



Congenital Diaphragmatic Hernia Questions & Answers

Written by CHERUBS 1999, last updated 2007 ~ www.cdhsupport.org

1. How did this happen?

CDH is caused by the diaphragm not closing or forming at around 8 weeks gestation. Organs that would should have been in the abdominal cavity then float freely into the chest cavity, taking up valuable lung space. Why it happens is not known.

2. What caused this?

The cause isn't yet known. We do know that sometimes it tends to run in families, primarily with genetic problems and other families. Studies also show that certain environmental factors might cause CDH; such as exposure to chemicals like Nitrofen or pesticides, excessive Vitamin A and Folic Acid. We conduct our CDH Research Survey to help study these common factors so that maybe someday other babies will be spared this birth defect.

3. What did I do?

There is nothing that you could have done to cause this on purpose. Until we know the cause of CDH, we really can't answer this question yet, but you cannot blame yourself for something we do not know the cause of yet.

4. Could this have been prevented?

Until we find a cure or a cause, this can't be prevented. Taking pre-natal vitamins is a plus- but taking too much can be harmful. There is just no way of knowing how to prevent CDH right away and parents can't blame themselves for not knowing how to prevent it.

5. How often does this happen?

CDH occurs in about 1 in every 2500 babies- this is more common than being struck by lightning or a tornado. It has close to the same occurrence rate as Cystic Fibrosis and Spina Bifida.

6. Has anyone else near me had this same thing happen?

By joining CHERUBS we can help you find other families who have been through this and we will give you information about families near you. Also, ask your doctor to put you in touch with some of his former patients- that is your best bet to find another family in your town.

7. Is there someone I can talk to who knows what this is?

Everyone at CHERUBS knows exactly how you feel. We have parents on-call to listen to you when you need to talk. You are no longer alone.

8. Could this happen again to me? Will all my children have this?

Without a family history of CDH or genetic abnormality in the baby, the chances are given as 2%. We encourage all of our members to seek a genetic counselor to talk about your odds of having another CDH baby.

9. Could this have been detected?

With today's technology CDH is being detected as early as 16 weeks gestation by ultrasound. Unfortunately, the United States does not have a national guideline or require licensing to perform an ultrasound. Make sure the person performing your ultrasound is fully trained.

10. Did the doctors/hospital do something wrong?

CDH is a birth defect, caused during fetal development. There is nothing that the doctors/hospital did that could have caused CDH.

11. How long will my baby be in the hospital?

There is no "normal" recovery time. It could be days or months. Be prepared for anything and hopeful for a quick and smooth recovery.

12. Do I have to give up my plans for breastfeeding?

Absolutely not. Most hospitals will provide breast pumps so that your baby can receive your milk. Your baby needs your milk more than ever. Keep the pump sterile and pump regularly to avoid mastitis.

13. Is there anything that I could have done during my pregnancy to help my baby?

Educating yourself greatly helps, also some moms are now receiving steroids to help with lung development and there is the option of fetal surgery. Rest, staying away from drugs, alcohol, and cigarettes and eating a good diet are the best things you could do for your baby. Also ask your doctor about taking steroids that may help your baby's lung growth.

14. Would things have been different if I had delivered at a larger hospital?

If your child is diagnosed in utero we encourage you to deliver at a large hospital, with experienced pediatric surgeons and an available ECMO machine in case ECMO is needed.

15. Do I have to have a C-Section?

Unless there is a medical need to have an ultrasound because of other complications involving your health or your baby's health, there is no reason to have a C-Section because the baby has CDH. Studies have shown that a vaginal delivery actually helps the baby's lungs because it stimulates surfactant (the secretions that line the lungs).

16. Do I really need to see a genetic counselor?

No matter what the outcome, it is always wise to speak to a genetic counselor. The genetic counselor will go over your child's records and your family's histories to see if there is a genetic abnormality that caused the CDH and to let you know your odds on having another baby with CDH.

17. My doctor says that my baby will not survive, what advice can you give me on keepsakes and what to do at the time of death?

