# Colorado Fetal Care Center



2023 OUTCOMES

# Congenital Diaphragmatic Hernia



## COLORADO FETAL CARE CENTER

The Colorado Fetal Care Center delivers some of the safest, highest-quality and most innovative fetal care available. From perinatal medicine to neonatal and pediatric subspecialty care, we offer a full array of services for mothers, parents, babies and families. We work with maternal fetal medicine specialists, midwives, obstetricians and family physicians locally and across the country and consider them an integral part of our team.

With more than 50 years of experience treating congenital diaphragmatic hernia (CDH), 24/7 access to the field's top experts and a dedicated neonatal intensive care unit (NICU) team, we achieve some of the best outcomes in the nation. We offer every treatment available, including some only offered by a handful of centers worldwide, and we've cared for hundreds of cases. That's why we say, here, the rare is common.

216+

Total patients treated since 2012

79%

Overall CDH patient survival since 2012

70%

Percentage of deliveries on site in 2023

**52%** 

ECMO survival rate in 2021 (National benchmark 40-60%)



### **Diagnostics**

Accurate diagnosis is the first step in creating a complete CDH care plan. Over the last decade our team of maternal fetal medicine specialists and pediatric surgeons has worked relentlessly to improve detection and treatment of fetal conditions, and our imaging services have grown significantly. Today we offer virtually every fetal diagnostic test and treatment available. The first test is usually an ultrasound, which shows us the location of the organs and the size of the lungs. We also perform fetal

MRIs, which help determine the severity; fetal echocardiograms, which show any related heart disease; and amniocentesis, which helps us determine if there's any genetic cause.

- 3,000+ ultrasounds performed in 2023
- 1,800+ fetal echos performed in 2023
- 300+ fetal MRIs in 2023

### **Genetic screening**

Some reports estimate that up to 30% of all babies with CDH have an underlying genetic syndrome. That's why genetic counseling is a part of all new patient visits at the Colorado Fetal Care Center. Our dedicated genetic counselors work with families and care teams to review genetic testing options and interpret test results when a genetic syndrome may be possible.

### **Screening tests**

- cfDNA (common aneuploidues like Down syndrome)
- Carrier screening (for autosomal recessive conditions)

### Diagnostic tests

- FISH
- Karyotype
- Microarray
- Depending on fetal abnormalities present: single-gene sequencing, multi-gene sequencing, whole-exome sequencing



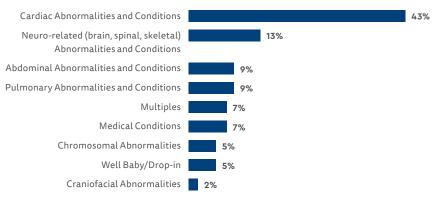
For families who choose not to pursue prenatal diagnostic testing or for babies born without a prenatal diagnosis, Children's Colorado offers an on-call team of genetic and metabolic physicians and nurses and a genetic counselor who can coordinate postnatal genetic evaluation. The team provides some of the most comprehensive genetic tests available, including rapid whole-genome sequencing. If a genetic diagnosis is identified, the team can help guide next steps for care. If not identified, the team can help coordinate further testing and follow-ups.

### **Labor and delivery**

As one of just a few freestanding children's hospitals in the nation with a dedicated labor and delivery unit, we provide a fully integrated, comfortable space for mothers and parents of high-risk babies that offers care from prenatal diagnostic testing to postpartum care. Our team of maternal fetal and obstetric providers, anesthesiologists and maternal fetal nurses specializes in caring for new and expecting patients through delivery and beyond. What's more, parents can stay in the same room for the duration of their stay.

Our space includes 12 rooms for labor and delivery, postpartum recovery and infant stabilization, plus triage and ultrasound rooms. That's in addition to two operating rooms for surgery: one for cesarean sections and one fetal surgery suite with space for as many as 35 clinicians at once.

### 2023 deliveries at a glance



Babies with CDH have the best chance for survival when they are born in a specialized center, with a dedicated and experienced CDH team to support them and their families. For severe cases of CDH, we provide the use of extracorporeal membrane oxygenation (ECMO), a machine that performs the function of the lungs while they are growing, as well as advanced treatments for pulmonary hypertension.



