

# CHERUBS

The Association of Congenital Diaphragmatic Hernia Research, Advocacy, and Support



**The Silver Lining**  
Spring-Summer, 2005

**CHERUBS**

270 Coley Rd.  
Henderson, NC 27537

**letter from dawn...**

Dear Members,

CHERUBS is now 10 years old! It seems like just yesterday that we had just a handful of members and we knew everyone's names, parents, birthdays and memorials by heart without the need for a database. As of this writing we now have over 1,700 members worldwide! What a long way we've come from 2 members and a typewriter. Stay tuned this summer when our web site will be getting a whole new look in celebration of one decade of CHERUBS reaching out to parents of CDH patients.

We had high hopes of a grand 10 year anniversary International Member Conference, but alas funds and time just didn't cooperate again this year. We are starting to work on next year's conference and we will have it even if we have to have it in my own back yard! There are local get-togethers

planned and posted in this newsletter and members from out of state and / or country are also invited so look and see if there is a get-together near you.

We have moved yet again. Please note our new address is CHERUBS, 270 Coley Rd., Henderson, NC 27537 and our new phone number is (252) 492-6003.

Another year has gone by since our last newsletter as we fell behind yet again. I thank you all for your patience and those of you who have subscribed to the newsletter will get an additional year free to make up for our tardiness.

We are still working on our books and also our CDH Research Survey Results. If you haven't sent in your survey (and your child is over 1 year old or a non-survivor) or your cherub's story and photo, please send them in. We prefer stories are e-mailed or sent

on disk so we don't have to retype them.

A huge thank you goes out to 2 people who have been a tremendous help to CHERUBS; Carol Lynn Cole, our new Newsletter Editor, and Shelly Evans, our Volunteer Coordinator. We would also like to thank our many other volunteers who help us to help you. We are always in search of more volunteers so please contact us if you are interested.

I hope everyone has a wonderful and safe summer.

Sincerely,  
*Dawn M. Torrence*  
President, CHERUBS



**CHERUBS' Newsletter Subscription & Parent Membership Fees**

In 2001 we implemented \$20.00 annual, Voluntary Parent Membership Dues. The dues are voluntary and tax-deductible. We ask that all members who can afford to make donations to please do so. We have no paid employees, only volunteers. Every dime of your donation goes directly to help us help CDH families.

Because of printing annual subscription dues of \$20.00 are required to receive a printed copy of our newsletter. It will be viewable on-line for free. If you cannot afford to pay for a subscription and are not on-line, please just check the appropriate box on the form below and we will do our best to ensure that you stay on the mailing list. If you paid for a printed subscription in 2004 it will carryover to this year because we were unable to get the newsletter out as scheduled.

**CHERUBS' Newsletter Subscription & Parent Membership Form**

Your Name: \_\_\_\_\_ Your Cherub's Name: \_\_\_\_\_

Your Mailing Address: \_\_\_\_\_

2005 Silver Lining Subscription (\$20.00): \_\_\_\_\_

2005 Annual Voluntary Parent Membership Fee (\$20.00): \_\_\_\_\_

Additional Donation: \_\_\_\_\_

I cannot afford to donate at this time, but please keep me on the newsletter mailing list \_\_\_\_\_

Please mail to: CHERUBS, 270 Coley Rd., Henderson, NC 27537



## New Arrivals

(\*siblings of Cherubs)

Danae Adame\*  
 Mia Marvelle Bayardo  
 Anyka Bolin\*  
 Kathleen B Booth  
 Mitchell Bowring\*  
 Theresa Brown  
 Jayce Lee Bult  
 Dylan Burgess\*  
 Cynthia C. Chen  
 Gregory Z. Couret  
 Eliana C. DiCicco  
 Carter R Egloff  
 Louis Ericson  
 Arianna Nadia Farooq  
 Erin Shawn Feaster\*  
 Faith Ella Halbeisen\*  
 Colin Hambel  
 Aaron Hanlon\*  
 Rebecca Faith Havar  
 Baby Hays  
 Arti Hodgson  
 Morgan Scott Judd  
 Liza Kelly\*

Matthew Kennedy  
 Logan J. Kremer  
 Baby Leffler  
 Peyton Rose Leone  
 Ryan Letford  
 Jacob William McGrath  
 Ashlynn Mikel Meldrum  
 Caleb Mitchell\*  
 Kevin Russell Morgan  
 Asmit Amit Mundra  
 Macy Khyra Lee Radford  
 Tyler James Reams  
 Nicolas Reid\*  
 Brianna Mary Roberts  
 Taryn Faith Rogers  
 Simon T. Ryley  
 Pan Sephton  
 Eli Simon Stukalsky  
 Nathan Suranie  
 Nathan Jay Thornton  
 Chloe Towne  
 Jack Towne\*  
 Baby Tuohey  
 Byron Vella\*  
 Baby Williams  
 Emily Wood\*  
 Jordan Jett Wolfson  
 Baby Yammarino

## This Newsletter Is Dedicated To the Memories of:

Philip Meade Austin  
 Natalie E. Bankes  
 Rachel Marie Barragan  
 Anthony Joseph Bergman  
 Ali A. Boner  
 John Boydell  
 Mitchell Robert Bracht  
 Kayla Rae Brewer  
 Gregory Z. Couret  
 Jacob Daniel Elizondo  
 Arianna Nadia Farooq  
 Sean Anthony Feaster  
 Faith Marie Florez  
 Jak W. P. Foster  
 Brandon Christian Frush  
 Avery Lynn Graham  
 Olivia May Halstead  
 Bethany Grace Hart  
 Adrian Pietro Higueros  
 Braeden Ryan Holmes  
 Julien Leroy Howson Jr.  
 Matthew Glenn Hueser  
 Austin Bradley Johnson  
 Kendall Reese Kennedy  
 Kevan Benjamin Mahendran  
 Landon E. Massey  
 Tyson Jonathan McCaffrey  
 Jacob William McGrath  
 Sara Joy Miller  
 Christian James Payne  
 Jordan Ann Poore  
 Oscar Sanchez, III  
 Kaleigh Lynn Schad  
 Eli Simon Stukalsky  
 Angel M. VanPuymbroeck  
 Aidan I. O. Yusuf

### Did You Know?

**CHERUBS Current Membership:**

1,732 families  
 121 medical professionals  
 34 grandparents/additional members

**CHERUBS Members Are In:**

44 countries  
 50 states in the U.S.

**CHERUBS Staff:**

0 Employees  
 17 Committees  
 67 Volunteers



**new members...****We Would Like To Welcome The Families Of The Following New Members:**

(This list includes only those new members who gave permission to have their names published.)

Hunter James Alexander	Avery Lynn Graham	Kevin Russell Morgan
Camille Rosette Archer	Dylan Cole Gray	Brayden Wayne Morris
Rachel Marie Barragan	Alisha A. Hahn	Elizabeth Faith Mumma
Mia Marvelle Bayardo	Olivia May Halstead	Asmit Amit Mundra
Savannah A. P. Bendik	Colin Hambel	Kinza Ymeen Muneeb
Anthony Joseph Bergman	Bethany Grace Hart	Caitlyn Makenzie Niemi
Payden Janelle Black	Baby Hatchell	Ryan Xavier Norris
Ali A. Boner	Rebecca Faith Havar	Emily Ann Pater
Kathleen B Booth	Baby Hays	Christian James Payne
Mitchell Robert Bracht	Adrian Pietro Higueros	Gabriel Plunkett
Alyssa Nicole Bradshaw	Jon "Jack" Guenther Hockenoyos	Jordan Ann Poore
Jack Hugh Brady	Braeden Ryan Holmes	Baby Poppe
Devin James Breneman	Julien Leroy Howson Jr.	Dylan David Potrikus
Kayla Rae Brewer	Matthew Glenn Hueser	Macy Khyra Lee Radford
Theresa Brown	Austin Bradley Johnson	Tyler James Reams
Jared James Buchamer	Morgan Scott Judd	Brianna Mary Roberts
Jayce Lee Bult	Sharon Beth Kaminker	Taryn Faith Rogers
Logan Thomas Byard	Kendall Reese Kennedy	Simon T. Ryley
Cynthia C. Chen	Matthew Kennedy	Jaiden E Sanchez
Jackson Walter Clark	Ryan Michael Kilgore	Oscar Sanchez, III
Gregory Z. Couret	Kaleb M. Kinert	Kaleigh Lynn Schad
Patrick Ryan Daly	Allie M. Kinniburgh	Pan Sephton
Isaac Kenyon Dean	Baby Korn	Robert Joseph Bryce Southwell
Alexander J. Diaz	Logan J. Kremer	Alyssia Angel Squyres
Eliana C. DiCicco	Baby Leffler	Eli Simon Stukalsky
Teresa Gianna Faustina DiPrimio	Peyton Rose Leone	Emma M. R. Sturkie
Lauren Ann Douglas	Devin Michael Lewis	Nathan Suranie
Niko H. Duerr	Caleb Oliver Loeks	Cassidy Nichole Sylves
Carter R Egluff	Kevan Benjamin Mahendran	Nathan Jay Thornton
Jacob Daniel Elizondo	Patrick R Marshall	Baby Tuohey
Arianna Nadia Farooq	Joseph H. Martino	Angel M. VanPuymbroeck
Sean Anthony Feaster	Landon E. Massey	Bethany Hope Wallace
Madelyn Rae Flannery	Tyson Jonathan McCaffrey	Ian Matthew Wallace
Faith Marie Florez	Jacob William McGrath	Baby Williams
Jak W. P. Foster	Ashlynn Mikel Meldrum	Jordan Jett Wolfson
Brandon Christian Frush	Sara Joy Miller	Baby Yammarino
Eric Tyler Gibson	Divine Faith Morales	Baby Young
Keri Marie Giddens	Noah Wayne Morano	Aidan I. O. Yusuf

