CHERUBS

The Silver Lining

Spring, 1999 Edition

Brought to you by
CHERUBS- The Association of Congenital Diaphragmatic Hernia Research, Advocacy, and Support
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CHERUBS
P.O. Box 1150
Creedmoor, NC 27522

Dear Members,

From our "Welcome To CHERUBS" column, you can see how much we have grown this quarter. So much is happening with CHERUBS, that it's hard to know where to start. We have over 365 members now, including members in 11 countries. Our web site has been visited over 17,000 times since it was created. Our membership is growing, and so is our newsletter. So many stories are coming in that we have had to increase the size of the newsletter. Please make sure to keep your child's story under 2 typed pages and please write your child's name on the back of any pictures that you send. Keep them coming!

After 4 and a half years, CHERUBS finally has a logo! We wanted something a little more "upbeat" and "childish" and not the common idea of what a cherub should look like (and what we have used in the past)- Victorian or Renaissance images. After all these years, it's nice to have something that is totally "ours" and not seen on commercial products.

We have many new volunteers and volunteer positions and even State and International Representatives. Please take a look at these columns to see if you can help out by volunteering. If you have volunteered and are not listed- please get those Volunteer Rules signed and in so we can put you back on the list. A huge "THANK YOU" to all our members that are volunteering- they are doing wonderful jobs! We'd be lost without our Secretary, Judi Toth, and all our many volunteers- they are helping so many families.

Keeps your eyes open this summer to T.V.'s 20/20 news show on ABC- there will be an episode featuring some of our members. AnaLisa Amen and her mom, Kristin Amen, and Dr. Michael Harrison will appear on 20/20 to tell AnaLisa remarkable story of in utero tracheal ligation and her miraculous recovery (home in less than 2 months after AnaLisa's birth!). An air date has not been set and the episode could air as late as September.

Dawn

CHERUBS State and International Representatives

As CHERUBS grows over the years, it is becoming harder and harder for me to keep up with everyone and how they are doing. Even now that we have a wonderful secretary in Judi, the both of us still can't keep track of everyone. Our "on-line CHERUBS family" has grown so close that we wanted all of our members, including those not on-line, to be able to have this type of support. We are hoping that "localizing" CHERUBS will achieve that. Our regional branches will not take away from our main group- the newsletters, matches, web site, and on-line services will still take place as usual- this is an added service. State and International Representatives will keep track of members and families in their regions and may have additional newsletters, get-togethers, web sites, and more for survivors and non-survivors. If your state has a representative, he/she will be contacting you soon (if they haven't already). If your state does not have a representative (or even if they already do), please consider volunteering. Our Representatives will be helping members, encouraging new families to join, contacting local hospitals and medical professionals, and can conduct such activities as get-togethers, newsletters, matching, web sites, on-line chats, and more. You do not have to be on-line to be a Representative. 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; Great Britain, Ireland, Scotland, Hong Kong, Holland, Spain, and Norway. If you are interested, please contact me or Judi for more details.

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

The Assessors Office Gang (Norman, Jay, Barbara, Anne, Linda, Christine, and Cynthia)- in memory of Bridget Jussaume
Norman and Rita Boudreau- in memory of Bridget Jussaume
The Burke-Parsons-Bowlby Corporation- in memory of Thomas Burton
Laura Burns- in memory of Megan Burns
Cheryl Burton- in memory of Thomas Burton
Irene Corsetti- in memory of Bridget Jussaume
Diana Cox- in honor of her son, Dallas Cox
The Family and Friends of Emily Ruth Surgis, in her memory
Laurie Favreau- in memory of Bridget Jussaume
Bob, Meribeth and Coburn Gillies- in honor of Brandon Hall
Susan Grubb- in honor of her son, Tyler Grubb
Christopher & Angelika Gursky- in memory of Bridget Jussaume
Renata Hoskins- in honor of her son, Kilian Roberts
Rachel L. King, RN
Jacob Langer, MD, FRCS(C)
Frank and Sheila Logiudice- in memory of Bridget Jussaume
Robert and Marie Lussier- in memory of Bridget Jussaume
B. Mayes Marks, Jr, PC
Elaine Moats- in honor of Kristin Moats
Kelly O'Reilly- in honor of her daughter, Emily O'Reilly
The Oregonian- in honor of Darrell Levi Hamilton
Michele Osmond- in memory of Bridget Hope Jussaume
Pam Pamula- in honor of her son, Cole Matthew Pamula
Andrea Pentzer- in honor of Lance Pentzer
The Retired Officers Association- in memory of Thomas Burton
Faliza and Paul Reynolds- in memory of their daughter, Yasmin Reynolds
Kate Rogula- in memory of her daughter, Hailey Rogula
The Rust Foundation- in honor of Brandon Hall
Judith Toth- in memory of her son, Christopher Michael Toth
Sophia Tucker- in honor of her daughter, Jessica Mary Tucker
Karen West, MD
Helen Wilder and Matthew- in memory of Bridget Jussaume

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

All of our wonderful volunteers
Darlene Silverman
Frank and Delores Fiedor
Beth Seyda
Heidi Schuppenhauer
Andrea Pentzer
Tracy Weissenberger

New Arrivals

(*siblings of Cherubs)

