PARENTS' RESOURCE GUIDE

Congenital Diaphragmatic Hernia

What is CDH: Congenital Diaphragmatic Hernia (di-a-frag-mat-ic)?

The diaphragm is a thin muscle that separates the chest from the belly. It moves up and down as you breathe to help the lungs fill and empty with air. During fetal (before birth) development the muscles in the diaphragm do not grow together leaving a hole. The hole or opening allows the intestines to move up into the baby's chest causing the heart to be slightly pushed to one side. This is called a diaphragmatic hernia. This will either occur on the left or right side of the chest. 80% of the holes in the diaphragm occur on the left side of the chest. Babies with this problem have lungs that did not grow normally causing the baby to have difficulty breathing. Diaphragmatic Hernia is a life-threatening emergency.

Most diaphragmatic hernias are discovered during a routine prenatal ultrasound by your doctor. Some cases are discovered when the baby is born. It is very important for the mother to deliver in a skilled hospital setting where the medical staff can take care of the baby at birth.

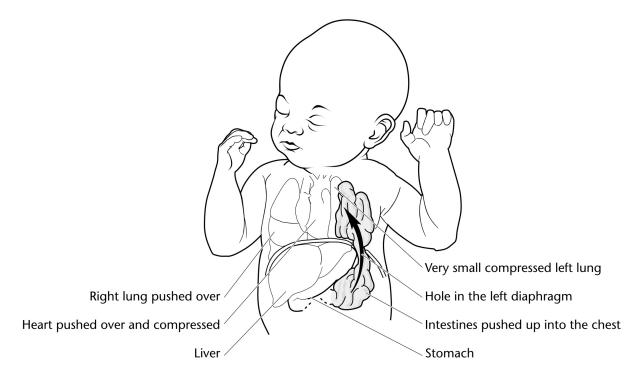


Figure A Illustration of a baby with a left-sided congenital diaphragmatic hernia.



What happens after your baby is born?

At the delivery hospital a specialized pediatrician called a neonatologist will monitor your baby's breathing at birth. Usually the baby has to be put on a ventilator to help the baby breathe. A tube will be put into your baby's nose or mouth. It will be either an NG tube (nasogastric) or an OG tube (orogastric). This tube goes into your baby's stomach and helps to keep the stomach empty.

The exact cause of congenital diaphragmatic hernia is unknown. Studies show that 1 in 2,500 to 5,000 babies will be born with this problem. The survival rate is between 50 and 75%.

An intravenous line (IV) will be started in your baby providing fluids and medications to prevent dehydration and infection. Also, a special intravenous line called an umbilical catheter will be started. An umbilical catheter is a long plastic tube that is placed in the umbilical artery and umbilical vein. The catheter provides IV fluids and medications and monitors your baby's blood pressure. This special catheter typically only stays in place for up to 2 weeks.

Treatment of Congenital Diaphragmatic Hernia?

All babies will need to have surgery to fix the problem. The timing of surgery varies from baby to baby. It is not an emergency for surgery. The emergency is how well the lungs are working. A special device called a pulse oximeter will be placed on the baby's hand or foot. This will allow the doctors and nurses to monitor how much oxygen is in the baby's blood. A special IV placed in the wrist will monitor the baby's blood pressure. Sometimes the baby will need special medicine to keep the blood pressure stable. The baby will be monitored constantly.

Babies with diaphragmatic hernia have both small lungs and high pressure in the lungs. This causes the baby to be very sick. Nitric Oxide is a medicine that can help make the pressure in the lungs lower.

If the baby's lungs are not working effectively, the baby may require special treatment called ECMO. This is a heart lung bypass machine. The doctors and nurses will talk to you about it if this situation occurs. The ECMO is a way that can let the baby's lungs rest and heal for a short period of time.

The baby will not be able drink formula or breast milk until after surgery. A special IV called a CVL (central venous catheter) will be used to provide IV nutrition and give medicines. It will stay in place until IV nutrition is not needed anymore. The catheter will provide TPN (total parenteral nutrition) which has all of the calories and nourishment needed for your baby to grow.