**our thanks to...****We Would Like To Thank The Following People For Their Gracious Help:**

CHERUBS UK Board Members	Advance Printing	Elaine Moats
Shelly Evans	Carol Lynn Cole	Amy Rademaker
Tara Hall	CHERUBS Australia Board Members	Judi Toth
David Marek	Patricia Jones	

<b>In Honor/ Memory Of:</b>	<b>Our Thanks For Your Generous Donation:</b>
<b>Aidan Gustavo Leibe</b>	Kimberly Leibe - in memory of her son
	Brian Hills
	Robin Sharbrough
<b>Alison Joanne Parker</b>	Bruce and Daphne Parker - in honor of their daughter
<b>Anastasia Michelle Vallins</b>	Elizabeth Sisley-Vallins - in memory of her daughter
<b>Anneliese Mae Browning</b>	Vicki Bilak - in memory of her granddaughter
<b>Anthony Pompeo</b>	Albert and Claudia Faraldi
<b>Baby Girl Florez</b>	Alvaro Florez and Maydelin Castillo-Florez - in honor of their daughter
<b>Bethany Abaurrea</b>	Raymond and Heidi Abaurrea - in honor of their daughter
<b>Caitlin Breen</b>	Charles and Kathleen Breen - in honor of their daughter
<b>Caleb Bishop</b>	Barbara Whitaker
	Kim Moyer
<b>Christopher Faraldi</b>	Albert and Claudia Faraldi - in memory of their son
<b>Colin Hambel</b>	Mary Hambel - in honor of her son
<b>Courtney Marie Young</b>	Wanda Young - in honor of her daughter
<b>Eli Patrick Cason</b>	Courtland Perry
	From his grandmother's friends at Miami Lakes Educational Center/ High School Division
	Lindsay Lee
<b>Eli Simon Stukalski</b>	Shana Stukalski - in memory of her son
	Tracy A. Lambert
<b>Eliza Maie Martin</b>	Allison Schmit
	Debra Pilger
	Deneen Olson
	Grant and Carrie Leum
	Kathy McCuskey
	Kristen Leach
	LeeAnn Belski
	Martha Hoffland
	Michelle Burwell
	Michelle McMaster
	Patricia Fukasawa
	Patt Roou
	Sara L. Curti
Timothy Noel	
Todd and Rebecca Martin - in memory of their daughter	
<b>EmaDean Owen</b>	Friends & Family of EmaDean - Mom and Dad, Adam, Linda, Diane, Alexis, Gwendolyn, Great Grandma and Great Grandpa, Grandma and Grandpa, Auntie Julie & Uncle Tracy and Kids, Uncle Buck & Aunt Shanna and Kids, Uncle Bobby & Aunt Deborah and kids, Aunt Brenda & Jeff and kids, Pat and Ron Simmons, Michelle Dunn, and Jacque Kasselmann
<b>Emma Sturkie</b>	Tim Sturkie - in honor of his daughter
<b>Grace Ellen Wright</b>	Trina, Randy & Jacob Willard

<b>Jenna Rose Dayton</b>	Beverly and Hugh Dayton
<b>John Brady Bell</b>	Devon & Christy Bell - in memory of their son
<b>Jon Guenther Hockenyos</b>	Rebecca Yerly - in honor of her son
<b>Jonathan Luke Rademaker</b>	Amy and Pete Rademaker - in memory of their son
<b>Kala Marti</b>	Faye Merolla
<b>Kayla Rae Brewer</b>	Kitty Swift
	Brad Brewer
<b>Kylee Freedom Green</b>	Margaret Green
<b>Madison Brooks</b>	Kipp and Christie Brooks - in memory of their daughter
<b>Mary Gray Reames</b>	Melissa Cantrell
<b>Mattson Houghton</b>	Christopher and Shyra Houghton - in honor of their son
<b>Megan Rene Miller</b>	Dean and Libbie Miller - in memory of their daughter
<b>Michael Dylan Schitter</b>	Melanie Markusic and Sharis Howe
	Shannon McCowen
<b>Nicholas A. Sayed</b>	Cingular Matching Gift Center
	Robin L. Sayed - in honor of her son
<b>Nizhoni Lee Hamm</b>	John and Gloria Nelson
	Michael Hamm - in memory of his daughter
<b>Oleyen Vollette-Kist</b>	Margaret Sondey
<b>Paige Muraglia</b>	Albert and Claudia Faraldi
<b>Patrick Joseph Hurdle</b>	Peter Hurdle - in honor of his son
<b>Patrick Murray Perala</b>	Jennifer and Scott Perala - in honor of their son
<b>Rachel Marder</b>	Nathan Walden
<b>Rachel Marie Barragan</b>	Brandi Barragan - in memory of her daughter
<b>Robert Joseph Bryce Southwell</b>	Prentice & Heather Southwell - in honor of their son
<b>Sara Kaitlyn Lindquist</b>	Beth Holliday - in memory of her granddaughter
<b>Sean Feaster</b>	Cynthia and George Hamrick, Regulatory Affairs/Quality Systems Dept.
	David & Julie Feaster - in memory of their son
<b>Shane Torrence</b>	Albert and Claudia Faraldi
<b>Sydney Elise Curlock</b>	Pamela Curlock - in memory of her daughter
<b>Taryn Faith Rogers</b>	Rachel Rogers - in honor of her daughter
<b>Teressa Gianna Faustina DiPrimio</b>	Philip DiPrimio & Rosemary DeSalvo - in honor of their daughter
<b>Thomas Carter Burton</b>	Joe and Cheryl Burton - in memory of their son
<b>Thomas Sawyer</b>	Michelle Sawyer Richardson - in honor of her son
<b>Whitley Caroline Connolly</b>	Aileen and Bill Parish
	Dade Behring Inc.
	Donald and Yvonne Haverlah
	Donna Caldwell - in memory of
	Elizabeth Connelly - in memory of her daughter
	Richard and Freda Hudson
	Roy and Nancy Morris
	Sammy and Nancy Cross
The Hudson Family	
Thomas and Debra Coley	
<b>William Francis Dechary</b>	Jenet L. Dechary - in memory of her grandson

<b>William Frederick Jackson</b>	Tamara Rosario
	James McQueen - in honor of his nephew
	America's Combined Charities
	Bill and Darlene Norton
	Gale Brees
	Lockheed Martin Combined Charities of Choice
	Paula Warren - in honor of Jackie Warren, mom of a 46-yr-old CDH Survivor
	Prudence Devney - in honor of her unborn cherub
	Tina-Marie Seubert
	Triangle Mothers of Twins & Triples

**volunteer spotlight...**

**Shelly Evans**



My name is Shelly Evans and I first found Cherubs about 9 years ago after my son, Shelton Earl died from CDH and a coarctation of the aorta.

CHERUBS was the only place that I could find that provided the information and support that I so desperately needed at the time. Being newly grieving at the time, I went from being obsessed with reading e-mails from Cherubs to going weeks without checking them

depending on my emotional state at the time. That is the great thing about Cherubs. There is always someone there when you need them. I decided to volunteer because I wanted to be a bigger part of Cherubs and help other families that were going through the same thing. I became the Texas State Representative, and then I added positions on the Welcoming Committee and the On-Call Grieving Committee. I admit I have slacked at times but have always enjoyed what I did for Cherubs and felt great when I could help another family out even if that was just lending an ear. I have recently become the Volunteer Coordinator and although I am still learning and not quite sure what to do most of the time...I am winging it and learning knowing that

Shelton and all of our Cherubs are with me to help me through. My goal is to help Cherubs find the cause of CDH and to let grieving families know that there is light and laughter again and provide support to the surviving families by making sure they have the information they need. I can't say enough about the wonderful people I have been blessed to meet and the amazing progress I have made in my grief all thanks to Cherubs. I am a singer and am pursuing a singing career while also having a career in real estate as a Realtor so I am extremely busy but I look forward to meeting many of you and talking with you all! HUGS to all Cherubs and their wonderful families!

