This document is in review.

All documents from Breath of Hope are always in review – if you see something that may need to be updated or changed, please contact us! boh@breathofhopeinc.com

**Breath of Hope, Inc**
**PO Box 6627**
**Charlottesville VA 22906**
**888-264-2340**
**888-BOH-CDH0**





# Bringing Baby Home

A Reference for Babies Born with Congenital Diaphragmatic Hernia

BreathofHope

**January 18, 2012**

*EVERY BREATH THEY TAKE IS OUR BREATH OF HOPE*

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.

## WHAT AN ACCOMPLISHMENT!

You have finally been told your child will be leaving the hospital. This is an amazing hurdle for your baby, you and the hospital staff that have been there through this all.

This is met with mixed emotions for parents. You might fear having to now take care of this child who was in such fragile health. There were times you thought this day would never come. At the hospital, you always had the nurses and doctors to oversee the care, help when you needed it, but now you will be in total charge of your baby's care. Be confident that you are the parent and parental instincts are 99.9% of the time absolutely in sync with your child. Get phone numbers of key personnel you may need to contact, not just for follow-up care but for general questions too.

If your child will require oxygen at home, you will need to contact a local medical health care supplier for this. Also, obtain a portable oxygen tank for not just doctor's appointments but in case the electric power goes out. This is also important – contact your local electric power supplier and tell them a young child that is oxygen dependant will be in the household. This way – they know this and can get help to you when the power is out.

If your child requires tube feeding, you will also need a medical supplier for the tubing and other supplies. Usually health insurance covers these services and supplies. Also, you can use the Breath of Hope Listserv; many parents might have practical information on supplies, companies and might also have solutions to some of the issues that might come up. One great tip is to use the Velcro Tabs office supply stores sell for computer wires - to keep all their wires and tubes together for mobile babies. It is also less expensive for a child to be at home on any sort of medical assistance, than to be hospitalized. Some children will be transitioned from the hospital to a nursing care facility to transition home; this is still a step in the right direction.

Medications also may be a factor; try to have one pharmacy supply all medications. You will only have one place to go to pick up the medications and will not have to travel to several different locations. Also, one pharmacy can better track potential interactions with other drugs.

Overwhelmed? There is so much to remember from medications to

## Research Information

In an effort to find a cause or better treatments for CDH, Breath of Hope provides this information so that you can participate in these research studies. We have members that have participated in these studies and will be happy to answer any questions.

Birth Defects Research for Children Inc. has a survey to complete which is compiling information on Birth Defects and exposures that may have been the cause, including environmental, military service or work related exposures.

http://www.birthdefects.org/

The following studies require blood testing and they can send the kits to your doctor or Hospital for participation. Please contact them directly for details and we have members that have participated.

Identifying Genes Which Cause CDH
Massachusetts General Hospital
Boston, Massachusetts
Drs. Patricia Donahue and Lewis Holmes
Contact: Meaghan Russell, Clinical Coordinator, at (617) 726-0828
mrussell@partners.org

DHREAMS - Diaphragmatic Hernia Research & Exploration; Advancing Molecular Science
http://www.cdhgenetics.com/index.cfm
Columbia University Medical Center
1150 St. Nicholas Avenue
New York, NY 10032
ph: (212) 305-6987
info@cdhgenetics.com

Daryl A. Scott, MD/PhD
Baylor College of Medicine
R813, One Baylor PlazaMail Stop: BCM 225
Houston, TX 77030
E-mail: dscott@bcm.tmc.edu

Web page: http://www.bcm.edu/genetics/facultyaz/scott.html



what to "watch for". Your child should have follow-up care and physical and/or occupational therapy. Even after a short stay in a NICU or PICU, there may be slight delays or some aversions. Parents need to also know that they each need a break and time to themselves and with one another through this period. The NICU experience is like going through battle, and we are all shell shocked from the experience. There is such a thing as Post Traumatic Stress Disorder and you may experience this from your NICU experience. Be kind to one another. Taking care of any baby is hard, but a baby who has survived congenital diaphragmatic hernia – can be especially challenging. They have even more accessories much of the time. Do not be afraid to ask for help and accept help. It is not a sign of weakness but a sign of strength to know when you need help. Also know that in time, you will return the favor to those that do help in return. Many believe just you sharing your beautiful child with them is payment enough!

When your child is about to be released, parents are required to learn CPR, how to use any equipment the child may come home using, and undergo various other trainings depending upon your child's needs. Ask questions and don't be afraid to practice over and over again until you feel comfortable.

The most common issue these babies may have is gastresophageal reflux/foregut dysmotility – it is reported to occur in 45% to 90% of infants with CDH. Reflux can be treated with medications, and many parents also use some sort of angle bed – raised head after and during the feeds. As these babies grow, they can outgrow reflux. But, if it becomes severe, a surgical procedure called fundolopation may be necessary. This is being done less today than ten years ago due to the advancement of medications.