Hold your baby. Many families regret not holding their babies, but none ever regret holding them. Take pictures and video. Take footprints and handprints and a lock of hair. Make plaster molds of footprints and handprints. Ask to keep your babies blankets, clothing, etc and store them in an air-tight, acid-free container. Hold your baby, sing to your baby, tell him/her that you love them and though you will miss them very much, it is ok to go. Take your time and don't let anyone rush you. Don't be afraid to cry, yell, scream, or whatever you feel you need to do. There is no emotion that isn't ok to feel.

18. Could my child have survived with surgery if we had known?

Each child is different. Babies with small defects sometimes don't make it while babies with large defects survive. Even after surgery, some babies don't survive.

19. What is life like with a child who survives CDH?

Again, each child is different. About 95% of our cherubs have feeding problems; 75% have asthma, 75% have reflux- though many cherubs do have "normal lives", some have complications such as hearing problems, cerebral palsy, developmental delay and a few have more severe problems. Many of our cherubs are doing so well that they play sports, go to college and a few are now parents themselves.

20. How will I know if I should let go?

You will know it in your heart when/if it's time to say goodbye. Don't let anyone tell you otherwise, because you will be the one who will be grieving. When/if you feel this, there will be no doubt that you are doing the right thing.

21. How can I help my baby while he/she is in the hospital?

You can read to them, talk to them, make tapes of your voice for when you're not there. Put chapstick on their lips, lotion on their dry skin (with doctor's permission), make sure everyone who comes into contact with your baby washes their hands and keep away visitors who are sick or who have been exposed to people who are sick. Most importantly – ask questions, educate yourself and just love your child.

22. Is there a prenatal indicator on how well a baby will do?

A baby with more lung development may do better than a baby with little lung development but there are many other variables that determine who a baby will do after birth. The baby's size will determine whether he/she is an ECMO candidate, should it be needed. Other organs displaced in the hernia should be checked for damage. Liver displacement is often noted on research studies as having a higher mortality rate with CDH. Most importantly – each child is different and there is no set rules or path for any CDH child.

23. Is it true that lung function is the deciding factor on whether my child will survive?

No. Good lung function certainly helps a baby recuperate more quickly but there are many factors that can come into play. More babies lose their fights from infections and pneumonia than from poor lung function.

24. Can organs move up and down through the diaphragm?

Yes. It is rather common for organs to move up and down the hole in the baby's diaphragm. During one ultrasound you might see more or less herniated organs than in another ultrasound.

25. Do I have to deliver at an ECMO center? What is ECMO?

It is highly recommended that all CDH babies are delivered at ECMO centers. Not all CDH babies will need ECMO but those that do are often too unstable to be moved from one facility to another and delivering at an ECMO center can spare them the needless trauma of a move. ECMO- (Extracorporeal Membrane Oxygenation) a very large and complex machine that takes over the work of the patient's heart and lungs. A very large catheter, a plastic tube, is placed in an artery in the patient's neck. Blood is then removed from the patient's body, oxygenated, and returned to the patient. The term ECLS (Extracorporeal Life Support) is sometimes also used.

26. What type of in utero procedures are available?

There is a promising new method in tracheal occlusion (also called "tracheal ligation"- it involved clamping off the unborn baby's trachea, forcing the lungs to grow and organs to move down) involving injected collagen. This procedure would eliminate surgery for mom and remove the threat of preterm labor.

27. How can I help avoid feeding issues?

First, it's very important to follow all medical advice given in your child's specific best interests. Every CDH patient is different and timing is very important on all therapies so ask before trying anything new. Many doctors often intubate patients through their noses so that the baby can use a pacifier.

28. How can I help my family and friends to understand that CDH is serious?

Sometimes it is hard to explain that CDH is much more serious than a general "hernia". Sometimes it helps to give them the address to our web site or to print off some brochures from our site to distribute to family members and friends.

30. Where I can find more information on CDH?

CHERUBS web site maintains an on-line CDH Research Library and encourages all parents to learn as much as possible about CDH.