~ Shelly



The **1st Annual Cherubs Walk-A-Thon** in memory of Shelton Earl Evans will be held Sept. 17th, 2005. Registration begins at 8 and walk at 10. It will begin and end at the First Baptist Church in Florence, Texas. Florence is on Hwy 195 in between Georgetown and Killeen. Sierra Moore has decided to have this fundraiser each year through her Girl Scout troop to benefit Cherubs. Registration for the walk will be donation only and the 1st 50 registrants get a free keepsake. Sponsorships are available to those that aren't able to attend to walk. Please contact Sierra Moore for more information at (254) 793-8062.

## cherubs' fundraising items...

CHERUBS' has 100's of items currently for sale as fundraisers, including mugs, lunchboxes, t-shirts, onesies, sweatshirts, calendars, journals, hats, bumper stickers, cookbooks and much, much more! Several items are now discounted!

Visit our web site at <http://www.cherubs-cdh.org/fundraisers/cafepress.html>



## 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, at (617) 726-0828
- Fryn's Syndrome**  
 University of California, San Francisco, California  
 Department of Pediatrics  
 Contact: Anne Slavotinek, (415) 514-1783
- Identifying Genes Which Cause CDH**  
 Emergen Labs, Salt Lake City, Utah  
 Contact: Mary Meade, MMeade@emergen.com
- Identifying Causes and Solutions of CDH**  
 CHERUBS, Oxford, North Carolina  
 Don't forget to send in updated forms and CDH Research Surveys!



## RECOGNITION...



**CONGRATULATIONS to UK CHERUBS!**  
 For achieving UK charity status!  
 You can visit their website at  
**[www.uk-cherubs.org.uk](http://www.uk-cherubs.org.uk)**

## stories of cherubs...

### AARON YOUNCE

I went for my 20-week ultrasound and the doctor told us that Aaron had a condition called CDH. Aaron was born on July 6, 1999. He wasn't breathing so they bagged him and sent him to Xray. In Xray they found he had a left-sided CDH, with stomach, intestines, and liver in his chest. He was vented and had chest tubes put in. Within a few hours they were transporting him to Wake Forest. I was still very drugged from the pain medications and I had a C-Section so I wasn't allowed to go with him. That was very hard. We had many scares over the next 24 hours. The next day, Aaron was switched from a conventional vent to an oscillating vent which raised his sats. Aaron had his hernia repair on July 9, 1999. It took about six hours. There was no diaphragm on the left side and they put in a Gortex patch. The weeks following were a total roller coaster of emotions.

Aaron then got a staph infection. He was started on Gentamycin. Over the next few days he kept going down hill. He coded several times and they had to continue to increase the vent settings. The doctor came to us and told us that we were at a point where they thought he needed ECMO but they had something experimental call nitrous oxide they wanted to try. That was the scariest point I remember clearly because the doctor had told us that ECMO was a last resort. A few hours after they hooked up the nitrous he was doing a little better. Dr. Baughman and Dr. Pranikoff stood by Aaron's bedside for the next few days watching and checking every machine. They were WONDERFUL! So we were able to avoid ECMO.

In early August, Aaron's lung had healed enough to take him off the oscillator and back onto a conventional vent. On August 6, 1999 (one month old), his chest tubes were taken out and we were finally able to hold our baby. They tried many times to take him off the vent and finally by mid-August they were able to take him off. The first time we heard him cry was one of the happiest moments of our lives. Aaron was then moved from PICU to NICU. Early in September Aaron's NG tube stopped up and apparently let fluids in his lungs so he went back on the vent for a few days. He recovered quickly.

By the end of September the doctor was running more tests because he couldn't keep anything through the NG tube down. They found he had severe reflux and adhesions on his intestines. A few days later we were going back to the OR. He had a Nissen Fundo, adhesions taken off his intestines, and a Mic-key button put in. He had done really well and was off the vent within an hour after the surgery. We stayed in the hospital for about seven days so the incision could start to heal. On October 7, 1999, three months, one day old, we finally took our baby home with oxygen and a heart monitor. We were so excited but nervous about taking him home.

The next year and a half, we felt like we lived with Aaron's doctor. He was in the hospital about six times mainly for breathing problems but they were all short stays. During this year and a half, he had physical and occupational therapies and a constant nutritionist. He was very underweight. We also had many problems with the feeding button. He couldn't receive the feedings with the continuous pump so we had to bolus feed every 2-3 hours. Thank god for my husband; he was a blessing. He got up at night at every other feeding with Aaron.

At 19 months old, Aaron started walking and eating. We were so excited because he would always turn blue when we would try to feed him. Anyway, by two years old, he was no longer using the feeding button. In December 2001 the button was taken out and the site repaired. In February of 2002 Aaron got very sick. He ran a fever for weeks and the doctors thought it was RSV, even though he tested negative. We were in the hospital for a week and on oxygen for another three weeks but he pulled through like a trooper.

Aaron just had his third birthday and he's doing great. He's finally gaining weight and learning more every day. He's an amazing little boy! I thank God for him everyday! Aaron has taught us a lot of things already in his three years. The most important thing I think is not to take a single minute with your kids for granted!

Well, there's so much more that I haven't said. I could go on and write a book, but I'm trying to keep it short. If anyone needs to talk or has questions please email at [ytweety417@aol.com](mailto:ytweety417@aol.com).

Julie Younce (mom of Aaron, 7/6/1999, 145 Vista Ln, North Wilkesboro, NC 28659, 336-838-5116, [ytweety417@aol.com](mailto:ytweety417@aol.com))

### PRESTON WATSON

Hi, I am Norma, mother of Preston, who will be 14 years old next week. I was 30 years old when he was born by emergency C-section, as the cord was wrapped around him. When he was delivered, I heard one little cry and he stopped breathing. The doctor said he was having trouble breathing and it might be a hernia. That didn't sound too scary to me, the hernia part. I had no knowledge whatsoever of CDH. I did not get to see him; they took him to X-ray and said he had a diaphragmatic hernia, and they had to handbag him for five hours. We were in a small hospital that did not have respirators for babies. They tried to air-flight him to



Winston-Salem, NC-- we lived in NC at the time-- but there was a storm and ended up having to have a ground ambulance transport him. My husband went over there with him, and they did surgery that evening to repair the hernia and put his bowels back in place. But his only lung had collapsed, and the chemistry messed up in his lung, and he was dying and needed ECMO.

The ECMOs available in 1988 were in Charlotte, NC and in Washington, DC. They had just been invented five years earlier. Thank the Lord Charlotte had a machine open, so he was air-lifted to there. We lived about 100 miles from Charlotte. He had four ECMO doctors and was in Charlotte Memorial Hospital. They were wonderful. He was on ECMO for 13 days-- that is a record, and on the 13th day he had a bleed in his brain and had to come off. They did not think he was ready, but had no choice but to take him off. He was on a respirator a while longer and had to have a VP shunt put in his brain-- then had it taken out, then put back in. He was hospitalized the first time for two and a half months. Most of that time was in neonatal, and since my husband was pastoring and working both, I drove back and forth to be with him on weekdays and on weekends. On Sunday my husband and I would go down and spend the night and spend Mondays with Preston.

We were so thrilled when he finally came home. At the time he came home, he did not have a shunt, but when the neurosurgeon was going to release him and did a CT scan, he needed a shunt, so he had to have that put in. It kept messing up; they did not know what to do. He was in the hospital every month for several months because of the shunt. He was scheduled for surgery one morning, and the evening before, I looked and all the fluid visible on the outside of Preston's head was gone, and he was fine! The shunt had started working due to answer to prayer, and he has not had shunt problems since! They put lots of tubing in his tummy so they wouldn't have to add any for a long time. He has mild cerebral palsy with a crippled left arm and hand and weak left leg, but can walk! He has a lot of scars on his lungs from the ventilator and all. He has been sick a lot with asthma and bronchitis, but the older he gets the better that is becoming. He has seizures and several mental illnesses. He has ODD, ADHD, OCD, Major Depression, Anxiety, Asperger Syndrome. His mentality is about the equivalent of a 7 or 8-year-old the last time he was tested. Three years ago he had strep, and it caused him to have a mental breakdown, which caused his mental illnesses to be worse and he lost a lot of ground. He was in private school in third grade when that happened. He is now still doing third-fourth grade work. I have been home schooling since then. So that is my story; we are taking one day at a time. He is a delightful son with a sense of humor if he is not stressed. We try to keep his life as stress-free as possible and keep his meds up-to-date. He is currently taking depakote, dexadrine, respiradol, luvox, buspar.

