



CHERUBS New Web Site!

www.cdhsupport.org

**CHERUBS - The Association of
Congenital Diaphragmatic Hernia
Research, Advocacy and Support**

Dear Members,

It is with my great pleasure that I write to you to introduce you to CHERUBS once again.

CHERUBS has undergone some major changes and continues to do so. Now 12 years old, CHERUBS has over 2000 members in 36 countries. CHERUBS UK now has Non-Profit Status and CHERUBS Australia has filed the necessary paperwork also. We are so proud of both of these groups! Our Ohio group also held a picnic this year and our Michigan group will meet this month. It was such a pleasure to meet so many members in Ohio. Hat's off to Tara Hall for holding the Ohio picnic for 7 straight years and it's always such a success and a source of support for so many members. We have many new Representatives but also need more. Please consider volunteering if your state or country is not represented.

We have a few business changes here at CHERUBS also. We are becoming Incorporated as of January 1, 2008. This will create more grant opportunities for us as well as give us more legal protection. We have several new Board Members, including Betty Mekdeci from Birth Defects Research For Children, Inc., attorney M. Shane Perry and our new accountant, David Cochran. We also welcome Amy Rademaker, our new Secretary and New Member Coordinator. We have so many new volunteers and are so thankful for all that

they do! Thank you, each of you.

We have a new web site! We worked hard on this site and thanks to a generous donation in memory of Jonathan Luke Rademaker, we were able to hire a programmer to create so many new on-line services for our members. You can see a list to the right of all the great features we can now offer parents through the internet.

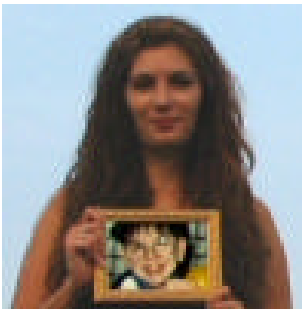
We have so many plans for 2008 and beyond and our new web site is just the tip of the iceberg. We are planning an Angel Ball and Golf Tournament in Raleigh for late spring, an International CHERUBS Member Conference, several state get-togethers, a few new logos, an Awareness Ribbon, and a long list of awareness and fundraising activities..

Our Parent Reference Guide has been updated and is downloadable from our web site. Our CDH Research Survey tabulations will begin in January.

Most importantly, CHERUBS is still here, still busy and still bringing awareness to CDH and support to the families affected by it. It is my privilege to be

part of such a wonderful group of people striving together to help each other and to find the cause and prevention of Congenital Diaphragmatic Hernia.

Sincerely,
Dawn M. Torrence,
President & Founder



**Dawn Torrence with a
photo of her cherub,
Shane Torrence**

Volume XII, Issue 1

Fall, 2007

CHERUBS New Web Site Offerings:

- Free Membership
- Member Forum
- Member Blogs
- Personal Member Photo Albums
- Monthly Chats
- Member Instant Message Network
- The Silver Lining Newsletter
- 100's of Stories of CDH Cherubs
- Downloadable Printed Materials
- CDH Research Article Library
- Current List of CHERUBS Volunteers and State & International Representatives
- Link Library
- Event Calendar
- Cherub Birthday & Anniversary Calendar
- CHERUBS Fundraising Items
- On-Line Donations
- 24 hour, 7 a week support from other members



CHERUBS

"The Silver Lining" Newsletter

**CHERUBS - The Association of
Congenital Diaphragmatic Hernia
Research, Advocacy and Support**
270 Coley Rd. ~ Henderson, NC 27537, USA
252.492.6003 ~ www.cdhsupport.org

As the end of the tax year approaches, please remember CHERUBS. We depend solely on donations and volunteers to continue our work.

CHERUBS Would Like To Welcome The Families Of The Following

Tarquin Mikhail Adcock
Marin Allan
Erik Blandford Anderson
Katherine Anderson
David Valera Angil
Baby Ashner
Victoria Marie Ayscue
Ines Bahurel
Noah D. Baker
Elizabeth Ballenger
Jessica Barry
Gracie Elizabeth Bell
Baby Benjamin
Baby Betts
Nathan Lee Bevan
Jayden Lee Blackshear
Joel Archie Jed Abel Blakley
Levi Daniel Blanchard
Kynlee B Bowlin
Devin J Breneman
christan I Brownfield
Patience Kay Lee Burnett
Camden Buzzell
Jesse Draper Byington
Jordanna Liberty Byleveld
Braden Ryan Cahalan
William Calabria
Brooklyn Shane Caldwell
Jacob Allen Cambre
Logan James Campbell
Tyrell James Campbell
Jessica Christina Canfield

Andy J Car
Miles Whalen Lloyd Chamberlain
Joe Richard Champagne
Brayden Isaac Cleghorn
Jason Anthony Collins
Sarah Violet Collins
Cadence Skyler Corkins
Lillith Kaidence Cory
Santania Wynette Courtney
Sarah Jane Crawford
Shannon Elizabeth Crawford
Catalina Cruz
Addisen Noel Curtis
Alyssa Murann Czarniecki
Christopher Lloyd Czarniecki
Tyler Ray Czarniecki
Laney Kate Daniels
Isaac Shire Dardzinski
Baby Davenport
Angelina Sierra Decker
Jeremiah Isaac Deskins
Anthony Jake Dicesare
Ally Rosina Dorrington
Rebecca Sarah Ellis
Noah Reagan Engebretson
Isabella Grace Ferrone
David Andrew Finkel
Candis Nakole Forman
Aidan Robert James Fraser
Daniel Bradley Gallagher
Ariana Sophia Gebow
Jack Ryan Gillham
Vivian Michelle Glennie
Serra Meghan Golden
Annabelle Marie Gomez
John David Gonzaba
Juan P Gonzalez
Pamela Montzerra Gonzalez -
Jimenez
Chance Green
Jacob Green
Grace M Greene
Celeste Hall
Taylor-Lynn Faith Halter-Rowley
Jacob Owain Hamrick
Taison Stone Harris
Madeline Joy Hausmann
Ira Lester Hays
Lila M Henry

Adam Charles Hess
Ethan Tyler Hess
John Clinton Deloux
Hollingsworth
Mattson Edward Houghton
Claire Noel Jackson
Floris Jansen
Ella Järlid
Derek Quinton Jarvis
Alexandria Katelyn Job
Erin L Jolivette
Landon Earl Jones
Logan Kasey Kessler
Gabriel Reza Kia
Christian P Kime
Logan King
Baby Kittel
Levi David Klassen
William Gregory Klinzing
Jordan James Knight
Andrew Ronald Kranzer
Eli Michael Krejci
Logan J. Kremer
Alexander Christopher Kruger
Sarah Belle Kuck
David D Lari
Aidan Gustavo Leibe
Tracey Lynn Lesner
Trenton Michael Lewis
Max Matteo Logozzo
Abigail Taylor Long
Juan Pablo Lopez Arce
Michael Joseph Lovejoy
Brian Lukkasson
Dalton Kirk Lunick
Baby Magee
John T Magguire
Isaac Mason Marsden
Lewis James Marshall
Isabella May Mason
Cameron J Matthews
Adrias McCarty
Colton J. McClure
Leon Patrick McDermid
Quinn Walker McGinnis
Marshall James McLennan
Joseph Patrick McPherson
Ian Wesley Meats
Gage Austin Mehle

Nathaniel Edward Melendrez
Leanne Elizabeth Meyer
Drake Alexander Michel
Faith Grace Miles
Ellie J. Miller
Hayley Caitlin Mills
Jonathan Cole Mitchell
Mason Theodore Mitchell
Peyton Elizabeth Mitzner
Baby Moloney
Kaylaya Arissa Morgan
Devon Morrow
Christopher David Murray
Gabriel Eric Nava
Owen Isaac Nelson-Looney
Clayton Dean Nunley
Jacob Oliver Ogilvie
Shelby Grace Olivarez
Emerson Rose Oliveri
Connor James Otero
Jacob Andrew Pagliarulo
Jonathan Nicholas Panetta
Weslee Raymond Paxson
Trey R. Powell
Liviana Estelle Price
Garrett Prince
Riley Jane Prochaska
Lily Elaine Quinn
Kathryn Victoria Randall
Riley Violet Redman
Emily Margaret Reed
Angela Kirstin Reedell
Jacob Thomas Reinhardt
Xena Michelle Robertson
Dominic James Rochon
Thomas Robert Blaine Rodgers
Kellan Floyd Rogers
Kayla Nicole Rubio
Bennett Ericson Rupert
Graham Walter Russell
Madeline Jo Rutheford
Rhea Lee Ruvala
Andrew Christopher Ryan
Sabrina Danielle Sachs
Landen James Sakshaug
Dante Lee Saldana
Braedon Hart Salinas
Mateo Santos
Blake E. Schauerermann



More New Members

Little Dee C Scheibly
Allison Faith Schmaltz
Jonah Michael Schmidt
Jesse S Sellen
Steven D Senesky
Payton Rose Shoemaker
Ethan Paul Smith
Jaxtyn Smith
Mathew Thomas Smith
Jarlene Faith Solangon
Sara J. Soltis
Baby Sorenson
Jordan D Spearman
Bryston Spohr
Chase Daniel Steiner
Luke Dylan Stevens
Zoe Amelia Stevenson
Soraya Stevenson Hays
Connor Gerald Sullivan
Hope Analise Magenta Sunseri
Asher James Switzer-McCoy
Chance Mckenna Talamantez

Kristen Marie Taylor
Sophia J. Thacyk-Cho
Alexander Frances Thalmann
Mia Anne Thiessen
Benjamin N. Toth
Aiden Zach Scott Towner
Nicholas Gilbert Treska
Emma Louise Van Cant
Kaylee Naomi Van Ede
Mckenna Lynne Varen
Baby Vaughn
Marco Vellutini
Dakota Mae Vosse
Aiden Jason Wade
Baby Walsh
Baby Gary Wallace
Chastity Auron White
Abigail Williams
Claire Elizabeth Williams
Gracie Jo Wilson
Neyo James Winkel
Baby Wyatt



Thanks to everyone's prayers and the Lord's Gift of Healing touch. Let us bring our butterfly home, that we all love so much. Daddy loves you Shelby.

You can become a Newsletter Angel by sponsoring or partly sponsoring the printing and mailing costs for an issue of our "Silver Lining Newsletter". Contact us to find out more about becoming a Newsletter Angel.

Newsletter Angel

This newsletter is partly sponsored by a donation made by Shane and Stephanie Oliverez, in honor of their daughter, cherub Shelby Oliverez. The following poem was written by Shelby's father, Shane Oliverez.

My Butterfly
My daughter Shelby who fluttered in our life.
Brought great joy to everyone- including me and my wife.
This is one butterfly that will not get away.
Our little Shelby is here to stay.
What a rough start she had begun.
Had brought our two families together as one.

Just A Few of The Items For Sale On Our Site

www.cdhsupport.org



We Would Like To Thank The Following For Their Help:

Heidi Cadwell
David Cochran, CPA
Lise Dill
Alyssa Hagen
Tara Hall
Lynne Hedrick
Kara Hess
Dawn Irons
Danielle Kessner
Jana Lewallen
Betty Mekdeci
Elaine Moats

Corin Nava
Jeanne Nava
Stephanie Olivarez
M. Shane Perry, PLLC
Teri Prochaska
Amy Rademaker
Kimberly Richards
Denise Richer
Deanna Shoemaker
Darlene Silverman
Brenda Slavin
Sheri Smith

Heather Southwell
Tammy Spohr
Judi Toth
Michelle Towner
Barbara Wagner
Dave and Jean Williamson
Children's Hospital of Philadelphia
Cincinnati Children's Hospital
Boston Children's Hospital
Brigham and Young Hospital
University of California Fetal Treatment Center
All of our Wonderful CHERUBS Volunteers!

Letters to CHERUBS

Removed upon request by author

Good morning Mr Torrence,

My name is Gianluca Venanzi, I'm the father of Agnese Benedetta. She was born with CDH in November 2005. Today Agnese is really fine.

In 2006 I founded the web site www.erniadiaframmatica.it, the first Italian web site dedicated to CDH. In 2007 I also founded an organization named FaBED (Famiglie di Bambini con Ernia Diaframmatica - Family of Child born with CDH). At present moment we work in cooperation with some Hospitals and some Medical Reserch Centres.

We have many members, such as doctors (probably among the best in Italy for CDH), parents and friends.

I will be very pleased to collaborate with you..

Waiting for your kind reply I remain, with the best regards

Gianluca Venanzi (Italy)

Dawn,

Congratulations on the new site. It looks great. You are amazing to stick with this important project thru thick and thin. Good idea to try to link your meeting with the APSA meeting. I will ask to arrange the links with both our Ped Surg site and our Fetal Treatment Center site. Good luck.

Michael Harrison, MD

University of California San Francisco



Dear CHERUBS,

Hi! I am Diego from Guatemala and i am writing, because we have a son that was born with CDH last year. I never had heard about it when we were told of the problem when mi wife was on her fifth month. At first the

doctors were not sure of what the problem was, but also a doctor specialized in problematic pregnancies from Mexico that was in the city he made a ultrasound and verified the problem. To make it short! We decided to go to Mexico City after trying to contact to different hospitals in the USA, but not even with the insurance i could ever pay such a big bill! So he was born in Mexico City, the doctors over there made a great job and right now he has 1 year and he is fine. Maybe later i could do something about giving more information to the people over here about these problems, so that in every case they can have a guidance of where to go, what to do and have a support!

Just by talking to someone about it that has gone through it makes you feel better.

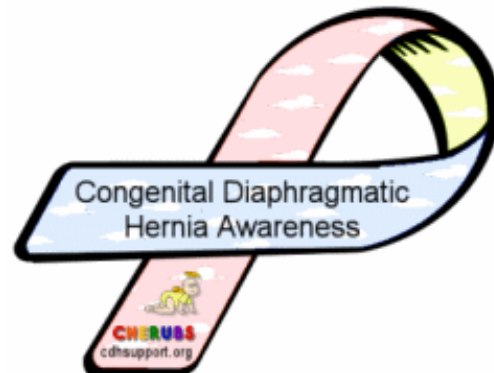
I almost lost my job because of taking so much time off in Mexico helping my wife. We had to go over so many changes and so many things that affected our entire life and it is hard to go through it. We also have a daughter now she is about to be 4 years old, and it was so incredible how she would make us feel better and told us all the time not to worry! We really did everything we could not to let him die, and pray so much! God was good to us and let our angel stay with us. I just wanted to tell you these story, because no so long ago, but after we went thought these i found in the internet these webpage and i think is great and that you all are doing a good job. There should be more of these everywhere and more information about it also. Theres always information about cancer and HIV, but never about these. So i also would like to keep in touch and if you have recent information about new ways to avoid or operate these with a much lower risk i would like to know and to give these information to all the people that needs it. I will send you a picture of the whole family! Blessings to everyone!

