CHERUBS
P.O. Box 1150
Creedmoor, NC 27522
USA

CHERUBS

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

The Silver Lining

Summer 2000

Dear Members,

It's been a quiet, but busy, summer here at CHERUBS, and we have a lot planned for the next few months; another Ebay Action in September, our first CHERUBS' Get-Together For Grieving Parents will be taking place in October, and the second volume of Cooking With Cherubs will be out in November. We hope all our members will help us out with our fundraisers and bereaved members will be able to attend the get-together in Virginia. We also need to ask for you help by volunteering. We have lost quite a few volunteers and need a lot of positions filled. For more details, you can read the article on "Volunteering With CHERUBS". We would also like to welcome our many new professional members. Thanks to our "free professional membership" promotion in July, our professional membership has almost tripled. I hope you all are doing well and as always, if you have any questions or need to talk, please do not hesitate to contact me.

Dawn M. Torrence, President and Founder

Brenda's Corner

By Brenda Slavin (reprinted from our Fall, 1996 issue)

As the summer has passed us all by, some of us reminisced about a previous summer that has resurfaced memories that are very painful. I have been reminiscing about last summer and the summer before. Last summer I was pregnant with our son Nicholas. In June all I could think of was "this is the month we found out about his diaphragmatic hernia". Or the summer before thinking Amanda was just learning how to hold her head up. On the sixth of each month I think of how old they would both be now. Although it has been one and a half years since Amanda died and eight months since Nicholas died, the emptiness remains the same. My grieving didn't stop one month after they died. It didn't stop at one year or almost two years. Maybe some of us don't shed the amount of tears we did in the beginning, but the pain is still very sharp and the emptiness is still there. Sometimes I can talk about the babies and other times I choke just trying to say their names. Grief definitely has no sense of timing. A couple of months ago my parents were in a Christian book store buying my nephew a bible for his confirmation. As they passed through the aisles they noticed several pictures of angels on the cover of several books. They just stopped and began sobbing in the store. They weren't embarrassed that there were several people in the store. They just held onto each other, each helping the other through the moment. My heart broke when my Mom told me about that. She couldn't even tell me without crying. Grandparents should not be forgotten in this web of grief. They not only miss their grandbabies but also hurt seeing the pain their child is going through. My Mom used to think she needed to be "strong" for me and my husband. She would bury her own hurt thinking her pain would make mine worse. Well finally she realized my pain couldn't possibly get any worse and I wanted her to grieve with me not without me. I think the word "strong" is a very funny word. I have been told by many people that I am a very "strong" person. The reason people think that is because they don't always see the real pain that lies in my heart. They are not there when I cry myself to sleep at night. Or they didn't notice that I walked out of the office when someone brought their baby in. I find it very difficult to look at another baby. I absolutely adore and love children. But I can't help but feel jealous of the mother who has her healthy baby and has no idea what losing a child feels like. I cry on every television program that shows a baby born and the baby cries in the delivery room. I never heard that sound from either of my children in the delivery room. The reason I don't grieve in front of certain people is that they make grieving seem like a contagious disease. We "the grievers" are accused of withdrawing from society. When in reality it's mostly society that has withdrawn from us. They don't want to see it, hear it, or be around it. These are not bad people. They are just naive to how to handle someone that has been through this kind of tragedy. I have found my lifetime friends and relatives. I had to "discard" those "friends" and family members who chose to distance themselves from me. I try not to be angry with them for hurting me this way. Sometimes I have to remember they do not understand what I have been through. They are embarrassed because they don't know what to say, what to do, or what not to do. But in order for me to move forward and handle this the best way I know how I am choosing to be with the people who have supported me and loved me through this difficult time. Many people have said that I have changed since the babies died. I can't say that I'm not slightly bitter about what has been taken away from me. I had two beautiful children and now I have none. I have become a more serious person. I get angrier when I see unappreciative parents, child abuse and neglect (right down to a parent allowing a child to stand in the seat of a car because the child doesn't feel like being put into a car seat) I want to scream at them "don't you realize how quickly you can lose that child? Don't you know how precious their little lives are?" Overall I think I have grown into a more compassionate person. I find myself to be a much better listener. And I'm now a better friend to those I do have left. So as we reminisce on the sad memories or we are facing the anniversary of our children's journey to heaven, we need to remember to listen and comfort each other. I know a lot of the parents of the Cherubs that are still with us want to be there for us. They may not fully understand our pain but they want to help us and comfort us. I pray that God grants us with the peace and the love that we all need to help us through this roller coaster of emotions. We must remember our children are always with us. We may not see them or hear them but we can always feel them inside our hearts.....loving us forever.

Naomi began to be afraid of everyone outside our family, the home nurses looked just like anyone of Gabriel's therapists or friends who came to visit. They didn't wear uniforms or badges so Naomi couldn't tell who was who anymore. Before, medical procedures had their own place, in the hospital, but now even home became unsure and unsafe to her. We carried her all the time so she wouldn't cry, but she seemed unhappy, so I called & asked about early intervention services and this time Naomi was eligible. She was now almost eleven months old and wasn't crawling, or able to do many things like get from sitting to other positions and she didn't make many sounds. Her eating was also concerning to us. She ate such a little bit & only foods that were soft and easy to swallow; figured it was because her stomach hurt so much that she didn't try to eat or move around much.

We have developed a nice partnership with our interventionist. She is a good listener and works on helping our family reach goals we have set for ourselves. She has arranged for Naomi to receive services at a local childcare center so that Naomi has the opportunity to interact with her same aged peers. I am struggling with how to meet the needs of all my children and still have room for a typical family life. There are times when as many as eleven therapists and other service providers are seeing our children weekly. My dreams of ballet lessons, soccer teams and little league have been replaced by the reality of PT, OT , visceral manipulation and speech therapy.

In July, just before Naomi's first birthday, her central line was removed. The fevers had stopped. We began the task of healing the emotional scars felt by everyone in our family. We know that Naomi still faces the possibility of more surgeries. The nissen may come undone again or the gore-tex patch may stretch and eventually tear as she grows. Naomi has been admitted to the hospital on a few occasions and had ear surgery to put tubes in to help with her recurrent ear infections. One particularly difficult episode occurred when the scar tissue caused a bowel obstruction, which made Naomi retch and vomit (her own poop) for about sixteen hours until it resolved itself. We are well aware that things like this can happen without warning, but we try to focus on the fact that we are all healing together. The effects of Naomi's medical condition touched all of our lives. We each try to find our place, discover our roles and learn ways to cope with and understand our feelings. That process continues today.

Lisa Nagurski (mom of Naomi Irene Hiishch'I Nagurski, 7/22/95, 1013 Vassar NE, Albuquerque, NM 87106, 505-268-1268, nagurskibl@aol.com)

Cooking With Cherubs Vol. II

Our second edition of our cookbook will be out in November. It includes 500 new delicious recipes. A huge thank-you goes out to Elaine Moats and Judi Toth for all their hard work in putting it together. And another huge thank- you to all the members who donated their wonderful recipes and recruited family and friends to donate too. Elaine and Judi did our first cookbook, so you can be sure that this cookbook will be equally as great. If you'd like a cookbook, you can order one on-line or fill out the form below. Checks and money orders (in US currency only please) can be made out to CHERUBS. Please mail your order to: CHERUBS, PO Box 1150, Creedmoor, NC 27522, USA.

Your Name: _____

Address: _____

	No.	Cost
Cooking With CHERUBS ($8.00 each)	_____	$ _____
Shipping ($2.50 each)	_____	$ _____
Donation	_____	$ _____
(in honor/memory of) _____		
Total Enclosed		$ _____

doing. Then I was approached by a resident I did not know, who told me that the surgeon would like to speak with me in a room near the OR. I felt sick all over and for a few awful moments, I thought Naomi hadn't survived the operation. I resisted going into the little room and waited until I saw the surgeon come down the hall. She didn't understand why I was worried and said the surgery was difficult and wanted to speak with me 'in private. Naomi was doing ok, but wasn't out of danger yet. There was an awful lot of scar tissue from the previous two surgeries. The surgeon said that she's had to re-repair surgeries like this before, but had never seen one that had "blown apart" so badly. The surgical nurse said that it got "kind of hairy for a while". They redid the nissen, this time using half the stomach in a method called a Thal modification and this time they used gore-tex to sew a patch on Naomi's diaphragm and they put another g-tube in her stomach, this time they used a "button" made of plastic which lays flush against the skin instead of the tube. Since the surgery was more difficult than expected, Naomi was admitted into pediatric ICU instead of SAC like the last time.

Again I was surprised to see how swollen and how awful my baby looked. This time there were more monitors, tubes, wires and plastic things than ever. Sometimes Naomi opened her eyes and whimpered, trying to cry. I rubbed her thigh (the only place I could reach) and talked to her and she would fall back to sleep. She seemed to be in such pain. We were transferred to the SAC unit a couple of days later, where Naomi recovered for a couple of weeks. We were back in our hospital routine again. Ben juggling work, the children (with help from his parents) and visits to the hospital. I stayed at the hospital, maintaining my milk supply and trading places with Ben once a day to go home for an hour or so. It was Easter time and the night before I stayed home long enough to color eggs with the children and make a pot of pueblo Easter pudding to put in the oven over night, so they'd awaken to familiar smells on Easter morning.

Naomi was recovering slowly. This surgery was much more difficult on her than the previous ones had been. Then she began to spike a fever. I worried that something was wrong with the patch and maybe her body was rejecting it. The doctors were sure it was probably something minor like an ear infection and prescribed antibiotics. The fever stopped in a couple of days and about two weeks after the surgery, it was time to try feeding Naomi small amounts of my milk. At first they tried to feed her with a pump hooked up to her g-tube, but Naomi cried and kicked the tube out, so that we had to go down to X-ray to reinsert her tube back into her stomach. After that they decided to let Naomi nurse. Sometimes she retched after I fed her but she didn't spit up anything. Soon she was nursing again and she improved enough so that we were able to go home .... but the fevers persisted. For the next eight weeks, every time the antibiotics ran out, Naomi would get a very high fever. She was admitted to the hospital and blood tests showed high white blood cell counts, indicating an infection, but they couldn't figure out where the infection was coming from. They sent us home with more antibiotics.

On the Friday evening before Memorial Day, Naomi had a fever of 104, so I called the hospital and was connected to the resident "on call". He seemed busy and suggested that I go to a drug store and get a refill on the antibiotics and call the surgeon on Tuesday. I was worried because the fevers had persisted for so long. I didn't know what to do. Ben and I talked and we decided to call our friend the pediatrician at home. He advised us to take Naomi into the hospital to have a CBC blood test done. It revealed a white blood cell count of 48,000 indicating a major infection so Naomi was admitted again. They wanted to do a CT scan and needed to have an IV in place. They stuck Naomi eight times and couldn't get a line into her veins. She cried so much, I cried with her and I wanted to take her home. They decided to do the scan without the IV. The next morning they decided to surgically implant a Broviac line, a central IV line, so we could take Naomi home and give her IV antibiotics there. The first line was placed near her groin and was difficult to care for, so Naomi was taken to the OR a second time that week and a new central line was inserted in her neck and came out of her chest. They did a test called an idiom scan to try to locate the infection but since antibiotics had been given the scan didn't show anything (they suspect that the gore-tex patch was the source of the infection, though).

Ben's parents stayed with the children again while I stayed in the hospital with Naomi and Ben went to work. Grandpa had found a medicine man on the reservation near his home who was willing to pray for Naomi and do some things for her. Since she wasn't well enough to travel, they asked us to gather together the clothes Naomi wore that day and so while Grandma stayed with the children, Grandpa made the trip back to Arizona to take the things to his brother who would take them to the medicine man. We had much hope that the prayers and good thoughts would help Naomi heal.

When the fever stopped we brought Naomi home and we were taught how to administer IV medications. We had to flush the line, hook up the IV medicine and let it dispense for about an hour, then disconnect the medicine and put other stuff in the line to help it clot. We had to do this twice a day for at least six weeks. The supplies were delivered in a huge box once a week and a home nurse would come twice a week to change all the bandages and check the IV site.

CHERUBS' eBay Auction

From September 15th to September 27th, we will again be holding auctions on Ebay. Proceeds will be going to help us reach more families. If you would like to donate items for auction, you can send them to: CHERUBS, c/o Dawn Torrence, 1109 Williamsboro St, Oxford, NC 27565. If you'd like to hold an auction, please contact us. So far we have only 2 families holding auctions- we need more volunteers! For more details, you can also visit our website.

New Arrivals

(*siblings of Cherubs)

Julio Adame*
Skyler Moon Bost
Rachel Burton*
Luke John Ditchfield
Christina Hocker*
Michael Phares Jonah
William "Will" Kibler
Kayla Alexandra Lee
Tobias Julian Lieshoff
Claire Logsdon
Ian Thomas Lund*
Paige Elise Lund*
Connor Ellis McLuckie
Noah Jonathan Nelles*
Kristen Rose Quintal
Dominic Joseph Reitz
Parker Daniel Setliff
Macy Kate Thompson*
John Richard Welsh
Natalie Dianne Whittle
Ashton Victor Lee Williams

This Newsletter Is Dedicated To the Memories of:

Lysa Marie Ienco
Bradley William LaBuda
Kayla Alexandra Lee
Connor Ellis McLuckie
Austin Ford Plank
Keyva Marie Roper
Louis William Santamore
Parker Daniel Setliff
Luke Joseph Thomas
Ashton Victor Lee Williams

Z

CHERUBS is an international organization for families and care-givers of children and adults who are diagnosed with Congenital Diaphragmatic Hernias (CDH). We are a volunteer organization an Internal Revenue Service recognized Non-Profit Association. Donations are very welcomed and tax-deductible. Checks can be made out to CHERUBS. The opinions shared in this newsletter do not necessarily represent the opinions of all members or staff. The information in this newsletter is by no means to be substituted for proper medical advice. Remember, every child is different. You can't compare the progress of another CDH child to the progress of your own child. They are all little angels.....CHERUBS

Contacting CHERUBS

P.O. Box 1150
Creedmoor, NC 27522
USA
919.693.8158
877.403.1944 (toll-free)
707.924.1114 (fax)

www.cherubs-cdh.org
dawntorrence@cherubs-cdh.org
info@cherubs-cdh.org
membership@cherubs-cdh.org
volunteer@cherubs-cdh.org
donations@cherubs-cdh.org

CHERUBS' Get-Together For Grieving Parents

Our very first get-together for grieving parents will take place October 20-22 in Woodbridge, VA at the Fairfield Inn on Price William Parkway (by Potomac Mills super mall). Woodbridge is just minutes from Washington DC.

This is an informal get-together of grieving parents only (no parents of survivors please). Though grieving grandparents are also welcome, we ask that you do not bring your children because we do not have babysitting services available and many grieving parents aren't ready to be around other children yet.

This is not a sponsored event so you will need to make your own travel and lodging arrangements. CHERUBS will be supplying refreshments only, so you need to cover your food expenses also. If you need a ride from the airport, please let Dawn know and we will do our best to have someone pick you up and take you to your hotel.

There is no schedule so we will be basically getting together informally and talking, crying, and hopefully, laughing a little too. This gives our grieving members the chance to meet friends from the internet and letters and will let us make new friends too.

