

Advanced Fetal Care Center



Children's Hospital Boston

www.childrenshospital.org/afcc



A new era *in* fetal care



The Advanced Fetal Care Center (AFCC) of Children's Hospital Boston is making a significant difference in outcomes for families facing complex birth defects and other critical challenges to the health of their fetus or newborn. Pushing beyond the pages of yesterday's textbooks, we are rewriting what is possible in fetal medicine, delivering hope—and healthy babies—through ground-breaking advancements and a commitment to the best in pediatric care.

Few centers offer the breadth and depth of expertise found at the AFCC. We are one of just a handful of comprehensive fetal care centers in the United States, and the only one in New England. We are the world's first and most experienced in performing successful fetal cardiac interventions—treating abnormalities *in utero* to reduce potentially fatal concerns after delivery. We are also seeing unrivaled results in treating congenital diaphragmatic hernia (CDH). Physicians call on us to diagnose, treat or monitor a wide range of complex anomalies. Parents remember us for the compassionate support we provide during pregnancy and beyond.



Comprehensive services

The AFCC provides complete, coordinated support in treating and/or managing complex fetal anomalies. Our services include:

- Diagnostic and consultative services throughout the pregnancy
- Fetal surgery or interventional procedures performed during pregnancy
- Surgery and supportive care at the time of delivery
- Treatment of the baby after birth

The AFCC's success is part of a long tradition of excellence at Children's. We are recognized as the birthplace of pediatric surgery and are home to many of the world's foremost pediatric physicians and researchers. For more than a decade, *U.S. News & World Report* has ranked Children's among the top pediatric hospitals in the United States. Children's is the primary pediatric teaching hospital of Harvard Medical School, where our physicians hold academic appointments. The AFCC also works in close collaboration with the Harvard consortium of hospitals, including Beth Israel Deaconess Medical Center and Brigham and Women's Hospital.



Multidisciplinary expertise

“We believe that the earlier an anomaly can be correctly diagnosed, the greater the child’s chances of experiencing optimal development and health.”

— RUSSELL JENNINGS, MD,
fetal and pediatric surgeon,
AFCC program director

In the AFCC’s first five years, more than 1,000 pregnant women received care from our center. The program is growing rapidly based on a reputation for clinical excellence and compassionate care.

AFCC services are overseen and coordinated by a core team, whose members include:

Alan B. Retik, MD, Executive Director, Surgeon-in-Chief, Urologist-in-Chief

Russell Jennings, MD, Program Director, fetal and pediatric surgeon

Judy A. Estroff, MD, and Carol E. Barnewolt, MD, Fetal Radiologists

Terry L. Buchmiller, MD, Pediatric Surgeon

Luanne Nemes, RN, MS, PNP, Clinical Coordinator

Donna Morash, RN, Pediatric Nurse

Kathy Furlong, MSW, LICSW, Clinical Social Worker

Linda Zaccagnini, RN, MSN, NNP, Neonatal Nurse Practitioner

Jill Krejdovsky, MS, Genetic Counselor

As each case may require, we draw on the expertise of physicians and other patient care specialists across numerous pediatric disciplines, including anesthesia, cardiology, general surgery, genetics, neonatology, neurology, neuroradiology, neurosurgery, orthopedics, otolaryngology, plastic surgery, radiology and urology.

Our multidisciplinary approach supports a fully coordinated care plan, one that is built on the collaboration of our pediatric experts and continuous communication between all involved.