Diego Saravia and Family

New Fundraising & Awareness Activities

[visit our web site for more information](#)

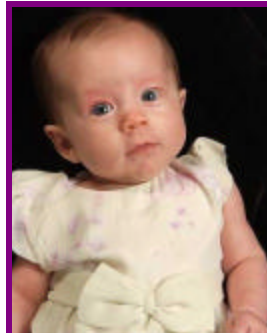
- | | |
|--------------------------------|---------------------------------|
| Angels for CHERUBS Campaign | Awareness Ribbons |
| New More Masculine Logos | Awareness Jewelry |
| 1000's of items in our E-Store | Awareness Clothing |
| CHERUBS Lullaby CD | Children's Books |
| CHERUBS Member Yearbook | CHERUBS T-Shirts |
| Golf Tournament | Adopt A Cherub Link Program |
| CDH Info Packet Parties | Cooking With Cherubs Cook-books |
| Local Fundraisers | Car Magnets & Bumper Stick |
| Car Washes | Web Site Posting Contest |
| Event Sponsorship Drives | CHERUBS on Myspace.com |
| Donations Jars | CHERUBS on Facebook.com |
| Cherub / Cupid Posters | CHERUBS New Web Site |
| Ebay Auctions | Upcoming CDH Research Site |
| Celebrity Auction | Downloadable Printed Materials |
| Parent Reference Guide Blitz | |
| Local Newspaper & Media Blitz | |
| New Member Drive | |
| Web Site Posting Contest | |
| CHERUBS Angel Ball | |
| Stories of Cherubs Book | |
| Operation Contact Hospitals | |
| Holiday Raffles | |
| Holiday Card Contest | |
| Baby Books | |
| Truffle / Bake Sales | |



2007 Donations to CHERUBS

In Memory Of:

- Abigail Davi - Veronica Silacci
- Abigail Taylor Long - Angela Freeman
- Abigail Taylor Long - Angie Williams
- Abigail Taylor Long - Betty J. Martin
- Abigail Taylor Long - Brenda and Kevin Brown
- Abigail Taylor Long - Bruce Eskew Family
- Abigail Taylor Long - Catherine and Michael Conklin
- Abigail Taylor Long - Dennis and Kathleen Long
- Abigail Taylor Long - Donna Mills
- Abigail Taylor Long - Douglas Taylor
- Abigail Taylor Long - Edward and Dorothy Irvin
- Abigail Taylor Long - Elizabeth Johnson
- Abigail Taylor Long - Jeffrey Cook
- Abigail Taylor Long - Joel Reese
- Abigail Taylor Long - Joseph and Maryann Cronin
- Abigail Taylor Long - Ken Zearfoss
- Abigail Taylor Long - Kimberly Belk
- Abigail Taylor Long - Maureen and David Melson
- Abigail Taylor Long - Michael and June Ruff
- Abigail Taylor Long - Shelly Mixson
- Abigail Taylor Long - Stephanie and David Cowan
- Abigail Taylor Long - Suzette and Allen Guest
- Abigail Taylor Long - Turner and Kathryn Wood
- Anslie Barnhill - Gerald and Maxine Grubbs
- Asher James Switzer-McCoy - Kimberly Switzer & Evan McCoy
- Brandon Michael Sheintul - The Baldwin Middle School Chapter of the National Junior Honor Society
- Carey David Niesen - Century 21 Arizona Foothills
- Carey David Niesen - Jill LeRoy
- Carey David Niesen - Karen Longtin
- Carey David Niesen - Marci Hageman
- Carey David Niesen - Tracy D Walter
- Colin Verweil - Mark and Ann Verwiel
- Daniel Latchford - Norman and Sandra Taylor
- Daniel Latchford - Sandra Taylor
- Hannah Elizabeth Svoboda - Julie Svoboda
- Isaac Shire Dardzinski - Cincinnati Childrens Hospital Medical Center, Dept. of Radiology
- Johnathan Luke Rademaker - Pete and Amy Rademaker
- Landen James Sakshaug - Kristin Morrow
- Lily Grace McDonald - Alison Conneally
- Lily Grace McDonald - Brian and Christina McGaffin
- Lily Grace McDonald - John and Beverly McDonald
- McKenna Lynne Varen - Alyssa Hagen
- Olivia Richards & her grandfather, Timothy K. Glynn - Charles and Kimberly Richards
- Olivia Richards & her grandfather, Timothy K. Glynn - Claud and Marion Kilbreath
- Olivia Richards & her grandfather, Timothy K. Glynn - Joel and Virginia Winter



Claire E. Williams
2007-06-07

- Olivia Richards & her grandfather, Timothy K. Glynn - Kreg and Elisa Hasse
- Olivia Richards & her grandfather, Timothy K. Glynn - Peter and Carol Glynn
 - Sarah Belle Kuck - Charles and Carol Iten
 - Sarah Belle Kuck - Diana Jones
 - Sarah Bell Kuck - Frances K. Eads
 - Sarah Bell Kuck - Mark & Lynn Murphy
 - Sarah Bell Kuck - Reed Bilbray
 - Shane Torrence - CIT
 - Shane Torrence - Craig Williamson
 - Shane Torrence - Dawn M. Torrence
 - Victoria Marie Ayscue - Kimberly Ayscue

In Honor Of:

- Adam Hess - Chuck, Kara and Aaron Hess
- Alex - Bichlien and Can Hoang
- Allison Lane Pruitt - Pamela Pruitt
- Bethany Taylor Abaurrea - Raymond & Heidi Abaurrea
- Brandon and Alyssa Thornhill & their cherub - Andrea Garner
- Brandon James Hall - Jeff and Tara Hall
- Izabella Grace Rogers - Nicole Buuck
- Jenna Rose Dayton - Col. Hugh and Beverly Dayton
- Jordan Spearman - Jennifer Luning
Caitlin Elizabeth Breen - Kathleen and Charles Breen
- Kristin Marie Moats - Brett and Elaine Moats
- Laura Condry McFatter
- Marissa Herman - Janet Sullivan
- Mattson Edward Houghton - Christopher & Shyra Houghton
- Patrick M. Perala - Scott & Jennifer Perala
- Ross Vosburg - Bob and Barbara Vosburg
- Shelby Olivarez - Shane & Stephanie Olivarez



Joel A. J. A. Blakley
2006-04-06 - 2006-04-06

Additional Donations:

- Mapes Stores
- Black River F W B Church
- Judith Peters
- Kristin Purdue
- Lori Knight
- Mapes Stores
- Pamela Lowin
- Sandra Taylor
- Barry Cooper
- America's Charities
- Wayland High School National Anti-Darkness Society, Inc.
- Abbot Laboratories Employee Giving Campaign



Kaleigh Marie Myers
2002-07-30 - 2002-08-16

This Newsletter Is Dedicated To The Memories of:

Tarquin Mikhail Adcock	Ally Rosina Dorrington	Daniel John Latchford	Dominic James Rochon
Katherine Anderson	Noah Reagan Engebretson	Aidan Gustavo Leibe	Mateo Santos
Victoria Marie Ayscue	Candis Nakole Forman	Max Matteo Logozzo	Allison Faith Schmaltz
Gracie Elizabeth Bell	Jack Ryan Gillham	Abigail Taylor Long	Payton Rose Shoemaker
Nathan Lee Bevan	Annabelle Marie Gomez	Lewis James Marshall	Ethan Paul Smith
Joel Archie Jed Abel Blakley	Chance Green	Cameron J Matthews	Makenzee Edell Spencer
Alan J. Brown	Jacob Green	Leon Patrick McDermid	Chase Daniel Steiner
Jesse Draper Byington	Ethan Tyler Hess	Quinn Walker McGinnis	Asher James Switzer-Mccoy
Braden Ryan Cahalan	John Clinton Deloux Hollingsworth	Marshall James McLennan	Chance Mckenna Talamantez
William Calabria	Derek Q Jarvis	Joseph Patrick McPherson	Alexander Frances Thalmann
Logan James Campbell	Alexandria Katelyn Job	Hayley Caitlin Mills	Mia Anne Thiessen
Shannon Elizabeth Crawford	Levi David Klassen	Gabriel Eric Nava	Aiden Zach Scott Towner
Sarah Jane Crawford	William Gregory Klinzing	Owen Isaac Nelson-Looney	Mckenna Lynne Varen
Christopher Lloyd Czarnecki	Jordan James Knight	Jacob Oliver Ogilvie	Marco Vellutini
Alyssa, Murann Czarnecki	Eli Michael Krejci	Weslee Raymond Paxson	Dakota Mae Vosse
Tyler Ray Czarnecki	Alexander Christopher Kruger	Trey R. Powell	Aiden Jason Wade
Isaac Shire Dardzinski	Sarah Belle Kuck	Kathryn Victoria Randall	Chastity Auron White

We Would Like To Welcome The Following New Babies:

(*Siblings)	Celeste Hall	Weslee Raymond Paxson
Diego Alejandro Adame*	Shelby-Lea Hamrick*	Trey R. Powell
Guage Michael Allen	Lila M Henry	Riley Jane Prochaska
Ines F Bahurel	Adam Charles Hess	Kathryn Victoria Randall
Gracie Elizabeth Bell	John Clinton Deloux Hollingsworth	Riley Violet Redman
Nathan Lee Bevan	Ella Järlid	Leon Patrick McDermid Rice
Joel Archie Jed Abel Blakley	Logan Kasey Kessler	Kellan Floyd Rogers
Kynlee B Bowlin	Christian P Kime	Bennett Ericson Rupert
Patience Kay Lee Burnett	Levi David Klassen	Andrew Christopher Ryan
Braden Ryan Cahalan	Jordan James Knight	Sabrina Danielle Sachs
William Calabria	Alexander Christopher Kruger	Landen James Sakshaug
Logan James Campbell	Sarah Belle Kuck	Allison Faith Schmaltz
Cadence Skyler Corkins	Daniel John Latchford	Jonah Michael Schmidt
Sarah Jane Crawford	Dylan Leibe*	Ethan Paul Smith
Shannon Elizabeth Crawford	Trenton Michael Lewis	Chase Daniel Steiner
Tyler Ray Czarnecki	Abigail Taylor Long	Asher James Switzer-Mccoy
Laney Kate Daniels	Juan Pablo Lopez Arce	Chance Mckenna Talamantez
Isaac Shire Dardzinski	Michael Joseph Lovejoy	Kristen Marie Taylor
Ally Rosina Dorrington	Lewis James Marshall	Nicole Grace Tennyson
Noah Reagan Engebretson	Leon Patrick McDermid	Mia Anne Thiessen
Jack David Evans*	Quinn Walker McGinnis	Emma Louise Van Cant
Isabella Grace Ferrone	Nathaniel Edward Melendrez	Kaylee Naomi Van Ede
David Andrew Finkel	Ellie J. Miller	Mckenna Lynne Varen
Mason C. Flax	Owen James Miller	Marco Vellutini
Aidan Robert James Fraser	Mason Theodore Mitchell	Dakota Mae Vosse
Jack Ryan Gillham	Ethan Moloney	Aiden Jason Wade
Annabelle Marie Gomez Gabriel Reza Kia	Luke Moloney*	Halle Warner*
Juan P Gonzalez	Kaylaya Arissa Morgan	Claire Elizabeth Williams
Pamela Montzerra Gonzalez-Jimenez	Gabriel Eric Nava	Diana I Williams
Chloe Elizabeth Stabrow Green*	Shelby Grace Olivarez	

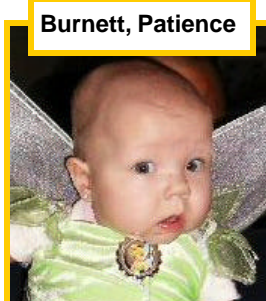
Photos of Cherubs



Landon Earl



Ella Ida Alma Järlid



Burnett, Patience



Gregory Zion Couret



Steiner, Chase Daniel



Cole Campsey



Julia Grace Carlson



Kathryn Victoria Randall



Ariana Sophia Gebrow



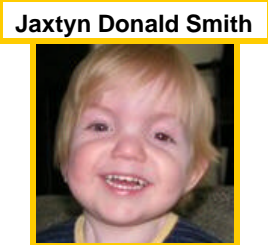
Devin Breneman



Marshall James McLennan



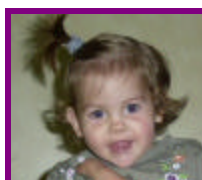
Christian Chance Green



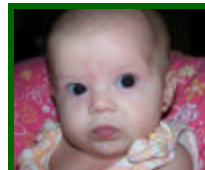
Jaxtyn Donald Smith



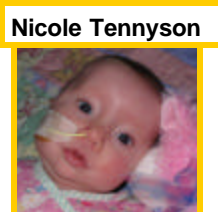
Jacob I. R. Green



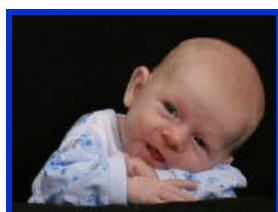
Kaylee van Ede



Riley Violet Redmon



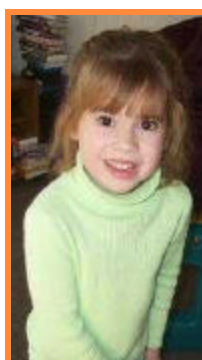
Nicole Tennyson



Landen James Morrow



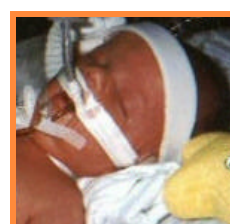
Bryston Spohr



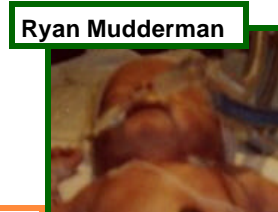
Saydie Halbeisen



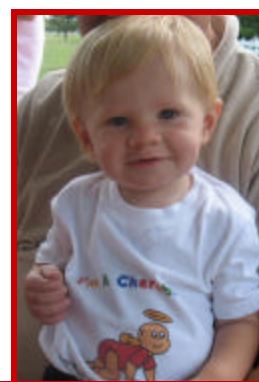
Rebecca Faith Havar



Sydney Olivia Matthews



Ryan Mudderman



Adam Charles Hess



Laila Alana Carrero



Juan Pablo Lopez Arce



Madison Brooks



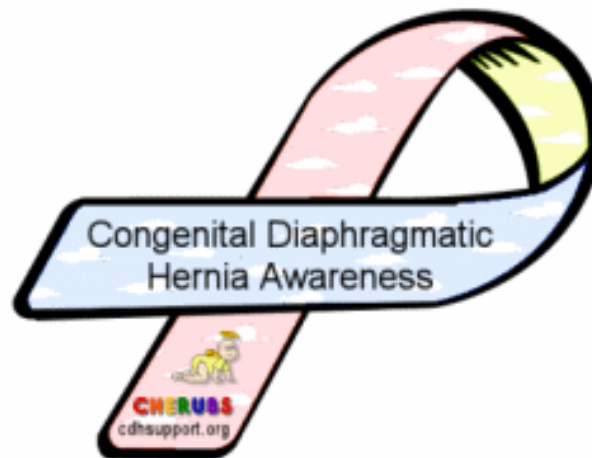
Olivia Raine Richards

Did You Know?

- Diaphragmatic Hernia can occur in utero (congenital) or later in life (acquired).
- Stonewall Jackson had a Diaphragmatic Hernia—most likely acquired in battle.
- CDH occurs just as often as Spina Bifida and Cystic Fibrosis.
- Over 2000 babies are diagnosed with CDH in the U.S. every year
- Diaphragmatic Hernia was first described in 1575 by Pare' after diagnosing an acquired DH
- Congenital Diaphragmatic Hernia was first reported in 1701 by Holt.
- Bochdalek and Morgani CDH are both named for the doctors who differentiated those types of hernias.
- CDH occurs fairly often in puppies and kittens
- CHERUBS oldest living CDH survivor is 53 years old
- The odds of having more than one baby with CDH is 2% if there are no genetic or chromosomal anomalies
- Infections and pneumonia cause more CDH deaths than poor lung function



To make our logos a little less bright and childlike, we came up with this alternative. You can purchase items with this logo on our website.



Our members voted on-line to select the colors and design of our new Congenital Diaphragmatic Hernia Awareness Ribbon. You can purchase car magnets with these ribbons through our web site. They would make excellent holiday gifts.

CHERUBS



You can also purchase 100's of items with our CHERUBS Logo (to the left). We also have over 100 cherub logo characters. They come in 3 sizes (infant, toddler, child), male and female and in all colors and shapes. We created the different logo characters so that every cherub would have a character that looked like him or her. Each cherub logo character has it's own set of fundraising items including clothing, hats, mugs, journals, bumper stickers, and much more!

Did You Know?

CHERUBS logo characters were created based on real-life cherubs and family members. There are over 100 cherub characters.