Kalley Madison Bray
Alli Nichole Bowers
Thomas Carter Burton
Kolbie Mae Davis
Brandon Edward Day
Steven Tyler Gartman
Mary Christine Hobbs
Fletcher Alan Hotz
Joshua Karl Kemper
Jack Lawrence Krueger
Cody Michael Lenhart
Kaleigh Grace Miller
Margaret "Meggie" Mitchell*
Matthew Ryan Mohr*
EmaDeane Rose Owen
Allen Marshal Rademaker*
George Michael Rogula, III*
Juan Heinrich Sampedro
Alisha Faith Swartz
Baby Girl Thompson
Baby Boy Tipton
Bailey Camerson Viset
Dylan Tyree Walls
Noah Brandon Wilson

On-Call Volunteers for Survivors

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Elaine Moats
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This Newsletter Is Dedicated To the Memories of:

Chaia D'Lynn Boyett
Thomas Carter Burton
Maddison Jane Carroll
Cierra Mae Desorcie
Steven Tyler Gartman
Bryton Daniel Heaton
Rebecca Christine Hodson
Andrew Walter Jenkins
Bridget Hope Jussame
Joshua Karl Kemper
Forrest William Lamberton
Mathias Jacob Lehmann
Kaleigh Grace Miller
Rowan Hale Moore
EmaDeane Rose Owen
Layton Neil Perkins
Wesley Alexander Robinson-Derrick
Alisha Faith Swartz
Baby Girl Thompson
Raven Thompson
Baby Boy Tipton
Leanne Renae Wheatley

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We Would Like To Welcome The Families Of The Following New Members:

Justin Wright Anderson
Christian Matthew Andrus, II
Baby Girl Bennethum
Baby Boy Blue
Taylor Jordan Boundas
Alli Nichole Bowers
Chaia D'Lynn Boyett
Kalley Madison Bray
Samantha Giovina Brown
Jonathan David Mark Bugeya Miller
Benjamin Burdett
Thomas Carter Burton
Maddison Jane Carroll
Phillip Brent Christain
Nathan Leroy Cranston
Jonathan Derek Crow
Emily Sue Daly
Kolbie Mae Davis
Brandon Edward Day
Cierra Mae Desorcie
Ethan Kelly Dunn
Reese Maverick Feith
Michael Christian Fogelgren
Steven Tyler Gartman
Millicent Jane Golding
John Michael Hall
Alicia Michelle Halley
Kaleigh Shayne Hamilton
Khyreik Ezra'el Hamlin
Charles "Chad" Franklin Harding III
Kelsie Madison Haymore
Bryton Daniel Heaton
Sean Allen Heiting
Sydney Cecilia Higginbotham
Rebecca Christine Hodson
Baby Girl Hopkins
Fletcher Alan Hotz
Bradley James Makanaokalani Jacobs
Andrew Walter Jenkins
Brady Wayne Johnston
Joshua Karl Kemper
Caitlin Victoria Kraft
Jack Lawrence Krueger
Forrest William Lamberton
Jessica Rose Lander
Mathias Jacob Lehmann
Cody Michael Ragland Lenhart
Sherry Ann Wheeler Macormic
Haley Morgan McGill
Baby McMerriman
Zayne George McVey
Abigail Metty
Kaleigh Grace Miller
Rowan Hale Moore
Rachel Elizabeth Murphy
Shane Ohlemeyer
Emily Frances O'Reilly
EmaDeane Rose Owen
Jacob Andrew Pagliarulo
Layton Neil Perkins
Andrew Nicholas Phillips
Dante Polito
Baby Girl Pruitt
Baby Girl Raikow
Mariane Rail
Wesley Alexander Robinson-Derrick
Baby Boy Roper
Caleb Michael Russell
Baby Scherrenberg
Maxine Dominique Schrijvers
Thomas Wilson Seay
Ole Jakob Serkland
Bradley Daniel Shuffield
? Smith
Carly Elizabeth Stark,
Alisha Faith Swartz,
Baby Girl Thompson,
Raven Thompson,
Bailey Camerson Viset
Jarod Levi Wagner
Dylan Tyree Walls
Breanna-Kay Crossley Warr
Michael E. Warren
Baby Boy Weber
Christina Elizabeth Webster
Kenneth and Becky Welch
Kinzie Rae Wertz
Leanne Renae Wheatley
Noah Brandon Wilson

Letters To CHERUBS

Dear CHERUBS,

Hi, my name is George Gates. My son, Laine, was born on Oct. 12, 1998 with CDH. He was diagnosed early, around 16 weeks, so we had a lot of time to plan. I found your web site very informative in answering questions that would come up and there was no around to answer.

Laine was born at University Hospital in Albuquerque NM. His first 48 hours were very rough, the doctors elected to put him on ECMO pre-op. Unfortunately, he was not stable enough to transport to the pediatric ICU (he was in the new-born ICU). So they ended up bringing the ECMO to him and basically did an emergency operation to get him hooked up. He was on ECMO for total of 11 days. The doctors had a hard time with keeping his sodium level low, they still don't why it was so high. On day 8 or 9 of being on ECMO they had to change out the "circuit", when they did that they decided to try him off. He went over an hour off ECMO. Two days later we arrived at the hospital to find that he was completely off ECMO.

They needed to wait at least 24hrs. before they would attempt his corrective surgery. Dr. Karen Chun would be the surgeon. She had told us that the surgery would probably only take 1 -2 hours. Well, the surgery ended up taking five and a half hours. He had no diaphragm at all, and everything except his kidneys were in his chest. She literally had to remove all his intestines and string them back in. He also had some respiratory problems during surgery, and there was a good chance of him having to go back on ECMO. Fortunately, he has a complete left lung and a partial right.