Norma Watson

## VICTORIA DESTINY LAVALLEE-KHALIL

First, excuse my English, I'm French. I'd like to exchange with other French people.

After 3 years of trying, I became pregnant. I lost blood at 10 weeks and the doctor said I'll probably have a miscarriage. But, she stayed. I had a second ultrasound at 20 weeks in our local hospital. It took a long time but they only said you are carrying a girl. 2 days after, I receive a phone call from my OB said they found out that the heart is a bit on the right side and they send me in a children hospital (hospital Ste-Justine in Montreal) for heart-ultrasound. The cardiologist said to me, the heart is OK but I see the stomach beside the heart. I was really gentle and explain a bit to me what is CDH. The next day, another ultrasound confirmed the CDH. The doctors insist for a genetic consultation and an amniocentesis. 2 weeks for the results but everything is OK. The genetic consultant insists for abortion (before the results of the amnio) but we were too in shock to say a word.

My husband and I cried and cried for days and nights. But one idea was clear, I'm 25 weeks pregnant and I'm going to do the best I can for that baby cause I love her so much. And we decide to name her Victoria.

I had a c-section (head up) at 39 weeks. She wasn't breathing on her own. They intubated her and operate at 7 hours of life. She was doing well. She was on oxygen (20%) for 4 days. The biggest fight was for food. She's was too weak to eat a lot and they wait more than 2 weeks to feed her through an ng tube. She lost a lot of weight. After the tube she gains a little bit of weight so they decide (after a big fight) to let us take her home (with the ng tube). I was pumping my milk and feeding her in a bottle every 3 hours (the rest of the milk send through the NG tube) for 4 oz. But her weight gain was too slow for the doctor.

The doctor pushes that to 5 oz every 4 hours and then she start vomiting. We change doctor and she said stop the ng tube (Victoria was 4months old). After that, her weight gain was still too slow (only the 3 percentile) so the doctor hospitalized to do a lot of tests (2 weeks of tests) everything was fine.



The thing is they (the doctors) put so much stress on us for her weight that we "create" trouble to feed her. It's like a wheel. Her pediatrician if she not gain enough that month it is tests and tests and now she want me to see the psy of the hospital.

But she's 16 months (May 03) 17 pounds, really brilliant, smart, cute, nice and happy girl. She's the queen of the day care. Everybody loves my little "doll". Thanks for reading my story and I really want to talk with you.

Annie Lavallée (mom of Victoria, 1/7/2002, 134 Henriete-caron, Chateauguay, QB J6J 5Y6, Canada annielavallee@hotmail.com)

## MARTIN SCHAU

This is the story of our son Martin who was diagnosed at birth with left-sided CDH.

On February 5, 5:39 PM (approx. 35 weeks gestation) our wonderful boy Martin was born. He is a miracle and a real fighter and we love him with all of our hearts.

The fact that Martin was born 4 ½ weeks early was no problem and he was a fine boy considering his weight – 2,500 grams. But right after birth Martin wouldn't start breathing. The doctors had a hard time figuring out what was wrong...and they were doing all kinds of things to him to keep him alive. Through an x-ray short after birth they concluded that Martin was born with CDH. We had never heard of CDH and the nurses told us that Martin needed an operation to get well.



Because Martin was really critical he was baptized in a hurry and then rushed to Odense University Hospital where they specialize on CDH. The ride in the ambulance took 2 long and very nerve-wracking hours. Martin was manually ventilated all the way to the hospital in the ambulance. The doctors put him on a high frequency oscillator (HFO) right away - which he was on for two weeks. We were both in total chock. We couldn't believe that our loving boy was on the edge and I don't think we've been praying so much to God ever....

Martin needed to be stable before the surgeons could operate him. Three days old the surgeons operated him and everything went fine. No Gore-Tex patch was needed. But this CDH is very, very unpredictable and Martin was for the most good, but he also had downs that really scared us. All the while he was on the HFO he was treated with all kinds of lung, blood and circulation medications - also Nitric Oxide. He also struggled with pulmonary hypertension.

15 days old we were able to hold our son. It was a fantastic moment, but also very scary because his need for oxygen increased, while he was on his mothers chest. He was put back in his cradle and settled at his normal level again. We held him more and more the next days and he became more and more stable. He loved to sleep on our chest (the doctors called it the kangaroo-method) and we loved it just as much to have him in our arms.

Three days later Martin was turning bad again. His feeds with breast milk had stopped because of severe vomiting, and as a result, he was put on TPN. The nurses had to keep aspirating the air every hour or so from his stomach. He was really feeling bad, and he was not as deeply sedated anymore, and you could tell by the look on his face that he was crying, but without a sound because of the tube. After a few days like this one of our fantastic doctors made a special x-ray on Martin which showed, that the suture from the first operation hadn't been able to hold and his intestines was again pressed against his left lung. Martin needed another surgery and they would do it the very next morning. That night Martin turned very, very bad, and the nurse and doctor on call didn't know what to do to help him. At last they called a very special doctor whom we really trusted, and within the hour he came to the hospital and put Martin on the operating table at once. It turned out that one of his intestines was cut of, and therefore it had no blood-circulation. This time they put in a Gore-Tex patch in the diaphragm and Martin did great. The next morning he was off the respirator and on a CPAP-vent and doing fine on only 60% oxygen. The next morning we were ready to be transferred onto a ward with only a little oxygen in a funnel and no tubes. We started trying to breast-feed him. He was really doing great but didn't have the strength to eat enough, and was fed the rest in an NG tube. We spent 1 week there and was then transferred to a hospital closer to home. Martin had a very hard time gaining weight because he could only eat very small meals and when he was given the rest in the tube he vomited half of it. On the new hospital we again tried breast-feeding but with no luck – he still didn't have the strength. He's weight slowly started to increase – and he was now free of oxygen.

On his original due date we were back at our home town hospital and stayed there for 1 week where Martins weight and eating pattern was monitored. It was our home away from home because Martins dad would stay there during the night too. For the first time we had Martin by our side 24 hours a day – GREAT, but also very scary since we had gotten so use to nurses and machines monitoring his well-being all the time, and now it was just us. Finally 6 weeks old we all came home. Martin was off of oxygen and tubes etc. Martin fed only from the bottle and was doing fine. He still had a lot of vomiting and could only eat small meals, and when he was about 4 months old the doctors found out that he had Reflux. He was put on medication and only 2 days later he was doing much better and eating a lot more.

Today Martin is 6 months old and doing great. He feeds every 2 hours but sleeps the whole night without eating and is gaining weight as can be expected. He still vomits about once a day due to his reflux but nothing compared to before. The doctors say it will get better when he starts eating more solid foods. He has just started eating porridge and stewed fruit and he loves it. He has never had a hard time adjusting to new flavors and that helps a lot.....

Martin unfortunately has had to go through surgery 2 more times in the last 2 months. On June 22 he had left sided inguinal hernia and was operated 3 days later. 3 weeks later the same diagnose – just this time in the right side. His testicle was undescended in this side and was put down during the second surgery on August 20. Both surgeries went well and he was coping with it great.

During Martins whole life we have stood together and have had tremendous support from family and friends. It is still difficult to cope with his slow weight-gain and the vomiting, but we are so thankful that Martin despite all he has been through is doing so well. He is developing well just a little behind schedule and is a happy little boy. We have really loved finding CHERUBS – which none of our doctors knew existed – they know now.....CHERUBS helped us a lot – to read about other families and their terrible and also wonderful stories, made us feel like we are not alone in this. We will use the list "Matches for parents of survivors" to get in contact with other parents and gain from their experiences.

Kim Danielsen Schau and Rikke Jul Schau (parents of Martin, 2/5/2003, Havrevænget 72, 8600 Silkeborg, Denmark, 0045 86817132, kimrikke@mail.tele.dk)

### ISAAC D. PRATT

My name is Alan Pratt and this is the story of how my son, Isaac David Pratt, came into the world. My wife Terri and I were expecting our fourth son. It had been a fairly normal pregnancy. Terri had never been able to stomach glucola without throwing up so her OB treated her as if she were a gestational diabetic. She had regular appointments and ultrasounds with no indication of any trouble.

Terri went to bed on February 12<sup>th</sup>, 2001 feeling as though she may be developing a UTI or some sort of bladder problem. She had been experiencing a slow leak and woke me around 4 am to tell me her concerns. We decided to have things checked out. It was there that they determined she was slowly leaking amniotic fluid. She was just over 33 weeks and we were both pretty scared. They did another ultrasound and still found nothing unusual.

The doctor made the decision to send us to a larger hospital with a special care nursery and a children's hospital nearby. He said his cutoff was usually 34 weeks and even though we were close he would send us. This decision may have saved Isaac's life.

