



Most people have not heard of a **Congenital Diaphragmatic Hernia**. Most people only hear about this birth defect on the day they receive the diagnosis.

Breath of Hope seeks to change that fact.

CDH infants require the most high-tech care hospitals can offer to stabilize them for surgery. There is a Trechual Occlusion Surgery (TOS) which has received some media attention, a “fetal” surgery. It does not negate surgery after birth to correct the diaphragm and it is still highly experimental. There are many factors why a patient may not qualify for this surgery. These infants must be treated at Level 3 or above NICUs which have ECMO (a heart-lung by pass machine) on hand. They are immediately intubated after birth and taken to the ICUs. If they do survive, it is a long process that can take from 4 to 6 months to discharge. After surgery, they must learn to breathe on their own or without vent assistance, how to eat and to grow. Some may need assistance with tubes for nutrition. We have known some infants to be in and out of the hospitals within a month and some who have endured almost a year in the hospital prior to discharge. Each infant is different. No two cases are alike though they may be similar.

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### What is CDH?

The diaphragm is the muscle that separates the heart and lungs from the abdominal organs and helps us breathe. It is believed that the diaphragm forms during the first trimester of development. For unknown reasons, the diaphragm does not close and the abdominal organs “herniate” into the chest cavity. This inhibits lung growth. We all need proper lung function to live. This is a layman’s description of CDH. Babies born with a congenital diaphragmatic hernia must be born in a hospital or medical center that is equipped to handle and treat their urgent intensive care.

A **Congenital Diaphragmatic Hernia** (often referred to as “CDH”) birth defect occurs in every 1 in 2,000 pregnancies in the United States. Congenital Diaphragmatic Hernias account for 8% of all major congenital anomalies. This figure translates to approximately 1,800 babies born with the Congenital Diaphragmatic Hernia birth defect every year. In comparison, Cystic Fibrosis occurs in every 1 in 3,000 live births in the United States, Spina Bifida has an occurrence rate of every 1 in 1,478 live births. Congenital Muscular Dystrophy has an occurrence of 1 in 6,000 births in the United States. A congenital diaphragmatic hernia occurs just as often as cystic fibrosis, spina bifida and more often than Muscular Dystrophy but Congenital Diaphragmatic Hernias often have fatal results. Approximately 50% of all Congenital Diaphragmatic Hernia births result in death.



## 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.

We carry out this mission through promoting public awareness, supporting the medical community and encouraging research efforts to one day successfully treat all those diagnosed with a congenital diaphragmatic hernia.

Breath of Hope, Inc. provides the latest information on the treatment and care of the congenital diaphragmatic hernia birth defect. We provide an online support group through Yahoo! Groups. This open forum of parents and relatives provides an environment where parents no longer feel alone and where they meet other families that have survived the trials and tribulations of receiving the diagnosis of a congenital diaphragmatic birth defect.

*Breath of Hope Website  
[www.breathofhopeinc.com](http://www.breathofhopeinc.com)*



## How can you help?

If you would like to write your Governor or Mayor to request them to proclaim March 31<sup>st</sup> as Congenital Diaphragmatic Hernia Awareness Day, please contact us at [cdhawareness@breathofhopeinc.com](mailto:cdhawareness@breathofhopeinc.com) We also can always use volunteers in your area! If you are a parent of a CDH child, we do request you wait for a year in order for you to be well on your way of recovery.

## Services We Provide

- Support - On-line Listservs/Forums
- Information – where to find information in the area you live, the hospital you will be treated and practical advice from families who have experienced having a child with CDH.
- Toll-Free Phone Number
- Expectant Parent's Gift including a NICU Baby Book
- The Awareness Articles, a Newsletter
- Congenital Diaphragmatic Hernia Awareness Day Ribbons and Campaign
- Bringing Baby Home – Booklet for families bringing their baby home from the Hospital
- In The Event of an Angel - booklet to Help Grieving Parents
- Blog of Information at:
  - <http://breath-of-hope.blogspot.com/>
  - NICU Terminology Brochures
  - Expectant - New Parent Booklet
  - NICU Equipment Booklet
  - Questions to Ask When Expecting a CDH Baby document
- Website: [www.breathofhopeinc.com](http://www.breathofhopeinc.com)
- Merchandise at Café Press and Zazzle
- Scholarship Fund for CDH Children
- Scholarship Fund for Medical Students and Nurses
- Fundraisers to help fund a Research Studies at a various Leading Medical Centers
- Annual Congenital Diaphragmatic Hernia Summit (since 2010) will be in Denver CO for 2012!
- We are also on Facebook, YouTube and Pinterest

## About Breath of Hope

Breath of Hope, Inc. is a nonprofit organization incorporated under the laws of the Commonwealth of Virginia. Breath of Hope is a tax-exempt under section 501 (c) 3 of the US Internal Revenue Code with no paid employees; our staff is made up of dedicated volunteer members.

All expenses are paid through tax-deductible donations, grants or donations in-kind.

Breath of Hope is always in need of funding to provide services to CDH families. Every donation is greatly appreciated and all are acknowledged. If you wish to make a donation in honor or in memory, we will send a letter to the family acknowledging your generous gesture.

You may send a check or money order to the address below in US Currency only please as our Bank conversion fees are costly. We also accept donations made by using your Credit Card or Bank Debit Card through your Paypal account. Another option is to visit our website and click on the "Donation" Button for secure processing.

You may also donate through Network for Good or Firstgiving, search for Breath of Hope and our address below.

For questions on donations or gifts in kind please contact Elizabeth Doyle-Propst at [Elizabeth@BreathofHopeInc.com](mailto:Elizabeth@BreathofHopeInc.com)

We appreciate the time you took to read our brochure. We believe that each person who reads about our Congenital Diaphragmatic Awareness Day<sup>®</sup> campaign is one more person who has become **AWARE**. Please do not throw this brochure away, pass it on – it may end up in the hands of someone who has been affected by this birth defect.

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