The baby will have surgery once he or she is stable. It may be days or weeks before surgery can be done. In the operating room, the pediatric surgeon will make an incision in the abdomen just below the rib cage. The surgeon will push the intestines and other organs back into the belly and close the opening in the baby's diaphragm. Sometimes if the hole is too big and the surgeon cannot sew the diaphragm together the surgeon may have to use an artificial patch (such as Gortex). Sometimes the surgeons perform repair of the diaphragmatic hernia when the baby is on ECMO.

What happens after surgery?

After surgery, your baby will continue to be on a ventilator to help him or her to breathe. The ventilator will be removed when your baby has recovered from surgery and the lungs are stable. This may be for days to weeks. The baby may have a chest tube after surgery. This tube helps drain fluid from the incision. The chest tube will stay in place for a couple of days. Babies with diaphragmatic hernia are very sensitive to noise and pain. The babies may be easily agitated. The medical staff will give medicines to help reduce any pain or discomfort your baby may be having.

The tube in the baby's nose or mouth will stay in place until the baby's intestines have started working. Feedings of formula or breast milk will be started in small amounts and increased gradually over time. When the baby is taking enough formula or breast milk to grow and gain weight, the IV will be removed.

The length of hospital stay depends on how sick the baby is and how well the lungs are working. On average the baby will have a hospital stay of at least one month to possibly as long as six months.

What are the greatest risks to my baby?

Sometimes, even though the doctors and nurses do everything possible, the baby's lungs cannot support life. This is the greatest risk of diaphragmatic hernia. The medical staff will always keep you informed about your baby's condition and is available to answer any questions or concerns.

Another risk to the baby is infection. The baby will be given antibiotics to treat and prevent infection.

Sometimes babies have feeding problems. It takes the intestines several weeks to heal properly after surgery. Your baby will not be able to eat large amounts of formula or breast milk right away.

Sometimes babies need to have a blood transfusion. The medical staff will talk to you if this needs to happen.

Are there any long term complications to my baby?

Sometimes babies that go home from the hospital may face some challenges. Here is a list of the possible complications.

- Feeding problems
- Gastrointestinal reflux disease
- Long term lung problems such as asthma
- Neurological problems .



Frequently Asked Questions

What is the survival rate?

National average of survival rates for CDH is between 50-75%

When can my baby go home?

Your baby can go home when he or she is taking enough formula or breast milk to grow and gain weight.

How long will my baby have to stay in the hospital?

The average length of hospital stay is 1-3 months. Some babies may have complications and will need to stay longer.

What other tests are done on my baby?

The doctor is going to schedule an echocardiogram (scan) of the heart, kidneys and head. Also, your baby will have blood drawn to monitor lab values. The medical staff will talk with you regarding the results.

Is it okay to have a vaginal delivery?

Most surgeons believe it is okay to have a vaginal delivery. It is not only safe for the baby, but the mother recovers from delivery faster than with a Caesarean delivery. Talk with your delivering doctor about this. If your obstetrician determines that you need to have a Caesarean delivery, the surgeon will agree.

Where do I need to deliver my baby?

Your high risk doctor will let you know which Columbus hospital you will be delivering at.

I live out of town. Where can I stay?

Nationwide Children's Hospital has a wonderful Ronald McDonald's House where families who live out of town may stay while their child is in the hospital. Ask the Children's Hospital program coordinator if this can be arranged for you.

How will all of this get coordinated?

Nationwide Children's Hospital has a program coordinator to help with these arrangements. You may contact Becky Corbitt RN, BSN, at any time during your pregnancy for any questions or concerns. Phone: (614) 722-6520.

When can I hold my baby?

This is a difficult time for most parents. Talk with the doctor or nurse to see when you can hold your baby.



The health care team at Nationwide Children's Hospital encourages family centered care. At any time you need to speak with any members of the team please ask. The staff is here for you and we want to help you to be involved with daily care.

Where do I follow up once my baby is discharged from the hospital?

You will want to find a local pediatrician to take care of all 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.

Support Groups

Local Support Groups: Ask the program coordinator for information.

CHERUBS: The association of Congenital Diaphragmatic Hernia Research, Awareness, and

Support. E-Mail: info@cherubs-cdh.org.net

Website: http://www.cdhsupport.org

Address: CHERUBS, 270 Coley Road, Henderson, NC 27537

Telephone: 252-492-6003

References

Notes

American Pediatric Surgical Association at www.eapsa.org/parents/resources

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