Laine never went back on ECMO, thank God, and was only intubated for a total of 4 weeks. Laine was on CPAP for 2 weeks, then he was weaned to only supplemental oxygen via nasal canula. The doctors feared that he would not nipple, but once again he proved them wrong, he took his bottle very well. Finally it wasn't a question of if he was going home, it was a question of when!!

Laine came home on December 3rd, 1998, just in time for Christmas!! He is now 5 months old and doing well. He was hospitalized for 5 days for a respiratory infection, and he has another surgery scheduled to repair a groin hernia. The doctors at UNM were very surprised that Laine lived, he was one of the worst CDH cases they have seen. They were also surprised that he went home after only just over seven weeks. They feel that he re-wrote some medical history, being that he had corrective surgery post ECMO and the rate he recovered from his whole ordeal.

There is a lot more to this story, but I just wanted to share a little of my story with you. My wife and I have been blessed with a very special Miracle. Thank you for having your web site

George Gates, father of Laine (10/12/98)

Dear CHERUBS,

I've been logging on to this web site for months now and have never had the time to write in. Every day is spent driving an hour into Boston to see my beautiful baby boy. I've been reading all the cherubs' stories hoping to read one similar to mine but it's become evident that not one is the same or even similar. Well, let me tell you our story, from the beginning.

I learned I was pregnant when Dante was 10 weeks old. I was very active during that time, mountain-biking, hiking, and swimming. I was very healthy at that time and was taking good care of myself, even taking vitamins every day. I had enjoyed an occasional beer or wine before I knew I was pregnant, but nothing excessive. I was surprised and thrilled about our evolving family. Eric and I had been married for less than a year (after dating for 10 years) and we had just bought a house in a neighborhood that was well-suited for kids. I enjoyed being pregnant. I didn't suffer from any of the usual nausea and I didn't miss PMS. The sixth and seventh month of my pregnancy, I gained 18 pounds and proceeded to get a little scolding from my OB. I wasn't eating any differently and I comforted myself with the thought that I was going to have a roly-poly healthy child. At 32 weeks, they decided I was measuring too large for gestational age and diagnosed me with polyhydramnios. My OB was extremely cautious and scheduled me for ultrasounds and 2 Non-stress tests twice a week. Every week, my anxiety over a problem with my baby lessened as each test came back normal. I was excited when my water broke on Jan 3rd, his actual due date.

As labor went on, I had thick meconium and his heart rate decelerated on contractions. I was rushed to the OR for an emergency C-section. I heard the doctors saying he had the cord around his neck when the delivered him. The pediatrician told me they were going to try to prevent him from crying so he wouldn't aspirate. I heard a whimper-like cry, like a wounded kitten, when he was transferred to the warmer with the pediatrician and nurses. The pediatrician turned his head to me and said he was o.k. even though I knew it wasn't. I asked what the Apgar was and he said 4 and 6. After that, Dante was rushed to the special care nursery and my husband went with him. Things became surreal and like a nightmare. I was able to see him for 5 seconds as an MD and respiratory therapist whipped him into my room in an isolette. They transported him to St. Elizabeth's NICU, a half-hour away. We were told Dante had PPHN, or persistent fetal circulation, that he was very sick and they weren't sure if he was going to make it. The doctors and nurses at Norwood Hosp. fought with my ins. co. to get me transferred to St. E.'s where Dante was. We won and I was able to be with him. My husband and I sat with him, day and night, just cupping his head with our hands and telling him how much we loved him and encouraging him to get better so he could come home and enjoy life with us. He was on an oscillating vent, had a chest tube and had multiple meds to try and open up his pulmonary vasculature and to keep his blood pH where they needed it to be. During his 18 days on a HIFI vent, we almost lost him hundreds of times, at one time he had bilateral pneumothoracies needing chest tubes on both sides. I couldn't stand the fact that thoughts of a funeral for my precious babe were actually going through my head. My husband and I prayed that Jesus and Mary would hold Dante and comfort him and heal him. Slowly, he became a little more stable and was able to go to a regular vent. He was writing his own book for the doctor's though and they couldn't quite figure him out. He had an EKG, EEG, Chromosome tests, multiple x-rays, etc. They sent him to Children's Hospital on Jan. 21 for a cardiac workup. Thank God, they found nothing! It took them a week before they found that he had an anterior right-sided CDH- supposedly a less severe hernia. They decide to wait until he was on lower vent settings till they did the surgery. He never reached the lower vent settings they were hoping for. He would get better and then have a set-back and the vent support would increase. He would have bronchospasms so intense that they had to bring him back from turning blue more times than I want to remember. They had to paralyze him once again for a couple of days so that he would allow the vent to help him. He is on major bronchodilator nebulizers, diuretics, and narcotics (Dilaudid and Ativan). They have tried to wean his narcotics but have been unsuccessful so the plan is for him to wean naturally as he grows—so far, so good. On Feb 15, he went in for his CDH repair. The hernia was larger than they expected and bilateral. A portion of his liver was on the right side, central, and a bit on the left. He came through the operation like a champ (Dr. Jay Wilson performed the operation and is touted to be the world's best CDH repair man. Thank God for him!) and we had hopes that that would be the cure. While he was in the OR they did a bronchoscopy to see if he had "floppy airways". He didn't but the pulmonologist speculates whether he has fewer bronchial trees than normal and that may be contributing to his vent dependency. He remains a mystery and nobody knows what to expect. At present, he's gone from 6lbs.11oz. to 11lbs. 7oz. being fed breastmilk through an NG tube. They just started him on Aminophylline and he hasn't had any bronchospasms since. From an x-ray 2 days ago, he's being treated for pneumonia with antibiotics and he also needed another dose of Lasix.