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

Our 31 new professional members
Becky M. Buist
Adam "AJ" Joseph Parrillo
Baby Blake
Skyler Moon Bost
Amanda M Bracher
Baby Camphouse
Luke John Ditchfield
Madeline Anne Dryburgh
Magwinn Emmick
Baby Firestone
John N. Gonzalez-Rivera
Kylee Freedom Green
Patrick J. Hurdle
Samuel Kristian Hval
Anthony Urban Iacobucci
Lysa Marie Ienco
Michael Phares Jonah
William "Will" Kibler
Bradley William LaBuda
Kayla Alexandra Lee
Tobias Julian Lieshoff
Claire Logsdon
Charlie Jeremy Mangley
Allyse N. Marinaro
Connor Ellis McLuckie
Jodi Marie Morrison
Cheyanne Marie Parker
Austin Ford Plank
Kristen Rose Quintal
Dominic Joseph Reitz
Kevin Riley
Keyva Marie Roper
Louis William Santamore
Parker Daniel Setliff
Haiden William Smith
Alexander William Snowball
David Alan Terpening
Anthony John Vanesko
Baby Verwiel
Kyanni Renea Watson
Allison Brooke Weldon
John Richard Welsh
Natalie Dianne Whittle
Ashton Victor Lee Williams
Corey Dean Woodring
Courtney Marie Young
Elyssa Catherine Zukin

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

Cookbook Recipe Donors
Judi Toth
Elaine Moats
Heidi Cadwell
Kate Rogula
Danielle Kessner

hospital, caring for her as she recuperated. Ben and I would switch places for about an hour each evening so he could spend time with Naomi and I could go home to spend time with the children. We were taught how to care for her g-tube (in addition to her incision). The clear plastic tube came out of her stomach and hung down about four inches. It had gauze and tape wrapped around it where it came out of her skin and the other end had a plug stuck in it. Since Naomi could no longer burp(a result of the surgery) we had to unplug the tube to let the air out of her stomach. We also had to flush it with a syringe of water several times a day. I also needed to continue pumping my milk every couple of hours to maintain the supply. I found a way to lay her on her cradleboard and lace her up, making room for all the wires and tubes coming out of her body. Some of the hospital staff expressed concern about it, but Naomi really liked it, the cradleboard brought her much comfort, and soon they were helping me lace her up when she cried. Our family pediatrician who works in the Indian hospital next door made time to stop in and see us often. It was very comforting to see a familiar face and he was always willing to answer questions about things we didn't understand.

Time passed and Naomi began healing and soon it was time for her to begin nursing again. Just like before, we started with small measured amounts in a bottle, and after a few days she was nursing again. Soon, she was home again. Naomi was eight weeks old now. We were hopeful that she would heal and we again began to adjust to the routines and issues we now faced as a family.

It was now autumn and Naomi's checkups had gone well. Her incision had healed nicely, but her g-tube needed to be cauterized a couple of times because tissue was growing up around it. Since she wasn't using it for feeding, the surgeon had it removed six weeks after the surgery. I remember leaving clinic that day feeling as though a ton of bricks had been lifted off my shoulders. Naomi had been freed of all her tubes and plastic things. She was all baby. Her next appointment wasn't for six months! My insides actually fluttered.

A week later those feelings crashed to the ground when Naomi vomited again. The next morning, on Halloween, we were back in the hospital for a barium swallow. It revealed that Naomi was refluxing again. It appeared that the nissen had come undone and Naomi's stomach was moving back up into her chest again. The surgeon drew some pictures on the white paper covering the examination table and tried to explain that another surgery needed to be done. But she said it would be best to wait as long as possible because Naomi was so small and there was simply not enough tissue inside to sew the repair. We needed to wait for Naomi to grow some for the surgery to have a chance of being successful, but waiting too long could be dangerous. When I asked the surgeon for her estimate on what window of time was likely she compared it to her stocks, when to buy, when to sell. She still just didn't understand.

It was a long, anxious winter. Naomi cried a lot and she spit up a lot. But I kept nursing her and she was growing. But I worried because she couldn't roll over, she couldn't sit up for very long, and she wouldn't lay on her stomach at all. She also cried constantly when she was in the carseat. When I called to inquire about early intervention services, I was told that she probably wouldn't be eligible. Through another parent, I learned that the hospital had a special baby clinic that could evaluate Naomi and give us ideas on how to help her. It took a couple of months and a few phone calls to get an appointment, but the feedback they gave us was helpful. They listened to our concerns and helped us seek out support and services we asked for. They put us in contact with a massage therapist who visited us a couple of times at home and once in the hospital to teach us massage techniques to help Naomi cope with the pain and discomfort.

As Naomi seemed to be getting sicker, I was becoming more and more anxious. I called a pediatrician I remembered who had been very supportive when Gabriel had been hospitalized often. I told him about Naomi's impending surgery and that I felt I had the support of our pediatrician from the Indian hospital, but I needed a friend at the "big" hospital. He invited me over for lunch in the cafeteria. He bought my three-year-old son a hot dog and as we talked, I shared my fears and he offered support and information. The partnership we formed has strengthened our family and has enabled us to make difficult decisions and work through things together.

It was during this time that we began contacting relatives hoping to locate a medicine man or native healer who could possibly help Naomi. Ben's pueblo relatives from his mom's family really tried to help, but there was no one alive in the village who did that kind of thing anymore. So Ben's dad began asking his relatives out on the Navajo reservation. All we could do was wait and hope.

Spring arrived and an X-ray revealed that Naomi's stomach had moved so far up into her chest, it was considered an emergency situation. It was time to operate again. Naomi was nearly eight months old. We arrived at the hospital the morning of the surgery, and again it took several sticks to get the IV in. As I handed Naomi over to the stranger in green scrubs, I realized that I may never get to hold her again. The surgery took six hours, not three. I began pacing the halls after five hours with no word on how she was

time I fed her. I would nurse her on my lap and up would come the milk, all over us, like a garden hose, just pouring out. Reality was setting in that something wasn't right and we had to go back to the doctor.

When I heard the surgeons voice on the answering machine, I got that creepy feeling again. I just knew something was really wrong or she would have had a nurse call. The results of the barium swallow showed that Naomi's stomach was rising up into her chest and was positioned so that she was refluxing all her feedings. I needed to bring Naomi back to the hospital that evening because she needed to have another surgery done the next morning. The plan was to make an incision along the same one used before, check the repair on her diaphragm and this time they would also do a nissen Fundoplication (use the stomach itself and sort of wrap it in a knot at the top to keep the food down) and then insert a g-tube (a feeding tube) in her stomach (so that the scar tissue would help anchor the stomach into place, and also in case she needed it for feeding purposes).

Even though I had sensed that Naomi wasn't healing properly and deep down, maybe I even suspected another surgery was necessary, I heard myself gasp with surprise at this news. Naomi was five weeks old. We called Ben's parents and they drove in from the pueblo and we talked. It was decided that they would spend the night so Ben could take Naomi and I to the hospital. I would stay with Naomi until she was ready to come home after the surgery. Grandpa and Grandma would stay with the children so Ben could go to work.

We were admitted into the pediatric sub-acute care unit (PSAC). I was familiar with the routine from my previous stays with my other children. Lab work, IV's, procedures which cause pain to my children (such as needle sticks) are probably the hardest time for me. Every instinct I have, every cell and neuron in my brain wants me to protect my children and keep them safe. I felt so helpless holding Naomi down as she screamed and cried while the nurses worked at getting the IV line in. It took three different people five tries to get the needle in correctly. Her veins were so tiny. I put my finger into her little hand, stroked her hair and talked to her. She cried so hard that her hair was soaked from sweating and she kept hiccupping long after she fell asleep.

I made myself a little bed of blankets and since Naomi couldn't eat before surgery (and wouldn't be able to after surgery for quite awhile) I made my way to the "pump room" to begin the routine of pumping my milk to maintain the supply until Naomi was able to nurse again. This time the pump was located in a closet filled with diapers and other supplies. There was a narrow path from the door to a chair and table where the pump was. Some of the nurses have since made the room homey and comfortable, but then it was uncomfortable and not very private since people sometimes unlocked the door to come and get supplies out. I didn't have a place to be alone with my thoughts.

Our room was filled with the night sounds of a pediatric hospital ward. The curtains around Naomi's crib were our walls. The machines were making their sounds, beep, beep, beep; hissssssssss; dong, dong, dong. Babies were crying and whimpering down the hall. While it was still dark, someone pushed the curtain aside and said it was time to take Naomi down to the O.R. I hold her in my arms, pulling the IV pole along as we are escorted through the hallways. We get into an elevator I'd never been in before. It goes down, the elevator door opens and there we are standing right in front of the operating room. I hold Naomi close and kiss her. We step out of the elevator and are greeted by a young Asian man in green scrubs, a stethoscope and green shoe covers. His mask is down around his neck. He smiles and introduces himself as the anesthesiologist. Someone interrupts and has me sign some papers. He tells me it's time to take Naomi now and says he'll take good care of her. I kiss her one more time and place her in his arms. He pulls up his mask and goes through the big double doors with Naomi. As the doors close behind them my mind is screaming noooooooo!, but I stand there and say nothing.

That morning has repeated itself over and over again in my dreams ever since. I was escorted to a waiting room crowded with people seated in chairs connected in rows. It reminded me of an airport. The tv was on and some children were playing on the floor. Ben and I sat together and waited. It was too noisy and busy to talk so we just held hands. After three or four hours the surgeon came to the door and called us out. We stood in the hallway as she again explained the technical aspects of the surgery. After she made the incision, they found a lot of scar tissue from the previous surgery and had to carefully cut it away. Naomi's liver and spleen had stuck together since the last operation and needed to be gently separated. The repair to the diaphragm appeared to be holding so they did the nissen to wrap her stomach and inserted the g-tube. This time she felt confident that Naomi's hernia was repaired.

Naomi was sleeping when we first saw her. She was so swollen, her face and everything. I didn't realize she would look so bad and I heard myself gasp as my heart skipped a beat. She had all the same tubes and wires as the first surgery and this time she had a tube coming out of her stomach. Ben put his arm around me as we each held one of her little hands.

For the next couple of weeks Ben juggled the children, work and visiting us. I stayed with Naomi in the

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

Beverly, Thomas and Hilda - in memory of Connor McLuckie
Buist, David and Mary Beth - in honor of their daughter, Rebecca "Becky" Buist
Bunch, Judy - in honor of her son, Ian Raymond Bunch
Cadwell, Heidi - in memory of her father, Peter Van De Carr
Callanan, David and Barbara - in memory of Bridget Hope Jussaume
Childress, Michele - in memory of her daughter, Kayla Mae Michele Childress
Cox, Diana - in honor of her son, Dallas Cox
Diaz, Stacy - in memory of Kala Marti
Doades, Brian and Kimberly - in memory of their son, Nicholas Robert Doades
Dolan, Kelly - in honor of her daughter, Skyler Moon Bost
Edson, Clifford and Lynn - in memory of Natalie Mary Fraissinet
Forestridge Elementary School - in memory of Connor McLuckie
Fremeau, Mike and Hollie - in honor of their son, Michael Fremeau
Hamm , Tonya - in memory of Jeremy Shane Torrence
Hanks-Sudderth, Pat and Jana - in memory of their son, Ty Haywood Sudderth
Hedrick, Lynne - in honor of her son, Daniel Rhys Hedrick
Hilton, Marilyn - in memory of Bela Toth
Holt, Thomas A. - in memory of his granddaughter, Sarah Ann McMerriman
Mailman, Randy and Ann Marie - in memory of Natalie Mary Fraissinet
Malverne Union Free School District - in memory of Natalie Mary Fraissinet
McLuckie, Matt and Amanda - in memory of their son, Connor McLuckie
Merolla, Faye - in memory of her niece, Kala Marti
People's Bank - in memory of Bela Toth
Perez, Kimberly White - in honor of her son Matthew Michael Perez
Pruitt, Pam - in honor of her daughter, Allison Pruitt
Reid, Pat, Cindy, Annie and Jacob - in memory of Connor McLuckie
Reynolds, Faliza and Paul - in memory of their daughter, Yasmin Reynolds
Sadler, Linda - in memory of Connor McLuckie
Schoenthaler Rob, and Lauren - in memory of Callahan Patrick Growney
Smith, Frederick - in memory of Bela Toth
Swindell, Terry and Wanda - in memory of Connor McLuckie
Torrence, Jeremy and Dawn - in memory of Bela Toth
Torrence, Jeremy and Dawn - in memory of Marian Kapela
Toth, Judi - in memory of her dad, Bela Toth
Toth, Judi - in memory of her son, Christopher Toth
Toth, Susan - in memory of her husband, Bela Toth
Vanesko, Jeff and Sandy - in honor of their son, Anthony Vanesko
Warren, Michael and Paula - in memory of Mike's mom, Jackie Warren
Westgate Auto Body, Inc - in memory of Ryan Matzuka
Whisler, Col. John C. - in memory of Bela Toth
Zukin, Maryann - in honor of her daughter, Elyssa Catherine Zukin

Volunteering With CHERUBS

We have lost quite a few volunteers who didn't send in their reports and potential volunteers who didn't send in their signed rules- this leaves a lot of volunteer positions unfilled. We especially need Representatives, Memorial Card Volunteers, members for our Welcoming Committee For Grieving Parents, Research Volunteers, and Translators. You do not have to be on-line to be a volunteer. CHERUBS runs solely on volunteers, without your help we can't reach families. Some positions take only a few hours a year, others several hours a week. If you are interested, please contact our Volunteer Coordinator, Barb, (810-249-5279 or Purphaze19@aol.com) for more details.

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, Chile, Denmark, France, Hong Kong, India, Ireland, Israel, Italy, Mexico, The Netherlands, Northern Ireland, Oman, Pakistan, Papua New Guinea, Romania, Scotland, Spain, Turkey, and the United Arab Emirates. If your state or country does not have a representative (or even if they already do), please consider volunteering.

