CHERUBS

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

The Silver Lining

Spring-Summer, 2004

CHERUBS
P.O. Box 945
Oxford, NC 27565

Dear Members,

Because this issue is late, we are combining the Spring and Summer issues into a larger issue with twice the number of stories. We need stories for future issues so please send them in. We prefer e-mail so we can save typing time but will accept mailed copies. Stories printed before 2005 will be included one of our many books going to print next Spring so please get your stories in as soon as possible. We also need photos for our 2005 Calendars. More information about our books and calendars can be found in this newsletter.

Other goings-on at CHERUBS include revamping of our Advisory Committee, Grant Committee, and many other committees. We have many new volunteers but we have also lost many volunteers. We have a new Volunteer Coordinator, Shelly Evans. We also have a new Silver Lining Editor, Carol Lynn Cole, who has started to take over the newsletter duties with this issue by implementing the new format. We are also in the middle of planning our 2005 International Members Conference, Grant Training, and Database Training for the 2004 CDH Research Survey Results.

Some of you may receive your Congenital Diaphragmatic Hernia Research Surveys in the mail soon, please fill them out the best that you can and mail them in by October 31, 2004. All CDH Research Surveys are 100% confidential and help us to try to find the cause and best treatment of CDH.

You may notice that several announcements from the past newsletter are being reprinted; this is because we want to make sure our members are aware of these events or changes.

Sincerely,
Dawn M. Torrence, President and Founder

CHERUBS' Newsletter Subscription & Parent Membership Fees

(As a reminder, we are printing this again….)

In 2001 we implemented $20.00 annual Voluntary Parent Membership Dues. Even though it is voluntary and tax-deductible less than 3% of members have donated. We are requesting again, that all members who can afford to make a donation do so. CHERUBS subsists off of donations – we are not government or grant funded, we do not have any corporate sponsors, and unfortunately 75% of our donations come from funerals of cherubs when families request donations in lieu of flowers. We have no paid employees, only volunteers. Every dime of your donation goes directly to help us help CDH families. Please note our Thank You column in this issue – the list may seem long but it covers an entire year's worth of donations.

Because of the high cost of print and mailing and our lack of support through member donations we are having to take some drastic measures. This is the last issue of our newsletter that will be mailed out free of charge. We never wanted to charge families for any of our services but the cost of printing and postage for 1,000 families around the world is impossible to cover. Beginning with our next issue, we request a $20.00 annual subscription fee to receive a printed copy of our newsletter. It will still 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. We truly do not want any parents to miss our newsletter issues, but we can no longer skip issues because of lack of funding when we know there is a need for information and support.

CHERUBS' Newsletter Subscription & Parent Membership Form

Your Name: _____ Your Cherub's Name: _____

Your Mailing Address: _____

2004 Silver Lining Subscription ($20.00): _____

2004 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, P.O. Box 945, Oxford, NC 27565

New Arrivals

(*siblings of Cherubs)

Rachel Marie Barragan
Ali A. Boner
Maya Renee Brooks*
Sara Friedlander*
Skyla Zoey Freedom Green*
Adrian Pietro Higueros
Allie M. Kinniburgh
Logan Anthony Joseph Kremer
Kevan Benjamin Mahendran
Kate Jewell McLuckie*
Elianna Marie Miller*
Noah Wayne Morano
Amber Elizabeth Morton*
Shane Robert Morton*
Kinza Ymeen Muneeb
Dylan David Potrikus
Brent Wallace Rademaker*
Jaiden E. Sanchez
Oscar Sanchez, III
Dalton Kolby Seibert*
Angel M. VanPuymbroeck
Ian Matthew Wallace

This Newsletter Is Dedicated To the Memories of:

Rachel Marie Barragan
Ali A Boner
Brandon Christian Frush
Adrian Pietro Higueros
Austin Bradley Johnson
Kevan Benjamin Mahendran
Jordan Ann Poore
Oscar Sanchez, III

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. It is approximately 60% of all new members)

Camille Rosette Archer
Rachel Marie Barragan
Mia Marvelle Bayardo
Ali A Boner
Alyssa Nicole Bradshaw
Cynthia C. Chen
Gregory Z Couret
Isaac Kenyon Dean
Alexander J. Diaz
Eliana C DiCicco
Carter R Egloff
Arianna Nadia Farooq
Faith Florez
Brandon Christian Frush
Baby Boy Hambel
Rebecca Faith Havar
Adrian Pietro Higueros
Julien Leroy Howson Jr.
Austin Bradley Johnson
Matthew Kennedy
Allie M. Kinniburgh
Baby Girl Korn
Logan J. Kremer
Kevan Benjamin Mahendran
Joseph H. Martino
Noah Wayne Morano
Kinza Ymeen Muneeb
Jordan Ann Poore
Dylan David Potrikus
Macy Khyra Lee Radford
Tyler James Reams
Brianna Mary Roberts
Jaiden E. Sanchez
Oscar Sanchez, III
Baby Pan Sephton
Alyssia Angel Squyres
Emma M. R. Sturkie
Nathan Jay Thornton
Angel M. VanPuymbroeck
Jordan Jett Wolfson
Baby Boy Yammarino
Baby Girl Young

CHERUBS' Books

In celebration of our 10 year anniversary in February, 2005 and as information guides and inspiration, we are planning on creating five books by spring:

1. Stories of Surviving Cherubs
2. Stories of Cherubs In Heaven
3. Grieving Our Cherubs
4. Surviving Your Cherub's Hospital Stay
5. I'm A Little Angel Too

We would really like our grieving parents to be involved in books 2 through 4 and surviving parents in books 1, 4, and 5. Depending on much information and how many stories we collect, we would like to include an additional book for expectant parents.

The first two books are self-explanatory. "Grieving Our Cherubs" will be more about the parents and how we handle the grief, funeral arrangements, memorials, birthdays, etc. "Surviving Your Cherub's Hospital Stay" will be about dealing with the hospitalization, medical terms, machines, lodging and transportation, doctors, nurses, etc. "I'm A Little Angel Too" is about siblings.

We need volunteers to help collect the stories and photos and put them together. And we would like all of our members to contribute. Stories in the first 2 books will come from stories already posted in The Silver Lining through the past 9 years.

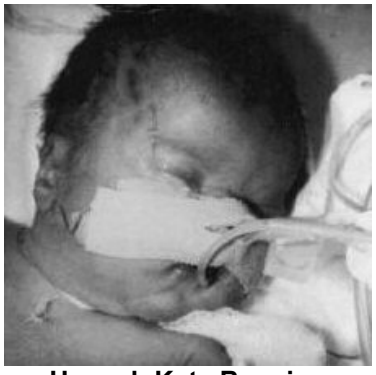
The books will be hard cover and will be sold on our web site. We will be using Cafepress.com to print the books so it won't cost us anything up front. We'll receive commission for each book sold so this will be a good fundraiser for CHERUBS as well as good references for our members.

If you're interested in helping out with this project, please call or e-mail Dawn at volunteer@cherubs-cdh.org.

We Would Like To Thank The Following People For Their Generous Donations:

Lawrence and Barbara Alampi – in memory of Owen Thomas Coyle
Tom and Marla Bennett – in memory of Owen Thomas Coyle
Kay Betts – in memory of Owen Thomas Coyle
Elliot and Barbara Brack – in memory of Owen Thomas Coyle
Kipp and Christie Brooks - in memory of their daughter, Madison Brooks
Scott and Kathy Browning - in memory of their daughter, Anneliese Mae Browning
Hanna and John Burleigh - in memory of Owen Thomas Coyle
Cherise Cameron – in memory of Owen Thomas Coyle
Todd A Cameron – in memory of Owen Thomas Coyle
Melissa Cantrell - in memory of Mary Gray Reames
Julia H. Cate – in memory of Owen Thomas Coyle
Norm and Grace Ching – in memory of Owen Thomas Coyle
Natalie and Zane Cody - in honor of their son, Dylan Joseph Cody
Heather Cooley – in memory of Owen Thomas Coyle
Linda and Red Davenport - in memory of Hannah Elizabeth Svoboda
Beverly and Hugh Dayton - in memory of their daughter, Jenna Rose Dayton
Elaine DeSalvo - in honor of Teressa Ginanna Faustina DiPrimo
Natalie & Roger de Silva - in memory of Eldon Clayton William Lockhart
Eileen, Bryan, Bridge, & Rory Doran – in memory of Owen Thomas Coyle
Albert and Claudia Faraldi – in memory of their son, Christopher Faraldi
Albert and Claudia Faraldi – in memory of Anthony Pompeo
Albert and Claudia Faraldi – in memory of Shane Torrence
Albert and Claudia Faraldi – in memory of Baby Marino
Albert and Claudia Faraldi – in memory of Kyle
Albert and Claudia Faraldi – in memory of Paige Muraglia
Keith Ficeto
Lisa Field - in memory of Kaylyn Marie Stiner
Carl & Cathie Firestone - in honor of their son, Lucas Carl Firestone
Denise Fishel - in honor of her daughter, Baby Girl Fishel
Carolyn Fortune - in memory of Kaylyn Marie Stiner
Beverly and Sam Fratinardo – in memory of Joshua Michael Stachowicz
Joy Garey – in memory of Owen Thomas Coyle
Lee and Amy Garrard – in memory of Owen Thomas Coyle
Jenny Godsey - in memory of Kaylyn Marie Stiner
James and Yvonne Green – in memory of Owen Thomas Coyle
Amos Greene - in honor of Caroline Connelly
Louis Grieco and Janice Dura- in memory of Joshua Michael Stachowicz
Brian Halliday - in memory of his son, Robert Severance Halliday, II
Michael and Mackenzie Hamm - in memory of their daughter, Nizhoni Lee Hamm
The Harris Family / Fireproof Food Systems, Inc – in memory of Laura Grace Culler
R. Patricia Hoemke - in memory of her great-grandson, Cade Andrew Turner
Julianne Howley – in memory of Owen Thomas Coyle
Kelly Howley – in memory of Owen Thomas Coyle
Aaron and Alysa Huizenga - in memory of Ethan Michael Huizenga
Integic Corporation – in memory of Owen Thomas Coyle
Ugo and Cathy Ippolito – in memory of Owen Thomas Coyle
Caroline Iwanchuk – in memory of Owen Thomas Coyle
Jeffrey and Leigh Juliano – in memory of Owen Thomas Coyle
Paula Finnegan Jones - in memory of Owen Thomas Coyle
Larry and Betty Kaufman - in memory of Kaylyn Marie Stiner
William King – in memory of Owen Thomas Coyle
Michael and Mary Beth Kuhn – in memory of Owen Thomas Coyle
Holly LaClair-Bogedain - in memory of Mara Noella Hufford
Rose Marie La Coppola - in memory of Joshua Michael Stachowicz
Joan and Anthony Lazzaro - in memory of Reese Sophia Jimenez
Gerald and Susan Litwak - in memory of Kaylyn Marie Stiner
Bob and Barbara Madole - in memory of their great-grandson, Joseph Zalon Shirk
Kelli Magistrelli
The Marist Mother's Prayer Group – in memory of Owen Thomas Coyle Nancy McCracken – in memory of Owen Thomas Coyle
Laura McFatter
Michael and Maureen McGuire – in memory of Owen Thomas Coyle
Robert C. McNamara, Jr.
Elizabeth, Brant, Christopher, & Kate Meleski – in memory of Owen Thomas Coyle
Jerry and Kathy Mohler - in honor of Caitlin Carrillo
Patricia Moore – in memory of Owen Thomas Coyle
Mike, Nina & Melanie Murphy - in memory of Kennedy Elaine Keckler
Courtney and Barry Nathanson – in memory of Owen Thomas Coyle
John and Gloria Nelson - in memory of Nizhone Lee Hamm

Hayley Chantelle Ginns
5/30/84

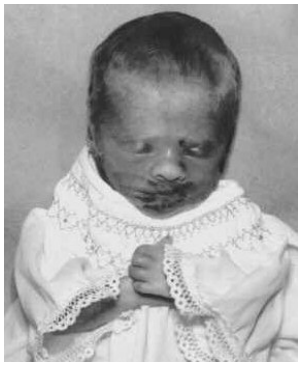


Hannah Kate Bowring
3/24/94-3/24/94

Aaron Jacob Hoewing
2/2/02

G. Calvin and June Norman – in memory of Owen Thomas Coyle
Christy O'Hara
Paramount Cards – in memory of Owen Thomas Coyle
Daphne and Bruce Parker - in honor of their daughter, Alison Joanne Parker
Steve and Shurile Pettite – in memory of Owen Thomas Coyle
Donna Pizzulli
Judy and Jim Pollak – in memory of Owen Thomas Coyle
Kellee Ridge - in memory of Kaylyn Marie Stiner
Ed Robertson – in memory of Owen Thomas Coyle
Charles and Amy Roehrig - in memory of Mara Noella Hufford
Rhett Sanders - in memory of Owen Thomas Coyle
Kim Schau – in honor of her son, Martin Schau
Rosemary Schwarzwalder's Bible Study Group - in honor of her great-granddaughter, Isabella Hope Kirby
Silvia Signorini-Bella - in honor of Ilaria Signorini
Timmy D. and Phyllis E. Smith - in memory of their daughter, Cherylynn Renne' Smith,
Timmy D. and Phyllis E. Smith - in memory of Kaylyn Marie Stiner
Timmy D. and Phyllis E. Smith – in memory of Owen Thomas Coyle
Timmy D. and Phyllis E. Smith - in memory of Mallory Mohr
Timmy D. and Phyllis E. Smith - in memory of Shane Torrence
Spotts, Fain, Chappell, and Anderson, PC - in honor of Olivia Jade Kloc
Beth and Jeremy Stafford - in memory of Owen Thomas Coyle
Angela Staup – in memory of Owen Thomas Coyle
Ted and Leslie Struckman - in memory of Kaylyn Marie Stiner
Julie and Brian Svoboda – in memory of their daughter, Hannah Elizabeth Svoboda
Peter Taylor - in memory of Anaiece Rejae Taylor
Tammy and Eric Thornton - in honor of their son, Nathan Jay Thornton
Edward and Ellen Warnecke – in memory of Owen Thomas Coyle
Ken and Terri Wright – in memory of Owen Thomas Coyle
Shannon Valentine – in memory of Owen Thomas Coyle
Robert and Jill Von Hagan – in memory of Owen Thomas Coyle
Bob and Barbara Vosburg – in honor of their son, Ross Vosburg
Bob and Barbara Vosburg - in honor of Dr. Jan German
Marietta Zacker – in memory of Owen Thomas Coyle
The Zimmermann Family – in memory of Owen Thomas Coyle

Saydie Halbeisen
4/19/00



Austin Bradley Johnson
7/6/99-7/8/99

CHERUBS' Fundraising Contest!

We are inviting all members and their families and friends to enter our 1st Annual CHERUBS' Fundraising Contest. The winner will receive $250.00 cash donated by local businesses specifically for this contest. Our goal is to raise $10,000 through this contest, but we need your help! This is a great way to earn money to attend our CHERUBS' International Member Conference in July! Take pictures of your event and it will be included in our newsletter.

Contest Rules:

1. You must follow all national, state, and local laws.
2. No gambling, bingo, raffles, scratch cards or other such questionable events.
3. All events must be safe! No skydiving, car racing, bungee jumping, etc by amateurs.
4. You accept all responsibility for collection of funds raised until the funds reach our main office.
5. When in doubt whether your event is a good idea, ask Dawn!
6. All direct donations are tax-deductible.
7. Donations can be made in honor/memory of your cherub.
8. The deadline for sending in your contribution is February 1, 2005.

Some Suggestions For Your Fundraising Event:

Yard Sale
Bake Sale
Lemonade Stand
Neighborhood Music Recital
Craft Show
Walk-a-thon
Car Wash
Marathon
Rubber Ducky Race
Read-a-thon
Ebay Auction
Phone Telethon
Art Show
Fashion Show
Talent Show
Recruit Friends, Family, and Businesses for Donations

CHERUBS' Art Contest!

We are inviting all kids (young and young at heart!) to enter our art contest. Cherubs, siblings, parents, and friends are welcome to submit entries. We are looking for artwork for our fundraising items. The only requirement is that the artwork includes cherubs. The artwork will be added to clothing, coffee mugs, holiday ornaments, clocks, calendars, and much more. All artwork will be featured on our web site and included on merchandise to raise funds for CHERUBS. The best part is EVERYONE is a winner because ALL artwork will be featured. Have your child submit a drawing and you can purchase his/her artwork on items that would make great holiday gifts. We will also combine entries to use on calendars or submit 12 seasonal designs for a calendar featuring just your artwork. To view our fundraising items that will feature contest entries, you can visit our web site at http://www.cherubs-cdh.org/fundraisers/cafepress.html

CHERUBS' New Fundraising Items

CHERUBS' has partnered with CafePress.com to offer our members hundreds of new fundraising items. Through CafePress, we are now offering clothing, hats, picture frames, bumper stickers, kitchen items, lunch boxes, carrying cases, clocks, and much, much more! You can purchase items with our logo or with individual logo characters that resemble your cherub. Because CafePress creates each item as it's ordered, CHERUBS' doesn't have to pay for any of the production – we get 100% of the profit without having to invest anything in these fundraising items!

