

Breath of Hope would like to thank those who have reviewed this booklet:

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All Our Documents are Always In Review  
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Please contact us if you see anything that may need to be corrected or updated.



[www.breathofhopeinc.com](http://www.breathofhopeinc.com)

Dedicated to All Families and Health Care Professionals affected by  
Congenital Diaphragmatic Hernia

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***Congenital Diaphragmatic Hernia  
Every Breath They Take Is Our Breath of Hope***

## **EXPECTANT PARENT HANDBOOK**

### **MISSION STATEMENT**

*Breath of Hope exists to raise awareness of congenital diaphragmatic hernia by working with parents, family members, and medical professionals to educate and support all who are affected by or want to learn more about CDH.*

Breath of Hope, Inc.  
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Public Charity



**Mail to:**  
**Breath of Hope**  
**PO Box 6627**  
**Charlottesville, VA 22906**

## What do I do now?

If you have this booklet, you have just found out that your child or unborn baby has congenital diaphragmatic hernia. The most important thing you can do is ask questions and learn about this birth defect. Your doctors are the best source, but if you do not feel comfortable with them, there are many other doctors, medical centers, and hospitals that can and will treat a child with CDH. What is most important is that you are not alone. You have valuable resources among the parents who have walked a similar path. Breath of Hope is a group of parents, family members, and friends who are all trying to learn more about CDH and be there when a cure is discovered. It is also important to know that each of these children with CDH is different. Cases might be similar, but each is as unique as a snowflake.

The best thing you can do for your unborn child is to give birth at a hospital with a Level 3 neonatal intensive care unit (NICU) with an ECMO (extracorporeal membrane oxygenation) machine. Approximately 60 percent of all CDH babies will be on ECMO after they are born, some even before, during, or after surgery. Transfer your care to a perinatologist or a high-risk obstetrics doctor who has had experience delivering babies with CDH (unless you have a great current OB that you trust and know will do his or her ultimate best for you and your child). Be sure to set up an appointment or several appointments to interview the surgeon, the neonatologist, and anyone else you feel you should talk with before your child is born. You can interview the doctors. We know that right now you feel you have absolutely no control and it is unnerving, but this is where you have control.

You are the parent and you know in your heart what is best for your child. Most of the time in the US, parents have four options for treatment:

1. Give birth at a Level 3 or 4 NICU with ECMO available. This is the “traditional” treatment for CDH.
2. Endoscopic tracheal occlusion fetal surgery prior to birth, if appropriate. Highly trained surgeons must perform this surgery, and it comes with risk to the mother. This option is available in only a very few medical centers in the US, and is only done on the most severe CDH cases.
3. Induce the pregnancy early or terminate the pregnancy, especially if there are other medical issues with the unborn child.
4. Choose a “compassionate birth”—wait until the baby is born and make an assessment then. Many doctors don’t mention this option.

None of these choices is easy. The unborn child’s condition, the mother’s health, and other factors can influence the best choice in each case.

Breath of Hope respects and supports decisions that a parent makes for the care of his/her child. We do not give medical advice; we encourage you to seek information from your doctors and your child’s doctor. We have parents who are constantly researching and have the experience of having had a child with CDH. We can tell you what information to dismiss that exists out there on the Internet; if it is more than three years old, it probably no longer applies.



**Breath of Hope, Inc**  
**Congenital Diaphragmatic Hernia**  
*Every Breath They Take Is Our Breath of Hope*

Please complete the following information, and send to Breath of Hope, PO Box 6627, Charlottesville, VA 22906. Once we receive this form completed, we will process your application and register you as soon as possible on our mailing list. You can also join our listserv and send this form in via email. We use your information to mail newsletters and cards, match you with parents in your area with your permission.

Name: \_\_\_\_\_

Address: \_\_\_\_\_

City, State, ZIP: \_\_\_\_\_

Home phone number: \_\_\_\_\_

E-Mail: \_\_\_\_\_

Alternative E-Mail Address: \_\_\_\_\_

Are you a parent of a child with CDH? \_\_\_\_\_

Child's Name: \_\_\_\_\_

Child's Birthday or Estimated Due Date: \_\_\_\_\_

May we send you our Comfort Care Package? \_\_\_\_\_

May we send your info to Colin's Sugar Bears (if you are expecting or in the

NICU to receive a Sugar Bear? \_\_\_\_\_

Hospital Child was (or will be) treated: \_\_\_\_\_

CDH Child's Date of Birth (and date of death, if applicable)? \_\_\_\_\_

\_\_\_\_\_

How did you hear about Breath of Hope? \_\_\_\_\_

If you have a Website or social media page, please provide the link information:

\_\_\_\_\_

None of the information provided will be sold to another entity or used for anything other than secure processing.

Thank you for taking the time and completing this form!

With warm regards,  
Breath of Hope, Inc. Board of Directors

**How should I prepare for this Special Baby?**

Nothing can really prepare anyone for this experience; each of us goes through the roller coaster of emotions in our own way, and if you are the mom, the hormones of pregnancy do not help. The most important thing is that you need people who will give you positive support as you go through this journey. We've included here a list of things other parents have found helped before and after the birth, and in the best- and worst-case outcomes.

