



The Silver Lining

CHERUBS – The Association of Congenital Diaphragmatic Hernia Research, Awareness & Support

2010 Annual Newsletter



Photo by Arce Photography. Model cherub Juan Pablo Arce

HAPPY BIRTHDAY CHERUBS!

CHERUBS is the world's first, oldest, and largest CDH non-profit organization. We are truly a grassroots organization - CDH families creating something out of nothing when there were no other CDH groups, information and services in 1995. CHERUBS was created to make sure that no family endures Congenital Diaphragmatic Hernia without support or accurate information. Our Board of Directors includes CDH parents, grandparents, survivors, nurses, doctors and the world's top CDH researchers. CHERUBS is run solely by volunteers and donations. At CHERUBS, every CDH family has an opportunity to honor or remember our children while doing good to help others and work together as a CDH community. No other charity in the world has such a respected, educated or experienced group of leaders who care so much about the CDH community.

CHERUBS has had many accomplishments and projects in our first 15 years. We are the first charity to promote CDH research, awareness and support. We created a model organization for other groups with our services, structure and projects. We created the first CDH newsletter and the first on-line listservs and forums for CDH families. CHERUBS is a founding member of ACDHO. Our CDH Research Database is the largest database in the world created by CDH families to compare medical histories that hopefully will assist the CDH research community. CHERUBS has spoken at International CDH Study Group meetings, given speeches around the country, given interviews for 20/20 and Mystery Diagnosis as well many other national media outlets. We hold the International CDH Conference for families and researchers. Along with several other CDH organizations and 1000's of families, we designed the official Congenital Diaphragmatic Hernia Awareness Ribbon and took a stand against the trademark on "Congenital Diaphragmatic Hernia Awareness". We created awareness products, the first CDH awareness store, logos and we proclaimed the cherub as the official international symbol of Congenital Diaphragmatic Hernia to represent those CDH babies who do not survive. And we have done it all through the hard labor of dozens of caring volunteers who want nothing more than to make the journey of CDH a little bit easier for families.

In 2010, as we celebrate 15 years of non-profit service to the CDH community, we continue our good work through more conferences and get-togethers, more on-line services and more research. We have kicked off the year with our "Save The Cherubs" CDH Awareness Campaign, 2 Congressional Bills to benefit CDH and other cause and launched our new web sites.

We are proud to serve over 3300 families in 38 countries and all 50 states affected by CDH since our creation. Through our dozens of free ground-breaking services and the friendships made within our member community, CHERUBS has positively affected the lives of 1000's of CDH families and inspired many new CDH charities and projects who have followed in our footsteps. We will continue to lead until Congenital Diaphragmatic Hernia is no more. We are devoted to finding the cause, prevention and best treatments for CDH.

We Need Your Help!

- ✓ Write your congressman or senator about the CDH Research Bill
- ✓ Update your membership form / profile
- ✓ Participate in our Save the Cherubs Campaign
- ✓ March this holiday season to raise CDH Awareness
- ✓ Adopt A CDH Hospital
- ✓ Donate items to our CDH HOPE Totebag Project
- ✓ Participate in fundraisers and events
- ✓ Participate in CDH Research Studies

Support
Congenital Diaphragmatic Hernia
Public Awareness



www.cdhsupport.org

CHERUBS – The Association of Congenital Diaphragmatic Hernia Research, Awareness and Support

3650 Rogers Rd. #290
Wake Forest, NC 27587

919=610-0129
info@cdhsupport.org

www.cdhsupport.org
www.cherubs-cdh.org

Letter from the President of CHERUBS



Dear Members and Friends,

It's another busy and productive year at CHERUBS!

First, I would like to share with you some wonderful news - we WON the petition against the trademark on "Congenital Diaphragmatic Hernia Awareness". The phrase is once again free to use by everyone to help raise CDH awareness! A very sincere thank you to our pro bono legal team at Parker Poe for their generous support and dedication to helping families affected by CDH. And a very sincere thank you to all of you who signed the petitions and fought beside us and to the following groups and charities for their support; CHERUBS Australia, CHERUBS UK, Little Lambs, Real Hope for CDH, Rainbow of Hope, The Olivia Raine Foundation and the Jack Ryan Gillham Foundation. Now, onward and upward to focus on more positive things and most importantly, the families and babies affected by Congenital Diaphragmatic Hernia!

2010 has been a great year so far for CHERUBS! I've had the opportunity to meet so many of you in person in the past year and to participate in so many great events and projects with such wonderful people. And there are so many more good things to come!

We'd like to welcome to our newest Volunteer Coordinator, Tracy Meats, who has been a huge asset to us in working with Barbara Wagner to help organize our volunteers and services. Tracy and Barb donate so much time and energy to CHERUBS, we truly would be lost without them!

We would also like to welcome to our Fundraising and Grant Committees, Gina Cappola Della Porta! Gina is an experienced grant writer currently working for a local university's research department. She is now heading up our Fundraising and Grant Committees and working on several events and grants. She is a volunteer but our goal is to hire her full time in the near future to secure funding for CHERUBS and all of our services. In the month she has volunteered for us, she has secured the Angel Ball, helped us find funding for the Save the Cherubs Campaign and started an NIH grant collaboration with Mass General for CDH research. Gina has no personal connection to CDH - she saw a post about our charity and felt guided to join our cause through the goodness of her heart. She is an angel!

CHERUBS has done a lot over the past 15 years with limited donations and only volunteers who are busy working other jobs and/or taking care of their cherubs or grieving their cherubs. I, myself, have donated over 25,000 hours to CHERUBS through all sorts of life's hurdles including taking care of a very handicapped cherub and then losing him at 6 yrs old and during my own grief - and while working another job and running my own company. CHERUBS deserves 100% undivided attention by people dedicated to our services and research for 8 hours every day! We can only do so much with a volunteer staff. It's time to move forward and to expand! It is time for a full-time staff. **Let me make this very clear - donations will NEVER pay for salaries at CHERUBS, even though that is common practice at most charities. Salaries will be paid for by grants or designated funds.**

Our goal, through our various projects, fundraisers, donations, Congressional Bills and grants, is to have an office, 3 full-time employees, and all 5 CDH funds full by the end of year, with a focus on more support services, financial assistance to families and \$100,000's to CDH Research. It's a big goal, but we've done more and gone farther than anyone thought a group of CDH parents could! We won't stop helping CDH families and searching for the cause, prevention and best treatments of CDH and with a full-time staff, we can do so much more!!!!

Our dream (shared no doubt by all CDH families) is that by 2025, we hope to fund the nation's first CDH hospital complete with surgery, ECMO, in utero treatments, research, long-term care clinics, genetic research, feeding clinics, support systems, financial aid and rooming for parents and siblings at the hospital so they remain together - staffed by the country's CDH leading experts. CHERUBS wants to do for CDH what St. Jukes does for Pediatric Cancer. How much will that cost? An astronomical amount of money! Yes, we dream BIG, but we're determined and focused and I believe that we have the volunteers, members and CDH researchers to make this dream come true!

That's the BIG focus - the 25 year plan - but we still have our current services, CDH support, CDH research and CDH awareness to focus on too! We need help to do all that we want to do and to do so much more! We are working on MANY projects and fundraisers to fund all of our services and are always on the lookout for more CDH fundraising ideas and volunteers!

We have an on-line store, sell bracelets, books, CDH Awareness kits, cookbooks, calendars, 1000's of items through CafePress and Zazzle. We've had events, formal balls, golf tournaments, car washes, 5k's, car shows, road rallies, raffles, etc.

We also have programs and events that are NOT fundraisers... just services to help families and raise awareness, such as our CDH HOPE totebag project, Adopt a Hospital project, Save the Cherubs Project and our CDH Conferences. And we are proud to participate in local events like the Durham Great Human Race, March of Dimes March for Babies and Christmas parades in several towns to help raise more awareness!

As we continue to celebrate our 15th anniversary, I hope that you are all as proud of how far we've come as I am. In 1995, we were 2 members with a typewriter. Now, we have over 3300 members worldwide. With each totebag that we mail out, or each Adopt A Hospital kit we send and each time I meet a new family or see old friends... I silently say thank you to all of you, our CHERUBS family.

Thank you for your continued support of CHERUBS and CDH Families!

Sincerely,
Dawn M. Williamson
CHERUBS President & Founder



CHERUBS Services

CDH Forums – <http://www.cdhforums.org>

Free, safe and confidential on-line message boards for families affected by CDH.

CDH HOPE Totebag Project – <http://www.cdhope.org>

Care packages for new and expectant CDH families

Save the Cherubs Campaign – <http://www.savethecherubs.org>

Our new 2010 national CDH Awareness Campaign

CDH Research Congressional Bill – <http://www.cdhbills.org>

Encouraging more federal funding to CDH Research

Adopt A Hospital Program – <http://www.cdhhospitals.org>

Providing CDH information and support for families at the time of diagnosis.

5 Funds for CDH – <http://www.cdhdonations.org>

Fundraising for CDH Research, Awareness, Scholarships, Financial Aid and all of our Support services.

CDH Conferences – <http://www.cdhconference.org>

CDH Events – <http://www.cdhcalendar.org>

Angel Ball – <http://www.cherubsangelball.org>

Personalized CDH Awareness Ribbons –

<http://www.cdhawarenessribbon.org>

Free, personalized CDH Ribbon graphics to help raise awareness

Local Support Services – <http://www.cdhvunteers.org>

Meet our State & International Representatives, Hospital Angels and On-Call Volunteers

CDH Baby Book – <http://www.cdhsupport.org/babybook.php>

Personalizable baby book written especially for babies diagnosed with CDH. Includes information as well as "typical" baby book material.

Stories of Cherubs –

<http://www.cafepress.com/cherubs/6191951>

Over 300 stories of cherubs in Volume I and over 150 stories of cherubs in Volume II.

Annual CDH Cherubs Calendar –

<http://www.cafepress.com/cherubs.415954058>

2010 wall calendar featuring photographs of over 600 cherubs.

CDH Awareness Song – <http://www.cdhsupport.org/songs.php>

Written by a CDH dad and performed by The Jammies, the video features over 700 cherubs

CDH Kids Song – <http://www.cdhsupport.org/kidssong.php>

A great way to teach cherubs and siblings about CDH in a fun, non-scary, easy to understand way!

CDH Street Sign Project -

<http://www.cdhsupport.org/streetsigns.php>

Raising awareness on the streets

CDH Awareness Shop – <http://www.cdhawarenessshop.org>

1000's of CDH Awareness items

CDH Awareness Kits-

<http://www.cdhawarenessshop.org/kits.php>

CDH Blog Ring - <http://www.ringsworld.com/cdhblogsring/>

Free E-Cards – <http://www.cdhcards.org/>

Free Photo Albums –

http://cdhsupport.org/members/album_personal_index.php

Free Blogs – <http://cdhsupport.org/members/weblogs.php>

Free CDH Awareness Web Site Blog & Myspace Templates –

<http://cdhawarenessshop.org>

Silver Lining Newsletter – <http://www.cdhnewsletter.org>

CDH News – <http://www.cdhnews.org>

CDH Videos – <http://www.youtube.com/cherubs>

CDH Event Calendar – <http://www.cdhcalendar.org>

Congenital Diaphragmatic Hernia Research Bill

I ♥ C.D.H. RESEARCH

Searching for the cause, prevention and best treatment of Congenital Diaphragmatic Hernia

www.cdhrefsearch.org

CHERUBS is very proud to present our Congenital Diaphragmatic Hernia Research Bill to be presented to Congress to help promote more federal funding for CDH research. With the help of our members, other CDH organizations and the public, we are determined to promote CDH Research to help save the lives of babies born with Congenital Diaphragmatic Hernia. Please visit <http://www.cdhbills.org> for more information.

In request of a Congressional Bill for the benefit of Congenital Diaphragmatic Hernia Research

Submitted by CHERUBS – The Association of Congenital Diaphragmatic Hernia Research, Advocacy and Support
3650 Rogers Rd. #290
Wake Forest, NC 27587
919-610-0129
research@cdhsupport.org

A BILL

To amend the Public Health Service Act to provide for the national collection of data on babies born with Congenital Diaphragmatic Hernia in a standardized manner, and for other purposes.

Be it enacted by the Senate and House of Representatives of the United States of America in Congress assembled,

SECTION 1. SHORT TITLE.

This Act may be cited as the ‘CDH Research Act of 2010’.

SECTION 2. FINDINGS.

The Congress finds as follows:

- (1) Congenital Diaphragmatic Hernia is a birth defect.
- (2) Congenital Diaphragmatic Hernia has a rate of occurrence of 1 in every 2500 babies.
- (3) Congenital Diaphragmatic Hernia affects approximately 1600 babies each year in the United States.
- (4) Congenital Diaphragmatic Hernia occurs when the diaphragm fails to fully form, allowing abdominal organs to migrate into the chest cavity and preventing lung growth.
- (5) The majority of Congenital Diaphragmatic Hernia patients have underdeveloped lungs and/or poor pulmonary function.
- (6) Congenital Diaphragmatic Hernia patients often endure long-term complications such as pulmonary hypertension, pulmonary hypoplasia, asthma, gastrointestinal reflex, feeding disorders and developmental delays.
- (7) Congenital Diaphragmatic Hernia survivors sometimes endure long-term mechanical ventilation dependency, skeletal malformations, supplemental oxygen dependency, enteral and parenteral nutrition and hypoxic brain injury.
- (8) Congenital Diaphragmatic Hernia has a survival rate of 50%.
- (9) Congenital Diaphragmatic Hernia has affected over 600,000 babies worldwide since the year 2000.
- (10) Babies born with Congenital Diaphragmatic Hernia endure extended hospital stays in intensive care with multiple surgeries. Extended hospital stays in some cases have exceeded one year.
- (11) Congenital Diaphragmatic Hernia is as common as Spina Bifida and Cystic Fibrosis.
- (12) Congenital Diaphragmatic Hernia is diagnosed in utero in only 75% of cases.
- (13) Congenital Diaphragmatic Hernia is treated through mechanical ventilation, heart and lung bypass (Extracorporeal Membrane Oxygenation) machines and surgical repair.
- (14) Congenital Diaphragmatic Hernia surgical repair is often outgrown thus leading to reherniation and requiring additional surgery.
- (15) Congenital Diaphragmatic Hernia does not discriminate based on race, gender, religion, economic status or lack of prenatal care.
- (16) The cause of Congenital Diaphragmatic Hernia is unknown.
- (17) Congenital Diaphragmatic Hernia takes more lives in the average year in the United States than lightening strikes, tornadoes, hurricanes and floods combined.
- (18) The average hospital bill per Congenital Diaphragmatic Hernia patient is \$500,000.
- (19) The estimated total annual economic impact of Congenital Diaphragmatic Hernia in the United States is in excess of \$800,000,000.
- (20) Annual Federal support for Congenital Diaphragmatic Hernia research at the National Institutes of Health is currently estimated at less than \$5,000,000.

SECTION 3. SENSE OF CONGRESS ON NIH FUNDING FOR CONGENITAL DIAPHRAGMATIC HERNIA RESEARCH.

- (1) In General- It is the sense of the Congress that the Director of the National Institutes of Health should increase the allocation of funds and other resources for Congenital Diaphragmatic Hernia research.
- (2) Measures To Increase the Research of Congenital Diaphragmatic Hernia shall include—
 - (a) Funds for national CDH patient registries through current databases kept by research organizations such as The International Congenital Diaphragmatic Hernia Study Group and CHERUBS - The Association of Congenital Diaphragmatic Hernia Research, Advocacy and Support for the purposes of finding commonalities in the search of possible causes and better treatments of Congenital Diaphragmatic Hernia.
 - (b) Funds for national CDH patient registries through current databases kept by research organizations such as The International Congenital Diaphragmatic Hernia Study Group and CHERUBS - The Association of Congenital Diaphragmatic Hernia Research, Advocacy and Support for the purposes of researching the long term health of survivors of Congenital Diaphragmatic Hernia.
 - (c) Funds for genetic research into possible causes of Congenital Diaphragmatic Hernia.
 - (d) Funds for research into more successful surgical and neonatal medical procedures that may increase the survival rate of babies born with Congenital Diaphragmatic Hernia.

SECTION 4. NATIONAL PUBLIC AWARENESS CAMPAIGN.

- (1) In General- The Secretary of Health and Human Services shall carry out a national campaign to increase public awareness and knowledge of Congenital Diaphragmatic Hernia
- (2) Measures To Increase the Public Awareness of Congenital Diaphragmatic Hernia under the national campaign under subsection (1) shall include—
 - (a) the dissemination of information on the definition of Congenital Diaphragmatic Hernia;
 - (b) the dissemination of information on good neonatal care of Congenital Diaphragmatic Hernia patients; and
 - (c) the promotion of good prenatal care and ultrasound to detect Congenital Diaphragmatic Hernia in utero.

How You Can Help In Honor Or In Memory of Your Cherub

1. Visit www.cdhbills.org
2. Download the sample letter and the bill draft
3. Edit the letter to input your cherub’s story to your Congressman
4. Print the letter and bill draft
5. Put them in an envelop with your cherub’s photo and mail to your Congressman
6. Get your family and friends to write too!

www.cdhbills.org



Ruben Aguirre, IV



Kavden Charles Mav



“Save the Cherubs” CDH Awareness Campaign

Cherubs are everywhere. They are your next door neighbor's new baby. The little girl on the swingset at the park. The teenager that sits behind your son in high school geometry class. The person behind you in the grocery store line. Their scars are hidden under clothes, their stories a bit sad and taboo to talk about - so the miracles are not seen with the naked eye and you have probably mistaken a cherub for a "normal" person many times. But they are there; walking miracles with invisible wings. And missing babies that belong to the grieving parents who you don't see grieve; your local bank teller, the man who held a door for you at the gas station, the old woman who drove the car in front of you at the stop light this morning. Cherubs are everywhere.

Unless you have been affected personally by CDH, you probably have never heard of it. The mission of "Save the Cherubs" is to make Congenital Diaphragmatic Hernia a phrase everyone knows how to say and everyone knows what it means. By raising awareness, we hope to raise research funds to save these babies - Save the Cherubs.

Congenital Diaphragmatic Hernia occurs when the diaphragm fails to fully form, allowing abdominal organs into the chest cavity and preventing lung growth. Babies born with CDH often endure long hospitalizations and other complications such as pulmonary hypertension, infections, feeding issues, asthma and temporary developmental delay. Some babies develop worse complications and sadly, 50% of babies born with CDH do not survive. The cause of CDH is not known.

Cherubs are people who were born with Congenital Diaphragmatic Hernia, a severe and often fatal birth defect that occurs as often as Cystic Fibrosis and Spina Bifida. Every 10 minutes a baby is born with CDH - adding up to over half a million babies since 2000. Yet, CDH is given very little media attention, virtually no research money and until CHERUBS came along in 1995 there was no information and no support for families of babies diagnosed with CDH. We have no national telethons, no large corporate sponsorships. We have been struggling for years to bring attention to CDH and now, we are going to do so on a national level.

For 15 years, cherubs have been the awareness symbol of Congenital Diaphragmatic Hernia (CDH). Through this project, families around the world are working with CHERUBS, photographers and the media to raise CDH awareness in a unique and striking photo and marketing campaign, which we hope will take your breath away and make you want to learn more about CDH and how you can help save these children.

CHERUBS - The Association of Congenital Diaphragmatic Hernia Research, Awareness and Support was founded in 1995 to give hope and information to families of children affected by Congenital Diaphragmatic Hernia (CDH). We are a 501(c)(3) non-profit global CDH organization with members in 38 countries. Run solely by volunteers and donations, CHERUBS strives to allow families to have free access to information materials, support services, awareness projects and to make a CDH connection with other families going through the same ordeal. We are just a grassroots organization of families working hard to make a difference and trying to give Congenital Diaphragmatic Hernia Awareness wings to take flight.