AREA	REPRESENTATIVE	PHONE#	AREA	REPRESENTATIVE	PHONE#
*AR	Barb Wagner	810) 249-5279	*ND	Elaine Moats	406) 232-5038
CA	Jill Coon	530) 582-1261	OH	Tara Hall	614) 777-4906
	Shirley DeMercurio	925) 439-8382	*OR	Heidi Forney	208) 584-3708
CO	Amanda Owen	970) 246-3337	PA	Tammy Sincavage	610) 796-7324
CT	Laura Webster	203) 284-2195		Brenda L. Eaken	610) 916-7027
DE	Susan Guariano	302) 731-1922	SC	Vanessa Hutchinson	843) 770-0109
FL	Tammy Warr	850) 235-9004		Susan Grubb	864) 877-1446
GA	Annette Lichtenstein	404) 325-2368	* SD	Elaine Moats	406) 232-5038
ID	Heidi Forney	208) 584-3708	TN	Leigh Cheney	615) 907-1301
*KY	Leigh Cheney	615) 907-1301	VA	Elizabeth Doyle	804) 293-4602
LA	Sheila Ezernack	318) 645-9361	WA	Heidi Forney	208) 584-3708
ME	Teri Morse	207) 538-4049	WV	Sharon Munson	304) 947-7162
MD	Brenda Slavin	410) 923-1032	WI	Karen Nuthals	608) 845-3167
MA	Heidi Cadwell	603) 878-2283	*WY	Elaine Moats	406) 232-5038
MI	Barb Wagner	810) 249-5279	Australia	Danielle Kessner	03) 9437 6778
MS	Marsha McInnis	601) 856-2831	Canada	Karen Jenkins	905) 852-9410
*MO	Barb Wagner	810) 249-5279		Dawna Haines	905) 852-4255
MT	Elaine Moats	406) 232-5038		Laurelle Lehmann	250) 838-2250
*NV	Heidi Forney	208) 584-3708	England	Kevin & Brenda Lane	01553 762884
NH	Heidi Cadwell	603) 878-2283	New Zealand	Nikki Hodson	064 4 5641333
NJ	Sophia Tucker	908) 684-8701	Germany	Renata Hoskins	08123/990229
*NC	Jeremy Torrence	919) 692-1270	Norway	Victoria Serkland	47-359-41284

On-Call Volunteers for Non-Survivors

On-Call Volunteer	Phone Number
Kate Rogula	(313) 565-8722
Amy Rademaker	(616) 844-4156
Danielle Kessner (Australia)	(03) 5135 6999
Laurelle Lehmann (Canada)	(250) 838-2250

On-Call Volunteers for Survivors

On-Call Volunteer	Phone Number
Elaine Moats	(406) 232-5038
Tara Hall	(614) 777-4906
Ann-Marie Peterson	(509) 735-7208
Jill Coon	(530) 582-1261
Grace Ore	(814) 833-6421
Heidi Forney	(208) 584-3708

pumping my milk while Naomi couldn't eat and was hospitalized. I was paged by the surgeon who was going to do the operation. She was the chief of surgery at the hospital and said a few things about the procedure, told me not to worry because "we do this all the time". I felt unsettled, scared and so sad to see my baby being hurt and in pain. The surgeon didn't understand.

Ben and I watched them whisk Naomi by, in her little see-through crib with the IV and monitors rolling down the hall. We waited on the bench in the hallway, holding hands and looking out the window. I remember something Ben said during a break in the silence about how she'll be just fine. After the surgeons did the operation, she'd come home, heal and we'd tell her about it someday.

A few hours later the little see-through crib with Naomi and even more equipment and lots of people in scrubs burst through the double doors, whisked by and back to a bay in the newborn ICU. The surgeon came to speak to us. She stood facing us and explained the technical aspects of the surgical procedures she had done and said she felt confident that Naomi would do well. She seemed in a hurry and went on her way. They made an incision and collapsed Naomi's lung. Then they moved her spleen, intestines and stomach down into Naomi's abdomen, and repaired her hernia by sewing her diaphragm on the left side near the esophagus, where there was a hole. After surgery, she was able to breathe on her own. We wanted to see Naomi and touch her to make sure she was ok. Once in NBICU, we scrubbed up and put on hairnets and yellow coats to cover our clothes.

She was swollen and sleeping under even more wires and things. There was a tube coming out of her chest and an IV line coming out of her forehead, another IV in her foot, oxygen and heart monitors, tubes down her nose... it was so hard to see her tiny little body like that.

We stayed with her until the doctors came to do rounds and Ben went home to tell everyone that things went well. We were hopeful that Naomi's surgery was successful, her stomach and other organs were now in her abdomen, she would now heal and soon we would bring her home.

I returned to my room and hospital routine for the evening and prepared to be discharged in the morning. I was going home without my baby, but wanted to be home with my family. I missed my children so much. Before I left I had to endure the baby class for moms, which is required before discharge, you know, the one where they teach you how to care for your baby now that you're going home. It was so hard because all the other moms had their babies with them as I sat there with empty arms. I don't remember a thing they "taught" us, but I remember the emptiness I felt as if it were yesterday.

Once home, I walked into my room and saw the empty crib there waiting. I wanted my baby so badly, I ached. But there was no time to grieve. The next few weeks were filled with juggling life at home with our family and being at the hospital with Naomi. Ben had to go back to work so I had to arrange for childcare for Kamani, Gabriel, and Jericho in order to spend time at the hospital with Naomi. I went every chance I could, several times a day, usually. I would hold her and rock her and tell her stories. I got to change her diapers a few times and then one evening they said it would be OK to give her a bath! It felt so good to take care of her, it helped me feel like her mom. Then one day the docs said it was time to feed Naomi some of my milk! It had to be measured, just a small amount, so I had to give it to her through a bottle. I was excited and terrified at the same time. But she drank it all up, so a few hours later they let me give her another bottle, this time with a bit more in it and she drank it all up too. We did this a few more times that day. The next day I was allowed to nurse her. We found a way to position her to make allowances for all the wires and things, then I held her in my arms and we nursed. I rocked and sang and we both felt so good inside.

Now that I was nursing the schedule got much more intense since I now had to be at the hospital every two hours. There was a lot of pressure because if I missed any feedings, it would be replaced by a bottle-feeding and they warned me that might mean that Naomi might come to prefer the bottle,

Then one day it happened. We got word that Naomi would be discharged soon. We were going home! At the appointed time, Ben brought the children so we could all bring Naomi home together. Everyone scrubbed up and put on yellow hats and hospital coats and after a mini lesson in CPR and incision care (the NBICU version of the baby care class) we gathered up Naomi, feeling so good that she was healing and would now begin her life with us.

Coming home meant all those adjustments families typically face when bringing home a newborn. New routines, sibling issues and a lack of sleep are all part of what we expect with a new baby. We had all really been through so much. Our older children had missed me, were worried and didn't know what to expect. Ben and I were reeling from the reality of Naomi's condition, so tired and trying so hard to be all things to everybody. Naomi had been through so much. She wanted to be held all the time so I carried her in a sling so she cried less. We also wrapped her up in a receiving blanket and laced her up in a Navajo cradleboard when she slept because we could prop her up. It supported her stomach snugly and was great for rocking her to sleep. But she spit up a lot. And it seemed that she suddenly started spitting up every

rustling in the breeze, feast days and the rain that falls. A sunflower is the flower that happiness grows and so Naomi was named after them.

She came into the world in the usual way and we were tickled to have her here. After the midwife checked her, the nurses took Naomi to the nursery to clean her up and I was taken to our room in the OB ward to rest and wait for her. Ben went home for the night excited to bring the news of Naomi's birth to our parents and our children, Kamani, Gabriel and Jericho who were all waiting at home. I must have fallen asleep listening to my roommate cooing to her baby, so excited to have my baby in my arms soon.

Someone was tapping me on the shoulder. I sat up in bed all bleary-eyed. It was a young nurse with a pink jacket and a stethoscope around her neck. She said she was from the newborn ICU. I wondered aloud," What do you mean, the newborn ICU?" This time I'd had a healthy baby, or so I thought. And then I thought, "Oh, no, not again". She explained that when they tried to check Naomi's heartbeat, they couldn't find her heart (my heart sunk). So they did a chest X-ray and found that her stomach and some other organs had slipped up high into her chest cavity through what they thought might be a hole in her diaphragm. So they pumped her stomach because I had nursed her and then stabilized her (my stomach suddenly felt sick). She reassured me that Naomi seemed so healthy since she weighed 8 pounds, 15 ounces but they were concerned. They thought she was born with a diaphragmatic hernia, and it could be very serious. I asked if I could see my baby. The nurse who'd helped me settle in brought me a wheelchair and wheeled me into another world. I felt so disconnected and unsettled, it was like a dream.

I remember so many wires and things, it was hard to find my baby underneath all of them. I saw the pain in my baby's eyes, those beautiful eyes, and was powerless to help. I wanted to pick her up, hold her close and make everything better. I was helpless. I shuddered. I stayed a long time, looking at her. I wanted to touch her, but wasn't sure. I felt like I was out of my body, watching this happen from afar. I went back to my room in the OB ward and called Ben, waking him to tell him the news. I curled up in my hospital bed, listening to the sounds of a mother in the bed next to me nursing and singing to her newborn baby and at some point, I fell asleep.

I spent most of Sunday sitting in a rocking chair next to Naomi's crib watching her sleep. I don't really remember if I got to hold her, but I don't think so. I really don't remember much about that day, it was a blur. I know I pumped my breasts every two hours, around the clock, in the "pump room" in NBICU, freezing it 'in little bottles and storing it in the hospital freezer. Since Naomi couldn't have anything by mouth, I had to ensure my milk supply by pumping as often as I would have been feeding her. I'm grateful to the parents who serve on the pediatric advisory board and worked with hospital staff to make the room a comfortable one. It turned out to be the only place I could be alone with my thoughts. Making bottles of milk for Naomi every couple of hours was somehow therapeutic, I felt like I was doing something to help her, but I longed to hold her in my arms and feed her myself. I was learning the routine of the unit, how to properly scrub my hands and nails before entering, and what goes on at different times of the day. I was also waiting to go down to the OB area to have a tubal done. There were too many births that day, so I had to be rescheduled for tomorrow.

Ben spent the day going back and forth from home to the hospital, checking on me and the baby, while at the same time, caring for the children at home. He also had the task of telling our parents and the children that Naomi wasn't as healthy as we'd hoped and the doctors were going to help her get better before we could bring her home.

A neonatologist approached me and said they were pleased with Naomi's status. Babies born with diaphragmatic hernias are typically very sick babies, unable to breathe, but Naomi appeared to have both lungs functioning,, but her stomach and possibly also her intestines were up in her chest, displacing her heart and lungs. But she was a nice weight and looked good. They were waiting for surgical staff to evaluate her so we could repair her diaphragm, placing her stomach and other organs in their correct positions. They were optimistic that once these repairs were done, Naomi would grow and develop and be just fine. Five minutes spent with this doctor helped reassure me, give me information and help me understand my baby's condition and helped me put things into perspective.

Monday morning, the pediatric radiologist and surgeons decided it was necessary to operate on Naomi that afternoon. Ben was juggling children and us at the hospital. I was trying to juggle my classes and a decision as to whether or not do have my tubal done. I decided to wait, and the spinal tap needle used during the birth was removed from my back since I didn't need it for my tubal, and I was finally able to shower for the first time. As I visited Naomi, a surgical resident brought me forms to sign to consent to surgery. He seemed in such a hurry, reading off instructions to me. When I read that one of the risks was death, reality hit and I got that creepy feeling, you know the one you get when you see police lights in your rearview mirror. He rushed off once the papers were signed, and they prepared Naomi to go to surgery. I was also trying to arrange for a breast pump because I was being discharged and needed to continue

Our Older Cherubs

In celebration of all the medical advances in the past 10 years, and in our effort to let our members whose cherubs are still little know what life will be like in 10, 20, or 30 years, we wanted to honor our older survivors. These are their stories, written by their parents and some written by our cherubs themselves. May they be an inspiration to other surviving cherubs and to our parents- no matter how long we have our cherubs, they know our love overshadows all the effects of CDH.

Sherry Ann Wheeler-Macormic was born September 18, 1968. After being over due with Sherry the doctor decided to induce my labor. After her delivery I began to worry because they did not bring her to me (as they did with my other girls). They came in to tell me she was having trouble breathing. So I went to see her for myself and she was having trouble and her tummy was sunk in unlike my other two girls who's tummies were rather big. The doctor began to tell us she had a broken diaphragm and that he would not know how serious it was until he did surgery to try and fix it. They kept Sherry in Pediatrics Intensive Care for a while, then they decided I could take her home until surgery. Doctor Parshall wanted to wait until she was 3 months old. Dr. Myan her pediatrician told me NEVER to lay her down flat, so I didn't. The reason was because her stomach, intestines & kidneys (everything) were in her chest cavity putting a tremendous amount of pressure on her heart and both lungs. Sherry would never take more than 2 to 3 sucks off of a bottle at any one time. So, I feed her ALL the time. It was very scary. She made it to 3 months old when Dr. Parshall decided to do her first surgery (she was so small, and it was so scary to have to do this surgery). When Dr. P came to talk to us after the surgery he said her diaphragm was not broken it was tissue paper thin and twice as long as it should have been so he doubled it and stitched it on both sides. Because Sherry's diaphragm was so long (and everything was in her chest cavity) her heart was pushed to the right side and her lungs were smashed with only 1/3 to 1/4 functioning. Due to the pressure on her heart and lungs this is why we never laid her down (we tried to defy gravity, and we did). One week after her first surgery we took her home. She still would not eat much so I fed her milk every hour.

After about 3 months I noticed she was not eating, and her tummy had sunk in again. So after a visit w/ Dr. P we went in for surgery #2, Dr. P said that one side of the diaphragm had come loose so he stitched it back up and a week later sent her home with us again, with no special instructions (except for her pediatrician who said again do not lay her flat). Her daddy, Carl, & I put her playpen at a 45-degree angle so that when I could not hold her, I could use a receiving blanket and safety pin her to the mattress, this way her body always stayed elevated. Sherry never was able to eat like my other girls. At 6 month I began to feed her rice cereal w/honey every other feeding. With a lot of persistence she was able to keep her weight up. Sherry made it another 6 months (1 yr. old) when her diaphragm came loose again. Dr. Parshall did surgery #3 this time he used some type of patch (I'm sorry I don't remember what it was) to hold it in place long enough for it to grow stronger. After surgery #3 he told us, if it worked and held for 1 year we could feel safe that she would live a normal life and be a normal child. Well it worked. Sherry was a normal child from that day forward. She was late setting up, crawling and walking, but made up for all that the next year. By the age of two she was doing all 3. We were still very careful with her until she was about 5 years old. Then we moved her to a regular flat bed and she did fine, so we eased up on being protective and let her be a normal little girl. We tried not to scare her about her scars as she got older and asked questions. We told her she was fixed as a baby and she was okay now and not to worry about it, as she got older we would tell her more details here and there, but this is the first time I've set down and told her everything. (note from Sherry: thank you Mom, I love you, Sherry ……)

Pat Wheeler (mom of Sherry Wheeler-Macormic)

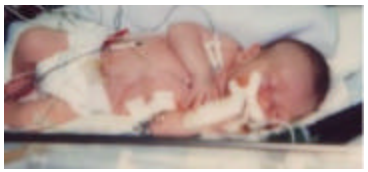
My name is Sherry Wheeler-Macormic, I am a CDH survivor, born September 18, 1968. My mother wrote a story about the details of when I was born. My story will start from where my memory begins. The most important thing I can remember is my parents NEVER treated me differently than any of my siblings. (Actually my youngest brother was the spoiled one …) We were all special in their eyes. I just had a little tougher time in the beginning then they did.

When I was in 3rd or 4th through 12th grade people began asking me questions about my scar when they would see me change in the locker room or if I stayed with a friend, especially when I went swimming. (*EVERYONE would ask even total strangers). I never really paid much attention to this scar on my side until then. Some of their questions went something like this: Yuck what's that on your side? Where did you get it? and usually a WHY/WHAT happened?? was the big question…. As a child you can just imagine how I attempted to answer these questions.

