Congenital Diaphragmatic Hernia: Information for Parents

Around one in 2,200 to 3,000 newborns is born with a congenital diaphragmatic hernia (CDH). The diaphragm is the muscle that separates the chest cavity from the abdominal cavity. It is a very important part of breathing normally. This defect allows the stomach organs to enter the space in the chest where the baby’s heart and lungs are. When this happens while the baby is still developing, it can be a life-threatening condition. It is important that the medical team identify this condition as soon as possible.

Most CDHs occur on the baby’s left side; male babies tend to have them more often. Some CDHs are very small and can be difficult to find. Others are large, sometimes with a complete absence of the diaphragm. Because the stomach contents are inside the area where the heart and lungs are, the normal growth of the heart and lungs may be affected.

Many babies with CDH have other problems. The most common problems involve the brain or spinal cord, the heart, the bones or muscles, the intestines, or the kidneys and bladder. Babies with CDH also may have issues with their chromosomes.

Although CDH is commonly diagnosed during a prenatal ultrasound, it is not always found before delivery. Ideally, if your baby’s CDH is known before birth, you should deliver in a hospital with a level III or IV neonatal intensive care unit so that your baby will receive the care he or she needs right away. If not diagnosed before delivery, medium to large CDH defects will be diagnosed after birth. If this happens, your baby may need to be moved to another hospital. Often these babies will look blue in the delivery room, or within a few minutes after birth, and will have a hard time breathing. You may notice that their chests are big and their stomachs are sunken in. There may be signs that their hearts are having trouble pumping blood to the body (weak pulses and pale skin). These babies usually require a breathing tube to be placed in their windpipes to make breathing easier.

A soft plastic tube will be placed in your baby’s mouth to remove air from his or her stomach. This will help get more oxygen to your baby. He or she will not be fed for several days. An intravenous (IV) catheter will need to be placed to provide fluids, nutrition, and medications.

When your baby is stable, he or she will go to surgery to correct the CDH. Depending on the size, your baby may require heart-lung bypass before or after surgery. The heart-lung bypass machine helps do the job of the lungs and heart to allow them to heal.

Most times, the CDH can be repaired with one surgery. After surgery, the baby’s care will include receiving baby pain medicine and nutrition and medication through an IV. Your baby may have a chest tube (see *Chest Tubes* in Diagnoses). This is a soft plastic tube that removes the air from the area outside of the baby’s lungs. This will be taken out at the bedside a few days after surgery.

Survival rates vary depending on the size of the CDH and the complications both before and after surgery. Unfortunately, about 50% of babies do not survive.

Follow-up appointments are very important in the care of babies with CDH. Some babies who survive can have abnormal muscle tone and delayed neurocognitive and language skills.