CHERUBS is fighting hard to search for the cause, prevention and best treatments of CDH. We invite you to help us to help these families and to help Save The Cherubs. Visit <http://www.savethecherubs.org> for more information.

Participating Photographers

- Ted Brooks
- Missy Severt
- Amy Price Photography
- Arce Photography
- Mandy Sroka Photography
- deAnn McGilberry
- Kristin Bones Photography
- Photo Memories By Lisa
- GJ Smith
- Loebach Studies



Cherubs Caroline King and Matthew Cheffer
Photo by Ted Brooks



Cherub Aaron Younce
Photo by Missy Severt



Cherub Braden Holt
Photo by Ted Brooks



Cherub Brooke Sroka
Photo by Mandy Sroka Photography



Cherub Juan Pablo Arce
Photo by Arce Photography



Cherub Gabi Monteiro
Photo by Ted Brooks



Cherub Celie McGilberry
Photo by dean McGilberry



Cherub Weston Cooper
Photo by Ted Brooks



Cherub sibling Miles Price
Photo by Amy Price Photography



Cherub Liviana Price
Photo by Amy Price Photography

CHERUBS 2010 International Member Conference

May 13- 16, 2010
Orlando, Florida



[Summer Bay Resort Holiday Inn Express](#)

Our conferences are designed for families of CDH survivors, grieving CDH families, adult survivors and CDH researchers!

Since our first conference in 2000, CHERUBS is proud to work with the world's best CDH hospitals and researchers to bring the families and the medical world together. Our 2009 conference brought together 8 CDH groups and families from 4 countries!

Members who have attended our conferences will tell you that they learned so much more about CDH, made new friends and gained a lot of support.

Because our conferences are confidential to maintain privacy and allow parents to talk freely about their journeys with CDH, we only allow members of CHERUBS to attend. This is also to keep our members safe and medical information private. All CDH parents are invited to join CHERUBS for free by registering at our site at <http://www.cdhsupport.org>

Expect to learn a lot about Congenital Diaphragmatic Hernia! Meet new friends, see old friends and participate in research for various hospitals.

For safety and privacy of our members, you MUST be a member of CHERUBS to attend. You may register for free at <http://www.cdhsupport.org/members>

Children are welcome and babysitting services will be provided during conference hours. Volunteer babysitters are needed and all parents who request babysitting are obligated to donate a minimum of 1 hour of volunteer time per child to help out.

The hotel offers free breakfast and shuttle to and from the amusement parks.

Families are responsible for all other meals and all transportation, accommodations and entertainment. CHERUBS does not charge a conference fee.

Many families of survivors are eligible for grants to cover travel expenses to medical conferences.



This summer CHERUBS was approached by the Discovery Channel for our assistance in an episode of Mystery Diagnosis. The producers requested graphics of adult late diagnosis of CDH and we submitted several graphics created by Shana Kelly, Tamara Klein and Dawn Williamson. Thank you, ladies!!!! Though the graphics weren't used in the show, we were able to give medical information and help raise awareness. If you slow down the credits on the show, you'll see CHERUBS listed and a link to our charity will be posted on the Discovery Channel site when the podcast is posted. We are very proud to have been a part of this episode and to help raise more CDH Awareness!

The episode is Season 7, Episode 10: "The Woman Who Couldn't Stop Burping". Check your local listings for channel information but this is what Discovery Health has listed as air times for reruns!



Upcoming CDH Events

- 2010 International CDH Conference May 13 - 16, 2010 Orlando, FL
- Peyton's Promise Run / Walk for Research May 15, 2010 Sea Isle City, NJ
- Round 4 Ryann Golf Tournament May 22, 2010 Tuscola, IL
- CHERUBS Oklahoma Member Get-Together June, 2010 Oklahoma
- CHERUBS NC Zoo Trip June 24, 2010 Asheboro, NC
- Jack Ryan Gillham Memorial Golf Tournament June, 2010 Huntsville, AR
- CHERUBS UK Summer Charity Ball July 10, 2010 Brighouse, United Kingdom
- CHERUBS Kansas Member Get-Together July, 2010 Kansas
- CHERUBS Ohio Member Picnic August, 2010 Hilliard, OH
- CDH Hope Totebag Baby Shower September, 2010 Raleigh, NC
- CHERUBS Golf Tournament September, 2010 Raleigh, NC
- CHERUBS Australia Annual Forum October 15-17, 2010 Brisbane, Australia
- CHERUBS Angel Ball October 30, 2010 Durham Hilton, Durham, NC
- Trick or Treat for CHERUBS Change for CDH Fundraiser October 31, 2010 International
- Christmas with Kasey November 13, 2010 Colorado
- CDH Ornaments Sale November - December, 2010
- National Children's Memorial Day December, 2010
- Journey to Faith 2010 Ann Arbor, MI

Raising CDH Awareness!



This Newsletter Is Dedicated To The Memories of The Following Cherubs:

Enrique Jesus Aguilera
 Brennen William Bradshaw
 Riley Owen Brewer
 Mason Bobby Bush
 Kevin M. Callihan
 Joshua Levi Campbell
 Maddison Jane Carroll
 Keira Isabella Caudle
 Zachary Elias Chapman
 Rhyan Andrew Charles
 Ryan Charles
 Kasey Colvin
 Danielle Nicole Cottingham
 Samantha Faith Cronquist
 Alicia Rose Curwain
 Mikayla Renee Depape
 Jeremiah Isaac Deskins
 Georgia Elizabeth Dickinson
 Matthew Frank Doerscheln
 Joshua Angel Echelbarger
 Nora Rae El-Gamel
 Jay William Leroy Evans
 Christopher John Faraldi
 Travis Lee Fenn
 Baby Ferraro
 Zoe Aris Fisher
 Ashley Hope Footit
 Averil Hope Gaynor
 Noah Samuel Geisler
 Emily Rae Godwin
 Annabelle Marie Gomez

Graciela Milagros Gonzalez
 Hannah Harris
 Aidan Dominic Hartley
 Brayden Jay Hawkes
 Quincy Thomas Haynes
 Andrew Weston Hobbs
 Julia M Hoffman
 Madison Ann Holiday
 Sylvia Houselog
 Tyler Isaac IIs
 Morgan Marie Jackson
 Ryan Joseph Russell Jaffry
 Khalil Malik Jones
 Rachel Renee Jones
 Findlay Lucas Jordan
 Mohamed Ibrahim Kalmoush
 Bob King
 Zoe Candice Kiser
 Maisie Alexandra Kroutil
 Hunter Elizabeth Rose Lamontagne
 Sarah Elizabeth Lasko
 Aayliah Daijah Lee
 Jake John Marshall
 Dawson Gabriel Martie
 Isabelle May Mason
 Austin Josiah McClendon
 Rhys Robert James McMahon
 Asher Thomas Miersma
 Careena Rose Mitchell
 Lewis Moore
 Javon Taylor Morgan

Kaden James Morrow
 Aaron Lee Murray
 Cody Ignacio Neil
 Nguyen Phuc Nguyen
 Shadow Blaise Odom
 Kaden Bradley Oldham
 Gian Matthew Evangelista Ordinario
 Matthew Damion Pahceco
 Jak Thomas Roy Parsons-Forshaw
 Levy Chance Peloquin
 Toby Hugo Pickstock
 Christian Leroy Ray
 Anna Riccioluti
 Ethan Xavier Ridley
 Nolan Ray Robertson
 Jocelyn Reigh Rosales
 Vincent Alexander Serna
 Michael Joseph "MJ" Skaggs
 Emily Ruth Surgis
 Chloe Elizabeth Tate
 Anastacia Callisto Tryfona
 Anastasia Michelle Vallins
 Bailey Jaycob Walters
 Bentley Willis-Hoehner
 Lily Angel Winsell
 Spencer Allan Workman
 Julia Cora Zieger

+ 18 additional babies whose parents declined publishing permission

CDH H.O.P.E. Totebag Project



Delivery of the first CDH HOPE Totebag to the Hobbs family at Duke University Medical Center

CHERUBS H.O.P.E. (Helping Other Parents Expecting) Totebag Program assists families expecting babies born with Congenital Diaphragmatic Hernia by providing them with much needed free information and support items through a community project in which all CDH families can participate and honor their children while helping new families affected by Congenital Diaphragmatic Hernia.

Donated items are collected by our members, CDH families and friends and put together into totebags by volunteers. Totebags are then mailed to families who are expecting babies born with CDH or who have newborns still hospitalized and battling Congenital Diaphragmatic Hernia.

Congenital Diaphragmatic Hernia (CDH) is a devastating birth defect that affects 1 in every 2500 babies. CDH occurs when the diaphragm fails to fully form, allowing abdominal organs into the chest cavity and preventing lung growth. The cause is not known.

50% of babies diagnosed with CDH do not survive. Of those that do survive, sometimes long hospitalizations and other issues occur. It is incredibly important for CDH families to have accurate information of all the treatments for Congenital Diaphragmatic Hernia so that parents can make informed decisions for the babies' care. Items included are a CDH Awareness Ribbon totebag, personal care items for baby and information for the parents and family. Our CDH Baby Book is over 200 pages of valuable CDH information and advice.

Over 100 new and expectant CDH parents join CHERUBS each year. This project was created for them, to help them through the first few weeks and months in dealing with Congenital Diaphragmatic Hernia.

These bags will ONLY go to families affected by Congenital Diaphragmatic Hernia. They will be sent out to families in the United States as they join CHERUBS membership.

For more information on CDH and CHERUBS, you can visit our site at <http://www.cdhhope.org>



Tote Bag Wish List

Our Wish List of Items Needed: Below is a list of items that we currently include in our totebags. Each totebag is different, dependent upon the items we have currently available.

- * Disposable Cameras
- * Baby Blankets (any material but wool)
- * CDH Baby Books
- * Button up newborn or preemie shirts
- * Small or preemie pacifiers
- * Travel packs of tissues
- * Chapsticks
- * Plaster Handprint and Footprint Kits
- * Baby Booties
- * Baby Hats
- * Pacifiers
- * Button up / snap front newborn shirts
- * Small bottles of hand sanitizer
- * Small bottles of lotion
- * Small picture frames (for the baby's hospital bed)
- * Baby's first haircut holders
- * Small teddy bears
- * Gas Cards
- * Restaurant gift certificates (national chains please)
- * Coloring Pages - DONATED by the family of Caleb Cox. Thank you!!!

You can send donations to our main office. Please make sure to note who the donation is from and if it is in honor or in memory of a cherub.

It would also great help to label the items with "Donated by _____ in honor of / memory of _____"

Dawn is the one who puts the bags together and labels items and it would really help save her time to have the items pre-labeled. But we will gladly accept ANY donations labeled or not!

Cash donations for this project will pay for CDH Baby Books and totebags.

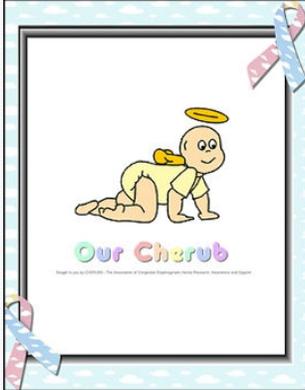
Please mail your donation to:

CHERUBS
3650 Rogers Rd #290
Wake Forest, NC 27587

Project Participants: All CDH families and friends can participate in this project to honor your cherub and to help other CDH families. Each donated item is labeled with the donor's name and the name of the cherub honored. No member is required to fill entire bags or hold events. Simply donate what you can, when you can!



CDH Baby Book



<http://www.cafepress.com/cherubs.374494584>

\$19.99

Genre: Children's Health
Paperback: 202 pages

Description: Baby Book for children born with Congenital Diaphragmatic Hernia

Synopsis: An atypical baby book with typical baby book contents such as handprints, photos, family tree and vaccination record - but also specialized sections for dealing with Congenital Diaphragmatic Hernia. A must have book for all new and expectant CDH parents.

OR download for free to print yourself at:

<http://www.cdhsupport.org/babybook.php>

To give you an idea of what's included:

Congenital Diaphragmatic Hernia

- What Is CDH?
- What are Fetal Interventions for CDH?
- Recent CDH Research News
- International CDH Study Group
- Medical Terms You Need To Know
- Questions & Facts About CDH
- ECMO
- Normal Values & Blood Gas Interpretation
- History of CDH
- CDH Treatments
- CDH Research Site

Getting Ready For Your Cherub

- Welcome To Holland
- Preparing For the Birth
- For Parents Who Are Expecting Cherubs
- Our Pregnancy
- Journal Entries
- Baby Showers
- Advice To Be Prepared
- Questions To Ask The Doctor About Our Cherub
- Music To Listen To
- Sources of Financial Help
- Advice For Family and Friends
- Earning True Gift of Motherhood
- Sources of Information and Support
- CHERUBS State & International Representatives
- I Wish Someone Would Have Told Me!
- Designating A Cherub Liaison
- Our Cherub's Blog

Our Cherub

- Our Family Tree
- Baby's Birth Day
- Our Medical Team
- Cherub's Medical History
- Important Medical Milestones
- Journal Entries
- Handprints & Footprints
- Mommy's First Hold
- Daddy's First Hold
- Hospital Visitors
- Cherub's Firsts Photos
- Baby's Milestones
- Journal Entries
- Baby's Favorites
- Going Home!
- Our Home Support Team
- Medical Appointments Calendar
- Delayed Immunization Schedule
- Our Cherub's Vaccination Record
- Journal Entries
- Feeding Diary
- Siblings
- Journal Entries

CHERUBS

- About CHERUBS
- Services Offered by CHERUBS
- Questions About CHERUBS
- History of CHERUBS
- CHERUBS 5 Funds For CDH Families
- CHERUBS Wish List
- How You Can Help CHERUBS
- Personalized Donation Sheet
- CHERUBS Resources for Families

- God's Loan
- CHERUBS Mission
- Adopt A Hospital Program
- No One Knows
- Stories of Cherubs
- CDH Calendar
- Submitting Photos & Stories
- Updating Your Membership Form
- Using CHERUBS On-Line Calendar
- How To Volunteer

Congenital Diaphragmatic Hernia Awareness

- History of the CDH Awareness Ribbon
- CHERUBS Cafepress Store
- Simple Ways To Raise Awareness
- CDH Awareness Kits
- CDH Statistics
- CDH Awareness Bracelets
- CDH Awareness Ribbon Magnets & Buttons
- Order Form
- Mementos, Scrapbook Items, Records

If You Have To Say Good-Bye

- Advice To Parents Who Have To Say Good-Bye
- Funeral Home Information
- Now I Lay Me Down To Sleep
- Little Angels
- Chronic Sorrow Grief Process
- Brooks To Read
- Are You There?
- Why Not My Cherub?
- Journal Entries

Visit our new web site with 1000's of pages of CDH information, research, awareness and support! www.cdhsupport.org



CHERUBS Angel Ball

Join us on October 30, 2010 in Durham, NC for our "Masquerading Angels" formal ball. Live band, silent auction, casino, celebrity guests!

www.cherubsangelball.org



CDH Awareness Song & Video



Kara Joan Hendricks

New CDH Awareness Song and Video! "I'll Never Let You Go" by The Jammies. Written by a CDH dad and performed by professional musicians.

<http://www.youtube.com/watch?v=vTChMLy2EFk>

Available on iTunes soon. Proceeds donated to CHERUBS to help raise CDH Awareness!

<http://itunes.apple.com/us/artist/the-jammies/id289127263>

Featuring 736 children and adults born with Congenital Diaphragmatic Hernia, affectionately known as "cherubs". Members of CHERUBS - The Association of Congenital Diaphragmatic Hernia Research, Awareness and Support <http://www.cdhsupport.org>

The Jammies - <http://www.thejammiesmusic.com/>

CDH Kids Song

This is a great little song to teach kids about CDH! Members use it for CDH survivors, siblings and sing it at the bedside. Not everyone can brag about being a "real live cherub!". Special thanks to Brandon Hall and Alysha Lane for organizing the kids in the photo at our 2009 CDH Conference and thank you to Ian Meats, Alysha Lane, Brooke Holt, Brandon Hall, Alyssa Richards and Braden Holt for performing!! You can view the video on our site. And thanks to Penny Campsey for helping to write it! Lyrics (sung to the tune of "I'm A Little Teapot"):

Real Live Cherub

*I'm a real live cherub but I don't have wings
When I was a baby the doctor had to fix things
My tummy was in my chest and it was hard to breathe
The doctor put it all back and here's where he fixed me!*



2009 American Pediatric Surgical Association Conference

In July, 2009 Puerto Rico, 3 CHERUBS Board Members (Brenda Slavin, Dawn Williamson and Barbara Wagner) represented our organization and CDH families at the American Pediatric Surgical Association convention.

We were able to talk to pediatric surgeons and start projects with several of them. We have an amazing project going on with the CDH Study Group, a group of about 90 CDH centers. We talked with doctors from every CDH center; we talked with many of the best CDH researchers in the world. We supplied data for families, ribbons for doctors (that were even worn during research speeches). Several surgeons even came up to us and thanked us for being there and for all we do for CDH families.... that touched our hearts so much to know they think we're doing a great service for their patients!!!

The conference went incredibly, amazingly well. We learned A TON about so many different things and now have all the absolute latest research on CDH. We talked with many surgeons on ways to help families, create more CDH awareness and research together. It was an extremely exciting and productive meeting.

We even went snorkeling with a few of the surgeons and shared flights with some as well. Every opportunity educated us more and more about CDH and what all CDH research centers (including CHERUBS) has to offer.

On Saturday we also met in person with Pam Lally of the CDH Study Group and talked about our databases and spent a few hours discussing our research and findings for both organizations. We have big, big, BIG plans and are so incredibly proud and honored to be working with the CDH Study Group and all 90 CDH Research Centers. It is CHERUBS objective to work with ALL CDH research centers and to accomplish as much as possible in the realm of CDH Research.

It took us 14 years to get here - but we did it. To do this research and have it make a difference. This is our 3rd attendance at an APSA conference - CHERUBS was the very first non-profit ever admitted into this event in 1995. In 2009, most of the surgeons knew exactly who CHERUBS is and what we stand for! We have come a long way!