The more questions I got the more I asked my parents & grandparents. (But, I still never felt uneasy about my scar) They all began when you had a herniated diaphragm and not to worry it's fixed your fine. Of course I always said "What's that?" My mom would tell me my diaphragm was not as strong as other new babies and my insides where moved around a little when I was born. Both my lungs had A LOT of pressure on them and I could barely breath, due to all these circumstances I could hardly eat more than a couple sips at a time. She had to continuously feed me so that I wouldn't starve. (there were no feeding tubes when I was born) Then came the biggy, she said my heart was under my right arm. (I can remember just starring at her and saying WOW) She also began to tell me the reason my scar was SO BIG…. I had to have several operations (3 by age 1) to repair my diaphragm. First was 1 month, approx. 6 months and again around my first birthday. Once I had heard the story of my beginning into this world, you can imagine how I answered all those kids in school. But, I also began to realize how lucky I was to be here to play with my friends, and be with my family. I did believe I was a ***bullet proof kid*** ☺ (like I said I was never treated differently). I was 5 years old when I began to play softball, I remember hitting my first (only) grandslam, it was so exciting…. Then we moved to the country in a little town called Coweta, my interests turned from softball to horses. I loved to barrel race and enter other events in Rodeo's …… (If my horse had an attitude my dad never ran to the rescue he would say "Ride 'um cowgirl" and always smiled…. Believe it or not I was daddy's little Tom Boy). Still to this day I love to ride horses and spend time in the country.

Now I'm a 31-yr-old full of life, with two wonderful parents that words cannot express how much I love them for all the special care. I have a wonderful husband, two dogs and we are expecting our first baby. (Due on March 4, 2001) We are very excited and nervous. We were concerned about me carrying a baby due to my birth defect, but have been told by my doctor that everything should be just fine. Yes I will have a little more attention than the average pregnancy, but hey I am a special person……. I'm a Cherub. I guess the moral to my story is until I found CHERUBS (2 years ago) I never new just how serious my defect was, with their help and research I have learned that I am VERY fortunate and I know why I'm still here. I believe it is to help all of the parents of Cherubs and the Cherubs themselves to know YOU CAN live a normal life and don't ever give up hope…. ALL Cherubs are Blessings from Heaven……

Sherry Wheeler-Macormic (cherub, 9/18/68, 13809 E. 87th Street North, Owasso, OK 74055, 918-272-6856, MsJJay@yahoo.com)



My name is Kathy Woodring and my husband's name is Daniel. We were expecting our first child in June of 1986. I felt good during my pregnancy except for the flu during my 7th month. The morning of June 30th I started going into labor and was at the hospital by 10:00 that morning. By 7:15 that evening I was in the delivery room. At 7:28 our baby boy was born.

makes me say what I think in half the time. Anthony continues to grieve with me. He needs me as much as I need him.. I respect that he grieves differently to me. I am vulnerable. I hate the roller coaster. I shouldn't feel guilty when I smile. I shouldn't push myself too hard. Sympathy cards soon get replaced by bills. Everyone you tell has a story to tell. Not everyone is a good listener. It's not fair, it's not right and we didn't deserve this. I wanted to be normal again but didn't know what normal was. Being sad isn't selfish. I had to pick up the pieces of my life and learn who I had become. Still numb with disappointment, Anthony and I made the decision to have more children. We felt such guilt when we admitted that we wanted another baby. We talked to each other about how we felt. We didn't listen to people who said 'wait', we didn't listen to people who said 'do it straight away'. We listened to our hearts and each other, and started trying to conceive when we were ready. We somehow thought that having bubba two would be like replacing Henry, it wasn't. We thought that by having bubba two, we would be closer to forgetting Henry, we couldn't. We wondered if others would think bubba two would be an answer to our grief. It didn't matter what anyone else thought. We were definitely going to do things differently this time. We decided not to tell others of our plans to have bubba two. We felt our lives had somehow ventured into public property and we wanted to have some space, some privacy, some time to ourselves. My innocence had abandoned me. I struggled waiting each month for a positive result, and then, when I eventually conceived, I worried that something would go wrong.

The roller coaster rides continue to rush us though so many ups and downs, so many highs and lows and so many twists and turns. Here we stand, dizzy, disorientated and without our son. We have made it through hours that we thought would never pass, and made it through days and weeks when we thought it impossible, but we did it. There are so many reminders in and outside our home, they are everywhere in every form, from advertising to books, movies, shopping centres and so on. I also have physical reminders of my own: a huge scar, and new padding around my belly.

Three days after losing Henry we were unable to look after ourselves. We cried constantly, didn't eat, slept badly, had little concentration and relied heavily on others for our basic needs. We managed our days hour by hour. We waited for someone to tell us Henry was alive.

At three months we were still in shock, but we started to learn how to cope. Some days were easier than others. Life was so very complicated now. Some of the people around us were expecting us to 'move on'. We weren't ready. We missed Henry terribly and cried almost daily. We carried our heavy hearts through a loneliness that defied description.

Three Years. We haven't come this far yet. I can't imagine where we will be or how we will be feeling three years from now. Whatever we do I know we will be missing our son, thinking. 'Henry would have. Henry should have. Henry could have.'

Sue Wilkinson (mom of Henry James Faure, 9/3/98- 9/16/98, 3 Grandview Rd., Melbourne, Victoria 3072, Australia, 03 9470 3414, bluebab@webtime.com.au)

Naomi is my daughter. She came into the world and into our waiting arms. As I looked into my newborn's eyes for the first time, I felt as though I stared straight into her soul and she into mine. Such beautiful, dark, Navajo eyes, just like her grandpa's.

I nursed her and Ben and I took turns holding her, and giving her messages of welcome. I was so relieved to see her. As an expectant mother, I knew, all too well that not every baby is born healthy. My son Gabriel has Downs Syndrome, and we've had quite an adventure. So I was really hopeful during my pregnancy that this baby would be alright. It was so good to have her here with us and such a relief to see that she looked fine.

Her Indian name, Hiishch'I (Sunflower), was decided on before she was even born. We went home to Ben's village quite often during the early summer months before Naomi was born. After seeing some dances, the whole family would all sit around the parent's kitchen table after eating stew with Grandma's oven bread and talk. We'd talk about all kinds of things, the past, the future, the children. Sometimes we'd talk about the new baby. Sunflowers were blooming everywhere. Naomi's Grandma thought it was such a beautiful name which brought to mind all the wonders of summer, the long days and warm nights, tall corn

needed constant reassurance. I worried Henry would be cold, lonely and frightened, it didn't make sense. I was so confused. Our pajamas were on our bed waiting for us, we put them on and snuggled together. We cried, eventually we fell asleep.

I face real fear every day. Fear that I will forget, fear that I am unable to live a happy life and fear of losing my sanity. My whole world has collapsed around me. My dreams and hopes are so out of reach. Lost is the fun free spirit, the dreamer, the hopeful. Sometimes I feel so on top of things, able to cope and able to put on a brave face to make it through the relentless obligations and normality of life, whilst other days I find it hard to make it from one room to the next. I find times where I laugh and smile and sometimes feel guilty for smiling, for being happy. It's confusing. It is so incredibly painful living without my son, a pain that generates from my heart and ripples through my entire soul. There is no solution, no easy way of dealing with this, no band-aid is big enough to heal me. I had difficulty understanding how life could go on, I wanted the clocks to stop, for the world to stop spinning, life would never be the same, we would never be the same. It was so difficult watching a world that seemed relatively unaffected by our son's death. Anthony resumed work a couple of weeks after the service. They wanted him back on deck. It took him a lot of courage to return and he struggled through the first few weeks. He put on a 'work mask' which helped him to get through each day. He divided his time into work time and grieving time. I worried he was pushing his feelings down and not dealing with them, but he was dealing with everything, in his own way. He finds some days easier than others, but manages to hold himself together. I took time off work. It gave me time to think. It gave me time to stay in my pajamas and hide away from the rest of the world when I needed to. Months after Henry's death, my well-worn pajamas are stashed in a drawer. I don't need them as much now. I have started to learn how to cope, and how to live without Henry, I have started to learn to smile again without feeling guilty, I started to believe in myself again, realising that I will never forget Henry. Sleeping is hard, waking is hard, breathing is hard, it's all so hard, and my arms feel empty. I yearn for my son. I grieve for him. I want my hands to keep busy to distract from the gravity of my empty arms.

These are some of the things I kept occupied with; I wrote letters to family and friends to thank them for their support. I made up a photo album of Henry's life. I visited family and friends. We practiced retail therapy, we spent money. I started a journal. We went to regular counseling sessions. I created a painting for my son titled 'Empty Arms'. I wrote to Intensive Care and thanked them for their support. I started writing this booklet. I had a strong urge to tell Henry's story. I tracked down a mother of a little boy who was in Intensive Care. Her son died shortly after Henry. We met and talked and continue to support each other. I located a Parent, Advocacy and Support Group for Diaphragmatic Hernias on the Internet. I consumed everything I could research from the Library. I made an album of all the cards and letters we received. Anthony bought me a rose gold locket. I put some of Henry's ashes inside. I wear it daily. We contacted the International Star Registry and named a star after Henry. I organised and donated a trolley housing a CD player, CD's and books for parents and children in Intensive Care. Engraved on the trolley are the words 'Henry's Trolley'.

Our family and friends had so much trouble dealing with our grief. We were new people, sad people. Most admitted that they didn't know what to say or do, and in the weeks following Henry's death we somehow found ourselves educating and consoling others. We made the decision to stop helping others and help ourselves. Some people had so much trouble they avoided us. Some rang often, others rang infrequently or not at all. Others used initiation and helped us where they could. Everyone was different in the way they dealt with us, we accepted that, but couldn't tolerate insensitive statements, questions, or band-aid solutions, that, to them offered us hope or meaning in our grief and healing. We wanted people to realise that they didn't have to offer us bandaids. We wanted people to listen, not talk. We were so appreciative to those who continued to say Henry's name and wanted us to talk about him. Mixed in with the bandaids were great acts of kindness and compassion. People would go out of their way, showing initiative, not waiting for the reply to 'If there is anything I can do.' Some friends rang almost daily, one cooked us dinner, another wrote a poem, Anthony's sister created a needlepoint, my brothers planted trees in Henry's memory, some friends sent cards and flowers on Henry's due date, a family friend prepared all of the food for after the service and our florist donated all of the memorial service flowers. We were also given rose bushes to plant in our garden. We were pleased people were acting on their hearts It meant so much that some avoided band-aids all together.

Having a son born prematurely in a traumatic birth, hearing a life threatening diagnosis and watching Henry undergo treatment and losing him has changed me, my perceptions, my relationships and so much more. I have come to the following conclusions: I am still a mummy even though my son is not in my arms. Maternal instincts don't just go away. Most people don't know how to cope with grief. They don't know what to say or do. Friends become strangers and strangers become friends. Some days I cry a lot, some days a little, but I still feel the same on the inside. Some days I am better at juggling my emotions. Grief

Our baby was born at San Antonio Community Hospital in Upland, California. He weighed 6lbs. 11oz. and was full term. Immediately after our baby was born his nurse (Patricia Stickler) knew he was having a hard time breathing; and she started working on him. I looked up long enough to see our baby boy, and his color was not good at all, and he was trying so hard to breathe. Our baby was taken to the "'sick baby" room, and I was taken to recovery. My heart was breaking. Dr. Joshi (our baby's pediatrician) had been called and was there immediately. She did all of the necessary procedures to keep our baby stable. (I don't remember all of medical terms.) The x-rays had been taken, and Dr. Joshi knew that our baby needed to go to Loma Linda University Medical Center (20 minutes away). LLUMC's ground transport team arrived within 15 minutes. My husband and mother-in-law were with me while waiting to hear what was going on with our baby. Just when I really started to panic, the neonatologist from LLUMC came to my room, and told us that, our baby was stable, but very critical. He told us that our baby had a diaphragmatic hernia. He explained how the hole had allowed his intestines/stomach to enter his chest, which had caused his left lung to be compressed, and his heart to shift to the right. I was trying so hard to comprehend. At that point, we were told that our baby would not survive without surgery. His chances of surviving the surgery were 50/50. My husband wasted no time in signing all of the necessary papers. I was taken to my room, very tired, and very concerned. About 8:20 p.m. that evening my baby was wheeled into my room in his portable incubator (our baby was now almost an hour old). I reached into his bed to touch his warm little hand, and to tell him that we loved him, to keep fighting, and we would see him soon. I knew the sooner they left the better for our baby. The transport team really had compassion for our baby, and they told us they would do their best with our baby. I closed my eyes when they wheeled him out the door. I sobbed like never before. My husband and mother-in-law had been so supportive and strong. My mother-in-law (Janet) just happens to be the most kind, caring, and selfless person I know. No wonder her son is also a wonderful person. My father-in-law (Vernon, bless his heart) had arrived shortly thereafter, and within 10 minutes he and my husband were on their way to LLUMC. This was about 9:00 p.m.. They arrived at about 9:20 p.m., and Dr. Branson had met with my husband and father in law; just before taking our baby into surgery, and told them that, he would do his best to help our baby boy. (Corey was now 2 hrs. old.) We named our baby just after we were told he needed surgery. (We had planned on naming him after we held him.) Corey survived the 3 hr. surgery, and was taken to NICU. My mother-in-law had also arrived to be with Corey. She had stayed with me for a while. The medicine they gave me to help me sleep kicked in a little. I knew I had to at least try to rest even knowing Corey was fighting for his life. I woke up on the morning of July 1st., and Corey was now 13 hours old. My husband, and in-laws had gone home about 6 hours before (when they knew Corey was stable). My husband picked me up, and we were with Corey within 30 minutes. Corey was on a ventilator, and was given a drug to keep him paralyzed. Corey continued to do well, and sixteen days later he was taken off the ventilator. He still needed oxygen, and shortly after the Dr's. took out his chest tube, they had to put in another one. That one was taken out a few days later. At one point we were told by one of Corey's Dr's. that his left lung looked like dead tissue. Corey's x-rays were showing much more than dead tissue, and his nurse couldn't wait to tell my husband and I the good news. His lung was indeed expanding, and was a functioning lung. The Drs. explained that Corey's CDH occurred late gestation, and him being full term increased his chances for survival. (oh yeah, Dr. Branson used a patch to repair Corey's hernia). When Corey was 25 days old he went home. Two days before my birthday, Corey gave me the best birthday present ever!!! Being able to bring him home was the best feeling in the world. Corey is now 14-yrs-old, and loves to play baseball (pitcher, 3rd base, short stop), and will be playing freshman football this September. (Corey's dad had to talk me into this one). Corey is also doing very well academically. Corey has big beautiful green eyes (like his dad and grandpa). Although Corey's grandpa is no longer with us, I know he would be proud. Corey has a younger brother named, Kenney who is 12-yrs-old. Corey does get asthma, and uses an inhaler when needed. My husband, and I have been truly blessed.

Kathy Woodring (mom of Corey Woodring, 6/30/86, 8308 Bella Vista Dr., Alta Loma, CA 91701, 909-989-6448, corken00@cs.com)

It was a bright and sunny day on Toms River North's football field, as we, the class of 2000, graduated! As I looked around, young adults, who have been my friends, classmates, and teammates for the past 4 years, and some of them even longer, surrounded me. I thought about all the memories and I wondered what destiny had-in store for us?