We're hoping he can wean off the vent while nasally intubated otherwise the issue of a tracheostomy and long term ventilation will be brought up. I'm concerned over the development of my child, I know we'll have to teach him how to eat, etc. and I know being nasally and orally intubated can lead to oral aversion and long-term issues. I just don't want to have another foreign body placed in my son and I'm afraid of him needing to be vented for a long-term, maybe even for life?!! The doctors have no way of knowing. I was hoping maybe somebody out there may have some insights, something?! You can e-mail us at SHOCKABETTY@prodigy.net. I apologize for this rambling e-mail. I hope it was received o.k., I'm pretty computer illiterate. So, anyone out there who prays would you keep Dante in your prayers? He's a brave strong boy who's doing his best to come home to Mommy and Daddy. We just pray that we do what's best for him and that's very tough to figure out sometimes.

Kristen Polito, mom of Dante Polito (1/3/99)

Stories of Cherubs

I had a textbook first pregnancy, that is almost everything in the textbook I had! Morning sickness (and afternoon, evening and night!), heartburn, "hormone" headaches, stretch marks, "pregnancy" itch, etc. etc. etc. I found a great OB/GYN who was very understanding and easy to talk to which helped me get through a very physically uncomfortable pregnancy. At 18 weeks I had a routine ultrasound. It was such a happy occasion, everything was fine with the baby and we were amazed that modern technology could allow us these first glimpses of our baby. Ten days overdue, knowing I was carrying a big baby and still no sign of labour, I went to my OB/GYN's for a check-up prepared to get down on my hands and knees and beg to be induced. I walked into her office and before I could open my mouth she said "Well, I've booked you in for an induction tomorrow." I was so happy, finally this huge baby would be out and I could hold it for the first time. That night I went to hospital and gel was placed on my cervix to try and get something happening. I had very mild contractions all night and didn't get much sleep. My waters were broken at 8:00am the next morning and then things started happening. From about 10:00am I had really close and very painful contractions. By 6:30pm I was ready to push. I pushed and pushed but this baby was not willing to come into the world. The head would crown and then retreat, over and over. After 2 hours it was decided the baby would need to be delivered by forceps. By this stage I didn't care, as long as they got it out! I was moved out of the birthing room down to the delivery room. My OB/GYN arrived. I also had the resident doctor and midwife in attendance and Julian (my partner) and my mum as support people. At 8:51pm after 13 long and painful hours of labour and a large episiotomy my baby was finally born (without forceps after all!). I delivered while on a birthing stool and as I slumped back against Julian in relief a sob of joy escaped from him. My OB/GYN asked me to tell everyone what the baby was a couple of times but I felt unable to move or even look down. Finally she said in a demanding tone "Danielle, look down. What is it?" I sat up, looked down and saw my baby for the first time. "It's a girl" I told everyone, my pain and tiredness completely forgotten. I held her in my arms and said to mum "She looks like I did in my baby photo's." and she agreed. I was told that they had to take her over to the "trolley" and get her cleared out as she seemed to be a bit clogged up. As my placenta was being delivered I asked how come she hadn't cried or made any noise yet and what was going on. I was given "reassuring" smiles while aspiration of her airways was carried out. That noise will live inside my head forever. I knew something was wrong but I wasn't too concerned at this stage. Julian told me later he knew something was seriously wrong from the start. I got onto the bed to be stitched and was told that they were taking her to the nursery and would call in the pediatrician "just to be safe". They gave me Alyssa for a quick cuddle before taking her away. I said hi and told her I was her mummy. We were looking into each others eyes and all I could see were her beautiful blue eyes, I didn't even notice she was turning blue. The midwife turned around, let out a gasp, said "This baby needs oxygen" and she was rushed off to the nursery. Julian went with her and mum left to tell our other family members what was going on. Julian's family were in the waiting room and had been for a while and my dad and a brother were at home, an hour's drive away.

The resident stitched me, covered me with a thermal blanket and left to find out what was going on. I was all alone in more ways than one. At about 10:00pm Julian returned and told me that the Pediatrician had arrived and ordered a chest x-ray. They had trouble contacting the on call radiologist but he had arrived and the x-ray was being taken. It must have been another half hour before anyone else came in. It was the resident who had been given the nasty job. She said to us "You have a very sick little girl." She briefly explained what the x-ray had revealed and said the pediatrician would be around once Alyssa was stablised to give more details. She told us she would have to be transferred to the Children's Hospital (Over two hour drive away). Julian asked what her chances were. "Not good." we were told. It was the first time we had ever heard of the congenital defect, Diaphragmatic Hernia. All through this I kept thinking that I should be crying, my baby was very sick and would most likely die. But I didn't cry, I couldn't, even though I tried. I was completely numb, inside and out. I could not understand what CDH was or how our baby could possibly have it. What on earth was going on?

A few moments later my mum came in and wanted to know what was happening. We told her what we knew and she practically ran out of the room. She looked very upset and I think she didn't want to upset us. My OB/GYN came to see us at some stage and was so angry that it had not been picked up on ultrasound. She said that she would call the radiologist first thing and have them go back over the films. I remembered the happy day of the ultrasound and wished that it hadn't been so happy and that the CDH had been discovered. At least we would have been able to deliver her close to the Children's Hospital. It was 11:00pm before the pediatrician came around. He explained what a diaphragmatic hernia was and that she needed to be transferred. The only thing to save her would be an operation to correct the abnormality. He said he had been in contact with a pediatrician from the Children's Hospital and was told to keep on with the treatment he had implemented until the ambulance arrived. I had a shower and was taken by wheel chair around to the nursery. As we rounded the corner we saw our families in the waiting room. It looked like they were holding their breath waiting to see how we were reacting. I gave them all a great big smile and could see their immediate relief. I had already decided that Alyssa was alive and I would think positively. If she died then I would deal with that situation as it happened.