Terri had 2 more ultrasounds at the larger hospital, still with nothing detected. The doctors from a high risk OB practice took over her care. They determined that because of his positioning and the slow leak that an emergency c-section was necessary. The section went well and Isaac was quickly whisked into a little room next to the surgery suite. It seemed like there were 20 people jammed into the tiny room working on him. I kept trying to look through the blinds and catch glimpses when a hurried staff member opened the door. I saw a single gloved hand doing compressions on his chest and at one point noticed he had been intubated.

The OB must have noticed my look of concern. He reassured us that he had seen hundreds of babies like Isaac and he would spend a little time in Special Care but would be fine.

I waited in recovery for Terri to arrive. When she did we nervously reassured each other that everything would be fine. A doctor came in and introduced himself as a Neonatologist from the children's hospital. He told us Isaac had a left sided CDH. His intestines were crowding the area where his left lung should be. He took me to see him. I looked at the chest x-ray. There was a mass of coiled intestine clearly visible in his chest. I touched him, squeezed his hand and I cried. He looked so perfect. How could this be happening?

They brought him in an isolette to see Terri. She reached her hand in and stroked his hair and told him that she loved him. The team quickly took him away across town to the children's hospital. She would not hold him for the first time until he was 13 days old. The next few days were a whirlwind. Terri was stuck recovering from her surgery and I ran between the two hospitals and our three boys at home. Isaac had pulmonary hypertension so they could not perform the surgery until it resolved. They kept him paralyzed to reduce any stress. Terri finally got to see him. She got a temporary release when he was a few days old. The day after he was born we had him baptized. It was a strange scene being around the isolette in NICU while the priest performed the baptism.

The surgery was performed with success when he was six days old. We began staying at Ronald McDonald house on and off. Things seemed to be going well until he went septic. He was so ill his skin looked bronze. He had a fever and couldn't keep his saturation levels up. Things did not look good and we tried to prepare ourselves for the worst. The powerful antibiotics finally began to kick in and he slowly got better. The nurses confided with us afterwards that they rarely see babies that sick make it.

The next obstacle Isaac faced was a high bilirubin. A GI doctor was called in and after a lot of time under lights and getting small amounts of breast milk this also cleared. The breast milk was another thing. Terri was constantly pumping milk. We had baskets of it in the NICU refrigerator. It was humorous when they began giving it to him at 1 cc an hour.

Isaac's blood pressure spiked next. A nephrologist consulted and put him on an anti-hypertensive. A radioisotope study was performed and found that a clot had blocked part of his left kidney. This was the cause of his high blood pressure. He would be treated with medication and "may" grow out of it. I guess the good thing is that this clot could have ended up anywhere (brain, heart, lungs...)

We took Isaac home a month after he was born. We took with us the warnings of reflux, susceptibility to respiratory infections, reoccurrence of CDH, hypertension and slow development overall.

We were referred to physical therapy. They laughed that he had even been sent to them. They said his motor skills were excellent. When Isaac was 18 months the nephrologists discontinued his medication. When he was 27 months he was put on antibiotics for an ear infection. It was the first time he had received them since being a patient in NICU.

Isaac is 2 ½ now. He is built like a tank and loves life as most children do. He is a normal terrible two year old boy. He is both antagonist and victim of three older brothers. The only clues to his traumatic beginnings are the scars on his chest.

To those going through the difficulties of a child with CDH there is hope and there is success.

We heal through love and prayer and we pray for you and your child to make it like Isaac did.

Alan Pratt (dad of Isaac, 2/13/2001, 3937 Columbia Rd, Medina, OH 44256, 330-723-7036, apratt5@msn.com)



## MATTHEW ALEXANDER WESTPY

We found out in August of 2001 that we were expecting our second child. We were so thrilled! The first 16 2 weeks of pregnancy, I was so sick that I was in and out of the hospital 3 times for dehydration. I was eventually sent home with an IV. I only had the normal morning sickness with our first son. I just knew in my heart that something was not right but the doctors kept telling me, the sicker you are, the healthier the baby is. Needless to say, our son was diagnosed with CDH at 18 weeks at a regularly scheduled ultrasound. After many ultrasounds, it was determined that Matthew's stomach, spleen, bowel, and liver was up in his chest cavity. The doctors were giving him about a 40% survival rate if he made it out of the delivery room. Matthew came 3 weeks early on March 15, 2002. Labor was uneventful and he was delivered naturally. Matthew was delivered in the OR so that the team of nurses and doctors could work on him as soon as he was born. After about a 2 hour, which seemed like days, they came out and told us that he was stable and that they were transferring him through the tunnel to the Children's Hospital of Philadelphia. When he arrived at CHOP, they called us for permission to place him on ECMO. We were finally able to see him about 5 hours after he was born. We had seen a baby on ECMO when we toured the NICU, but it still can't prepare you for seeing your own child with all the tubes. His weight went up and down which was to be expected on ECMO. On his 10<sup>th</sup> day, the doctors told us that he was ready for surgery. The surgery was done right in the NICU since they couldn't move Matthew to the OR. The surgery took about 3 2 hours and Matthew did exceptionally well. The only complication was that the ECMO circuit needed to be changed. Another risky procedure, but once again it all went well. We were so thankful that the surgery went well and thought there was finally an end in sight. Matthew was so alert. He always knew when we were there and he would follow us with his eyes if we walked around. The doctors were amazed to see how alert he was considering the amount of drugs that he was on to keep him sedated. He was on ECMO for 17 days and when it came time to trial him off, he came off right away. The doctors response to his blood gas levels was too good to be true. Another obstacle behind us!

Unfortunately, Matthew never really had a great day again after he came off of ECMO. He had developed an infection and was on 5 antibiotics for which it was not clearing up. We almost lost him on April 10<sup>th</sup> but he did a complete turn around after he was placed on the oscillating ventilator and nitric oxide. After the episode of almost losing him, my husband and I labeled him as a fighter and thought for sure that he would make it through all of this.

After a couple of days, he was placed back on the regular ventilator and his settings were excellent. Matthew was once again stable. On April 15<sup>th</sup>, we came to the hospital and Matthew was being placed back on the oscillating ventilator. We knew it wasn't good. He was at 100% oxygen and his sats were really low. We spent the night at the hospital as we had many nights. At 1:00 in the morning, the nurse told us to get some sleep as the next day would be a long one. At 3:00 in the morning, they were knocking on the door telling us that Matthew had taken a turn for the worst. When we walked into the NICU, there were many doctors

standing around him and working on him. They said that his little heart was giving out and that they had already done chest compressions on him. We never thought we could make the decision to let our little guy go, but I guess a parent knows when it is time. We made the decision to let him go as there was nothing else that could be done for him. All of his medications and life support were turned up but nothing was working. The doctors switched his vent over so that we could hold him. This was the first and last time that we held him. He passed away in our arms within 10 minutes of holding him. We bathed him, dressed him and rocked him.

We are especially grateful for all of the wonderful nurses and doctors that took care of Matthew. They were all so compassionate. We never once felt that Matthew wasn't in the right place.

Although we only had one short month with him, we are so grateful that we had that time. The one thing that keeps us going everyday is knowing that Matthew is in Heaven where there is no more pain and suffering. We know that we will be with him again someday.

We had a picture blown up for our room and no matter where you are standing, it looks like he is always watching us and waving to us. He is now our guardian Angel. Not every parent can say that they are the parent of an Angel.

Kerry Westpy (mom of Matthew, 3/15/02 - 4/16/02, 3 Stehr Street, Branchville, NJ 07826, 973-948-7437, rkwes@earthlink.net)

## ISABELLE YAP



I first found out I was pregnant in mid-October of 2002, just a couple of days before I was to fly to Hong Kong on business. When I returned from Hong Kong, I went to my family doctor right away to confirm the pregnancy. Sure enough, I was pregnant and now I had to find an OB. When I got in to see my OB it was November 22, 2002 and at that time I found out that I was already 13 weeks pregnant. My entire first trimester had flown by without my knowing it. Of course, I now know that the most critical time in the gestation of a baby is those first 12-14 weeks. By the time you move into your second trimester, your baby is fully formed and everything should be in place. So, if there is anything wrong with the baby, it has already happened. In any case, I had a very uneventful pregnancy. I can honestly say that

it was a pleasure to be pregnant and I enjoyed every aspect of it. All my tests - urine, AFP, Glucose - came back fine. No problems at all. The Sonogram showed a healthy baby kicking away inside me. We decided not to find out what the sex was. It was more fun that way. I gained the right amount of weight. The monthly measurements were all fine. My blood pressure was always low.

