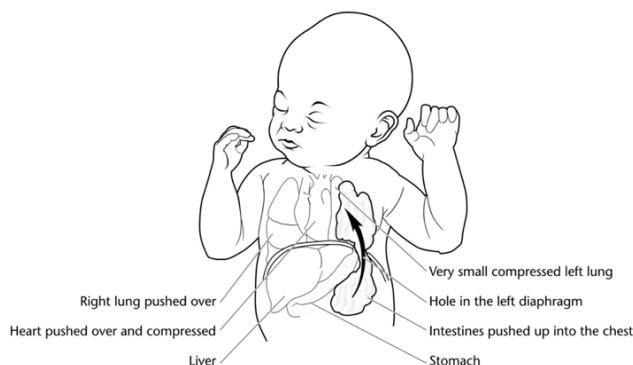


# Congenital Diaphragmatic Hernia (CDH)

The diaphragm is a thin muscle that separates the chest from the belly. It moves up and down during breathing to help the lungs empty and fill with air. Sometimes when the baby is developing before birth, the muscles in the diaphragm do not grow together completely. This leaves an opening (hole) that allows the intestines to move up into the baby's chest. The pressure of the intestines pushes the heart slightly to one side. This is called diaphragmatic hernia.

Congenital diaphragmatic hernia (CDH) can occur on either side of the chest, but most of the time it is on the left side. Babies who have CDH have lungs that have not grown normally, making it hard for the baby to breathe after birth.



## Cause

The exact cause of CDH is not known. Studies show CDH happens in 1 in every 4,000 live births. It is congenital, meaning that it happens before your baby is born.

## How CDH is found

You may have a prenatal ultrasound done while you are pregnant to learn about the health of your baby. A diaphragmatic hernia is usually found during a routine prenatal ultrasound, but sometimes it is discovered when the baby is born. CDH is a life-threatening emergency. That is why it is very important for you to deliver in a skilled hospital setting where the medical staff can take care of the baby at birth. The survival rate for babies born with CDH is 70 percent.

## Care during your pregnancy

A baby with CDH cannot be treated before birth. Your doctor will have a detailed plan to watch your pregnancy very closely. Ideally you will be able to have a normal vaginal delivery. If a cesarean section (C-section) is needed your doctor will discuss this with you. It is important to call your doctor if you have any questions or concerns during your pregnancy.

Additional tests, including fetal MRI, fetal echocardiogram and amniocentesis, may be recommended to assess the severity of the CDH and to find possible chromosomal abnormalities.

## Ohio Fetal Medicine Collaborative

If this problem is found while you are pregnant, you will continue to receive care from your doctor and may be referred to the Ohio Fetal Medicine Collaborative (OFMC).

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Through the OFMC, you will see a doctor who specializes in taking care of high-risk patients. You will also meet with a pediatric specialist at Nationwide Children's Hospital to learn more about your baby's care after he or she is born. Nurse coordinators will be available to help answer your questions and concerns; guide you through your pregnancy; and prepare you for what to expect.

You will deliver your baby at a hospital that is prepared to care for high-risk babies.

## Care after your baby is born

At the delivery hospital, a neonatologist (a doctor who specializes in treating newborns) will observe your baby.

- Your baby will receive care in the hospital's neonatal intensive care unit (NICU).
- Your baby will be put on a ventilator to help with breathing.
- An ultrasound of your baby's heart, kidneys and head will be done
- A tube will be put into your baby's nose or mouth. This tube goes into your baby's stomach and helps to keep the stomach empty.
- An intravenous line (IV) will be started in your baby's arm, hand, foot or scalp. The IV provides fluids, nutrients and antibiotics to prevent dehydration and infection.
- Your baby will be taken to Nationwide Children's Hospital, Main Campus, for further care in the Neonatal Intensive Care Unit.
- An infant with CDH has two conditions that cause him to be very sick: small lungs and high pressure in the lungs. Nitric oxide is a medicine that can help lower the pressure in the lungs and help your baby survive.
- If the lungs are very damaged and your baby is not getting better, a special treatment called ECMO may be needed. The ECMO process uses a heart-lung bypass machine. ECMO is a way for a baby's lungs rest and heal for a short period of time. The doctors and nurses will talk to you about this if they decide that ECMO might help your baby

## Surgery

All babies who have CDH will need to have surgery. Your baby will have surgery once he or she is stable. It may be days or weeks before surgery can be done. The pediatric surgeon will make an incision in the abdomen just below the rib cage. The surgeon will guide the organs back into the belly and close the opening in the baby's diaphragm. If the hole is large it will be closed with a patch.

## Care after surgery

After surgery, your baby will receive care in the hospital's neonatal intensive care unit. Your baby will need to be on a breathing machine. Other treatments your baby will probably need after surgery are:

- Antibiotics to prevent infection
- Fluids and nutrients given through an IV
- Oxygen
- Pain medicines as needed
- A tube placed through the nose into the stomach to drain the stomach to keep it empty (nasogastric or NG tube).
- Your baby may have a chest tube. This tube helps drain fluid from the incision. The chest tube will stay in place a few days.

Feedings are started once the intestines are fully healed after surgery. Feedings of breast milk or formula are started very slowly with either the bottle, nasogastric tube (NG) or a gastrostomy tube. The tube is removed when your baby's intestine works properly.

The total length of time your baby will stay in the hospital will vary. It will depend on whether your baby is born with other health issues or if there are complications after surgery. It may be several months or more depending on your child's recovery after surgery.

You may be able to take your baby home once he or she is feeding well; gaining weight; and when the lungs are working well.

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Sometimes, even though the doctors and nurses do everything possible, the baby's small and damaged lungs do not heal and the baby dies. This is the greatest risk of diaphragmatic hernia. The medical staff will always keep you informed and is available to answer any questions or concerns.

## **Follow Up**

Your baby will need regular follow-up appointments to measure growth, development and nutrition. You will want to find a local pediatrician to take care of the routine checkups, immunizations, and doctor's visits. The program coordinator can help if needed. The pediatric surgeon will follow up with your baby's surgical needs.

## REFERENCES

American Pediatric Surgical Association

**EAPSA.org/Parents/Resources**

9/2/11