ex-utero intrapartum treatment (EXIT)
- Immediate postpartum access to cardiac therapy
  (IMPACT) procedure
- Vesicoamniotic and thoracoamniotic shunting
- Fetal intrauterine transfusion



### All the top specialists a mother and baby could need

The Fetal Concerns Center is a multidisciplinary team of physicians covering various specialties. Our program includes highly trained experts in the following areas:

- Maternal fetal medicine
- Fetal surgery
- Fetal cardiology
- Fetal imaging

many are ranked among the Best Doctors in America.®

In addition to the core team of physicians, additional specialists from many various disciplines are involved on a case-by-case basis. coordinators who work closely with families to coordinate their care and to be a single point of contact throughout the entire process.

Go online to learn more about our specialists and watch their profile videos: chw.org/fetalspecialists

#### One of a kind in Wisconsin For more than 15 years, families across Wisconsin and the country have turned to us to manage their



high-risk pregnancies and fetal

- The only program of its type in the state of Wisconsin
- Only fetal and pediatric heart provided by fetal and pediatric
- Only nationally ranked pediatric heart care program
- The only program in the state to offer fetal surgery
- Only children's hospital in the integrated birthing center and NICU
- The first and largest Level IV NICU in the state

 All of our specialists are boardcertified

### Performing lifesaving surgical interventions before birth

The Fetal Concerns Center is the only program in the state of Wisconsin to perform fetal interventions, which means we operate on a baby who is is still in the womb. Fetal surgery is a relatively new treatment option, which allows some conditions to be corrected or significantly improved before the baby is even born.

We offer a wide range of fetal interventions, including fMMC repair, TTTS treatment, and more.



Amy Wagner, I

### First in Wisconsin to perform fetal surgery for spina bifida repair

Traditionally, spina bifida has been treated with surgery after the baby is born. During the surgery, the hole in the back is closed and the spine covered.

In the mid-1990s, physicians began testing different methods for treating spina bifida before birth. Although prenatal treatment does not cure spina bifida, the results from this study showed babies who had the surgery before birth were less likely to need a ventriculoperitoneal shunt (a tube that helps drain excessive fluid collections in the child's brain). The study also showed that some of the motor skills were better than those who received the standard surgery after birth.

The Fetal Concerns Center now performs prenatal spina bifida surgery to close the opening on the spine prior to birth. The first surgery was performed in 2014, and we are the first (and currently the only) center in Wisconsin to perform this surgery. The surgery is performed between 19 and 25 weeks' gestation. Fetal myelomeningocele repair is performed by a multidisciplinary team of surgeons, including a fetal surgeon, pediatric neurosurgeon, maternal fetal medicine specialist, fetal cardiologist, anesthesiologist, as well as others.

Amy Wagner, MD, is a co-director of the Fetal Concerns Center and is the fetal surgeon in all fMMC repair surgeries. She trained under Drs. Michael Harrison (known as "the father of fetal surgery") and Diana Farmer at the University of Calfornia-San Francisco, where the first fetal treatment center in the United States was developed. The Fetal Concerns Center completed the first prenatal spina bifida surgery in Wisconsin in 2014. Joe and Melanie Donnerbauer of Little Chute, Wis., discovered their son, Miles, had a severe form of spina bifida in Melanie's 18th week of pregnancy. The Donnerbauers chose to undergo in utero corrective surgery to repair the spinal defect, and Miles was born six weeks after the surgery.

#### Learn more about their story: **chw.org/miles**



### Experts in caring for pregnancies with multiples

The Fetal Concerns Center is one of a few perinatal centers in the country and the only one in Wisconsin specializing in complications of pregnancies with multiples. Our team of maternal fetal medicine and pediatric specialists trained extensively with worldrenowned pioneers in the study and treatment of twin related conditions to learn the art and science of diagnosing and treating these complications.

Pregnancies involving multiple fetuses carry an increased risk for both mother and babies. The benefits of working with a fetal center that has an established multifetal pregnancy program include:

Early diagnosis and treatment

Early diagnosis of complications from a pregnancy of multiples may make treatment before birth possible. If we suspect that there will be difficulties at birth, or if we believe that babies will need surgery soon after birth, we will help plan and coordinate the best possible care for the mother and her babies.

• The latest equipment

Critically ill babies who are treated through our program have access to the state-ofthe-art Neonatal Intensive Care Unit at Children's Hospital of Wisconsin. It is the



first and largest Level IV NICU in the state, and we care for more than 700 neonates each year.

Individualized care and support

A specialized nurse care coordinator works one-on-one with families to provide information and support before birth.

Some of the twin-related conditions we diagnose and treat include:

- TTTS
- TRAP sequence
- Other twin pregnancy complications

TTTS is an imbalance in the blood flow between identical twins that share one placenta but have separate amniotic sacs. When the placenta is shared, blood vessels within it connect the twins' blood supply, allowing blood to flow between them. If the blood flow becomes unequal, the twins will grow at different rates with the smaller (donor) twin pumping blood to the larger (recipient) twin. The condition is found in about 15 percent of monochorionicdiamniotic twin pregnancies.