My name is Rebecca Marie Buist, but most everyone calls me Becky. I was born on April 23, 1982 to my loving parents, David and Mary Beth. However only a few moments after I took my first breath of life, the doctors told my parents that I was born with a left sided diaphragmatic hernia. Needless to say they were heart broken and anxious as their first born baby girl was whisked away to have the first of what would be 3 surgeries. The first surgery was fairly successful, but the next few weeks would be critical. I had my second surgery at two months and after that one I was fine until I was 5 years old. I was in kindergarten when I had my last surgery as a result of scar tissue from pervious surgeries that had "rubbed against each other" and caused a kink in my intestines. Once that was fixed, I was "good to go"!

I do have scars on my stomach, but- it really hasn't phased me too much! I live by the beach, so to wear a bikini while body boarding in the waves, is not comfortable at all! (Besides, I don't exactly have washboard abs!) The only other visible scars I have are three pinhole cut downs, from the IVs on each wrist. One time in first grade, there was this mean little boy who teased me about the scars. Naturally, I didn't like being made fun of, so I did the best thing I could think of. I told them that I was scuba diving in the Fla. Keys, where I was attacked by a monster great white shark! Then I proceeded to show him the scars that were on my stomach! He was so impressed with my adventurous near death experience, that I was the single most popular kid in my grade! To this day, when people ask me what happened to my wrists, I tell them that a shark attacked me when I was very young. They are always dumbfounded and amazed! What can I say, I'm a drama queen!

My Mom always used to say that she was glad I was a girl with a CDH rather than a boy, because boys tend to be into sports and a lot more active than girls are. She figured that I could just be content to play with dolls and sing in choirs, since there wasn't any peer pressure to play ball and act wild. However, I wasn't the "play with dolls and do quiet things" kinda girl. I was the only girl to play with the boys on the playground, playing basketball and football and anything else they did! I played on the 6th grade basketball team and the junior high school teams too! When I entered high school I started to play field hockey and lacrosse. I was the varsity lacrosse goalie since my freshman year, beating out 3 others for the starter spot. I continued to play all four years, improving my game a little more each year. This past year was amazing- it finally all came together! My team's record was 20 wins 2 losses, and we made many headlines! Including winning our championship for the first time ever. I was MVP of the team, I was player of the week, I made 1st team All-Shore, and 2nd team All-County. I was goalkeeper for the Ocean vs/ Monmouth All-star game and was MVP of the team too!

This fall I will be attending Kean University (Union, NJ) to study marketing and/or education. I can't even tell you how excited I am to be going away to school. Kean is about 15 minutes away from New York City, I love the city and I hope some day to work there, if I decide to do marketing and business. In high school I was involved with DECA, which is a business club that involves marketing students with role-plays, written tests, and business presentations. The competition has 3 levels, regionals, states, and finally nationals, where you go and compete with students across the country. This year I had the opportunity to go to the nationals and compete in Kentucky. It was so much fun!

At this point in my life, I have so many great experiences already! Nothing has ever held me back from doing something that I really wanted to do. I consider myself a very strong willed person with a sunny personality and a bright outlook on life. I have a very supportive and loving family including my 2 brothers, David 15, and Ryan 8. I always live life to the fullest and I find something good in everyday. What does destiny have in store for me? Only God knows. All I have to do is aim for the moon, that way if I fall short ... at least I'll be amongst the stars!

This is me, with my doctor and surgeon, Dr. Mike Marchildon. The Marchildon Family are our close friends and every year on my birthday, my parents write and send pictures to Dr. Mike. This is me, Becky Buist, in the year 2000!

Becky Buist (cherub, 4/23/82, 732-255-3601, teachersvet@compuserve.com)

was quiet except for the words we spoke and tears we shed. There were no doctors or nurses, no noisy machines. A little while passed and a nurse helped remove the lines and tubes and peeled away a facial bandage that covered his nose and cheeks. We saw our son for the first time. We were asked if we would like to give Henry a bath. We did. We dried him gently and continued to talk to him as we wrapped his body in a bunny rug. We were so incredibly sad, so angry and so upset with ourselves. In our minds we had failed as parents. We had watched him die. We felt helpless and useless. We hated ourselves for not being able to protect him. My parents were called and arrived fairly quickly. Together we felt the pain. We held each other as the questions without answers filled the air. We all held him, kissed him. It was torturous. This was so wrong, so unfair, we were holding our dreams, our future in our arms, and he wasn't breathing. Nothing in our lives had prepared us for this. It was horrible. We took hours to say our goodbyes, it felt like minutes. Leaving Henry in the room was incredibly painful. We left our hearts and love of life in that room. The atmosphere in the normally bubbly Intensive Care was now so quiet. The staff were genuinely upset and were comforting as we were helped from the room. We were silent as we navigated our way through the long corridors back to our room. We were limp and empty. Anthony's brother, hearing of Henry's death, had come straight into the hospital. Mum, Dad and Anthony's brother held us and helped us gather our things. We needed to leave. We could not stay knowing that Henry was no longer alive. We ached with grief. Anthony and I held each other tightly.

We went home. It was a long and painful drive. I sobbed uncontrollably. I was numb. Only hours ago we had been sitting by Henry's bed confident of his progress. Once home, I had a bath and put on my pajamas. There was a cold silence. No beeping machines or ventilator noises, no doctors or nurses performing their daily duties. Anthony cried, I cried, my parents cried, Anthony's brother cried. We filled the oceans that afternoon. I spoke to my doctor, who gave me advice on the management of my milk. The pain of my breasts added to the pain in my soul. The thought of having Henry in a cold room alone distressed us. We wanted to organise the funeral quickly. As with so many other things over the last thirteen days, we had no idea of what to do. We never thought that we would have to organise our son's funeral. I called a local funeral director and made an appointment for the next day. The rest of the day remains blurry. The next day the funeral director brought around a small urn decorated in teddy bears. She was very gentle with us, and helped us through the possibilities. Anthony and I had discussed everything, and decided upon an unattended cremation and a memorial service. We chose an outfit for Henry to wear and gave the funeral director a musical toy and a gold angel to be cremated with him. That night, after an incredibly depressing day, Anthony and I prepared a service that celebrated Henry's life and showed how much we loved him. It was our job as parents to do the best we could. Anthony and I were inseparable We held each other and cried almost constantly. We felt the torture of organising a service for our baby. It was horrendous. We asked Anthony's brother and a dear friend to read for us at the service. They were invited over and together we read their scripts. My parents wrote a beautiful letter to Henry and offered to read it at his service. We were so thrilled that they wanted to share such a personal letter. We had some visitors who were kind enough to sit with us, listen, hold our hands and wipe the tears from our cheeks. On the morning of the service it rained, but the sun somehow managed to shine between the clouds. Anthony and I went early to the chapel to spend time with Henry and set up the table. Anthony placed flowers, toys and special gifts around the tiny teddy bear urn. The sun streamed in through the leadlight windows behind the table. Family and friends filled the chapel. We were astounded by the number of people who attended. We had asked that no children attend. I could hear continuous sobbing from every direction. Although incredibly difficult, the service was beautiful. We were rich in support. I had worried that everything would go wrong. The roller coaster was still roaring, emotional highs and lows welled up such confusion. We were still waiting to wake up from this nightmare. An after service get-together had been organised at Mum's, but Anthony and I did not want to attend. We had made plans to scatter Henry's ashes at Warrnambool, and wanted to do it directly after the service. We could not face bringing our little boy home in an urn.

We set off to Warrnambool. Anthony drove carefully. He had a look of sadness and determination on his face. We had wrapped the urn in a bunny rug and I held it tightly in my arms. The urn moulded to my body. It was the longest time I ever held Henry. We arrived at Warrnambool and located a favourite place of ours. It was a mountain overlooking a lake and the ocean. We walked to the top and laid down flowers. We wept as we scattered Henry's ashes and said our goodbyes. We sat there oblivious of time, only noticing the day was ending by the sun sinking behind the mountain. We stood to go home, but were unable to leave. Eventually we had the courage to say a final goodbye and started the walk down. Lead lined the soles of our shoes. Each step was torturous. I was awash with feelings of abandonment. Anthony pointed to some ducklings bobbing for food in a river. He said the most reassuring thing: 'Look, this is a place of love and life. It is a place of families and birth. This is the place for Henry.' We drove slowly towards home. I

held his hand and talked to him constantly. We read him stories and pulled the tail of a musical toy to distract from the relentless beeping machines and the thumping of the high frequency ventilator. We placed little soft toys in his bed. It was heartbreaking, but we kept going. We washed our hands several times a day, and limited Henry's visitors as there was a real fear of transmitting germs. Infection was a great possibility and Henry would have difficulty fighting off any infection at this stage.

On the 10th of September Henry was stable enough for surgery. It was scheduled for the following afternoon. I worried all night, 'Would he make it another day without an infection? Would we miss the window of opportunity?' My parents, Anthony and I waited in the Intensive Care waiting room on the afternoon of the surgery. We attempted to remain calm. The colour drained from our faces as we walked paces within the tiny room. We held each other. We cried, and we waited. The surgeon had large hands and a gentle face. He told us of the procedure and relayed a feeling of confidence. He informed us of the risks, and they worried us, but we continued to cling to hope. In our minds, if Henry could make it through this operation, he would have a greater chance of survival, a greater chance of coming home. Three hours crawled by. Henry's trolley was wheeled past the waiting room door, he had survived the operation and was being returned to his area within Intensive Care. I was desperate to see the surgeon and after several more excruciating minutes he walked down the hallway towards us. I checked his eyes for the Sorry look. It wasn't there. He smiled. We cried. He told us that the surgery was successful. Henry's intestines were now out of his chest and where they were supposed to be. His lungs were now in enough space to form. A thousand thank you's were not enough. Slight colour returned to our drained and aged faces and within seconds we were by Henry's bed. A large scar extended from the centre of his chest on a slight angle to the left side of his body. It was covered in a plastic film. We celebrated his strength and for the first time the roller coaster seemed to slow a little. We were able to catch our breath.

We adapted to living at the hospital, our old normal life seemed so incredibly far away. Our new life lay on a bed in Intensive Care. We ate at odd hours, slept badly and communicated by public phones with family and friends. We were prepared to live at the hospital for a lifetime if it meant we could be with Henry. There was nothing for us at home. For five more days we watched the outside world scurry through their normal lives from large windows. We wondered when we would be able to take Henry into the outside world, away from the machines, away from the hospital. We talked about all the things we could do with him, places we would go and things we would do together as a family. Each day signaled a little improvement and we felt confident enough to allow Henry some visitors. We began to make arrangements for the upcoming weekend for Anthony's parents to meet their grandson. We were enthusiastic for them to see our beautiful little boy. My parents visited daily. They kept buying Henry toys and things and would sit with him each evening. They wrote in his diary and took photographs at every opportunity. The love and dedication they showed saddened me. I felt such overwhelming guilt. I felt responsible for putting everyone, including Henry through this. I began to question my diet, my lifestyle. I wanted a reason for Henry's condition. There wasn't one to be found.

On the 16th of September our worst fears were realised. Henry showed signs of an infection. The word sepsis still rumbles through my brain over and over again. Henry's usual pinkish skin had changed to a murky grey. We were asked to sit in a nearby waiting room. The surgeon had been called and he spoke to us. He would attempt surgery if Henry became stable once more. That surgery never eventuated. Henry's heart stopped beating. The doctors gave us five minute updates, until eventually he was stable. We refused to sit in the waiting room any longer, and told the doctors we wanted to be with our son. They were supportive of our needs, and warned us of Henry's stability and his now bruised and bloody appearance. We cried when we saw our little boy. His chest was now very bruised, there was blood in his ventilator tubes. Doctors explained that Henry had been given heart massage and more medication. It was horrific seeing Henry like this. Guilt and fear once again consumed me. We talked to the doctor in charge, we asked questions that we thought we would never want the answers to. We stroked Henry's body gently. We told him of our love for him. Within minutes a beep sounded that I will never forget. I looked to the monitor that I had studied for thirteen days and watched his heart rate jump around erratically. Doctors and nurses jumped into action. It was frantic, they gave more medication, altered lines and tubes and once again began heart massage. Watching those thumbs pressing up and down on my baby was incredibly distressing. I felt so helpless, so pained. Someone in the room sat us down and gave us tissues to wipe our eyes. The thumbs kept moving up and down, up and down. Henry was not responding. Henry was separated from the tubes that had maintained his life. He died in the arms of his daddy at 11.40 am that morning. Anthony passed Henry to me, his little body now limp. I held him tightly. This was my first hold. I felt the crash of my heart as it fell from my chest and onto the floor. I was oblivious to the world around me. We went to a nearby room where we could be alone. Tears poured from our eyes. We asked 'Why Why?' and wailed 'No No No'. Henry's eyes were closed and he had a gentleness on his face. For the first time in thirteen days all

Ours is a 25-year-old story with a very happy ending. We hope it may help someone else who has to endure this devastating situation.

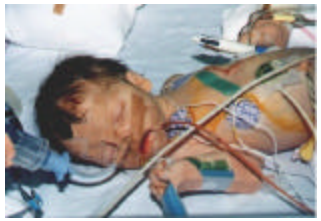
Back in 1974 I became pregnant for the second time with my son, Rick. Our first, Jennifer who was only 7 months old at the time, was healthy and a joy so we were thrilled with the idea of another baby so soon. I thought my pregnancy was normal until my 8th month. Since my obstetrician must have also thought things were fine, no tests were ever ordered. I found out later that I had developed polyhydramnios during pregnancy, which would have accounted for my large weight gain and trouble breathing. But other than that, I always felt excellent during both pregnancies and didn't even experience morning sickness.

About five weeks from my due date I started having what I thought were Braxton-Hicks contractions in the middle of the night. Since they were coming irregularly I waited for a few hours. They suddenly stopped and I fell back to sleep. Upon waking in the morning I phoned the doctor to inform him. He suggested making my next appointment in ten days rather than two weeks. Oh boy, such concern! When I was examined he told me I was already half dilated and told me to go home to bed. Why I wasn't hospitalized, I'll never understand. But at the time, I was young and naive and thought all doctors were saints. Three days later my water broke and I immediately went to the hospital. After a few good contractions, Rick was born about four hours later following a natural, no med delivery as his sister was. He was instantly found to have a problem (he was bright blue). I was allowed a quick kiss and he was whisked away to the pediatrician. The pediatrician on call that night first thought it was a collapsed lung and ordered x-rays. Upon viewing them, he identified his problem as CDH. Thank God for Dr. Robert Childs of Hazleton, PA. He had just finished his residency at Hershey Medical Center where he had seen numerous cases. The decision was made to transfer Rick there. Unfortunately, it was a very foggy night and the State Police helicopter was grounded. So Dr. Childs accompanied the ambulance crew and Rick's Dad, all the while monitoring and squeezing the ambu bag to assist Rick's breathing. The doctor in charge of him at Hershey, Dr. Shochat, performed surgery on him at nine hours old. We were told he had a 10% chance for survival. Without getting into all the details here which would lengthen this considerably, I'll say that after a rocky start Rick slowly improved and was discharged home to us after seven weeks. He only had one other surgery at four weeks old. In the beginning his left lung was only a "bud" and since he had high concentrates of oxygen they couldn't tell us what the future held. But we didn't care. They told us to take him home, love him and allow him to grow and act as any other child. Loving him was easy and luckily, we were blessed with no other long-lasting effects from the CDH. After only a few checkups at Hershey it was found that his right lung had expanded and he has no vision impairment from the oxygen.