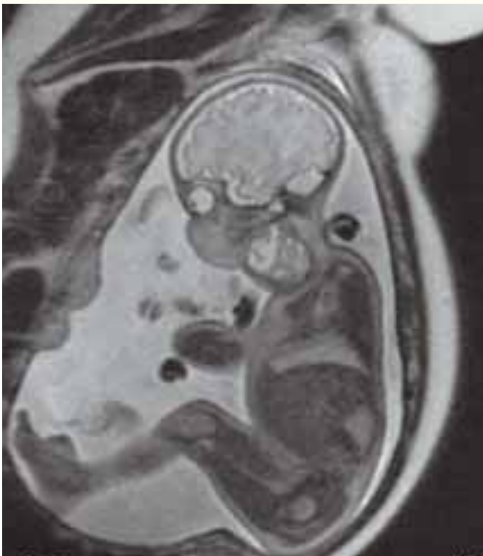


The AFCC holds weekly meetings—attended by more than 80 health care professionals from multiple specialties—to share expertise, and to discuss current treatment options and outcomes of complex cases.

AFCC areas of specialization

- Airway obstruction
- Bladder exstrophy
- Cervical teratoma
- Cleft lip and palate
- Cloacal anomalies
- Congenital brain anomalies
- Congenital cystic adenomatoid malformation (CCAM)
- Congenital diaphragmatic hernia (CDH)
- Congenital heart defects
- Congenital high airway obstruction (CHAOS)
- Congenital orthopedic anomalies
- Conjoined twins
- Fetal tumors/ masses
- Gastroschisis
- Hydrocephalus/ ventriculomegaly
- Intestinal obstruction/ atresia
- Kidney, bladder and genital abnormalities
- Myelomeningocele (spina bifida)
- Hydronephrosis
- Omphalocele
- Pleural effusion (hydrothorax)
- Posterior urethral valves
- Pulmonary sequestration
- Sacroccocygeal teratoma
- Skeletal dysplasias
- Twin reversed arterial perfusion (TRAP)
- Twin-to-twin transfusion syndrome (TTTS)
- Vascular anomalies and lymphatic malformations (aka cystic hygroma)

Accurate, detailed diagnosis



The AFCC is experienced with medical challenges that others may see only occasionally, if at all. Our expertise, coupled with state-of-the-art technologies, enables us to provide an extremely fine diagnosis of complex fetal anomalies. This greatly supports families and referring physicians in determining the most appropriate course of care.

“What makes physicians happy is the AFCC’s timely and diligent communication, and help in getting patients seen quickly by all appropriate services. Patients appreciate the amount of time spent talking with them. The staff goes above and beyond to accommodate patients at one of the most stressful and frightening moments of their lives.”

—LISA DUNN-ALBANESE, MD,
perinatologist at Brigham & Women’s Hospital



Diagnostic tests through the AFCC include:

Fetal ultrasound, providing images denoting the size and position of fetal organs and many structural anomalies.

Fetal magnetic resonance imaging (MRI), enabling us to acquire additional anatomic information. The AFCC is setting a new standard in fetal MRI that draws on our expertise in pediatric imaging.

Fetal echocardiogram (fetal echo), a highly specialized, detailed ultrasound examination of the fetal heart, performed in the event a fetal cardiac abnormality is suspected or when hemodynamic assessment is warranted.

Families have the opportunity to meet with AFCC care team members and pediatric specialists to review images and discuss results. Our goal is to provide the most complete information to pregnant patients and their families. We outline treatment options, risks and long-term outcomes based on our experience and the most current data. We honor and support the personal treatment decisions that each family makes.

A strong line of communication is maintained with referring physicians. We provide timely feedback about diagnostic findings and potential treatment options. We also remain available for consultation throughout the pregnancy and can assist in the coordination of delivery and postnatal care.

Compassionate care



We understand the anxiety many families feel when contacting our center. Terms like “suspected birth defect” or “anomaly” can be difficult to take in and understand. Parents and physicians familiar with our program say our initial telephone intake assessment—with an experienced nurse who knows what questions to ask, what information needs to be gathered and when to listen—greatly helps in reducing stress and preparing for the next steps.

Compassion is a guiding principle throughout the care process. We believe in honest and open discussions about test findings and treatment options. Our social worker is available for supportive counseling and resource assistance including providing information about travel accommodations, arranging tours of the hospital or connecting parents to the Center for Families, a much-used resource center at Children’s.