Cherub Brandon Hall wearing our "I'm A Cherub" fundraising t-shirt

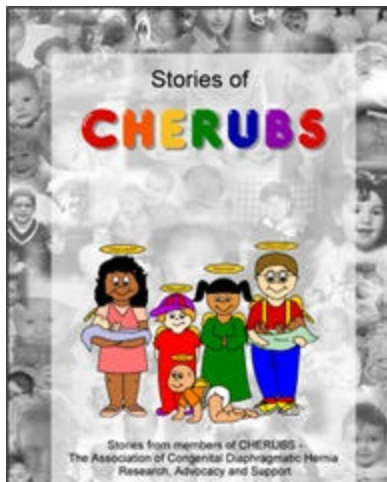
Disclaimer

The information on all pages of this newsletter are for education only. It is not meant to be used in place of proper medical care and advice. CHERUBS does not encourage or discourage any medical treatments or procedures. Our purpose is to educate families and medical care providers so that they may make the best decisions for the patients' interests. You can not compare your child to other children born with CDH, they are all different. The opinions aired by members are not necessarily the views of all members, staff, or of CHERUBS.

CHERUBS was founded in 1995 with just 2 members and a typewriter. Today, CHERUBS has over 2000 members and a website that has over 3000 visitors a month with over 300,000 hits



Stories of Cherubs



"Stories of Cherubs" is available on our web site for \$34.99 and would make a wonderful holiday gift for family, friends or your cherubs doctors or NICU team. Over 500 pages and 300 stories and photos of children born with Congenital Diaphragmatic Hernia. Families tell tales of what life is like to have a child with CDH and to sometimes lose those children. Heartfelt and honest, these stories are a wonderful tribute to cherubs and their families. This book is must have for family members and friends who struggle to understand CDH as well as wonderful guidebook for new and expectant CDH parents.

CHERUBS Congenital Diaphragmatic Hernia Research Survey

Starting in January we will be tabulating our 2007 CHERUBS CDH Research Survey Results. This survey includes non-surviving cherubs and cherubs over the age of 1 year old. You will be able to download and fill out the 22 page survey from our web site. With over 2000 CDH patients in our database we have a real opportunity to conduct research that may someday help find the cause of CDH. Please stay tuned to our web site for updates on all known CDH research studies.



Aussie cherubs proudly showing off their surgery scars

Stories of Cherubs

Cadence Skylar Corkin

born 1/9/06

Hi my name is Kara Gleeson , I just subscribed to the Cherubs site and I am following through with our story. After 2 years of trying to have our second child , two miscarriages , the last one February 5 2006 , I got pregnant for Cadence in April. In July we had our first ultrasound and that's when we found out something was wrong they could see her stomach up in her chest. We found out days after the ultrasound was done not the day but we knew something was wrong because the way the tech was acting. We found out it was our girl we had been hoping for . When the nurse called me to tell me something was wrong she said it was nothing to worry about that it was just a little hole. Boy were they miss-informed. Anyway my doctor sent me to see specialist almost three hours away from home. That's where we had to go every week from then on to get ultrasounds to check and make sure she was ok. I went through two amnio's to check for lung maturity neither one was good, they finally decided that I was to be induced sun. January 8 2006. I had her naturally at 11:07 pm the 9th. The whole room was full of specialist waiting for her arrival. Once she was born she couldn't get any air and was immediately put on a vent. She stayed on the vent for months and was put on a oscillator but eventually had to be on ECMO. She remained on ECMO until her heart and lungs were well enough to get her through her hernia repair on January 24. She nearly made it through her surgery because she got cold and they had to stop , it took 4 hours longer than expected , its was a terrible agonizing wait to say the least. She eventually started to get better, her chest tubes came out , she was weaned off her oxygen which that in itself was amazing because she only has one functioning lung that is small and a upper lobe that doesn't work. I finally convinced them to let me feed her with a bottle instead of having a tube down her throat all the time which she hated and I think made things worse. I took the time and got her to eat and was told I had 48 hours to get up to full feeds and I could take her home, well we did it and we did really well for a week then something was wrong she stopped eating and pooping and then started throwing up blood. We immediately rushed her back to the hospital in Syracuse April 2 , she had a bowel obstruction for her getting scar tissue from her hernia surgery. While I didn't feel it was right they wanted to do a funduplication and put a g/j tube in her to feed her because they had to do surgery to remove the obstruction. I agreed to it because I thought they would know best. During these three operations her stomach wouldn't go around her esophagus to do the nissen funduplication so they stapled her stomach to her throat, this surgery took longer than expected also. She spent two more weeks in intensive care ended up having to have a blood transfusion because she was throwing up blood. She couldn't eat because her stomach and esophagus were so eroded by stomach acid that's why she had the transfusion. The nissen was to get her to not throw up but she can. We got to come home the end of April after Easter. She is a strong little girl she is almost 6 months old now and weighs 11 pounds, they said she will always be small and that is one of there concerns of her. They want her to gain weight. I think she doing great for only having half a diaphragm. We have frequent visit with her surgeon and she answers all my questions weekly it seems. We had one little slip up with her feeding tube coming out which scared the hell out of us, but we got it replaced and she is ok. We go back to see her doctors July 18 for her developmental assessment and to see her pulmonary team. It has been really hard but she is all we could have ever dreamed for.



Written by Cadence's mom, Kara Gleeson (New York) in 2006

Elizia Chicoine

12/14/05 - 12/23/05

At the 30th week of pregnancy, we found out our little daughter had an important deficiency in her thorax called Congenital Diaphragmatic Hernia (CDH) – (1 in 2500). The doctor's prognosis gave us only a 20% chance that our daughter would survive. Even after that news we decided to follow through with the uphill battle and having to be at the hospital on a daily basis for meticulous follow ups on our baby's development.

The bad news just kept coming, and we found out that Elizia was also having problems with her heart. The last two months of pregnancy were plagued with unbelievable ups and downs and the burden of the unknown. However, we were very well informed as to the nature of the problem and what type of treatment Elizia would need at birth. The most important thing we needed to understand was that the hole in her diaphragm was causing her vital organs (stomach, intestines, liver) to push against her rib cage and was preventing the normal development of the lungs. However, it was impossible to determine, until Elizia would be breathing on her own, what type of pulmonary tissue was in place to allow a real chance of survival.

On December 14 we were admitted to the hospital to induce labour. At 3 p.m. my extra-super, beautiful little girl was born, and her vital statistics were quite good considering her condition. Her chances of survival were then upgraded to 50%. The first treatments went so well that when they were ready to transfer her to CHEO, they gave us a 70% chance that Elizia would survive.

CHEO (Children's Hospital of Eastern Ontario) - During the transfer from the General hospital to CHEO many complications were beginning to arise. Elizia's pulmonary pressure began to rise and her prognosis was reverted back to the same as before the delivery. The goal in the first 8 to 10 days was to stabilize her pulmonary pressure while keeping a good blood pressure. Since only one lung was present in the echogram, we had to hope that it would be enough to allow future development after the operation. Many medications were administered to her through intravenous to help her get through the critical first few days. She needed to be hooked up to a special ventilator to help her breathe and supply enough air to maintain her vital statistics. One of the essential medications used to prevent her from fighting the ventilator was Pavulon. It would paralyze her and prevent her from suffering too much because she couldn't breathe normally.

YOYO (ups and downs) - During her 9 days of life, Elizia was a living yoyo as many different levels were attained. The first was at her birth when she showed signs of improvement. Then the first down was when she was transferred to CHEO and was put on a special ventilator. On the second and third day her vitals improved greatly, but on the fourth and fifth things turned worse again. So much so that when an echogram was done on the Monday after her birth (the fifth day), the neonatologist noticed a deterioration of the pulmonary mass which diminished all hope. It was at that time that we realized our daughter would not win this fight. We were then told that if there were no improvements by Friday we would need to make a decision. After the terrible news, we needed to gently prepare our daughter for her journey towards the light. While we were preparing, our little Elizia had a week of great improvement to which point the doctors told us she would make it to the surgery. The surgery consisted of lowering all the organs stored



in the thorax and repairing the hole in the diaphragm. The Thursday before the fateful day was the best Elizia had, we could definitely see some major progress.

The last day and the last moments - Around midnight, the doctors on hand were trying a maneuver in the hopes of lowering the O2 levels for the operation. This maneuver turned out to be Elizia's final rites since her reaction to it considerably increased the pressure of her lungs. The doctors announced to us that that night would be critical and to be prepared for anything. Around 4 a.m. they informed us that Elizia had continued a downward spiral and they were trying to stabilize her but that it wasn't working. All we could notice was the dwindling numbers of O2 and NO2. I will always remember the multiple critical moments and the decision that we had to inevitably make. The main neonatologist was called and upon arrival I cracked. I understood the end had come.

Everyone who was asked to assist in the final moments was called: family, friends and missionaries. The Elders had graciously blessed us and Elizia the day before not knowing that that she was in her final moments. The time had come to make sure the day would pass in peace, harmony and serenity to accompany our little Angel towards the light. We were told that Elizia would be brought into a private room where we could spend our last moments with her. She was placed on a special respirator that was used to keep her alive. The intensity was at its maximum in this room where Elizia would spend her last moments. Everyone was saying their goodbyes, and I was feeling great enlightenment mixed with great sadness. I felt I had the chance to help this little soul find enlightenment but at the same time my daughter was leaving me. I will never forget those magical moments.

Many minutes later it was time to finally disconnect our little girl and to let her rest in peace. We were informed that when she was disconnected that she would only live a few minutes. And that is exactly what happened. We had just enough time for a final prayer and to sing her a song to accompany her through the passage of her soul. The four hours that followed were precious hours were Mommy held her daughter with love. The first steps of her grieving process.

Today the mourning continues its path, and I am filled with gratitude towards this Angel that was sent from heaven to help me grow and give me strength to realize my new potential. I will never regret anything. Having our Angel for 9 precious days has made me the happiest man in the world.

Written by Elizia's dad, Gabriel Chicoine (Canada) in 2006

Madeline Adell May

Born 1/3/03

I have wanted to send in my story for the past three and a half years, and now I can finally do it! I'm Jessie mother of Madeline Adell May born January 3rd 2003. I had Adell when I was 19 years old. My husband (Adam) and I found out about Adell's CDH at about 5 months gestation. We had a routine ultrasound and were then sent to a specialist in Indianapolis, IN. We had an amniocentesis done because they thought that the baby also had Down's Syndrome. That appointment was miserable. They told us that it was a left-sided CDH and the intestines, spleen and stomach were in the baby's chest cavity. We both cried so much and all I could think about was how I was going to get through this and tell our families. The next four months went by so slow. The specialist appointments seemed so pointless that I considered not going. A month before the baby was born we went on a tour of the hospital and met with the surgeon that would be repairing Adell's hernia. It was completely depressing, all I could think about was having to bury a baby. The surgeon was very honest and gave us some harsh statistics and facts. I was induced about 10 days early and gave birth to a 5lb 8oz baby girl. I barely saw her as they handed her from person to person into the other room. An hour later when we finally got to see her I remember walking in the NICU and seeing all of the babies. Some of them were small, others had lights on them and some were on oxygen. But none of those babies could have prepared me for what I would see when I saw my baby. I kept saying there is no way that this baby is mine. I wanted one that had lights on it or maybe oxygen tubes but not all the stuff that was attached to my baby. She had pic lines, IV's in her naval, a ventilator tube, Nitrous tanks, suction tubes and so much more. Instead of a regular ventilator, Adell was on an Oscillator which made her stomach and chest rise and fall rapidly, it looked so painful and it was loud. We didn't touch her, and to be honest I didn't even want to at that moment, I was too afraid. Everything stimulated her, noise, lights, touching her, and even talking. The next day they told us that Adell also had a heart defect (co-archtation of the aorta) that needs to be repaired. She did well and at 7 days old they switched her from the oscillator to the regular ventilator. On day 8 they took her into a 5 hour surgery with two doctors. The heart surgeon put her on her stomach and repaired her heart through her back under her shoulder blade. Then they flipped her over and the other surgeon repaired her hernia. We were blessed she had enough diaphragm to stretch without using anything synthetic. Although he didn't have to use anything synthetic, Adell's stomach muscles were stretched to much and the surgeon could only put skin back together. So the surgical sight was very large and thick and her organs made her stomach bulge out to the side. After surgery the doctors explained to us what they call the honey-moon period, were the babies look good and then have a turn for the worst a few days later. She moved to the PICU for recovery. She did so awesome. She was in a lot of pain from her chest tube, suction, and surgical sight. I can't imagine the pain she was in. She had a lot of edema and swelling. When they would adjust her head the fluid would shift. It really bothered me and I had a tough time. I would see her tears, her face and body cry, but I could not hear it. After recovery in the PICU they moved us back down to the NICU on Jan. 14th. Through all of this Adell never went on ECMO. Three days later they decided to take her off the ventilator, I was so nervous. As soon as that tube was out I heard her cry, she was very horse, upset and would not calm down. So they gave her sedation and she fell asleep. A few minutes later she was blue and not breathing. The pulmonology team had to resuscitate her and re-intubate her. So again I was upset and we had a big set back. Adell was back on the ventilator. I kept thinking that I did not want her to have to come home with a trach or a g-tube. Finally they gave her some breast milk through a feeding tube through her mouth, 5 cc at a time. On Jan 23rd they tried again taking Adell off the ventilator. This time it worked and she stayed off. This was also the first day that we got to hold Adell. The next day a baby boy was beside Adell with a CDH. It made me feel helpless, he had just been born. He was doing poorly and they shut down the NICU to put him on ECMO to try to save his life. I think he hemorrhaged and then died. I never saw his parents but my heart ached for them. The statistics proved to be true and at that moment I began counting every single blessing and accomplishment that we had. On Jan. 25th we began breastfeeding. I was a firsttime mom trying to breastfeed a sick baby in the NICU behind a small screen. But I was so happy to have the chance to try. Breastfeeding completely wore out Adell. We would watch her stats and sometimes her heart rate and oxygen levels would drop while she was trying to eat. Before the alarms would go off, my husband and I would pull off her monitors so that the nurses wouldn't run over and record her set backs. Then we would set her up and rub her back to stimulate her to start breathing again. We knew it was wrong but we just wanted to work with her ourselves. Breastfeeding was just too hard for Adell. I tried everyday and we also gave her bottles. The nurse taught me a few tricks on getting her to take her entire two ounces of breast milk. On Feb 10th she was weened her of all of the morphine and pain killers and was moved to the Grad-unit. We spent five days there and on valentine's night Adell and I got to spend the night alone in a room. It was the very first time I felt like a real mom. Adell had to drink all of her bottles if we wanted to be able to come home the next day. It was a lot of pressure on the both of us. I forced every bit of the 2oz bottles down Adell. The next day we did the paper work to check out. The doctor on call told me that she didn't think it was a good idea to take Adell home and she thought that we would be back within a couple of days. We did not listen. Instead we took her home on Feb 15th. Adell came home without a trache, feeding tube, or any meds. At three



months old we had to take her to the emergency room for breathing difficulty. Her left lung is underdeveloped and to this day she still gets out of breath easily. She was put on breathing treatments and still does them occasionally. We saw a few specialist for eating because that seems to be Adell's only problem. She has never wanted to eat. As an infant she never took more than 2oz of formula at a time. None of the specialist suggestions worked. She just doesn't require a lot of food. So we always set aside a certain amount that she has to eat and drink before she can get down from the table. She is very defensive about her size. She does not like to be called tiny or small and she will let you know that she is big. Considering her start at life and her eating issues she has not been a sickly child she is very resilient At one year old she weighed 14lbs. She was a little slow at meeting the milestones of a baby. She crawled two weeks after her first birthday and walked two weeks after that. She is now going on 4 years old and weighs 24lbs. We have a son born in Feb. 06. He is 9 months old and weighs 23lbs. He is almost bigger than her. We no longer go to any specialist. Her heart is fine. At some point she might need cosmetic surgery to repair her stomach and the bulge that sticks out, although I am paschal to it and it doesn't bother her. Another issue we have found out is that Adell needs glasses and cannot see very well. I don't know if this has anything to do with her start in life but I am curious to know. Adell is an extremely strong-willed child and perhaps that is why she did so well. She is very opinionated and can remember anything. She knows what she wants and is determined to do it. We are so in love with her, our lives would be so boring without her. Thank you for letting me share. We are so proud of Adell!