Throughout his childhood Rick behaved as normally as any child I've seen. He was a healthy, intelligent, handsome, loving boy who grew to a man with the same attributes. We've just enjoyed a year of having him home with us after serving six years in the Navy aboard an aircraft carrier. Having him home completes our family again with his 26-year-old sister and 15 year old stepsister. I am truly blessed to have such a great husband and family.

At the time of Rick's birth, birthing partners were not allowed in the delivery room. That also meant that when his CDH was diagnosed my husband was not with me. Again I'll say thank God for Dr. Childs. He was very supportive and informative throughout all our visits during and after Rick's hospitalization. It was our loss when we moved a few years later. I also found the staff at Hershey to be unbelievable. They would explain things at every visit and phone call. However, the one thing missing was any kind of support group of parents who had gone through this. I'm so glad that with the computer age we will be able to reach more families going through this. That's why I joined "CHERUBS" as a state rep. I sincerely hope anyone who needs to talk--night or day--will feel comfortable enough to call me.

Brenda L. Eaken (mom of Richard Cheslock, 8/24/75, Shoemakersville, PA, 610-916-7027, BLEAKEN@aol.com)



Ariana was born on the 8th of May, 1990. She is our third child & was dubbed the wild child when she was 2, she has also been referred to as action girl! This is a quick summery of her life to date.

Detected at 17.5 weeks via an ultrasound, 13 ultrasounds & 1 amnio between 20-34 weeks, 6 days overdue, born naturally with an audience of 13 Dr's & nurses. I think we had a lot of tests as not too many babes had been detected through pregnancy & I believe they got their worth with us! We were kept up-to-date & never felt 'left out' of the goings on.

When she was 2.5hrs old, she was stable enough to start surgery. It took 2.5hrs. Her stomach, all of her large & small intestines, 1/3 of her liver & her spleen had managed to move through the hole in her left diaphragm. Her bowel was mal-rotated. She had 1/3rd of the top lobe of her left lung. 4 weeks later we where home. She threw up constantly, badly. At 11mths she had 2nd surgery, a Fundoplication. She had no valve at the top of her stomach, so they created one for her. She has not received her nickname without cause. At 2, she unlocked the front security screen door & went wandering off down the street. At 3, she climbed a 6ft pool fence (no foot holds), at 3.5, she managed to get onto the roof of the house. She scaled our 6 ft fences to visit the neighbours! She drew on walls, tables & chairs. She never sat still for a meal & still doesn't today. Her mind seems to work at double the pace of the rest of us, so does her body! She has managed to a great deal more, good & bad, but I'm only allowed one page!

In her first year of school, I was called up to the Deputy's office 4 times. This year, she's in her 5th year & I've only been up there once ..... so far. She took up Karate last year, but we had to ban her from that because she was starting to beat up on her sisters every time they annoyed her. By rights, she should have had a few broken bones with the tumbles she has taken but she hasn't?

She is a generous person, always willing to share. She is the one that accepts the dare, always the first to 'give it a go'. She gives everything she does 110%, be it good or bad, behavior or habit. There is a peaceful quiet that settles on the house when she is not here, that becomes a gaping hole if she is gone for more than a day. There is no doubt that she is the spice in our house, & we have 4 kids! She drives me crazy, she stirs up her sisters & brother. She is life at the fullest & we wouldn't have her any other way. She is our wild child, our action girl & we love her.

There is no doubt in my mind that this girl will succeed in everything she does, lets hope WE can survive what she has in store for us.

Joanne Kjaersgaard (mom of Ariana Kjaersgaard, 5/8/90, 25 Jindabyne Circuit, Forest Lake, Qld 4078, Australia, 07-3372-8687, lak@data3.com.au)

Rick and I tried to have a baby for about 5 years. He had a son, Bobby, 3, and I had a son, Kenny, 7, when we married. Finally after we had given up, I got pregnant. This was in 1977 and I didn't have any problems during my pregnancy, so no types of test were done. On February 5, 1977 our daughter Kelly was born. My doctor came and told me that we had a girl, but there were problems and they needed my consent to operate immediately. He told me she had a congenital diaphragmatic hernia, and a cleft palate. I had never heard of a CDH before, so I asked questions about her palate. The doctors told us it was minor compared to the CDH, and if she lived, we would worry about the cleft palate later.

A thoracic and cardiovascular surgeon was called in from another hospital to do the surgery. Kelly was 3 hours old when the surgery was performed. I was taken from the delivery room on a stretcher so that I could see her before they took her to the operating room.

We called friends and family and asked them to pray for Kelly. I prayed for God to do what

had sat by him all night. They told us about the care Henry was receiving and gave us two polaroids the nurses had taken. He looked so tiny and vulnerable laying there, connected to the machines. We kept in contact with Intensive Care. 'Stable' became such a celebrated word. It was difficult to be so far away from my baby. The day passed slowly and we counted each and every hour. By the end of the long day we were starting to feel a little more confident about Henry's survival. We decided Anthony should spend the night at home, he had not slept for days and had been coming and going from both hospitals, he needed the rest. At 1am I called Intensive Care. A friendly voice spoke. She was the nurse looking after Henry, she asked me how I was feeling and showed genuine concern for my predicament. She told me that Henry was no longer stable. She suggested that if possible I should come in to see him. The shake in her voice seemed to indicate that perhaps Henry was in real trouble. I phoned Anthony and told him to come quickly. I was helped into a wheelchair. I had a catheter and a drainage bag. I was uncomfortable to say the least, but my physical pain was not a priority. I sat and waited, every minute waiting for Anthony seemed like an hour. I watched the clock tick slowly. I desperately wanted to be with Henry, hoping he didn't die before we arrived.

We reached the hospital after a slow and cautious drive. Anthony wheeled me through the long corridors and we waited outside Intensive Care until we were given permission to enter.

In a large room at the end of a long corridor I saw my son. He was attached to so many machines. He had lines, tubes and things I had no idea of their name or purpose. Henry was laying on his back, his arms and legs extended to his sides. The nurse looking after Henry introduced herself. She told me that since our conversation Henry had regained stability. I tried desperately to understand everything she said, but I was still on painkillers, and was in such a state of shock. I understood that Henry was stable, he was on life support, still within the dangerous 48 hour period, and I was unable to do anything to help him. It was incredibly confusing time. We felt such a surge of powerlessness. I was physically and emotionally exhausted and felt so sick being out of bed, but we stayed with Henry for a few hours. A single touch reassured me. I wanted dearly to hold him, protect him, help him, but it wasn't possible. We touched his body and smelled his hair, we took polaroids. I held the polaroids to my heart as Anthony drove back to my hospital.

We cried, and started to question 'Why...Why us...Why Henry?'. I was helped back into bed. I rested for the remainder of the night, calling Intensive Care every couple of hours. Anthony went home, and the night passed slowly.

The next morning was brighter. We had been informed of accommodation at Henry's Hospital. Anthony made arrangements for my transfer. I hated being separated from my baby, and at midday, only 36 hours after Henry's birth, I was discharged. No longer on painkillers, I could see Intensive Care clearly. There were other children, on similar beds. Computer screens had lines and numbers, machines beeped and ventilators wooshed around me. It was terrifying. Reality hit and it hit hard. I felt so helpless and stupid. I had no idea of the complications of prematurity and had never even heard of a diaphragmatic hernia. We started to learn, we asked questions and were supported by a great team of doctors and nurses. We were given as much information as we could

absorb. The doctors were not confident of Henry's ability to make it through, he was faced with two substantial problems. There was the realistic possibility that Henry's treatment could give him brain damage, blindness, deafness or more. Our love for Henry was unconditional. We wanted him to survive regardless. The doctors tried to keep our feet on the ground, but we clung desperately to hope. It was all we had. I was producing breast milk and had been so looking forward to putting my baby on my breast. It was stressful not being able to hold him, feed him, bond with him. I was taught how to express using an electric breast pump and every three to four hours I would go into a room to express. I adapted to writing Henry's name on each bottle, sterilising procedures and storing my milk. We started to document Henry's life. We took photos and began writing in a diary a nurse had made.

Time took on a new perspective, and eventually the critical 48 hours passed. Henry was doing well. He had a long road ahead, but we developed a margin of confidence. Each hour continued to crawl by, and each day lasted an eternity. We sat with Henry hour upon hour, day upon day, asking questions and learning. We watched as his tubes and lines were changed, saw him receive blood transfusions, sat with him when he was given medication to paralyse him, and listened to the sound of suctioning of the fluids in his throat. It was incredibly distressing to watch as others cared for my baby, all I could do was talk, listen and learn.

We talked to so many people, doctors, surgeons, neonatologists, paedeatricians, nurses, dieticians, radiographers, ultrasound technicians. It was all so confusing. Henry had small steps forward and some steps back, we learnt how to cope with good and bad news. Anthony and I had our maternal and paternal instincts and not the normal parenting environment, so we did what we could. We wiped Henry's eyes,

my legs. I was now terrified. The nurses at reception asked my name, it was difficult to speak. I was helped into a cubicle and Anthony rejoined me. Within minutes I felt an incredible surge of fluid. The nurses were great. They strapped a heart monitor to my belly. We heard the heartbeat. It was strong. A doctor was quick to examine me, she told us that there were a variety of possibilities now that my waters had broken. Labour may begin, an infection could develop signaling the need to get the baby out of my womb, or the baby could remain safely in the womb for the next eleven weeks. It was obvious now that every hour the baby remained in my womb would be considered a bonus hour. It was an incredibly confusing time. There were so many new faces, medications, procedures and technical terms. Our minimal intervention birth plan was now in the wind. I was given an injection of steroids to aid the development of the immature lungs, antibiotics to fight infection and was put on an IV drip. The next 24 hours were incredibly difficult. I had an ultrasound, but due to a miscommunication, I was rushed to delivery suite for the impending birth. Anthony held my hand and stroked my face. The cervix was thought to be dilated, but was not, and the rush of faces into the delivery suite settled. The baby was not going to be born at this stage. It was difficult to remain calm. Twenty four hours passed by slowly and I was given a second steroid injection. I was now on a drip of ventolin to help ease the pains I was having. The ventolin did ease the pain, but added to my feelings of disorientation. I was moved to a ward where it was possible to stay for the duration of my pregnancy, however long it may be. I started to feel a little more confident. Anthony and my parents were very reassuring but we were all so shocked. Prematurity was not known in my family and the pregnancy had been progressing normally. When the ventolin course was complete the pains returned. We timed them. A nurse helped me through each pain. The decision was made to move me back to delivery suite.

More new faces introduced themselves, in the end I had no idea who was who. A surgeon spoke to me briefly and told me that he thought the baby needed to be delivered. An infection had developed, I was moved to theatre for a caesarean. I was in a lot of pain and extremely frightened.

Anthony sat beside me, we looked deeply into each others eyes. I could see his fear, but he smiled through his anxiousness. We were silent. I was confused and disorientated, I relinquished control. I was now in the hands of Anthony and the many people who filled the room. The surgeon began the procedure, and within minutes I looked up to see a little purple baby.

Our baby. Our son. He weighed 1600 grams and was 40 cm long. My heart was filled with such love. He was so beautiful. I reached out to touch him, but without any co-ordination my touch missed. I had been prepared for the situation of not being able to hold him, but it was difficult. Our moment of joy turned to fear quickly. We waited to hear his cry. He never did. In the corner of the room a team of people surrounded him. The voices I could hear were distorted, and I was unable to see what was happening. I could hear a strange hissing of air, and knew that they were trying to get him to breathe. I wanted someone to tell me what was happening, but was willing to wait until someone had time to explain everything.

Anthony and I continued to look in each others eyes. We were so confused and frightened. We waited. The sound stopped, the voices continued. I felt a chill run through me. The surgeon continued and after several long minutes we saw Henry, alive, in a humidicrib, and on his way to the hospital neonatal nursery. Anthony was asked for his name. Henry James was given an identity.

I was moved to a recovery area, Anthony rejoined me and together we waited an eternity to find out how Henry was doing. We feared the worst. The paedeatrician came and stood by my bed, he had the 'I'm so sorry eyes'. The look that says 'prepare yourself, I have something horrible to tell you'. He told us that Henry was very sick. 'Sick', I thought, 'He's alive, he's alive!'. My mind was dancing, until the music stopped and I started listening again. Sick? How sick? Whilst in recovery, Henry had been given an X-ray. It showed he had a congenital abnormality? specifically, a left diaphragmatic hernia. There was a hole in his diaphragm and his intestines had moved through the diaphragm and into his chest. His immature lungs were barely functioning, and his left lung had not fully developed because of its lack of space to grow. He was struggling even with a ventilator. We were told the next 48 hours were going to be the most difficult and there was a real possibility that he would not survive. He was now too sick for the neonatal nursery and required transport to Intensive Care at a nearby hospital. Soon I was wheeled down the corridors to the neonatal nursery. Outside in the hallway my parents and Anthony were crying. I thought I was too late. I feared the worst yet again, but Henry was alive and preparations were being made for his transfer. My time with Henry remains blurry. Before Henry's transfer I saw him once again back in my room. It was difficult to see his face behind a large ventilator tube. The transport team gave us two polaroids before leaving. I was now going to be separated from my baby, not by rooms, but by kilometres. I felt incredibly sad and confused. Surely this wasn't really happening, surely I would wake up in the morning, in my own bed, pregnant. Anthony held my hand until I fell asleep. He stayed the night by my bed.

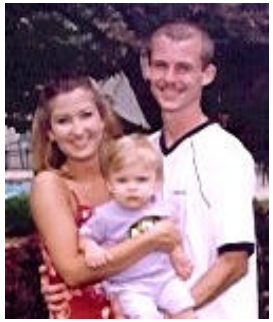
I woke early. I saw the hospital room. This was no dream, this was real. Anthony was still by my side. My parents walked into the room as I was waking. The smiles on their faces told us Henry was alive. They

was best for her. I wasn't really sure what to pray for. She came through the surgery just fine, but when we were taken to NICU, we weren't prepared to see her with all those tubes in her little body or hooked up to all those machines. I remember strangers gathering in the hallway to look in at her and I heard one tell another, "Come look at this one, she's in bad shape". I believe that's the moment the shock wore off and I'll never forget hearing those words. Kelly had some close calls the first 24 hours, but when she started improving, she really did a good job of it. We visited her every day and stood beside her and rubbed her little arms and talked to her, hoping she knew we were there. When the feeding tube was removed, we had a hard time feeding her because of the cleft palate. She was able to go home 10 days later. Some of the nurses called her a little miracle. We had to isolate her from family and friends for a while and her brothers had to wear masks around her. We were told not to let her cry, if possible, because of her small lung.

The next 20 months were not easy. She had a lot of intestinal cramping from the CDH, but I think the fact that she had to sit up to take her bottle because of her palate may have kept her from having more than she did. She choked so easily I was almost afraid to feed her. When she was 20 months old her cleft palate was repaired. Due to the cleft palate, she constantly had ear infections, had tubes placed in her ears 3 times, and, at 14 years old had her last surgery to repair her eardrum that had taken a beating from all the infections. She has a slight hearing loss. She had speech therapy for four years.