To take a look at our many new items you can visit our web site at http://www.cherubs-cdh.org/fundraisers/

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!

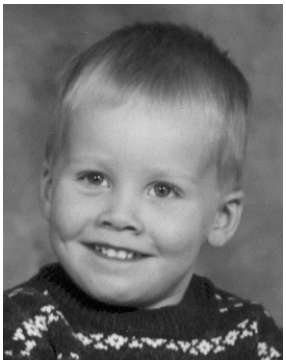
We Would Like To Thank The Following People For Their Gracious Help:

Heidi Cadwell
Carol Lynn Cole
Shelly Evans
Carl Firestone
Tara Hall
Danielle Kessner
Crawford Knott
Elaine Moats
Alicia O'Malley
Phyllis Smith
Robert Soderlund
Judi Toth

Stories of Cherubs

Jakob Nelson Andriacchi

My story is so different from any other that I have read so far. I found out I was pregnant in April of 1998 and everything was going well until my last trimester. I was so weak all the time and could barely get up to go to the bathroom. I also was gaining a lot of weight unexplainably. I went to 2 different doctors and they both told me it was normal, that the baby was probably just positioned in an awkward way. I was also told that the weight problem was of my own doing, which I knew wasn't because I ate healthy food and in moderation. Being that it was my first pregnancy and that I was only 20 years old I believed the doctors considering they were supposed to be the professionals. I didn't find out until the day I went into labor that the weight gain was caused by an excessive amount of amniotic fluid.



On October 19, 1998 I went into labor and everything was going fine. My son, Jakob Nelson Andriacchi, made his appearance into the world at 11:08 pm weighing 7 lbs. 5 oz. and was 18 1/2 in. long. He was perfect! Jakob's hair was dark brown and it stood straight up, but the tips were blond. He was doing great and 2 days later we went home.

When Jakob was a couple of weeks old he started projectile vomiting. Every time he would eat he would throw it back up. His pediatrician switched him to soy formula, which made absolutely no difference. When Jakob was 5 weeks old he had an ultrasound and was tested for pyloric stenosis. The results were good and he was diagnosed with gastroesophogeal reflux. I was told that this was something he would grow out of in time. As he got older it did get somewhat better so I was positive that he would outgrow it.

At 8 months Jakob had to have surgery for an undescended testicle. The testicle wasn't present at birth but I was advised to wait until he was older because usually it would make its way back down. Unfortunately this was not the case. His left testicle had twisted and cut off the blood supply, so it basically had died and it was removed. Jakob did extremely well after the surgery, so once again I thought things would be better.

Jakob always had ear infections and upper respiratory infections of some sort or other. It basically started when he was 2 and was put in daycare. So I blamed that as the culprit to his many illnesses. Shortly after Jakob's 3rd birthday he started complaining of stomach aches so we went back to the doctor. I was beginning to think this was our second home. The doctor thought the stomach aches might be due to a milk allergy so milk products were taken out of Jakob's diet. The stomach aches continued so we went back to the doctor again. This time the doctor said it was behavioral. I knew better, you could tell that it really hurt him so we went to a new doctor. Once again, the stomach aches were blamed on a food allergy and I still didn't buy it. So off we went to Jakob's normal pediatrician again and he ordered a bunch of tests. Before we had the results from those tests, Jakob was having a hard time breathing so we went to the walk in clinic. This was on April 1, 2002. If only this whole nightmare was a joke. Jakob had a chest x-ray done and a right-sided Morgagni hernia was detected. I was told that Jakob would need to have surgery and an appointment was scheduled for later in the week. I was hysterical, I didn't know what this was and the walk in doctor didn't know much about it either. Jakob was also diagnosed with the beginning stages of pneumonia so he was given a nebulizer treatment to aid his breathing and antibiotics. When we woke up in the morning Jakob's eyes were almost completely swollen shut. Back to the walk in clinic where we were informed that he had an allergic reaction to the nebulizer treatment. My poor little man looked like an alien.

I picked up his medical records from his normal pediatrician because I was disgusted that this wasn't found before. I was told at the walk in clinic that this was something he acquired before birth so I was pretty upset that in 3 1/2 years of doctor's visits it was never found. Later that day we went to a new pediatrician that was recommended by a friend. She said that he would need surgery but that it was an elective surgery and it could wait. She also advised that it would be best to have the surgery done at the Marshfield Clinic because we don't have any pediatric surgeons at our hospital. We met with the surgeon here still just to get more information. Once again I was told it was an elective surgery and everybody made it sound like it was no big deal.

On April 16, I woke up to Jakob throwing up all over me and my bed. Throughout the day he threw up 17 times and had diarrhea 6 times. We went to the doctor and were told he had gastroenteritis and were sent home. A couple of hours later he wasn't doing any better so my dad came down and we went back to the walk in clinic. When we arrived they told us that there was nothing they could do for us because the hernia was so large. I was never told that this was a large defect, but they said it was better that it was big because organs were less likely to get stuck. We then went to the ER. They gave Jakob an IV for about 2 hours because he was dehydrated and then sent us home because it was "just a virus."

The rest of the night and the next day Jakob felt great. We had one of the best days of our lives and he got to see everybody he loved. We went up to my sister's house and visited with her and her 2 daughters. We all took a little bike ride to the store which is only about 2 blocks away. Jakob loved it! He had so much fun. That night Jakob woke up throwing up again. But this time he was throwing up bile so I called my sister and we went back to the ER. Another x-ray was done and I was told that there was a blockage and Jakob would need emergency surgery. I was so scared! I still didn't have the information that I wanted and nobody seemed to have the answers. I was reassured over and over again that this was a routine surgery and that Jakob would be fine. My sister called my dad and he rushed to the hospital. The surgery was scheduled for the next morning because Jakob needed to be rehydrated again. He was hooked up to an EKG all night also. I slept in bed with Jakob, my sister slept in the other bed and my dad slept in the chair.

Morning came and it was time to head to surgery. I was the only one allowed in pre-op and they gave Jakob the anesthesia while he was still on my lap so that I was the last thing he would see before surgery. The waiting was horrible and after about an hour and a half the surgeon came out and told us everything went great. I was so relieved. My dad left the hospital for a little while and my sister and I waited in Jakob's room. I was getting really impatient because it was taking a long time for him to get out of recovery. The nurses told me time and again that he was ok. Finally after 2 1/2 hours in recovery, I got my baby back. He was so lifeless and it was blamed on the anesthesia but it was more than that. Jakob was sitting on my lap resting his head on my chest as we rocked. He was holding on to my so tight and I kept kissing his head and telling him that I loved him and that everything was going to be alright now. The nurse wanted to check his incision so I lifted him up right when my dad was walking back into the room. All of a sudden Jakob threw his head back, his eyes rolled into the back of his head and he was making these horrible noises gasping for air. I was told to lay him on the bed and we were shoved out the door. A code was called and there were doctors and nurses running in and out of his room. First I was told that he was going to be transferred to the ICU, and then they said he was going to have to go back to the operating room because they had to open his chest. Then the surgeon came out. He looked like he had got shot the way he threw his self against the wall. He just lowered his head shaking no. I screamed and screamed and started swinging at everything and everybody. My dad had to pretty much tackle me and sit me in a chair. The doctors had absolutely no explanation of why my son died. They kept blaming it on his heart, which he never had problems with his heart.

I went in and held my baby, rocking and singing and telling him how very much I love him. He was so heavy and so cold, but it still didn't seem real. My son couldn't have died. It was horrible leaving that hospital without him. I only had Jakob back from recovery for about 10 minutes before he died. I thank God that he made it back to me so I was the last face he saw. He never took another breath after that. When I got home that day there was a message on my answering machine from the Marshfield Clinic informing that Jakob's appointment was for the following Monday, which was the day he was buried.

About 2 weeks after Jakob became an angel, I started collecting medical records because I knew something wasn't right. My aunt is a doctor so I sent her all of the records and that's when I got the disturbing news. My son died from lack of oxygen. After having surgery on his diaphragm he was only given oxygen for 32 minutes. He was released from recovery with a heart rate of 148 and an oxygen level of 92%. Released to the floor, not even ICU, without oxygen. It kills me to think of my only child laying in the recovery room alone, without his mommy, suffocating to death. I have a lawsuit in progress and will fight as long as necessary for justice and to keep this from happening to another child.

Mommy loves you baby! You will forever be in my heart!

Jennifer Andriacchi (mom of Jakob Nelson Andriacchi, 10/19/98-4/18/02, 634 Iron St, Ishpeming, MI 49849, 906-485-4034, marjamom@chartermi.net)

Trevor Lowell Grossett

I had been with my boyfriend for about a year when he decided he wanted us to have a baby. I was only nineteen almost twenty at the time. Everything was going smoothly until just shortly after we broke up. I went to what was supposed to be just a routine two week check-up. Everything other than my belly measured two centimeters too big. My doctor was not overly concerned but said I should have an ultrasound anyway. I think he initially sent me for that ultrasound because he knew how bad I wanted one. I was hoping to find out the sex of my baby.

So on the day of my ultrasound I walked in that room feeling very excited because I was about to get to see my baby. After lying there about 20 minutes or so the technician said she would have to go check the films and would be back in a minute. I laid there another 20 minutes before her return. When she did finally come back she said there was a slight problem but couldn't discuss it with me. I was very persistent and she finally told me that she was unable to find my son's stomach. It wasn't where it was supposed to be; it was in his chest. That was all she would tell so I had to wait until my doctor called me with more details.

So I went and waited about 2 hours and finally he called. His news was not what I had expected. He told me that my son had a diaphragmatic hernia. Which of course I had no idea what that meant. He began to tell me that my son had his intestines, his liver, and his spleen in his chest which was squishing his left lung and had pushed his heart into the middle of his chest. I was in shock and starting crying immediately. He told me that they were going to send me to Sparrow hospital in Lansing for better care and preparation for my son's birth. He said that if I gave birth to my son at our local hospital he would die. I was scared out of my mind and I was going to have to do it all with only the support of my mother.

I went to Lansing just a few days later to receive a level 3 ultrasound. That was when I found out my baby was a boy. I was so happy and yet scared at the same time. They decided that day that they wanted to do an amnio. I gave my permission and they performed the test right then and there. My mother was standing by my side the whole time holding my hand and wiping away my tears. The doctor also decided that day that he would have to send me to University of Michigan Hospital in Ann Arbor so my son could be born in a hospital with an ECMO machine.

I had to wait about two weeks for the amnio results(which came perfectly normal other that my son's chromosome #9 was backwards which had no effect on him) and all the while I was traveling back and forth to Ann Arbor for ultrasounds and to meet the team of surgeons and tour the facility which was extremely huge. The OB I had met that was going to deliver my son decided to set up an inducement for January 26 2001 which would put me over 36 weeks. I thought that was so far away considering it was only the beginning of December. So I continued to have the basic prenatal care at my regular OB as well as visits to Ann Arbor.

We had a wonderful Christmas, which I spent with my entire family. Everyone was so worried about me because I hadn't cried yet. Well little did they know I was crying myself to sleep every night. My mind was consumed with panic and worry. I was so very scared and I felt completely alone. On the morning of New Year's Eve at about 7:00 a.m. I woke my mother up because I believed my water had broke. We drove to our local hospital and they immediately put me in an ambulance and sent me to Ann Arbor. After 15 long ours of labor my little Trevor was born at 9:57 p.m. He was a mere 5lbs. 4ozs. He looked so healthy to me but I knew he was very sick. I couldn't see him for about 4 hours after he was born (that's how long it took to stabilize him). When I finally could see him it was only for a few minutes so I could sign the paper giving them permission to hook up the ECMO machine. That was my biggest fear even though I knew it was a possibility. They tried every vent they could but he still couldn't breathe very well. That was the longest night of my life.

I was discharged the next day but refused to leave my babies side. He looked so little and helpless. The next 14 days were awful. They said to me at one point that they couldn't leave him on ECMO forever. But I refused to give up hope that my little boy was going to come off that machine and be ok. And that is exactly what he did at 14 days old he came off ECMO and stayed stable. He amazed many people that day but I was not surprised I knew he could do it. But then at 20 days old it was time for his surgery. It took them 5 hours before they came to tell me that he came through with flying colors. However they were unable to put all of his intestines in yet there wasn't enough room. It took them a few days but they finally got everything back where it goes. Trevor was doing great and we started our recovery process and we were on the road home. Or so I thought. Trevor had a left lung the size of a quarter but the sac around his lung was normal size so had to have a chest tube. He took very well to eating from a bottle so I thought we were going to be able to go home soon. I was very wrong because they couldn't take the chest tube out. Without it he had difficulty breathing.

After a month and a half they were able to remove the chest tube. And so I began to learn how to care for my son at home. He had to have oxygen and a feeding tube (sometimes he was too weak to eat on his own) and his incision had to be left with the skin not closed and a patch (he didn't have enough skin to close it on his own). I learned everything that I had to and on March 3, 2001 I was finally able to take my little boy home. He only had his feeding for 3 weeks before he pulled it out himself and his oxygen was gone after about a month. We had to return to the hospital that November because he developed herniated scar tissue were his incision is. That was an easy surgery compared to everything else we went through. He has a battle with growth and pneumonia but he is thriving well and is now only slightly delayed with a few things that doctors think he should be doing. Trevor is now 2 years old and I feel like a very lucky woman to have my little angel with me today. I named him Trevor Lowell because his great-grandfather's middle was Lowell. See my grandfather died a year before Trevor was born so he never got to meet him. I believe he did meet him though, I believe he was Trevor's guardian angel. He truly is a survivor.

Angela Earl (mom of Trevor Lowell Grossett, 12/31/00, Alma, MI 48801, 989-463-2921, aearl@chartermi.net)

Alexander Phillip Castaldo

He was born on June 11, 2002 and was given very little chance of surviving the first 2 weeks due to the severity of the CDH. He had virtually no diaphragm at all, no lung development at all on the left side and only partial development on the right. His heart was pushed to the right. Major surgery was performed 1 week after birth to correct the hernia using a Gore-Tex patch. He was also put on ECMO immediately after birth.

The first 2 weeks, he did not look like he was going to survive, and the doctors were surprised on daily basis, when he started showing signs of improvement. Totally sedated for 4 weeks, though he showed signs of life when the sedatives started wearing off. The next 4 weeks, he was off the ECMO, using forced oxygen only, no more sedatives, but his arms had to be restrained because he was constantly pulling the oxygen tube out of his nose. At this point he started becoming very active and starting to show signs of recognition.

At three months, he was finally off the forced oxygen but still with an oxygen clip on his nose, and he progressed steadily. His mother and grandmother at his side almost constantly, talking to him, holding him.

At four months, he was doing so well, he finally left the ICU and was transferred to the Blythedale Children's Hospital in Vahalla, New York for continued care.

As he went along, they finally weaned him off all oxygen. No more tubes except a feeding tube, since he never learned how to suck from a bottle.

Then came the great day we were allowed to bring him home for the first time, only for the weekend and with an oxygen bottle, just in case, but never needed. He was doing very well.

Things progressed so well, he was discharged from the Children's Hospital the first week of December and we finally brought him home permanently. This was the end of 2 months of constant shuttling back and forth from home to the hospital, to make sure one of us was there at all times. In this period, there were only 1 or 2 nights that the mother or grandmother or both were not at his bedside, holding him, taking him for walks and just loving him.

At home, he was a very beautiful child, loved to play, loved to be played with. And obviously, considering his problems, a very difficult child to deal with, but with such a great personality developing.

How great to start everyday, going into the kitchen and finding him there in his high chair or stroller looking up to see who it was and giving a great big smile.

He was doing so well, front teeth starting to develop, starting to vocalize, learning to call his grandmother. Looking and acting like any normal child. We had him at home for four months and he had us totally wrapped around his finger, we were completely captivated. It did not look like there was anything seriously wrong with him, a totally normal child. He was a few months behind in his physical development, but that was all.

He developed a hernia on Friday, March 14, 2003 and we took him to the NY Presbyterian Emergency room. There they pushed the hernia back, and told us to make arrangements for surgery that week, and he should be ok. Saturday, the hernia was very swollen again and he was obviously in a lot of pain, so we notified his surgeon and rushed back to the emergency room.

He never made it. He died in the car about fifteen minutes before we reached the hospital; with my wife trying desperately to save him with the CPR she was taught just for such an emergency. When he died, it was dark and we thought he had just fallen asleep. He died constantly calling for his grandmother, and we could not do anything other than just talk to him because we were driving and he had to be in the infant seat.

He died with his name for his grandmother on his lips and we already miss him terribly. He just died yesterday.