We Would Like To Welcome Families Of The Following Cherubs Into Our Membership:

Noah Adkins
 Enrique Jesus Aguilera
 Edyn Grace Allinson
 Alejandro Aziz Alva
 Sofia Yvonne Alvarado-Ruiz
 Baby Anema
 Teresa Maria Aragon
 Baby Argo
 Kyle Evan Matthew Ayres
 Austin Badgley
 Alex Jayden Baker
 Anthony Joseph Barbieri
 Scarlett Ray Benitez
 Quinn Ashton Blackshaw
 Cameron Ashton Bond
 Kailyn Brooke Bost
 Aneska Bothma
 Lewis Nathan Richard Boyd
 Amanda Mary Bracher
 Brennen William Bradshaw
 Michael Nelson Bradshaw
 Riley Owen Brewer
 Riley Saige Broun
 Ashley Elizabeth Browne
 Josiah Daniel Brueske
 Aiden Wesley Btig
 Finley George Burriss
 Lee William Burton
 Mason Bobby Bush
 Ashley Grace Cain
 Aidan Amerino Calandra
 Kevin M. Callihan
 Joshua Levi Campbell
 James Calvin Carey, V
 Baby Carrington
 Maddison Jane Carroll
 Claire Catlett
 Keira Isabella Caudle
 Zachary Elias Chapman
 Rhyan Andrew Charles
 Ryan Charles
 Baby Chaudhari
 Owen Chitty
 Jacob Tyler Christianson
 Sorcha Aine Clarke-Hagan
 Baby Clarkson
 Trinity Ann Coleman
 Gavin Jeffery Douglas Coles
 Nathan Collins
 Kasey Colvin
 Daniel Cora, Jr
 Danielle Nicole Cottingham
 Ryan Hilarion Crasto
 Angelia Danielle Crawford-Shelton
 Samantha Faith Cronquist
 Miles Immanuel Crume
 Trinity Faith Crump
 Seth Lee Curtis
 Alicia Rose Curwain
 Nicolas Raul Custodio
 Charlie D'Angelo
 Angelina Sierra Decker
 Baby Depape
 Mikayla Renee Depape
 Undecided Derry
 Jeremiah Isaac Deskins
 Georgia Elizabeth Dickinson
 Antony John Didone
 Max James Dingwall
 Matthew Frank Doerscheln
 Bobby Joseph Dominguez
 Finley Anabelle Dooley
 Floyd Edward Dubois
 Robert Lee Dumford
 Sharice Claire Dunn
 Joshua Angel Echelbarger
 Keane Christian Edwards
 Niklas Isaac Egli
 Nora Rae El-Gamel

Baby Endres
 Bridgette Elysbeth Ernst
 Jay William Leroy Evans
 Garrett Lee Ewers
 Bailey Matthew Ezernack
 Christopher John Faraldi
 Travis Lee Fenn
 Baby Ferraro
 Samuel Kenneth Finzer
 Zoe Aris Fisher
 Ashley Hope Footit
 Wyatt Joseph Forte
 Jessica Eva Foster
 Daniel Ben Frankli
 Natalie Fuentes
 Averi Hope Gaynor
 Noah Samuel Geisler
 Cash Charles Gentry
 Alexander James Gervais
 Eric Tyler Gibson
 Millicent "Millie" Eliza Girdlestone
 Mallory Miracle May Givent
 Jack Garison Gleana
 Emily Rae Godwin
 Timothy Goff
 Annabelle Marie Gomez
 Graciela Milagros Gonzalez
 John "Keoni" Nicholas Gonzalez-Rivera
 Kayley Mae Gregg
 Taylor Marie Hallenback
 Hannah Harris
 Aidan Dominic Hartley
 Brayden Jay Hawkes
 Ian Carter Hayes
 Ian Haynes
 Quincy Thomas Haynes
 Jaron Noah Hege
 Elianna Denae Hernandez
 Shelby Hildreth
 Alice Hiley
 Alex Hoang
 Andrew Weston Hobbs
 Dylan Matthew Hodges
 Julia M Hoffman
 Thijs Rinze Hogenhuis
 Madison Ann Holiday
 Megan Honeycutt
 Bre'ahna Hooks
 Bre'ahna Jade Hooks
 Breanna Lynn Hosmer
 Sylvia Houselog
 Ethan Michael Howard
 Anthony Hunt
 Tyler Isaac IIs
 Elijah Scott Jaburg
 Amber Jackson
 Gabriel Aden Xavier Jackson
 Morgan Marie Jackson
 Ryan Joseph Russell Jaffry
 Macy Jelinek
 Clark Johnson
 Finlay James Johnson
 Richard Keith Johnson
 Arwyn Kathleen Doris Johnstone
 Khalil Malik Jones
 Rachel Renee Jones
 Findlay Lucas Jordan
 Mohamed Ibrahim Kalmoush
 Chase Leroy Kelly
 Osmund Wyatt Kidd-Ward
 Baby King
 Bob King
 Baby Kinman
 Zoe Candice Kiser
 Dallas Aiden Kislow
 Dallas Aiden Kislow
 Tyler John Kordus
 Ryan Connor Krafft

Maisie Alexandra Kroutil
 Albin Oliver Lackberg
 Leslie Nicole Lafon
 Hunter Elizabeth Rose Lamontagne
 Natalia Milagro Lapene
 Anaid Marie Lara
 Sarah Elizabeth Lasko
 Teegan Renae Lawrance
 Aayliah Daijah Lee
 Winston Lee
 Tracey Lesner
 Cali Summer Lizarraga
 Dustin R Lockett
 Joshua Alonzo Lozano
 Charley Brooke Zoya Mae Maher
 Kiyari Juliet Manriquez
 Armida Marqez
 Jake John Marshall
 Dawson Gabriel Martie
 Aniyah Renee Martinez
 Riley Joseph Marzolf
 Isabelle May Mason
 Aiden Walter Andre Mayer
 Mia James Mccabe
 Austin Josiah Mcclendon
 Quinn Erin Mccomb
 Baylee Elaine Mccoy
 Caden Joshua Mcculloch
 Jessica Brook Mcintyre
 Aven Lynne Mcleod
 Rhys Robert James Mcmahon
 Ary Jewels Mcveay-Rameriz
 Hope Annabelle Messer
 Michael William Micallef
 Asher Thomas Miersma
 Derek Vito Minervini
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 Westyn Keith Montgomery
 Lewis Moore
 Mattie Ellen Moore
 Javon Taylor Morgan
 Kaden James Morrow
 Harrison Moses
 Michael Alton Mueller
 Aaron Lee Murray
 Aaron Lee Murray
 James Thomas Naifeh
 Cody Ignacio Neil
 Keeley Jade Nelson
 Nguyen Phuc Nguyen
 James Wesley Nichols
 Shadow Blaise Odom
 Kaden Bradley Oldham
 Kayla Mae Olmstead
 Gian Matthew Evangelista Ordinario
 Logan Gage Owen
 Amanda Pauline Pagano
 Matthew Damion Pahceco
 Jak Thomas Roy Parsons-Forshaw
 Savanna Rai Payne
 Levy Chance Peloquin
 Barnaby George Peters
 Toby Hugo Pickstock
 Lindsay Pirrung
 Hailey Noelle Quick
 Christian Leroy Ray
 Joyce Ray
 Angela Kirstin Reedell
 Emma Ballard Reinhardt
 Jacob Thomas Reinhardt
 Jim Beau Reinhardt
 Baby Reynolds
 Anna Riccioluti
 Baby Richard
 Ethan Xavier Ridley
 Nolan Ray Robertson
 Bryce M Robinson
 Owen Darren Robson
 Mekhaai Rodde

Madeline Rodriguez
 Jocelyn Reigh Rosales
 Jodie S
 Henry Jesus Samayoa Jr.
 Brielle Theresa Santo
 Martin Jul Schau
 Zachary Schmid
 Jacob Charles Schueller
 Baby Scott
 Zade James Searcy
 Jaylen James Secor
 Savannah Joan Seebode
 Vincent Alexander Serna
 Chandler Reid Shannon
 Baby Sharp
 Conner Gage Shaw
 Madelyn Lilyanne Simonton
 Michael Joseph "Mj" Skaggs
 Scarlette Jayden Skrove
 Gabrielle Rose Smelko
 Bailey Carley Smith
 Andrew Robert Snyder
 Samantha Lynn Stewart
 Raquel Marie Stockwell
 Ella Rose Stone
 Allisyn Grace Strickler
 Laura Allison Sumner
 Emily Ruth Surgis
 Chloe Elizabeth Tate
 Adalyn Grace Taylor
 Kelci Taylor
 Sidney Taylor
 Dakota Marie Tenney
 Baby Thanh Tam
 Dylan Thorner-Benseman
 Kaelyn Treadwell
 Anastacia Callisto Tryfona
 Lorenzo Santos Valles
 Anastasia Michelle Vallins
 Kellan Van De Venter
 Luke Anthony Vannuccini
 Joshua Vidic
 Cassandra Marie Wainwright
 Bailey Jaycob Walters
 Eva Louise Walton
 Abigail Watermulder
 Nevaeh Nicole Weaver Johnson
 Gavin Werner
 Emma Marie Westcott
 Josiah Wheeler
 Maddox Malakai White
 Wendy Strother Wierenga
 Carlos Mikaere Wilkie
 Davian Tajan Williams
 Kaiya Alexis Williams
 Bentley Willis-Hoehner
 Allie Kathryn Wilson
 Jared Lee Wilson
 Caleb Presley Winchester
 Lily Angel Winsell
 Zoey Anne Wood
 Noah William Workman
 Spencer Allan Workman
 Julia Cora Zieger
 Jacob Thomas Zimmerman

+93 more members who parents did not wish to be published

New Arrivals

Enrique Jesus Aguilera
Edyn Grace Allinson
Kyle Evan Matthew Ayres
Quinn Ashton Blackshaw
Aneska Bothma
Lewis Nathan Richard Boyd
Brennen William Bradshaw
Michael Nelson Bradshaw
Riley Owen Brewer
Finley George Burriss
Lee William Burton
Mason Bobby Bush
Ashley Grace Cain
Aidan Amerino Calandra
Joshua Levi Campbell
Claire Catlett
Keira Isabella Caudle
Zachary Elias Chapman
Rhyan Andrew Charles
Ryan Charles
Baby Chaudhari
Baby Clarkson
Gavin Jeffery Douglas Coles
Nathan Collins
Daniel Cora, Jr
Ryan Hilarion Crasto
Alicia Rose Curwain
Nicolas Raul Custodio
Charlie D'Angelo
Baby Depape
Mikayla Renee Depape
Max James Dingwall
Matthew Frank Doerscheln
Bobby Joseph Dominguez

Floyd Edward Dubois
Robert Lee Dumford
Sharice Claire Dunn
Joshua Angel Echelbarger
Keane Christian Edwards
Niklas Isaac Egli
Nora Rae El-Gamel
Jay William Leroy Evans
Travis Lee Fenn
Baby Ferraro
Zoe Aris Fisher
Wyatt Joseph Forte
Natalie Fuentes
Averi Hope Gaynor
Noah Samuel Geisler
Mallory Miracle May Givent
Jack Garison Gleana
Emily Rae Godwin
Graciela Milagros Gonzalez
Alex Hoang
Andrew Weston Hobbs
Bre'ahna Jade Hooks
Bre'ahna Hooks
Sylvia Houselog
Gabriel Aden Xavier Jackson
Morgan Marie Jackson
Clark Johnson
Finlay James Johnson
Mohamed Ibrahim Kalmoush
Chase Leroy Kelly
Dallas Aiden Kislow
Maisie Alexandra Kroutil
Leslie Nicole Lafon
Winston Lee

Joshua Alonzo Lozano
Charley Brooke Zoya Mae Maher
Jake John Marshall
Dawson Gabriel Martie
Aniyah Renee Martinez
Riley Joseph Marzolf
Mia James Mccabe
Austin Josiah Mcclendon
Quinn Erin Mccomb
Caden Joshua Mcculloch
Aven Lynne Mcleod
Rhys Robert James McMahan
Westyn Keith Montgomery
Lewis Moore
Harrison Moses
Aaron Lee Murray
James Thomas Naifeh
Nguyen Phuc Nguyen
James Wesley Nichols
Kayla Mae Olmstead
Logan Gage Owen
Matthew Damion Pahceco
Toby Hugo Pickstock
Emma Ballard Reinhardt
Jim Beau Reinhardt
Baby Reynolds
Baby Richard
Nolan Ray Robertson
Owen Darren Robson
Madeline Rodriguez
Jocelyn Reigh Rosales
Henry Jesus Samayoa Jr.
Zade James Searcy
Jaylen James Secor

Savannah Joan Seebode
Vincent Alexander Serna
Madelyn Lilyanne Simonton
Michael Joseph "Mj" Skaggs
Scarlette Jayden Skrove
Bailey Carley Smith
Andrew Robert Snyder
Samantha Lynn Stewart
Chloe Elizabeth Tate
Kelci Taylor
Baby Thanh Tam
Kaelyn Treadwell
Anastacia Callisto Tryfona
Kellan Van De Venter
Joshua Vidic
Nevaeh Nicole Weaver Johnson
Josiah Wheeler
Davian Tajan Williams
Bentley Willis-Hoehner
Allie Kathryn Wilson
Jared Lee Wilson
Caleb Presley Winchester
Zoey Anne Wood
Noah William Workman
Jacob Thomas Zimmerman

+72 more members

CHERUBS invites you to donate or fundraise for a great cause! Please support our 5 CDH Funds:

CDH Family Support Fund – to fund the dozens of services and projects that we provide to families affected by Congenital Diaphragmatic Hernia

CDH Research Fund – to fund our CDH Research Survey hosting and to contribute to CDH research facilities.

CDH Family Assistance Fund – to help families of the financial hardships of dealing with CDH.

CDH Awareness Fund – to bring more awareness to Congenital Diaphragmatic Hernia through various projects

CDH Scholarship Fund – to help with the education of survivors and family members of those affected by Congenital Diaphragmatic Hernia so they can go out into the world and bring about more CDH research and awareness

This will all be funded through donations, grants and fundraisers. Member and the general public will be able to donate directly to a particular fund of their choosing. Donations not allocated to a specific fund will be deposited into the CDH Family Support Fund. We are very excited about all 5 of these new funds!

Donations are tax-deductible. You can donate in 1 of 3 ways:

1. Through PayPal - a secure site that we've used for 10 years that takes most major worldwide credit cards. <http://www.cdhdonations.org>
2. Through Firstgiving.com - another secure site we've used for a few years. You can also set up a firstgiving page in honor or in memory of your cherub to raise money for CHERUBS.
3. Through Postal Mail - you can send a check or money order (in United States currency only please) to:

CHERUBS
3650 Rogers Rd #290
Wake Forest, NC 27587
USA



We Are Sincerely Grateful For the Following Generous Donations:

Since July, 2009

In Honor / Memory of:

Abigail Taylor Long - Douglas Taylor
Abigail Taylor Long - Jeffrey Cook
Abigail Taylor Long - Mary Jo Taylor
Adam Hess - Charles & Kara Hess
Aidan Leibe - Kimberly F Leibe
Alex Mendoza - Avendra
Anastasia Vallins - Elizabeth Sisley-Vallins
Andrew Hobbs - Dan & Betty Orr
Andrew Hobbs - Dawn Kernagis
Andrew Hobbs - Digestive Health Physicians
Andrew Hobbs - Digestive Health Physicians
Andrew Hobbs - Floyd Jr Brothers
Andrew Hobbs - Gene & Becky Hobbs
Andrew Hobbs - Martha Lou, Patrick & Steve Green
Andrew Hobbs - Robert & Loraine List
Andrew Hobbs - Stephanie Harward
Andrew Snyder - Michele Snyder
Andrew Snyder - Michele Snyder
Andrew Weston Hobbs - Allison Ross
Andrew Weston Hobbs - Anna Grace Burns
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Andrew Weston Hobbs - Daniel Houtz
Andrew Weston Hobbs - David & Noelle McLaurin
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Andrew Weston Hobbs - Richard Moper
Andrew Weston Hobbs - Sharyn Tieszen
Andrew Weston Hobbs - Susan O'steen
Andrew Weston Hobbs - Teresa Burklew
Aoife Hopkins - William Hopkins
Ashley Burch - Bryant & Stratton College
Autumn Nicole Turner - Patrice Bechtold
Baby Boy Raymond - Jacqueline Trovato
Bailey Griffith - Kate Strein
Benjamin Fetter - Jill Fetter
Braden Holt - Abington Senior High School
Braden Holt - Dave & Karla Holt
Brayden Jay Hawkes - Gemma Brookes
Brian Lukkasson - Linda Lukkasson
Brianna Hosmer - Michelle Hossmmer
Charlotte Keiller - Tiffany J M Keiller
Chase Kelly - Brian & Arah Kelly
Chloe Tate - Christopher Tate
Christian Leroy Ray - Glenda Hammock
Christopher Strode - Kristin Strode
Clara Knapton - Alan Knapton
Claude Mcgilberry / Celie Mcgilberry - Deann Mcgilberry
Claude Mcgilberry / Celie Mcgilberry - Lilly Beck Originals
Cody Travis Streetman - Clarissa Streetman
Cole Campsey - Scott & Penny Campsey
Cooper Gulycz - Christine Kessler
Courtney Young - Wanda Young
Dawson Gabriel Martie - Cynthia Martie
Declan Armstrong - Kathleen Armstrong
Elijah Jaburg - Patricia & Larry Ketterman
Elijah Jaburg - Harry & Pat Ketterman
Emma Marian Klein - Waterford High School
Emma Marie Ray - Joan & Rita Canning
Emma Marie Ray - Nicolette O'connor
Emma Marie Ray - Skip & Edie Kayne
Emma Marie Ray - Terry & Ann Parker
Emma Marie Ray - William & Kathryn Sterrett
Floyd Dubois - Arlington Community High School

Floyd Dubois - Tracy Oliver
Floyd Edward Dubois - Jack Zimmerman
Floyd Edward Dubois - Jonathon Evans
Floyd Edward Dubois - Wanda Burk
Floyd Edward Dubois - Whitney Brake
Gabriel Kolacia - Toni Hood
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Hanna Rae Rose Larrison - Teddi Seabrooks
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Hannah Svoboda - Linda Longoria
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Kasey Colvin - Christmas With Kasey
Kasey Colvin - Nicolle Colvin
Kasey James Colvin - Alice Smith
Kasey James Colvin - Athena Bush
Kasey James Colvin - Carol Ann Wheling
Kasey James Colvin - Donald & Pamela Struck
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Kasey James Colvin - Jennifer Heiney
Kasey James Colvin - Jerry & Lavonne Mercure
Kasey James Colvin - Nicolle Gridley (Nicolle Colvin)
Kasey James Colvin - Regina Neal
Kasey James Colvin - Scott & Theresa Gridley
Kasey James Colvin - Steven & Tifani Sorensen
Kasey James Colvin - Nicolle Colvin
Kylee Freedom Green - Freedom Green
Landon Kelly - Matt & Shana Kelly
Laney Kate Daniels - Brandon Daniels
Laura Mcfatter - David Mcfatter
Logan Wagner - Kevin & Barbara Wagner
Luca James Richard - Brian Connor
Luca James Richard - Cheryl Schneider
Luca James Richard - Donna Bryski
Luca James Richard - Fleet Feet Sports Samantha Morales
Luca James Richard - Randi McIntyre
Luca James Richard - Stephanie Gibbons
Luca Richard - Kristen Yakutis
Luca Richards - Aaron Anderson
Maisie Alexandra Kroutil - Dustin Kroutil
Maisie Alexandra Kroutil - Jarmila Bertrand
Maisie Alexandra Kroutil - Nancy, Gary Young
Marley Jane Steinglass - Desiree Casillas
Mary Edna Reece Hoy - Rebecca Zepf
Mary Jane Steinglass - Desiree Casillas
Mia James McCabe - Margaret L McClain
Mia McCabe - Rosemarie Cereghino
Michael Wolfe - Brian & Ann Wolfe
Michael Joseph Skaggs - Megan Skaggs
Mikayla Depape - Joshua Pringle
Natalie Ellen Bankes - Elisha Cozine
Noa Womer - Matt Womer
Noelle Mather - Allyson Lapiere
Olivia Raine Richards - Kimberly Richards
Ooi Zi En - Han Hwee Ping
Patrick Perala - Scott Perala
Robert Cook - Dave Sachs
Robert Cook - Eric Cook
Rubin Aguirre IV - Nelson & Margaret Raines
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Sean Feaster - David & Julie Feaster
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Zoe Aris Fisher - Andrew Filipowski & Jennifer
Mclane
Zoe Aris Fisher - Brittany Morgan-Claudio
Zoe Aris Fisher - Brian Hassler
Zoe Aris Fisher - Elaine Ramsperger-Russo
Zoe Aris Fisher - Emily & Cole Fisher
Zoe Aris Fisher - George Kerber
Zoe Aris Fisher - Heidi Pehrson
Zoe Aris Fisher - Jeremy Schlusell
Zoe Aris Fisher - Nancy Dimsdale
Zoe Aris Fisher - Richard Thomas
Zoe Aris Fisher - Ronald Geizer & Gerldine Fein
Zoe Aris Fisher - Steven & Cindy Mann

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Joy Anderson
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Karen Macdougall
Karen Macdougall
Kenneth & Laurie Suszek
Kristi Weldy
Laura Mcfatter
Linda Fewell
Monika Nash
Patricia Donahoe, Md
Paul & Rosemary Picker
Sarah Anderson
Shana Kelly
Susan O'Steen

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Abbott Laboratories
America's Charities
America's Charities
Avendra Fundrasier - Casual Day
Cafepress
Capital One Associates
Goodsearch
Not Just Music
The Volunteer Center of Duham

CDH HOPE Totebag Donations:

Adam Hess - Charles & Kara Hess
Addisen Curtis - Shauna Curtis
Alexander Nazareth - Judy Nazareth
Bryer Floyd - Milinda Floyd
Braden Holt - Dave & Karla Holt
Braden Holt - Rachel Holt
Caleb Cox - Paige Cox
Caleb Cox - Shandi Cox
Caleb Koehn 0 Leah Koehn
Ian Meats - Chris & Tracy Meats
Jason Collins - Cindy Collins
Kaleigh & William Myers - Will & Karen Myers
Kasey Colvin - Brandon Murrow
Kasey Colvin - Nicolle Colvin
Kasey Colvin - Ouray Sportswear
Kristin Moats - Elaine Moats
Landon Kelly - Shana Kelly
Logan Wagner - Kathy Shelton
Logan Wagner - Kevin & Barbara Wagner
Michael Joseph Skaggs - Megan Skaggs
Mike Hyziak - Gail Hyziak
Robert Thompson
Shane Torrence - Ann Vaughan
Shane Torrence - Craig & Dawn Williamson

How You Can Help Babies Affected By Congenital Diaphragmatic Hernia!