Written by Adell's mom, Jessie May (Indiana) in 2006

Fallon McClelland

Born 3/27/03



My 4th pregnancy was not planned but after the initial shock of being pregnant again, I started to feel happy and excited to be having another baby. We already had Jake 5, Britt 3 and Laine 1 and had thought our family was complete, but this baby didn't think so. I started to have some spotting 6 weeks into the pregnancy and I went to my doctor who ordered an ultrasound and told me to rest. It continued on through the week. I was devastated. I can remember thinking 'please let me keep this baby, this is my last chance' because I knew if I miscarried we wouldn't have tried for another baby as we already had the 3 kids we had planned on.

The ultrasound showed a heartbeat and a tear in my uterus wall, probably from lifting the other kids I was told. At 12 weeks I saw my gynecologist and he did another quick scan to make sure all was well. At 14 weeks I had another scan which measured the risk of Downs Syndrome and I can remember seeing the baby on the screen. I could see all its fingers and toes. I was amazed that in that short time how perfect the baby looked compared to the little dot I had seen only 8 weeks earlier.

When I was 19 weeks, Jake was rushed down by ambulance to Dubbo Base Hospital with pneumonia, 163 km east from where we lived. I was booked in for my regular 18-20 week scan the next day so I left Tim at the hospital with Jake and went to have the scan. The woman who did it was training another lady, so she said it might take a bit longer as they would have a good look at the baby. I told her that was fine. Being tired from the rushed trip to hospital with Jake I fell asleep for a few minutes while they did the scan. It was so relaxing. I asked if everything looked fine and told them about my previous bleed and she assured me everything looked great.

Everything progressed normally from there; I planned on working until a week before my due date, which was April 10th 2003. On March 26th I drove to Dubbo to see the gyne but while waiting in his surgery I had felt a massive contraction that lasted for ages. I told him and he said things were just moving along. Later, Tim went to donate blood and while I was waiting for him I had another pain. Being at the hospital I thought maybe I should go over to maternity and be monitored but nothing else happened so I decided against it. By 3 pm the next day, I felt terrible. I didn't know if I wanted to go to the toilet or be sick so I rang Tim at work and he came home. He took one look at me and said 'We're going to the hospital!' I had had very quick labours with Jake, Britt and Laine. Laine came so suddenly I just made it to the Nyngan Hospital for his birth and they had stopped delivering babies months before.

So off we went for the 163 km drive to Dubbo. Tim had second thoughts on this and took me to the Nyngan Hospital where they quickly put me in an ambulance given my last performance! I still didn't have much pain and actually felt slightly embarrassed that this was going to be a false alarm. We left Nyngan at about 4.30 pm. We got there and 15 minutes later at 6.08 pm I gave birth to our 4th baby, a little girl we named Fallon Jessica. She weighed 8 lb 1oz (my biggest baby). I remember that when she came out she was crying but she was nearly navy blue in colour. I thought "She's OK, I can hear her crying' The nurse took her straight over to the bed and started giving her oxygen. My gyne had arrived just before the birth and he said "The baby just needs a bit of oxygen to help her along, she'll be fine". I watched while they gave it to her and I could see her nose go pink, then her face and then the rest of her body. They gave her to me to hold and she was fine! I only stayed in hospital for 24 hours as she was my 4th baby. She appeared to be doing what all babies do so we went home.

Fallon was fine until she was 5 months old when she contracted bronchitis and pneumonia. She was admitted to Dubbo Base for 5 days, where she had x-rays, IV antibiotics and oxygen. She seemed to get over this although her cry was like a little kitten's cry until she got her strength back. At 8 months of age she had only rolled twice in her life and still couldn't sit up. I thought this was odd, especially when the other kids were right on target with their milestones.

She got very sick then and she couldn't even sit up with our support. She whimpered all the time and her temperature would not go down. After 3 days she was sent to Dubbo by ambulance again. Bronchitis and pneumonia were diagnosed once again, but this time something was really wrong. I can remember at about 11 pm on that Sunday night, the pediatric registrar came up to me and told me that she thought something was wrong with Fallon's diaphragm. She felt it hadn't formed properly. She told me she would mention it to our pediatrician first thing in the morning and Fallon would need to have a CT scan to have a better look. She also said she would need a general anesthetic for this. I told her that Jake had had a suspect episode of Malignant Hypothermia (which is a reaction with general anesthetic – another life threatening medical problem for our family) and as none of the other kids have had a GA we didn't know if they were carriers of MH as well.

The registrar spoke to our pediatrician the next morning and they decided to compare the previous x-ray with the current one because of the risk with Fallon and the GA. Each day we were there I asked the doctor on his rounds what they intended to do and he told me to go and see him in 2 weeks when Fallon was discharged, as they couldn't locate the 1st x-rays. Fallon took a long time to recover from this stint in hospital; she was very weak, pale and still whimpered like a kitten. I took her back in early December for her check up. She had just started to sit up at 8 ½ months old and the doctor was happy with her progress. Her follow up X-ray was due in March to make sure all was well. There was no mention of her diaphragm.

On March 2nd 2004, we went to have the chest X-ray then go to the doctor. The radiographer seemed alarmed when he checked the X-ray and

told us to wait in the waiting room. We waited for ages then the radiologist came to speak to me. He said he had spoken to our pediatrician and we needed to go straight to see him. I asked him if there was something wrong with Fallon's diaphragm and he said there seemed to be an abnormality but the doctor would explain it more. I took her to the doctor and he told me she would need to have the CT scan to investigate more. It was May 12th before we could get into the hospital to have the CT and Fallon was 13 ½ months old. She was constantly sick with chest infections and couldn't crawl or pull herself up; she simply didn't have the energy. They had to sedate her heavily for the CT because of the MH risk. The next day I took Fallon to a physiotherapist who came regularly to Nyngan from Royal North Shore Hospital. One session with her and Fallon started to crawl! Her crawl was a bum hop and she used her left leg to bounce herself off the ground and used her right leg and arms to push herself along as she bum hopped. We were so excited she has started to move by herself and she looked so funny!

The next Tuesday we got the call to say that Fallon needed to see a respiratory specialist at Sydney Children's Hospital. The specialist's registrar rang that afternoon and he spoke to Tim about what was happening. I was at work and I rang the registrar myself as I couldn't fathom what was happening. He told me we were booked in for 3 days in the care-by-parent ward and that Fallon would have another CT scan as they had found a mass on her lungs and her kidney was in the wrong spot. With further testing they would decide what they would do however, she would probably require surgery at some stage. I went to bits. This was a whole new problem ahead of us. I pictured my grandfather who we called Dad O'Brien on dialysis all those years and he had eventually died of kidney failure. What was going on? What was wrong with my baby?

On June 16th we were at Sydney Children's Hospital as Fallon had been sick again. The respiratory specialist decided not to do the CT because she was too sick to be sedated and went off the CT results from Dubbo. Her kidney was definitely in the wrong place and she needed to see a surgeon. Tim and I were in the kitchen of the care-by-parent ward when this loud man came bowling in asking if we were Fallon's parents and introduced himself as Dr Bruce Currie, a pediatric surgeon. He was the funniest man I had ever met and he was so down to earth and friendly. He told us that Fallon had in fact had a Congenital Diaphragmatic Hernia and she had been born with it. It should have been picked up in my pregnancy ultrasound. The operation was scheduled for July 22nd 2004 and she would be nearly 16 months old. It would have been done straight away but she was not well enough. I found heaps of information on the Internet about CDH and Cherubs Australia was a lifesaver.

From then until July 22nd, Fallon was sick twice more with chest infections but on the day of the surgery she was well enough for things to go on as planned. It was about 2 pm when she went into theatre. I carried her in and laid her on the operating table and I kissed her and told her I loved her. I could hear the machinery starting up and they put the mask on her face. I could only think of the day we nearly lost Jake from his life threatening reaction to the GA and here I was leaving my sick baby with these people to have a major operation with the Malignant Hypothermia risk hanging overhead. The anaesthetist told me she would be fine and she was in the right place if something went wrong. Someone escorted me out into the hallway and I had to find my way back to the waiting room. However, I got lost, broke down and cried my heart out. We waited for over 4 ½ hours for some news. Finally, a nurse came out and said she was fine and they would call us very soon to see her. I was let into recovery with Fallon while she was still out of it. She had a morphine drip in and was on oxygen and she looked so sore. I just held her little hand and cried.

Dr Currie came and spoke to me and told me that the problem was a lot bigger than they first thought. Her spleen had moved through the hole into her chest cavity and her left kidney was partially through plugging the hole. The kidney doing this had actually saved her life as it kept everything working in a fashion. He had put the spleen and kidney back in place, taken out her bowel and put it back properly and sewn up the hole in the diaphragm. The hole was so big he had to sew the diaphragm to her ribs, as there was not enough diaphragm to sew together. He was pleased with how everything went and expected a full recovery. Fallon was taken to the ward later on that night and I slept in a chair beside her. I was too frightened to leave her. She was kept unconscious for about 36 hours and fed by a drip for 5 days. She still had her morphine drip in but the nurses slowly decreased her dosage and she became more alert. On about day 4 she was very itchy from the morphine and cried and scratched her face constantly with her little bandaged arms. They took out her catheter and slowly weaned her off the oxygen and morphine. On day 5 she could drink clear fluids and by day 6 she was sitting up and playing. Her bowel was very sluggish from the surgery and she had to be on medication for that for several months. The last few days in hospital she had a ball. All the tubes were out so she could bum hop around the ward, very slowly at first and then flat out. I could not believe the change in her as she even pulled herself up to standing in the cot one day. A few of the nurses said to me they had never seen a baby this old with CDH.

We left hospital and went home after 10 days. I think it was when we got home that it all hit me, all the what ifs came to mind, the threatened miscarriage, her colour at birth, her sicknesses and her late development with gross motor skills all made sense and, most importantly, it was a miracle she had even lived. Fallon didn't walk until she was 21 months old and we were so excited when she did! Finally she was back on track. She had a lot of catching up to do but she was still with us and that is what mattered the most. Fallon is now 2 years and 5 months old.

Update: Fallon is now 3 yrs 8 months, she is such a happy child, she really takes in the things around her with open arms, she is such a good little girl, never any trouble to take anywhere. She has had to overcome a few health issues since her surgery in 2004, she had her tonsils and adenoids removed in Sept. 2005 and has had a few bouts of pneumonia and always has asthma/chest infections to battle with. Luckily we have a great GP and pediatrician she sees. She is in her 1st year at pre-school, she's not very coordinated, but she certainly tries her hardest at everything she does. She is my angel, a true miracle.

Written by Fallon's mom, Leah McClelland (Australia) in 2006

Asher James Switzer-McCoy

7/4/07—7/4/07

My name is Kim Switzer and I recently joined CHERUBS and would like to share my sons story with you.

It began at the end of January when I found out I was pregnant after a miscarriage a year earlier. I was ecstatic and terrified at the same time. I had the usual morning sickness and as the weeks flew by I became more confident that baby was sticking. We passed the 12 week mark and finally I was able to feel relieved, I was so sure that nothing could hurt my baby now. When I was 13 weeks pregnant we went for our first ultrasound and saw baby's heart beating so fast, it was surreal. The pregnancy continued to progress normally. My doctor was a little worried since I was hardly showing, but it was the same when I was pregnant with my now 3 year old daughter.

Our next ultrasound was at 18 weeks and 6 days and it is a day I will always remember. I saw our baby kicking up a storm and thought it was strange that it was moving so much and yet I didn't feel all the movements. Pretty soon the tech starting saying "Look at his legs moving so much....he sure is an acrobat" So when we asked her if that meant baby was a boy, she said she would have to talk to the radiologist before she could tell us. She continued to take her pictures and she got really quiet, but i just assumed she was concentrating on getting good shots. After she left the room Evan,



my fiance, said that she had put a question mark on one of the pictures, the picture of his stomach. That worried me for a few minutes until she came back in and said that yes our baby was a boy! Evan and I were so excited, our family would be complete! As soon as we were out of the office we were on our cell phones calling our families to tell them the good news.

The next day, May 29th, I went in for my monthly appointment. It was the day my life changed forever. My doctor said that she reviewed my ultrasound results and that my son had a hernia in his diaphragm. She drew me a diagram to show me what she meant, but she was very vague. After that she tried to listen to the heartbeat, but was unable to find it since the doppler she was using was ancient!! So I hopped off the table and she told me she was referring me to a specialist at the hospital. I was to wait for him to contact me for an appointment. A week went by and I hadn't heard anything, so I called my regular ob/gyn's office to get his number. I called his office and they finally made an appointment for me the next week. The week went by so slow, I felt like I was dying. My fiance and I did as much research as we could on CDH and found it all pretty grim so when we arrived at our appointment at the hospital we were pretty messed up. Dr. Olatunbosun is the chief doctor for obstetrics at Royal University Hospital so we put our complete confidence in him, and all that he told us was that the severity can vary between cases and that we really couldn't know how bad it is until baby would be born. He sent us for a diagnostic ultrasound the next week(3 weeks after I first found out about Asher's condition.)

The tech was very nice and explained that the ultrasound would take a little longer than normal, about 30-45 minutes. So I lay on the table letting them to their work, all the while keeping my eye on the clock. A half hour passed and she was still taking her pictures, soon a hour passed and she was still going at it. Finally 1 hour and 40 minutes later she finished. As I wiped the gel of my belly she said that Dr.O would be looking at the results and I should wait in the waiting room for him. He came in 15 minutes later to tell my sister and I what we really did not want to hear. Asher's condition was placed in the poor prognosis category. He explained that they measure the size of the lung to the size of the head to determine how severe the damage is, then place them in a category; excellent, good, and poor. He then went on to explain that the excellent category usually consists of deformities that are not life changing(missing fingers, limbs) the good category is where they can do surgeries that allow the baby to have an almost perfect life and the poor category, where Asher was placed, is where the baby would have to depend on machines for a while and there is no guarantee on how good a life the baby would have. This is when Dr.O brought up induction, and explained that it would be a good consideration for me. My sister and I left shortly after that and when Evan got home from work I explained everything to him and we made a decision to induce.

The following monday I called Dr.O's office and told him that we wanted to induce, so he had us come in the next day to talk about the induction. So when Evan and I arrived and he started telling us the opposite of what he had told my sister and I, basically repeating what he had said at our initial appointment. There is no way of knowing that it is as bad as they think etc. I was completely dumbfounded. How can tell me this when 4 days earlier he was talking about induction?? Dr. Olatunbosun then referred us to another specialist and we had an appointment with her the following friday, June 29th. As we left Dr.O's office Evan and I did not know what to think. The doctor and totally contradicted himself and changed our sons diagnosis within a matter of 4 days, once again giving us false hope. We decided that we would hear what this other doctor had to say, but we were still pretty sure we wanted to induce if it was bad.