Anthony Castaldo (dad of Alexander Phillip Castaldo, 6/11/02-3/15/03, 37 Barbara Drive, Warwick, NY 10990, 845-986-8594, tcastald@warwick.net)

Jared Kenneth Pongo

I don't want to think how hard November 14 2000 was for my husband Ken and I..... tears come to my eyes still to this day. I was seven months pregnant and no real issues with the pregnancy except for placenta previa. Our baby stopped moving and at 8:00 am we went to the hospital to see what was wrong. After numerous ultrasounds and fetal stress tests it was determined our baby was in distress! 1:00pm they decided to do an emergency c-section. I was so scared for our little baby boy. Ken held my hand tight through the whole ordeal. At 2:14 pm our beautiful baby boy Jared was born. He weighed in at four and a half pounds, which is good for 32 weeks gestation. The first thing out of my mouth was why isn't he crying? I knew deep down that something was not right!! After a few hours the doctor came in the recovery room and told us that Jared was a very sick little boy. They wanted to transfer him to a hospital that had better equipment, to determine the severity of the situation. Once we were at the other hospital we could only wait...it seemed we were waiting forever. Finally at around 8:00 pm.the neonatal specialist told us the grim news...Our sweet little angel has no lungs. The hernia was located on the right side which is more rare than the left side. The bowels and other organs gave no room for the lungs to develop. I screamed and cried like a knife was in my heart. My husband Ken was a wreck. Why us?? - the famous question. We finally got to hold our little angel at 8:30pm. when they rolled me in to see him I couldn't believe all the tubes. My God poor baby....

Ken and I took turns holding him and decided right then and there that Jared suffered enough. It was the hardest thing I have ever had to do in my entire life. I sang you are my sunshine, I sang that to him in the womb. He held on for quite a while. I said "You can go now baby". Shortly after that he died in Ken's and my arms. Better to pass with us then with someone he doesn't know I thought...Planning Jared's funeral was a nightmare. How strange I thought, to be sitting in a funeral home planning your son's arrangements. I don't even know how we got through that? Thank goodness we had a lot of support from family and friends. The flowers kept coming to the house for weeks! I couldn't bear to keep them too long in the house it smelled like a flower shop. It only reminded me of what we endured. I still don't know why this happened to us. I thank God for the short time we had together. I do know this for sure. Jared is in a better place. .I will see him again!! He was my first child and Ken's second.

I think of my sweet Jared Kenneth Pongo everyday, I still cry for him often. Thank you for this website it has helped me so much over the last couple of years.

Dedicated to My beautiful Jared. Mommy loves you

Dalena Pongo (mom of Jared Kenneth Pongo, 11/14/00-11/14/00, 1432 4st NW, Calgary T2M-2Y9 AL, Canada, dalenapongo@home.com)

Blake Hanlon

Where to begin with Blake's story? It is such a long story, but I guess it starts with my 18-week ultrasound. As you normally do, I went in totally oblivious to the fact that anything at all could be wrong with my baby. After the normal bouts of morning sickness, tiredness, and a two-day stint in hospital for a burst cyst on one ovary, I went in to that room beaming and looking forward to seeing my baby on the screen. We all know that the normal screening takes around twenty minutes, but I was there for what seemed like an hour. Finally the sonographer said she was having trouble seeing the heart, and it was probably just the way the baby was laying, but she wanted to get the doctor in to have a look. I said sure and was still totally oblivious to the fact that anything could be wrong and didn't think anything more of it. I was just happy to be looking at my baby on the monitor. After awhile the doctor came in and started scanning. He switched off the machine, told me to "wipe myself off," and he was going to tell me what they had found. A tumour in my baby's chest! CCAM, this too comes with the same amount of problems as CDH, only we weren't told anything about CCAM except that we had to wait six weeks, then go back and have another ultrasound to see if this "tumour" had grown at the same rate as the baby or faster. Hopefully, it wouldn't grow at all.

Six weeks went by; I was 25 weeks pregnant. The same doctor did the scan and again said that my baby had a tumour in his chest; it had grown but not at the same rate as the baby, so that was something positive. The doctor did mention CDH but said that there was no indication that this was what was wrong with my child. I had to wait another four weeks, go back, and have another scan.

Four weeks later at 29 weeks, I walked in to the ultrasound clinic still not sure what on earth was going on. I certainly was not enjoying my pregnancy because I knew something was wrong but didn't know if it was life threatening or not. Nothing had really been explained to me. It was at this scan that the proper condition was diagnosed. Of course when the doctor mentioned bowel in the chest, I just lost it and started crying, saying this was worse. Unfortunately the doctor's bedside manner left a lot to be desired and he couldn't wait to get me out of the room, so I went away not really knowing much about this condition called CDH.

I was later referred to the Royal Women's Hospital at Randwick because this is the only hospital that is close to home that dealt with high-risk pregnancies. I have to say that the staff that I was involved with really did care, and they took the time to explain everything to me. I spent a day there meeting with specialists, having an ultrasound and an MRI, meeting the social worker and the high-risk obstetrician. The HR-OB was very forthcoming and didn't hold anything back. My unborn baby had a right-sided diaphragmatic hernia. From the pictures, they could see liver and bowel in his chest, and in the doctor's words - "Prepare for the worst, but hope for the best." He also mentioned that it was one of the worst cases he had seen for some time. Needless to say, I walked away that day not feeling very positive at all.

The next few weeks were very busy and very draining. With hospital visits every two weeks, work, looking after my 3-year-old, and keeping up with the normal everyday things that life throws, I didn't have a great deal of time to "THINK." As the delivery date got closer, I started to develop a feeling that something really bad was going to happen. When I tried to explain this feeling to people, they would just look at me. There was only one person I told who seemed to take me seriously, and as she said a mother's instinct is very strong.

My waters broke on the evening of Saturday 22 June 2002. My daughter had been induced, so I didn't know what it was like to have my waters break naturally, so I honestly didn't know it had happened. The only reason I knew something was up was when at 5.30 a.m., I woke up and noticed the bed sheet was stained pink. So I rang the hospital, and they said to monitor for contractions and to ring back in one hour.

During this hour, my husband and I talked about it and knew that once I went to the hospital, I wouldn't be coming home until our son Blake had been born. After the hour, I rang, and they asked that I come in. My husband and I calmly got organized, dropped my daughter off at Scott's sister's house, and away we went. As my husband said, "Here we go, are you ready?" No, I wasn't, but I had no choice. I was admitted that day because I lived a fair distance from the hospital and because of Blake's condition. I was only 2 cms dilated, but they wanted me to go into natural and established labour. If my baby didn't arrive by Tuesday morning, they were going to induce me. So Sunday turned into Monday and still nothing. I was lucky to be sharing a room with a really nice lady who was in for pre-eclampsia, so we managed to keep each other occupied.

It was now midnight on Monday night. We were waiting for the nurse to come in and do her final rounds. Obviously she was running really late and finally came in. She didn't have too much time for either of us, so she hooked me up to a fetal monitor and took Jo's stats. Jo's heart rate was 44, so the nurse went and called the night registrar. Meanwhile, I was having small contractions and was watching my son's heart rate on the screen. The registrar came in to find out what was happening with Jo, and I was watching in horror as my son's heart rate nose-dived down to 60. I panicked and screamed for the registrar, the nurse came running, and they were both trying to figure out if it was my heart rate or my baby's. The registrar then got the senior doctor, and before I knew it, I was calling my husband to get him into the hospital because I was going to the delivery suite to monitor the heart rate. That must have been when the doctor went out to ring the HR obstetrician because she came back in and said they weren't happy with what was happening and that he had to be delivered immediately. Forms were signed, tears started flowing, and my husband finally arrived only to see me on a gurney being wheeled down to the operating theatre.

Written in memory of Blake Hanlon

Our hands have touched, our paths have crossed
A love is gained, a love is lost
Just for the moment we kissed your face
of our innocent child that we can't replace

Just for the moment a maternal touch
would say the words that meant so much
A soft caress, the gentle tears
that made those minutes last for years

Just for the moment we held your hand
our broken hearts in your command
So much to tell you, so little time
but you'll always be with us in heart and in mind

They took part of us when they took you away
as much as we love you, you weren't meant to stay
We gave you a hug that for always must last
as facing the future means leaving the past

Our souls have merged, we live for you
perhaps we are living your life too
We will carry on, we can't always stand tall
because just for that moment, we had it all

After what seemed like an eternity, Blake finally arrived at 2.07 a.m. on Tuesday 25 June 2002. He wasn't doing so well, and all I really remember, apart from being scared senseless, was my beautiful boy, surrounded by lots of people in green scrubs, being given CPR. Scott & I were just crying and watching and trying really hard to be strong. All I wanted is what every mother wants and that was to hold my newborn. I wanted to tell him how much I loved him, how much we needed him, but unfortunately we weren't given that chance. We got the thumbs up from one of the people in scrubs, and I saw him being taken away.

Finally I was in recovery, and I was just so anxious to see Blake. Touch him. I was eventually taken to the maternity unit at which time I demanded that they take me to NICU. All they kept saying was that I had just undergone a major operation, and they didn't think the bed would fit into the NICU. I didn't care; I just had to see Blake. So they transferred me to a wheelchair, and I finally got to see my baby up close. I couldn't stay for long-- the doctors had work to do-- so I touched him and told him I was there and that I loved him and that I would see him again soon. Unfortunately, I didn't see him again until Tuesday evening. All day I was slipping in and out of consciousness. Too much morphine!

Tuesday evening my brother finally arrived from Melbourne, and I proudly walked him down to NICU to show off my beautiful boy. He looked so small with all the tubes. In fact, he was only 4 pounds 10 ounces, so he was tiny. They can give me no medical reason why he was so small. He was born full-term. Again, I touched him and told him how much I loved him and that I was so proud of him. I told him he was doing well and to hang in there and I would see him in the morning. I thought I needed my rest if I was to give him the 100% emotional and physical support that he would need. All the visitors left and Scott & I were finally left alone to reflect on the last 24 hours. We both fell asleep and didn't wake until morning.

I think it was around 6:00 a.m. Physically, I felt wonderful. I got up, had a shower, and was looking forward to spending the day next to Blake's bed. I could finally be with him. I rang down to the ward and told them I was on my way. They asked that I wait until 7.30 a.m. because they were having a change over of staff. So I waited and Scott & I were talking about how he must have done OK during the night because they didn't call us. Our bubble was to burst soon after, because a doctor walked in not long after that and advised us that Blake had had a really bad night. The machines were up at 100, but Blake could not oxygenate his blood, and he kept deteriorating. If he kept going downhill, there was nowhere else they could go. Scott ran out of the room, and I hobbled down to NICU. As soon as I walked in, Scott said, "You had better tell Kirrily," and all I remember is the doctor saying, "There was nothing more they could do." Why? That is the million-dollar question I will ask for the rest of my life.

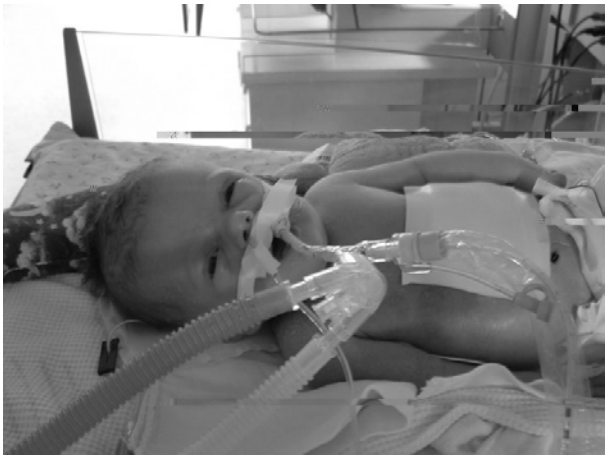
Everything from this point is hazy. We called our family to see Blake for the last time and to be there while he was baptised. I couldn't believe this was happening. Everything seemed to slow down-- we were waiting for everyone to get there. Didn't they care, because they seemed to be taking their time? It was Wednesday morning, so they had to fight peak-hour traffic, but we just wanted Blake to be at peace. We didn't want him to suffer unnecessarily. Finally everyone was there except my daughter Amy. They forgot Amy! I rang the kindergarten and asked my friend Natalie to bring her in. Natalie has since told me that she has never driven so fast in her life. Amy finally arrived, and she got to hold her little brother for the one and only time. Blake was baptised and everyone got to have a cuddle. After that everyone was asked to leave. Because Blake couldn't swallow he had to have his mouth cleaned and suctioned. It was here that I left Scott with Blake and went downstairs to buy my son an outfit. I looked for something, but nothing was appropriate. What could be, when you know your son is not going to live? I eventually bought a little angel bear, with blue wings and took it back upstairs to give to him. He had opened his eyes. Scott told me Blake had opened his eyes! I missed him opening his eyes! I guess in the scheme of things, it is not important, but to me it is a major thing that I missed. Scott sat down, and cuddled Blake. They took his tubes out, and while Scott & I cried and told our son it was OK to go, he passed away. He didn't suffer, and for that I am grateful. Scott asked if I wanted to hold him, and of course I said yes. As I was nursing him, he moved! What was this! He wasn't gone; he was fighting. I smiled and told Kate our midwife that my son was a fighter, and he didn't want to go, but she just said that it was the organs shutting down.

After what seemed like an eternity we went to the privacy of our room. This was in the maternity unit, and all I could hear were babies crying. It was not fair. All I wanted was to be like the other mothers-- happy and full of the wonderment that is a newborn baby, but this was not to be. We spent that night with Blake. I asked that we be moved to another ward because I couldn't stand the sound of the babies. We watched the football as a family, and we bathed him and dressed him. I think I must have kissed every inch of his perfect body. He still smelt like a newborn baby. I took all of that in. His smell, the way he felt, how soft he was, how beautiful! I didn't sleep, I couldn't. I wanted to spend every second that I could with him. I sang to him, told him stories, took him outside and showed him the stars. It was a cold night! I kept him wrapped up snug and tight, and the whole time all I wanted, all I prayed for, was for some miracle to happen and for him to open his eyes and cry.....and before I knew it, it was time to say goodbye. The hardest thing I have ever had to do, will, ever have to do was to hand him over, and as I handed him over to Kate, I just kept kissing his forehead and kept saying, "I love you, I love you, I love you" and with that I turned and walked out of that room and away from my baby.

I will not say that Blake is with his maker, because this has certainly tested any faith I may have had. All I will say is that Blake is at peace; he is not suffering, and I know that wherever he is, he is looking down on me and my family and making sure that we are OK. He IS the shiniest star in the sky.

Kirrily Hanlon (mom of Blake Hanlon, 6/25/02-6/26/02, 11 Dural Crescent, Engadine NSW 2233, Australia, khanlon@nswtrb.com.au)

Hannah Abigail Paslay



Dear Cherubs,

Our daughter, Hannah Abigail, was born January 9, 2003 at Saint Francis Hospital in Tulsa, OK. She is our fourth child and our only daughter. Hannah was diagnosed at 29 weeks with CDH and thanks to your website we were able to prepare ourselves for what would lie ahead. After Hannah was born we discovered that her condition was very serious and doctors made the call to put her on ECMO the day she was born. After 12 days on ECMO, she made the successful transition to a ventilator and came through the hernia surgery fine (the hernia was on the left side and 90% of the diaphragm was missing). Since coming off of ECMO we have been taking it a day at a time.

She is 3 weeks old today and despite other complications she has continued to progress with victory. We thank God that she is still with us and we praise Him for the work that He is doing in her life. We know that a long road is ahead of us concerning her stay in the hospital and her care at home, but we are blessed beyond measure that God would count us faithful and give us Hannah. There are so many people praying and believing with us for Hannah's continued progress and healing. Thank you for the ministry of Cherubs and we look forward to participating as Cherub members. Please let us know if we can do anything to help or assist others in our area. God bless.

Pastor Clayton & Jessika Paslay (parents of Hannah Abigail Paslay, 1/9/03, 6003 West 37th Street, Tulsa, OK 74107, 918-446-9955)

Brayden William Ross

I went in for my 18 week ultra sound hoping they would be able to see what sex the baby was; I never thought that there might actually be something wrong. A Diaphragmatic Hernia? I had never heard of it before but at 22 weeks when I had a diagnostic ultra sound and it was confirmed I started searching for any information I could find. I search the net expecting one or two sites and was shocked when my search engine found over two thousand sites.

My neonatal care was moved to Westmead Hospital so that after the baby was born and as soon as the baby was stable they could move him next door to the Children's hospital for surgery.

We lived thirty minutes away from the hospital and in the last weeks of my pregnancy I was having nightmares of not making it to the hospital in time (my second labour lasted 1 1/2 hours) because I knew that if he wasn't born at Westmead he might not survive transport.

A week before Brayden was born I went in for my weekly appointment and was instructed that they would put me in for a induction on the 13th of March, it was the only day that week they could get me in and I didn't want to have him on that day because it was his daddy's birthday. As it happens I didn't get a say in the matter.