1. Check your health insurance benefits. Be sure you have a copy of the policy and know what your benefits do and do not cover. Many major hospitals have a policy that on the thirtieth day a baby is in the NICU Medicaid takes over as the primary insurance. NICU stays are extremely expensive.
2. Ask questions! Ask to have appointments set up with the surgeon and with a neonatologist. Many hospitals will do this; if they don't, they should. Remember, you can interview them. Ask to tour the NICU and/or PICU.
3. Go with your instincts! If you believe something is wrong with your baby, your baby is uncomfortable, or you need a second opinion, ask for it. It's better for you to be wrong or proven wrong than for your baby to suffer or get sick. Doctors are human and can make mistakes, and very good doctors rely on parents' instincts. They have seen all too often a parent come in or call the NICU because they had a feeling, to find out that something was indeed going wrong with their baby.
4. Keep a diary or journal. Write down who said what, which treatments your child received, and your feelings.
5. Bring a plastic container/bin with a lid. Fill it with a few books you can read to your baby, baby lotion for you or for your baby's peeling skin, a disposable camera, a pad of paper and a pen, a stuffed animal for your baby.
6. TAKE PICTURES and/or video. (Even if you never look at them again, you will always have them.)
7. KEEP A POSITIVE ATTITUDE. Your baby needs positive energy.
8. Nurses—Develop a relationship with the nurses. Remember, it's not *what* you say, but rather *how* you say it that matters. If you should have a problem with a nurse, speak to him/her first. If there is still an issue, go to the head nurse or your child's doctor and ask for that nurse to be reassigned. It might be personality; it could be a bad day. Of forty NICU nurses, maybe two will rub a parent the wrong way.
9. Doctors—Write down the doctors' names. Ask that you receive input on your baby's status *every day*. Don't always get status reports from nurses. Don't allow anyone to make you feel as if he/she doesn't have time for you and your baby. You and your insurance

company will receive a bill for these services—and you want *service*.

10. Breath of Hope Listserv—Contact the parents with any complaints, questions, advice, or anything else. You can call someone to post for you and someone will respond, then that person will call you back in the NICU with an answer. Use us at Breath of Hope; that's why Breath of Hope is here.
11. Know the visiting hours and NICU policies. Some only allow two visitors at a time. Many will give you a history number to use when you call in to obtain information.
12. Choose *one* person to give out information about you and your baby. Give that person the daily update and let them relay it to those who are concerned. You might not want to repeat the same thing twenty times a day, every day. You can also start a blog, use social media page or Caringbridge has a community of those facing medical issues and limits access to those in the community to keep people updated.
13. Breastfeeding—If you want to breastfeed, speak to a lactation consultant at the hospital. Their consultations are usually free.
14. Baby care—You can do many things for your baby, depending on your baby's condition at the time:
  - a) help take their temperature
  - b) massage their arms and legs with lotion to keep their muscle tone
  - c) brush their hair with a soft toothbrush
  - d) "cradle" them by putting your arms around their head and their feet—encircle them with your arms, even if you are not able to touch them; this has been proven in NICUs to comfort babies
  - e) sing to your baby
  - f) read to your baby or tell your baby stories
  - g) pray with and for your baby
15. Photographs—Now I Lay Me Down to Sleep (<http://www.nowilaymedowntosleep.org/>) provides professional photos at no charge to parents who have lost a child.
16. Take care of yourself. This is very important. Eat regularly, keep hydrated, and rest. You cannot be completely there for your baby without doing these things.



Even after doctors repair the problem with your baby's diaphragm itself, CDH often has other potentially complicating factors. Your expert medical staff will work to handle any of these conditions if they arise.

**Pulmonary hypertension** is an increased pressure in the arteries supplying blood to the lungs. This increased pressure shunts blood away from the lungs and decreases the supply of oxygen to the body. This is normal blood flow while the baby is inside the uterus, because the baby is not breathing on his/her own. However, once a baby is born, the arteries in the lungs need to relax to let blood flow through the lungs and exchange gases. Blood running through the lungs rids itself of carbon dioxide and picks up oxygen to supply the body. Pulmonary hypertension is a life-threatening complication. If the oxygen levels are low, more aggressive treatment options, including nitric oxide therapy and a heart bypass machine, can be attempted.

Nitric oxide (NO) is a gas that dilates the pulmonary blood vessels and lowers pulmonary blood pressure. By supplying NO directly into the lungs, the pulmonary vasculature (blood vessels in the lungs) relaxes, but the systemic blood vessels (blood vessels in the body) do not. This lowers the pressure in the lungs but not the blood pressure in the general body. Blood is able to circulate through the lungs to pick up oxygen and rid itself of carbon dioxide. Unfortunately, NO treatment works more effectively in babies with pulmonary hypertension from other causes and does not work as well with CDH, but is still used when cases warrant it.