A high percentage of these children are underweight – in one clinical study over 50% of CDH infants weighed below the 25$^{th}$ percentile. The most important thing for these babies is to have the nutrition they need for growth – they may need NG Tubes or Gtubes for feeding. Please do not take this personally; we all want oral feeding to happen, but you must remember that it is most important that they grow and thrive as much as possible. Eating could be a challenge. Fighting your infant to take a bottle or nurse to the point that it compromises their growth is not worth the stress. It is more important for your love and cuddling to be felt than for them to feed orally from their parent. If your child is a great oral feeder, that is wonderful. Growth helps these babies and their lungs. Always remember that reflux could cause your child to refuse to eat, too. At high school graduation, no one speaks of how much or how their child ate as an infant or a toddler.

**Upper gastrointestinal study**, pH probe and/or gastric scintiscan should be considered for all CDH Infants before discharge and at 1-3 months after birth if symptoms, 4-6 months after birth if symptoms, at 9-12 months after birth to be considered for all patients, 15-18 months if symptoms, and annually through age 16 if symptoms.

**Esophagoscopy** should be considered if there are symptoms at 1-3 months after birth, 4-6 months after birth, at 9-12 months after birth if symptoms or if there are abnormal gastrointestinal evaluations, at 15-18 months after birth, and annually through 16 years if symptoms.

**Oral Feeding Evaluations** should occur before discharge, 1-3 months after birth, 4-6 months after birth, 9-12 months after birth, 15-18 months after birth, and annually until age five.

**Hearing Loss** can be a concern and should be evaluated in these infants who survive CDH. It can occur even if they were not treated with ECMO. The cause remains for the most part unknown. It could be several factors including the treatment for respiratory failure and/or combination of medications they may have taken. Almost half of these infants may have some degree of hearing loss. They should be evaluated before discharge and every six months to age three, then annually to age five. Early discovery of any hearing loss will allow early intervention which will help their development.

**Developmental Screening Evaluations** should occur before discharge, then 1-3 months after birth, 4-6 after birth, 9-12 months after birth, 15-18 months after birth, and then annually to age 5 depending upon their assessments.

**Pulmonary function testing** should be at 4-6 months after birth if indicated, 15-18 months after birth if indicated, and annually through age 16.

**RSV prophylaxis immunizations** should be done prior to discharge throughout RSV season during the first 2 years after birth (if evidence of chronic lung disease).

During cold, flu and RSV season, many parents isolate their CDH babies and young children from the general public as well as anyone who may have a virus, cold, or bacterial infection. Hand sanitizer will become a staple in your household. Others may be critical of you as a parent because you will appear to be overly cautious about your child's exposure to any cold symptom. But, parents of these children will tell



# *WELCOME TO HOLLAND*

***By Emily Perl Kingsley***

I am often asked to describe the experience of raising a child with a disability - to try to help people who have not shared that unique experience to understand it, to imagine how it would feel. It's like this...

When you're going to have a baby, it's like planning a fabulous vacation trip - to Italy. You buy a bunch of guide books and make your wonderful plans. The Coliseum. The Michelangelo David. The gondolas in Venice. You may learn some handy phrases in Italian. It's all very exciting.

After months of eager anticipation, the day finally arrives. You pack your bags and off you go. Several hours later, the plane lands. The stewardess comes in and says, "Welcome to Holland."

"Holland?!?" you say. "What do you mean Holland?? I signed up for Italy! I'm supposed to be in Italy. All my life I've dreamed of going to Italy."

But there's been a change in the flight plan. They've landed in Holland and there you must stay.

The important thing is that they haven't taken you to a horrible, disgusting, filthy place, full of pestilence, famine and disease. It's just a different place.

So you must go out and buy new guide books. And you must learn a whole new language. And you will meet a whole new group of people you would never have met.

It's just a different place. It's slower-paced than Italy, less flashy than Italy. But after you've been there for a while and you catch your breath, you look around.... and you begin to notice that Holland has windmills....and Holland has tulips. Holland even has Rembrandts.

But everyone you know is busy coming and going from Italy... and they're all bragging about what a wonderful time they had there. And for the rest of your life, you will say "Yes, that's where I was supposed to go. That's what I had planned."

And the pain of that will never, ever, ever, ever go away... because the loss of that dream is a very very significant loss.

But... if you spend your life mourning the fact that you didn't get to Italy, you may never be free to enjoy the very special, the very lovely things ... about Holland.



you it is better to be overly cautious and appear rude to some than to rush your child to the hospital ER in respiratory distress. A simple cold in CDH babies and young children may develop into pneumonia. Their lungs are already fragile. For a baby without CDH, pneumonia is serious, but for a CDH baby, it can be deadly.