CDH Research

- Write your Congressmen and ask for their support of the CDH Research Bill
- Donate to the CDH Research Fund
- Volunteer to be on our Research Committee
- Submit links to our CDH Research Library
- Post only accurate CDH data on your site or blog
- Help raise CDH Awareness
- Make sure your CHERUBS membership form / profile is accurate and up-to-date
- Join the following research studies:

Identifying Genes Which Cause CDH

Massachusetts General Hospital
Contact: Meaghan Russell, Clinical Coordinator,
at (617) 726-0828
mrussell@partners.org

Identifying Genes Which Cause CDH

Baylor College of Medicine
Daryl Scott, M.D., Ph.D.
Phone: 713-203-7242
E-mail: dscott@bcm.edu

Genetic Molecular Basis of CDH

DHREAMS Study
Columbia University Medical Center
ph: (212) 305-6987
info@cdhgenetics.com

Fryn's Syndrome

University of California
San Francisco, California
Anne Slavotinek, (415) 514-1783

Identifying Genes Which Cause CDH

Emergen Labs, Salt Lake City, Utah
Contact: Mary Meade, MMeade@emergen.com

Early childhood follow-up of congenital diaphragmatic hernia survivors.

Duke Children's Hospital
Jennifer Benjamin, MD, 919-668-4000

Identifying Causes and Long-Term Survivors of CDH

CHERUBS
Wake Forest, North Carolina

CDH Support

- Participate in the CDH forums and support other families also dealing with CDH
- Adopt a Hospital and supply CDH info to newly diagnosed families
- Never give medical advice to other CDH families
- Donate to the CDH HOPE Totebag Project
- Hold a Baby Cherubs Shower and gather totebag donations
- Donate to the CDH Family Support Fund and help fund our services
- Donate to the CDH Family Assistance Fund and help families with expenses
- Donate to the CDH Scholarship Fund
- Hold a fundraiser
- Visit members of the CDH blog ring and offer support or a kind word of encouragement
- Share your cherub's story and photo to inspire others
- Submit your story to our newsletter
- Volunteer to be a State or International Representative
- Volunteer to be an On-Call parent
- Volunteer to be a Hospital Angel
- Help put together items for the CDH HOPE totebag project such as handprint and footprint kits
- Attend conferences and meet other families
- Attend conferences and meet other families
- Pray for cherubs and their families
- Offer condolences to the families of those cherubs lost
- Lend a shoulder or an ear to other CDH parents
- Help to keep our forums, events and projects safe, confidential and free of drama and focused on helping families

CDH Awareness

- Wear the CDH Awareness Ribbon Button
- Wear a CDH Awareness Bracelet
- Wear CDH Awareness clothing
- Put a CDH Awareness magnet or bumper sticker on your vehicle
- Post information about CDH on your blog or personal web site
- Tell people about CDH
- Include information about CDH in your church bulleting, club newsletter or other materials
- Give a presentation about CDH at your local school, club or church
- Contact your local media about your story
- Have a blood drive and give out information about CDH
- Hold a fundraiser and give out information about CDH
- Hold a balloon release and give out information about CDH
- Have a birthday or memorial party and give out information about CDH
- Post flyers or posters about CDH
- Participate in CHERUBS events and fundraisers
- Give CDH Awareness items as gifts for birthdays and holidays
- Order CDH Awareness Kits for family and friends
- Participate in the Save the Cherubs campaign
- Donate to the CDH Awareness Fund
- Participate in a local Christmas parade dressed as cherubs and handing out CDH info
- Participate in our Trick-or-Treat "Change for Cherubs" campaign
- Participate in our Valentine's Day CDH awareness campaign

CDH Awareness Shop

Welcome to the home of the Official Congenital Diaphragmatic Hernia Awareness Ribbon and 1000's of official CDH Awareness Items. CHERUBS CDH Awareness items have been available on-line since 1998, raising awareness in 38 countries making our stores the oldest and largest CDH Awareness shops in the world. Money raised in these shops goes to help families affected by Congenital Diaphragmatic Hernia through our CDH Research, CDH Awareness and CDH Family Support Funds.

From books, bracelets, ribbons and onesies to totebags, skateboards, awareness walk items - we have it all and more! To keep prices low we use a variety of manufacturers and also volunteers to create these items. Some are sold directly by CHERUBS, some by stores such as Cafepress and Zazzle. To shop go to <http://www.cdhawarenessshop.org>



CHERUBS CDH Awareness Ribbon Items



Official CDH Awareness Ribbon



Personalized CDH Awareness Items



CDH Cherubs Calendars



Drawings by Cherubs



Awareness Event Items



CDH Awareness Kits



Adopt A Hospital CDH Kits



CDH Awareness Posters & Journals



CHERUBS Conferences & Get-Togethers



CDH Awareness Ribbon Buttons



CDH Awareness Bracelets



CDH Awareness Bumper Sticker Magnets



CDH Totebags



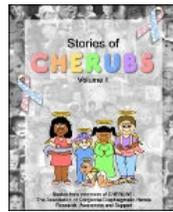
CDH Anatomy Lesson



CDH Holiday Ornaments



CDH Baby Book



Stories of Cherubs Books



I Love C.D.H. Research



CHERUBS Angel Ball



Cherub On Board Maternity T-Shirt



CDH Superhero Logos



Holiday Items



CDH Logo Items



CHERUBS Logo Items



CDH Wings Logo



CDH Awareness Victorian Logo



CDH Awareness Flourish Logo



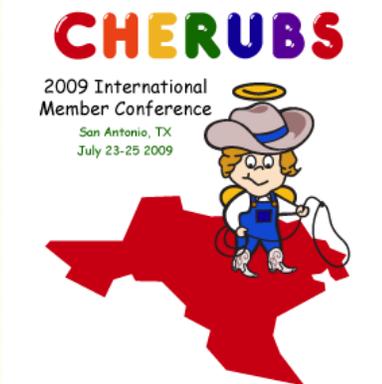
Congenital Diaphragmatic Hernia Educational Items



"I Help CHERUBS" for Medical Professionals

CHERUBS 2009 International CDH Conference

San Antonio, TX



Our 2009 International Member Conference for families affected by CDH was a wonderful success!

We had 17 families and 8 organizations represented from 4 countries. It was truly an international CDH conference. One person called it a "CDH Summit" but we hate to use the word "summit" as that is a meeting of peace of countries / organizations who can't get along - and we most definitely all get along! :) It was a "CDH Conference" - for and about Congenital Diaphragmatic Hernia. It included CDH Research, Awareness and Support.

It began on Wednesday with our Pizza Party and Introductions. We presented Danielle Kessner of CHERUBS Australia with a cherub statue. In 2000, CHERUBS members presented Dawn with a crystal statue. Now that CHERUBS Australia and CHERUBS UK have their own non-profit status and president, it is fitting that all 3 have the statue. Brenda Lane of CHERUBS UK received hers on Thursday as they missed the Pizza Party. Also at the Pizza Party, the new CDH song "I'll Never Let You Go" by The Jammies was unveiled. We will post that video in a few days.

On Thursday, we were blessed with incredible guest speakers!!! Daryl Scott MD and David Pearson from Baylor's CDH Research Team were wonderful! Their presentation was very informative and the parents were able to ask lots of questions. We all learned quite a bit about genetics and CDH! Then Dr. Kevin Lally presented from the CDH Study Group and we learned about the history of CDH, the future of CDH and all the research that the group is doing. And Pam Lally was so sweet to provide us with the latest (unpublished) survey tabulations. The parents were able to ask more questions about ECMO, CDH repair and survival rates. It was extremely informative. On Friday, Drs. Meaghan Russell and Mauro Longoni from Boston Children's spoke on their CDH Research Study. We learned even more about CDH and genetics and how they use mice to create diaphragmatic hernias. The parents got to ask more genetic questions. They bought us copies of CDH News, their newsletter, as well and it featured a photo of last year's conference! :)

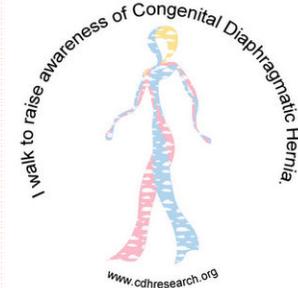
On Saturday and also on Friday we had round-table discussions and parents had the opportunity to talk to each other about their stories and various topics dealing with CDH. We all learned a lot from each other and we laughed, cried and shared so much. The doctors sat in on the discussions and learned from parents just as we learned from them. It was such a blessing to have the opportunity to do this. And on Saturday, the kids learned a little song about CDH and performed it for us.

This conference was also a milestone for CHERUBS - it was the first time the Presidents of all 3 CHERUBS have met in person. Dawn Williamson of CHERUBS (USA), Danielle Kessner of CHERUBS Australia and Brenda Lane of CHERUBS UK came together for the first time this year. We also welcomed Kim Richards of The Olivia Raine Foundation and Michelle Brown of Little Lambs. Not to mention doctors from 3 more CDH studies - Kevin and Pam Lally of the CDH Study Group, Meaghan Russell and Mauro Longoni of Mass General / Boston Children's CDH Study and Daryl Scott and David Pearson from Baylor College's CDH Study. All 8 organizations are members of ACDHO, The Alliance of Congenital Diaphragmatic Hernia Organizations - a group of CDH organizations and research centers dedicated to working together to help support, protect and advance the CDH community. 8 CDH organizations all together at once to help each other and CDH families!!!!

We want to say thank you to our guest speakers and to Karen Myers, a member who went above and beyond to make this conference possible. We'd also like to thank Barbara Wagner, who showed what a CHERUBS volunteer is all about with all she's done to help us. And all of our wonderful volunteers and sponsors!



CDH Awareness Events, Fundraisers and Members Meeting Members!



On Saturday, March 27th, CHERUBS members participated in the Triangle's Great Human Race. It is an annual 5k walk / run for local Raleigh - Durham non-profit organizations. We walked in memory of Andrew Hobbs and Shane Torrence and in honor of Oz Kidd-Ward



2009 Ohio Member Picnic



2010 March of Dimes March for Babies, Durham, NC
The Williamson Family



Dawn Williamson and Erin Fisher walking in memory of Shane Torrence and Zoe Fisher at the March for Babies



2009 Pennsylvania Member Picnic



Christmas with Kasey
A hugely successful event In memory of Kasey Colvin.



SC CDH Road Rally



2010 Pennsylvania Member Picnic



Michigan Bowl-a-Thon
Shane Wagner, Tresia Robinson, Logan Wagner, Barbara Wagner, Kevin Wagner and Larry Shelton

CHERUBS Adopt A Hospital Program

Provide Information & Support To Families Affected By Congenital Diaphragmatic Hernia

Would you like to help families affected by Congenital Diaphragmatic Hernia? Would you like to do something in honor or in memory of a cherub? CHERUBS has created a new program that will soon be helping CDH families across the country.

How does it work? You make a \$100 donation to CHERUBS and we order and put together the materials and send them to the hospital in honor / memory of your cherub.

CHERUBS Adopt A Hospital Care Package Includes:

- 1 copy of "Stories of Cherubs" Volume I
- 1 copy of "Stories of Cherubs" Volume II
- 1 CDH awareness mini-poster
- 20 Parent Reference Guides
- 30 CHERUBS CDH Info Brochures
- 40 CDH Awareness Ribbon Pins
- 10 copies of our latest newsletter



Delivering items in memory of Caleb Cox



Each item (except the CDH ribbon pins) is labeled with a sticker that says "Donated in honor of _____" or "Donated in memory of _____"

These items are then available to all CDH parents admitted into these hospitals. Upon joining CHERUBS, new parents will soon receive more information and support through our CHERUBS H.O.P.E. program.

These items are an invaluable source of support and information for families affected by Congenital Diaphragmatic Hernia. Because there are so many hospitals, CHERUBS cannot possibly afford to donate to all hospitals and we are inviting our members and the general public to help us to help CDH families.

Your donation is tax-deductible!

Hospitals Currently Adopted:

- Brenner Children's Hospital - in memory of Zoe Aris Fisher
- Children's Healthcare of Atlanta at Egleston - in honor of Jessica Barry
- Children's Hospital of Philadelphia - in honor of Braden Holt
- Duke University Medical Center - in memory of Shane Torrence
- National Children's Hospital - in memory of Amanda & Nicholas Slavin
- OSF St Francis Medical Center - in honor of Christopher Strode
- Saint Joseph's Hospital, Denver, Colorado - in memory of Kasey Colvin
- OSF St Francis Medical Center - in honor of Christopher Strode
- Our Lady's Hospital for Sick Children, Crumlin, Dublin - in honor of Aoife Hopkins
- Palmetto Health Richland - in honor of Abigail Taylor Long
- Seton Hospital (Austin, TX) - in memory of Cody Travis Streetman
- St. David's Hospital (Austin, TX) - in memory of Cody Travis Streetman
- Stormont-Vail Hospital - in memory of Michael Joseph Skaggs
- The Children's Hospital at St. Francis - in honor of Laney Kate Daniels
- Toronto Children's Hospital - in memory of Ethan William James Marchand
- University of Alabama Birmingham Hospital - in memory of Caleb Cox
- University of Kansas Medical Center - in memory of Michael Joseph Skaggs
- University of Michigan - in honor of Logan Wagner & Declan Armstrong
- University of North Carolina, Chapel Hill - in memory of Dawson Gabriel Martie
- University of Virginia - in memory of Debra Jones and in honor of Cole Campsey
- Wilford Hall Med Center - in memory of Kaleigh Myers & in honor of Raelyn Turner



Billboard at St. Joseph's in memory of Kasey Colvin

CHERUBS Congenital Diaphragmatic Hernia Research Database

CHERUBS Congenital Diaphragmatic Hernia Research Survey is the combined efforts of over 2000 CDH families and medical professionals. It takes information on the medical, family and exposure histories of CDH patients and compares data to look for the cause, prevention and better treatment of Congenital Diaphragmatic Hernia. Participation is voluntary, anonymous and free to all CDH families and medical staff. Data can be tabulated live for research and reference purposes.

Sneak Peak at our new database:

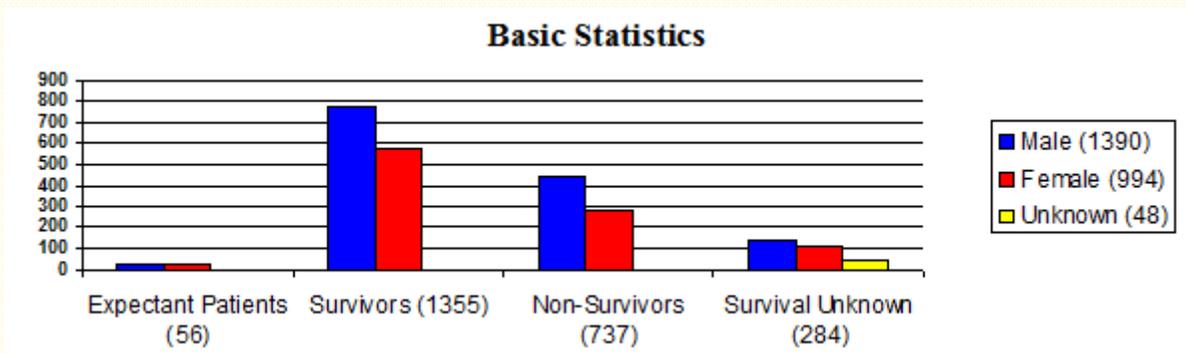
We've been hard, hard at work for months now on the Congenital Diaphragmatic Hernia Research Database site!!! Once completed, this site will survey all CDH parents and researchers and allow research statistics to be tabulated on the fly!

This CDH Research Study is the only long-term, in depth CDH study of it's kind in the world. It is the largest database of CDH patient, family medical history, pregnancy history and long-term care data. Together with the CDH Study Group and their database of 1000's of CDH patients immediate care and medical histories, we hope to learn information that will help all babies born with Congenital Diaphragmatic Hernia and learn how to stop CDH from happening to babies of the future. It is 100% confidential, server secure and HIPPA compliant.

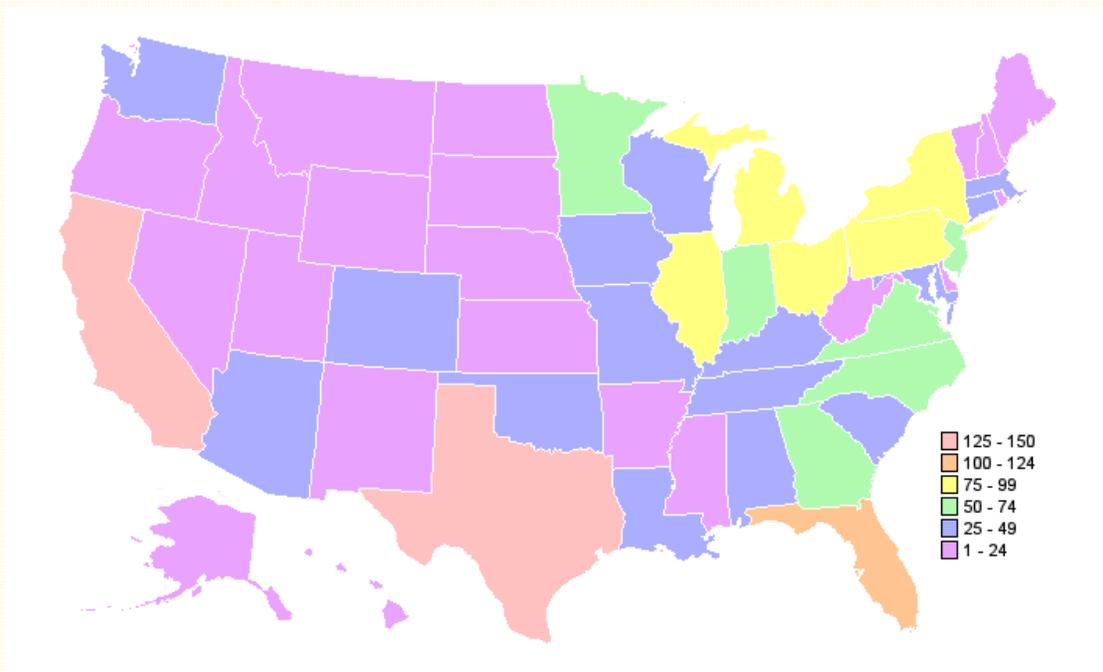
This is CDH research happening right NOW! CDH Research that every patient and every family can join in to help - regardless if your child is a survivor or non-survivor or whether you have DNA samples available (as many parents of non-survivors do not). Every CDH family can participate. Every CDH family can make a difference!

