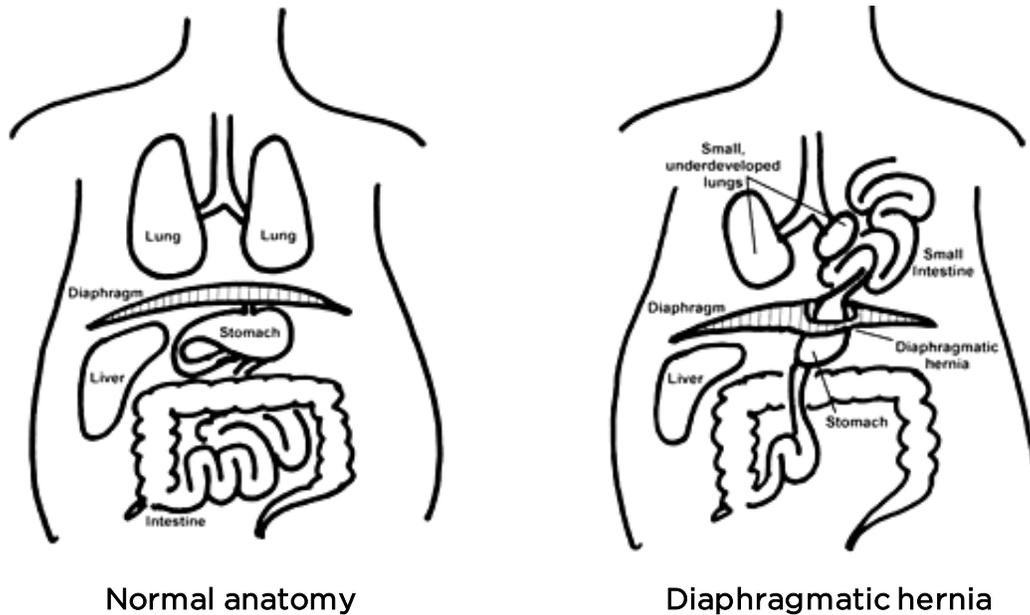


Congenital Diaphragmatic Hernia (CDH)



What is congenital diaphragmatic hernia (CDH)?

The diaphragm is the large muscle that separates the chest from the stomach area (abdomen) and helps with breathing. Congenital diaphragmatic hernia happens when the diaphragm does not form completely, and instead has a hole. Organs that should be in the abdomen slip through the hole in the diaphragm and into the chest. Once in the chest, these organs take up space that should be available for the lungs to grow. The intestine is the most common organ to slip through the hole, but other organs such as the stomach, liver, spleen, and kidneys can too.

How does the healthcare team know my baby has CDH?

Before Birth

In many cases, your healthcare team will find CDH before birth during a routine prenatal ultrasound. During the ultrasound, intestine or other organs are seen in your baby's chest, as well as smaller lung size.

After Birth

If not found during pregnancy, CDH may be found soon after birth if your baby has trouble breathing. An X-ray will be done to verify if they have CDH.

Diaphragmatic hernia may also be found in an older infant or child who has frequent respiratory illnesses. This is less common and less serious.

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To Learn More

- General Surgery
206-987-2794
- Ask your child's healthcare provider
- seattlechildrens.org

Free Interpreter Services

- In the hospital, ask your nurse.
- From outside the hospital, call the toll-free Family Interpreting Line, 1-866-583-1527. Tell the interpreter the name or extension you need.



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How did my baby get this condition?

- CDH occurs early in pregnancy while the muscle is forming.
- CDH does not usually run in families and researchers have not been able to link certain chemicals or nutrients as a cause of CDH.
- The exact cause of CDH is unknown, so there is no way to prevent it.

How is congenital diaphragmatic hernia fixed or treated?

Your baby will be monitored and treated in the Neonatal Intensive Care Unit (NICU) right after delivery.

Surgery is needed to move the abdominal organs in their chest back down to the abdomen and to close the hole in the diaphragm. Surgery is often done within the first two weeks of life. If the hole is small to medium size, it is closed with stitches. If the hole is large, a Gortex patch is used to fully close the hole.

While surgery is important to fix the hernia there are other problems that babies with CDH might have. Most babies will have some degree of pulmonary hypertension. This means the heart has trouble pumping blood to the lungs because the arteries to the lungs are thicker and stiffer than normal. Surgery does not cure this problem, though over time this usually gets better on its own.

Most babies will be on a breathing machine (ventilator) before and after surgery to help take some work off their lungs. Some also need ECMO (Extra Corporeal Membrane Oxygenation). This is a type of bypass machine that allows blood to receive oxygen outside the lungs. This is mostly needed if pulmonary hypertension is a problem.

Babies with CDH usually have small, stiff lungs. There is no cure for this problem but over time your child's lungs slowly grow larger, and the stiffness in the lungs and blood flow to the lungs improves. Oxygen, medicines, and sometimes ECMO are used in the beginning to help.

Will my baby be in pain?