Often the best support comes from parents who have been there before. Our family-to-family network matches families now coming through the AFCC with trained volunteers who have a child with a particular health concern, for information and emotional support.

Many complex anomalies require that a child’s health be managed over time. We not only treat or help monitor medical concerns during pregnancy and birth, but also help prepare parents for the realities of life ahead. We value the relationships formed with the many families who have come through our center.



Ryan Haigh from Atlanta, GA.

While *in utero*, Ryan was diagnosed with severe right-sided congenital diaphragmatic hernia (CDH). After extensive evaluation and family discussion with Jay Wilson, MD, and AFCC program director Russell Jennings, MD, Ryan underwent an EXIT procedure with trial of ventilation and placement on ECMO. He underwent subsequent repair of his diaphragm and spent two months at Children's Hospital Boston recovering from his surgery. Ryan is now an active and healthy toddler.

“We’re here to listen and offer comprehensive information and complete support.”

—DONNA MORASH, RN

Ground-breaking procedure

“Luanne urged us to relax and get ready to deal with whatever was ahead. She said we needed to do some tests, determine the size of the growth and understand what we were facing...We knew immediately we were in the right place.”

—SUSAN DAVIS,
AFCC parent
of Loren
(pictured)



AFCC highlights

- The world's first successful cardiac stent placement *in utero*.
- The world's first and most experienced center for fetal cardiac interventions.
- Routine use of EXIT to ECMO procedures at delivery to treat anomalies including airway obstruction, congenital diaphragmatic hernia (CDH) and congenital cystic adenomatoid malformation (CCAM).
- Successful separation of conjoined twins from a triplet pregnancy following comprehensive prenatal evaluation.

Surgery or other intervention becomes an option when doctors predict that the fetus will not live long enough to make it to delivery or live long after birth. New treatments and supportive care through the AFCC are improving the quality of life for this special group of newborns through their first years and throughout childhood.

The AFCC is leading the way in:

Fetoscopic surgery, which uses minimally invasive techniques to correct congenital malformations without the need to remove the fetus from the womb.

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. We are the only center to date successfully performing these procedures.

EXIT procedure, or 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.

Coordinated deliveries that bring together at the time of birth all pediatric and obstetric specialists necessary for critical care.



CDH success

TWENTY YEARS AGO,
ABOUT ONE IN FIVE
CONGENITAL DIAPHRAGMATIC
HERNIA BABIES SURVIVED.
TODAY, THE NATIONAL
AVERAGE IS 50 PERCENT;
AT CHILDREN'S IT'S CLOSE
TO 90 PERCENT.



Inpatient care

When inpatient care is required, the AFCC staff coordinates care for both the mother and newborn with maternal fetal specialists, neonatologists and the intensive care units of Brigham and Women's Hospital or Beth Israel Deaconess Medical Center, where delivery typically takes place. We also alert all involved specialists within Children's of the delivery.

As a newborn transitions to inpatient care at Children's, physicians and nurses from all relevant disciplines regularly monitor the baby's progress and treatment. Children's is one of the nation's most advanced centers for inpatient infant care and is home to several specialized care units and programs including: the Cardiac Intensive Care Unit (CICU), the Craniofacial Anomalies Program, the Congenital Diaphragmatic Hernia Program, the Multidisciplinary Intensive Care Unit (MICU), the Myelodysplasia Program, the Neonatal Intensive Care Unit (NICU), the Neonatal Neurology Program, the Surgical Critical Care Program, the Surgical Nutrition and Metabolism Program and the Vascular Anomalies Center.

One center, coordinated care



We recognize the demands facing today's obstetricians who work to provide the best care for their patients. In many cases, we have formed consultative partnerships with physicians, providing the added fetal and pediatric expertise to their practice in maternal care and high-risk obstetrics. At the same time, we're helping ease the burden for expectant parents in obtaining and navigating necessary care services.

Through a single, centralized program, the AFCC coordinates tests and services, acts as a resource for the most up-to-date information and links families and physicians with Children's world-renowned specialists in fetal care for diagnosis, treatment and/or care management.