One of the treatment options for TTTS is fetoscopic laser ablation, which is a minimally invasive fetal surgery aimed at disconnecting the shared blood vessels between the twins in the placenta. Fetoscopic laser ablation is only offered by specially trained physicians at select treatment centers like the Fetal Concerns Center. Studies show an 80 to 85 percent survival rate for at least one twin following laser ablation and both twin survival rate of 65 to 70 percent. The approach also greatly reduces the risk of neurological damage to the babies before birth.



In 2012, Heather Hanson was 18 weeks pregnant with twins when she received the diagnosis of TTTS. At 21 weeks, she underwent laser ablation surgery, and the twins, Evan and Owen, were born at 30 weeks. They are now healthy toddlers, developing normally for their age.

Go online to watch a video detailing Evan and Owen's inspiring story: chw.org/evanowen



As one of the nation's top fetal heart programs, we have helped thousands of families receive the expert care and support they need. The Herma Heart Center is ranked as the 6th best pediatric heart program in the country by U.S. News & World Report. Our surgical outcomes are consistently ranked among the best in the country, including the best published survival rates worldwide for treating hypoplastic left heart syndrome, an uncommon and complicated congenital heart disease. We are committed to providing the best care for each patient and baby.

Our fetal heart services include:

- Fetal echocardiography (fetal ultrasound or fetal echo), to assess a fetus's heart structure, rhythm and function
- Fetal magnetocardiography (fMCG), which can diagnose fetal heart rhythm abnormalities more accurately than fetal echocardiography
  - o This allows for a better understanding of the type and cause of rhythm problems so that treatment can be better tailored. fMCG is only available in a handful of centers in the world.
- Consultation with a fetal cardiologist to discuss the diagnosis and treatment options
- Dedicated Fetal Heart Program nurse coordinators who assist with care coordination and serve as a consistent resource throughout pregnancy
- On-site labor and delivery facilities, which allow mother and baby to stay close together
- Access to world-class fetal and pediatric heart surgery for common to complex congenital heart conditions

#### World-class heart care before birth

Almost 1 in 100 babies is born with a heart problem. Many of these defects can be diagnosed before birth, allowing for extensive counseling with a physician and timely access to cardiac treatment to provide the best chance for a good outcome. Hundreds of families each year trust experts from the Fetal Heart Program, which is a multidisciplinary team from the Fetal Concerns Center and the Herma Heart Center at Children's Hospital of Wisconsin, to provide the best possible care through pregnancy, birth and beyond for babies with congenital heart disease.



Jennifer Van Asten learned that her son was diagnosed with hypoplastic right heart syndrome (HRHS) during her pregnancy. She received care from the Fetal Heart Program during the remainder of her pregnancy, and after Pearce's birth, he had the first of three heart surgeries at the Herma Heart Center. Today he's a growing, active boy and receives his follow-up care at a Children's location just 20 minutes from his Greenville home in northeast

Learn more about their amazing story by visiting chw.org/pearce

### Superior support for patients and referring physicians

Everything at the Fetal Concerns Center is designed to meet the unique needs of each patient family and referring physician – from patient rooms, and even

#### **Care coordination**

Experiencing a high-risk pregnancy or learning that your fetus has a birth defect can be extremely stressful and emotional. Often, many different specialists need to be consulted, and it can quickly become overwhelming. Our dedicated Fetal Concerns Center care coordinators provide a consistent point of contact for the patient family throughout the entire process. They assist with scheduling appointments and answering the family's questions, ensuring that they feel educated and empowered about their diagnosis, while also providing all the emotional support they need at this difficult time.



We work closely with referring physicians to be sure that all aspects of each patient's care are highly coordinated and communicated. We view our relationships with referring physicians as partnerships, and we work together to ensure the best possible care for each patient, seamlessly transferring care back to the original physician whenever possible. The Fetal Concerns Center doesn't require patients to deliver their babies at our hospital, and we work directly with the patient and referring physician to determine the best care plan for each individual case.

#### Care closer to home for local families

Patients who live in Wisconsin take comfort in knowing they can get the high-quality, highly specialized care that they need close to home, rather than having to travel outside the state for care. This allows them access to their local support networks during this difficult time. For families with other children, they are able to get the care they need while continuing to be with their families.

#### Ease of access for out-of-town families

The Access Center at Children's helps patients from out of town coordinate travel, accommodations and visits to the Fetal Concerns Center. Highly trained access navigators serve as liaisons with patients and the Fetal Concerns Center staff, helping gather medical records, register, and schedule appointments. They also assist with financial approvals and lodging at the Ronald McDonald House or a nearby hotel.

#### Wraparound care and support

Children's offers a variety of wraparound support services, including prenatal breastfeeding education, child life services for sibling support, social work, and spiritual care.



# We're here for your questions

Contact us to learn more about our program, get answers to your questions, or to set up an appointment. Call us at **(414) 805-4776** or toll-free at **(855) FETALWI (338-2594)**.

### Learn more online

Visit **chw.org/fetalconcerns** for more information about the Fetal Concerns Center.



#### Fetal Concerns Center

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The Fetal Concerns Center operates in close collaboration with Froedtert & The Medical College of Wisconsin to deliver high-quality, comprehensive fetal care. Our providers are employed by the Medical College of Wisconsin.