Kelly is now 20 years old and works as a Dental Assistant. She hopes to begin college soon to become a Dental Hygienist. She is a beautiful young lady and we thank God for our "miracle". Thank you, CHERUBS, for what you are doing for parents. I wish you had been around 20 years ago!

Written by Dodie Dickerson in 1997 (mom of Kelly Dickerson Wright, 2/5/77, 220 Innisbrook Way, Fayetteville, GA 30214, 770-461-8874, Benjibell@aol.com)



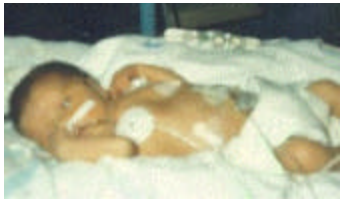
I feel so fortunate to be able to say that I can't remember anything about having CDH other than growing up with the scars. I have a large one across my chest and one from the feeding tube in my stomach, and I also have scars at the veins on my arms and ankles from IV's.

Throughout my teen years I was ashamed of my scars. My friends were always asking what happened? I would never wear a two-piece bathing suit, but as I got older and realized how lucky I am to be alive, the scars didn't matter anymore.

At the age of 22, my husband Jeff and I found out we were having a baby. We were so afraid that our baby would have a CDH. I was also worried about my being able to carry a baby. Being aware of my history, the doctors took every precaution during my pregnancy. They did special tests that showed no signs of CDH in our baby. They could not tell about a cleft palate, which I also had at birth. In fact, the cleft palate caused me many problems until I was 14 years old.

On July 10th, l999, our daughter Kaley, was born. She is a healthy and normal child and I had no problems during pregnancy or giving birth. We are so very thankful.

Kelly Dickerson Wright (cherub, 2/5/77)



Our son Brian Holsworth was born on January 17, 1989 with CDH. He was 2 months premature and weighed 3 pounds 15 ounces. He was born at John Muir Hospital in Walnut Creek, CA and immediately taken to Children's Hospital in Oakland for surgery. I had to stay in the hospital after the birth, but the rest of the family went to Children's Hospital with Brian during his surgery. It was hard not to be there with him and wonder if he would survive. I was glad to hear the news that he made it but the next few days would be critical. I was able to get out of the hospital the next day and visit Brian.

It was very scary watching our baby survive, but I never had any doubts of his strength to live. He continued to improve daily and luckily was only on the ventilator for one week. He was tube fed and able to tolerate breast milk and was then transferred back to John Muir Hospital after only 2 weeks. He spent another 2 ½ weeks at John Muir to gain weight, learn to suck and maintain his health. He left the hospital after 4 ½ weeks and he weighed 4 pounds 12 ounces. This was incredible considering he was 2 months premature and had CDH. Brian as an infant was diagnosed with mild Cerebral Palsy. He went through physical therapy weekly from about 6 months. He walked at 18 months. He continued Physical therapy for most of his life with various Orthopedics in his shoes. He continues to improve and we have decreased therapy to where we work with him at home and only visit the Therapist occasionally now. Brian is very athletic and it is a lot of work to stretch with Brian and keep him loose so he can continue to play sports well. We are constantly reminding him to think about how he walks so he can continue to improve himself. This is a tough reminder with some frustration.

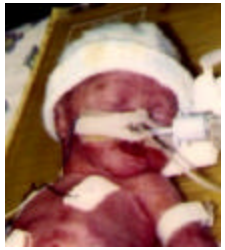
Brian is a great athlete and has an incredible drive to excel in sports even though he is smaller than most kids his age. He currently plays basketball, baseball and golf. He made Scholar Athlete for Little League Baseball for the past 3 years, which means you have at least a 3.0 grade during baseball season. This year he made Little League Majors as an 11year old and had a 3.6 grade point average. He also made the 11-year-old all-star team for Canyon Creek Little League. We are very proud of Brian, he has overcome a lot and has to work a lot harder than most kids in school and sports. He has a great attitude and a big heart and I believe this is what has got him this far starting from day one. Brian is the oldest of our 3 children. Brian is 11, Kyle is 9 and Alyssa is 5.

Rhonda Holsworth (mom of Brian David Holsworth, 1/17/89, 51 Placid Ct., San Ramon, CA, 94583, 925-735-6466, rholswo51@aol.com)

Hi my name is Judy and I am the mother of Hayley who is 16 years old, and a survivor of CDH. Hayley was born on 30th May 1984 at 6.10am in the morning. She was 6 lb 15 oz. I dreamt two weeks before she was born she would be born with an abnormality, and I was not surprised when she was. Mother's intuition they say! Hayley was born in one and a half hours, blue and quite lifeless. They took her off to the nursery and put her in an incubator on oxygen, hoping she would start breathing on her own. When her condition deteriorated soon after, the paediatrician was called in. Hayley was intubated, and a retrieval team was called in from a city hospital. They told us the prognosis did not look good, as they thought she had a large diaphragmatic hernia. I did not have any idea what that was, so my husband and I could only be guided by what they told us. That day was such a blur, driving to the city just hours after I had this beautiful baby, not knowing what would happen next. Hayley was taken to surgery when she was just 8hrs old. They repaired her left sided defect, and pulled her stomach and intestines down into place. She also had a large pericardial cyst around her heart, so they drained a little of that and used the tissue to repair her diaphragm. She was returned to ICU and remained on a ventilator. Her oxygen sats did not improve and her x-rays still showed large amounts of liver in her right chest. Her lung thankfully had expanded a little on the right side. She battled on through the next 6 days, having good and bad days. ON day 7 they decided to operate again. This time they removed two ribs on the right side and pushed the liver down, removed more of the cyst from the heart, and repaired the right side. Hayley also had a defect in the middle of her diaphragm, which was not able to be repaired. She was sent back to ICU still on a ventilator with the "wait and see" attitude. Hayley had a chest drain, which became infected 2 days later which did cause some concern, but she overcame that, and a bad bleed from her umbilical drip and she came through that also. Hayley just kept improving to everybody's amazement, and after 6 weeks she came home. What a nightmare that was with feeding! It would take her about 1 hour to feed from me and then she would vomit the whole lot again, just in time for next feed. After 3 days she stopped feeding all together and went a terrible grey colour. I took her to the paediatrician, and he put her in ICU with pneumonia. Her hospital stays were always long and frequent in the first year. Just one chest infection after another, and her reflux was so bad, I didn't think she would ever

endeavors there is to do. We had adopted 5 children during our marriage and had assumed that at our age (over 40) we were finished adding children permanently to our family. When Jodi's birthmother's parental rights were terminated, we were asked if we would like to adopt her. Miracles do still happen! Jodi has been a true blessing to our family and to all those who know her. Jodi has Attention Deficit Disorder due to the FAS. She is in the 1st grade this year. She takes Ritalin only during school hours and is doing wonderfully in school since she started taking it last year. Another miracle...at the age of over 50, we are in the process of adopting our 4 year-old medically-fragile foster child who has lived with us since she was 7 months old. She has Beckwith-Wiedemann Syndrome. Repair of the characteristic omphalocele, resulted in massive necrosis of the intestines that resulted in most of her intestines being removed. She is thus labeled with Short-Gut Syndrome in addition to the BWS. Julia will be number 7 and I think she will be the last of our permanent children. We will continue to keep foster children as long as we are physically able. I'd be happy to answer any questions and provide any support I can. Thank you for providing this group. I wish I had had access to this type support when Jodi was small. There were so many things I didn't understand and didn't know quite what to ask the doctors about.

Donna Morrison (mom of Jodi Marie Morrison, 3/30/93, 222 Kelly Spring Rd., Harvest, AL 35749, 256-851-9664, dmorrison@ispchannel.com)



Anthony and I had a great life. We both had good jobs, he a manager within an advertising company and myself a teacher of intellectually disabled students. In my spare time I painted and had several successful exhibitions. We were social people, getting together with our friends regularly. We went to the movies often, saw a show now and again and had many cups of coffee and meals at our favourite cafes. We had a house fifteen minutes from the city and over a few years had completed some renovations. All in all we were normal people leading a normal life. Anthony and I wanted a family, we were in our early thirties, we waited until the moment was right. One weekend we went to Warrnambool. It was lovely being there amongst the greenery and near the ocean. It was there Henry's life began. Two weeks after our trip I began to feel sick. I made an appointment with my doctor. There, I had a pregnancy test. The lines on a simple urine test confirmed my suspicions. I was pregnant. The doctor hugged me, then sat me down. I continued to look at the test. I was incredibly happy. This was my first pregnancy. The schedule was set. I was due November 18th. It seemed so very far away. I drove straight in to see Anthony at work. I bought chocolates and told him. He was ecstatic. We told our families immediately, we were bursting to share our good news. They were all so happy for us. I didn't drink or smoke, I avoided our cat and watched my diet. I read everything in sight. We started to create a nursery, looking at furniture and baby goods. Having a baby consumed our every moment together. We talked constantly about plans, the nursery and the birth. Together we looked at hospitals, and decided upon a birthing centre at a local public hospital. We wanted a minimal intervention birth. Anthony pampered my every need. As the pregnancy progressed I rested in the evenings instead of going out. We enjoyed our time together, the three of us. I went along to my regular doctor and midwife visits. Everything was normal, or so I thought.

At 18 weeks I heard the heartbeat. I cried. I was so happy. Anthony came along to each ultrasound with me. At our first ultrasound we were so excited. On a small monitor we saw our baby moving inside me. We were reassured that everything was normal. We watched the ultrasound over and over again at home. On our second ultrasound we found out I was carrying a boy. In the 29th week we attended our first antenatal class. We met other expecting parents. We compared bellies, expected dates and pregnancy stories. It was such an exciting and informative evening. We went home buzzing with excitement.

It was difficult to sleep the night after the antenatal class. I thought it was a mixture of excitement and worry. I complained to Anthony of a rough night. I had a shower and got dressed. My belly seemed even bigger than normal and the baby seemed high, almost under my ribs. There was a trickle of fluid down my legs. It was then the roller coaster scooped us up. I contacted the Family Birthing Centre and after a short question and answer time the midwife instructed me to come into Emergency. We navigated our way through peak hour traffic. It was so incredibly frustrating being stuck behind trams, trucks and cars. We did our best to remain calm, but the fluid was trickling out each time I moved slightly. We eventually made it to the hospital. I got out, Anthony parked the car. I walked towards reception holding my hands between

Our daughter Samantha was born on March 21, 2000, one day shy of my actual due date. She weighed 7 pounds 6.5 ounces and was 21 inches long. I had been having contractions for the past 5 weeks so the doctor decided to go ahead and induce me. After finding out that my daughter had CDH on January 4, 2000, I was a little hesitant about what would happen after she was born, but I wanted to go ahead and do it, the waiting was killing us. My parents and in-laws were great. They all made sure our 3-year-old son was okay and taken care of. 6 hours after the doctor decided to induce, our daughter Samantha was born. She let out a little cry and was rushed to the incubator. There, with a total of 9 doctors and nurses there just for her, she was intubated. They let my husband and I touch her through the incubator and rushed out the door and to the Children's Hospital that was attached by tunnel to the hospital she was delivered in. Two hours later we got to go and see her. It was the hardest thing I have ever had to do. Seeing one of your children hurt is the worst possible feeling. Samantha was put on ECMO when she was 22 hours old, her heartbeat was 205. Day 5 on ECMO they decided to go ahead and repair her hernia. With the blood thinner medicine it was risky, but with her being stable, this would be the best time. On day 6, she was 7 days old; they had to open her back up because her legs were purple and swollen. There wasn't any blood circulating to her legs. The surgeon told us it was because everything was in the stomach area now and wouldn't let blood pass. He said they would possibly have to put in a gortex patch to make the stomach area bigger. Once they got inside they noticed her stomach was filled with blood and fluid, they left a suction drain tube and didn't have to put in the patch after all. She had hypertension, this was keeping her on ECMO longer than they wanted, but on day 14 they decided it was time, she went through 2 circuits. Once we graduated to the progressive side we worked mainly on feeding issues. She had reflux so bad nothing would stay down. After weeks of trying on May 5, 2000 she had her 5th, and so far final surgery, to get a G-button and the Fundo wrap. This allowed us to feed her through a tube placed directly in her stomach, and the Fundo kept her from throwing up her food. Four days later, On May 10th, after 7 weeks and 1 day in the hospital Samantha got to come home!

Today Samantha is 4½ months old and still has feeding problems. We are doing all feeds through her G-button because she won't eat by mouth. She is not aspirating; she just doesn't want to eat and gags when we try, and she is on blood pressure medication to treat the hypertension. She is on track developmentally and physically and by looking at her you would never know what happened to her. She smiles all the time and makes everyone's day. She is truly our family's miracle baby.

Michelle Hudson (mom of Samantha Marie Hudson, 3/21/00, 5926 Sterling Green Trl, Arlington, TX 76017, 817-429-2955, michellemhudson@hotmail.com)

Jodi was born March 30, 1993, with left congenital diaphragmatic hernia of Bochdalek and left lung hypoplasia. Her small bowel, colon and spleen were in the chest where her left lung should have been. The diaphragmatic defect was approx. 4 cm in diameter. Repair was done at 2 days of age. She was on mechanical ventilation for only five days and weaned completely off oxygen in 10 days. She had a fundoplication and gastrostomy done at 18 days of age because of failure to thrive due to significant reflux. She was on continuous, slow drip-feeds for a long time due to "dumping" syndrome. Jodi also has Fetal Alcohol Syndrome. Jodi came to live with us at the age of 2 months as a foster child. Jodi required feeding through her G-tube for about three and 1/2 years. She had a super-hyper gag reflex. She would nibble on crackers but not swallow. She started to eat around her third birthday. We continued to supplement through the G-tube for another year. The G-tube was removed at the age of 4. We were told that she would live her life with only one lung, but the rudimentary left lung has fully developed. Docs don't know everything! We have done foster care since 1974 and consider it one of the most rewarding

get well. When she wasn't in hospital I would have to do physiotherapy three times a day and thread a suction tube down her nose into her chest to suck her lungs out, to try and stop the infections. It seemed her underdeveloped lungs were not coping with the stress. At 1 yr old she only weighed 7.5 kgs.. Hayley didn't walk until she was 22 months old, and when she started to walk her health also started to improve. She still had hiccups along the way, but the next years seemed to sail through for her. It is funny,. but bronchial pneumonia, chronic asthma, RSV infections, bronchillitis, chronic reflux, etc seemed to be just run of the mill illnesses to our family, were unheard of to my friends, and their children. Hayley is now sixteen, still tiny, weighing just 40kgs, and surprisingly very healthy. She still has an anterior diaphragmatic hernia in the middle of her diaphragm where her left lobe of her liver sits up through it. She still has a small pericardial cyst around her heart, and her heart is rotated. But besides that she is normal!! They will not attempt to repair the abnormality at this stage as it is not causing any problems, but they will keep a close eye on it, and having children of her own may not be possible, but we will cross that bridge when we come to it. So for a little girl who they said on many occasions would not live she certainly did prove them wrong.