Below is some information tabulated from our survey that includes members who joined CHERUBS by April 30, 2009. The following data only includes primary patient information - it does not include secondary memberships (grandparents, additional parents, etc) or CDH researchers memberships.

This data includes 2431 CDH patients (those who joined before February, 2009). It does not include all other non-patient or secondary members.



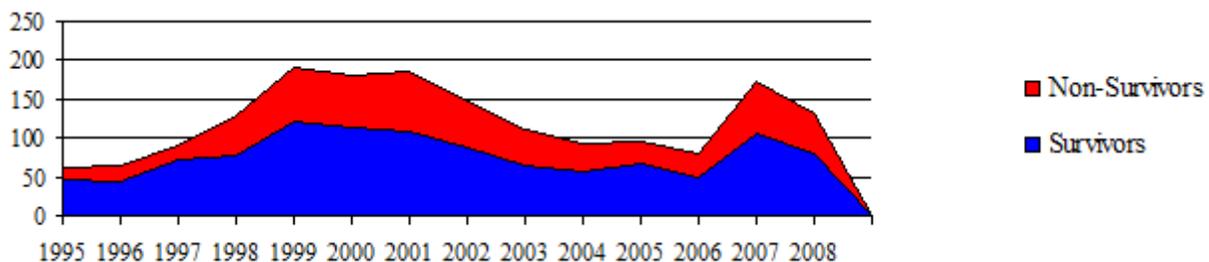
CDH Patients In CHERUBS Membership By State:



Country	Expectant Patients			Non-Survivors			Survivors			Survival Unknown			Total CDH Patients
	Female	Male	Gender Unknown	Female	Male	Gender Unknown	Female	Male	Gender Unknown	Female	Male	Gender Unknown	
Alabama	0	0	0	5	7	0	11	13	0	0	0	0	36
Alaska	0	0	0	1	2	0	0	6	0	0	0	0	9
Arizona	0	0	0	4	8	0	7	12	0	2	2	1	36
Arkansas	0	0	0	2	3	0	6	5	0	2	2	0	20
California	1	1	1	12	25	0	37	52	0	4	7	0	140
Colorado	0	0	0	5	6	0	5	8	0	4	4	2	34
Connecticut	0	1	0	2	3	0	9	10	0	4	0	2	31
Delaware	0	0	0	1	1	0	2	0	0	0	0	0	4
Florida	0	1	0	10	12	0	27	46	0	4	3	1	104
Georgia	1	2	0	6	12	0	15	17	0	2	6	2	63
Hawaii	0	0	0	0	0	0	3	2	0	0	0	0	5
Idaho	0	0	0	1	1	0	5	5	0	1	0	1	14
Illinois	1	1	0	15	16	0	25	31	0	3	2	2	96
Indiana	0	1	0	9	10	0	11	19	0	2	4	1	57
Iowa	0	0	0	3	7	0	4	6	0	1	4	1	26
Kansas	0	0	0	2	3	0	3	5	0	3	2	0	18
Kentucky	0	0	0	4	4	0	6	12	0	0	3	0	29
Louisiana	0	0	0	5	6	0	4	8	0	2	4	0	29
Maine	0	1	0	0	5	0	2	4	0	0	0	0	12
Maryland	0	0	0	9	6	0	10	15	0	1	1	0	42
Massachusetts	1	0	0	4	7	0	13	19	0	0	0	2	46
Michigan	0	2	1	11	14	0	17	28	0	4	3	1	81
Minnesota	1	0	0	6	9	0	10	17	0	6	3	0	52
Mississippi	0	0	0	1	5	0	3	3	0	0	0	0	12
Missouri	0	0	0	5	5	0	9	7	1	0	2	1	30
Montana	0	0	0	0	0	0	2	1	0	0	1	0	4
Nebraska	1	0	0	3	3	0	3	8	0	0	0	1	19
Nevada	1	1	0	1	2	0	1	1	0	0	1	0	8
New Hampshire	0	0	0	0	2	0	4	6	0	0	0	0	12
New Jersey	1	0	0	3	10	0	19	16	0	3	4	1	57
New Mexico	0	0	0	1	5	0	3	5	0	0	2	0	16
New York	0	2	0	10	14	0	20	23	0	5	5	1	80
North Carolina	0	1	0	8	10	0	16	18	0	3	8	1	65
North Dakota	0	0	0	0	0	0	1	3	0	0	0	0	4
Ohio	2	1	1	8	21	1	17	35	0	4	7	1	98
Oklahoma	0	1	0	8	11	0	7	8	0	1	1	0	37
Oregon	0	0	0	0	4	0	4	10	0	1	1	0	20
Pennsylvania	0	0	0	8	14	0	25	18	0	9	8	1	83
Rhode Island	0	0	0	0	1	0	2	2	0	0	0	0	5
South Carolina	0	1	0	5	5	0	5	11	0	0	2	0	29
South Dakota	0	2	0	0	1	0	3	2	0	0	1	0	9
Tennessee	0	0	0	1	7	0	7	9	0	2	3	0	29
Texas	5	1	0	16	29	0	28	48	0	9	10	1	147
Utah	1	0	0	3	6	0	0	3	0	2	0	0	15
Vermont	0	1	0	1	1	0	0	1	0	0	0	0	4
Virginia	1	1	0	19	7	0	9	17	0	2	1	0	57
Washington	0	0	0	2	11	0	9	11	0	3	3	0	39
West Virginia	0	0	0	1	1	0	2	7	0	2	1	0	14
Wisconsin	0	0	0	5	7	0	13	10	0	0	3	2	40
Wyoming	0	0	0	2	4	0	0	3	0	0	0	0	9
Washington DC	0	0	0	0	0	0	0	0	0	0	0	1	1
Puerto Rico	0	0	0	0	1	0	0	0	0	0	0	0	1
Overseas Military	0	0	0	0	0	0	0	0	0	0	1	0	1
Unanswered	0	0	0	0	0	0	2	3	0	0	0	2	7
TOTAL	17	22	3	228	354	1	446	629	1	91	115	29	1936

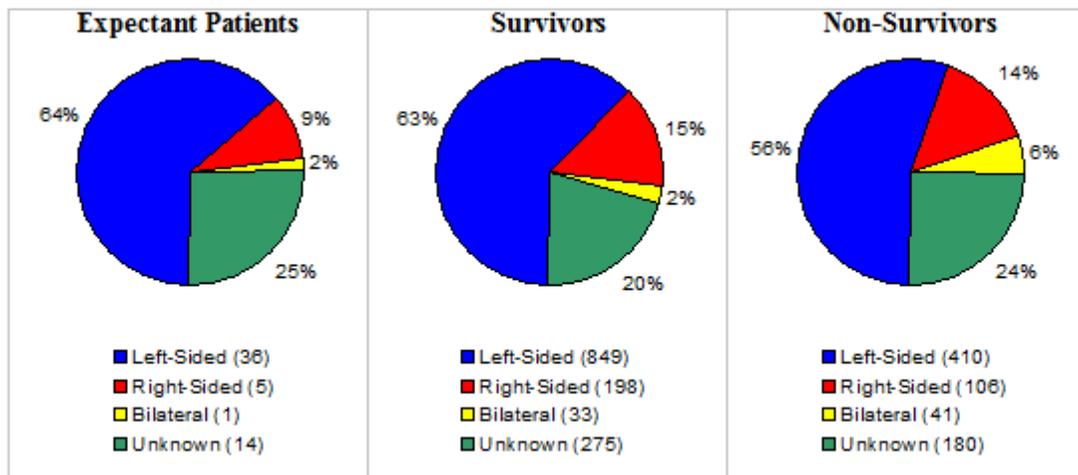
CDH Patients In CHERUBS Membership By Country:

Country	Expectant Patients			Non-Survivors			Survivors			Survival Unknown			Total CDH Patients
	Female	Male	Gender Unknown	Female	Male	Gender Unknown	Female	Male	Gender Unknown	Female	Male	Gender Unknown	
Argentina	0	0	0	0	1	0	0	0	0	0	0	0	0
Australia	0	2	0	18	25	2	32	43	0	2	2	0	126
Bahamas	0	0	0	0	1	0	0	0	0	0	0	0	1
Belgium	0	0	0	0	1	0	0	1	0	0	0	0	2
Bermuda	0	0	0	0	0	0	0	1	0	0	0	0	1
Brazil	0	0	0	1	0	0	1	0	0	0	0	0	2
Canada	1	1	0	8	23	0	29	38	0	7	4	1	112
Chili	0	0	0	0	0	0	3	0	0	0	0	0	3
Colombia	0	0	0	0	0	0	0	0	0	1	0	0	1
Denmark	0	0	0	0	0	0	0	3	0	1	1	0	5
Finland	0	0	0	0	1	0	0	0	0	0	0	0	1
France	1	1	0	1	1	0	1	1	0	0	0	0	6
Germany	0	0	0	2	1	0	1	2	0	1	0	0	7
Great Britain	1	1	0	15	20	0	29	39	0	3	7	6	121
Hong Kong	0	0	0	1	2	0	1	0	0	0	2	0	6
India	0	0	0	0	2	0	1	4	0	0	0	1	8
Ireland	2	0	0	3	5	0	11	5	0	0	1	1	28
Israel	0	0	0	1	0	0	0	0	0	0	0	0	1
Italy	0	0	0	0	0	0	0	1	0	0	0	0	1
Malta	0	0	0	0	0	0	1	0	0	0	0	0	0
Mexico	0	0	0	0	3	0	0	3	0	0	0	0	6
New Zealand	1	0	0	3	5	0	5	5	0	0	1	0	20
Norway	0	0	0	0	0	0	1	2	0	0	0	0	3
Pakistan	0	0	0	0	0	0	0	2	0	0	0	0	2
Panama	0	0	0	0	0	0	0	1	0	0	0	0	1
Peru	0	0	1	0	0	0	0	0	0	0	0	0	1
Portugal	0	0	0	0	0	0	1	0	0	0	0	0	1
Romania	0	0	0	0	0	0	0	0	0	1	0	0	1
Saudi Arabia	0	0	0	0	0	0	0	1	0	1	0	0	2
Scotland	1	0	0	1	3	0	2	2	0	0	0	0	9
Singapore	0	0	0	0	0	0	0	1	0	0	0	0	1
South Africa	1	0	0	0	0	0	3	2	0	0	0	1	7
Spain	0	0	0	0	0	0	1	2	0	0	0	0	3
Sweden	0	0	0	0	0	0	1	1	0	0	0	0	2
Switzerland	0	0	0	1	0	0	0	0	0	0	0	0	1
Taiwan R.O.C.	0	0	0	0	0	0	0	1	0	0	0	0	1
The Netherlands	0	0	0	4	0	0	2	1	0	1	0	0	8
The Philippines	0	0	0	0	0	0	1	0	0	0	0	0	1
Turkey	0	0	0	0	0	0	0	0	0	0	0	1	1
U.S.A.	17	22	3	228	354	1	446	629	1	91	115	29	1936
Unanswered	0	0	0	0	0	0	0	0	0	0	0	1	1
TOTALS	25	27	4	287	448	3	573	791	1	109	133	40	2441

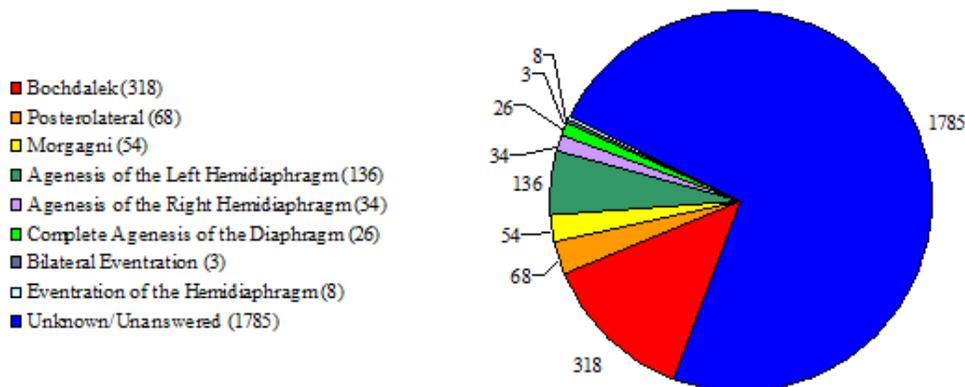


SIDE AND TYPE OF CDH

Side & Type of CDH	Expectant Patients			Non-Survivors			Survivors			Survival Unknown			Total CDH Patients
	Female	Male	Gender Unknown	Female	Male	Gender Unknown	Female	Male	Gender Unknown	Female	Male	Gender Unknown	
LEFT-SIDED													
Left-Sided Bochdalek CDH	7	5	1	26	42	0	82	115	0	6	18	3	305
Agenesis of the Left Hemi-Diaphragm	0	0	0	17	47	0	33	36	0	1	1	1	136
Eventration of the Left Hemi-Diaphragm	0	0	0	1	0	0	2	1	0	0	0	0	4
Left-Sided Morgani CDH	0	0	0	2	1	0	5	4	0	1	0	0	13
Left-Sided CDH (type Unknown / Unanswered)	10	10	0	98	162	1	230	299	1	44	50	14	919
Left-Sided Posterolateral CDH	2	1	0	8	5	0	17	24	0	2	1	0	60
Total	19	16	1	152	257	1	369	479	1	54	70	18	1437
RIGHT-SIDED													
Right-Sided CDH (type Unknown / Unanswered)	1	2	0	35	41	0	55	90	0	8	9	4	245
Agenesis of the Right Hemi-Diaphragm	0	0	0	3	8	0	4	17	0	1	1	0	34
Right-Sided Bochdalek CDH	0	0	0	1	4	0	4	3	0	0	0	0	12
Eventration of the Right Hemi-Diaphragm	0	0	0	0	1	0	1	2	0	0	0	0	4
Right-Sided Morgani CDH	0	2	0	6	5	0	12	7	0	1	0	0	33
Right-Sided Posterolateral CDH	0	0	0	2	0	0	2	1	0	0	0	0	5
Total	1	4	0	47	59	0	78	120	0	10	10	4	333
BILATERAL													
Bilateral Morgani CDH	0	0	0	0	1	0	4	1	0	0	0	0	6
Bilateral Posterolateral CDH	0	0	0	1	0	0	0	2	0	0	0	0	3
Bilateral CDH (type Unknown / Unanswered)	0	1	0	7	12	0	8	9	0	1	0	0	38
Bilateral Eventration of the Diaphragm	0	0	0	2	1	0	0	0	0	0	0	0	3
Complete Agensis of the Diaphragm	0	0	0	6	11	0	2	7	0	0	0	0	26
Total	0	1	0	16	25	0	14	19	0	1	0	0	76
UNKNOWN													
Unknown Side, Bochdalek CDH	0	0	0	0	0	0	1	0	0	0	0	0	1
Unknown Side, Morgani CDH	0	0	0	0	0	0	0	2	0	0	0	0	2
Unknown / Unanswered	5	6	3	72	106	2	113	159	0	44	55	18	583
Total	5	6	3	72	106	2	114	161	0	44	55	18	586
TOTALS	25	27	4	287	447	3	575	779	1	109	135	40	2432

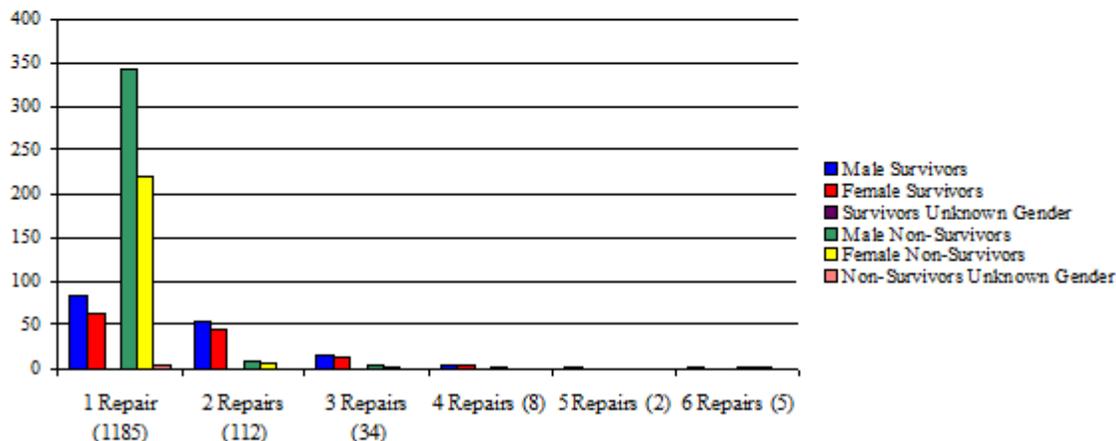


Type of Congenital Diaphragmatic Hernia



CDH Repairs

	Survivors			Non-Survivors			Totals
	Male	Female	Unknown	Male	Female	Unknown	
No Repairs	83	64	0	342	220	3	712
1 Repair	608	425	0	92	60	0	1185
2 Repairs	54	45	0	8	5	0	112
3 Repairs	15	14	0	3	2	0	34
4 Repairs	4	3	0	1	0	0	8
5 Repairs	2	0	0	0	0	0	2
6 Repairs	2	0	0	1	2	0	5
Multiple Repairs	685	487	0	105	69	0	1346
Unanswered	13	22	0	0	0	0	35



CHERUBS has been tabulating CDH Research Studies since 1997. Now, with the help of 1000's of CDH families and researchers around the world and with the other organizations of ACDHO, we are so, so proud to announce that our years of hard work will be able to benefit the CDH community even more.

This site will be FREE for ALL to use. CHERUBS does not wish to be paid for it's use or to "own" or trademark Congenital Diaphragmatic Hernia Research. You do not have to be a member of CHERUBS to participate. ALL CDH families, organizations, researchers and the general public will be allowed to access and use this information and research. All we care about and want is finding the cause, prevention and best treatment of CDH.

This is only just a tiny bit of what this CDH Research Study will include. There will be 4 separate studies:

1. CDH Patient Information - created from CHERUBS membership form data. This is our basic patient information, some of which is shown above. Pregnancy history, CDH diagnosis, side of CDH, type of CDH, hospital stay, CDH repairs, other birth defects, complications, etc.

2. In Depth CDH Research Survey - 12 very detailed pages of maternal exposures during pregnancy, pregnancy histories, family medical histories, chemical exposures, birth defects, genetic issues, lung capacity, long-term therapies, pregnancy testing, labor and delivery, CDH repairs, complications and much, much more.

