

Congenital Diaphragmatic Hernia (CDH)

Congenital Diaphragmatic Hernia (CDH) is a birth defect that affects how the lungs grow.

What is CDH?

CDH affects the muscle that helps you breathe (diaphragm). The diaphragm divides the baby's chest and belly. CDH is a hole in the diaphragm. This hole can be on the right, left, or both sides. The hole is most common on the left. The stomach, spleen, liver and intestines can move up into the chest through the hole. As a result, there is less room for the lungs to grow and develop. This makes it hard for the baby to breathe after birth.



How does CDH happen?

CDH happens in about 1 in every 2,200 babies. It happens early in pregnancy when the muscle does not form correctly. Most times, the cause is not known. Genetics could play a part.

How is CDH diagnosed?

CDH is usually first seen during an ultrasound of the baby. The baby's stomach, liver or intestines may be seen in the chest instead of the belly. Our doctors also do an echocardiogram (ultrasound of the baby's heart) and an MRI to look more closely at the CDH and other parts of the baby. Certain measurements are taken to help guide the care of your baby. We may also offer genetic testing.

CDH can range from mild to severe based on the test results. Babies with CDH can have trouble with:

- Breathing
- Feeding
- Growth and development
 Some babies with CDH will not survive.

How is CDH treated before the baby is born?

The hole in the muscle cannot be fixed before the baby is born. There is a research study focused on helping a baby's lungs grow during pregnancy. Only some babies may benefit from this. Your doctor will discuss this with you if this study is an option for your baby.

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What does this mean for my pregnancy?

- You will have extra doctor's visits.
- You should plan to deliver in a hospital with a special unit that takes care of sick babies right after birth. This is called a Level III Neonatal Intensive Care Unit (NICU)
- This could change your birth plan.
 Your doctor will talk to you about where and how you should deliver.

How is CDH treated after the baby is born?

- Your baby will most likely have a breathing tube put in right away.
- The breathing tube is connected to a machine that will help your baby breathe (ventilator).
- Your baby will have a tube through their nose or mouth into the stomach.
 This tube sucks air and fluid out of the stomach and intestines.
- Your baby will be cared for in the NICU.
- Babies with severe breathing problems might need a special type of care to support their heart, lungs, and blood pressure (ECMO or extracorporeal membrane oxygenation).

- Surgery is needed to move the organs from the chest back into the belly and to close the hole in the diaphragm.
- Depending on how your baby is doing, surgery could happen days to months after birth. Your doctors will decide with you when to do the surgery after your baby is born.

The amount of time your baby has to stay in the NICU depends on how your baby is doing with breathing, feeding and growing. Your baby will have a big care team. You are a part of that team. Babies with CDH might need:

- Oxygen therapy
- Many medicines
- More than one surgery
- More calories to grow
- A feeding tube, especially if the baby has breathing problems or does not like to eat by mouth
- Regular follow-up with doctors after leaving the hospital
- Therapies to help meet developmental milestones

Babies may need these things for weeks, months, or even years.

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