



Press Package for Breath of Hope Inc.

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Breath of Hope Incorporated History


In January 2004, a small group of parents who saw that there was a need for a supportive group of families formed a Yahoo Support Group. At that time there was no active group available. The goal was to support all families who had children born with congenital diaphragmatic hernia. The foundation of Breath of Hope was and always has been to support families, one at a time. The first step to becoming a Public Charity in the United States is to incorporate the organization and on May 17, 2004, Breath of Hope was incorporated as a non-stock nonprofit organization in the Commonwealth of Virginia.

In 2006, Breath of Hope's Mission Statement was revised as follows:

Breath of Hope exists to combat the congenital diaphragmatic hernia birth defect. We are committed to supporting parents, children, family members and friends facing the diagnosis of a congenital diaphragmatic hernia birth defect. 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.

By Laws, a Business Plan and The IRS's 1023 Form was completed and mailed to the IRS on Saturday, March 31, 2007. On July 25, 2007, the IRS determined Breath of Hope, Incorporated a Foundation and Public Charity. The first organization ever to compare congenital diaphragmatic hernia birth statistics to other birth defects was Breath of Hope, Inc. The statistics and copyrighted information is still on the Breath of Hope website and was originally in the Business Plan which was submitted to the IRS.

 **The Congenital Diaphragmatic Hernia Awareness Campaign** had originally been brought up on the Yahoo Group's Listserv in April 2006; however, no one acted upon researching how this would be implemented. The original Awareness Ribbon created was black and yellow to symbolize the Bumble Bee Logo that had been chosen. In May 2007, Stacy Everett Harding and Elizabeth Doyle-Propst started to research how other Awareness Campaigns were implemented. The Congenital Diaphragmatic Hernia Awareness Ribbon was redesigned. The Turquoise Ribbon is original – not from a template but created by Ms. Harding with the unique tails which were not symmetrical. A Sample Proclamation and Sample Letter were originally drafted by Ms. Harding to give anyone who wished to contact their Governor or Mayor and request March 31st be Congenital Diaphragmatic Hernia Awareness Day.

 **In July 2007, Breath of Hope's Board of Directors** all sent letters, Sample Proclamations and Brochures to their respective Governors and Mayors requesting they Proclaim March 31, 2008 as Congenital Diaphragmatic Hernia Awareness Day. An announcement about Congenital Diaphragmatic Hernia Awareness Day was made on July 31, 2010 to the public in the second Newsletter published and to the Support Forum.

🌿 31 States Issued Proclamations for March 31, 2008 to be Congenital Diaphragmatic Hernia Awareness Day. This was an effort made by those members, family and friends of Breath of Hope's Yahoo Group.

News Stories in 2007 – 2008

🌿 A Day for 'turquoise' Monday, March 31 – Story about Breath of Hope's Director, Jean Ashner. (3/26/2008) Gasconade County Republican – by Dave Marner

<http://gasconadecountyrepublican.com/content/view/334/50/>

🌿 Chesterton girl survives congenital diaphragmatic hernia – Story about Jaslyn Parker, Mom is Tiffany (4/1/2008) Northwest Indiana (nwi.com) – By Annette Arnold

http://nwitimes.com/news/local/article_13645653-b00b-5b5f-b8b2-f13b793051a3.html/

🌿 Congenital Diaphragmatic Hernia: My Granddaughter's Experience After Birth – by Kathy Reed O'Gorman (9/21/2007) – Associated Content

http://www.associatedcontent.com/article/384118/congenital_diaphragmatic_hernia_my.html?cat=52/

🌿 There were several Letters to the Editor written for Congenital Diaphragmatic Hernia Awareness Day – March 31, 2008 and several other news articles however the links have expired.

News Stories - 2009

🌿 Saint Louis Hospital to Study Birth Defect – North County Times – Associate Press Article which was originally published March 31 continued to run in newspapers around the world. Several Breath of Hope Families sent donations to Breath of Hope in memory of their children. All chose to redirect these funds to aid medical research which would benefit CDH. A press conference was held at Saint Louis Children's Hospital where the doctors, parents and families gathered to speak and also award \$16,000 raised.

http://www.nctimes.com/lifestyles/health-med-fit/article_c42be7da-1686-5778-8ded-d9e5d62307b7.html?mode=story/ North County Times (April 8, 2009)

<http://www.guardian.co.uk/world/feedarticle/8434629/> Guardian.co.uk – Associated Press Article by Betsy Taylor

Press Release and featured on the Saint Louis Children's Hospital website:
http://www.stlouischildrens.org/content/Features.htm?page_id=2588&inCtx12view=10&inCtx12pg=0&inCtx12news=9&site_id=1&minor=1&inCtx12news_id=188&major=2/

🌿 Raising Awareness About CDH – Story about Tiffany and Rome Frericks and their son, Cadan Christopher. The Frericks were one of the families who also attended the Saint Louis Children's News Conference on March 31 and raised funds for that effort. By Rajah Maples Tuesday, April 07, 2009 Connect TriStates

http://www.connecttristates.com/news/news_story.aspx?id=283999/

☛ Grieving Parents Raising Money, Awareness to Fight Birth Defect – Story about Jaime and David Smith and their daughter, Ryann Hope. The Smith's were also one of the families who attended the Saint Louis Children's News Conference on March 31 and raised funds for that effort. The News Gazette by Deborah Pressey April 19, 2009.

http://www.news-gazette.com/news/local/2009/04/19/grieving_parents_raising_money_awareness_to_fight_birth_defect/

☛ Group supports Breath of Hope for Babies Facing Deadly Condition by David R. Maurer – Daily Progress, March 30, 2009. Article about Elizabeth Doyle-Propst and Brian Propst's daughter Cecilia and how awareness led to the forming of Breath of Hope.

http://www2.dailyprogress.com/cdp/lifestyles/health_med_fit/article/group_supports_breath_of_hope_for_babies_facing_deadly_condition/37955/

☛ Breath of Hope has an Audio Public Service Announcement which can be sent to Radio Stations this is available via email, please contact boh@breathofhopeinc.com

☛ Breath of Hope also drafted the original Resolution HR 204 – Congenital Diaphragmatic Hernia Awareness Day – March 31, 2010, which was introduced to the Senate Judicial Committee by Senator David Vitter (LA). The Health Care Bill has taken up much of the Congressional time we will continue to try to have this Resolution passed in Congress.

http://www.change.org/actions/view/national_congenital_diaphragmatic_hernia_awareness_day_-_march_31_2010/

☛ Breath of Hope awarded five scholarships in 2009 for \$2,000 each with gratitude to GMAC Financial Services. The recipients included two diaphragmatic hernia survivors, a beloved NICU Nurse furthering her Graduate Education in Nursing, a future doctor and an aunt to a diaphragmatic hernia survivor.

<http://www.breathofhopeinc.com/scholarship-awards.html/>

☛ Breath of Hope will be awarded 5 scholarship for the 2010 – 2011 academic year for \$1,000 each.

☛ Since 2007, Breath of Hope has distributed over 500 Expectant parent packages, thousands of brochures, educational materials. We have supplied hospitals and medical centers with our NICU Terminology Brochures, Expectant and New Parent Booklet, NICU Equipment Booklet and now our Bringing Home a CDH Baby Booklet. These materials have been reviewed and advised by Medical Professionals, parents and researchers.

☛ Breath of Hope encourages families to fundraise for Medical Research for their hospitals and medical centers, communicate any new information they obtain to their respective doctors and hospitals and hopes that through these efforts many will have the same advantages all over the United States in health care for their CDH family member.