As each case requires, we team with pediatric specialists in:

- anesthesia
- cardiology
- coordinated care
- fetal research
- general surgery
- genetics
- interventional cardiology
- neonatology
- neurology
- neuroradiology
- neurosurgery
- orthopedics
- otolaryngology
- plastic surgery
- radiology
- thoracic surgery
- urology
- vascular anomalies

OUR MULTIDISCIPLINARY TEAM PERFORMED THE FIRST
SUCCESSFUL FETAL CARDIAC INTERVENTION AND REMAINS THE
MOST EXPERIENCED IN THESE PROCEDURES IN THE WORLD.

Towards tomorrow.. fetal research



Children's is known for successful leading-edge treatments. A big part of our success comes from our commitment to research and advancing the frontiers of what's possible in medicine. We are home to the largest research program at a pediatric institution in the world. Moreover, our researchers work just steps from our physicians and patients, creating the shortest possible distance between "bench" and "bedside," and giving our doctors a vital jump-start on applying laboratory discoveries to patient care.

Of particular interest to the AFCC and the families we serve, is our pursuit to better understand the origins of fetal anomalies and to detect and treat fetal disorders as early as possible. Specific areas of focus include:

- pioneering the use of perfluorocarbon, an oxygen-dissolving liquid, to increase the capacity of underdeveloped lungs of newborns, such as those impacted by congenital diaphragmatic hernia (CDH) and who have difficulty being weaned from ECMO
- studying the etiology of spinal cord injury and brain maldevelopment in myelomeningocele and the fetal surgical repair of this anomaly
- developing minimally invasive therapies for complex twin placental anomalies including twin-to-twin transfusion syndrome (TTTS), the TRAP (twin reversed arterial perfusion) sequence and umbilical cord entanglement
- exploring the use of fetal cells to produce tissue to repair congenital anomalies
- studying the genetic causes of congenital diaphragmatic hernias
- participating in 5-year NIH trial with Beth Israel Deaconess Medical Center studying outcomes of fetal ventriculomegaly
- studying outcomes of children with congenital brain anomalies

We're excited to help shape new advances in fetal care, and we look ahead to their potential in serving tomorrow's families.

Referring a patient

Patients come to us in one of two ways: a phone call by a referring physician, or by contacting our center directly.

Phone consultation: During the initial call, we outline what medical information is needed to go forward (copies of test results, etc.) and provide counsel in the way of a supportive dialogue for asking questions and expressing concerns or anxieties.

Appointment scheduling: From here, diagnostic tests and appropriate appointments with specialists are scheduled. We will review all prior medical information.

AFCC appointment: Appointments consist of diagnostic studies to confirm or specify a diagnosis, followed by a multidisciplinary evaluation by select specialists of the AFCC team. Appointments are coordinated by AFCC staff to ensure the most efficient and appropriate scheduling.

Treatment options/ recommendations: Options are discussed at our weekly multidisciplinary fetal care conference. Diagnostic findings, treatment options and follow-up is communicated to referring physicians in a timely manner.

Treatment or postnatal care: If there is an indication for fetal intervention, it is coordinated by the AFCC team. If fetal intervention is not indicated, coordination of postnatal care is planned to ensure the best possible outcome for the infant and family.

Additional assistance, such as supportive counseling, travel and hotel information, tours, an introduction to Children's Center for Families and application to Devon Nicole House (Children's family residence) can be arranged.

For more information, visit us on the web at www.childrenshospital.org/afcc or call (617) 355-3896 or 1 (866) FETALCARE. FAX (617) 730-0302.



Contact *us*

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For families residing outside of the United States,
please contact Children's International Center:

International Center
Children's Hospital Boston
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Boston, MA 02115 USA
www.childrenshospital.org/international

Telephone: (617) 355-5209
FAX: (617) 730-0627
E-mail: international.center@childrens.harvard.edu





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Children's Hospital Boston

The Hospital for Children



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