My original due date was set at 5/31/03. I decided to work until a couple of days before my due date. But, when I went in for my check up on the 30th, I was only about 1cm dilated and maybe 30% effaced. So, I hadn't progressed very much. She had me come back in on June 5 and was getting ready to have me start some stress tests every two days, but decided to check the amniotic fluid level. My OB said nothing at that time except that she wanted me to go to the hospital to begin induction. She said the amniotic fluid was a little low and that since I was about 5 days overdue, it would be best. So we did. It took them about 4 hours to admit me and get me settled in the room to start the pitocin and antibiotic drips for the Induction and Group B Strep. I was psyched. I was going to have a baby in my arms sometime that day or the next day. I wasn't feeling any contractions yet, but the nurse said I was having them. I was only about 2 cm dilated and maybe 50-60% effaced, so it was going to be slow going.

At some point a couple of hours into all this, I had to get up and go to the bathroom. So, when I got back in bed and had the nurse hook me back up to the EFM, the baby's heart rate dropped. She repositioned me a couple of ways and it came back up to normal so everything was OK. However, a couple of hours later, I had to do the same thing. This time, after they hooked me back up, the baby's heart rate did not return to normal and at one point dropped to about 80.

The nurse called the doctor and the verdict came back that the baby was not going to withstand labor very well and that he recommended a c-section. Because I had low amniotic fluid, the contractions were probably compressing the baby's cord in some way. Of course, I wasn't at the point of feeling contractions yet, so I had nothing to go by. But we decided to follow the doctors' suggestion and signed the paperwork.

Things were happening so fast. We signed the paperwork, they gave my husband, Glenn, and mom some scrubs to get dressed in, they wheeled my bed to the OR and moved me to the Operating table. They began prepping me for the epidural while they chatted and joked around. Just another routine c-section in the life of an OB. No worries, no indication that anything other than minor fetal distress was the problem. They laid me down, strapped me down and put the screen up. I think they even started the surgery before they let Glenn and mom back in to the OR. So much going on, but it all seemed so surreal at the time. Glenn peeked over the screen when they pulled the baby out and announced that it was a little girl. I can still remember how happy he looked. My mom squeezed my hand and repeated what he had just said. Then all hell broke loose. The neonatologist said "Oh, oh - something is not right" - "she looks too small". They handed her over to his team and they started to work on her. Apgar scores were low,

they couldn't intubate her - she wasn't breathing. Glenn walked over to the table to see what was happening. What all the commotion was about. And when the doctors realized that he wasn't one of them, they ordered him back to my side. My mom was telling me that everything would be OK, that we had a little girl. I started shaking uncontrollably and the anesthesiologist asked if I wanted something for the shakes. I just nodded.

The last thing I remember was Glenn saying he was going with our daughter to the NICU and that he would be back soon to tell me how she was doing. I woke up later in the recovery room with my mom at my side and the nurse on the other side starting to give me instructions about what I needed to be able to do to be released from recovery. Nothing yet on our little girl. No word. I don't know how long I had been out. Maybe 30 minutes? My mom asked to have the doctor paged so she could find out what was happening. When he called back he said the NICU doctors weren't telling him anything. He wasn't even sure what was going on. Finally my mom decided she needed to get up to the NICU to find out what was taking Glenn so long. The nurse checked me out and asked if I could wiggle my toes yet? No, not yet.

The nurse was telling me that I would need to be able to wiggle my toes and lift my butt off the bed before they could move me. She was giving me some instructions on some other things that I would need to know when my mom came back from the NICU. The look on her face said it all. Something was seriously wrong. The nurse stopped talking and my mom gave me the bad news. She said, "Sweetie, it doesn't look good. The doctors can't figure out what is wrong with her and they said that she probably wasn't going to live much longer". My whole world came crashing down. I let out a howl from the bottom of my soul. How could this be possible? I had such a wonderful pregnancy. All my tests were fine? What happened? Why did I take that long flight to China? I should have stayed home the minute I found out I was pregnant. So many things were going through my mind. I just couldn't believe that I had carried this little baby in my belly for 9 months just to lose her.

My mom told the nurse in not so many words that I had to be taken up to the NICU to see my daughter. The nurse said that I had to be able to move my legs, toes and butt before they could let me go up there. By that time, I was already wiggling my toes, so I knew it wouldn't take much longer. Mom told me that Glenn had called a priest to come in and baptize our baby girl. She also told me that Glenn had named her Isabelle. What a beautiful name. I was gaining more mobility and the priest finally showed up. He came by and blessed me, said a prayer and told me he would make sure that our baby girl was baptized. He left to do just that. I was able to lift my butt from the bed about 5 minutes later and the nurse had to let me go. They got the bed ready for the orderly to wheel me up there and Glenn showed up. He said that she had just been baptized and he hugged me and cried and said sorry about 100 times. What did he have to be sorry about? It wasn't his fault. It was all my fault. I must have not taken care of myself during my pregnancy. I'm the one that was carrying her, so something I did caused this - whatever it was that she had.

It was much later that I came to realize why he was apologizing. He was her daddy and because of that, he should have been able to protect her. He was apologizing to me because he couldn't protect her. He couldn't save her and keep her safe. He had failed in his fatherly duties. When I realized this, my heart broke again. It took me a long time to convince him that there was absolutely nothing he could have done. God had a higher purpose in this and he was not at fault at all. I still think that he doesn't believe that. When they finally got me up to the NICU and I saw her little body laying there with all those tubes and machines around her, I just couldn't believe how beautiful she was. How could something so perfect have something so wrong with her? Why couldn't they save her? The doctor had three theories and one of them was CDH, but the one he kept telling us about was esophageal fistula. The esophagus wasn't formed and they couldn't get any oxygen into her lungs. He was positive that it was that, but he couldn't be sure.

The nurse managed to get Isabelle into my arms with all the tubes and attachments on her. I had my little girl in my arms and all I could think of is that she wasn't going to live long enough for me to take her home. She looked so small and fragile, but so perfect. Her little toes and fingers were perfect. Her little nose was just like Glenn's nose. She had a full head of black hair just like her daddy. Long arms and legs. The doctor said she weighed 5 lbs 12 oz. She is so small; but so perfect. We took pictures. I held her and cried. I kissed her little hands and forehead and told her I loved her very much. She looked so peaceful. I knew she wasn't going to open her eyes. I wished she would open her eyes. I wanted to see her eyes, but they had put that gel in them and they were closed tight. She was non responsive. Asleep.

I think I held her for about 30-40 minutes and then she passed. I had the nurse put her back in her little bed and she asked me if I wanted a locket of hair. Yes, please. The nurse, Jennifer, was so nice. She gave me some of the pictures she had taken and a hand print in plaster that she did for us. I noticed that Isabelle had one eye open in one of the pictures, but she had all those tubes in her mouth and chest. I couldn't bear seeing all the tubes. I asked if they could take them out. I wanted to see her face. I had to see her face without the tubes. The doctor said OK and she took them out. We took more pictures of her and I held her again for another few moments. I touched her little face and kissed her cheek. I asked if I could keep her little blanket with me. I needed to take something of hers with me. I had to have her close by. They gave her another blanket and gave me the one she had been wrapped in to take with me.

By that time the nurse had come back to give me a pain killer and take me back to my room. She said I needed to rest. I had just had major surgery and I needed to lie down and rest. I said OK and they took me away from my baby girl. I saw her again one more time before they released me from the hospital. I was so scared to see her little body, all cold and lifeless, but to this day I

give thanks to the nurse that convinced me to see her again. I was able to hold her one more time and even though she didn't look the same as the day she was born, she was still beautiful and perfect.

We didn't find out until after the autopsy a week later that she had been born with a sever liver up diaphragmatic hernia and that her lungs had been so compressed that they had never formed. So, anything the doctors would have done would not have saved our little girl. We gave her to God and we thank God every day for the few hours he gave us with her. She was born at 10:15 pm on June 5, 2003 and passed at 1:47am on June 6, 2003. We are now expecting her little brother, due Sept 8, 2004 and we pray every day that he is OK. But, we know he is and that he has a little guardian angel looking over him every day for the rest of his life.

I will end this with a saying that I saw in an Empty Cradle brochure that I was reading the day I was released from the hospital. It reads: "An Angel in the book of life wrote down my baby's birth and whispered as she closed the book....."Too Good For Earth!". I don't know who wrote this, but I carry this saying in my heart every day since the day I read it.