### NICU and neonatal surgery

Our center houses one of the largest CDH programs in the country, and our expertise and experience translates to some of the best CDH survival rates anywhere. With a focus on your patient's long-term quality of life, our care model integrates with the best subspecialty care available.

**Level IV NICU:** Just steps away from our labor and delivery unit, our Level IV NICU offers the highest level of care with full ECMO capabilities. We treat more than 2,000 newborns each year, caring for any condition affecting a newborn no matter how rare or critical — we see more and treat more neonates with complex congenital conditions and severe complications of prematurity than most other centers. Our high volumes not only allow for the development of specialized teams, but they also build our surgical and medical subspecialists' experience and expertise.



### Clinical volume survival 2012-2023

ONLY Institution in CO and in seven surrounding states ranked in neonatal care by U.S. News & World Report

Esophageal atresia/tracheoesophageal fistula	90%
Gastroschisis	100%
Hirschsprung's disease	100%
Hypoxic ischemic encephalopathy (Only includes babies treated with therapeutic hypothermia)	
	89%
Intestinal atresia	98%
Myelomeningocele	95%
Omphalocele	92%

96.52% 36

Overall NICU survival rate from 2022, despite high-risk population

Board-certified neonatologists



Designated at the platinum level by the Extracorporeal Life Support Organization

**Neonatal surgery:** Here, we perform more than 400 neonatal surgeries per year, and our level of expertise in postnatal imaging and interpretation, neonatal surgery and neonatal intensive care allows us to understand and plan for each baby's future care. Our fetal and neonatal multidisciplinary teams work closely together to coordinate post-surgical and specialized care. Not every baby born at the Colorado Fetal Care Center will need neonatal surgery, but due to the complexity of conditions treated here, about 70% of them will.

**Dedicated CDH team:** When it comes to treating CDH, our team must move swiftly and without error. A dedicated team for every CDH patient ensures consistency, builds expertise and makes for a calmer delivery and a more stable transition to life outside the womb. Our team is committed to being there every step of the way.

Pulmonary Hypoplasia Clinic: The Pulmonary Hypoplasia Clinic at Children's Colorado is the only multidisciplinary clinic in the Rocky Mountain region offering complete, long-term care for children with small, underdeveloped lungs, including those with pulmonary hypoplasia, pulmonary hypertension and related conditions. Our nationally ranked pulmonology and neonatology programs work collaboratively with teams across the hospital to bring together every aspect of these patients' care, including ongoing evaluation of their neurodevelopmental, behavioral and nutritional health, as well as any surgical needs that may arise.

### Research and trials

Children's Colorado is one of the largest universityaffiliated healthcare research complexes in the world, and as a result, we are continually working to develop new therapies across the perinatal spectrum. We were among the first in the nation to perform fetoscopic endoluminal tracheal occlusion (FETO) and developed

Active research studies

a ground-breaking inhaled nitric oxide treatment, which is now the standard of care for treating infants with persistent pulmonary hypertension. Our research in this area continues. We are currently examining the role of miRNA in CDH to continue advancing care, and have several other studies in progress. Some of our current CDH trials include:

### Fetoscopic Endoluminal Tracheal Occlusion Trial (FETO)

The goal of FETO is to combat the limited lung growth often caused by CDH. The procedure blocks the unborn baby's airway with a balloon-like device, which allows fluid to build up. This helps their lungs grow, which may improve the baby's quality of life.

### Micro RNA as a Maternal and Neonatal Biomarker to Predict Congenital Diaphragmatic Hernia Severity

This study aims to learn more about predicting disease severity among babies born with congenital diaphragmatic hernias. The goal is to study CDH before birth to better understand how to treat babies with this diagnosis once they are born. The possible benefits of research from data and samples include learning more about what causes CDH and other diseases, how to prevent them and how to treat them.

### Contact us

We happily accept referrals, consultations and requests for second opinions. We'll give you an honest appraisal of the best care options for your patients and families.



720-777-4463



childrenscolorado.org/Fetal-Care

### Learn more

Scan the QR code below to read more detailed information about the Colorado Fetal Care Center's work, including our services, capabilities, innovations and more.



# Colorado Fetal Care Center

Children's Hospital Colorado

Maternal Fetal Medicine Labor and Delivery Fetal Surgery Fetal Cardiology Neonatology Pediatric Subspecialty Care

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