Alyssa was receiving hand ventilation as the doctor felt it the most gentle form of ventilation. She looked so alive, she was very alert and followed us with her eyes. It was like she knew who we were. Her eyes were the darkest blue eyes I had seen. All of our family were allowed to visit with her and there was no restriction placed on us at all in this regards. My dad, an aunty, a close cousin and my best friend all came to the hospital. Most of the closest people to us saw Alyssa alive and alert. We were shown Alyssa's chest x-ray and the hernia was pointed out as that "big black mass". How could something so big be missed on the ultrasound? It was thought that a lot of her gut was up in the left part of her chest and her heart had been pushed across to the right side. Her left lung had not grown very much at all and her right lung was slightly small. We were told no matter what the outcome she would have brain damage. They were unable to get enough oxygen through to her brain because of the size of her lungs. This did not worry us at, as long as she lived! It was about 1:00am that the transfer team arrived and all our family left. Julian was to stay at the hospital with me overnight and we would travel to the Children's the next morning. We had both been a long time without sleep and everyone felt it would be unsafe for us to drive until the morning. The transferring doctor came and spoke to us. He said it was a large hernia and her chances were not good. He told us babies they expected to live often died and those expected to die sometimes lived. He said they just didn't know. He said it was high possibility that she would not even survive the trip and if she did it would put things in a favourable light. They would call us the moment they arrived. We went to say good-bye to Alyssa and I said "Oh, she's fallen asleep." They explained that they had paralyzed her in order to give her the best chance of surviving the trip. I felt sick to the stomach when they said that but trusted them just the same. Before falling asleep that night, holding the photo's of Alyssa we had taken, I had my first cry. Neither of us slept much and we were both awake at 5:00am that morning when the call came through from the Children's. The nurse came into our room, smiled and said "She made it." We were so relieved and happy. As soon as I was examined and discharged and we went home to prepare for our trip to the Royal Children's Hospital in Melbourne (Victoria, Australia). To our clothes in the suitcase I added a knitted bonnet, some booties and a change of clothes in which to bring Alyssa home from hospital in. The bonnet was to keep her head warm in hospital. She was such a big baby that the one used for her in the local hospital was too small. Julian called the hospital before we left and was told that she had improved throughout the morning after a very rough time during the ambulance trip. We said good-bye to our parents and set off expecting to return soon with our baby all mended. We finally got to the hospital and were shown to an interview room where we waited. A nurse and doctor arrived to explain Alyssa's current situation. She had deteriorated over the past couple of hours and we were warned that she did not look like she had when we last saw her. A social worker also came in and counseled us. Were not able to see Alyssa straight away as they were "working" with her. When they finally led us through to Intensive Care there were a number of medical staff surrounding her. As they moved away I couldn't believe my eyes. I burst into tears. There were tubes everywhere and her skin colour was strange and patchy. For the first time since she had been born I realised that she actually was so very sick. I couldn't stand to be there, looking at her like that. We left really quickly. It was breaking our hearts to see her. We wanted to go for a walk and get some fresh air so we could gather ourselves. We were told that it wasn't a good idea as she could die anytime, in fact her heart had stopped a number of times already that morning and they had struggled to keep her alive for us to see her. She was not responding at all and if for some miracle she lived and became stable enough to operate on she wouldn't have a very good quality of life. By this stage she had severe brain damage, she would never walk or talk. They were unable to get a reading on her blood pressure and we were asked what we wanted the doctors to do. We both said that we would never want to be left to live that sort of existence. We agreed that the best thing to do was to turn the life support off. They asked if we would like to hold her after this was done. Julian said no and I said "Well I do." He said he would come and sit with me but that was all. Well, I had not held her very long when Julian said "Come on, my turn." He was so glad he held her, he would have regretted it forever if he hadn't. I don't know how long we spent with her, it was like time had come to a complete stand still. When we decided that we were ready to leave we handed Alyssa back to the nurse. She cuddled her so close, kissed her and was whispering to her. It was very touching to see that she cared so much for our baby but it also hurt me a great deal. This nurse had probably spent more time with Alyssa than we had. I know our children are not possessions for us to own but I felt for an instant like Alyssa belonged more to the hospital than to us. Of course I carried her inside me safely for 9 long months and she is more alive to us now than anyone else but I felt what can be described as nothing else except jealousy when the nurse said good-bye to our baby. I felt guilty for feeling that - just the beginning of the many guilty feelings to come.

In the years that have since passed, tears, far to numerous to count, have been shed over our beautiful little girl, Alyssa. Alyssa only lived for 20 hours and 20 minutes but touched us in a way nobody else ever could. She changed us and our lives so completely and brought so much pain into our lives, yet I would not give up my few precious memories of her for anything. "You are so beautiful to me, You're everything I'd hoped for, You're everything I need, You are so beautiful to me." (From the Joe Cocker song we played at her funeral.) That's Alyssa and how we, her mummy and daddy, thought of her and always will. We just wish we could still have her here with us in body. She will always live in are hearts and souls and is remembered each and every day, for the rest of our lives. We love you Alyssa xxxx

Danielle Kessner (mom of Alyssa Catherine Kessner, 5/21/92-5/22/91, 3 Mooralla St., Bald Hills, Queensland 4036, Australia, kessam@cyberbiz.net.au)

Our daughter, Emily was born January 16,1995. It was the worst and best day of our lives.

