Congenital Diaphragmatic Hernia

Congenital diaphragmatic hernia (CDH) is a birth defect where there is a hole in the diaphragm, the muscle between our lungs and belly that helps us breathe. Because of the hole, the intestines, stomach, and even some of the liver can go into the chest and squeeze on the lung and heart. This can lead to poor growth of the lungs and their blood vessels, which then can cause problems right after birth with how the heart and lungs work. Also, the abnormal lung blood vessels can lead to high blood pressure in the lungs.

After birth, babies with CDH are cared for in the neonatal intensive care unit (NICU) and may need to be helped with a breathing machine (ventilator). They usually have surgery between 2-7 days of age to fix the hole in the diaphragm. At the same time, any intestines, stomach, or liver are put back into the belly. Babies with very large holes may need to go on a form of heart-lung bypass called ECMO (extracorporeal membrane oxygenation) before the hole can be fixed.

CDH survivors are at increased risk for several problems that are described below. The primary care clinician (Medical Home) should be familiar with using oxygen at home, how to use feeding tubes for babies who cannot eat everything from a bottle or by breastfeeding. Babies with CDH usually need follow-up care with multiple specialists; the Medical Home can help coordinate that care.

How often does CDH happen

CDH is estimated to occur in about 1 of every 3000 births.

What is the chance of survival, or other problems?

Among all babies born with CDH, about 3 of every 4 survive to go home. Most babies who do not survive have other serious birth defects or problems with how many chromosomes they have. Many other problems can also occur, as discussed below. Generally, the bigger the hole in the diaphragm, the more common these problems are.

Where do “guidelines” for care come from?

The American Academy of Pediatrics (AAP) published guidelines in 2008 called Postdischarge Follow-Up of Infants with Congenital Diaphragmatic Hernia (click for PDF download).

What do we screen for before your baby goes home?

- Newborn screening, also called the “State Screen” or “heel stick,” is a blood test for multiple problems
- Hearing screening
- Congenital heart disease screening (most babies with CDH will have at least 1 heart “echo” and do not need this screening)
- Car seat testing

Other Problems

Lung problems

Infants with CDH usually have "high blood pressure" in their lungs (also called pulmonary hypertension) at birth and for the first 1-2 weeks of life. For some, this will continue after they go home. Most babies with CDH need to go home on at least a little bit of oxygen given through the nose by a small tube (cannula). Some babies with pulmonary hypertension will also need medication. Other medicines that babies with CDH may need when they go home would usually be managed by Pediatric Cardiology or Pediatric Pulmonology (heart and lung doctors for babies and children). Most infants and children with CDH are at increased risk for lung infections and should be followed closely by their doctors.

Reflux disease (spitting up that causes pain or poor growth)

Reflux is a common problem. Many infants with CDH will need "anti-reflux" medication when they are discharged home or within a few years after birth.

Feeding problems and growth

Poor growth is a common problem in babies with CDH, especially in the first few years of life. Poor growth in height (or length) remains a concern until at least age 12. Often, babies with CDH are sent home on high-calorie formulas or human milk with added calories to help them grow better. Those who cannot drink enough by bottle to grow may need to have some or all of their feedings via a plastic tube placed through their nose into their stomach or intestine. "Tube" feedings are usually managed at home by a team that includes your baby's doctor, a Pediatric Gastroenterologist (GI or stomach doctor), and speech therapists who help teach eating by mouth.

Behavior and developmental problems

Babies with CDH can have language and motor problems (crawling, walking). These are more common if they had ECMO or spent a long time on a breathing machine. Most children with CDH have normal learning and activity. Babies with CDH are at increased risk for autism (about 1 in 10) and other behavior problems that may benefit from therapy at home and educational support in school.

Hearing loss

Some type of hearing loss has been reported in about 50% of CDH survivors. This problem appears to be decreasing over the last 10 years, but still must be closely followed. Repeat hearing screens are recommended every 3 months after birth for the 1st year of life, then every 6 to 12 months until age 5.

Surgical problems

About 1 in every 10 babies with CDH may have a recurrent hernia where the hole in the diaphragm reopens. Usually, these are babies who needed a "patch" to fix their hole. This problem happens less often if your baby's surgeon used a "muscle flap" to fix or patch the hole. This problem rarely happens if no patch was needed. Babies or children whose hernia returns may not have any problems or they may develop breathing and/or feeding difficulties. Children with CDH are also at increased risk for blockage in the intestine and abnormal chest wall or spine growth. These problems may occur many years later and will need care from Pediatric Surgery and/or Pediatric Orthopedic Surgery.

Where can you get other information & support?

Cherubs (CDI International)
Helps families of babies born with congenital diaphragmatic hernia by providing support services, promoting research, and raising awareness.

Breath of Hope
Detailed information for families in all stages of caring for a child with congenital diaphragmatic Hernia. Include booklets about expecting a child with CDH, bringing your baby home, how to answer your children's questions about a baby in the NICU, and managing sensory processing and feeding disorders.

Authors & Reviewers

Initial Publication: October 2018; Last Update: October 2018
Current Authors and Reviewers (click on name for bio):

Author: Michelle Yang, MD