Angela Yap (mom to Isabelle, 6/5/2003-6/6/2003, 2327 Caringa Way #2, Carlsbad, CA 92009, 760-603-0983, monamon@aol.com)

## NATALIE BANKES



When I found out I was pregnant, I had a lot of emotions because I was only 19. I was still very happy though because family has always been important to me and I have always known I wanted children. When I was 10 weeks I woke up and noticed that I had started to bleed. I was so nervous and upset but it seems so small to me now compared to everything we went through. Everything ended up okay and they put me on bed rest for three days. Because of the bleeding when I was 20 weeks along I had a level 2 ultrasound. They informed us that we were having a little girl and everything looked okay to the technician but they wanted the doctor to take a look because they couldn't get a good picture of her heart. So the doctor came in and after looking for what seemed forever, she told us that our baby had CDH and an umbilical hernia. She told us that it is very serious

and can be fatal. I was so shocked the only thing I could do was get on the computer and research anything I could about CDH. After a lot of searching we decided that we wanted to give her the best chance possible and went to CHOP for more tests. That was where we found out that she had a 50/50 chance. So, I started getting non-stress tests twice a week at the hospital close to where I live but had visits in Philly because that was where we felt was best. At 35 weeks my water broke. They life-flighted me to HUP where I had a C-section and had Natalie at 9:19 at night on June 5, 2003. They transferred her to CHOP and that began her 12 weeks of life. The first few days it seemed she was doing well and would have surgery soon. But then she went down hill and started to retain fluid and went from five pounds to twelve. The doctors thought she had an infection but couldn't find it. They told me to call my family up because they might never see her again. I was devastated. Somehow my strong girl made it through and when she was one month she started to lose her fluid slowly. I have to add in here that I only made it through all her swelling and all the calls from the doctors because of the support I had. My family was always there. I also had two other families that had CDH babies in the same room with Natalie that helped me through. They became my other family and still are to me. By two months Natalie had lost all her fluid and was doing great. They even let me hold her. That was the best feeling ever. I saw her beautiful eyes and they even fed her a small amount of breast milk through a tube. I thought it would only be a matter of time before we took her home. She had her surgery and they found that her liver was extremely large and obstructed. They had never seen this in a CDH baby and told us that her chances were slim. They couldn't do the tests they needed to do because after surgery she swelled up again to 13 pounds. After surgery she never recovered. She seemed to get worse and worse each day. It seemed all I could do was sit there with her and pray for pee. It never came. One night she had a huge episode and they had to hand bag her for an hour. The hospital called a cab to come pick me up and I was there very early in the morning. It was then when I was sitting with her that I knew she wouldn't be with us much longer. Natalie was fighting so hard for us but I knew it wasn't fair to her. I told her it was okay that I loved her so much and she would always be with me. I went out and called her daddy and told him the doctor wanted to meet with us. He made it up as fast as he could (he couldn't stay with us because of work). The doctor then told us that there was nothing else that they could do. They could continue doing what they were doing but it just wasn't working. We had a decision to make. I knew the right decision to make but it was so hard to admit it. Letting go was the hardest thing ever. The next day 8/28/03, we told the doctor that Natalie had been through enough and it was time to let her go. Our family came up and we asked the nurse to play her rocking horse for her when they took out the tubes. The brought our little girl into us and we just held her and kissed her and loved her.

Even though it was so painful it still felt good to hold her without those tubes. They did an autopsy and we found out that her left lung was extremely small and that she had a very rare cyst in her liver. She could not have made it. I have comfort in the fact that I was with her almost every day of her life and I loved her and did the best thing I could ever do for her. I stopped her suffering. And I know I will see her again.

Linsey Getkin (Natalie's mom, 6/5/2003-8/28/2003, 1114 Salem Blvd, Berwick, PA 18603, 570-752-6880, lgetkin@pretiumpkg.com)

**MATTHEW BRIAN GISLASON**

My sons name is Matthew Brian Gislason and he was born about 2 months early with and undiagnosed right sided diaphragmatic hernia. I went to the hospital earlier that April 28th of 2004 with what I thought were contraction. They put me on the monitors and took some of my urine to the lab to check to see if I had a bladder infection. The lab results came back and said that it was positive and that it wasn't contractions it was just fake labor and if I were to go home and take the antibiotic and some Tylenol I would feel so much better. I left the hospital at about 7:45pm and went home, at about 9:30pm I was screaming in pain and crying (thank goodness I live with my parents). I mom grabbed my dad, called the hospital and told them that we were on our way (thank real goodness that we only live 3 blocks from the hospital). I got to the hospital at about 9:40-9:45pm and Matthew was born at 10:02pm. All that I really remember was that when they took him out he was pretty blue and barely made to small cries and them they intubated him and whisked him away as fast as I could remember. My pregnancy went extremely well and I had no idea at this point what was going on except that he was 2 months early. They took me to my room and the doctor came in and said that it did not look good we should call our pastor. Our pastor came I was so beside myself that I had no idea what was going on I had yet to see him and now they are telling me that he may not even make it. We all just sat and prayed and prayed and then it was like God listen in and gave a chance, the doctor came back and said that they stabilized him and the helicopter was on there was to take him to a hospital that had a NICU. They sent me to be admitted at the same hospital because they did not know what was to be the outcome of all this. When I got there at about 4am I went to see my baby and there he was all hooked up to these tubes, all these doctor standing around working with him I was so scared.

The next day did not look so good they were telling some very scary numbers about his survival chances... like 10%. I knew that I had to keep praying and that I could not give up hope. I knew that Matthew was everything to me and that I was not going to give up with out a fight. At this time they were scared that oxygen sats were so low that we were looking at brain troubles, all of a sudden I got a call from the NICU and they said that his sats went up and he was doing better. He was still on the oscillator and tons of medications but was doing for his little 3lb 9oz body (his birth weight).

Many days went by waiting for the day of surgery; my little fighter was not giving up. Then that day came May 6, 2004. I went to see him that morning and told him that I loved him and told him to be strong and not give up. The nurse told me to come and stand by her for a second; there he was trying to open his eyes for the first time. I knew right then at that moment God and Matthew were telling me that it is going to be alright. They said that this kind of repair was going to take 2-3 hours maybe. I went to my room at 7:30am and waited; at about 8:20 they called and said they had gotten started. I waited with my family. Then it was 9:10 or so and they called me and said that they were closing him up and to head down to talk to the surgeon. It went better then they thought. I was happier then ever.

Today is May 19, 2004 and he is off all ventilators and just on some oxygen through nasal canulas. He is on just diuretics that he is receiving through his NG tube and a bunch of added nutrients through his IV's. I am so proud of his and his incredible strength. I know how scary this is and what all families are going through who are going through this. Never ever give up hope, I know that I am not out of the woods yet and we have some time before I get to bring him home but I have gotten to hold him, kiss him and see him longer then they all thought that I would of. He is now 3 weeks old and getting stronger. I think one of the things that have helped me through all this is that the hospital (Fairview University Riverside in Minneapolis MN) has a web site for parents that have children in the NICU. It had been very therapeutic and helpful for me to keep people up to speed with what is going on since I live about 100 miles from the hospital. If you want to see my baby the site is [www.caringbridge.org/ok/matthew](http://www.caringbridge.org/ok/matthew) I thank everyone for their support it means the world to me and my son. We love you all.

Jennifer Gislason (mom of Matthew)

**HANNAH ALYSABETH HAMBY**

I have wanted to write this story for a while now but have had trouble sitting down to do it. My story begins on May 10, 2002. Hannah Alysabeth Hamby was a very special and wanted addition to our family but God had other plans for her. I went into labor almost five weeks early without having any clue that my daughter was ill. Her heart rate was constant and no other alarming symptoms showed until after her birth. They were not able to stop my labor because I was already dilated to seven when I arrived. Hannah didn't breathe or cry after she was born but she had a heartbeat. The doctors worked on her and tried to get her to breathe but failed. After many attempts the doctor decided to insert a feeding tube and take an x-ray of her chest where the found the tube was back up into her right shoulder and they told me they would try one more thing and if it didn't work they would let me have her in her last moments. When that hospital door opened and I saw her beautiful face I knew she needed to go. It was the hardest thing I have ever had to do but I held that little girl tight as she drifted out of this world and into heaven. I know the exact moment she left that sick body and suffered no more. That day was so difficult. Later that night the doctors told me she had CDH and briefly explained it to me and then left me to sort it through on my own. My husband was still serving in the Marine Corps 1,500 miles away. It was only a few days later that I discovered Cherubs and spent hours reading all the information I could. On May 13 I laid my beautiful daughter to rest. I had to explain it to my 2 year old son, Isaac who really missed his baby sister. Now as I write it feels as though this happened just yesterday and the hurt is still so raw. That is the way grief is I guess. It can heal a bit but is

so easily exposed again. It has now been two years since her death and I have another daughter, Emmalee Abigail Hamby born on January 19, 2004. She means the world to me and I love her so much. I was very nervous throughout the pregnancy but she was completely healthy and wonderful. My family feels like it is still missing a link without Hannah but we are doing well and I feel very blessed to have had her even though it was only for a few hours. Her short life changed me forever. I want to thank Dawn for creating this web site. I hope that I will be able to impact someone else's life the way she has mine. Isaac still asks about his sister and we decorate her grave for every holiday. Our family will always long for her to be with us but we are glad to know that she is in heaven waiting for us to join her and she is not in any pain. I have written a poem in memory of her and would like to share it with all of you who have experienced the pain of losing a child.