I was due to ring the hospital at 6:30am to find out when to come in for the induction but at 3:10am I got up to go to the toilet and my water broke. It took all of fifteen minutes to get to the hospital (I was worrying for nothing) and at 12:16pm Brayden William was born.

I got a quick look at him after they had intubated him and off he went to NICU and I didn't see him again for three hours.

When we finally got in to see him he was sedated and was hooked up to every machine imaginable. All his lines ran through the open vessels of his belly button. When he was two days old he got a mild infection and the medication line in his belly button started leaking so they had to stick his belly button closed.

On Saturday 16th March Brayden was stable enough to be transferred to the Children's Hospital and the lines in his belly button were removed and placed in the artery in his leg. Finally it seemed like the first big hurdle was nearly over.

His lungs were oxygenating his blood well, but his blood pressure could not be kept high enough to keep the blood flowing in the right direction through the valve in his heart that connects the two upper chambers. Not enough oxygenated blood was getting through his body. By early Sunday morning Brayden's O2 levels dropped to just 9% and we were told that he wouldn't make it.

At 11am Craig and I had to make the decision not to prolong Brayden's suffering and had to call our family to tell them to come and say goodbye.

We had him Christened. Everyone got to have a cuddle while he was still with us, and we had moulds done of his hands and feet. Then Craig and I held him as he peacefully left us. Everyone had another cuddle and we gave him a bath, with help from his sisters. We dressed him and took him out to the court yard for more cuddles and after our family left we said one last goodbye, gave him one last kiss and handed him to the nurse who sat outside with him until we left.

The hardest thing I have ever had to do was to leave my son and walk away.

We are grateful for the four days we had with Brayden, some people don't even get that. Our precious little angel with wings of GOLD. For a moment in our arms, Forever in our hearts.

Kristine Ross (mom to Brayden William Ross, 3/13/02-3/17/02, 26 Frank St, Mt. Druitt NSW 2770, Australia, kristross@telstra.com)

George Walen

I was driving from my office to grab some lunch when I got a frantic call on my cell phone from my wife, Jennifer. She was at her 20-week ultrasound appointment, and told me, between sobs, there was a problem and begged me to get there as soon as I could. The ultrasound technician coldly said our son's stomach was in his chest and this was very bad. She had gone to get the doctor, leaving Jennifer alone, stomach bare and heart broken. I heard her agony and floored it.

A million scenarios ran through my head about the health of my wife and whether or not we were looking at a fourth miscarriage. I wondered if my wife's hyperemesis, which put her in the hospital for six weeks during the first trimester, and all the anti-nausea drugs we tried had affected the fetus. I wondered if we had chosen incorrectly that keeping Jenn on her anti-depressants had somehow caused our baby harm. I cried and slammed the steering wheel repeatedly all the way to the doctor's office.

By the time I got there, the mood was decidedly calmer. The doctor said the baby had what was called a congenital diaphragmatic hernia (CDH) and suggested we change to a high risk O.B. and switch our care to Vanderbilt Hospital for the birth. Vanderbilt was the only hospital in the area set up to handle what would prove to be a harrowing birthday for our son.

We met with our new O.B., Dr. Rani Lewis, soon after and she gracefully explained what we were going to be looking for in future ultrasounds. She showed us the stomach bubble in his chest, showed us his heart beat was strong, and reassured us as best she could, while giving us the grim statistic, that even at a hospital as advanced as Vanderbilt the baby still only had a 60 percent chance of survival.

I began to do my usual shtick of preparing for the worst, telling everyone the baby had a one-in-three chance of dying with Jennifer informing folks the baby had two-in-three chances of living. She did great counterbalancing my skepticism while I did my best to prepare our families for every contingency.

Dr. Lewis set up a planned C-section for August 30, 2002. Jenn and I arrived with my brother Alec and Jenn's mom Teresa around noon and prepared for the coming of George Roman Walen, named after his great grandfather George Roman — giver of bear hugs, unconditional love, and possessor of big, warm chocolate brown eyes. Jenn was whisked into the prep area for her spinal block while I donned a funky one-piece hypoallergenic scrub suit and waited for the signal to come to the surgical room.

I found Jenn there strapped to the table, with a gaggle of nurses and surgeons hanging out in the corner waiting to rescue George. Dr. Lewis arrived and the cutting commenced. I watched the whole thing with awe and amazement. I saw George stick his hand out and wiggle his fingers from his mommy's tummy. I couldn't help but laugh. They eventually pulled the rest of him out and he was a purple, nearly-motionless being. But he was beautiful and I fell in love instantly. Jenn got only the briefest of looks as Dr. Lewis held George over the curtain for my wife to see before handing him over to the anxious crowd of doctors waiting to intubate him and take him to the NICU.

George was put on a ventilator, placed in a chemically-induced coma, and essentially hard-wired to every bleeping machine (pun intended) the hospital seemingly could find. I waited with Jenn, Alec and Teresa in recovery as my wife woozily got her wits about her to hear what the lead pediatric surgeon, Dr. John Pietsch, had to say about George.

Our little man was stable, and seemed not to need ECMO, a heart and lung bypass machine often used in cases like this. Within 48 hours, George was deteriorating rapidly. He was put on ECMO after all, and he looked awful. He blew up like a balloon with swelling around his face and neck being the most noticeable. It broke all our hearts. Two days into being on ECMO, Dr. Pietsch repaired George's hernia. He used an experimental patch made from a genetically modified pig intestine. Only one other child at Vanderbilt had ever undergone this procedure, just eight days prior, so there was no predicting its efficacy. We mused with Dr. Pietsch that our little Jewish son was no longer kosher, but nobody in our family keeps truly kosher anyway. Dr. Pietsch also informed us that George's hernia was far worse than we were led to believe. He was missing nearly 75 percent of his diaphragm, and his left lung was severely compromised by bowel and stomach invading the chest cavity. We were in for a long struggle.

George survived the surgery, was taken off ECMO after four days and slowly but surely made his way towards consciousness. He was almost a month old before he opened his eyes. When we saw them, it was our first sign of the light at the end of a coal-black tunnel.

All was not smooth sailing, however. George faced pulmonary hypertension, pneumonia, fluid buildup in the chest cavity, and a blood infection. He was tremendously uncomfortable at times, trying to cry but not able to make a sound for the tube in his throat. He would tear up and make such unhappy faces and swipe at the tubing. It was gut wrenching, but proved he was winning the fight for his life. Somehow he kept getting stronger. After six weeks, the doctors experimented to see if he could breathe on his own. The ventilator tube was pulled, and we were given the chance to hold our son for the first time. We bawled with happiness, overwhelmed with pure, unadulterated love. It's a feeling that is so indescribably wonderful, it can't be compared to anything I've ever experienced or could hope to experience again in my life. The joy, however, was fleeting. George's underdeveloped lungs simply could not handle the task of breathing on their own. Over the next 10 days, he was weaned down from the ventilator until finally he was freed for good. We rejoiced, as did his nurses and doctors.

The next hurdle to overcome was feeding. Since George's birth, Jenn was pumping breast milk every three hours to give him the necessary nutrients and antibodies we knew he'd need. It was administered to him via a nasal-gastric (NG) tube for over a month while he was on the ventilator, so we knew his system could handle it. It was now time to teach him to suck and swallow. This proved to be much harder and possibly even more emotionally trying than anything else we faced with George.

Here was this beautiful baby who if he would just eat would come home with us. But he was still so weak, he was unable to expend the necessary energy to nurse or take a bottle for any length of time. Jenn diligently tried to get George interested in the breast, but it was just too hard for him. We started using a special bottle called a Haberman, which allows you to control the flow of milk, and found he could handle it fairly well. It kept the milk coming at a slow enough pace he wouldn't get overwhelmed, but if he was really vigorous we could speed up the release so he could take more in before he passed out. What he didn't take from the bottle continued to go into his NG tube.

We were given a target of 60 ccs of milk per feed every three hours. Once George could handle that, we could take him home. It seemed he never took more than 40. We would feed him for up to an hour sometimes just hoping he would suck a little more down, but we were told that it was counterproductive to feed him for more than 20 minutes since he would end up burning more calories than he would be taking in.

We battled on with him for about 10 days. George, meanwhile, had had enough with the NG tube and pulled it out himself. The nurse who had worked with him since he was on ECMO, Vicky Gregory, decided to feed him without replacing the tube to just give him a rest from the routine poking and prodding he had to endure countless times a day. George took 50 ccs. She was encouraged and continued to feed him without the tube, and he continued to do well. We slowly coaxed the doctors into letting us take the little guy home without meeting his intake target or the NG tube as long as he continued to gain weight, even if it was just a little bit.

After his circumcision and a day of recovery, George was finally cleared for release — eight weeks from the day of his birth.

Since coming home, George has continued to face problems with nutrition. He never took to nursing at all, so he was put on a high calorie formula. He spit up like a fountain several times a day, and faced unbelievable bouts of gas and constipation. Thankfully, he gained weight, if ever so slowly, and was very happy most of the time. We discovered bouncy chairs and Mylicon drops worked well for gas, and the occasional suppository helped get his bowels moving. But his interest in eating never really picked up.

At about three months of age, George entered daycare and Jenn and I went back to work full-time. This has proven to be a bad move. George picked up the flu and bronchitis in his first two months there. And when he got sick, he lost all interest in eating. At five months old, George was diagnosed "failure to thrive." He was admitted to the hospital to get another NG tube put in, and we were taught how to insert it if he pulled it out or for when it was time to change nostrils to avoid irritation of the nasal passage. Under the care of pediatric GI specialist Dr. Dedric Moulton at Vanderbilt Children's Hospital, we came up with a goal of 4.5 ounces per bottle fed five times a day. He would be fed by bottle first, with the remainder poured through the tube. George would vomit the increased volume quite often at first, but eventually started taking more on his own and spitting up less — that is until he contracted rotavirus, a severe intestinal bug that causes severe diarrhea and vomiting, at daycare. It got so bad he nearly refused to eat altogether, and the doctor told us to go to the ER. Thankfully, his dehydration was caught in time and he bounced back in a few days.

With this latest scare, our pediatrician suggested if we could afford it to take George out of daycare to avoid what he termed "daycareitis," basic exposure to a host of germs and viruses all kids get at some point, but found more common in close quarters such as schools and daycares. I've since quit my job and become a stay-at-home dad.

While George had gained significant weight with the NG tube, over 10 percent of his body weight in less than two weeks prior to the rotavirus, it was still not enough to satisfy his doctors. George is quite small and weak, and at six months of age is just 11 pounds. He's not rolling over and is only now holding his head up on his own. He needs to pack on the weight, which will give him the energy and muscle strength to catch up on motor development. To achieve this, Dr. Moulton has put George on a continuous feed of high-calorie formula throughout the night. As he bulks up, it is hoped he'll want to eat more on his own and negate the need of the NG tube. We pray that by seven months of age he'll be free of tubes once and for all.

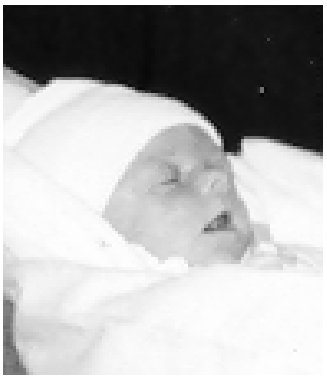
Through all of the struggles, one thing has become crystal clear — George is a miracle. He wakes up each morning with a smile and giggle, and brings such light and joy into our lives. And best of all, he is proving to be the embodiment of unconditional love his namesake exuded with such tenderness. And he certainly has his great grandpa's big, warm, chocolate brown eyes.

Drew Walen (dad of George Walen, 8/30/02, 8005 Sawyer Brown Road, Nashville, TN 37221, 615-662-1831, dandjwalen@comcast.net)

Sean Feaster

My husband David and I had been married for 2 ½ years when we decided to have a baby. I was 34 and had a 9-year-old son (Jimmy) from my first marriage, and David was 33 and had a 13-year-old son from his first marriage. The baby was due June 6th and I would have a c-section in late May/early June.

Because of my age I was concerned and cautious with this pregnancy. But other than morning sickness, things seemed fine. We had an ultrasound on December 23, 2002. I was 16-17 weeks along. The ultrasound technician did not say much during the scan. She said everything would be sent for analysis and my doctor would get a report. I wonder now if that is their policy, or if she just didn't want to say anything to us.



At Christmas we showed off our ultrasound pictures, and I started to relax. Then on Dec. 27 the hospital called saying my doctor wanted me scheduled for genetic counseling and a Level 2 ultrasound as soon as possible. I was terrified and called my OB/GYN. They said to calm down and not worry (too late!). The ultrasound showed the baby might have a hernia or a hole in the diaphragm or the diaphragm was missing. My first feeling was relief that it was something "physical" and not "mental." I figured they could fix something physical. Next I checked the internet using the only terms I could think of: fetus hernia diaphragm. The only thing I found was "Congenital Diaphragmatic Hernia" (CDH). What I read was not comforting!

At the hospital on Monday I was a wreck. The genetic counselor (Beth) said there were other suspicious things which the doctor had not mentioned. There was a concern the baby might have a cleft lip, cleft palate, a missing kidney, and a larger than normal head. And yes, they were looking for CDH. Beth told us babies with one abnormality usually have more. She talked about all kinds of potential problems. Beth was very open and honest with us.

The ultrasound confirmed the CDH. The good news was they didn't see any of the other defects. I would need to have Level 2 ultrasounds frequently, and in a few weeks they would do a fetal echocardiogram. Mostly we heard they couldn't tell us much yet because it depended on how well the baby's lungs developed. The liver was in the abdomen, but it could move up and down throughout the pregnancy. I had an amnio done, and they also did a FISH test so we could have results in ~48 hours. Both results came back fine. There were no problems with the baby's chromosomes. Beth warned it did not mean there was nothing else wrong. There could still be problems which don't show up on ultrasound or amnio. But it was still a relief.

We had an Echo on Feb. 5. They didn't see any major heart defects (no holes or anything). Because the heart was pushed over and turned, some things did not go in a normal route, but blood was flowing to and from the heart the way it should. There were some things they couldn't see well though because the stomach was in the way.

I read everything I could about CDH. I read every Cherubs story. I was frustrated because there didn't seem to be much difference between the babies who lived vs. the ones who died. I did read that babies with heart problems in addition to CDH would most likely die. That scared me. Although they didn't see anything terribly wrong with our baby's heart, it wasn't completely normal.

We met with a surgeon who explained what we could expect with the CDH repair. She was very optimistic based on the reports she'd seen on our baby. She said she'd guess his chance of survival would be 80-90%. She even thought he might not need ECMO. She said babies on the bad end of the scale generally do poorly, and ones such as ours on the good end tend to do much better. We felt very positive after talking to her.

At about 6 ½ months the baby was lagging in weight (11th percentile), but he was growing consistently (the lag wasn't getting any worse). I started having Biophysicals once a week to keep an eye on things. My chart was now marked as "Diaphragmatic Hernia" and "IUGR".

Thomas Jefferson University Hospital in Philadelphia (an hour away) was the closest hospital with ECMO, so I transferred my care to the MFM group at Jeff. At our first appointment we had an ultrasound and another Echo. We were told the hole in the diaphragm was very large and that the baby had "severe dextracardia" meaning the baby's heart was pushed way to the right (practically against the ribs). We talked to a Neonatologist, toured the NICU, and saw a baby on ECMO. The docs reviewed the ultrasound results, and said the stomach was still up along with a significant amount of bowel, and the liver was still down. The baby was still smaller than they'd like, (15th percentile now), but measurements showed everything was proportionate, meaning he would just not be tall (David is 5' 6" and I am 5' 1" so that wasn't surprising). They were concerned about his limbs possibly being short and his head looked lemon-shaped, but they could not give us

any indications of what this meant! Also, I had polyhydramnios, which explained why the baby was so active. I started having NSTs twice a week.

One day when I was 7 months I started having contractions. They were 7-10 minutes apart, so David called the doctor. We were told to go to our local hospital to be monitored because it was much closer than Jefferson. The monitor showed I was contracting every 3 minutes. I was only a fingertip dilated and not at all effaced. They ran tests and started an IV for fluids. Results of a fetal fibronectin test were negative – meaning there was 99% probability I would NOT go into labor in the next two weeks. But I kept contracting. I guess the hospital didn't want to be responsible for sending me home since my official doctors were at Jefferson, so at 3 a.m. I was transferred by ambulance to Jeff. At Jeff they did another cervical exam (still no change) and talked about options. I was exhausted. David noticed the contractions were slowing down, and when I dozed they completely stopped. Finally they did an ultrasound to check on the baby. He was fine, and his heartbeat had been perfect the entire night. At noon on Friday they finally let us go. A couple of weeks later, I had another bout of contractions during an NST and was sent to triage. After a couple of hours, I was sent home with a prescription for a urinary tract infection.