Friday rolls around and we are again waiting in an office. Finally we get in to see Dr. Jocelyne Martel. She immediately made us comfortable, whereas with Dr.O we were a little intimidated. She apologized for making us wait so long to see her, we were supposed to see her all along but she was out of town. She then asked us to tell her what we have been told about Asher's condition and what we understand. I told her how Dr.O had contradicted himself and that we were very confused and just wanted her to tell us exactly what she knows from the results. She was very sincere as she told us that she had already seen 2 cases of CDH this year(she handles all of the northern Saskatchewan and Manitoba cases) both of which were not nearly as bad as Asher and they had been delivered in Edmonton. She explained that we could opt for surgery but would have to go to Edmonton for the delivery as they have the necessary equipment, but she said that with the severity of Asher's hernia and the extensive damage to his heart and lungs she did not think that even with surgery it would be able to give him a good chance at life. Evan and I told her that we wanted to induce as soon as possible as we were nearing 24 weeks. Since it was Canada Day weekend we would have to wait to the following Tuesday, July 3rd to be induced, and she told us to be there at 7am so we could do the amnio first(we asked to have one done)

That weekend was the hardest of my life, knowing that it would be the last weekend with my son. I tried so hard to remember every little move he made. I took so many pictures of my belly and just spent time rubbing it. Tuesday morning came and I went to the hospital. Dr.Martel was already there getting everything ready and soon we were in the ultrasound room and doing the amnio. Once she was finished she inserted 4 tablets of certavil to soften my cervix. I was then shown to my room at the end of the hall of the antepartum ward. I got my IV around 10 am when I started cramping. Around 2 pm my contractions started getting painful and the nurse offered me some pain medicine that I honestly cant remember the name of. It was heaven and soon I sunk into a drug induced sleep. I was told to call the nurse anytime I needed more pain meds, but around supertime the contractions were too intense and since I was only dilated a fingertip they gave me demerol with a button I could push as often as every 6 minutes. Around 10 pm I feel asleep and woke up with very painful contractions at 2 am. The nurse checked me and said I was going to be moved to the delivery ward. My mom (who had stayed with me) called my sister and Evan to come to the hospital.

It all happened so fast after that. Evan showed up and was talking to me and all of a sudden I felt like I had to poo. I knew this meant it was time to push, so I told the nurse but she told me to wait since the doctor on call would be here soon. I tried singing, crossing my legs...everything, but there was nothing I could do. At 2:46 am July 4th 2007, Asher decided it was time to appear and he slowly slid out without me having to push. I remember apologizing to the nurse for not waiting and to my mom. I told her to shut up when she told me to calm down....I felt so bad and started to cry. The nurse wrapped ashur up in his special blanket Evan and I bought him and brought him to me. He was so peaceful I could hardly believe something was wrong with him. I held him for a long time, and noticed that we was twitching a little, muscles relaxing the nurse said. The second time he twitched he smiled at me. A big beautiful smile as if to let me know that hes safe and happy. That is a moment stuck in my head forever, the only time my son smiled at me. After Evan held him for awhile we let the nurse take Asher and clean him up. It was close to 3:30 by then and I told Evan to go home, he was exhausted and it wouldn't be comfortable to sleep in the chair in my room, so my mom and Evan left and the nurse came in to bring Asher to me one last time. She had him in a little green bunting bag with a knit hat and wrapped in a little knit blanket. She told me that she had taken his hand and footprints for me so his hands would stain me. I left him wrapped up and just cuddled with him for a couple more hours, we even had a nap. Then the nurse came in to help me into the shower. I sat there and it finally hit me as I looked at my flat stomach, my son was gone!

Then the nurse helped me back into my gown and put me in a wheel chair to take me back to the other room. She gave me a box and his blanket we had bought him. As she was wheeling me down the hall, I passed a room where someone had just given birth and I heard the baby cry. When we got back to my room the nurses got me settled in and the delivery nurse showed me the box, it had his outfit she had put him in along with his memorandum card with his prints on the back, and his id bracelet. It was 5 am by then and I passed out for a couple hours and woke up hysterical at 7 am. I called the nurse and she came to talk to me for awhile until I calmed down, I called my mom to come and get me and I was discharged and at home by 11 am. We had an autopsy done on Asher and the preliminary results have shown that both of his lungs were hypoplastic and compressed as well as his hypoplastic right jaw. We are still waiting for the final report, but his amnio results show that he had a normal set of chromosomes.

Written by Ashton's mom, Kimberly Switzer (Canada) in 2007

Bennett Rezsö Russell

12/22/05 - 12/22/05

From the moment I found out I was pregnant. I was over the moon – my whole family was. Bennett was going to be my first baby, and was a very wanted, if not planned, baby. His big brother Drew (my husband's son from his first marriage) had requested a little brother, and we were very happy to be able to fulfill his wish!

I was about 19 weeks pregnant when we found out that Bennett had a Diaphragmatic Hernia. I had been sent to a perinatologist, for what they thought was an amniotic band, "not a big deal, just something to keep an eye on". When the doctor said that Bennett had CDH, it felt like the wind had been taken out of our sails! To make it worse, the doctor has only seen this once in his 20 years of practice – and didn't really know, I guess, what to do. I felt very lost – what do we do now?

My sister, Jolika, found Cherubs after searching the internet. I read what other people had gone through with their Cherubs – some with happy endings, some not. I read everything and anything I could find out about CDH, as did my sister. I would tell my husband, Andrew, our findings (he is not one for sitting in front of the computer!). We knew we had a long tough road ahead of us but we were pretty positive that we were going to get through it. It never entered my mind that we wouldn't.

We pretty much had to figure out what to do and where to go. We live in Hope Town, an island of the Abacos in the Bahamas. So we knew we would have to go somewhere in the States that specializes in CDH. We knew we either wanted to go to Shands or CHOP (Children's Hospital of Philadelphia). Friends of our's had friends in Philadelphia, who happened to be a heart surgeon and had done his residency with another doctor who knew Dr. Scott Adzick (head of the Center for Fetal Diagnosis and Treatment at CHOP). This led to me being contacted by Kelli Young (Kelli Young is the Surgery Advanced Practice Nurse in the Pediatric Neonatal and Fetal Surgery Dept. at CHOP) She is also such an amazing person who helped to make this horrible ordeal that little bit better. She was also the first medical person to really explain what we were up against.

A week later, we went to CHOP, and that was when our world started to crumble. We knew that Bennett's stomach and probably his intestines were "up" - we also knew that we did not want his liver to be up - that would be a whole lot worse. After a day of testing, MRI's, scans, etc. we met with Kelli and the doctors and they told us what we were dreading to hear - his liver is up. I just started to cry, because I knew that our little baby was going to have such a battle ahead of him. We were also told that his lung to head ratio was not good - basically because all of the organs that were in his chest cavity, Bennett's lungs were not having a chance to grow. It was one of the worst cases they'd seen. That was December 14th, I think! They told me to return mid-January – I was so happy that I was going to be able to spend Christmas with my family! Drew was due to spend Christmas with us for the first time and everyone was excited. Bennett's due date was March 6th, but they wanted me there earlier because the amnion and corion membranes of my placenta were not fused together and they were worried that it could rupture at any time. How little did we know then....

A week later, everything came crashing down. I noticed a pinky-brown mucous-like substance after I had gone to the toilet. I called my doctor here in Abaco, and also the on-call obstetrician at CHOP. I was told to spend the rest of the weekend in bed and go see my doctor on Monday. So I did, and everything was fine. That day was my husband's birthday, but because everything going on, we did nothing. That night, about 2:15am, I lost my amniotic fluid. I was on the phone with my doctor here, trying to figure out what to do. Finally my brother-in-law drove us to the mainland, which is only accessible by boat. Because of bad weather between here and Florida, I could not fly out then. I flew to Nassau first thing in the morning, where after examining me and finding that I had lost most of my amniotic fluid, they were going to airlift me to the States, but then I was questioning, if CHOP had given us 50-50 chance that Bennett would make it IF I made full-term, then, at 29 weeks, did he have a chance?

Was it worth the extra stress of flying elsewhere? Once again, I called Kelli. She explained that I would have to be at least 32 weeks for Bennett to go on ECMO - that his veins would be too fragile any earlier. So basically, I would give birth and he would just go to sleep because of the lack of oxygen. Even if I could get to CHOP, there was nothing more that could be done. Kelli continued to call me at the hospital, to see how I was doing; she made herself available to the doctors in Nassau (they hadn't had much dealing with CDH) if they needed any information or help from her. She called my husband in Hope Town before he went to pick up his son Drew in Minnesota (I told Andrew to go get him and bring him to Nassau, while I flew to Nassau – Drew could spend time with his cousins while I was in hospital – I didn't want his Christmas to be ruined too), to see how he was doing. And she checked up on me after I got out of hospital. As far as I am concerned, she went above and beyond what she had to. And words can not express what her support meant to us.

So I was induced and on December 22nd I started going into labour. Much to my horror and pain, the anaesthetologist that was on call could not be found. I had to do it with Demirool only – I was not happy! Up until this point, my sister Jolika had been by my side during the day, my Mother taking over the shift after she finished work, with many quick visits in between. They pretty much held my hand and my heart through all of this. During the worst of my labour, my husband arrived, coming straight from the airport, after dropping Drew off at my sister's house. He walked into the room and walked right out. I don't blame him – I was screaming the whole place down. And then, there he was, Bennett. My husband, and my brother, hearing the lull, came in. Up until the day before, we still had not decided on a name. Then I thought of one name that had stuck in my mind – Bennett, meaning "little blessed one". I talked to Andrew and we agreed. Bennett was handed to me, so tiny and beautiful. He attempted to take a few breaths – thank goodness Kelli had warned me of this, so we were as prepared as we could be. He never opened his eyes. And then he quietly slipped away. I remember at one point wanting to open them, but then deciding against it. I just couldn't believe it was all happening...that he was gone. He never cried, never made a sound.

We both understand that things happen for a reason – we know that Bennett would have had such a long and hard road ahead of him. And we know that with us living here would have made things even more difficult – no hospitals nearby, etc. I would have been away for so long and Dewey would have had to stay here to work. We know Bennett would have suffered. I know that this way, the way it happened, that he went peacefully and he didn't suffer. We know all of this. But it does not make it any easier.

From the moment I found out I was pregnant, I dreamed about my baby, what he/she would be like. When we found out that Bennett was a boy, I thought I would have been disappointed, because I had wanted a little girl. But the minute I knew I was having a boy, all I could do was think about what he was going to be like, as a baby, as a boy and as a man. It was not just Bennett that was taken from us, but all our dreams for him. I never thought I would be envious of someone else's screaming baby. I never got to hear my baby cry or laugh. We never had the chance to make any memories with Bennett. I will always wonder what our precious little angel would have been.

Written by Bennett's mom, Erika Russell (Bahamas) in 2006



Angela Reedell

Born 6/13/05



Our "wild ride" started in mid-October of 2004. We had planned on "trying" to get pregnant after we got back from a trip to Holland, and oops... we got pregnant while there. We were beyond happy, since it only took 5 days to get pregnant. Now I live by the idea that getting pregnant was the easy part!!! We went on a trip to Punta Cana and I read the "what to expect when you are expecting book"... so I had some sort of clue what I was in for. I really had NO clue... but we were ready for an adventure... to meet our baby!!

My pregnancy was tough from day 1. I was feeling morning, noon, and nightly sickness ever since week 6 and it didn't get any better. I had a subchorionic hemorrhage at 9 weeks, thought I was having a miscarriage, then didn't, and then at my 20 week routine ultrasound appointment, I was told that "we think there is something wrong with the baby's head... you need to go see a specialist". It turns out that our little girl's head was fine. But luckily they did send me for a level 2 ultrasound. My baby was active at all times of the day, so they checked everything out and she looked good. They said the heart looked good, but they couldn't get a feel for it's exact location, but they said to not worry, we would take another look and see what was going on. So, two weeks later I went back, and they said the heart looked perfect, but it was being "pushed" by some other "organ" out of it's perfect position and they couldn't tell what was doing it. They told me that I was going to see the surgeons and specialists at Children's Hospital of Philadelphia. I was scared beyond belief.

About 2 weeks later I was in the MRI machine, having numerous tests, fetal echocardiogram, more ultrasounds, and numerous meetings with counselors, social workers, surgeons, you name it, we talked to them. They gave us the facts at the end of a long day, our little girl was going to be born with CDH. They said her condition was VERY favorable, and everything looked great. The only organ that had "migrated" was part of her intestine, and they confident that she would have a nice recovery. Of course they told us about the fact that she would be on a vent and would have a tough road ahead of her, but we knew she was a fighter and would make it through well.

The next few days were tough. I was upset, but after talking to other parents whom have been through it, I began to feel better. We toured the NICU, and got acquainted to where Angela would spend her first few weeks of life. With every appointment we felt better because she was growing and moving and the docs were sooo confident. We just couldn't wait to meet our little princess. I also couldn't wait to not be pregnant. I was sooo sick for the entire pregnancy that I only gained 14 pounds at the time of her birth. It wasn't fun, but I'd do it all over for her in a second!!

At 37 weeks pregnant, my ultrasound showed that Angela was in a breech position... and they said they would not attempt to turn her, so we scheduled a c-section for June 15th, 2005. I was ready for it. I had finished up work on the 9th of June and figured I had a few days to "prepare" for her arrival. To our surprise, on June 12th, at around 10pm... my water had broke. I called the hospital, and of course they said for me to come in, they'd have to "gather" all of the medical staff that was required, and then I'd have my little girl. I was sooo ready to have her. We arrived right around midnight - so much for a planned c-section. They confirmed labor, had one last ultrasound, and off to Labor and Delivery. My husband, my mom, and my sister were by my side. I even got to watch Back to the Future, Part 2! I wasn't in a lot of pain, and I was already dialating, but she was breech, so off to the c-section I went.

On June 13th, 2005 at 4:26am, Angela Kirstin Reedell was born at 6lbs 10oz and 20.5" in length. I knew I wouldn't hear anything or see her, but luckily my hubby watched the whole surgery, watched her being pulled out (butt first), and then after they got her stabilized he took some pictures. He brought back the camera and I just wanted to stare at it. I couldn't believe she was here.

Back in my recovery room, I was talking about everything that had happened and just couldn't wait to see my precious little angel. We named her Angela Kirstin because it means "Angela of Christ"... we fell in love with the name... and it was perfect when we saw her little perfect face.

About 8 hours after my surgery, I was taken over to see Miss Angela for the first time. I had given birth at the University of Pennsylvania and Angela was at Children's Hospital of Philadelphia. They work together on many high risk cases, and are actually linked underground. The moment I saw my daughter I fell in love! She was the most precious little person... even with all the tubes and wires. She had to be restrained (both arms and legs) soon after birth because she was pulling all the wires off. It was incredible... she was a fighter from the moment she was born.

The next day I was feeling better and walked over to see her in the NICU. Angela was in a room with only CDH babies... so we knew we weren't alone. She was doing well. She was totally stabilized and the surgeon told us she was ready to have surgery on Wednesday morning. Wednesday was hard because all we could do was wait. It was about 2 hours, and the docs came out with great news. The surgery went perfectly, she was recovering nicely and they had high hopes for our little girl. Now the hard part would be for her to recover from the surgery, learn to feed from a bottle, and be weaned off the morphine. Each day got a bit better and wires and tubes were removed. I was discharged on Friday, and it was tough to leave her, but I knew she was in the best care possible and that she would be home soon. We had to stay strong... for all of us!!

Finally we were able to hold Angela at 5 days old (Saturday). It was incredible to hold our little bundle of joy... even with the tubes, but we were making progress. Sunday was father's day... and our present was that they removed her ventilator. We heard the first raspy cry ever... it never sounded so sweet. The nurses all sort of chuckled and said "it is a nice sound now... we'll call you in about 6 months and ask what you think...". We chuckled... it was a joyous day!!! It was a great first father's day for Scott.

Each day she grew stronger, started taking breastmilk from a bottle, and they were weaning her from oxygen. She was going through all of her x-rays, was off morphine, and passing tests left and right. We were told that she would be able to go home soon. She was only 16 days old and they said "she can go home tomorrow"... we were BEYOND elated!!! The last test was the PFT's... and they had to be the day before discharge. According to her pulmonologist she had 77% lung capacity at 17 days old... which is great for a CDH baby. She still had an NG tube in, but we mostly fed her by mouth. They said that many times babies eat better when they are home... we were hopeful.