**Scoliosis and chest wall deformity screening** (physical exam, chest radiograph, and/or computed tomography of the chest) should be in follow-up care at 9-12 months after birth (or sooner if you notice something abnormal) and annually to age 16. When the diaphragm forms in development, so does the spine. It is believed that scoliosis may occur in approximately 17-27% of CDH survivors. It is important to follow up with their care and early intervention is best.

Most parents of CDH infants and children fear reherniation, and it has been reported in 8% to 50% of patients with CDH. One predictor is a large defect that requires a patch to repair. If your infant or young child has increased reflux activity, decreased feeding, increased gagging, or you hear crackling noise in their chest as they breathe – take them to the doctor. Sudden onset of gastro-intestinal illness could be a virus or could also be re-herniation. These are just a few symptoms that have been reported prior to diagnosis of recurrent diaphragmatic hernias. Monitor and record any changes to relay to the doctor(s). If you truly feel something is not right, insist upon x-rays for your peace of mind. Occasionally there are children who have no symptoms who will require surgery for a recurrent diaphragmatic hernia. The lifetime risk of recurrence is not known. There are many children who have never had an incident, but it best to be overly prepared with information.

**Bowel obstructions** or adhesions are also something that happen in these children and usually are rapidly symptomatic. The explanation of this is that their intestines are usually herniated. When the initial repair is done, they are pushed back to the lower thorax. In this process and through growth, sometimes problems occur. Be aware of any intense pain your child might have in their stomach area. If accompanied with fever, no bowel movement, or blood in the stool, immediately get them medical attention.

**Pectus excavatum** – sunken appearance of the sternum can be prevalent in CDH children. Most of the time it is more cosmetic but in some cases the heart is displaced. The Mital valve prolapse could be present and there is a decrease in lung capacity. Surgery might be recommended.

**Psychological Issues**

Parents have reported that many of their children have sensory issues. They may not like their hands or feet being held – for fear that an IV will be coming next. They associate someone holding their hand or foot with pain to come soon. They may have issues with certain fabrics or textures and touching them. Some have reported to have mild to very severe oral aversions. Sometimes it is anything in their mouths, and sometimes it is just certain textures. There are many therapists now that specialize in children who have had medical issues and the stress they feel after.

If your child has had multiple surgeries and procedures, this could be a huge issue. Age has a whole lot to do with their reactions, but there are things you can do to help your child. One mother trached a Teddy Bear for her son and gave him a toy medical kit to help him. You can also request that any IVs or surgical procedures be done in another room, not their hospital room if they are older. This way they can feel "safe" in their hospital room. Never feel that you should be quiet or that you don't know your child. If you feel you should say something – SAY IT. You know your child better than anyone. Remind health professionals that yes, your child is their patient but your child is your baby – always. There is a connection between parents and children that the best health care professionals know could help them in the care for their patient.

Studies out there also suggest a higher percent of CDH children on he Autism Spectrum. (Remember, since 1994 the DSM came up with new criteria for diagnoses of Autism Spectrum Disorders.)

There are also parents who obtain copies of their child's medical records. We would recommend not only to have the hard (paper) copies but to also save them on a CD. There are some parents who even provide copies of these CDs to any new doctors that might come into their child's life. It saves time and also a parent giving the entire history. Not all hospitals are on-line with one another nor or all doctor's offices and until they are parents must be the source. This is one idea which could make life easier.

**Resources for Parents of CDH Children:**

**www.breathofhopeinc.com**

BreathofHope-subscribe@yahoogroups.com – Our Mainlistserv for families and friends



BreathofHope-ParentsofSurvivors-subscribe@yahoogroups.com – Our Listserv for parents of survivors of CDH

ecmo_kids-subscribe@yahoogroups.com

**American Academy of Pediatrics**
http://www.medicalhomeinfo.org/

**Gtube.org**
Organization that has a mailing list /email list for gtube info - support
http://www.gtube.org/

**Oley Foundation** – For Adults and children tube feeding or TPN IV Feeding http://www.oley.org/

**Pediatric/Adolescent Gastroesophageal Reflux Association** (PAGER)
http://www.reflux.org/

**PH Association**
PH Association - with a list of Doctors/Specialists
http://www.phassociation.org/

**Medical Research**
Search engine for summaries of medical studies
http://www.ncbi.nlm.nih.gov/entrez/query.fcgi

**Alexander Graham Bell Association**
Non-profit group with info and resources
http://www.agbell.org/

**John Tracy Clinic**
FREE information, classes and correspondence courses
http://www.jtc.org/

**The VIII Cranial Nerve**
How the inner ear and nerves connect
http://www.sfu.ca/~saunders/l33098/Anatomical%20Glossary/CNVIII.html

Sources of Information for this document: Post discharge Follow-up of Infants With Congenital Diaphragmatic Hernia – from American Academy of Pediatrics

The many parents of children who have shared their lives with Breath of Hope.