We had a special Oxygenation test on May 2nd. This was a way to determine how well the baby's lungs were developed. First they measured the baby's oxygen intake while I breathed room air. The graph showed a lot of resistance getting oxygen to the baby. Then I breathed oxygen through a mask for 10 minutes and they checked the level again. We could immediately see the difference in the graph. We were told it was the best outcome they'd ever had with this test, and they felt the baby would do well. We were ecstatic. Then I met with another surgeon to talk more about what would happen when the baby was born. He said there were several indications which made him think our baby would have a very good chance.

The big day finally arrived, and Sean Anthony Feaster was born at 9:28 a.m. on Wednesday, May 28th. He weighed 5 lbs 4 oz and was 18 ½ inches long. Even though we had been continually told we wouldn't know what we'd be dealing with until he was born, things could not have gone more differently than we expected.

When the c-section started the doc never said he started cutting, nor did he tell us when the baby was out. There were so many people in the OR, and I couldn't tell what was happening. The nurse came and told David not to worry about not hearing the baby cry. She wasn't sure if we realized they would intubate immediately and "he" wouldn't be able to cry. David said, "He?" She said, "Oh, you don't know what you had?!" She went to check, and when she came back, David turned to me and said, "You were right. It's a boy." We were both crying.

We were told David would be able to see Sean briefly and take a picture. But then someone said, "Get that camera from Dad." They grabbed it from David and took pictures for us. I think I knew then that something was wrong. Otherwise they would have let David see him. They handed us two pictures, and we continued to cry. Sean was taken to NICU, and David and I were taken to the recovery room to wait for info. They said it would take about an hour to get Sean situated and then they would let David up to see him. Over an hour passed, and we were told it would take a little more time. So we waited some more. We tried to act calm, but we were very worried.

Then the neonatologist came into the recovery room with another doctor and a social worker. I knew that was not a good sign. The doctor said Sean was very sick. He had a significant amount of bowel and part of his liver in his chest, and he had a problem with his heart! Immediately I thought of my research which said most babies with both CDH and a heart problem would die. Sean had Tetrology of Fallot (TOF). We were told the team of neonatologists almost lost Sean at one point, but he was now fairly stable. Jefferson was not equipped to handle cardiac problems, and Sean needed to be transferred to A.I. duPont Hospital for Children in Wilmington, Delaware (which is only 20 minutes from our home in Newark, Delaware) immediately and placed on ECMO. We were confused. We were at Jeff because we thought they were the only ones in the area who had ECMO. As it turns out the Nemours Cardiac Center at AI does have ECMO, but it's only used for cardiac patients. And until now there had been no indication Sean had a heart problem.

We were devastated. The docs asked if we had any questions. I said, "Is there ANY chance I can see him before he goes?" David told them I had not seen Sean at all, and David had only caught a glimpse. I hated to delay Sean from getting the medical attention he needed, but I wanted so badly to see him. When they brought Sean in I was so happy and so scared. He was beautiful. We were able to touch him, and the social worker took pictures with a digital camera. I told the transport team, "Whenever you need to go, just tell us, because if you're waiting for me to tell you to leave, it won't happen." I knew Sean had to leave, but I couldn't bring myself to tell them to take him. It was so hard to see him go. I was terrified he would die before he got to AI. David left to follow Sean to AI. I felt so lost and scared, but I wanted him to get to Sean too. Sean needed his Daddy a lot more than I did. At the time I thought nothing in my life would ever be harder than what I just experienced. Unfortunately I was wrong.

Just as David arrived at AI a surgeon called me saying Sean was very ill and needed to go on ECMO immediately. He couldn't wait for David to get to the unit and wanted my verbal ok to go ahead in order to save Sean's life. A social worker (Judy) at AI called to tell me Sean had been baptized and kept me updated while Sean was in surgery. Sean was successfully put on ECMO and was safe for the time being. Not long after going on ECMO they were able to turn the flow down 50%. Sean was able to do half of the work himself! We knew then how strong he was.

A.I. is an amazing hospital. The Cardiac Unit has rooms for parents so they can stay at the hospital. The room was set up so that when Sean was well enough he'd be moved there, and we could help take care of him. The room had beds, a bathroom, a TV/VCR, and a telephone. They provide parents with meals and other necessities. It was a wonderful set up for people like us with very sick children. We were able to literally live at the hospital.

David called me often. He told me about the people caring for Sean and how great everyone was. He said he sat with Sean and told him how much we loved him and how I wanted to be there and that he'd bring me soon. There were times when he couldn't sleep and would go sit with Sean in the middle of the night (another advantage of being at the hospital 24/7). David said when he sat with Sean, an hour felt like five minutes. But to me, sitting in another hospital unable to be with Sean, five minutes seemed like five HOURS.

I was desperate to get to A.I, but because of a problem with my blood pressure, I didn't get out of the hospital until Sunday. Saturday night David came and brought pictures of Sean. He looked so different than he did the day he was born. For the rest of my life I will regret missing those first days with Sean. There's no way to describe how it feels to be separated from your baby. I asked David about Sean's

limbs and head and neck. He said, "Julie there is nothing wrong with him on the outside. He looks perfect." A geneticist saw Sean and said he looked perfectly normal on the outside.

When I finally got to AI, David said, "Do you want to go see Sean?" What a question! I was nervous, scared, and excited. David took me to CICU and there was my Sean! Even through all the tubes and wires, he looked absolutely perfect. Sean's left eye was swollen shut because his head had been turned since he went on ECMO, and his head was flattened from always lying on that side, but he was still adorable. I leaned close to him and said, "Hi Sweetie," and he opened his eye! David told Sean, "See, I told you I was going to bring Mommy." I didn't want to stop touching him. I wanted to make everything better. I didn't want to ever leave him again.

Jimmy came to visit that night. I took him to see Sean, and it was the first time I had both of my sons together. I loved it. Jimmy was thrilled to have a little brother. He often asked me if the doctors knew yet if Sean was going to live. We took the camera so Jimmy could have picture of Sean to take to school. And I took a picture of Jimmy and Sean. Thank God I did because it is the only picture I have of the two of them together.

The next day was Sean's CDH repair. The surgery went fine. They put Sean's organs where they belonged and repaired the hole in his diaphragm. Sean had virtually no diaphragm on the left side. There was only a small lip, so they used Gortex. The next morning the doctors made adjustments to Sean's settings to see what he could tolerate and tried clamping off the ECMO lines to see if he would be able to come off. I saw Sean turn purple and it looked like he was struggling. He was not ready to come off, but they were able to turn the flow down. Now Sean was doing 75% of the work himself! His blood gases were great after the CDH repair. He was putting out urine which meant his kidneys were working. We were thrilled to hear he pooped for the first time a couple of days after the surgery. It meant his intestines were functioning too! The nurse said sometimes Sean would even try to take his own breath in addition to the ventilator which seemed like a good sign.

I spent as much time as I could with Sean. It was so hard to get up and leave him. Mostly I held his hand or stroked his forehead, and sometimes he grabbed hold of my finger. At times the nurse would tell us not to stimulate Sean because of his heart rate. That was so hard. Whenever David talked to me or the nurse, Sean would open his eyes or try to move. He knew his Daddy's voice. Sometimes he would lift his arms and get so feisty they had to strap his arms down. He was strong and he was a fighter. He opened his eye(s) a lot. I know he saw and heard us. We told him what a good boy he was and how strong he was. And we never left CICU without telling him we loved him and that we'd be back later.

The doctors tried clamping the ECMO again one day. Sean handled it for about five minutes then started to have problems. It was progress. He just needed a little more time. Three days after the surgery the doctors decided to do Sean's TOF repair. They had hoped to get him off ECMO first, but he still was not able to do all the work himself. They didn't know how much of that was due to the heart problem, so they wanted to fix it and see what happened. David and I felt fixing the TOF would improve things tremendously. Sean was already doing most of the work himself, so it seemed logical that the boost the heart repair would give him would be more than enough to get him off ECMO. We knew ECMO saved Sean's life when he was born, but we also knew he needed to come off soon.

The surgeon repaired the hole in Sean's heart with "a rather large patch," and said except for the fact that Sean's heart was still on the right, things went routinely. The doctors let Sean rest over the weekend and kept him pretty heavily sedated. As usual, whenever they lowered the meds, he would start to move and get mad!

On Saturday fluid built up around Sean's heart, and they had to drain it. During the procedure the doc nicked Sean's lung. Air built up in his chest, so they put in another chest tube to get the air out and keep his lung from collapsing. Sean was very swollen from his surgeries. His kidneys stopped functioning after the heart surgery, so he was given Lasix and they turned the ECMO back up. They tried feeding Sean breast milk, but he did not digest it.

On Monday they tried changing Sean's settings again, and he did not do well at all. He got VERY sick. It took all day for them to get him back to where he had been in the morning. It was so scary. It made me wish he was still inside me where he had been protected and safe. Tuesday morning an echo showed Sean's heart still wasn't pumping blood properly. One side of his heart was larger than the other, so one was getting too much blood and the other not enough. They wanted to take him back to the Cath Lab and put a hole in his atrium. The blood flowing through the hole would be blue blood, and with his lung problem, Sean really needed oxygenated blood, but this was the only option they had. They wanted to do the procedure right away and were unhooking Sean's equipment to take him to the Cath Lab while I signed the consent form. Seeing my tiny, sweet baby going in for another procedure was heartbreaking. The procedure went ok, and Sean's blood gases were stable throughout the afternoon. That evening the doc said there weren't any major changes in Sean's status but they hadn't expected immediate results.

Sean's blood gases were fairly stable throughout the night -- not great, but consistent. His chest tube was draining a lot of blood, but no one seemed concerned, so I tried not to worry. I noticed he hadn't been putting out any urine at all. He was still very swollen so an attachment was put on the ECMO unit to remove fluid. Wednesday evening Sean was still the same. I never asked what the next step for Sean would be. I was too afraid of the answer.

Thursday morning we were shocked when we saw Sean. The swelling was gone, and he looked so much smaller! It was a drastic change from the night before. He looked tiny, and his eyes were huge in his little face. Unfortunately, Sean's blood gases were not very good, and his bilirubin levels were rising which was a sign his liver was not functioning properly. The nurse said they weren't planning anything special for Sean that day. Just then another baby was being transported in, so I had to leave CICU.

I was in our room when a nurse popped in and said a doctor was looking for me. The doctor came to our room and I started to panic. Part of me thought she wouldn't tell me anything bad without David there, but I was wrong. She said the doctors got together that morning and discussed Sean's case. Everyone who had worked with Sean was involved in the meeting. They even called doctors at other hospitals to get input. Sean wasn't getting any better; in fact he was getting worse. She said Sean had been on ECMO for the "magic" two weeks. They tried Nitric Oxide several times, but Sean still had too much lung resistance. His kidneys had shut down days ago, and now his liver was shutting down. His blood gases were not good, and his blood pressure was low. All of these were very bad signs. She said there was nothing else the doctors could offer him. The more she talked, the harder I cried. She went on to say we needed to make a decision. We could wait until things got worse and the doctors would make the decision to take Sean off ECMO, wait until something happened such as a stroke or a blood clot which would kill Sean, or make the decision ourselves to remove Sean from ECMO. She said some parents can't

bring themselves to make the decision so they just wait and let God make it for them. And some parents don't want to see their child go through anything else. She knew the decision would be especially hard for us because Sean was still opening his eyes and looking at us. As far as they could tell Sean's brain was still ok.

I couldn't believe what she was telling me. We always knew it was a possibility, and we had seen some of the signs, but it still seemed unreal. I kept thinking, "Is this really it? Is this the end? It can't be!" I didn't want to give in. I said, "If we wait, does *anyone* think there's *any* possibility Sean might get better?" I had to know if there was ANY hope at all. If there was the slightest glimmer, I would cling to it. She looked me straight in the eye and said, "No." Everyone had exhausted every option. There were no more tricks to pull out of the hat. She said Sean's heart surgeon (Dr. Norwood) was the most aggressive doctor she's ever known. He will try anything and everything, and even he couldn't come up with anything else. As I thought about this later I realized the doctors probably knew taking Sean back to the Cath Lab on Tuesday was a long shot. I'm pretty sure they didn't think it would work, but it was the only thing they could think of to try. I take comfort in that because I know the doctors really did do absolutely everything they could think of. Now Sean was basically being kept alive by "heroic" measures.

I called David and he said he'd be there right away. It seemed to take forever for him to get there. Finally he walked through the door and put his arms around me. Neither of us said anything. We just cried. When we pulled apart, I was not prepared for the look on David's face. But I completely understood the look because I felt the same thing – complete sadness, total devastation, and helplessness. David said, "I don't want to lose my son."

We went to see Sean. I looked at him and thought, "How can I let him go?" "What will life be like without him?" My heart was breaking. Thinking back, I admit Sean did not look good that day. Maybe it was because he was so thin and frail looking now that the swelling was gone. He didn't seem as strong as he had before. I don't remember him trying to lift his arms at all that day. He opened his eyes, but he looked tired and worn out. I was hoping the doctor would have something new to say. But there hadn't been any miraculous change in Sean's condition.

I told David what the doctor said about our options. David said no matter what we chose it would still be decided by God. He was right. I had gone over the options all morning. Part of me thought, "Why make Sean go through anything else?" But when I thought of actually letting him go I didn't think I could go through with it. No matter what we chose, the outcome would be the same. Sean would die. We would never bring our baby home from the hospital. David said, "I think we only have one choice." He had told me that while I was at Jeff he had promised Sean he'd never let anything else happen to him. He cried as he reminded me of this promise to Sean. We couldn't let Sean go on knowing there was no hope. We would ask the doctors to remove Sean from life support. Sunday was Father's Day, and I thought maybe David would want to wait until after that, but he didn't. He was adamant about not wanting to risk ANYTHING else happening to Sean. We didn't want him having a stroke or throwing a blood clot. Sean had been though so much. It would have been cruel, and it would have made David break his promise to Sean. We would call everyone to come say goodbye. After everyone saw him, we'd spend time alone with Sean. We thought it best to wait until evening to remove Sean's support. It would be quieter and there would be fewer people around.

Telling people was horrible. My father was so upset he couldn't bring himself to come say goodbye. Jimmy took it hard too. I took him to see Sean, and before we left Jimmy went to Sean and squeaked out, "Bye Sean" and started crying. I knew it was the last time I'd see my sons together.

The afternoon went by quickly. I was looking forward to things quieting down and being alone with David and Sean. As the last of the family left it started to storm. It had rained almost every day while Sean was in the hospital. I kept thinking the sun would finally come out the day we knew Sean would be ok. So it was fitting there was a storm on Sean's last night. Sitting with Sean was bittersweet. He was so beautiful. His skin was so soft. He had his eyes open quite a bit. We took pictures of each of us with Sean. And the nurse took some off all three of us together. Then we just sat watching him, holding his hand, touching his face, rubbing his arms and legs, and trying to memorize every detail.

The doctor explained what would happen. He said we could be there with Sean. It wouldn't be easy to watch him die, but I could never have walked away and left him by himself! Then they would clean him up and bring him to our room for us to hold. The doctor told us to take our time and let him know when we were ready. I couldn't imagine us having the emotional strength to tell him we were ready to let Sean go. How do you choose that moment? While we were sitting with Sean another baby was being brought in. The baby must have been very sick. Practically everyone in the unit was helping to get the baby stabilized and settled. There was a lot of activity around the baby, and I couldn't help but think this was probably exactly what it was like when Sean was first brought in. Normally we would not have been allowed in the unit while all this was going on. But no one ever asked us to leave. They just pulled the drapes around us.

After a while we went to take a walk and get clothes for Sean. When we got back everyone was still busy with the other baby. I was glad because it meant we had more time to spend with Sean. It was getting very late, and after a while we decided to go to our room for a bit The nurse said they were wrapping things up with the other baby and would call us as soon as the doctor was free. Soon the nurse called and said the doctor was ready. It was just after midnight on Friday, June 13th.

When we got to CICU, David walked directly over to Sean without washing his hands first. I was surprised, then I realized there was no reason to wash up this time. The doctor asked if we wanted to have an autopsy done. Sean's little body had already been through so much. I didn't want him being cut open again, but we agreed to let the geneticist have a tissue sample. I briefly wondered if the geneticist would use the sample to see if there was anything else wrong with Sean. If there was something else, I wasn't sure I wanted to know. He would always be my perfect baby.

The doctor told us once they gave Sean the pain medication we could not change our minds. And then it was time. For months I had prayed this moment would never come. For weeks I had begged God to let Sean get better. Now all I could do was pray for a miracle. Maybe, just maybe, Sean would be able to breathe and his heart would work on its own once the machines were turned off. I knew the chance of that happening was minute, but I still wished for it. There was nothing else I could do except be there for my baby, my Sean, and comfort him as he passed away.