When I was about 13 weeks pregnant, I was in a car accident, and went to be checked by my family doctor, she said there should be no problems but to have an ultrasound to be sure. I went to the ultrasound with my husband, Tim, this was our second child so we were very excited, hoping for a girl, our son, Jeremy was two at the time. The technician that was doing the ultrasound said we could see the screen shortly, I never saw any concern in her face. Then she made a call and was specking to the radiologist, he was watching our ultrasound from his office. She kept telling him to look at the right side of the screen. We started asking if there was a problem and she said no. We left that day and I felt very concerned, after two weeks I went back to my doctor and asked about the report, she said there was no problem. Another week passed and I still did not feel confident, I made another appointment and told my doctor to read the ultrasound report to me. When she started reading her faced dropped. She told me that the baby had a major birth defect with only 10% chance of living. I sat in her examining room for two hours by myself while she called several doctors and specialists and made appointments for myself and my husband. When I left I returned home to tell Tim, he was shocked, the very next day we meet a perinatal specialist, he did another ultrasound and talked and explained a lot to us. I think we both had been told so much we never remembered half of what he said. We told our families, my mother and mother-in-law both work in the medical fields and both of them knew little of CDH. We did research, we never came across your site, which would have helped us a lot. Over the next couple of weeks we meet with the neonatologist , the surgeon and we had a tour of the ICU of the children's hospital. This still did not prepare us for what was to come.

On January 16,1995, my due date, I was induced, we also had a midwife, she was doing her masters at university and followed my pregnancy, she was a great help. I had an easy labour compared to my first labour with my son, and gave birth on my own with no medications. Emily was born, she weighted 7lbs. 8oz., a good weight. The doctors and nurses from the children's hospital were all waiting in a small room off the high risk delivery room for her arrival. She was taken there as soon as she was born. We were told she would not be allowed to breath at birth, she may die if she tried to breath. We heard one little breath and it scared me. A priest was standing by to Baptise her, which was done. We waited with some members of our family in the recovery room, I was able to walk around and wash myself, unlike with my son's birth, I was so disappointed that I couldn't try to breast feed or hold her. We waited anxiously and finally were allowed to see her for a few minutes before she had to leave to go to the other hospital. I was shocked with the tubes and ventilators. She looked so helpless. My husband went to see her that night with my mother and his parents, when he returned he was speechless. They gave him a picture to give me to keep. The next day I went to see her, it was all so overwhelming, she was paralysed with medication and on the JET ventilator. This vent puts in 400 breaths per minute. She was not stable enough to operate and told us she may never stabilise. I returned to the hospital that afternoon, only a few people visited me, I guess they did not know what to say. That night a lady in labour was put in my room, she delivered the next morning and returned to the room with her baby. I was so envious of her. I called my husband and told him to come get me I was going home. I was discharged and went to see my daughter.

My husband left to go home with our son, the surgeon came to tell me that they were going to operate, she seemed stable enough. Emily's stats were always going up and down, so they had to take everybody out of ICU to operate, if they moved her they were afraid she would die. A few parents were very upset because they could not go into see their own children for several hours. After 3.5 hours they came to get us and said all went well, her organs were all aligned properly, when they tugged on her liver everything else came down in it proper place, he CDH was on her left side. The doctors told us the next 24 to 48 hours would tell us how she would be, the time passed and she did well. After a couple of more days we had arranged for our son to finally see his baby sister, he was so excited, since our house was complete confusion and he did not understand why she was not home. My sister-in-law had a baby three weeks before Emily was born, and he was home so it confused Jeremy. We waited for a while and they kept telling us to wait outside , finally they told us to come in and we were told her lungs had collapsed and she was in terrible danger. She would most likely not make it. We were shocked, she was doing so well, this was the start of all the ups and downs. Over the next several weeks, one or both lungs kept collapsing, infections were setting in and she was continuously coming off the Jet vent and then back on, finally she came off the Jet vent and on to another vent and then finally after 7 or 8 weeks was finished with them. Emily was 5 weeks old before we held her, the first night I held her it was very uncomfortable, with all the equipment hooked up to her , but I didn't want to put her back in her bed. They started her on a feeding tube with water and worked up to formula in a few days, sometimes she kept it down but sometimes it would come back up, she was only having 2 to 3 cc's of formula. Emily was moved out of ICU and into the Special Care Nursery, the doctors were arguing whether to try bottle feeding her, I hoped they would agree to do that, I just wanted her to do something that seemed natural to us. She did start on the bottle, but it was such a battle she would have the formula and then spit it back up, I was trying to prevent them from putting the feeding tube back in. My husband, Tim and myself took shifts one weekend , one of us was always at the hospital so we could feed her, we stayed for three days, and finally they agreed to let her go a couple of days later, April 16,1995. She came home just with medication to keep her lungs cleared, but that decreased over a few weeks. Emily was home for 4 days when we had to bring her back, she would not take the bottle. The surgeon sent us back home that day and told us if she didn't start eating in the next two days they wanted her back, we worked so hard at home and finally she gave in and starting eating. Emily was able to be at her brother's 3rd birthday party which felt so good. She had to return in September 1995 to have another surgery to close her stomach muscle. There was not enough muscle to close after the first surgery. This was only a short stay at the hospital. Emily is still small for her age and I think she always will be but that is minor. In November of that year Emily had an audiogram and she was diagnosed profoundly deaf. We used sign language for 2 years and in June 1998, she had a Cochlear Implant in London, Ontario. She is doing very well, she has even tried saying a few words.