3. CDH Support Survey - survey on how CHERUBS can better help CDH families and what other services are needed

4. CDH Researchers Survey - taken from CHERUBS membership forms for medical professionals, this helps doctors and nurses to better help CDH patients and their families.

We are very, very excited about this project and look forward to unveiling it soon!



LaneyKate Daniels

6/15/07

".....I love to tell the story of Jesus and His Glory.....", a hymn sung many times in my life without the experience to understand the concept of the song. But now... now I have walked with Him. And I DO love to tell the story...

It was a really nice day in January of 07, we left home early that morning to arrive at 9:00 am at the Diagnostic Imaging Center to find out if my kicker was a boy or a girl. My mother was meeting us there and I was really excited to be able to share this with her. We entered the exam room and the nurse began to look around and take measurements of my little kicker. She was showing me the heartbeat and how the baby was waving its hands. And before she told us, she asked one more time, "Are you sure you want to know the sex of the baby?" And we stated "Yes!! Do you know yet?" Her response in a chuckle, "I'm sure.... No doubt about it... it's a GIRL!" Elated doesn't describe the emotion I was aloud to focus on for the next 3 days.

For it was 3 hours later when I went to have a follow up appt. with my OBGYN, he informed me that the technician had seen something and wanted him to double check and then let me know. So we did, one more picture of my sweet baby girl, who now had booties, a hat, and a rose print outfit to leave the hospital in. He (OB) then confirmed the technician's suspicion. He told me my little Girl had a hernia. Okay still in my head, no big deal, hernia's are just a weak muscle right? No life threatening issue right? He told me that she was going to be fine, but I'm sending you to a specialist on Mon (this was a FRI).

Mon morning would be described later as my "doom's day". The specialist examined my little girl and concluded that it was CDH, that she would probably not have a high success rate of making it to term without an in utero procedure. I was knocked down, scarred beyond. Confused. We were advised to choose a hospital to have the procedure performed. After deciding on the hospital and making plans to travel there, we were contacted by the HR department of that hospital the night before we planned to leave. They informed us at that time, this procedure was out of date, and no longer being used..... anywhere!

My husband and I then canceled our plans and decided to regroup. We began praying, met with family, and began educating ourselves on CDH. We also immediately, began searching for a new M.F.M.

We met Dr. Fred Fumia of St. Francis Hospital in Tulsa, Ok (1 hr from our home) on the following Monday. He new our story, and he lovingly took us in. He explained what the challenge in front of us was going to be. That it was going to be tuff, sometimes downright hard. But she did have a great chance of making it to term and a good chance of survival. We then met the E.C.M.O. team, the pediatric surgeons, and Neonatologists of St. Francis. We were blessed. We were confident.

June 14, 2007 (41 wks) I was induced into labor that Thursday evening. By Friday at 2:52 Our daughter, LaneyKate, entered this world with a bold and strong cry!!! A blessing from God Almighty! She was immediately intubated and taken to the E.O.P.C. there at St. Francis. LaneyKate continued to do well on the classic ventilator for the first day and a half. At that point it was just getting to tough for her to handle alone. On Sunday Morning at 9 am she was placed on E.C.M.O. She was also finally able to "wake up" and we saw her sweet little brown eyes on Father's day. We were blessed.

They had placed a tube into her stomach to keep the gases drained out to keep it from expanding anymore. That tube rubbed an ulcer on her stomach and because of the anti-coagulant in the E.C.M.O unit, the bleeding wouldn't stop. On Wed morning, the stomach had enough... it ruptured. The surgeon called us and asked us to get to the hospital quick, we have some decisions to make. His first recommendation was to take LaneyKate off of E.C.M.O. and do the surgery. We were not comfortable with that, knowing she wouldn't be able to sustain her life with it. The final decision was go get another surgeon and perform the surgery and repair while on E.C.M.O, and get in and out as quick as possible. So they did. A 4-hour surgery in an hour and a half. We were blessed.

The surgery went great. He had briefed us previously that he would also be placing a feeding tube in since he would be working with the stomach. It was very much a possibility that she would need one and it would be easier to do it now, we agreed.

Afterwards he came up, and again the description must be elated. He told us how once he opened her up, he was amazed!! He described a yolk like material that bridged the gap where LaneyKate's diaphragm hadn't formed. So her stomach and intestines were only allowed to go so far. They were also still packed together. No twisting, no separating. He then told us he did not insert a feeding tube in her stomach. He told us, "I have faith that she will not need one." We were blessed. For where her body had not met up to the standard, God bridged the gap and made her whole!

She came off of E.C.M.O the very next day. She continued to grow strong and breathe on her own a little more every day. Day 15 she was extubated and we finally held her in our arms (for we held her in our hearts the first 14 days).

She was now able to try to eat on her own by her own power. We asked to breast-feed and were encouraged, but also explained to that she probably wouldn't latch for lack of a sucking reflex or an oral aversion. But we were encouraged to try, at least for the bonding experience. After 5 min with the lactation consultant, LaneyKate was latched on and eating! Our moment of privacy and bonding experience was over. Every Doctor and Nurse had to see this "E.C.M.O. baby" that was nursing. We were blessed.

LaneyKate spent a total of 34 days in the unit. The Doctors were very leery to let us leave. They were expecting a major setback to occur any time now, because we didn't really have one. They were shocked that we were able to take her home with no oxygen, no monitors, no feeding tube.... It is a miracle. We were blessed.

LaneyKate will soon be celebrating her 1st birthday, It is very emotional to think about a year ago today, and the thoughts and emotions I was struggling with then. But I knew then, and I know, That God has control of my life, and his plans for me are perfect, and he is the one who sustains me. I am blessed!!

Written in 2008 by LaneyKate's parents, Brandon and Carrie Daniels (OK, USA)



Andrew Burdette

2/24/08 – 2/25/08

October 2007

I started to feel better during this month, except for the tired feeling. Because of a procedure that I had done in April 2007, I was to have my first ultrasound at 16 weeks gestation to check the length of my cervix to make sure it was going to be competent enough to carry the baby. If not they would put a stitch in me. My ultrasound appointment was on October 30th 2007. My husband had a mandatory meeting for his job so my best friend and my daughter went with me. We were able to find out the sex and that supposedly our baby was healthy. It was a boy, which we were all ecstatic over.

From here on I had ultrasound appointments every other week until I was 24 weeks pregnant. This was just to check my cervix, but they looked at the baby as well. I had the routine ultrasound at 20 weeks to check all measurements of baby as well. Everything was normal. I complained about my technician and asked for another one to do my last two. I was told that this was going to happen and it did not.

January 30, 2008 (29 weeks) - I went to the fifth ultrasound. I asked to have this because I was feeling lots of increased pressure and I wanted to make sure my cervix was still closed. This is where it all began. She told me that I need to go directly to my regular OB because something was wrong with the baby's stomach. It looked larger than normal. She also said something about me having increased amniotic fluid. She told me she was going to have the radiologist fax my report to my OB, but I wasn't supposed to know that. I left feeling confused and upset.

I called my best friend (Emily Smallwood) who works with me and she went with me to my OB's office. We sat in the waiting room for about 2 hours before we were seen. The report didn't tell my doctor anything so she made me an appointment for the next morning with a high risk OB doctor.

January 31, 2008 (29 weeks) - I saw the high-risk OB doctor who told us the baby had a right-sided congenital diaphragmatic hernia (CDH). The doctor explained that this is a hole in the diaphragm where the intestines migrate into the lung cavity, which prevents the lungs from growing and can displace the heart. He also said that right sided is less common than left sided. He said it might be genetic so they asked me about getting amniocentesis. I told them I was not interested in this as it was too late to terminate the pregnancy. I did not want to know if anything else was wrong. Most of the time this defect is a random hit and not associated with other issues. We (my husband, Emily and I) were told that there is no known cause for this. We were also told that the baby had a 50/50 chance of survival.

I asked this doctor how this could have been missed in all of the other ultrasounds. He said maybe the technician did not have clear pictures of everything and so the angle that the radiologist was reading the pictures from made everything look normal. He said I could get the report and pictures and bring them with me at my next appointment and he would go over them with me. He also said that maybe my baby's case might not be severe. Things might have started shifting after the 24-week ultrasound although the diaphragm does not close between 6 and 8 weeks. He was sending us to Children's National Medical Center in DC for further testing to determine the severity of the defect and hopefully get a better understanding of what was actually going on inside of him.

I went home to wait for Children's to call me with my appointment. They called later that day and my appointment would be on Feb. 7, 2008. My appointments were for a fetal MRI, ultrasound, consultation with a surgeon, echocardiogram of the baby's heart, and a consultation with a genetic counselor.

Emily and I began doing research on the internet that afternoon before going to Children's so we could be prepared and have our questions lined up for the "experts". We found a surgery that could be performed in utero up to 24 weeks gestation. The procedure would insert a small balloon on the end of the trachea of the baby which would be inflated and take up room in the chest cavity to prevent the organs from migrating into this area which would allow the lungs to develop normally. Because the defect was not caught in any of my early ultrasounds, I was not eligible for this procedure, which might have saved my baby's life (no guarantee). We also found that every baby with this condition is different. All babies respond differently. There is no prenatal test that can diagnose and tell exactly if your baby will make it or not once born or have any other issues that are associated with this defect after birth.

My regular OB had called me sometime between this diagnosis and my next appointment. We talked about how upset I was at Community Radiology for missing the diagnosis. She said she called them to see what was going on and why it was not noticed. She left a message and never heard back from them, which didn't surprise her. She also told me she was hesitant about sending her patients there for their routine 20-week anatomy ultrasound.

February 5, 2008 (30 weeks) - I had a regular OB appointment today. I told the doctor what was going on, as she had no record of what the high-risk doctor had determined. The OB told me that the defect is fixable, which technically it is. However, it is the lung damage that is the problem. I asked her why this was missed on all of my previous four ultrasounds (especially my 20 week ultrasound) and she said that possibly nothing was displaced yet; i.e. his organs were not moved around yet. She also said that maybe the lung damage might not be that severe because they might have been able to develop some. I left feeling somewhat relieved but I had not been evaluated at Children's yet.

February 7, 2008 (30 weeks) - My husband, Emily and I traveled to Children's today for all of the testing. I had the fetal MRI first followed by the ultrasound. We were taken into a room to get the results of the MRI and ultrasound. We were told that our case was very severe and the baby would definitely need ECMO (heart and lung bypass machine). She also said that he was right sided. Emily wanted to know the head to lung ratio because in our research we found that this was a good indicator of prognosis. The doctor said this was used for left sided CDH and she hadn't calculated it yet but she knew that the baby's was a 0.4 or below. 0.4 is a very severe case and chances are survival is minimal. She also said he might have a clubbed foot and flexed digits.

Next, we went to see the surgeon. We had to wait for an hour in a waiting room full of babies. The surgeon told us that babies on the ECMO machine are on there for two weeks. After that they take them off regardless of whether or not the babies need it to sustain life. We asked about surgery and ECMO. In our research we had seen that it is more risky to do repair surgery on ECMO but that it is done. At Children's they do not do repair on ECMO machine regardless. Note: This is not the case at Johns Hopkins as was told to us by another mother of a CDH baby from Frederick that also started her testing at Children's.

ECMO has many side effects, one of which is a brain bleed, which could cause death. This is caused by the blood thinners that the babies are put on. Using this machine is still not a guarantee of life. One day the baby could be doing fine and the next could be going down hill drastically and then bounce back up again. It is a big roller coaster ride.

After lunch, they performed an echocardiogram of his heart. This was a positive test. His heart was functioning and was anatomically normal.

We then went to see a genetic counselor. We talked about everything that had gone on that day and she was there for support. She asked about our family history to try and get a "feel" if there could be any other genetic problems associated with this defect since I was not having an amniocentesis. The results of an amnio also help the doctors prepare for what after delivery could be like. If the doctors new of other abnormalities, then the prognosis could be better determined and could be grimmer.

From here we made the decision to go to John Hopkins for a second opinion and to determine where we wanted the delivery to take place. Since we knew he would be placed on ECMO and Hopkins does do surgery on this machine and they leave them on longer if needed we thought that we would go here what they had to say. We were not comfortable with how we were treated at Children's either. We felt like they were very cold and inconsiderate, except for genetic counselor. We made an appointment with Hopkins to see if we would be more comfortable and to confirm our diagnosis. In the meantime, we continued to do research.

February 13, 2008 (31 weeks) - I had a follow-up appointment with the high risk OB. I was told that the baby had fluid around his lungs. This meant he was in heart failure but as long as he was inside of me he was fine. They didn't expect me to make it to 36 weeks because of all my fluid and that it would be a miracle if he came out alive at full term. The prognosis kept getting worse it seemed every time I went to a doctor appointment. I had talked about delivering in Frederick so I would be comfortable with the surroundings during delivery and to be close to my family as they are all close. The doctor told me it was up to my regular OB. I would have to ask her that. He also told me to keep checking for movement of the baby.

I did bring my ultrasound report to my appointment like we had talked about in the last. I did have the pictures and also the full reports that they (Community Radiology) sent to my regular OB doctor's office. He looked at them and determined that you can see a shift in the organs, especially the heart as early as 18 weeks. He said there was no reason why this defect (CDH) was not caught sooner. The heart being shifted should have been enough of a red flag for the radiologist to have written something up on the report so I would have been seen by him (high risk OB) for a better ultrasound to determine exactly what was going on.

During the next week, my husband and I had discussed the issue of not even putting the baby on ECMO. His CDH was so severe and there are so many side effects associated with this machine that we didn't want our baby or us to suffer. We also wondered that if we were not going to use the ECMO (Hopkins and Children's have them, Frederick doesn't); what was the reason for having to travel over an hour to deliver. We wanted to deliver at FMH so we and our family could have the time to bond with him prior to his passing.

February 20, 2008 (32 weeks) - I went back to be regular OB and asked her about delivery. She said I would have to contact a lawyer to have it documented what our wishes were exactly, but she didn't see a problem with our decision.

I called the genetic counselor at my high risk OB doctors office and asked her if she ever heard about what my doctor told me to do and if she new of where I could start to look to find the right kind of lawyer. She told me she would look into it and let me know. She did call FMH and ask to talk to the director of the neonatology department (Dr Miller) to see if and what kind of problem they would have about me delivering at that hospital. Dr Miller wasn't in at that time so she was going to call my genetic counselor back to talk with her. My genetic counselor was going to call me back once she heard something.

February 21, 2008 (32 weeks) - I received my phone call from the genetic counselor on our way to Hopkins. She said that Dr. Miller would not feel comfortable delivering me at that hospital because they are not equipped with the equipment that he might need to live. Since all CDH babies are different she said that we should deliver where they're in a facility that was better able to handle this type of situation. A little bummed I was but we would still have to see what the day brought.

We went to Hopkins and had another ultrasound. They confirmed Children's diagnosis. One of Hopkins OBs came in and talked to us during the ultrasound about what she saw. They did not have any reports from Children's. We asked the technician if he had a clubbed foot or flexed digits. They were looking for him to open his hands so they could determine if he had Fryn's Syndrome. This is the flexed digit part. They determined that it was very unlikely that he had a clubbed foot or even flexed digits. We asked about how many people I could have in the delivery room, which I had been worried about since it was now going to be a hectic delivery. She told me as many as I wanted unless something bad started to happen. We also asked about a scheduled induction since I was so far away so we knew we would be there in time. The OB told us if I go into labor early, they would send a chopper for me. After lunch, we had a consultation with the neonatologist. She explained to us what they would do once the baby was born and she was more thorough than Children's. I was really impressed with them. We discussed with her about not using the ECMO. She explained that we would have two options for when the baby is delivered. One was not to assess him at all and see what happens; and the other was to try to get him stabilized and then transport him to the NICU for further assessment. She said that she has seen no parents not do anything whose baby had CDH. We toured the NICU and PICU (ECMO unit). She explained machines to us that our baby could be hooked up to. She did this by using babies that were currently in the NICU.

My husband and I went home to think about what direction we were going to take after the delivery and she was going to call on Monday, February 25, to make notes on our chart. I had to make follow-up appointments for another ultrasound and to see the OB doctors since we had decided that was where we wanted to deliver.

February 23, 2008 (32 weeks) - My water broke around 1:30 p.m. (right before my daughter's birthday party). We called an ambulance to pick me up. I was put in a labor and delivery room at FMH. They had to determine if my water had broken since it was so bloody. It took them a long time to determine if this was the case. It was confirmed that my water had broken. I was not considered in active labor since my contractions were not consistent. At this point, I was trying to determine if I was going to leave or just deliver there. Dr. Miller, the head of the Neonatology Dept. came in to talk to us about our options. The OB that would deliver me, two nurses and some of my family were in the room when Dr. Miller came in. Dr. Miller said that based on Hopkins report of a 1% survival based on 40-week gestation that she would not do nothing when the baby came out. She said they would try to get him intubated and stabilized so they could transport him to the NICU for further evaluation. She was well aware that we were not going to put him on the ECMO at Hopkins (FMH doesn't have one). She further stated that he wasn't eligible for ECMO since he was so small. We know this isn't true since he weighed 4 lbs 10 oz and there are smaller babies on ECMO; eg, 4 lbs 6 oz. We asked her if we would still have the decision to transport him to another hospital if we wanted to. She told us yes we would have that choice.

A doctor (lady forget her name) from neonatology department at Hopkins had called and told me since he was premature on top of having CDH and fluid around his heart, there was 0% chance of survival. Transferring my care there should not be an issue. There really was not need for this as to his outcome was fatal. This should have been enough for FMH to not do anything because they were basing their decision on the initial report of Feb. 21, that he had less than 1% survival chance and that is why they thought they should try to intubate.

We decided to stay there for delivery since I was close to home and we thought we were in control of what kind of care we wanted for our baby. I asked how long I would have to stay there before my contractions became consistent and they said it could be a couple of weeks. This was not the case. The nurses on the 7a.m. to 7 p.m. shift on the 23rd were great. The nurse who came on duty at 7 p.m. was not friendly and didn't want to do anything for me. My contractions started to pick up during the night. I was very uncomfortable around 3:30 a.m. I got a new nurse sometime during the night.

February 24, 2008 (32 weeks) - I got my epidural around 10:30 a.m. I got a new nurse at 7 a.m. and a new neonatologist was on call as well for this day. He came in and introduced himself and that was about it. The new nurse was caring and showed concern for me.

At some point after my epidural but before lunch, I was asked by my nurse if we were interested in having a social worker come talk to us about dealing with the death of a child. I said why not since that information could not hurt and we would have it in case we needed in the future. Someone came to my room around 1:00 p.m. and did not give us any information of that sort. Again many of my family members were in the room at this time. First, she asked if our religious beliefs had anything to do with our medical decisions. I said no. (What does this matter?) She told us that the neonatologist that we talked to yesterday had called social services because we were going to murder our child if we chose not to transport him. He had to be stable to be transported. I felt sorry for her because a lot of my family jumped on her for saying this when it wasn't her fault and she was just reporting what she was told to do.

At this point, I was considered to be in active labor. I had my epidural. I could not be transported to Hopkins.

I had my baby at 5:22 p.m. Andrew Martin was 4 lbs 10oz and 17 in. long. He tried to make a noise and then he was whisked behind a curtain where the neonatology team assessed him and got him intubated. They transported him to the NICU. My husband and Emily followed him to the NICU while they were manually hand bagging him to try to pump oxygen into his lungs. From that point on I had no contact with anyone on how he was doing. The neonatologist kept asking my husband why I was not there. I guess he thought I should have jumped out of bed and ran down there. I finally did get to go see him in a wheelchair. The neonatologist did not ask us anything nor did he explain what was happening to him. He just stood there with his arms folded.

