Extensive care, expert insight

The clinicians in the AFCC see expectant mothers whose fetuses have been diagnosed with or are suspected of having an extensive range of conditions. These can include:

- cardiovascular
- cerebrovascular
- colorectal and pelvic malformations
- craniofacial anomalies
- esophageal and airway disorders
- gastrointestinal and thoracic
- genetic or chromosomal
- infectious diseases
- neural tube defects
- neurologic
- orthopedic
- pulmonary
- renal and urologic
- disorders of sexual differentiation
- tumors and cysts
- vascular anomalies

Our team approach

Since its inception, thousands of pregnant women have been referred to the AFCC for diagnostic studies, counseling, treatment and care when a fetal anomaly is suspected or diagnosed. Depending on their unique case, patients may be seen by specialists across disciplines including:

- cardiology/cardiac surgery
- developmental medicine
- general surgery
- genetics
- interventional radiology
- neonatology
- neurology
- neuroradiology
- neurosurgery
- nursing
- orthopedics
- otolaryngology
- patient services
- plastic surgery
- radiology
- urology

This team approach ensures a comprehensive care plan built on the collaborative involvement of our pediatric experts and ongoing communication with patients and their primary obstetric team. The AFCC also works closely with Harvard area hospitals, including Beth Israel Deaconess Medical Center and Brigham and Women’s Hospital, along with many local and non-local obstetricians and maternal-fetal medicine (MFM) specialists.

Surgery and interventions

In cases where a fetal intervention may be necessary, the AFCC will discuss risks and long-term outcomes based on our experience and the most current data. All necessary services are centrally coordinated by the AFCC team. Interventions performed in conjunction with the AFCC include:

- **Fetal cardiac interventional procedures**, using a needle or catheter to treat certain fetal cardiac abnormalities. Tiny balloon catheters can be inflated to open abnormal heart valves or other obstructions. Boston Children’s Hospital is the only hospital successfully performing these procedures.

- **EXIT (Ex utero intrapartum treatment)** conducted at the time of the delivery, often for a congenital defect that blocks the airway. The baby is partially delivered through Cesarean section and remains on placental support (still attached to the umbilical cord), giving surgeons time to treat the obstruction and secure the baby’s airway so that by the time the cord is cut, the baby can breathe independently.

- **EXIT to ECMO (extra corporeal membranous oxygenation)**, where, following an EXIT procedure, a baby is temporarily placed on a heart/lung bypass machine that circulates oxygenated blood through the body. Surgeons are then able to complete the delivery and repair the abnormality while giving the baby’s lungs and heart time to develop and heal.

- Additional surgery, performed as needed once the newborn is stabilized.

72% of babies born to mothers seen at the AFCC go on to receive specialty care at Boston Children’s.
Continuous collaboration
Care at Boston Children’s means access to the nation’s top-ranked children’s hospital and the most experienced pediatric specialists in the world. At the AFCC, we collaborate with centers and programs throughout Boston Children’s to provide seamless care once a baby is born. These are just some of the centers at which AFCC babies are seen.

Fetal Cardiology Program
The Fetal Cardiology Program is dedicated to correcting and preventing defects of the fetal heart in utero and is the world’s first and most experienced center in performing successful fetal cardiac interventions, treating abnormalities in utero to reduce potentially fatal concerns after delivery. In 2001, a team of Boston Children’s pediatric cardiologists, with MFM specialists at Brigham and Women’s Hospital, successfully opened a narrowed heart valve while a fetus was still in the mother’s womb. Today, Boston Children’s has remained at the forefront of fetal cardiac care and has performed more than 185 fetal cardiac interventions.

Congenital Diaphragmatic Hernia Program
The Congenital Diaphragmatic Hernia Program treats and manages long-term follow-up care for children born with this complex health concern. In many cases, diaphragmatic hernias can be successfully treated in newborns, and the outlook for babies born with CDH is increasingly positive. The program treats more than 20 newborns with CDH each year, with a success rate among the best in the world. Boston Children’s survival rate is consistently 10 percent higher than the national average.

Esophageal and Airway Treatment Center
The Esophageal and Airway Treatment Center is dedicated to the care of infants, children and young adults with complex esophageal and airway problems. For Boston Children’s, these very rare esophageal conditions are not rare at all. Since 2010, our clinicians have cared for more than 600 patients, making us the most experienced institution in the world when it comes to treating these complex conditions.

Spina Bifida and Spinal Cord Conditions Center
The Spina Bifida and Spinal Cord Conditions Center is one of just a few centers in the world that offers complete coordination of care among all specialty areas. Its clinicians have pioneered innovative surgeries, such as ETV/CPC as an alternative to shunting, spinal cord detethering, neonatal spina bifida surgery and robotic bladder augmentation. It is also the only center in New England and one of only a few in the country that treats children with spina bifida into early adulthood.

Leading the way in innovation
Boston Children’s is continuing to advance what’s possible in fetal medicine. Through the joint work of researchers, genetic specialists, surgeons and other care providers, the AFCC is breaking new ground in the understanding of fetal anomalies, with the goals of early detection and treatment. Clinicians and researchers in the AFCC are currently overseeing or contributing to a variety of clinical research projects, including those in the fields of:

- cardiac surgery
- cardiology
- complex care
- general surgery
- neurology
- newborn medicine
- radiology
- urology

Just a few of our ongoing studies include:

Preserved Umbilical Vein Use as Autologous Shunt Conduits in Neonatal Cardiac Surgery. This is a prospective, single-center, safety and feasibility trial to evaluate the use of autologous umbilical vein as shunts or conduits in neonatal cardiac surgery.

Fetal Renal Extracorporeal Evaluation (FREE). This study is testing a painless, entirely non-invasive way to evaluate kidney function of a fetus using an MRI machine.

The Neural Tube Defect Biomarker Study. This study is looking for markers or labels in expectant mothers’ urine and blood that are associated with a diagnosed spinal cord condition.
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