On June 30th, at 17 days old, we arrived at our house at 11am. Both Scott and I looked down at Angela in her carseat and said "w hat do we do now"? We were first time parents, she was almost 3 weeks old, and this was the first time we have had to be responsible for this little person. It was a fun time. Angela pulled out her NG tube the night she got home... and hasn't had any troubles since then. She has done great.

Today our little girl is over 1 year old. She has astounded all of her doctors with her recovery. She walked at 8 months old, she finally crawled at 9.5 months old, has the energy of about 10 toddlers, and is learning new things every single day. She for all intensive purposes is a perfect little 1 year old. We would like to thank every one of our friends, family, doctors, and people who were support to us. We count ourselves as blessed every moment of the day for Angela's great recovery... and hope that someday they can find the cause of this defect and prevent it from happening to any other children.

Written by Angel's mom, Megan Reedell (Pennsylvania) in 2006

Jaila Berrios

4/24/06 -4/24/06

My husband and I were really excited to learn if at our eighteen week check if we were having our second boy or girl. We were pleased to find out that we were having a baby girl. The very next day our world changed. My OB/GYN wasn't his normal happy self and my heart dropped when he said something was wrong. He tried to explain what CDH was but we were frozen. The next following months were a series of learning as much as I could about the birth defect, an ultrasound twice or more a month, and an emotional rollercoaster.

I could tell by all the ultrasound pictures that not only were she already beautiful but she looked like her sister and father. I decided on naming her Jaila for no reason other than the fact that her siblings names started with J. I just wanted her to fit in with others.

A week before her scheduled birth, I felt like I was crazy from anxiety. I was feeling all that one person could feel at one time. I was happy and at the same time I was depressed. The day before the delivery, I ate at Ruby Tuesday and tried to stay calm because I didn't want the baby to stress out. My husband seemed nervous but okay at the same time. I know deep down he was feeling the same as I. I just hope that he was ready for the next day.

The day of delivery was very exciting as if Santa was near and I was a four year old. I was calm considering what I knew was about to happen. I was rolled on the operating table about 12:45pm. Jaila was delivered at 1:18pm and immediately there were problems and everyone knew it. She couldn't cry, scream, or breathe. As she came out she looked at her father as if she was requesting his help and later he told me how helpless at that moment he had felt. About two hours later the nurse called me while I was in recovery for permission to place her on ECMO. I said yes but that cause more problems. Eventually her doctor called my husband and said he had done everything he could do and he didn't think she would make it through the night. My husband I made the decision that we didn't want her to suffer any longer and we pulled the plugs and held her until she died in our arms. Jaila wouldn't have survived for as long as she did if it wasn't for technology. She was pronounced dead at 10: 24pm and then came more cries from the parents. We continued to hold her until it got to hard so we gave her to the nurse.

Five days later we had a memorial and she was even more beautiful in her death. I love so much and everyday is a struggle without my baby Jaila. The only thing that soothes the pain is knowing that one day I'll see her again and God is perfect and makes no mistakes. Knowing Jaila in my tummy for nine months and the nine hours she was on earth I completely understand why God needed something so beautiful to take to heaven. He could brag about the flower he got from me. Clearly only heaven could handle something as beautiful as my cherub in heaven, Jaila Berrios.

Written by Jaila's mom, Latoya Berrios (Virginia) in 2006



Kirra Graham

Born 1/7/2003

During a 13 week scan it was noted that the baby I was carrying had a thickened NT sac behind the neck, and I was told that I should have a CVS done as this could mean that the baby may have chromosomal damage. The next week I had the CVS done and then had to wait an agonizing 2 weeks for the results.

My husband took the day off work to come in with me and we were over the moon to find out that all was well. What's more, I found out that I was having a girl! We have 2 wonderful boys, and I fell pregnant again hoping I would be blessed with a girl. So you can imagine how excited I was, not only to be told my baby was healthy, but also was a girl.

However, my excitement was short lived when I had my 18 week scan during which I was told that my baby had her stomach in her lung area. At the time, naive as I was about it, I said "Oh that's OK it will just go back won't it?" But I soon found out it wasn't that easy.

I can still remember how devastated I felt. I had to drive 45 minutes back home through city traffic (Brisbane) and I don't know how I managed. My husband Ian and I had to go back to the hospital the next day to meet with the team of specialists and they fully explained everything and they gave my baby a 50/50 chance of surviving. I was asked if I wanted to terminate and of course I said no. I would be forever wondering "what if?" So the months went on and each time I had to go for another ultrasound, starting with an MRI scan. I hoped they would say it was all just a mistake but that never happened. Instead they would remind me that things weren't looking good and let me know in a subtle way that I should prepare for the worst. I dreaded going to the hospital because to me it felt like my baby was normal. She moved heaps and kicked strongly, but they said it would seem this way because she didn't need to breathe in the womb.

I was 32 weeks when they said I had started to fill with fluid. However, they didn't want to syringe it out as I may have gone into labour and they wanted me to go as close to term as possible. This was so she would be more mature, thus giving her lungs the last few weeks to expand. They had scheduled my inducement for the 39th week so they hoped the fluid wouldn't get too much.

Finally I made it to week 39 and the day was the 7th of January, 2003. After 6 hours in labour, Kirra Renae was born at the Royal Women's Hospital in Brisbane. I didn't even get to look at her. My husband put his head on mine as soon as she came out and then they took her away. The midwife said the doctors would come and get us when she was stable. Four hours went by and I kept asking why wasn't anyone coming to take me to see my baby, but no one would answer me. (Later I found out why, no one thought she would live.)

Finally in the 5th hour they said we could go see her. I was not prepared for what I saw or heard. How could you be? There were machines and IV lines everywhere and the oscillating vent made her body shake. Her skin colour looked bruised in places from the lack of oxygen she had suffered. The doctor said that they had found stomach, intestines, bowel and some liver in the lung space and couldn't see any lung at all on the left side. He said that her heart was pushed to the right side and they could only see a small bud that was her right lung. He gave her less than 10% chance of surviving and thought it best if we had the hospital chaplain come in. That brought me out of my shock and I said no way, that she was going to fight and that she was strong and she would live. They told my husband that they didn't think she would make it through the next hour let alone the night so



he should bring in family to see her. He drove home and got our sons, my father and my brother (my mum was with me). After they all came and went I was given a sedative and slept. I woke early the next morning and went to see Kirra. She had had a rough night because they said she couldn't be moved even slightly or else her sats would drop. They were just trying to bring her sats back up when I came in. I held her little hand and within minutes she was stable again, much to everyone's surprise.

By the 3rd day they had completely turned off one of her blood pressure medicines. On the 7th day they operated. We were told that she wasn't going to be anymore stable and if they didn't operate she would go downhill anyway, and that even then they didn't think she was strong enough and not to get our hopes up. They turned the isolation room she was in, into the operating room, as she still could not tolerate movement. Yet again they were stunned by Kirra as none of her vitals even changed during the 50 minute operation.

Kirra continued to improve and on the 16th day the oscillating vent was turned off and she started to breathe against the normal vent. On the 20th day the nitric oxide was fully off and 2 days later she was extubated, though she had to stay on 75 mls of oxygen through nasal prongs. Kirra was 34 days old when she was able to breathe the same air as us and she came home one day before she was 3 months old. She had only mild reflux, and we moved from the city to get her cleaner air. She avoided the winter colds and flu.

Kirra is now nearly 2 years old and has never looked back and has had no more problems. Last month she was fully discharged from seeing the doctors, and they say she may only get a little breathless running in school.

Wow I am so glad I went through with my pregnancy! I have a beautiful daughter and she is my shining star. I will be forever grateful to the doctors and nurses who helped save our daughter. I believe that hope and strength helped her too, and the heartfelt thoughts of friends and family banded together, brought strength to her as well. I hope this story lets others know that no matter how bad things seem there will always be a "silver lining!"

Written by Kirra's mom, Sandy Graham (Australia) in 2006

Cameron Anthony Kennell

11/20/97 - 11/21/97

My story starts in July 1997, it was my 20 week scan & I was told the baby wasn't in the right position to see the chest wall & could I come back the next week. The following week I was told my son had a severe diaphragmatic hernia to the left side & was very unlikely to survive so it would be best if I terminate my pregnancy! Well as you could imagine I was devastated, I refused to terminate & was referred to a hospital with better equipment, I developed polyhydramnios & was kept in hospital for 7 weeks before my son was delivered by c/section which was on the November 20, 1997. He weighed 10 lbs, 10 oz & we called him Cameron Anthony after his dad. The doctors made it clear there wasn't much hope as it was a bad hernia. He held on for 18 hours but then lost the fight on the November 21, 97. I still don't regret not having the termination, otherwise I would never have seen my son's big chubby face. Eleven months later, I had another son who was stillborn. This time through a totally different reason. You wouldn't believe my terror at being told I'd lost another child. They are now together at the crematorium & I visit almost every week. I went on to have a healthy boy & girl to go with my 9 year old son but it doesn't get any easier & I'll never forget. Finding this site is a Godsend in itself. I thank all of you who take part in it.

Written by Cameron's mom, Sandra Kennell (Great Britain) in 2003



Colin Raymond Hambel

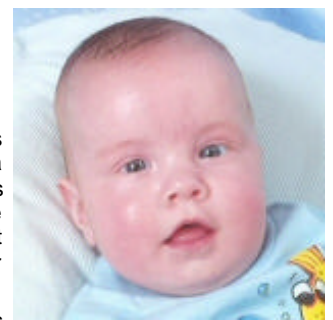
Born 11/8/04

Our little Colin was diagnosed with CDH in utero at about 21 weeks gestation. After hearing the exciting news that we would be blessed with our second son, the doctor informed us of the problem and sent us directly in for a more detailed ultrasound. Devastated, we then learned that Colin's stomach was occupying the left front area of his chest cavity, with his heart shifted all the way to the right. The doctors informed us that the early appearance of the hernia (before 24 wks gestation), the size of the defect (allowing the entire stomach in the chest), and the significant shift of the heart indicated a poor prognosis. We held on to hope, however, and were happy to hear that no other abnormalities appeared to be present. We knew we would do all we could to give him the best chance we could.

After returning home, we began to do research, with the internet as an invaluable resource. Our care was transferred to St Joseph's and CHOC in Orange, California, both of which have a lot of experience with CDH and the best doctors and medical treatment capability we could have asked for. Being at the right place is so important, both for the treatment for the baby and the support for the parents. A subsequent ultrasound showed the heart structure and function looked normal. At each checkup and ultrasound, I hung onto each word and each vision on the ultrasound screen, searching frantically for more information on the current status of the hernia, the heart and lungs, the fluid level, etc. to the point of almost driving myself crazy trying to look for signs that things would turn out okay.

We decided that our first son, Jacob, who was only 16 months old when we found out about Colin's CDH, was too young to understand what was going on and would be too young to visit the NICU after the birth, so we held off on telling him about his brother. This was a difficult decision, but seemed to work out for the best. We also struggled with how many people to share Colin's condition with. We decided to tell family and a couple of close friends only, and for our wider circle of friends, wait until the birth, so not so many people had to worry for so long, as we did. I met a friend through Cherubs, who although she lost her little boy just two months before Colin was born, was a wonderful support through the remainder of the pregnancy as well as the hospital stay.

My fluid levels were consistently high, though not quite polyhydramnios, but I decided to stop working about 6 weeks before the due date to give us time to prepare. The timing was perfect, because the following week, my fluid levels began to skyrocket and the minor Braxton Hicks contrac-



tions I had been experiencing became more frequent and uncomfortable. At 5 weeks, 2 days to go, I was given a shot of terbutaline to stop the contractions, but just two days later, they started again and there was no stopping them. I was so frightened, as I wanted to keep him in as long as possible to improve his chances, but the time for him to start fighting had come.

He was 4 lbs 15 ozs. at birth, and was quickly taken to the NICU, with time only for us to hold his hand and tickle his toes through the isolette. Being alone in a maternity room is a terrible feeling, and while I wanted to stay where I had easy access to visit Colin, I couldn't wait to be able to sleep at home. The next time we saw Colin, he was stabilized on an oscillating ventilator and a host of IVs and medicines. He stayed fairly stable and on day 4, he had his operation. His stomach, spleen, and intestines were moved back into place, and fortunately he did not need a patch. Long days at the hospital became our routine, our life. It was difficult to try to give adequate time to care for both our sons. The following week was spent weaning Colin onto a regular ventilator, and on day 11, he was extubated. His first cry was like music, we were so happy. After two more weeks learning to breast and bottle feed, we brought him home to meet his brother for the first time. He was on reflux medicine till 3 months, but now at 6 months appears to have no major lasting effects beyond his scars.

I am still amazed each morning when I first pick him up out of his crib. This experience has taught us so much about faith, hope, family, and friendship. We know we have witnessed our own little miracle.

Written by Colin's mom, Mary Hambel (California) in 2005

Kevin Russell Morgan Jr.

2/1/05 - 2/7/05

It was amazing when I went back to my Drs. after severe bleeding and was told that I didn't lose my baby. I was then scheduled for an early ultrasound just to make sure everything was O.K. then it was canceled because his heartbeat was good, the bleeding had stopped and everything looked normal. I went for my regular ultrasound with no worries at all just excited to find out if it was a boy or girl. I first saw the look on the techs face when she told my husband that he was having a son but everything wasn't OK. The doctor told us we had a 50/50 chance of him making it so of course we took it. We cried for days and I didn't get out of bed but then I realized that if he was going to be OK then I had to be too. I guess I would say I pretended like nothing was wrong for the rest of my pregnancy other than a few extra appointments nothing was wrong to me. I was in my own world.

They scheduled to induce me so everything would be set up for our little bundle when he arrived. I was so nervous that day but I got to the hospital and it was normal again I guess they are used to not making parents panic. Our son arrived a little after 5 PM on February first he was six pounds, eleven ounces and was beautiful. He even made a little bit of a noise. Then he had to be put on an oscillator and taken away. I waited almost two hours before I got to see him. They finally took me to him and I knew he would never come home. I got to be with him for five minutes then they rushed him to Children's Hospital. Luckily it was literally across the street from Magee. My husband went with him and in the morning I went too. We spend countless hours hoping and praying for him to get well. The day of his surgery was perfect. He wasn't doing very well so they decided to do it. After the surgery they said he had been the best baby they ever had through the surgery and he was doing great. That night we were so happy he was doing wonderful then he crashed. They made us leave and decided to put him on ECMO. As they were putting him on his heart stopped for over an hour and he was gone. The doctors put him on anyway I supposed to let us say good-bye and we got to have him baptized. Our wonderful baby boy was six days old when we decided to take him off of the machines. Our decision was a good one I believe since he had no brain activity at all after his heart stopped. Thank you for reading this

Written by Kevin's mom, Melissa Morgan (Pennsylvania) in 2006

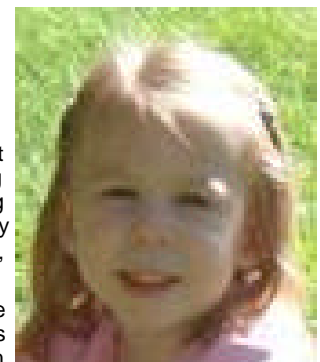
Brianna Mary Roberts

Born 9/20/04

This is the story of my daughter, Brianna Mary Roberts. On February 6, 2004, my husband and I found out that we were expecting our second child. We were very excited and our 4 year old son was thrilled about being a big brother. Somehow, I knew something was wrong from the beginning. I kept telling everyone that I just had a feeling that there was something wrong with the baby. After I made it passed 16 weeks I started to calm down. Then, on May 19th, at 19 weeks gestation, we went into my doctor's office for an ultrasound. Like most parents, we went in excited, expecting them to tell us the sex of the baby. We weren't prepared for the news we were about to receive.