We stood on either side of Sean and each held one of his hands. I heard the doctor tell someone to turn off the machines. We cried as we held onto Sean and told him how much we loved him. We touched Sean's face, his hands, his arms, his legs, and his hair. I don't know

the exact moment when Sean died. His eyes were open the whole time. That made it hard, but I was also glad Sean saw us as he died and knew we were there with him. Suddenly his chest moved and he seemed to be trying to take a breath. I said, "It's ok Sean." I wanted him to know it was ok for him to let go. He didn't need to keep fighting for us anymore. He could finally rest. David must have felt the same way because he said, "It's ok Sean. You go be with Jesus." It seemed like we were only there for a few minutes, but it must have been longer because the nurse and doctor told us we needed to go. I didn't want to walk away yet. I hated the thought of leaving him. But we did. For the first time, I left CICU without telling Sean I'd be back later.

The nurse brought Sean to our room and said she thought we'd like the way he looked now. I was afraid to look at him until she was ready to hand him to us. She gave us a memory box and started to hand Sean to me, but I told her to give him to David first. For the first time we looked at Sean and saw him with no tubes or wires or tape. He was so cute! He seemed smaller than he had in his bed. He looked like he was sleeping. He looked like the angel he now was. The nurse took pictures of the three of us then left us alone and said to call when we were ready for her to take Sean back. David held Sean briefly then gave him to me. He felt wonderful. Finally, after all this time, I had my son in my arms. We took turns holding him and used up a roll of film. I couldn't hold Sean close enough or long enough. I knew I would never have enough time with him. I didn't ever want to call the nurse. I wanted Sean with me forever. But eventually I let David call her. She came and took our baby away. I would never see Sean on earth again. I would never touch his face again. I would never hold his hand again. I would never get to do any of the things I had dreamed of doing with him.

Several months later we met with the geneticist. He found that Sean had 13 ribs, a hemi-vertebrae or butterfly-shaped T7, and some other minor variations including a transverse palmar crease and a fifth finger clinodactyly. Sean's chromosomes were fine however, which rules out a lot of things. There is the possibility that Sean had Fryns Syndrome, but the geneticist thinks it is unlikely. Sean did not have all of the features consistent with Fryns. Due to all the blood transfusions Sean was unable to be tested for 22q11 deletion, but David and I were tested and our results were normal.

We had a beautiful funeral service for Sean. He certainly made an impact on many lives during his short time with us. David and I love talking about Sean, and we think of him constantly. I've heard people who've lost a child say the baby who died is not the one they were meant to have. I don't agree. If I wasn't meant to have Sean, God wouldn't have given him to me at all. What I am trying to accept is that for some reason God decided Sean wasn't the baby I was meant to "keep." But there's no doubt in my mind I was meant to have him. Sean will never be with me physically again, but he will always be in my heart.

Sorry this was such a long story. Believe it or not, the original version I have for myself is 42 pages! Please feel free to contact me. I have read some excellent books, but it would be nice to hear from someone who has been through the same things we have.

Julie Feaster (mom of Sean Feaster, 5/28/03- 6/13/03, 1 Ferris Court, Newark, DE 19702, julielfeaster@yahoo.com)

Dylan Cole Gray

Dylan Cole Gray came into this world on February 8, 1994. He gave one big cry and then nothing. The nurses and doctor worked on him in my room for a few minutes and then told me that they were going to take him to the nursery. They told me that they thought he had fluid in his lungs.

About 30 minutes later Dylan's pediatrician came in and told me that Dylan had been born with CDH. He told me that Dylan was very sick and that he needed to have surgery right away. Dylan was taken to Children's Medical Center in Dayton Ohio. This is where the hernia repair was done. I was told that everything was fine for the moment.

The next morning I got a call from the hospital saying that Dylan needed something called ECMO. They told me that this was the only way he had a chance to live. I told them to do what they had to do. I told my doctor that I had to go be with my baby. He released me. I went home to say goodbye to my 22 month old son (Trevor) and then we were on our way to be with Dylan. He was already hooked up to ECMO when we got there. They sat down with us and told us that they didn't think that Dylan had a left lung and that his right lung was very small. They told us that he only had a 5% chance of survival.

He looked to sick. I remember thinking that I had made the wrong choice and that he didn't deserve to go through all this. I remember on the sixth day of being on ECMO so well. That's the day we found out that the left lung was perfect and that the right lung was underdeveloped. A nurse told me that Dylan was a fighter and she knew that he was going to make it.

Dylan came off ECMO after 11 days. Our next step was the ventilator which took the longest. When he was 6 weeks old he came off though and he was no longer on the paralyzing medicines. I finally got to hold my baby for the first time.

Dylan came home when he was 6 weeks old. A week later he stopped breathing in my arms. He had to be put on an Apnea monitor. He was also put on a special formula due to digestion problems.

At 18 months we found out that Dylan was deaf. The doctor's say that he was deaf at birth but he passed all the hearing tests before we brought him home from the hospital. He is behind his peers because of speech limitations but other than that he is a normal 9 year old child. We no longer have to worry about him getting sick all the time. It has been 3 years since he has been hospitalized for any sicknesses.

I thank God everyday for saving my son's life. Dylan is such an amazing boy.

To those that have been through what we have been through I want to say enjoy your child. They fought hard to get where they are. And to those you have lost your precious children I am so sorry. Just remember the love and joy you felt when they came into this world. Your children will live on through you.

Tammy Mowery (mom to Dylan Gray, 2/8/1994, 125 Stella Street, Celina, OH 45822, 419-584-1999, jrscelina@hotmail.com)

Nathan Clarke

Nathan Clarke born at the Mater Mothers on the 23/1/1992, Brisbane. Nathan was diagnosed at 21 weeks in utero with a L-CDH. That was a day to remember, all these words the doctor was saying, what did it all mean? After that we had so many tests and scans for the rest of my pregnancy. They told us our baby had less than 50% chance of survival. I just wasn't prepared for it. I remember it like yesterday right on my 40 week check up they told me his heart beat was strong that was it, I cracked after all this time. I remember saying "Then why is my baby going to die?" That was it. The doctor wouldn't let me go home. They took me up stairs to bring him into this world.

It was the longest 2 hours of my life because here I was fighting not to give birth to him; maybe I thought if he stays inside me he is safe. I remember there was me, my husband and a nurse then bang the room was full of doctors and others. I didn't even see or hear him cry. The doctor brought a photo of him into us to show what he looked like.

When we got to see him there where so many tubes and he was paralyzed so he didn't move. I remember my father saying he looks like a remote control doll and with that he left the room. I think I must have spent nearly all night in with him just looking at him. Here he was normal size yet fighting for his life.

Exactly 24 hours later they came and told us he was stable so they would operate. We waited and waited then someone asked us too follow them, we both thought that was it, something had happened. But when we got over to the children's hospital a doctor explained what they did and how they did it. Nathan's stomach and intestines where up in his chest cavity, his heart was pushed to the right and his lungs were very small and squashed.

Nathan has had 2 repairs now and has been in and out of hospital with gut and bowel obstructions for 11 years. Nathan has asthma and a small hearing problem. Late last year he was diagnosed with Asperger's syndrome and now with coeliacs disease. We are now waiting for a bowel biopsy to see if there is any damage to the bowels. Nathan has had speech therapy, occupational therapist and physiotherapy. Nathan also has scoliosis. He even went bald at one stage! Nathan has had teeth problems in the past too.

Nathan was born a fighter and still is. He does not get a temperature like every one else; he goes cold and clammy. Nathan has a very high tolerance to pain it's like he doesn't feel it. Nathan is very good with math and science but his writing just doesn't connect, a small motor problem.

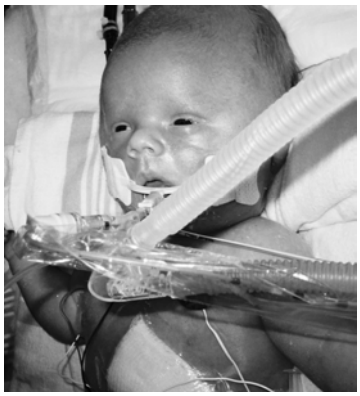
Nathan is a very special little boy he looks like other boys his age but he's not. Nathan you are the reason I get out of bed everyday, you give me heartache and joy but you are my miracle boy and I love you very much.

Monique Clarke (mom to Nathan Clarke, 1/23/93, Orion Road, Orion Road 4285, Australia, 0755432016, moniqueclarke@bigpond.com.au)

Caleb Ayers

I first found out I was pregnant in April 2002. We weren't trying, so just the thought was strange, but when I took a pregnancy test and it was positive, I just couldn't believe it. After the shock wore off, we were excited about having another baby. My husband really wanted a boy and our daughter, Kiley, kept telling us she was having a brother.

In the first five months, I had an easy pregnancy, no sickness or anything. Around the third or fourth month, I picked out a name, Reilly Caleb. Reilly is my maiden name, but I didn't want him (if it was a him) to be called Reilly. I didn't want my children's names to rhyme, so I picked out Caleb. When the time came for our 20-week ultrasound, I was so excited. The only thing we thought about was, is it a boy or a girl? We never thought that something might be wrong with our baby, why would it? In the room the technician asked if we'd like to know the sex and then told us it was a boy!!!!!!! We were so excited, but then the technician asked me to be very still, she wanted to recheck something that didn't look right. After a few minutes, she pointed to the screen and showed us how the stomach and heart were right beside each other. She went to get the midwife and they were going to send me to a specialist, who does level 2 ultrasounds. The midwife wrote down diaphragmatic hernia on a card and gave it to me. I could not understand what was going on. I went home and looked up diaphragmatic hernia on the internet. I still had no clue as to what was going on. How could something be wrong with my baby?



The next day we went to see the high-risk doctor. They explained everything to me right then. They told me about ECMO, all the complications, but most importantly I could tell they were really going to do everything they could to save Caleb.

I was getting BIG, and I started to become so uncomfortable. I started having a lot of pain in my ribs, every thing took the breathe out of me. I went to the doctor and they did an ultrasound to measure Caleb and my fluid. It was in the low 50's (normal is between 10-20,) because of Caleb's problems; he wasn't breathing in the fluid so it was just building up. Within a week it was worse. It went to 61; they had to drain about 1-½ liters. The next week it was right back; they ended up draining fluid 4 times (anywhere from ½ to 2 liters.)

We were going to have a scheduled c-section at 38 weeks. On Monday Nov. 25, 2002, Caleb didn't want to wait any longer. At 6:13 p.m. Reilly Caleb Ayers was born. He weighed 5 lbs. 12 oz. He was 19-¼ in. long. They told us that he would not be able to cry, but he did make a small sound. They had to incubate him right away. While I was being put in my room, the dr. called and told us that Caleb needed ECMO. He told me it would be a miracle if he made it through the night. All I wanted to do was see my baby. Finally around 11:00 that night I was allowed to go upstairs to see him. When I got there, he had tubes all over him. I wanted to pick him up so bad. His bed was raised so I couldn't even look at his face or touch him (I wasn't able to stand up yet.)

On Dec. 2, they had to change the ECMO circuit; we really thought we were going to lose him. After the change, he did not do well. The next morning the doctor realized his heart catheter was off somehow. They needed to replace it. The surgeon told us he was more worried about this than the surgery, the nurse told us that she did not think they had ever done that before. That was so hard to walk away from him and go wait in the waiting room. After what seemed like forever, the surgeon came out and told us that Caleb did great!!!!!! I was so excited; I just knew he was going to make it. Caleb was still not able to come off ECMO, so on Dec. 5 they had to do the surgery while he was on it. After the surgery, they told us that Caleb had his stomach, intestines, spleen and part of his liver in his chest, but they saw a good amount of lung tissue. (We were told he would probably have very little or just a lung bud.) He did great during surgery. Caleb continued to be depended on ECMO, on Dec. 14, they told us they didn't think he could survive without ECMO. They were going to try to wean him again using nitric oxide to help him, and if it didn't work they would discuss "other options." My heart broke. The next day, Dec. 15, was my mom's birthday and Caleb's due date. We sat (& paced) the waiting room all day. Finally the doctor came out and said he was doing great without the ECMO, they were waiting on the surgeon to come and remove it!!!!! I was so excited; I couldn't wait to be able to hold him.

Caleb was doing okay without the ECMO, but every time his medicine wore off his oxygen levels dropped and he still had pulmonary hypertension. Dec. 18 was the first time I saw Caleb pitch a fit. It scared me to see him like that. The next day his numbers kept dropping so they had to put him on a drip to keep him paralyzed. He had this stuffed bear at the foot of his bed and he would rub it with his feet. His feet were very ticklish. He loved holding hands; he never wanted to let go of your finger. No body could resist from rubbing his head. He just wasn't the same after the drip. The dr. ordered an experimental drug to help with his pulmonary hypertension. His numbers started going back up. They let Kiley come in his room for the first time on Dec. 20. Then the dr. tried steroid to help his lungs.

On Monday Dec. 23, the dr. tried weaning him off the nitric, but with no luck. His oxygen levels were not high enough. They talked to us; there was nothing left to try. They finally let me hold him, but his tube came out so it was only for a minute. They incubated him, we didn't think he was coming back to us, but he did. They told us that we would just have to decide when to take away all the tubes. I could not take away anything from him. He still had a chance in my mind. We just prayed that we would not have to make any kind of decision like that. The next day his numbers slowly dropped and continued to drop. His x-ray on Christmas morning showed air outside his lung, meaning he had a hole in his lung. We never had to make the decision to take him off. We all held him; he passed away in my arms on Christmas day. We gave him his first bath, and dressed him for the first time. He looked so cute. They let everyone in a room where we could all hold him. I don't know how long we stay there, but it will never be long enough. The hardest thing I've ever done in my life was hand Caleb back to the nurse, knowing I would never hold him again.

Everyone tells me that time will ease the pain, but so far it hasn't. I miss him more and more. All I want to do his hold him and kiss him. I wrote all this on April 25, the day Caleb should be 5 months old.

Julia Ayers (mom to Caleb Ayers, 11/25/02-12/25/02, 125 Courtney Oak Dr., West Columbia, SC 29170, 803-996-9324, kyrs27@aol.com)

Jack Robert Ellis

My son was born on January 2, 1996 in Binghamton, NY during a horrendous snow storm. His condition was undiagnosed since my first pregnancy was normal and I delivered a healthy baby girl. My water broke at home and I was only 35 weeks along. After many hours of labor, I delivered what I was hoping to be a beautiful, healthy baby boy. Once they placed him in my arms, he stopped breathing. I then got the nurse who called for help. From that moment on, it was somewhat of a blur. Doctors running, nurses calling for portable x-rays, a complete panic. After they performed his x-ray and diagnosed him with this condition, he was going to be transferred to Syracuse (1 hr. away) but the highways and airports had been closed due to the state of emergency. About this time I was wishing I lived in Florida!! I didn't know what this condition was; I didn't know what needed to be done to fix it or even if it could be fixed. The pediatrician I had at the time was (I won't comment). After much debate and persistence, they called the area neonatologist from a local hospital over who diagnosed my son and said he needed ECMO. One of the many miracles of this story is that the transport team from Syracuse was already on their way down to Binghamton to pick up a baby born with a heart defect. Since that child wasn't as sick as my son, they left her here and took my son back to Syracuse. He spent one night there on a ventilator and they airlifted him to Buffalo the next day. Once in Buffalo, they performed many tests to see if he was a candidate for ECMO and then placed him on it. My husband followed the ambulance and then drove to Buffalo to be with baby. I finally arrived (what seemed like weeks later) 2 days later. I can't explain to you the pain of seeing your newborn baby hooked up to all that equipment, not to mention not being able to hold him after delivering him. They "swooped" him off after I gave birth and I didn't see him again until right before they took him to Syracuse. They let me come and touch him before they took him. In all of my life, I can't tell you the awful feeling of sitting in that wheelchair and watching them wheel my son away from me not knowing if I was ever going to be able to hold him again. Those next 2 days were like years for me. The next hurdle was when they did his repair surgery. He was a right-sided hernia and his chance for survival was very slim. They only gave him an 18% chance. Having to say goodbye to him that morning was worse than the day I delivered him. I couldn't imagine God letting me have him for 10 days and then take him from us. The many hours he was in surgery were so painful for us. I know that those that were around me were thinking "if he isn't going to have a "normal" life, you don't want him to survive!" That isn't what I was thinking at all. I was sitting there thinking "if you have to sew his arms to his head please God keep him alive!" The surgeon then came out and I remember seeing his big huge hands come at me and he said "I think Jack is going to be just fine!" I swear to God I thought I just won the lottery. Never have I ever loved to hear words more than those. Each day was a challenge, trying to get him off ECMO, trying to then get him off the ventilator. There were good days and there were bad days. I remember after 2½ weeks, I had to make a trip back home (3 hrs away) because we had a 4 yr old who was with my mom and I think she was afraid we were never coming back. That day I left Jack's side I remember talking to him and asking him to continue to be strong for mommy and get better. I left and went down the elevator. My husband was staying with him but walked me out to the car. The nurse came out on the street to get us because all his vital signs dropped. I came running back up to be at his side and as soon as I sat down and touched him and talked to him they all came back up. He didn't realize it but he was KILLING ME! The next week they instructed us that each day they would turn down the ventilator settings so he could breath each day more on his own than use the machine

and their calculations said it would be approximately another week or so on the ventilator. The next morning I called from the hotel to see how he was before I came over. The nurse said "you're never going to believe what happened?" After I picked my heart up off the floor, I was able to get the words out. He had pulled the ventilator out and was breathing on his own. The roller coaster ride continues!!