God Bless you all!



### Hannah Alysabeth

We never will forget when she came into our lives  
Or how beautiful were her shiny little eyes.  
They never once were opened; no tears from them were shed  
Her cuddly little body never even fed.

A diaphragmatic hernia is what the doctor said  
When he laid her fragile body on my hospital bed  
Nothing we can do they said as they walked right out the door  
My heart began to break; my tears began to pour.

I held my little Hannah gently upon my breast  
Then felt her tiny body slip away to rest.  
We all were there to kiss her upon her little head  
Then we laid her in a casket; her only baby bed.

O' the pain I felt as I watched them close the door  
To know her pretty face will be gazed upon no more.  
One more time I screamed, as I had to walk away  
Then they laid her tiny casket in a place we call her grave.

Now she walks with Jesus down the streets made of pure gold  
How I wish to be there for her hand I long to hold.  
I know she will be waiting beyond the pearly gates  
To hear her cry out mommy, O I can hardly wait.

The day is fast approaching when all of us will be  
Sitting down with Hannah underneath a great big tree.  
The choir of angels will be singing O' how great Thou art  
And my family and me will never have to part.

Lori Ann Hamby (mom of Hannah, 5/10/2002- 5/10/2002, Tulsa, OK, 910-428-4775, proudmary1@msn.com)

## on-call volunteers...

Need someone to talk to? These parents are on-call day and night to listen to any members who need to talk.



### For Grieving Parents:

Shelly Evans – (512) 489-2185  
Freedom Green – (410) 363-7465  
Marion Lansdon – (360) 882-5502  
Karen Myers - (210)403-3483  
Malini Rao – (972) 423-1871  
Kristen Stiner – (402) 502-9310  
Amy Rademaker – (616) 844-4156

Danielle Kessner - (03) 5135 6999 (Australia)  
Laurelle Lehmann – (250) 838-7000 (Canada)

### For Expectant Parents:

Kerrie Chamberlain – (541) 855-2370  
Jody Hill – (913) 859-0389  
Jessica Mayfield – (636) 944-8834  
Anne Wolfe – (610) 481-4178  
Rachel Wyatt - 01908 565574 (UK)

### For Parents of Survivors:

Michael Culwell – (918) 647-5850  
Carol Lynn Cole – (816) 305-3832  
Jolene Ferguson – (419) 334-7140  
Tara Hall – (614) 275-0858  
Elaine Moats – (406) 234-5038

"Far away there in the sunshine are my highest aspirations. I may not reach them, but I can look up and see their beauty, believe in them, and try to follow where they lead" - Louisa May Alcott

## get togethers...

### AUSTRALIA 2004

Our 2004 Get Together was held at the Coogee Sands Resort at Coogee Beach in Sydney. The staff and management of the Coogee Sands ensured that we had a wonderful stay with them and could not do enough for us. Morning and afternoon tea were provided for the day as well as the conference room which was well set up for our use. Alicia, Kristine, Kirrily and Lynda outdid themselves in their organization of the event. Members came from as far as Townsville and Perth and a wonderful time was had by all.

Alicia arranged for us to have Drs Nadia Badawi and John Levison as our special guest speakers and we felt very honoured to hear the latest in data and research on CDH. One of our fundraising efforts will be to assist John to travel to Boston Children's Hospital in order to learn as much as he can from medical personnel who have set up a clinic specifically for CDH children. John and Nadia's aim is to set up a similar clinic here in Australia.

We were also lucky enough to be able to discuss individual health concerns of our surviving Cherubs with Nadia.

Nadia has also been able to assist some parents in acquiring referrals to specific specialists. What would we do without these wonderful people who are so willing to give of their time for our cause?

After an exhausting but informative day, we dined at a wonderful restaurant, walked along the esplanade, enjoyed a

late night drink on the rooftop of the resort and then headed to bed (well, some of us anyway!). Breakfast was enjoyed in a beachside café watching a Nippers' Carnival take place before heading off to the airport/loading the car for our trips home.

Danielle Kessner  
CHERUBS Australia



## upcoming events...

### CHERUBS UK SUMMER GET-TOGETHER 2005

This year's get-together will be held at Rachel Wyatt's house (40 Tudor Gardens Stony Stratford Milton Keynes MK11 1HX) on Saturday 25th June, from 12 noon to 5.30pm. Rachel is a Cherubs committee member, on call volunteer and mum of Max, a right-sided CDH survivor. Everyone is very welcome - parents of survivors and non-survivors, Cherubs and siblings. It will be an informal day; everyone is very friendly and there will be plenty of fun for the children. Lunch will be provided. We really hope that you will be able to come and meet other people affected by CDH.

We will ask for a small donation on the day to cover the cost of food. Directions will be sent out nearer the time. Cherubs UK will be holding its AGM at the get-together too - everyone is welcome to attend. If you would like to come, please let us know by the middle of June- either by post to Rachel Wyatt at the above address or by email - [nigel@magentanetwork.co.uk](mailto:nigel@magentanetwork.co.uk) If you have any questions then please phone Rachel on 01908 565 574 (9AM - 9PM only please). When contacting Rachel please indicate the number of adults, number and ages of children, any special dietary requirements, high chairs and cots needed etc.

We hope to see you there!

**mORE UPCOMING EVENTS...**



**Ohio**

August 20, 2005  
3:00 PM  
Hilliard, OH  
Contact Tara Hall  
614-275-0858

**Australia**

The CHERUBS Australia Annual Get Together will take place on Saturday, 22<sup>nd</sup> October at the Royal Children's Hospital in Melbourne, Victoria  
Contact: Danielle Kessner  
kessam@austarnet.com.au  
03 5135 6999 (within Australia)

**Texas**

**1st Annual Cherubs Walk-A-Thon**  
First Baptist Church in Florence, Texas  
Please contact Sierra Moore for more information at (254) 793-8062.

**CHERUBS state & international representatives...**

Our members are encouraged to contact our Representatives. For your Representative's e-mail address, please visit our web site. Our Representatives are helping members, encouraging new families to join, contacting local hospitals and medical professionals, and conducting such activities as get-togethers, newsletters, parent matching, web sites, on-line chats, and more. We still need volunteers so please consider volunteering. If you are interested, please contact Dawn for more details.

<u>REGION</u>	<u>REPRESENTATIVE</u>	<u>PHONE#</u>	<u>REGION</u>	<u>REPRESENTATIVE</u>	<u>PHONE#</u>
Australia	Danielle Kessner	(03) 5135 6999	MA	Heidi Cadwell	(603) 465-3311
Canada	Karen Jenkins	(905) 852-9410	MD	Brenda Slavin	(410) 535-2645
Canada	Laurelle Lehmann	(250) 838-7000	MO	Carol Lynn Cole	(816) 305-3832
Canada	Pat Panetta	905-294-7102	MO	Jody Hill	(913) 859-0389
Denmark	Kim Schau	0045 86817132	MO	Jessica Mayfield	(636) 944-8834
Germany	Renata Hoskins	907-245-8817	MS	Melissa Clark	(228) 432-8942
Great Britain	Rachel Wyatt	01908 565574	MT	Elaine Moats	(406) 234-5038
Great Britain	Kevin & Brenda Lane	01553 762884	NC	Barbara Hagemann	(919) 873-1853
India	Shankari Murali	91-80-25283423	ND	Elaine Moats	(406) 234-5038
India	Malini Rao	(972) 423-1871	NE	Kristen Stiner	(402) 502-9310
Ireland	Mick and Mary Blake	01 4921595	NH	Heidi Cadwell	(603) 465-3311
New Zealand	Nikki Hodson	04 9724841	OH	Tara Hall	(614) 275-0858
South Africa	Karen Howard	0118802981	OK	Michael Culwell	(918) 647-5850
AK	Renata Hoskins	(907) 245-8817	OR	Marion Lansdon	(360) 882-5502
AL	Alicia O'Malley	(256) 389-8110	PA	Tammy Sincavage	(610) 796-7324
AR	Kristen Stiner	(402) 502-9310	RI	John & Charlene Cassese	(401) 884-0269
CO	Dave & Clare Retterer	(720) 570-4022	SD	Elaine Moats	(406) 234-5038
CT	Toni Fiorillo	(907) 245-8817	TX	Shelly Evans	(512) 489-2185
IA	Kristen Stiner	(402) 502-9310	TX	Malini Rao	(972) 423-1871
ID	Tonya Rupe	(208) 552-1889	WA	Marion Lansdon	(360) 882-5502
IL	Rachele Alessandrini	(708) 283-9006	WV	Sharon Munson	(304) 947-7162
KS	Jody Hill	(913) 859-0389	WY	Kathy Browing	(307) 332-4759

**DISCLAIMER:** The information on all pages of our literature and web site 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.