The ultrasound technician was going through everything and pointing everything out to us. Then she came to the chest cavity where she pointed out the heart. I noticed a big black area right next to the heart and saw her label it as the "stomach". I thought I must have been looking at it the wrong way because that couldn't possibly be the stomach next to the heart! About 5 minutes later, she proceeded to tell us that she thought our baby had a Diaphragmatic Hernia and explained the basics of it. As I laid there crying hysterically, she informed us that it was a girl! The doctor set us up an appointment at the hospital for a level 2 ultrasound with a maternal-fetal medicine specialist to make the final diagnosis.

I was terrified and a complete mess. I couldn't believe this was happening to us. The worst part was that our level 2 ultrasound was not scheduled for 3 days, and my doctor wouldn't give me much information about CDH, he wanted to wait until we had a definite diagnosis, even though the ultrasound technician said that she would be shocked if the hospital said it was anything different. So, for those 3 days I did my own research. I read lots of facts and statistics about CDH and that was also when I found the CHERUBS website. I read many stories about other children with CDH, both



survivors and angels. These stories helped me a great deal. Knowing that there were many others who had gone through what we were about to go through. The survivor stories gave me hope and strength while the stories of CDH angels helped me prepare for the reality and severity of the situation.

After several doctors appointments, ultrasounds and non-stress tests, my water decided to break on September 18th, a few weeks before my due date of October 12th. At first, the doctors wanted to hold off my labor so they put me on a magnesium-sulfate drip, but then they decided to go ahead and let my daughter come into the world. My labor progressed wonderfully, and by the time I was dilated to 9 cm, my room was completely full of doctors and nurses, mostly waiting for the baby, who they knew was going to need a lot of help. My beautiful baby girl was born on September 20, 2004 at 1:09 AM. She let out two very small and weak cries before they whisked her away to the NICU.

By the time I was able to go up and see her three hours later, she was already hooked up to a ventilator. The doctors told me that her chest x-ray showed a small right lung and they could not see a left lung at all because of all of the bowel that was invading her chest cavity. She had severe pulmonary hypertension. She was stable, but they did not know for how long and they might have to resort to placing her on ECMO (life support). This terrified me. I had read many good and many bad stories about the ECMO.

By that evening, her oxygen saturation levels were dropping and her carbon dioxide levels were high. The doctor told me that if her oxygen level dropped any more, there would be a risk of brain damage. They had to change her ventilator to an oscillator and they also hooked her up to nitric oxide. She held out through the night, but by morning, they had to put her on ECMO. The pediatric surgeon made an incision in the right side of her neck and placed two cannulas (tubes) down a major artery to her heart. One tube removed the blood from her heart and brought it out to this huge machine. The machine took the carbon dioxide out of her blood, oxygenated it and then sent it back through the other tube to her heart. The whole process looked horrifying, but I had to keep reminding myself that it was keeping her alive and would hopefully help her to get better. My husband could not even go into the room to look at her, it was too much for him.

While she was on the ECMO, her right lung started leaking fluid into her chest cavity, so the surgeon had to insert a chest tube to drain it. On one of her many chest x-rays they were finally able to see that she did have a left lung, but it was only about the size of a pinky nail. Brianna was on the ECMO for a very long 12 days. They tried her off of the ECMO on Friday, October 1st but she didn't even last an hour before her numbers went bad and they had to start the ECMO again. They decided to try her off the ECMO again on Saturday, and to my surprise, she did very well. She was able to keep her oxygen saturation levels up and her carbon dioxide levels down, with the help of a ventilator, of course. The surgeon removed the ECMO cannulas from her neck Sunday morning.

Brianna seemed to be doing well and they scheduled her hernia repair surgery for Wednesday, October 13. Then on the morning of October 8th, Brianna took a turn for the worse. They couldn't wait any longer, they rushed her into surgery to repair the hernia. After about 2 and a half hours, the surgeon came to tell us that the surgery went well. She told us that Brianna only had about 1/5 of a diaphragm and that her stomach, all of her intestines, her spleen and part of her liver were all up in her chest cavity. They had to use a pretty large gortex patch to fix her hernia. They also had to insert a second chest tube, this one into the left side of her chest.

The first couple of days after her surgery were very scary. She had to be placed back on an oscillator and nitric oxide. They started giving her steroids to try to help her lungs grow and strengthen. Many of the doctors and nurses have now told me that they really didn't think that Brianna would make it through that first night. But, she did, and things finally started to go uphill from there.

Brianna was put back onto a regular ventilator, her right chest tube was removed and they started to feed her through a feeding tube. I was able to hold her for the first time on October 17th, she was already 4 weeks old. Her lungs started to grow very rapidly and soon her left lung was as big as her right lung and they were both functioning very well. Her left chest tube was removed on October 20th. They tried to take her off of the ventilator on the 21st, but she was working too hard to breathe on her own and her respiratory rate was very high so they had to reintubate her. She was tried off again on the 28th and this time she did very well and was able to stay off. She now just had a nasal cannula. The doctors prepared me for all of the many feeding problems that they anticipated Brianna to have. They said she would have a lot of reflux problems and spit up a lot. They also said that she would have a hard time learning to feed from a bottle. But, Brianna did not show any signs of reflux and on November 2, she was bottle fed for the first time and took right to it like a pro! Her feeding tube was removed the following day.

On November 8th, Brianna's nasal cannula was removed and she was breathing all by herself! After 8 very scary weeks, we were finally able to bring our baby girl home on November 14th! She had to have one more surgery on May 20, 2005 to repair a hernia in her muscle where the original surgery had been done, but she did so well though that, we were released the next day. Brianna is now almost 2 years old and doing great! The scars will always remain, but that's alright because they remind me everyday of just how lucky we are to have her here.

Thank you very much for the CHERUBS website. It has been very informative and has helped us get through the hardest time of our lives! I hope my story can inspire and give hope to other parents who have or are expecting a child with CDH

Written by Brianna's mom, Kelly Roberts (Colorado) in 2006

Emma Fahey

I discovered I was pregnant with our second child in December 2003. Daniel, our eldest, was 2, and had been born with no problems at all. It was a shock to find out, at 19 weeks, that the baby's heart was on the right hand side. There was no indication at this stage of any other abnormality, and a visit to Leeds Heart Centre showed the heart was working perfectly. Even so, we were devastated; little did we know of the scale of the heartache still to come.

We battled on, with scans every 4 weeks, when, like a bolt out of the blue, the stomach and bowels were seen to be in the chest cavity - a diaphragmatic hernia. This was at 35 weeks. Having had the scan early on a Friday morning at the beginning of July at our local hospital, we had to wait until Monday to go to see the consultant at Leeds General Infirmary. We had some idea of the implications of a diaphragmatic hernia, and over the weekend, emotions veered from complete despair, to hopefulness, and a sense of the whole thing being surreal, and so bad it could only happen to someone else.

At 9am on Monday in Leeds, we were told our baby had a 20% chance of survival. I remember it like it was yesterday, and I still can't imagine a worse moment in my whole life. Anyone who has had this news will understand that the emotions can't be described. The consultant was so sympathetic and compassionate and understood how we were feeling. He answered all our questions - why had it happened? Was it something I had done? We were plunged into a whole new world, an all-engulfing thing that would completely take over our lives from that moment.



We drove home in a stunned silence. Nothing mattered anymore – work and other things were just insignificant - friends and family rallied round, and my Mum ran our house with military precision.

Every minute of every day seemed like a lifetime. I could hear the clock ticking like I was heading towards impending doom and there was nothing I could do to stop it.

Days went by - I went out occasionally to playgroup with Daniel, to the hairdressers, to Tesco's, all the while looking at other people thinking how it was strange the world could carry on so normally whilst ours had come to a standstill. Friends with toddlers Daniel's age offered support, and some people just didn't know what to say.

Five weeks went by in this limbo. I went to Leeds every Wednesday for a scan, and each time I saw the baby I felt like crying, as it was destined to a fate I just couldn't help. We were on a rollercoaster of weighing up our 20% chance, being positive and then plunging back into despair.

Towards the end I had a feeling of inevitability. I had 3 litres of amniotic fluid drained due to polyhydramnios in mid-July and felt physically better. When my waters finally broke on Sunday evening at home, I think we were relieved the limbo we were in was finally going to be over, and we would know one way or the other what was to become of our little one.

I had our little girl early the following morning, and I saw her briefly before she was taken to NICU. She looked healthy, she was on time and 6lb 10oz - the same weight as her big brother. They looked just like each other.

Three hours later, we were in NICU sitting next to our daughter. She was anaesthetised, paralysed and on life support. We were told she was stable and funnily enough I felt pretty calm, although my husband Simon was shocked and tearful.

This was the beginning of the long haul. It was four days later that Emma finally had her operation. I honestly felt like I had won the Lottery - she had made it in my eyes. However, following her to the theatre (after one false start the day before) wasn't nice. We sat next to her for 10 days before we had to go home to start coping with Daniel and the daily trips to Leeds to see Emma. With a few ups and downs, Emma eventually made it out of NICU and onto a surgical ward. She had a feeding tube and I was expressing every four hours like clockwork - it was a focus for some semblance of a routine.

Emma finally came home at the beginning of September, age 5 weeks. There was a spell in November when she went into hospital with bronchiolitis. We have struggled on with various issues as they've cropped up. It's been a bit like feeling your way in the dark, with no-one locally really aware of the implications of looking after a diaphragmatic hernia baby - feeding, breathing, day to day activities, and how to work round routines with Daniel, oxygen levels, chest infections, when to go to the doctors without seeming to be a pest (assuming you have a doctor who knows about CDH – in my experience, not all of them do). It's been a long hard slog, but we now have an 11-month-old little miracle who can eat, sleep, breathe quietly (most of the time), and do all of the things other babies do at playgroup. She thinks the world of her big brother, and he her. At her christening next month, there won't be many dry eyes, as she's special to everyone who knows her.

I have heard of three other cases in the North of England and have been in touch with 2 other parents; one 18-month-old boy and one 10-month-old boy. The third baby didn't survive. I would love to hear from other parents who found themselves in our position, and I am so pleased to have found a point of contact - I would offer in return any support and help I can. Just to chat with other parents of Cherubs would be great.

Written by Emma's mom, Donna Fahey (Great Britain) in 2005

Benjamin Satyawan

Born 7/22/07

Ben was diagnosed with Congenital Diaphragmatic Hernia in a late gestation of week 36. When we were first told about the defect we were both devastated. We first felt how unlucky we were to have a very rare case. Now we understand that that was the luckiest day of our lives to know beforehand and get every specialist doctors ready for the day.

We kept the gender of the baby for a surprise. But knowing the baby has the defect, we would like to know the gender to name him and start calling him by the name. It was a baby boy. He was our second child; our first is a 3.5 year old girl, so it was happy news wrapped in a bad news.

One week after, we were given a tour to see the special care nursery. I guess they wanted us to be prepared for those wires that are going to be attached to our little one. The fetal specialist did another scan, she said the CDH is on the left hand side. Only the bowel came up to the chest and the rest of the abdominal organs were in place; which was a little unusual. She hoped that the baby would have a full term of 40 weeks, so that he will be more matured for the battle.

In the afternoon, on the same day, the water broke. We rushed up to the hospital. They did not want to induce the contraction nor do a caesarean section. Vaginal delivery has the best outcome as it squeezes out water out of baby's lungs. Ben was born at 10 o'clock in the following morning. He was so blue and purple. There were four doctors in the room tried to save his life. After 5 seconds of cuddle with mom, he was put straight on the oxygen in thermal cot and was sent straight away to the special care nursery. Daddy was with him when the doctors tried to stabilize him. He was put on a high frequency ventilator with all other wires attach to him. They did an x ray. It was a positive case of CDH. Only bowel was misplaced as expected. They could not say how big the hole was. Not until they do the operation.

The operation was going to be done in Children Hospital. They had to transport him in an ambulance. But first they need to stabilize him and move him from high frequency ventilator to the normal ventilator which is available in portable version that can be carried with the ambulance. Ben was transported a day after. And the children hospital had to stabilize him once again. That night the surgeon told us that the operation will be carried tomorrow morning. They did not want to delay the operation once the baby is in stable condition. They were afraid it was only a honeymoon period before it gets worse.

That morning on the day of his operation, we met the surgeon and anesthetic team. They explained everything. The surgeon said he would rather not put patch on the hole to avoid another operation. The best way to go is to fix the hole properly to give a permanent result. We sent him to the operating theater and gave him a kiss before he went in. It was the saddest moment. The operation was 2 hours long. The surgeon told me the operation was successful, the hole was quite large. But it does not matter anymore whether it was big or small, it is fixed now. The affected lung had a good



expansion after he removed the bowel back to the right position. He said not to worry about any other consequences like gastro reflux as some babies might not have one.

After 2 days of recovering. He was off the ventilator. It was very good news. He was in pain when he woke up because the morphine was reduced to avoid respiratory problem. After two days of breathing on his own, suddenly he turned blue and had difficult breathing. Doctors again put him on the ventilator. They did three x-rays on that day. They said the one of lungs was collapsed and the chest was filled up with water. They water were supposed to be absorbed by the body. I guess Ben was too tired breathing by his own.

We have never stopped praying since the problem was diagnosed. The answer of our pray was revealed on that day. Since that down day, he was recovering fast, much faster than the doctors expected.

He was off ventilator again in two days. He was put on CPAP, a lighter breathing support. He was off CPAP after 2 days. He starts to breath by his own since.

He started to get hungry and getting very unsettled every time he woke up. Doctor started to introduce a 20ml every 3 hours via the feeding tube and increased it gradually when they found out the bowel was in a cooperative condition. In 24 hour, he took 60 ml, a full size meal for a baby. Doctor wanted mom to breastfeed him, rather than rely on the feeding tube that make him lazy. It took 3 days for him to learn how to suck the milk. Ben passed the hearing test as well. Finally, he was discharged from the hospital after 16 days of battle. We were so happy that day .

Doctors said it was the best case of CDH they have ever seen. They said it couldn't be any better.

We are writing this story to give victims of CDH a hope and a positive mind. We were lucky to know it on week 36 instead of week 20, so that we had a very healthy pregnancy. Even if you find out on Week 20, don't feel discouraged. Keeping your pregnancy to the best healthy condition is the important and the only thing mom can do before the baby is born.

Pray and pray a lot, it really helps. God will not give you a test that you can't bear and is more than your capability.

There are still miracles in the making as long as you really have that faith and ask for it from God. Nothing is impossible for Him. Thanks God for that speedy recovery of our baby boy.

Written by Benjamin's parents, Henny K Dewi & Effendi Satyawan in 2007

Kaylaya Arrisa Morgan

Born 2/27/07

Joe and I recently brought home our baby girl Kaylaya Arissa. She was born with what is known as a Congenital Diaphragmatic Hernia. She had a right-sided hernia and her liver was up in her chest where her lungs should have been growing, her chances of survival early on were lower than 50%.

We found out at 18 weeks that something was wrong and that her heart was displaced. On Halloween last year we got the diagnosis of CDH and were told that her liver, at that point, was as far up as her shoulder. CDH is more common in boys and more common on the left side. With Arissa being a girl and being right-sided, she was determined to be different I guess. Typically right-sided hernias are said to be more severe because the liver slips up into the chest rather than the the stomach and bowels, the liver is a dense organ and it's said to more difficult for the lungs to grow. It took us completely by surprise when we were given the option to terminate the pregnancy, it was just something that we had never even considered. Both of us said no without even looking at each other. We decided then that our job was to give her the best fighting chance possible.

We went on a search and found a surgeon, Dr. Kays, in Florida where it was said he had a 92% success rate rather than the national 50% given to these babies. We were told that he tends to be pretty optimistic when predicting the chances of survival and at our consult with him he gave our baby girl a 40%. She had an LHR (lung to head ratio) of .58 and typically in studies babies under a 1.0 LHR are considered severe and babies under a .6 LHR are considered a non-survivor. Luckily with all of that against her Arissa had an isolated case of CDH and she was in absolute perfect health besides the fact that her diaphragm didn't form, though we weren't sure of that until after she was born.