Over the next few weeks it was time to focus on feeding. Trying to get him to take a bottle wasn't going well. We stayed in Buffalo for a total of 2 months before they transferred him back home to a local hospital here in town. We worked on getting him to eat more, keep the food down and breathe! Once we were home here locally, I spent every day there trying to get him to bottle-feed. We were able to finally get him off the oxygen and now it was just feeding, feeding, feeding. He was breathing so fast that he was burning off all the calories. Mixing oils, pediasure, whatever we could put in there to get him to gain weight and keep the food down without spitting it up.

I decided I wanted to learn to put the NG tube in each day so I could take him home. I was able to bring him home the first part of April. I spent the next 4 weeks focusing on nothing other than his weight and what he was eating. It's funny because you get somewhat obsessed with it. We then took him back up to Buffalo in mid-May for his g-tube surgery. He spent the next 11 months being tube fed and we just tried to feed him little bits here and there to see what would happen. He at least was gaining weight. After his 1st birthday he started eating solid foods and we did night tube feedings to keep the calories going. I am proud to say that with the help of his doctors, family, friends and God he is now a healthy 7 yr old boy in the 1st grade. If I had to go back, I wouldn't change a thing.

Tricia Matthews (mom of Jack Robert Ellis, 1/2/96, 44 Rotary Avenue, Binghamton, NY 13905, 607-770-8640, TMatthews@lourdes.com)

Nizhoni Lee Hamm

Hi, I am Mackenzie and my husband is Michael. We were just newlyweds and anxious to start a family. We tried for a few months and happily in April we found out we were pregnant. The day I took the pregnancy test, we went straight to the hospital. The doctor confirmed the pregnancy and we started the planning of our new baby. Our doctor calculated a due date of Nov 23, 2002. I was a healthy mom, ate good food, exercised, and took my vitamins. I felt I was doing a good job taking care of my little baby. My husband was the best! He was so excited to be a dad. He took me to every doctor's appointment. All our appointments went great. The baby had a great heart beat!

Then the time for the ultra sound. We were 20 weeks along and we went anxiously to our appointment. We decided that we wanted to find out if our baby was a boy or girl. The appointment went great. We saw our baby GIRL!! Everything seemed to look great on her body. The only thing that the doctor told us was that according to the size of the baby, I would be due Dec. 4th. That did seem more like what I was thinking in the first place, since I always had a longer than normal cycle. That was cool news, because Dec. 4th is my husband birthday. He thought that would be really cool if they would have the same birthday. My husband picked out her name (Nizhoni – which means "beautiful"). Then we continued to go to the monthly, then weekly doctor visits. Every appointment, the doctor told us how healthy the baby's heart beat was and how she was growing great. The doctor even told us that she might come early. We were so excited and couldn't wait to see our little girl.

Then finally late Friday night, I started to have really good contractions, so we went to the hospital. When I got there, my contractions slowed down, but since I was a week over due they decided to keep me there. They started to induce me Saturday morning. Everything was going great! Then I was getting ready to deliver! Delivery was going smoothly and I only had to push about 6 times and our little girl joined us! Nizhoni was 19 ½ inches long and weighed 6 lbs 8 oz. My husband cut the cord, I grabbed her little foot, but then I noticed she hadn't cried yet. I looked at the doctor and asked him what was wrong. He assured me that everything was fine, because he thought she was just holding her breath. All the nurses were all so happy and excited and saying how everything was going to be okay. But then they moved her to the warming table and they started to bag her lungs. At this point I was really scared, but I still had to deliver the placenta and get stitched up so I didn't have much time to look at our little girl. Then I heard her cry a couple of times very lightly. Then a Neonatal Specialist came rushing in, tried listening for her lungs and noticed something was seriously wrong. She rushed Nizhoni to NICU. Everything was going so fast that I felt like I was in a warp zone. I was frantic and so scared. I did not want to lose our little girl. Everyone in the room kept reassuring my husband, me and my mother that everything would be fine. I kept telling myself that many babies go to the NICU and come out fine. I just could not imagine what could possibly be wrong with our little girl, because every appointment went great and I kept good care of myself.

Then the worst news came. They wanted us to go to NICU; they told us the machine was breathing for our baby. They were trying to stabilize her so they could fly her to a hospital to have surgery. When we got to NICU, we saw them shut of the lights and disconnect the machine. Our Precious Little Girl was Gone. She lived for 1 hr and 5 min. From 4:20 pm – 5:25 pm. Everything from there on out was a nightmare of disbeliefs. The next day we had the autopsy that confirmed the CDH. I had never heard of that before, so I was so concerned at what caused it!

We held our baby all night till the next morning! The nurses were a blessing to have all their help. We did everything with Nizhoni that we would have done if she was alive. We took so many pictures of her, which I am very blessed to have. And instead of our little girl being born on Daddy's Birthday we had a beautiful Funeral on Dec. 4th. We buried her in our hometown cemetery, and we bought our plots on each side of her. We have a beautiful headstone, with the help of Grandpa Hamm and relatives! Thank You!! We put a bench right beside our plots, so we can sit out there and have peaceful times talking to Nizhoni!

With the help of our faith in God and our support group (which we have met great couples who also lost babies) we keep living each day, day by day to the best of our ability. We have been trying to get pregnant for several months now, and I am currently taking chlomid, hoping that will help me ovulate so we can get pregnant again. We love talking about Nizhoni and how beautiful she is. We try to keep her

memory alive, because she is and will always be our first born beautiful girl!! We are going to Name our next kids after Nizhoni Lee. Girls will have Nizhoni for their middle name and boys will have Lee for their middle name. And our first girl will be named Faith Nizhoni! If we didn't have faith in the Lord, I don't know what life would be like! Until we re-unite in Heaven, We love you Nizhoni!

Michael & Mackenzie Hamm (parents of Nizhoni Lee Hamm, 11/30/02-11/30/02, 35646 154th Street, Frazee, MN 56544, 218-334-3632, hammm01@hotmail.com)

Nadia Helen Gould

Nadia Helen Gould was born at 2.45pm on the 10 September 1999 at 33.5 weeks. She weighed 2.470kg and was 46cm in length. During the pregnancy Jon and I needed and were constantly given Hope, so that is what we named her: Nadia.

I had an amnio at 17 weeks and, as the obs. did a full fetal at that time, nearly didn't return for another. I had an easy pregnancy with my first child and had just the one scan at 19 weeks, so I didn't really see the need. But I loved to see my babies on the screen so returned just for the sake of it at 21 weeks!! Little did I know that I was to see Nadia on the screen every week for the next 11 weeks.

The scan at 21 weeks revealed what the obs. was sure was a hole in the diaphragm and told me the smallest bit about CDH and that these things often righted themselves. On returning the next week there was a bigger shadow and the group looking at the pictures was beginning to question what they were seeing. By the third week the shadow was even bigger and they started to talk about a cyst on the lung. By 25 weeks this "cyst" was so large it was advised that it be drained immediately and then a shunt put in as a permanent drain. This way the lung (left) would be able to grow. By now I was under the care of a superb obst. (Jan Dickinson) at King Edwards Hospital for Women in Perth. Jan saved Nadia's life. She drained the "cyst" - a ghastly experience that meant piercing through the uterus and into Nadia's, chest and drawing the fluid out. (I had two courses of steroids to help the lungs a little in case the procedure bought on labour.) On the screen Nadia's heart, which was pushed far over to the right, moved back into place and her left lung began to look a little more like a lung. I was told that the "cyst" would probably fill up again over 4 or 5 days and therefore a shunt would need to be inserted for drainage. Returning 5 days later the cyst had not filled up at all. We were told that the vessels around her heart were looking much less stressed and they confessed that Nadia would not have survived passed 26 weeks without the drain as the heart was under too much strain.

It was decided that I should be scanned weekly to view the "cyst". Over the course of the next 8 weeks or so the "cyst" filled up slowly with fluid. Meanwhile they were very unsure of all the other shadows that they could see and found it very difficult to work out where the stomach and other organs really lay. Looking back I wondered how many pre-diagnosed cases of CHD they had actually seen because CDH was never really mentioned by the team at Kind Edwards.

At 32 weeks it was decided that another drain was required. This time Nadia would not have a bar of any needles going anywhere near her!! Initially they wanted to paralyze her to keep her still during the drain but they never got near her and I passed out due to the drug they gave me to stop the uterus contracting. I started to contract anyway (!) and ended up in the hospital for the night but luckily the contractions stopped. Another attempt at a drain was scheduled for the following Friday.

Meanwhile I was growing bigger and bigger. I was HUGE with fluid and the following Thursday evening, after a rather strange day involving a great deal of rushing around preparing for Nadia's arrival (!) my waters broke. (Nadia really did not want any more invasion of her space!!) Contractions were few and far between but I was kept in over night and Jan and the paeds were booked to see me in the morning. The scan showed that there were still gallons of fluid in me and that there was no way Nadia could get her head down for a natural birth. So a C-section was scheduled for 2pm that afternoon. The operating room was packed full of doctors and paeds - Nadia had 5 waiting just for her!!

With my waters lapping the boots of the doctors, Nadia let out a hearty squawk. She was handed immediately to the paeds who immediately intubated her. They wrapped her and held her up to me. I saw her nose and eyes and then she was gone. And this was the hardest part of all. I was now powerless to help her. I had to immediately focus on the c-section recovery. Jon was able to follow Nadia and he was impressed with the number of doctors assessing her. She had 3 x-rays over a course of 1/2 an hour. By the third it was clear. She had a large hole in the diaphragm (left side) with her stomach, spleen, intestine/bowel and a small corner of liver sitting neatly in the left lung area. She was breathing with a little help from the ventilator and did not need oxygen.

They decided to immediately move Nadia to Princess Margaret Hospital for Children and the repair was scheduled for the next morning. Jon went with Nadia, following her ambulance on the short journey. Jan came and explained to me about the fluid, all the scans etc: because the stomach and gut were squashed into the lung cavity, there was not enough room for Nadia to swallow fluid, pass through the stomach and the gut and out again. So it kept building up in her stomach (what they thought was the cyst) and in me.

I was able to telephone directly through to Nadia's nurses and did so every hour or so. She had her operation the next morning and Jon was there to talk to the doctors. The operation took 1 1/2 hours and the surgeon (Mr. Gordon Barron-Hay) declared it was a satisfying job. Jon and Nadia's doctor phoned me to say that she was strong and her vitals were good and she needed no help with oxygen. I spent the day ensuring I would be free from the epidural by the evening so that I could visit Nadia the next day. I longed for her and if it wasn't for the wonderful nurses - especially the night nurse who came and talked to me regularly, I would have gone mad. Jon came to collect me the next (Sunday) morning and at last, there was my wee girl. I was fully prepared for the sight of her and focused wholly on talking to her hoping she would recognize the old nag that had been spurring her on all those weeks. She was heavily dosed on morphine but I was able nuzzle my face right up to hers. It was wonderful. Returning back to my hospital that evening was awful. I sat on my bed, desolate, wondering what on earth I was doing there. There were no rooms available in the neo-natal ward for me so I couldn't stay with Nadia. But I was desperate to get out of my hospital and be with my family so I called for the doctor on duty and requested that I be discharged. She agreed I could be discharged the next morning.

For the next week I set off to the hospital every morning and stayed until late evening. Expressing my milk every 3 hours, and taking care of Nadia. Deep down I was as scared as, but remained focused on the fact that Nadia seemed to be kicking all the hurdles to touch. There was joy in her first bowel movement, joy as the morphine doses came down, joy as she was able to tolerate more and more breast milk - through a nose tube. The ultimate was day 5 when the doctors took her off the ventilator. I sat there all afternoon watching every breath she took. Day 6 she went onto the breast for the first time - very hard and tiring for her, wonderful for me. By day10 she was moved into the nursery attached to the neo-natal ward and I was moved into the hospital. I was now responsible for all her care, except her obs.

She gradually weaned off the nasal tube and onto the breast and began to put on weight. Day 14 Nadia came home.

Nadia had emergency surgery to relieve bowel blockages at 6 weeks old. She was home within 5 days. She has suffered reflux and has remained small for her age. Her diaphragm took a while to regenerate of its own accord and her x-rays continue to pull the punters.

But she is now a robust and healthy 2 year old, talking like a 12 year old with the attitude of a 16year old!! Nadia, you are my hope for all that is good about love and life.

Caroline Gould (mom of Nadia Helen Gould, 9/10/99, 47 Millne St., Bicton WA 6157, Australia, 08-9319-9641, jon_cazz@primus.com.au)

Joshua Tobechi Onwubuche

Excitement filled our hearts when an ept test confirmed I was pregnant. We were so elated when our first prenatal visit confirmed the pregnancy was super normal. This was our first baby and being so far away from our families it was a blessing to start our own. Just like a deflated balloon our joy was immediately crushed during the ultrasound @ 20 wks. When we were told Joshua had cdh it took over a week for us to truly understand what we were up against and like most people we went through the motions of why us and what did we do wrong. We decided to keep the pregnancy and stay positive. Things were going as expected and every week was a blessing because I knew it improved his chances.

Joshua was born on 04/14/03 @ 39wks after an induction. I took a quick peek at him and he looked so beautiful we were positive he would make it through. His battle for survival started and 3hrs later I had to sign consent to place him on ecmo. This broke me totally and all the strength I had through pregnancy faded and I was reduced to tears my husband remained strong and positive. His surgery was done 36 hrs after he was born and our worst fears were confirmed it was a big defect with very little lung tissue on the left side and a malformed one on the right side were the heart had moved to. The doctors told us there was little hope and over the days Joshua improved. He was tried off ecmo after 7 days but he failed he was later tried on the 12th day and he did well, the joy that filled our hearts was incomparable. He was decanulated but sadly his blood gas was taken again after an hour and his co2 level was abnormally high so he was put on a high frequency ventilator where he developed a hypertension and never made it through.

On the 1st of May 2003 Joshua gave up the fight and became an angel at 9.15 pm .I felt so honored that in my arms I ushered him to heaven were he'd never feel any pain and he'll be perfect. The nurses came around with my sister in law and together we sang JESUS LOVES YOU. He was my sweet angel who put a fight so he could meet us and I was so proud of him and thankful to God for giving us the time to get to know each other. He took his last breath after his father said goodbye. He was cremated so we can take his ashes home to Africa to rest in peace.

Joshua you meant so much to us, you will be greatly missed..... mommy

Alali Orupabo (mom to Joshua Tobechi Onwubuche, 4/14/03-5/1/03, 2900 S Gessner Rd #2208, Houston, TX 77063, 832-242-3680, alachidi@aol.com)

Camille Rosette Archer

Hello, my name is Kristie Archer, and I have just recently found your website. Our daughter, Camille will be celebrating her second birthday on January 6th 2004. She was our first child, (we now have a son, 4 months old), so we think that she is developing properly, for the most part, we don't have another to compare her to. She has an enlarged belly, we think bigger than the average kid, she is otherwise quite petite; and she has a difficult time with bowel movements, she gets stiff legged, and cries, she won't move, but cries for me to be there. She appears to be in great pain, but the second that she is done, there is no lasting pain. This is the problem that bothers my husband and I the most right now. Is this normal for kids, or does she have problems with her intestines, or stomach? It is with almost all bowel movements, and they are soft, so the Doctor's answer of giving her a stool softener seems of no use.

Her story begins 2 years, and 9 months ago. The pregnancy went well. I don't drink, smoke, or do drugs. I am/was a Pastry Chef, so my biggest downfall was sweets. My initial AFP results were high; they thought that they took the sample too soon, so they tried again. The results were lower, but still high, so I had an amniocentesis, where they found nothing. The rest of the pregnancy was fine. My due date was Dec 28, and when Friday, Jan 4th rolled around with no baby, we did an ultrasound to check the level of the amniotic fluid. Everything was still good. Saturday night at 10PM, we were far enough along in labor to be admitted into the hospital. They ended up having to break my water, give me Pitocin, an epidural, and then we did 3 hours of pushing. At this point they concluded that I would need a Cesarean because of "Failure to progress". And at 3:03PM on Sunday Jan 6th - The 12th Day of Christmas, they pulled out our little girl. I had so much medication in me at this point that I had almost no awareness of what was going on. But, she let out one small cry, they put her near my head so that I could see her, and then they took her away to take x-rays. I was still out of a few hours later when they were explaining that her intestines, and her spleen, etc had gotten through a hole in her diaphragm, and had collapsed her lung, and she had a

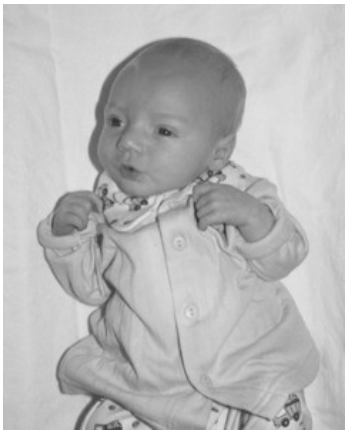
50/50 chance of making it through the surgery to place them where they belonged. Her appendix was also on the wrong side, but they felt no need to move it. Tuesday evening she was getting worse and they took her by helicopter to Mass general hospital, where they had the Ecmo machine. She ended up not needing it, and came back to Baystate, a week later. She progressed much quicker than anyone had anticipated. For the first 2 weeks, we were not allowed to touch her, she had her eyes, and ears covered so that she could stay calm and relaxed. I was still recovering from the Cesarean when they took her to Boston, and I pumped my milk and froze it the whole time. She took to nursing right away, once they let her (at 2 weeks). At 18 days old, she was allowed to come home. We were advised not to let anyone with a sniffle near her, because of her weakened immune system. The doctors at the hospital were all taken aback by their failure to catch this during the pregnancy, they still don't know why they missed it on the ultrasounds. So today, she appears like lots of other kids. She has the chest pectus, which our doctor (who has only dealt with this one other time), says that we should wait until she is 8 or 9 to talk about doing anything. Our biggest priority now is finding out about her bowel movement problem, it is very difficult to stand by her while she cries in pain about even the smallest of messes.