We know that Emily has done very well, after reading so many of the stories on this site I know how lucky we are. I never knew the extent the CDH could cause till now. We were told by different professionals Emily's chance of survival was from 10% to 50%. I told Emily's surgeon that I felt if she was meant to be she would. We had opportunities to travel to different centres in Canada and the U.S.A. We let Emily prove herself, she is very independent at times and I know her personality has a lot to do with her progress.

Having a child with a birth defect puts a lot of stress on your marriage and your relationship with you other children, be strong and work through it. I wish all those parents expecting CDH babies in the future lots of luck, and for those who have lost their children I will always keep you and your stories in my mind and appreciate our daughter.

Kelly O'Reilly (mom of Emily Frances O'Reilly, 1/16/95, 11 Symonds Place, St. John's, Newfoundland A1E 3A5, Canada, 709-726-6725, nlis@nfld.com)

When I found out that I was pregnant both Darren and I were so excited, we had just married a couple of months earlier, and everything seemed to be falling into place nicely. I was lucky with my pregnancy I had no morning sickness, I felt great. We were going to a local GP for our antenatal visits. When we heard our babies heart beat for the first time it was so exciting, it was spot on he said, so we had no reason to have any concern. Our GP did not have the facilities for scanning so we were sent along to another Doctor for it, we were so excited, we took along a video tape to record the moment.

The Doctor scanning us didn't say anything until I was about to hop off the bed when he just casually said, "your baby has an abnormality, I suggest you terminate" and with that he left the room. Once we went into the other room where he was he asked us if we had any questions, we asked a few general ones, such as what are the babies chances, what was wrong with our baby. He said that he didn't know, and that he would refer us to a specialist in Wellington Hospital. That was on a Friday afternoon, so we were left for the whole weekend only knowing that our baby could die, because there was something missing and the stomach was in the chest. Not much to go on, but I got on the Internet and found CHERUBS, I wasn't even sure if I had the right defect! I read some of the statistics and held on to the positive ones.

On the Tuesday of that week we had our appointment at Wellington Womans Hospital, it was confirmed our baby had CDH, but she had a chance and we were hanging on to that. We would out her sex, because I needed an identity to my unborn child, my Mum went along to, to help is digest all this information.

The rest of my pregnancy I tried to stay positive, I got polyhydramnios and was "drained" four times, with the average of about 1.5 litres being taken out each time, it certainly wasn't pleasant, but it was a small price to pay for my little girl, who we had decided to name Rebecca, Becky for short.

We were told that Rebecca had no obvious liver in her chest and that was supposed to be great news, we had an amniocentesis, and that came back fine, so Rebecca had no other complications. We were told what to expect when Rebecca was born, we weren't going to be able to hold her, she would be rushed away, things will be up and down etc. I thought I was prepared…

I was induced at week 38 of my pregnancy, I was lucky I had a relatively easy labor I had Darren and my Mum, my midwife Catherine and a team of NNIC nurses waiting, Rebecca was born at 8:43pm, my midwife put her in my arms for a few seconds, I got to say Hi to her and introduce myself, I told her I loved her and I gave her a kiss, she had one little eye open looking at me. Darren went with Rebecca to the neonatal unit. I didn't see her again for a few hours. Rebecca's doctor came and saw us before we went to see her, he said that things weren't good, she did have some liver in the chest, and Rebecca probably wouldn't make it through the night. Then I saw her, she was so beautiful, I couldn't believe that this was my little girl. It was so strange, she looked perfect, how could she be so messed up inside. I didn't even notice all the tubes, all I kept hearing was the machines beeping, it was horrible. She had already been medically paralysed, so her body just lay there, I held her hand all night.

The next days things hadn't improved, so they inserted a chest drain, it helped a little. Then for days after that she only improved only a little. Rebecca got really puffy because she was paralyzed I was sick of hearing people say how big she was, she was born 2685grams, hardly big. Rebecca had big feet, just like her Daddy, some newborn booties were even too small! Things just continued at that point, she got a longline just before Christmas, but then on Christmas Day she started to go downhill, her longline had an infection in it, not only that so did her ventilator tube. We took all Rebecca's Christmas presents to the hospital and opened them there, telling her what they were (still paralyzed). She slowly got a little better after those infections had been dealt with, so on New Years Eve they decided to take off the paralyzing drug. My baby opened her beautiful eyes, they were dark blue. She held my figure, she even smiled, it was wonderful. She was weaned off Nitric, off the blood pressure drugs, things were looking good. This lasted for about a week then she went downhill again. Yet another infection had invaded her little body. They told us that she was going to die within a couple of days, the surgeon gave us an option, we could let her die slowly over the next few days, or we could let her have the operation, but she would probably die on the operating table. We decided to go for the operation, we had come this far I still had to give her a chance, the operation was to be the next day. I stayed with Rebecca for the whole night, we were luckily able to stay at the hospital for a couple of nights.

The next morning I read to her "Green Eggs and Ham" I cried most of the way through it. Then we took her to theater. She was allowed to take her Winnie the Pooh with her, she would have loved that. We said our good-byes, not knowing if we would see her alive again. We waited and waited we were told it could take five hours. But two and a half hours later we were told we could go and pick her up, she had done wonderfully through the whole operation, and she had a patch on her diaphragm. We got her back to NNICU, and she was doing great, oxygen requirements were great, ventilation was being weaned.