So I relocated to Florida a little over a month before she was born, since there is a risk of preterm labor with DH babies. She was born on February 21st and within hours was put on VA ECMO (a machine that works as the heart and lungs, it pumped all of her blood out of her body and through a machine that oxygenates her blood and circulates it back into her body, understandably it's a very critical time where almost anything can happen). Dr. Kays decided that her condition was so severe with so much of her liver in her chest, and so little room for her lungs to expand that he wanted to do the surgery while on ECMO when she was only 5 days old, this was a concern because she was on blood thinners to try to prevent blood clots forming in the ECMO machine where they could break loose and send a blood clot through her system. Dr. Kays put a Gore-Tex patch in to serve as her diaphragm now, only about 2-3% of her own diaphragm had a chance to grow, so it is a large patch to make up for the other 98%. It is sewn to some muscles and her ribcage on the right side where there was nothing else to sew the patch to. Her own diaphragm will continue to grow and by the time she's an adult it will only be a small percent of her diaphragm rather than 98% of her diaphragm.

After the surgery Dr. Kays told us that over 75% of her liver was in her chest. She had a small left lung that had been trying to grow between her ribcage and her heart and he described her right lung as a "pancake". After a long two weeks on ECMO blood clots had started to form in the 'wrong' places and the circuit needed to be changed so they decided to try her off ECMO completely because she had done so well when they stopped the machine after a previous blood clot scare. We were told the next day that there was a 90% chance of her going back on ECMO. Her heart was having trouble pumping blood to her lungs because the pressure in her lungs was too high and blood was backing up in her liver. Dr. Kays worked his magic with some fine tuning, flipped her on her belly with the cannulas still in her neck, chest tube, breathing tube and IVs and Arissa never took another step back. She had tolerated everything from day one with no desats and from then on she was on her way home, we weren't always sure but I guess she was. She was soon off the oscillator and onto a vent. After 2 weeks she was able to go to a CPAP. I was able to hold her for the first time when she was 1 month and 1 day old. She spent 6 days on the CPAP then went to just a nasal cannula. One day later at 5 weeks old she was moved down from NICU III to NICU II.

We spent the next 25 days in NICU II working on her feedings without too many problems, the main concern was her weight gain. With her being a right-sided DH, so much of her liver had gone up into her chest that there wasn't much room for anything else to fit so the rest of her organs stayed down for the most part only a small portion of her bowel had slipped up during the last few weeks of the pregnancy. This being the case she doesn't have as many problems eating as they'd expect from a left-sided DH. She does use more calories than other babies eating because she works harder



to breath with her lungs being so small so her weight gain has been slow going. She's 8lbs 6oz now at 13 weeks so we have some catching up to do. It ended up being a total of 61 days in the hospital before we took her home, and 91 days away from home for me. It has been a LONG pregnancy and first few months of her life, but I wouldn't change it for the world. She's amazing and has gone through more than most people go through in a life time.

I'll be the first to admit that Baby Girl has an attitude, but I'm sure that's what got her through this and I promised the Lord that if she got through this I'd be willing to put up with anything she had to give me :) There were times when I thought we might be asking too much of her, especially when we had to hold her down through the breakthrough pain, but to the moms out there that are going through the same thing right now, she's one of the happiest babies now, after it all, that I've ever seen. With the way she fought I knew she wanted to be here just as much as we wanted her here and there was no way I'd ever have given up on her. For some reason she was meant to fight this battle and Joe and I were meant to be there for her while she did it. I felt from the very first day we found out that she had CDH that she was chosen for me, I don't know if I've done anything special for her but I know that she's changed my entire outlook on life, I've always believed in miracles but never thought I'd be given one.

We're home now, and she's on a very small level of oxygen just until her lungs finish healing. She doesn't really need it but Dr. Kays thinks that it can only do good now. To be quite honest I'm not sure how much she actually gets, she's a Houdini with that nasal cannula, at this point I'm just short of wrapping her head in medical tape to keep it on. Her lungs will continue to grow throughout childhood so she's going to live a completely normal life.

Written by Arrisa's mom, Jessica Morgan (Maryland) in 2007

Meeting Members

In April, 3 CHERUBS members traveled to Maryland to meet the Varen family and sweet little cherub, McKenna Lynne Varen. It was our honor to meet and hold this little angel, who passed away just a few days after our visit. McKenna will always hold a special place in our hearts. From Left to Right—Judi Toth (mom of Christopher Michael Toth), McKenna Lynne Varen and her mom Alyssa Hagen, Dawn Torrence (mom of Shane Torrence) and Brenda Slavin (mom of Amanda and Nicholas Slavin)



Photo to the left - Nate and Corin Nava, parents of Gabriel Nava and Dawn Torrence, mom of Shane Torrence, met in N.C. in August



Michigan Get-Together

Flint, MI - Nov. 10, 2007

From left to right: Faith (inutero), Shane (sibling), Logan (survivor), Casey (survivor), Allen (sibling), Trevor (sibling), Carsen (sibling), Alyssa (sibling), Brent (sibling)



CHERUBS 2007 Ohio Member Picnic



CHERUBS Australia 2007 Member Conference



CURRENT CDH Research Studies!

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

Fryn's Syndrome
University of California
San Francisco, California
Contact: Anne Slavotinek
(415) 514-1783

Identifying Genes Which Cause CDH
Emergen Labs
Salt Lake City, Utah
Contact: Mary Meade,
MMeade@emergen.com

Outcome Predictors In Infants w/ Congenital Diaphragmatic Hernias (CDH)
The Center for Advanced Maternal Fetal Care
Vanderbilt University
615-936-3413 or 1-877-338-8786

Identifying Causes and Solutions of CDH
CHERUBS
Henderson, NC
(252) 492-6003
Don't forget to become a member and send in your CDH Research Survey

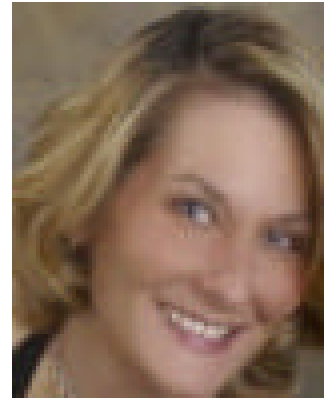
Upcoming Conferences & Get-Togethers

2008 CHERUBS international Member Conference
2008 CHERUBS Australia Conference
2008 CHERUBS UK Conference

North Carolina Member Picnic
Ohio Member Picnic
Contact your Representative for more info!

Brenda's Corner

Maintaining a Healthy Marriage is Worth the Investment



For Surviving Families of Cherubs

As you know having a special needs child requires a lot of physical and mental energy. These children become your world, and rightfully so. Marital problems can come into play when one parent feels the need to control all aspects of the child's care. These parents feel overwhelmed and can feel that they have lost their own identity. The other parent feels excluded and not trusted to care for their own child. These feelings in turn, can develop into resentment for each parent. Both parents need to be actively involved with the child's care and needs. Both parents have so much to offer the child, but in different ways. The parent in control needs to step back and ask themselves, is the way things are being done by my partner really unsafe for our child? Or is it really they are not doing things the way I would do it? Think about how you would feel if you were the excluded parent. Talk openly and honestly with your partner about your feelings of being overwhelmed or feeling excluded. Is there another family member or friend that can offer a break to both of you? It is essential to take time out alone with and without your spouse. Time with each other alone can bring back the closeness you probably both crave from each other. Take time alone to read a book, call a friend, go out to lunch, go shopping, fishing, golf etc. This time will give you back both your identity and self worth. If you do not take the time to invest in your marriage, what do you think the outcome is going to be? Marriage is already difficult without adding a special needs child or other children into the picture. You have to work even harder when this is added to your marriage. Sure, you both have changed since your child was born, however you now have a choice. Do we wish to grow together or continue to grow further apart?Invest wisely

For Non-Surviving Families of Cherubs

In a marriage that has suffered the biggest loss imaginable, there are so many difficult paths a person must go through alone, and together with their spouse. Initially, the absolute shock their child has died can make both partners numb. This is probably the only path you two are on at the same time. We all go through the normal steps of grief but at different times and in different ways. This is where the foundation of the marriage can begin to crumble if not carefully cared for. It is absolutely normal not to be on the same path because clearly you are two different people. As one goes through anger, the other may be going through sadness. The angry partner cannot understand why the sad partner isn't angry too. And certainly, the sad partner cannot understand how someone can always be so angry. You begin separate paths without even realizing it. Maybe you already resent your partner for not feeling the way you do. Again open honest communication is a must; however, empathy needs to be added. As crushed as you may feel, you need to reach deep into your soul for the compassion to help your partner. Neither of you wants to be alone in this horrifying journey. Problems also may arise if you are stuck in a certain phase of your grief. You may not be talking daily about your phase of grief, but in many aspects of your life it shows. Angry people tend to take their anger and frustration out on the world and their spouse and they may not be aware of their own actions and words. They become argumentative with family, friends and even strangers about things normally they would not. They also become less patient and more frustrated in situations that they normally would not. They are viewed as bitter and angry people. Over time, very few family and friends wish to be around them. It is essential for this person to seek therapy not just for their marriage but for themselves. A counselor or therapist can help you move through this phase in a more healthy productive way. If not addressed this phase may lead to further depression, alcohol, substance abuse or other unhealthy addictions. This only adds more problems to the marriage and all of your relationships in your life. It is not the world's fault your child died. Your family and friends want to be there for you, but you need to let the anger go to gain peace in your life again. It's okay to need someone to help you through this. After all you are not meant to be a martyr.

If you are stuck in the phase of sadness, first of all I can personally empathize with you, as I was stuck in this for a long time after I lost both of my children. When you are consistently sad about the loss of your child, you completely lose sight of everything around you. You fall further within yourself and the wall around you grows so large, people cannot get in to be there for you or to help you. You may fall into a deep depression. No longer does anything in life become enjoyable again. Maybe if you laughed or started to enjoy life again you feel your child would be disappointed in you. You so want to "show them" how much you love them by letting their death become the center of your life. This is so far from what our cherubs want from us. They want us to be happy again. They want us to laugh. They want their parents to become closer instead of further apart. They want us to stay married instead of getting divorced. They want us to have more children if we want more children. They want to smile down on us instead of crying for us. They want us always to remember them with more smiles than tears. Again, if you find yourself in stuck in this phase please seek a counselor or therapist. It is normal to feel sad. It is not normal when sadness consumes your life. You also are not a martyr and should not be ashamed to need someone to help you. Don't be afraid to let people in to help support you. They do want to be there for you but may not know how.

For Survivors and Non-survivors of Cherubs

If you do make the decision to go into counseling or therapy whether alone or with your spouse, please go whole heartedly. Do not go to please your spouse. Do not convince the therapist you are "fine". Therapy can be very grueling. You are taking your inner most deepest emotions and laying them out to a stranger. Please invest 100% into it. To not go to the core of your emotions will only rob yourself of truly healing. Remember, you and your marriage are worth the investment.

I wish each and every one of you peace and love. The best gift you can all give is yourself....

Brenda Slavin RN

Bereaved Parent Advisor and Maryland State Representative

Mommy to Amanda (11/06/93 - 11/01/94), Nicholas (11/06/95 - 11/06/95), Stephen (09/23/97), and Michaela (06/03/01)

CHERUBS State Representatives

Our State and International Representatives do so much to help us to help CDH families. They welcome new families in your state/ country and listening to them and helping them with information about CDH. They can also help you with our web site and match you up with a local family. They also plan state and country get-togethers. Please do not hesitate to contact them!

State	Representative	Phone Number	E-Mail Address
Alaska	Renata Hoskins	907-245-8817	rhoskins@cherubs-cdh.org
Arizona	Phyllis Smith	501-305-9003	psmith@cherubs-cdh.org
Arkansas	Bethany Gillham	479-305-0448	bgillham@cherubs-cdh.org
California	Tammy Spohr	530-273-2156	tsphor@cherubs-cdh.org
Colorado	Kelly Schitter	303-926-0989	kschitter@cherubs-cdh.org
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Washington DC	Judi Toth	443-404-8510	jtoth@cherubs-cdh.org

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Papau New Guinea	Danielle Kessner	03 5135 6999	dkessner@cherubs-cdh.org
Scotland	Marie Brown	01389 380120	mbrown@cherubs-cdh.org
South Africa	Karen Howard	011 880 2981	khoward@cherubs-cdh.org
The Netherlands	Chantal Verzijl	0031- 30 6931411	cverzijl@cherubs-cdh.org

CHERUBS On-Call Volunteer Parents

Our On-Call Volunteers are available 24 hours a day, 7 days a week if you need to talk. Please do not hesitate to contact them if you are having an especially hard time and need a shoulder to cry on.

Please also contact our office at 252.492.6003 for questions about CDH or CHERUBS and remember that our web site is also available 24 hours a day, 7 days a week!

On-Call for Grieving Parents

Volunteer	Phone Number	E-Mail Address
Amy Rademaker	616-844-4156	arademak@cherubs-cdh.org
Freedom Green	410-363-7465	fgreen@cherubs-cdh.org
Karen Myers	210-403-3483	kmyers@cherubs-cdh.org
Malini Rao	972-423-1871	mr Rao@cherubs-cdh.org
Shelly Evans	512-864-5976	sevans@cherubs-cdh.org
Danielle Kessner (Australia)	03 5135 6999	dkessner@cherubs-cdh.org
Laurelle Lehmann (Canada)	250-838-7000	kschau@cherubs-cdh.org

On-Call for Expectant Parents

Volunteer	Phone Number	E-Mail Address
Kerrie Chamberlain	541-664-9016	kchamberlain@cherubs-cdh.org
Tammy Spohr	530-273-2156	tsphor@cherubs-cdh.org

On-Call for Parents of Survivors

Volunteer	Phone Number	E-Mail Address
Elaine Moats	406-234-5038	emoats@cherubs-cdh.org
Tara Hall	614-275-0858	thall@cherubs-cdh.org

**CHERUBS - The Association
of Congenital Diaphragmatic
Hernia Research, Advocacy
and Support**

270 Coley Rd.
Henderson, NC 27537
USA

Phone: 252-492-6003
Fax: 815-425-9155
E-mail: info@cherubs-cdh.org

www.cdhsupport.org

CHERUBS was founded in 1995 to support families of children born with Congenital Diaphragmatic Hernia (CDH) and to research possible causes and better treatments for CDH. CDH is a devastating birth defect, affecting 1 in every 2500 babies.

Currently, CHERUBS has over 2000 members in 36 countries and all 50 states; including parents, grandparents, foster parents, pediatric surgeons, genetic counselors, pediatricians, nurses, ECMO directors, respiratory therapists, and epidemiologists.

CHERUBS is an IRS approved 501(c)III non-profit organization located in North Carolina. Membership for parents is free and our organization is run solely by volunteers and funded through donations from members and the public. For more information on CHERUBS and CDH, please feel free to contact us or visit our web site at www.cdhsupport.org

Please update your CHERUBS Membership Information!

The information on your membership form is 100% confidential. We do not share or sell your information to any other organization.. The information on our membership forms is used to contact you, match you with other families, notify you of local events, send you newsletters and cards and to conduct research. Every medical question that you answer helps us to research the cause and prevention of CDH . Please make sure to keep this information up to date.

Please clip out, fill in and mail to CHERUBS

CHERUBS, 270 Coley Rd, Henderson, NC 27537, USA

Your Name: _____

Mailing Address: _____

Phone Number: _____ E-Mail Address: _____

Cherub's Name: _____ Birthdate: _____ Deathdate: _____

I would like to make a tax-deductible donation of \$ _____ in (circle one) honor / memory of:

It costs approximately \$30 to print and mail 4 newsletters per year to each member. Please let us know if you wish to continue to remain on the newsletter mailing list.

I would like to stay on the CHERUBS mailing list. I will view the newsletter on-line to save costs