While I was still in the delivery room Emily and Joe waited in the breast pump room of the NICU for the doctors to talk to them and explain what they were doing for Andrew. In the meantime one of my labor and deliver nurses came back into the NICU to see how Andrew was doing. She asked Emily how he was doing and she told her that my husband and she had no idea. She offered to go check on him for us. She reported that they were still working on him and that the neonatologist would come talk to us soon and that he knew we were there waiting to speak with him. Emily and Joe finally met with the neonatologist about 1 hour after he was born, just briefly in the NICU "consult room" where he showed them an x-ray of Andrew's chest. You could see his stomach in his abdomen but nothing else, his entire chest cavity was shadowed and we couldn't tell what was what. He didn't show them where any of his organs were. Emily asked the neonatologist to show us his lungs (specifically) and all the doctor said was they were waiting for a sonogram of his chest to determine the exact placement of the liver so they could put in another chest tube (they didn't ask permission to place the tube, he just said they were going to do it). So Emily asked again to have him point out the lungs and he said they wanted to put the tube in first. Never had any other report from this man! At this point Joe went to tell me what the doctor had said-not much, and to bring me to see Andrew. Emily stayed behind and got to take a picture of Andrew and touch his arm. Basically Emily and my husband had to hunt the neonatologist down to ask him information and then he still didn't give any. Emily and my husband tried to ask questions of the Dr. but he seemed to refuse to answer any of them.

At this point all we were waiting on was for Hopkins to come and get him. The neonatologist told my husband around 6 p.m. that Hopkins had been called and they were on their way. He finally left at 11:30 p.m. The doctor from Hopkins that was going to take him came to my room and I told him I had been forced under duress to sign the consent form for him to take him or we were going to be turned in to social services for trying to murder our baby. He did not want to take him because he did not think he would survive the transport and I was not allowed to be transported with him so I was not going to be with my baby when he died. FMH refused to release me for 24 hours. He called me when he got to Hopkins and told me that his heart had stopped and he had to give him adrenaline and something else had happened during transport, I just can't remember and I have not requested his medical records yet (I was kind of waiting to see the outcome of your advice). He was on an oscillating ventilator and he didn't think he would survive the night since his blood gas levels were high. Andrew was not able to get enough O2 in and CO2 out. I was so mentally and physically exhausted. I asked them not to call if he died during the night as I wanted to get some rest.

February 25, 2008 MY DAUGHTERS BIRTHDAY

I called Hopkins this morning. He made it through the night but they didn't know how much longer he was going to make it. I was not allowed to be discharged until 5:30 p.m. Hopkins knew we were coming as soon as I could get released so they were trying to keep him alive long enough for us to say our goodbyes. I still have not gotten to really take a look at my son at this point. He was whisked away and when I went to see him in the NICU I felt like I was rushed and wasn't supposed to be there.

I sat in my room all day at FMH. No one came to see me except for the nurses. They came to check on me and were supportive. No doctors came to explain what had happened; it was like they were afraid to talk to me. My regular OB did come early and get me released early around 1:30 p.m. The Head of Labor and delivery came and asked us if everything was OK. I told her that the people she was in charge of were great it was the other area that I was upset with. I complain of one nurse though that I had on Saturday night.

When my regular OB came to talk with me and release me, another lady came in to talk with us as well (nursing director?). We told her about the situation and how we thought it was wrong how they treated us with threats and coercion. Had the neonatologist been up front with us about calling social services, we would have left and delivered at Hopkins where I could have been with my baby and not prolonged his or our agony. We also complained about not being told what was going on. She asked if we would like to have another meeting in a few weeks and we told her yes. I do not want to talk with them without legal help.

We went to Hopkins and he was still on the ventilator. We said our goodbyes to our baby and left to get something to eat while they dressed him in preparation of pulling the plugs and to allow us to take pictures before and after death. They put the outfit we had taken on him and wrapped him in his blanket after they turned off the machine. We were called back in to say goodbye again and take pictures. He was perfect on the outside. The only thing visible was the cut on his cheek which I assume was from where they ripped the tape off to remove the breathing machine. We were getting ready to leave and I asked about the blood test for chromosome abnormalities. They said it was too late to do a blood test and that he would have to have a skin biopsy. I agreed to this only because we thought that was the only way we would know anything. Two weeks later I found out that they had already taken blood for this test that afternoon before we got there. That means there was no need to do a skin biopsy. We did not have an autopsy. We were not given any of his bracelets. No one explained to us what they had done to him all night and day. Yes, we knew he was going to die and he did die but it would have been nice to know what both hospitals did to him all night and day. We left Hopkins that night after he died.

We made funeral arrangements the next morning. We told them that we would like for him to be buried in the clothes (a sleeper and blue blanket) that we took to Hopkins. When we arrived at the funeral home, he was in a hospital blanket and onesie. I was devastated. I asked where his clothes were and the funeral director said this was what Hopkins sent. There was nothing I could do as the funeral was starting in 1 hour. After the funeral, I called Hopkins and was put on hold and then transferred to a social worker. She said they had just given her the outfit. I told her it was too late as we had already had the funeral and I needed it for that. I asked why they had taken it off of him and I also asked about the genetic test. She said she would find out and call me back. She mailed me the outfit. She called back and didn't have any answers and couldn't find anybody that knew anything about the outfit and the only thing she could think was that they didn't send people to the morgue with clothes on. Further, she said I would have to talk to someone else about the genetic test. She did give me a name and number of who I could contact.

I received the clothes 2 days later and they had several blood spots on them. One of these spots was at the top and was very large. He was completely unhooked when we left and there was no blood on him at that time. I called the social worker back thinking she could find out about the blood or at least give me a person I could talk to. She said she would find out and let me know. She did call back but however, again nobody knows why. This is all very disturbing to me.

This is the roller coaster that I was on for not a very long time. I greatly miss my son and think about him everyday.

Written in 2008 by Andrew's mom, Tracey Burdette (MD, USA)



Lila-May Brooks

11/11/06

I found out I was pregnant 4 days after my 20th birthday. I was exciting and scared all at the same time. This was my first baby and I was going to be a single Mum. For 20 weeks I had horrible morning sickness where I couldn't keep water down. Everyone told me I would get better but I just couldn't see it happening until I went and seen an osteopath and he worked wonders. I went for my 13wk scan and they said the baby was very healthy and of normal size. A few weeks later I went and had my 20 wk scan and found out I was having a little girl. I was over the moon. They said my little girl was in fantastic healthy. On the 10th November 2006 I was getting cramps in my lower stomach and lower back pain but I brushed it off and kept going I went shopping for about 6hrs and brought a new bed and put it together and cleaned up. I kept waking up and going to the toilet and the pain was getting strong by this time, so I got mum to rub my back. I had strong pains that come and go every min or so. Mum decided we should go to the hospital by time I got to the hospital I was 9cm dilated. I laughed when the nurse told me that. 1 and half hrs later Lila-May was born. She was born at 36 wks, 5lb 2oz, 50cm long and a shade of purple, foaming at the mouth, grunting and chest recession.

The Doctor put her in NICU with oxygen, antibiotics and Nasal Gastric Tube. We weren't allowed to nurse her for 3 days. On day one they done a chest X-ray that showed she had some fluid on the lungs (Well so they thought). They said the antibiotics would help improve it by the next day. So the next day she had another chest X-ray and it still showed "fluid", so they gave her more antibiotics. On day 3 they sent her for an Ultrasound to see if they could find anything else. When they preformed the ultrasound the lady said to be "It looks like she has a diaphragmatic hernia on the right hand side." I just looked at her. I had no idea what she was talking about. When I went back to NICU with Lila-May the Doctor come over and gave me a bit of idea what a diaphragmatic hernia was. With that I just went back to my hospital room and dropped into a heap on the floor and sobbed and blamed my self for it happening. The Next day the surgeon comes in to talk to mum and I about the operation and what was going to happen. By this stage Lila-May was starting to come along well. I was even able to start to breast feed her although it hurt it was the best thing ever. Day by day she was getting better. It was day 9 and the Doctors where talking about sending her home soon. I was so exited that I would be taking my princess home with me soon. One of the nurses changed her feeding plan from every 3hrs to every 4hrs and she lost 150g over night. That set us back 1-day .I was so upset and angry with the nurse because being a new young mum I had no idea that was the wrong thing to do. Day 11 Lila-May Marie Brooks was able to come home. I was so exited I just wanted to show her off to the whole world. On the 29th November 2006 she had to go back to the Paediatrician just for a check up. He sent Lila-May for a chest X-Ray. I was feeling very run down that day as I was dealing with the stress of a new baby that had something wrong with it and my mum was having chemotherapy for breast cancer. The Doctor told me he would call me if there were any changes in the chest X-Ray. Once I had got home and was starting to unwind I got a call from the Paediatrician saying " You need to pack a bag and come up to the Hospital ASAP her heart is turning side ways that means her intestines are moving up". Once I got to the hospital they rushed Lila-May up to a children's hospital in Brisbane by ambulance. Her operation was booked for 2 days later. Her operation only took 1 and half hrs and it was complete. The surgeon come and seen me and said it went very well and only took 3 stitches. She went into PICU for half a day and then she went back up to the ward and come home on the 5th Of December 2006. Few months passed and she was doing well. In March I had a party for my 21st Birthday and had citronella candles and she started to "bark" like a seal then she went a very pale colour and was finding it hard to breathe. So we called an ambulance and took her to hospital. She was fine once we got to hospital it was just croup and the citronella made it worse. I took her to the Paediatrician for a check up as I could see a bit of a recession in her chest and he sent for a chest x-ray. The Operation had come undone. The next day she had an ultrasound and it confirmed she had diaphragmatic hernia again. This time I knew what was going on. This time we saw the top Paediatric Surgeon Dr Debra Bailey. Her operation was booked for 2 weeks later. We arrived at the hospital the night before her operation. Next morning Mum and I took her down to the operating room. 3 and half hrs later we got to see Lila-May in PICU. She was so swollen and had tube coming out of every part of her body Possible. It felt like someone had ripped my heart out just seeing my 6-month-old little girl laying there on life support. She was put in a drug-induced coma and given a cocktail of drugs for pain and to keep her body and mind in a coma. She also got a collapsed lung and a gas ball in her lung, which meant she needed another drainage tube. By this stage she

was even more swollen and her skin was very tight and shiny. 4 days later there was no real progress and I was a mess. I couldn't eat and I couldn't sleep in case something happened and Lila-May needed me. The head Paediatrician of PICU organised for me to be able to nurse Lila-May. I was so happy I got to nurse her and talk to her and at the same time I was so scared I would hurt her in some way. The next day she seemed to get better as the days went by she got better and she was breathing more on her own. They tried to take her off life support 4 times but each time her body couldn't handle it. So the next day she was breathing even more and said we will try her today. I was so excited. They told me it would take a few hrs for them to wean the machine down so she was breathing her self. They suggested I go for a walk and they will call me when they were going to take her off the life support so I could be there for it when it happens. The nurse forgot to call me. I got to PICU once it had finished. I had a very strong feeling something was happening to her. The next day we went back to the ward and she screamed for 2 days straight due to drug withdrawals. Once she was fine to travel we got transferred to a hospital close to home on the Gold Coast. Lila-May Lost all of her skills. She couldn't suck, swallow, she was cross-eyed, couldn't lift her head and couldn't roll over. I would change her outfit around 8-10 times a day because she was dribbling so much. I asked the Doctors could she have brain damage. They said wait around 1-2 months and see if she is back to normal.

She is Now a 17mth old Beautiful Little Girl that's full of life. She runs around, climbs, talks and even goes to kindy. All 7 of her keyhole scares have healed well. She has been classed as an asthmatic and can't go on the grass when she has a cold or she will stop breathing and cleaning products set her off. She can't have cows milk or normal formula she needs to have soymilk.

Written in 2008 by Lila-May's mom, Leanne Brooks (Australia)



Jeremiah Deskins

9/27/07 – 1/12/08

At the routine five-month ultrasound, it was determined that Jeremiah was a boy, and there were some issues. It was first thought Jeremiah had a heart condition and I was sent to OSU for a diagnosis. It was deemed that Jeremiah had a Diaphragmatic hernia, something neither I nor anyone I knew had ever heard of. The diaphragm is a large muscle that supports the lungs and also separates heart and lungs from stomach and bowel. Without this muscle in place, throughout gestation the stomach, bowel, and intestines grew to take up the left side chest space where the heart and lung where supposed to form later in gestation. It is impossible to determine the extent of damage or the outcomes of these babies until they are born. You can be given predictions or best estimates through ultrasound and fetal MRI. Even those are not reliable. I had an MRI and the results were not good. Jeremiah was given a thirty percent chance of survival to surgery. I was given the choice to abort. I remember the doctor at OSU asking me "Would you rather lose him now or lose him later?" After consideration, I decided to try everything I could. Sometimes miracles happen and this being my son I decided it was my job to ride this out with him. Sometimes being a parent isn't easy. It was planned I would have him at OSU and he would be transferred to Nationwide

Children's for treatment and surgery, which may need to involve ECMO, extracorporeal membrane oxygenation. Loosely defined, heart lung bypass to take his tired heart and unformed lung tissue out of the picture and mechanically draw blood out of his body, oxygenate it, and send it back in. This treatment has made strides in CDH care and outcomes, though not without risk. It can only be used on babies of a certain weight and can cause intracranial bleeding.

I had experienced some preterm labor due to a gallbladder infection and spontaneously spent some time hospitalized to keep him in utero as long as possible to let the right lung form as completely as it would. At 37 weeks we decided to induce because he had not grown in the past several weeks. He was born September 21st at 2:47 pm. He was moved to Children's immediately after. Once transferred, the neonatologists were having issues with stabilizing his blood pressure and oxygen saturations. They transfused him and replaced his ventilator to a high frequency oscillating ventilator to deliver smaller, faster breaths more often. He was given paralytic medication, Vecuronium, and several more meds to keep him comfortable. At the height of this, he was on 23 intravenous life support medications. One of these became a staple in his every-day regimen. Sildenafil, you may know it as Viagra, was given to him for pulmonary hypertension (high blood pressure). They also ran the respiratory therapy Nitric oxide in his vent. This helped relax his narrowed pulmonary vessels. This was another idea that kept us off ECMO.

While he was in his coma, I read a certain book to him that thousands of other kids probably have. It's called "God Gave Us You". I had always wanted him to know that he was special and just the way he was meant to be. I was thankful to be able to do this because for the first few days we weren't allowed to touch or talk to him. He was "stimulus sensitive", meaning noise and touch upset the delicate balance they were trying to maintain in him. If he got annoyed or scared, his heart rate and blood pressure would plummet and it would be another race to stabilize him again. This is quite common with CDH babies in the early stages.

The goal was that at some point they would be able to take him off some of these medications to do the hernia repair, but after 6 days it was clear that wasn't happening and his condition was deteriorating. In the past, it was thought that the hernia repair for these babies had to be done immediately after birth, but now the thinking is to stabilize them and give them the best chance at coming through with good timing. In Jeremiah's case, waiting for the right timing was difficult. He was on so many medications that they weren't sure he could handle surgery. They prefer not to do it on an oscillating ventilator either. There was a possibility that he may not wake up once he went under. It was time to try the surgery regardless. It was either don't do it and let him die, or go ahead and see how it goes. So, what do you do? We went ahead, and he did wake up. Several days after he was back on a regular vent, and the meds were dropping off. Jeremiah opened his eyes again at 11 days old. When they told me they were DC'ing the Vecuronium I sat in that room for 2 days waiting for him to wake up and see me. I knew it would take awhile for it to wear off, and I wasn't expecting him to do cartwheels or anything, I was just determined to be there when he woke up. Once he was awake, he was a constant character in the NICU. He demanded and got constant attention and began to develop a distinct personality for a child who had lived through so much.

He was -for the most part -taking off. We started NG tube feeds of breast milk and finally got rid of TPN (IV nutrition). All this being as complicated as it is, the worst thing about the NICU is when your child is seemingly healthy (in comparison to how they were) but then they have feeding issues. Some days he would bottle feed, and some days he made the nurses and I use his feeding tube. Sometimes he would even go all week feeding by mouth, only to quit again. He got his G tube then so that we could take our time and learn to bottle feed at home. He went in to surgery again to close his Wound-Vac. This was used because the internal organs were too large and the area of skin too small to close after his first surgery. Closing a hernia repair without adequate room can hasten re-herniation, a huge fear for CDH parents. After the Wound Vac closure, he had a Nissen fundoplication for severe esophageal reflux. Once all the surgeries were said and done, he finally came home 3 months to the day of his admission, Friday December 21st. He was home for 22 days leading a normal-for-us life and getting to just be a baby. He went to Christmas dinner the next day and met some extended family, though he mostly slept the whole time. We spent New Year's together, just me and him, and had a little . He went to the grocery store and Christmas shopping at Kohl's on the nicer days. We took him everywhere; feeding pump, oxygen tank and all. I suppose I should mention, he did wear his little teddy bear mask for threat of airborne germs, just in case any of his medical team is reading this. Everyone was instructed to gel their hands before touching him, too. And, obviously, no one argued with me!

All things considered, he led a nice life at home for the little while he was with us there. On Friday, January 11th Jeremiah somehow yanked out his G tube. It was a large orange tube that the surgeons had put in place before we came home. I took him to ER to have it replaced but there was an issue finding the right size. (It had been thrown around in conversation at clinics that his tube would be getting changed out to a Corpac, like every other kids', so I didn't think to bring in his huge orange tube. which complicated everything!) It took several hours and he was hungry, grouchy and probably a little uncomfortable from having various tubes placed and removed. He was tired when we went home and was on his feeding pump in the car. At home he slept on and off and whimpered a little while awake. I assumed he was just a little sore from the experience and didn't think much of it. He wasn't constantly crying and was able to get some sleep. At 10 that night, I restarted his feeds (he was on continuous feeds from 10pm to 6 am) and we went to

bed. I by all rights should have put his monitor on him, but he had been coming off his oxygen during the day and had not been apnic since the early days. I decided since he was finally asleep to leave him be and not undress him to rig him up.

I woke up to turn his feeding pump off at 5:30; I don't know why it was done early. He was awake and looking around. We went back to sleep. He died in his sleep somewhere between 6 and 7 o'clock the morning of Saturday January 12, in bed with Mommy. When I woke up, Jeremiah was looking over at me, with his little left eye half open and his hand in his mouth like usual. It looked like he honestly just gave out in his sleep. My first reaction was to start CPR, but I knew he was gone. When I gave him a breath, I heard the gurgle of fluid and could not get anything in. My mother tried to call the EMT's for me, but couldn't dial the phone. I called and told them he was gone, they assumed I didn't know what I was talking about and construed it as "he's not responding". I told her, "I've taken this boy's vitals a lot in our day, there is no pulse anywhere." I called my immediate family and they all came over to hold him and talk before they took him away. When we were done, my brother offered to walk him out to the squad, but I did it. I wonder how many neighbors in that apartment complex were looking out the window at us. Seeing a silent yet teary girl carrying her dead child to waiting medical personnel.

Later that day, my mother, brother and I went to the funeral home and bathed and dressed him. We took footprints and pictures.

On January 15, my mother, brother and I went with Jeremiah and the funeral attendant to the crematorium. I did not want to have to decide where to leave him in burial. With cremation, he comes with me wherever I end up. He was 4 days dead and in a little white box. I walked him in and took him to the oven myself. I carried him everywhere in life. If I carried him in and through, I was going to be the one to carry him out. That's a very bittersweet memory for me, and I'm glad I did it.