Then again backwards, and from there slowly it kept going downhill. I think I really did know by then that she wasn't going to make it. On the Saturday night I stayed up all night with her, she was awake the whole time too, we had a great time, I even "played" with her. She had a paddington bear hanging from her open incubator and she loved to watch him, and I was swinging him around, she loved it. On Sunday, I told Darren he couldn't go to work the next day, I knew Monday was her day. We went in on Monday morning and her saturation were in there 30s. I read Green Eggs & Ham again, she opened open eye and watched the whole time I read to her, she was so weak. The Nurses said not to touch her that she was fragile, I told them I wanted to hold her, she was going to die and I needed to hold her.

They got me a chair and placed my little girl in my arms, I got to hold her for a couple of hours, so did Darren, then they said that they were going to turn off the Nitric and that they may be enough for her to pass on, so I held her again. Within 30 minutes she had gone, I told her she could go, that it was alright, it was the hardest this I have ever said. I am glad that I told her that because everything else we ever asked of her she never let us down, and I didn't want her to feel as though she had with this. They took out Rebecca's tubes, we then bathed her and dressed her, she looked so beautiful, at peace. I don't regret any of our decisions that we made for Rebecca, I miss her terribly. I still talk to her all the time, I tell her how much I love her most. Rebecca will always be our first child, and we will share our memories of her with her brothers and sister to come. She is the best thing that has happened to me, and my time with her was amazing.

Darren and I would like to thank some people: Firstly Rebecca's Nana and Grandad, they have been so wonderful to both Darren, Rebecca and I, I know they would have it know other way as Rebecca is there first grandchild. Rebecca's Aunty Michelle, who bought her so many teddy bears. Jacqui and Kak, Peta and friends and family who are there for us. Catherine Lynch our Midwife and the doctors and nurses who cared. Most of all we would like to thank Rebecca, she was the most precious wee girl, we are both so proud of her, she gave us wonderful memories and we will treasure them always. We love you sweetie, you are now safe in Mummy & Daddy's hearts forever.

Nikki Hodson (mom of Rebecca Hodson, 12/15/98-1/18/99, 65 Karamu Crescent, Wainuiomata, Wellington, New Zealand, 0064 4 5641333, nik.daz@ihug.co.nz)

I live in Phoenix AZ and am a 32 year old mother of 2 beautiful and healthy girls ages 4 and 2. In February of 1998 I learned that I was pregnant again, a big surprise, but a welcomed one. We were elated when we learned at 17 weeks that we would have a son and that he was healthy. The technician had a difficult time seeing all four chambers of our son's heart but said it was because he was asleep in a bad position and it was nothing to be concerned about. She said that we would see what the radiologist thought and if needed I could have a "freebie" ultrasound just to scan the heart. Two weeks later I saw my OB who said that the radiologist said everything looked great, no need for a follow-up ultrasound. I said well she said it would be free, we would like to take advantage of that, it would be "fun" to have another ultrasound.

She told me let's wait until your next visit in 4 weeks, we will see more. So at 23weeks I had my "for fun" ultrasound and my life would never be the same again. The technician lied to us and said everything looked great. The next week my OB's office called and said that the technician saw a shadow on the right side of the chest and was unable to view the babies stomach. She ordered a level 2 ultrasound. I got a hold of the second ultrasound report from the radiologist and was terrified. It reported that the abdomen measurement was lagging behind by 2 weeks. It stated that they were concerned about a large cyst in the chest, and the absence of a fluid filled stomach. They were also unable to get a good view of the heart.

We went in for the level 2 completely clueless. The technician told us our son had a congenital diaphragmatic hernia and believe it or not we were relieved. We thought oh it's just a hernia, no big deal. The cyst they saw was the stomach, just in the chest. CDH is caused by a defect in the diaphragm. It allows the abdominal contents to enter the chest and impede the growth of the lungs. The doctor came in and told us he had a 50-50 chance at surviving, we were devastated. I had an amniocentesis that day which came back normal.

The weeks that followed were pure hell. Specialist after specialist all with grim and bad news. We learned that son's hernia involved the liver stomach and bowel. The liver reduced his chance of survival to about 30%, but we never gave up. They were unsure if he also had Ventral Septal Heart Defect. He also had a 2 vessel umbilical cord. The pediatric cardiologist was unable to see any blood supply going to the left lung raising the possibility of severe hypoplasia (underdevelopment). We were told by doctor after doctor to terminate, we never considered this. But it made us realize just how grave our son's condition was.

I developed polyhydramnios, which is a bad sign for this condition. Polyhydramnios is excess amniotic fluid. Due to this condition I was induced at 36 weeks. Our son entered this world at 10:50pm on 10-15-98. He was placed on me with the cord still attached and then accessed by the neonatologist. She realized there was nothing that could be done for our precious son, and he later died in my arms. We later learned that his chest had bowel, spleen, colon, stomach, and liver inside it. His left lung was only 1.5 cm, too small to sustain life. I still get numb when I type died, it seems so real, and it is so real. I miss my precious boy and am thankful that I have so many pictures of my precious son and even some video. One day I hope to show my little girls their baby brother, the brother they so desperately wanted.

Thank you for reading our story.

Dawn Brucher (mom of Nicholas Brucher, 10/15/98-10/16/98, 2032 E. Indigo Brush Rd., Phoenix, AZ 85048, 602-759-1462, dbrucher@hotmail.com)