Kristie Archer (mom of Camille Rosette Archer, 1/6/02, 18 Maplevale Drive, Palmyra, VA 22963, 434-591-0914, karcher@ceva.net)

Hunter Alexander

I just want to thank you for your web site. It helped me tremendously when my son was three hours away from home at Hershey Medical Center. We came home for a break from the hospital one day, and I decided to do some research online and found your site.

My son's birthday was the worst day of my life! I never in my life thought I'd have to have a C-section, being I had the perfect pregnancy and perfect delivery with my first son, Dustin, who's now 8. They started to induce me with Pitocin on Tuesday. They said one of the side-effects of the drip is that a contraction can get stuck, but it's very rare. They took me off the drip overnight to see if my body would go into labor naturally, which it did. I was in hard labor most of the night with no pain killer. They were waiting until I got to 5 cm to give me my intrathecal. I got a shot of Nubain in the middle of the night to help with the pain, but it made me vomit all night, so I decided to just tough it out. I never got past 4 cm, so they started the drip again about 7:30 a.m. Wow, did the contractions come on strong then. But then guess what happened. I was in hard labor with no pain killer when my contraction stuck at the peak of it. OUCH! Hunter decided to come out, anyway, even though I was only 4 cm. His head got stuck and his heart rate dropped to 40 and kept dropping. My OB stuck her hand in and shoved his head back up. His heart rate started to climb again, and we were rushed to OR for an emergency C-section.



I come out of recovery anxious to hold my baby but can't because he's on oxygen waiting for the Life Lion to take him to Hershey. What!?!! My son was hospitalized at Hershey Medical Center on May 28, 2003. He had to go on the oscillator ventilator on June 4 he got so bad. Hunter wanted to breathe on his own, but they didn't want him to, so he kept fighting the ventilator. That was the worst night of the whole ordeal because they told us he would have to go on ECMO and would call us that night after they got him on it.

We had a miracle. We went into the NICU the next morning after praying all night and telling ourselves that ECMO just might be what he needs to live to a nice surprise. He wasn't on the ECMO machine. He was off the oscillator ventilator and on the regular ventilator. Hunter got VERY annoyed with the oscillator ventilator the way it kept vibrating him, so they took him off and put him on the regular ventilator. The doctor kept observing him, and his pressures kept getting better. On June 10, the day after my birthday, he finally had his repair. I got to hold him for the first time when he was 23 days old on Father's Day when he came off the ventilator.

Hunter had to get off his NG tube before he could come home, and he was being a little stinker. I stayed there from morning until night to care for him until he came home, even though my husband had to come back home and go to work. The bills were still coming in, but I refused to leave, so I took a month without pay. FINALLY, on July 7, Hunter came home. The first week was terrible. He was in a strange place. He was so used to the hospital since day one that he didn't know he was home, but we all adjusted very, very well. He is WONDERFUL now. His acid reflux is getting better, needs less Zantac and Reglan. His scar's so diminished now, you can barely see it, but it is there to remind us all. His developmental milestones are right on track. He's even doing some things sooner than babies his age. We are very blessed! I will say how most parents get stressed out when their babies cry for extended periods, which is normal. I can't help but just look at him and smile and hold him even closer because with that tube down his throat, I didn't hear him cry for a long time. I cherish it!

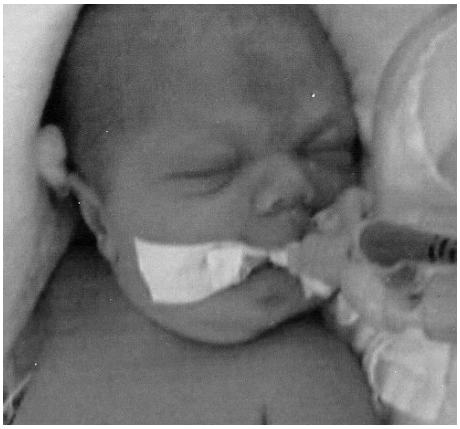
Donna & James Alexander (parents of Hunter Alexander, 5/28/03, RR 1 Box 178R, Rome, PA 18837, 570-247-2676, dalexander@edix.com)

Brianna Nicole Adams

Hello, my name is Debbie and my daughter had CDH. My husband and I found out that she had this at my 22nd week ultrasound. When the doctor told us that was what she had, I cried for a couple of days. I asked myself, “What did I do, was I being punished for this”? The doctor told us to go online and read up on the condition, that’s where I found this website.

My due date was August 9th, 2003 and Brianna was born on August 6th, 2003. On the night of Aug.5th my husband and I went to the hospital and she was born at 12:50pm. That night she was the taken to Children's Memorial Hospital in Chicago. Her blood gas levels was not very good, so she was put on the oscillator on and off during her stay at Children's. She was also put on ECMO and only on it for 9 days, which it was a short time for what the doctor said. She was put on so many medications and the doctors and nurses did everything that

they could do for her. On Aug.27th.I went to see her and before I left they had taken a blood gas, when it came back it was very good, so I went home. My husband and I went to see her the next day and she was slowly going down hill. When we finally said that enough was enough we had to let her go, it was the hardest thing I ever had to do in my life, I didn't want to let her go, we didn't have enough time with her, she was suppose to come home and be healthy.



When it was time to let her go the doctors took off all of the IV's and the last thing they took off was her breathing tube, the doctor then gave her to me to hold for the first time and she passed away in my arms on Aug.28th. She only stayed with us for 22days, it was so hard.

My husband and I have a two year old son, his name is Zachary. If we didn't have him I would probably be a basket case right now. I was glad to see there are more families out there dealing with the same condition and being able to seek support from different families.

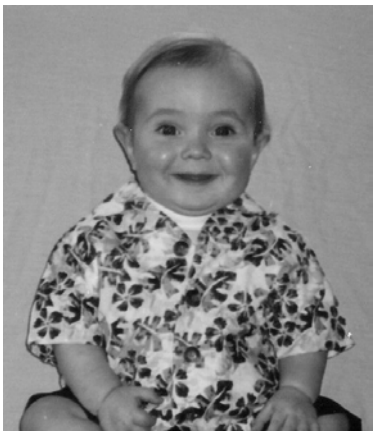
I want to thank you for having this website and for the thoughts and prayers from everyone. Thank you.

Debbie Adams (mom of Brianna Nicole Adams, 8/6/03, 1854 N Lewis, Waukegan, IL 60087, 847-707-0736, angelbrianna03@yahoo.com)

Brendan Beck

I was thrilled to become pregnant with our second child, but had a difficult pregnancy from the start. I had severe morning sickness and vomited several times a day for five months. I felt terrible all of the time and was in a daze most of the pregnancy. I had a normal sonogram at 20 weeks, but I knew something was wrong. My OB kept saying- you may be right, but keep thinking positive and try to eat.

I had excessive amniotic fluid in the third trimester, and went into pre-term labor at 28 weeks, so my OB ordered another sonogram where the tech said something was wrong but she didn't know what, and the radiologist said everything was fine. My OB read the report, and decided to send me for a level 2 sonogram (By now I was 37 weeks along) based on the tech rather than the doctor. I had the sonogram and the perinatologist knew right away it was CDH. He told me my baby had a 50% chance of survival at this point. I had an amniocentesis immediately to determine if his lungs were mature, and they were. The perinatologist thought they should schedule a c-section right away, as I kept going into labor and was on tributaline to stop the contractions. The neonatologist thought they should wait as long as possible for the baby to grow. I ended up having a c-section on June 6, 2002- I was scared because I knew Brendan was alive in utero but I was scared he would die after birth. They told me he may not cry and would be intubated immediately, and transported to San Diego Children's Hospital through an underground tunnel between Sharp Mary Birch Hospital for Women where he was delivered. It was good that they knew Brendan was coming- we had a great surgeon Dr. Nicholas Saenz, who reserved an ECMO line for us in the NICU if needed. Brendan did cry, but was intubated, emergency baptized in the tunnel during transport by the chaplain (my husband took lots of pictures) and hooked up to all kinds of things in the NICU. Meanwhile, I was lying on the OR table crying and fearing for his life.



The birth of my first son had been so joyous with a jubilant atmosphere in the room, and this time all I could see what my agonized reflection in the anesthesiologist's glasses. He was very kind and just kept patting my hand. The nurses didn't look at me. My sister stayed with me in my room, while my husband and other family members were at Children's with Brendan. Even though he was critically ill, they were allowed to sit by his bed in twos. He had a left-sided hernia, and his stomach and intestines were in his chest with an almost full size right lung, but only a bud on the left. He initially did well, so Dr. Saenz performed the hernia repair with a patch within 24 hours, and it went well. Then Brendan developed severe pulmonary hypertension and started downhill. He ended up on ECMO for 10 days- the longest 10 days of my life. On Father's Day, 2002 he finally started to improve and was weaned off of ECMO. It was the first time we had received good news of his condition. He improved rapidly from then on. He was on oxygen a total of 54 days, and in the NICU a total of 8 weeks. He had surgery while there for a fundoplication, appendectomy, g tube insertion and repositioning of his intestines. He came home in early August and it was very difficult. He was having g-tube feeds every four hours; he retched and vomited several times a day, and was on breathing treatments and some oral meds. We had about 2-3 dr. appointments every week! He saw so many specialists for everything- he had tests to check his eyes, ears, physical and mental development. He had a bowel obstruction due to scar tissue adherence in late September, and we were back in the hospital the entire month of October with first the surgery, then he got rotovirus in the hospital and then a respiratory infection and he had trouble breathing, but did not require oxygen. His pulmonologist, Dr. Park does an outstanding job caring for Brendan, as does his pediatrician Dr. Dechairo. Dr. Dechairo has called me every day we were in the hospital for an update since he took over his care after the NICU. We had twice-weekly visits to him, and then weekly, now we are at about every three weeks. Brendan stopped retching and vomiting at 8 months old, and then started to eat. (He existed only on g tube feeds until then.) He is now 10 months old and is only on tube feeds overnight, and eats formula, baby food and table food during the day.

He just started crawling (he is a little terror and gets into everything), and is considered developmentally appropriate for his age in every area except speech. He weighs 19 pounds and is 27 inches tall. He smiles a lot, and loves to play (even after all of this-he is a happy baby).

We kept him isolated at home because he is considered "medically fragile", and just got the ok to take him out into the world. We took him and his brother to dinner at the Spaghetti Factory and then the grocery store, because his big brother Jordan had been waiting to ride in the two-child seat cart at Albertson's with him. It has been a long and hard year- we have been through a lot. But we are lucky, and our hearts and prayers go out to the families who lost their cherubs.

Laralee Beck (mom of Brendan Beck, 6/6/02, 15091 Saddle Creek Drive, Valley Center, CA 92082, 760-751-3000, horncharts@abac.com)

CHERUBS 2005 Calendars

We will be offering 2005 Calendars as fundraising starting on December 1, 2004. Our calendars will come in different styles and sizes and would make great gifts.

Photo Calendars - To have your child's photo included please send them via mail or e-mail by October 10th. Please be sure to include your cherub's name on the back of his/her photo.

Drawings Calendars – Please submit your child's (cherubs and siblings) drawings of cherubs and angels to us by October 10th. Please make sure to include his/her name on the back of their drawing.

We have had a slack in Newsletter Tribute sales so we have no tributes for this newsletter. To purchase a tribute please send in $10.00 (made out to CHERUBS) along with what you would like inscribed in your tribute.

Local Get-Togethers

Alabama State Get-Together
September, 2003

Upcoming Get-Togethers

Ohio
September 20, 2003
Columbus, OH
Contact Tara Hall
614-275-0858

Alabama
September 18, 2004
at Spring Park in Tuscumbia, AL
Contact Alicia O'Malley
256-389-8110

Australia
10/23/04-10/24/04
Coogee Sands, Sydney
Contact Danielle Kessner
(03) 5135 6999

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.

CHERUBS State and 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 for states that are not listed, states that have "*" by them (we have temporary Representatives for those states), and the following countries; Belgium, Brazil, Chile, Columbia, Denmark, Egypt, France, Greece, Hong Kong, Israel, Italy, Japan, Lithuania, Malta, Mexico, The Netherlands, Northern Ireland, Norway, Oman, Pakistan, Papau New Guinea, Peru, Romania, Saudi Arabia, Scotland, Turkey, United Arab Emirates, and Venezuela. If your state does not have a representative (or even if they already do), please consider volunteering. If you are interested, please contact Dawn for more details.

REGION	REPRESENTATIVE	PHONE#	REGION	REPRESENTATIVE	PHONE#
Australia	Danielle Kessner	(03) 5135 6999	LA	Sheila Ezernack	318-645-9361
Canada	Karen Jenkins	(905) 852-9410	MA	Heidi Cadwell	603-465-3311
Canada	Laurelle Lehmann	(250) 838-2250	MD	Brenda Slavin	410-956-4406
Canada	Pat Panetta	905-294-7102	MO	Carol Lynn Cole	816-305-3832
Denmark	Kim Schau	0045 86817132	MO	Jody Hill	913-859-0389
Germany	Renata Hoskins	907-245-8817	MO	Jessica Mayfield	636-944-8834
Great Britain	Rachel Wyatt	01908 565574	MS	Melissa Clark	228-432-8942
Great Britain	Kevin & Brenda Lane	01553 762884	MT	Elaine Moats	406-234-5038
India	Shankari Murali	6164934	NC	Barbara Hagemann	919-873-1853
India	Malini Rao	469-232-0245	ND	Elaine Moats	406-232-5038
Ireland	Mick and Mary Blake	01 4921595	NE	Kristen Stiner	402-502-9310
New Zealand	Nikki Hodson	04 9724841	NH	Heidi Cadwell	603-465-3311
South Africa	Amanda Dean	+2712 5474207	OH	Tara Hall	614-275-0858
South Africa	Karen Howard	082 850 0851	OK	Michael Culwell	918-647-5850
Spain	Sonia Winkels	34-91-3004029	OR	Marion Lansdon	360-882-5502
AK	Renata Hoskins	907-245-8817	PA	Tammy Sincavage	610-796-7324
AL	Alicia O'Malley	256-389-8110	RI	John & Charlene Cassese	401- 884-0269
AR	Kristen Stiner	402-502-9310	SD	Elaine Moats	406-232-5038
CO	Dave & Clare Retterer	303-644-4779	TX	Shelly Evans	254-793-3039
CT	Toni Fiorillo	203-467-2222	TX	Malini Rao	469-232-0245
IA	Kristen Stiner	402-502-9310	WA	Marion Lansdon	360-882-5502
ID	Tonya Rupe	208-552-1889	WV	Sharon Munson	304-947-7162
IL	Rachele Alessandrini	708 283-9006	WY	Kathy Browing	307-332-4759
KS	Jody Hill	913-859-0389			

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 Parents of Survivors	For Grieving Parents	For Expectant Parents
Carol Lynn Cole - 816-305-3832	Shelly Evans - 254-793-3039	Kerrie Chamberlain - 541-535-4744
Michael Culwell - 918-647-5850	Freedom Green - 770-479-0378	Jody Hill - 913-859-0389
Jolene Halbeisen - 419-333-8384	Marion Lansdon - 360-882-5502	Jessica Mayfield - 636-944-8834
Tara Hall - 614-275-0858	Karen Myers - 228-396-9647	Anne Wolfe - 610-481-4178
Elaine Moats - 406-232-5038	Malini Rao - 469-232-0245	Rachel Wyatt - 01908 565574 (Great Britain)
	Kristen Stiner - 402-502-9310	
	Amy Rademaker - 616-844-4156	
	Danielle Kessner - (03) 5135 6999 (Australia)	
	Laurelle Lehmann - (250) 838-2250 (Canada)	