His memorial followed on the 18th. People I hadn't even met in person came. Jeremiah was there, in his little marble block with Cherubs on it. (The cherubs on his urn became a memorial tattoo on my chest that Saturday.) People from the hospital also made the trip, from Nurses to Chaplains to lactation consultants!

One true thing all special needs parents have in common are that we take nothing for granted. No smile or word or quirk is insubstantial. We take it all in and attempt to hard wire it into our memories. I was proud of my son, proud because he was a survivor. We had one hell of a story to tell together. In the early days, people who came to see him looked at him with absolute pity, but once he was home, it was undeniable that there was a baby underneath the equipment and medical jargon. I learned a whole new level of compassion from him that I never would have thought possible. I think a few people did. I have learned that when someone matters to you, let them know because you aren't guaranteed tomorrow. Even after seeing him go through so much and even expecting his death for so long, it was still a shock because in the end I thought he was okay.

I still don't know why things happened the way they did. I could have put him on the monitor, but if it was time for him to go, what good would it have done? He'd have either died with me struggling over him, died in the squad, or died on the crash cart. Maybe it's best he went silently with no fighting, in bed with me. Either way, I spend a lot of time beating myself up for that.

I could be angry, I could be angry about a lot. I could be angry with his father who never took the time to even meet him but called the day he died to get a death certificate for the child support office. I could be mad at God mostly. Mad that he gives something to take it away. But, I try to avoid those thoughts. I doubt God did anything in an attempt to hurt me, and good came from Jeremiah's life and death. That much good can't be overshadowed by negativity. So, I've decided that if I am miserable and angry, my son's life and death are for nothing. But, if I go on and try to help, tell his story and work to find a cause, then he left an impact that everyone can see. In that impact, I have made his struggle worthwhile. I think that's what it's all about, living a life that's worthwhile. His was only 3 month and 22 days long, but it was a worthwhile life. Why shouldn't mine be the same?

Written in 2008 by Andrew's mom, Tracey Burdette (MD, USA)



Trey Lamont Vance

5/31/04

We knew we were having a little boy and were very excited about his birth. We also knew we would name him Trey. Trey would be named after his cousin whom had passed tragically two years prior to his birth.

Trey was born at King Edward Memorial Hospital on Monday, May 31st, 2004 via c-section with breathing problems. This alerted the surgery team and nurses that there was a problem. Dr. Stephen West, Trey's pediatrician immediately became involved and two scenarios developed. Later, it was determined and confirmed that Trey had a midline hernia due to the fact that his diaphragm did not fully develop in the womb. X-rays showed a mass in his chest cavity that did not belong there. Upon further testing, it was discovered that his liver and a portion of his bowels were in his chest cavity due to the deformity of the diaphragm known as Congenital Diaphragmatic Hernia (CDH). It was then determined CDH could not be treated in Bermuda so plans were made to transport Trey to Children's Hospital Boston.

The medi-vac arrived in Bermuda at 8pm that evening and around 11pm the flight team came to collect Trey for transport to the medi-vac. Trey was placed in a portable incubator and connected to life support although he could breathe on his own. This step was taken as a precautionary measure by Trey's doctor to support his airway during the 1 ½ hour flight to Boston. Due to my having a c-section, Trey's father traveled with him on the air flight. I was not able to join them for several days until I had some recovery time under my belt.

Due to problems with the air flight plane, Trey and his dad never left Bermuda and they returned to the hospital in the wee hours of the morning in an attempt to leave again early the following morning. In the meantime, another plane and crew was dispatched to Bermuda to take Trey and his dad to Boston. Again, Trey and his dad left the hospital at 8am the following morning to travel to Children's Hospital Boston.

On arrival at the hospital in Boston, Trey's dad kept a constant vigil at his bedside despite not knowing exactly when the surgery would be performed. These were some very tense moments for me not being able to be there with Trey and not knowing if he would survive the intended surgery. More tests were run at Boston Children's and it was determined that Trey was not in any significant distress and his body had adapted to his organs being displaced including his heart which was displaced to the left significant by his liver and bowels being in his chest cavity. I received constant updates in Bermuda from my husband and made plans to travel to Boston on the Thursday after Trey was born with my sister Sherry.

I was released from the hospital on Thursday morning and arrived in Boston later that evening. I immediately headed to the hospital being pushed in a wheelchair by my sister and arrived to see Trey in isolation connected to many machines. It became very apparent that Trey's health was really at stake. I spent a few hours by Trey's side and retired to the hotel to return in the morning.

Friday morning we had the opportunity to meet the surgeons who would be performing Trey's surgery. We also had the opportunity to hold Trey for the first time despite him being connected to several machines and IV lines. This was also the day that Trey was scheduled for surgery but no specific time was given. We were advised when an operating theater became available Trey's personal care nurse would have to disconnect him from all stationary equipment and connect him to the portable equipment and transport him to the operating room in 15 minutes.

Holding Trey for the first time was a joyous and sad moment for my husband and I as we were unsure that Trey would survive the surgery. Trey's father's time was cut short as the call was received and Trey had to be in the operating room in 15 minutes. Trey reached the OR at 2pm and the surgeons and fellows came again to talk about the strategy of repairing his diaphragm.

The strategy was to pull the dislocated organs out of the chest cavity and put in the general vicinity of where they normally are within the body. His heart was to shift back to its normal position per the surgeons. To repair the hernia, a partial diaphragm would be created using gor-tex material, which was described to us as being similar to heavy raincoat material. The length of the surgery was not given as the surgeons wanted to take their time. Once the surgeons had 'opened up' Trey they would figure out the best way to perform what needed to be done.

In the family waiting room we gave contact details to the liaison nurse and returned in one hour for an update. One hour passed and no incision was made. The surgeons, had however, established a good IV line and inserted the epidural, which would be his source of pain control. We reported back in another two hours and the incision had finally been made at 5pm. At 6pm, one of the fellows came out of the operating room and gave us an update on the progress of the surgery. All of Trey's organs had been placed in their general vicinity and settled in their correct place as expected. His heart had shifted to its correct position and they were working on the repair of the diaphragm. The repair was larger than the surgeons expected and would look similar to sunglasses. At 7pm the head surgeon, Dr. Jay Wilson and another fellow came out of the operating room and advised the operation was completed and was a success. They commented that throughout the procedure Trey's heart rate and blood pressure never dropped which was a very good thing. Our prayers had been answered but he was not out of the woods yet.

We were able to see Trey about 1 ½ hours later in the NICU (neonatal unit intensive care unit). He was still under heavy sedation, which he had been since his departure from Bermuda and now he was on the road to recovery and awareness.

On Saturday, my family and my husband's family traveled from DC & NY to visit. Many tears were shed as they visited with a small, swollen, sedated baby boy connected to many machines. The very next day when we arrived for our visit, Trey was disconnected from all the machines except one IV for nutrition and the epidural for pain control. The surgeons had started to slowly wean him off the sedation drug as well. My sister was due to return to Bermuda in two days, but she wanted to see Trey open his eyes and he did so on Tuesday but he was still groggy. She left Wednesday and Trey was completely awake and taking in his world for the first time since being sedated. He was very alert and actively trying to remove his IV line. To prevent Trey from removing his IV line his hands were wrapped up. Slowly Trey was weaned off all IV lines and we attempted to feed him breast milk via a feeding tube through his nose, which feed directly to his stomach. Feeding Trey didn't go very well and became a stressful time for us as parents.

Very early, the following morning we received a call from one of the fellows requesting that they establish another IV line for nutrition in Trey's neck because all his other sites had been "blown" and were inaccessible. We agreed as the feeding of breast milk was not going well. Upon our arrival that morning at Trey's bedside I noticed that some of his hair was gone and I questioned his nurse, and she explained they had shaved the hair and kept it for me so that they could find the vein in Trey's head to establish the IV in his neck.

Feeding was slow as Trey did not know how to suck having been connected to a ventilator via his mouth, so this was a task. Slowly Trey became stronger and learned how to suckle and swallow his milk. He got stronger but had difficulty putting on weight and keeping it on. It also became apparent that Trey was well enough to be moved out of the NICU to a regular ward. This frightened us as he would no longer have a personal care nurse 24 hours a day, however, we would be able to spend the night in the room with Trey. A room became available and Trey said good-bye to his wonderful personal care nurses in the NICU. He met his new nurse and she was just as wonderful.

That night both my husband and I stayed in the room with Trey. My husband slept in the crib with Trey and I on a sofa chair. The cribs were big enough to allow an adult to sleep with the child. Trey stayed another few days on this ward and finally they disconnected him from the machine that monitored his heart rate, breathing and pulse. That night was a very restless night as we continually checked him to ensure he was breathing. Whilst on the machine if his respiratory rate became too low an alarm would sound and the nurse would check to ensure things were OK. Now we felt we had to monitor Trey like the machine and ensure he was breathing OK for our own piece of mind. At rest Trey's breathing became very shallow which caused us some concern.

Finally, Trey weighed enough to be released from the hospital but he had a follow up clinic appointment in a week's time so we stayed with friends in Boston before we got the OK to return to Bermuda. We returned home 3 weeks after Trey was born with a very frail baby on a commercial airline flight. He did very well and has excelled so far.

Trey has really grown and had a slight developmental delay, but we have sought the help of the local services here in Bermuda to help him in the areas he needed. Today, you would never believe that Trey had such a traumatic start to his life. He is such a Blessing to us today and we love him dearly! We will forever be indebted to the all the staff at Children's Hospital Boston.

Trey reached all of his necessary milestones and continues to do so. He's a happy and generally healthy boy. He loves to play and explore which is his favorite past time. Trey has not had any residual effects from his CDH and has had several check ups since which with Children's Hospital Boston and he continues to pass these checkups with flying colors.

Our miracle boy will live a normal, happy, healthy life and we thank no other one than God.

Written in 2008 by Trey's parents, Corey and Sandra Vance (Bermuda)



Dakota Cawvey

12/22/07

Me and my Husband were getting ready to have our 15 year Anniversary. (07) Then we found out I was pregnant. We were in shock and so happy. I even did 4 pregnancy test's thinking each one was wrong. We already had Mikala who was going on to 9 years old in June. With a miscarriage before and after Mikala, we were just so excited. I had an ultrasound in my first trimester to confirm the due date and then another one at 20 weeks. He told us that our baby had a diaphragmatic hernia. He explained how the hole had allowed his intestines/stomach to enter his chest, which had caused his left lung to be compressed, and his heart to shift to the right, and that his chances of surviving the surgery were 50/50. All I could do was cry and try to comprehend what he was telling me and my mom. My sister was in the waiting room and when we came out, me and my mom were both crying, we just kept saying he has a hole in his side. I don't think we heard one word the Doctor said to us. The only thing I heard was, it's a boy, and 50/50.

I had to go to Loyola to see a team of OBGYN Specialists and have another level 2 ultrasound. The news we got from them was even worse. They told us he only had a 4% chance of surviving or could go into heart failure and die, and that we could terminate the pregnancy. While crying from this news, me and my husband both said NO.

So during the rest of my pregnancy, I had weekly ultrasounds, fetal echo's and fetal non-stress tests. They got us in touch with the Doctors from the NICU and we talked to them about what they could do for Dakota after he was born. Problem was they did not have an ECMO (temporary heart/lung bypass machine). So our plan was to have Dakota there at Loyola and if ECMO was needed they could transport him to Chicago's children's Memorial. Around 11 Months I went into Labor and we rushed to Loyola. The Doctor's did not want him to be born so soon and for him to stay put till he was full term. They said I had 46% water when I should have less, This was due to the baby peeing and not swallowing like a healthy baby would do, this had to do with his CDH. They put me on bed rest and I had to take medicines to stop the contractions.

On 12-2-08 4:07 AM. Dakota was born emergency C-section. He let out 2 cries and was taken to the other side of the room where about 17 NICU Doctors waited for him. Sadly I never got to hold him. We had our Camera and a nurse went and took 3 pictures of him and I then got to see him that way. During the rest of the morning my Husband was with Dakota in the NICU. By 11:30am, the NICU Doctor came to talk to me, saying Dakota was stable and they were concerned he needed ECMO. So Chicago's Children's Memorial Ground Transport Team arrived to the NICU. I asked my Husband to go see if they could bring him to my room before they left with him. They had no problem with that. And by 1:00pm, they came in my room with Dakota in a small portable transporter along with My Mom, Sister Corie, My Husband and Mikala and my niece Madison. I sat in the bed crying as I got to hold his hand through the hole in the transporter. I kept telling him, Mommy's here Dakota and I love you so much. My Husband got to ride with them to Chicago's Children's Memorial. I told him not to leave Dakota's side and to keep calling me on what's going on. The first 3 days, they told my husband that he seemed to be going the opposite

direction of needing ECMO. But this was just what they called the honeymoon stage. There is a duct in the heart that closes after a few days. Once his closed, this is when he started getting worse.

When I got to leave Loyola on my 3rd day we rushed right to Children's to see Dakota. I could not wait to see him, thinking I would be able to kiss him and hold his hand. When we got to his room I just started crying seeing him laying there. He had this ventilator in his mouth, his body was being shaken by a machine they call the oscillator, with all kinds of things hooked up to him. I was in shock and was standing by his bedside crying. One of the Doctors came over and got me a chair to sit on, because I was close to fainting. That's when they started talking to us saying Dakota was getting worse and needed ECMO. We signed the papers, and in just minutes, they had O.R. In his room and got him on ECMO.

We were so glad that the 1st time they weaned him down on ECMO, he did great and so he was only on ECMO 9 days. The day after he was off of ECMO and the oscillator, and put on a regular ventilator. The doctors got very concerned because he was moving back words again. They put him back on the oscillator, while giving him a medicine that opened the Duct in his heart to help with the pulmonary hypertension (severe pressure in his chest) and it worked. He was doing great again. The doctors then were on stand by for the open window to do his Surgery. He was so puffy and had so much fluid on him, that they thought it was best to wait until he was stable and having no other set backs. As of 12-31-07 he had lost all the extra fluid he had on him and they set the date for his surgery 1-3-08!

His surgery lasted 2 hours and when the Doctor came in the waiting room to talk to us, He said that Dakota's hole in his diaphragm was so big that he had his small and large intestines/ stomach and spleen in his chest. He had to use a gortex patch to seal the hole. He told us that Dakota had some muscle in the back but none in the front, so he had to attach the gortex patch to part of his ribs. He told us that Dakota was a very lucky baby and that he was surprised he lasted as long as he did. When the Doctor told us this I cried tears of joy, saying to my husband that the power of prayer is a very powerful thing. And of course, thank God for the Doctors for keeping him alive and with us. We found out also the next day that Dakota's left lung is close to a normal size, that he had more lung mass then they thought he had. Out of all of this, the hardest thing has been trying to get Dakota off of the ventilator. The 1st try only lasted 3 days with a C-pap in his nose. The second try he lasted one day and the third try was not even 3 hours. His blood gases would not come back so good, and in the end they had to take a small camera down his throat to see what was wrong.

They found out he had floppy airways called Tracheomalacia and Bronchomalacia. So they had to do a Tracheotomy (trach) in his neck. At first when they ran this by us we were not so sure about this idea. The doctors told us this was the only way to help him breathe without gagging. And that keeping the ventilator in his mouth was not a good idea.

He is a more happy baby since he has had the Trach and even with the ventilator on his Trach, Its great seeing his full face. Dakota is now 4 months old and very close to coming home. We are getting trained on how to take care of him. We have also learned that Dakota's heart has moved to where it should be. (to the left in place) and his lungs are still doing great. He has a feeding tube and they don't think it's a good idea to do the one in his side. So the feeding tube stays in his nose. Over all, he's a very very happy baby and loves to smile and has a lot of girlfriends in the NICU and now on the TCU 9Th floor.

Written in 2008 by Dakota's mom, Beverly Cawvey (IL, USA)

Parade of Cherubs



Join CHERUBS as we raise Congenital Diaphragmatic Hernia across the country during the 2010 holiday season by marching in Christmas parades! Dress your cherubs up, create a float, hand out ribbons or flyers!

Join us in Raleigh, North Carolina as we march in the televised parade in front of 1000's on our "Save the Cherubs" float. CDH survivors and siblings are welcome to ride! Or create your own parade team in your town!

Hold a bake sale, car wash or other fundraiser to raise parade entry fees. Then buy / make some wings and march! Vistaprint.com offers extremely affordable banners, flyers and shirts.

Make sure to send in your photos!

Come see how some CDH families are raising funds for CHERUBS on Firstgiving!!!! You can get a FREE fundraising page for your cherub also! Thank you all so much for helping up to help families affected by Congenital Diaphragmatic Hernia!

Brienna Jaburg has raised over \$2000 so far for cherub Elijah's birthday. Wow, Brienna, WTG!!!!!! We need to get you on our Fundraising Committee! :)
<http://www.firstgiving.com/briennajaburg>

Desiree is raising money in memory of Marley Jane -
<http://www.firstgiving.com/desireecasillas>

Kim is raising money in memory of Asher - <http://www.firstgiving.com/babyasher>

Kara is raising money in honor of Adam - <http://www.firstgiving.com/karahess1>

Dawn is money in memory of Shane - <http://www.firstgiving.com/shanetorrence>

Barb is raising money in honor of Logan -
<http://www.firstgiving.com/loganscdhfundraiser>

Paige is raising money in memory of Caleb - <http://www.firstgiving.com/paigecox>

Allison is raising money in honor of Baby Forte -
<http://www.firstgiving.com/babyforte>

Bessie raising money in memory of Emily -
<http://www.firstgiving.com/bessiebatton>

Elizabeth is raising money in honor of Isabel -
<http://www.firstgiving.com/isabelruth>

Heidi is raising money in honor of Julia - <http://www.firstgiving.com/juliaqcarlson>

Megan is raising money in honor of Alyssa -
<http://www.firstgiving.com/honoralyssa>

Stephanie is raising money in honor of Cody -
<http://www.firstgiving.com/codyajmaerten>

The Decker Family is raising money in honor of Angelina -
<http://www.firstgiving.com/angelinadecker>

Photos of Cherubs



Ethan Paul Smith



Chloe Tate



Jordan James Knight



Xavier Mumaw



Quinn Erin McComb



Toby Pickstock



Ciaran Baggett



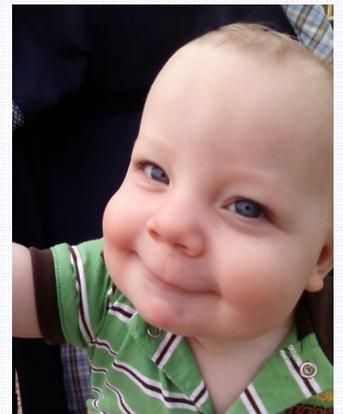
Alicia Rose Curwain



Christopher Rodriguez



Scarlett Benitez



Owen-Logan Gage

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We are looking for more Representatives and also Hospital Angels (on-call parents for CDH hospitals). If you would like to volunteer please contact us at volunteer@cdhsupport.org

We have many volunteer positions available. You can donate a few hours a month or a few hours a day!

More information can be found on our web site at <http://www.cdhvolunteers.org>

On-Call Volunteers to Lend an Ear or Shoulder:

On-Call	Name	Phone Number
Expectant Parents	Dawn Williamson	919-610-0129
Grieving Parents	Freedom Green	603-465-3311
Grieving Parents	Karen Myers	210-403-3483
Grieving Parents	Troy Miller	919-358-3711
Survivors	Brenda Johnson	651-460-4605
Survivors	Tara Hall	614-937-6998
Adult Survivors	Elizabeth Lopez	919-360-1728