The hole in the diaphragm and position of the intestine in the chest at birth does not hurt. This is simply the way the organs developed. Your baby's healthcare team pays close attention to pain both before and after surgery. We partner with you to prevent and relieve pain as completely as possible.

How serious is congenital diaphragmatic hernia?

It depends on the size and development of the lungs. If the hole in the diaphragm is small and the lungs are a good size, your child may have little trouble breathing after surgery. If the hole is larger and the lungs are small and stiff, your child may need breathing support and to stay in the hospital for a longer time. Sometimes doctors can predict how serious the CDH is from measurements taken on prenatal ultrasounds and MRIs, but sometimes it is hard to know until your baby is born. Your baby's doctor will discuss this with you after your baby is born and the medical team has a better understanding of your baby's condition.

How can I prepare for the birth of my baby?

You can begin to prepare for the birth of your baby through prenatal counseling at Seattle Children's Prenatal Diagnosis and Treatment Center. There you will meet a team of experts that specialize in caring for babies with CDH which includes pediatric surgeons, neonatologists, cardiologists and maternal fetal medicine specialists. You can ask questions and get to know the team who will be caring for you and your baby and learn more about CDH, its treatment, and complications. You can also take a tour of the hospital units and family resource facilities to better plan for your time here.

You will also want to create a birth plan with your obstetric team who will deliver your baby. Vaginal delivery is safe unless there are other health concerns for you or your baby. The decision will be up to your obstetric team. CDH does not require cesarean section. It is recommended that you deliver the baby at the University of Washington Hospital because our NICU teams work at both facilities and transfer to Seattle Children's Hospital for treatment is streamlined and performed by our NICU transfer team.

Please plan to have another adult follow your baby to Seattle Children's while you're still in the hospital. You may join the baby as soon as you leave the hospital, or come to visit daily if you need to stay in the hospital longer yourself.

What happens when my baby is born?

Right after delivery your baby will be examined by specialized pediatricians called neonatologists. If your baby is having a hard time breathing, oxygen or a ventilator will be used to help. Your baby will be taken by ambulance to Seattle Children's. At Seattle Children's your baby will go to the NICU. Your baby will likely need to be on a ventilator until after surgery.

What about feeding my baby?

If you are planning to breastfeed your baby, the hospital staff will do everything we can to support your breastfeeding goals.

During the evaluation period in the NICU and the first few days or weeks after surgery, it may not be safe to breast or bottle feed your baby. If so, your baby's food will be provided through an IV (intravenous line) with a mix of protein, sugar and fat. This special mixture is called TPN (total parenteral nutrition).

Once your baby is ready for feeding, formula or your stored breastmilk is slowly introduced. Very small amounts of breastmilk or formula are given at first. Feedings may be done by mouth or by a small NG feeding tube (a small tube that delivers food from their nose to their stomach). Then, your baby will gradually be offered more breastmilk or formula and less IV nutrition (TPN). Once your baby can handle a reasonable amount at a time, you can begin directly breastfeeding. Your baby will need a lot of energy and coordination to feed by mouth; this can be stressful for some babies with breathing problems from a diaphragmatic hernia. Nurses and infant feeding therapists can help you and your baby with the transition to feeding by bottle or breast. By the time they go home, some babies are able to eat everything by mouth, but many still need extra nutrition, which they can get through an NG tube.

How long is the hospital stay?

Most newborns with CDH are in the hospital for several weeks to several months depending upon their recovery and complications. The first part of the hospital stay will be in the NICU, followed by a period of time on the surgical unit. Every recovery is different. Your baby will be ready to go home once they have recovered from surgery and can gain weight without the feedings from the IV.

When it is time to go home, some babies with diaphragmatic hernia still need oxygen and an NG tube to support continued growth. You will have plenty of time to practice and become comfortable using them. Usually these treatments can be stopped after a few months when your child outgrows the need.

What is the long-term outlook for my baby?

Children with CDH often have long-term issues around feeding or breathing, such as gastroesophageal reflux (GER) and more frequent respiratory illnesses. The number and seriousness of these problems varies from child to child. Most babies with CDH cared for by our Congenital Diaphragmatic Hernia and Pulmonary Anomalies clinic will reach expected growth and developmental milestones by kindergarten.

The Congenital Diaphragmatic Hernia Clinic (CDH clinic) at Seattle Children's will follow your baby closely over the first year of life and long term. In this clinic, you will see a general surgeon, pulmonologist, cardiologist, dietitian, and nurse to help you coordinate any follow up visits and address any long-term concerns.

Where can I get more information?

- Read more about Seattle Children's Hospital Congenital Diaphragmatic Hernia Program at seattlechildrens.org/conditions/congenital-diaphragmatic-hernia/.
- Visit the American Pediatric Surgery Association (APSA) website at www.eapsa.org.
- Contact CHERUBS, a parent support group offered through The Association of Congenital Diaphragmatic Hernia Research, Advocacy and Support. Visit their website at cdhi.org/cherubs-the-support-division-of-cdh-international/.