Judy Ginns (mom of Hayley Chantelle Ginns, 5/30/84, 16 Janderra Street, Buderim, Qld 4556, Australia, 0754452555, whisps@beachaccess.com.au)

More Older Survivors

Michael Warren
2/17/58

Paul Flammger
8/11/83

Angela Barricklow
2/27/84

Carly Cribben
6/22/81

More Stories of Cherubs

This is the story of Trent Montgomery Sincavage. I would like to dedicate this story to all of Trent's doctors and nurses. Trent was born on April 14, 1999 at 6:05pm. I only got to see him for a second and he was taken to the resuscitation table. Next thing I know the NICU team, at the Reading Hospital, was working on him. My husband, Jim and I were told he was very sick and could possibly have a heart condition. An hour went by and the Neonatologist, Dr. Wirth, came into my room and explained that Trent had a Congenital Diaphragmatic Hernia, and that he needed to be treated at the Hershey Medical Center. He told Jim and me that Life Lion would be at Reading within 30 minutes. All I can remember thinking was Trent needed to be baptized. Dr. Wirth did make a point to tell Jim and me that a NICU nurse, Trisha, had diagnosed Trent within minutes of my delivery and that he was very proud of her. I will never forget what Trisha and Dr. Wirth did for me and my husband, not to mention Trent. Trent was baptized before he flew to Hershey. As soon as the baptism was finished the Life Lion staff prepared Trent to leave. Trent was very feisty that night. He kept pulling at his tubes, they finally had to tie his arms down.

I was discharged from the Reading Hospital within 14 hours after delivery and my husband and I drove to Hershey. When we arrived at Hershey, Trent was very stable. His nurses and Doctors spoke to us and told us of things that could possibly happen. I remember staying with Trent the entire day not wanting to leave, but I knew I had to take care of myself to be strong for Trent. My husband and I stayed near the hospital and I was able to sleep that night. I'll never forget the sound of the phone ringing at 7AM on April 16th. I leaped out of bed, answered the phone and it was the NICU unit. Trent had severe pulmonary hypertension, the nitric oxide failed and his only hope was ECMO or he would die. My husband and I raced to the hospital we got to see Trent before his surgery and through my tears a nurse laid her hand on mine and said, “it will be okay”. My husband and I then left the NICU unit.

The pastor from our church soon arrived and he kept Jim and I calm. He said to me, “what do you see in Trent's future?” I thought about it and I said, “I see three black belts.” (Trent has 2 older brothers Alex, 9 and Harrison, 5. Alex and Harrison take Karate lessons and both are working toward their black belts) I could really see Trent with his black belt! That thought made me smile and somehow I found an inner peace.

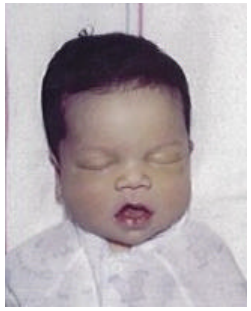
After the ECMO procedure was done, Dr. Cilley spoke to Jim and me. He told us Trent made it through and explained what ECMO would do for Trent's lungs. He told us Trent's primary diagnosis was severe pulmonary hypertension and the CDH was secondary. Dr. Cilley gave us the cold hard facts of the battle Trent faced. I needed that, I needed him to be straightforward with us and he was. I felt that inner peace again. Trent was on ECMO for 10 days. He was decannulated on April 26, 1999. Trent was placed back on the ventilator. The next 3 days were very rocky. Jim and I didn't leave his side. I remember the neonatologist, Dr. Marks telling Dr. Dillon, the surgeon "he needs his repair" and Dr. Dillon would say," we will wait to Friday." Indeed the surgeons waited until Friday, they knew what was best for Trent.

Friday, April 30, 1999 Dr. Dillon repaired Trent's hernia. The surgery took a little over 4 hours. I never prayed so hard in all my life. My husband was a wreck and I was strong (totally opposite of when Trent went on ECMO). I knew at this point it was up to God to handle, all I had to do was trust in him. When Dr. Dillon finished the surgery he spoke with Jim and me. He told us that Trent did well and he was on the ventilator, however he may need to be put on nitric oxide and the oscillator. The repair was made with his own tissue. His left lung is very tiny, because he has two spleens and one of his spleens grew where the lung should have grown.

Later that day Trent went on the oscillator and N.O. He became very ill. The doctors suspected that the pulmonary hypertension was back, so tests were ordered, but there wasn't any pulmonary hypertension. So perhaps he had an infection, so they gave him antibiotics, but it didn't help. Jim and I were standing by Trent when the Neonatologist, Dr. Marks came and told us we were up against a wall----but there was still some room to move. I remember yelling at God that day. I told God that he was wrong and it wasn't Trent's time to go, I was really mad. I did manage to calm down and I did find the inner peace again. I knew yelling and acting like a mad person wasn't going to help anyone. The doctors and nurses were doing all they could and I knew that. On the evening of May 4th we

to us. We would hate anything bad to happen to her. Natalie’s sister, Rachael, loves her to death she is always cuddling her and kissing her and playing with her but we try not to let her get to rough with her as we get worried that some thing might happen. We try not to leave her out as Natalie needs more attention than we give to Rachael ....and I feel that Rachael gets a little upset that we don’t get to spend as much time with her as we would like to. Natalie will be getting her heart operated on before Christmas this year, 2000.

Dianne Whittle (mom of Natalie Dianne Whittle, 2/9/00, P.O. Box 579, Batemans Bay NE, NSW 2536, Australia, 0244729245, ellen@eurocom.com.au)



My name is Adriana Williams. I am 24 and I just lost my son Ashton to CDH about 7 weeks ago. And it was the hardest thing to do. Saying goodbye was the worst. I hated seeing him with all the monitors and everything on.

He was 5 months in utero when we found out. They confirmed at 7 months in utero. When the doctor told me I about got sick. I worried and prayed every day after that. But unfortunately all the prayers in the world couldn't save him. He was gorgeous. He was my baby. He held on for his mommy for 6 days then his little body couldn't take it any more. He died in my arms were he wanted to. I cherish every memory and picture of him. He had so much stuff wrong he wouldn't have survived no matter what. His heart was moved over to the wrong side, his stomach and some intestine were up in his chest, and his lungs were under developed.

On the 6th day they told us he wasn't going to make it and that we only had a few ours left with him. So they put him on a portable ventilator and let every one hold him. It was the saddest thing in the world. I hate going to the cemetery and looking at a gravesite. I just wish I could hold him one more time.

I would like to write this prayer, which was said at his funeral. I would like it posted for all the grieving parents: Lord, the loved ones gone from us we trust now to your keeping... Bring them home at last to you, wake them from their sleeping, soothe them with your tenderness, touch them with your grace, take them from this world to find a brighter place... Care for them like children, Lord, and let them always be within your gentle heart for all eternity... And though we loved them very much, we'll find our peace somehow, in knowing we will meet again although we're parted now.

I would also like to write a poem for the grieving parents. It has helped me. Its like whoever wrote it knows exactly what you feel when you lose a child. It's called Oh Mother, my mother. Oh Mother, my mother I touch your tears, invisible fingers soothing your skin. I know you think of me so often in the day, in the night, in your dreams, going into a empty nursery knowing I'll never be there, but I am...in your heart in your soul, I shall always be for you gave so unselfishly of yourself. Inside of you, you created such a world for me a world of laughter, of love, of sadness, of sorrow, every emotion people come to know you shared with me. And even though I may never feel your arms around me I felt your heart beating, like a lullaby, singing me to sleep and your spirit giving me a safe haven already protecting me nurturing me preparing me for things to come. But sometimes the journey of life pulls souls apart and yes, I had to go on
to another place. I wish I could stay. I wish the decision I could make and I know you do too. Know this wherever you are: I will always remember that yours was the first love, the first joy, the first soul I will ever know you gave me courage to go on my journey I hope I can do the same for you. Your heartbeat will always call me to you. Love, your child.

Thank you very much for letting me write this I hope it will help other grieving parents because it hits home so much and you feel everything the poems says. Thank you.

Adriana Williams (mom of Ashton Victor Lee Williams, 7/6/00-7/11/00, 612 Cascade Rd, Cincinnati, OH 45240, Williamsadi@aol.com)

going to survive when I heard the bad news. The Doctor called the NETTS team in so they could transfer Natalie to a Hospital that could help her. They arrived at 3am in the morning. The NETTS team worked on Natalie to stabilize her so they could transfer her to Sydney's Children's Hospital, in the mean time I tried to get some sleep. In that time, but I was to distressed and upset about my baby which I only got to hold for a brief second after I had her, and didn't get to hold her for another 6 days. I didn't get any sleep and when they arrived they explained the condition a bit more to me but they did not know the extent of it. After the NETTS team put little wires into her all over the place and tubes up her little nose to help her breathe. It looked very scary but it was necessary to keep her alive. I hoped that she would survive. They weighed Natalie before we left to go to Sydney Hospital; she weighed about 3.5kg. We arrived in Sydney around 7am in the morning and I hadn't had any sleep and I was feeling very exhausted. When we arrived at the hospital I met with doctors, nurses, social workers, and the surgeon. They took x-rays and ultrasounds and all sorts of tests, so they could see the extent of the Diaphragmatic Hernia. When they were doing all the tests they also found she had a heart condition called Tetralogy of Fallot (a congenital defect of the heart consisting of 4 abnormalities that results in insufficiently oxygenated blood pumped to the body). I thought she wouldn't survive at all having this as well as the hernia. Before they could operate on her to fix the Hernia the doctors wanted her to be stabilized so things would go well when they operated on her. I was told the operation would go ahead on Saturday and I was all excited that it was going to happen and she would be better. Saturday came around and they told me not today probably tomorrow, as the doctor would like to see her a bit more stabilized so we waited another day. As she laid there, it was sad to see her with all the wires attached to her and tubes up her nose, but it was all necessary for her to stay alive. The tubes up her nose were for oxygen, and another to her stomach for gas and, they would feed her through this tube after the operation. She also had IV lines in her arms and senesces on her to monitor her breathing blood pressure, and oxygen in her blood and a couple of other ones for temperature and that. Natalie was also a few drugs to help with the pain and to keep her fluids up. The doctors Finally went ahead with the operation the next day, which was a Sunday morning, when the operation took place; it went for about 2 ½ hours. The operation went well. But they had to keep her in ICU for the next few days to see how she went after the operation. Natalie was in ICU for about three weeks all up before the doctor though she was well enough to start her on breast-feeding. They transferred to another ward so we could try and get her feeding sorted out. While she was in ICU I was expressing my milk every 4 hours for the first 3 weeks. I didn't think I was able to breast feed her but I kept at it and we are still doing well with it she is now 9 weeks old and still on the breast on demand feeding and putting on weight. My husband and my other daughter came up to Sydney and visited Natalie and myself on the weekends. My other daughter is 3 years old and when she saw Natalie with all the wires on her she said "Natalie is broke, the doctor's fix her up" which was sad but I think she sort of understood why Mummy was in hospital with Natalie. My mum gave Natalie a big teddy bear while she was in ICU and Rachael (Natalie's sister) named the bear after one of the nurses that looked after Natalie. I also had a few other visitors while I was there which was great support from Family and Friends. They took me out so I didn't have to live in the hospital the whole time. Which I needed a break from it all as some times, it just got to be too much. My husband had to go home and work and look after my other daughter, which I think he handled very well under the circumstances. When we finally got to go home, we were transferred to our local hospital so that doctors could get to know her condition in case she had any other problems and also to make sure she was putting on weight and doing well. Now she is doing very well and we still have appointments to follow up on her heart condition. We went to Sydney on the 13th of April and saw the heart doctor. He told us that she would be operated on when she is about 9 to 18 months old. Hopefully there will only be one operation needed and that it all goes well. Hopefully they will be able to operate soon on her heart. It will be open-heart surgery, which I am frightened about it, but I think she will do well. Everyone tells me she will be fine. If she doesn't get the operation it will cause to much strain on her body as she gets older and cause her not to be able to cope anymore so it's important to get this operation done soon...

13-4-2000 We saw the heart doctor and I asked him if it will be a once off operation, he said hopefully. My husband and myself feel a bit relieved that she doesn't have to go through a lot of operations. And if its all goes well I hope she will be able to live a normal life. She is very special

finally left the hospital (after reading Trent "Goodnight Moon" - he was read that book every night). My husband and I went back to the Ronald McDonald House and I thought for sure we would receive a call that night from NICU. I fell asleep and it was the deepest sleep, and during my sleep a miracle happened. I woke at 7am and immediately called NICU, Trent's nurse was delighted to tell me that he had a great night! I couldn't believe it, Jim and I were so happy. I sure do believe in miracles!

On May 10th I held Trent for the first time. He was still intubated so he had to lay on a pillow. Jim was not with me, he was home with Alex and Harrison. I had Trent all to myself, what a day. On May 11th Jim held him for the first time and then he gave Trent to me. While holding him I noticed his tube was really moving around and Trent was gagging, he had managed to partially pull his tube out! Trent was extubated and put on oxygen. Jim and I started going home at this point. We lived an hour from Hershey, so one of us would stay in Hershey and one of us would go home to Alex and Harrison. While I was at home on May 14th, NICU called, it was Trent's nurse, Martina, calling to tell me that Trent was breathing room air. This was another great day.

The next issue for Trent would be learning to eat. He was given an NJ tube, he really didn't like that, he kept pulling it out. (Needed to tie his hands down again!) Trent had a lot of reflux and was put on medication, which did help.

Trent was discharged from Hershey on 5/27/99. Before he was discharged I had everyone who was involved with Trent sign a t-shirt, given to Trent by the Life Lion Crew. The t-shirt has a picture of Life Lion and it reads "I flew on the Lion". The shirt is filled with over 30 signatures and hangs proudly in Trent's bedroom.

Trent was readmitted to Hershey in June for 3 days, he had a difficult time with drug withdrawal. By the end of July 1999 he was drug free. Trent is now 16 months old. He is currently receiving physical therapy. He is tolerating food and no longer uses a bottle! He is also part of the Children's Miracle Network.

I would like to thank several people: Alex and Harrison for being the best big brothers to Trent. My neighbors, Bob and Nancy Moore, who opened their hearts and home to Alex and Harrison. (they took care of Alex and Harrison for two weeks while Jim and I stayed in Hershey.) Jim's family and my family for all their support. Our church & all of our friends for their support. The NICU staff at the Reading Hospital, especially Trisha and Dr. Wirth. The entire NICU staff and the entire pediatric staff at Hershey, especially Trent's primary nurses Jeanie D. and Larissa, the Neonatologists, Dr. Mallow, Dr. Marks, Dr. Waterberg and the Pediatric Surgeon's, Dr. Dillon and Dr. Cilley. Donna and Tammy for making Jim and me laugh! Most of all God for giving us Trent.

Even though there were really difficult days, there were also great days, something good did come out of all this, Jim and I did make a lot of new friends and I was able to find courage and inner peace in myself that I didn't know I had. God Bless us all.

Tammy Sincavage (mom of Trent Montgomery Sincavage, 4/14/99, 1820 Lincoln Ave., Wyomissing, PA 19610, 610-796-7324, TTSiceskate@aol.com)

My name is Barbara Eisele, and I am the grandmother of my precious angel, Reese Gabrielle Eisele-Elizondo. I have been a member of the Cherubs organization since March of 2000, after Reese was born. I have waited to submit her picture and story; but I have read ALL of the cherubs stories to date, and I'm finally ready to share mine. Reese Gabrielle Eisele-Elizondo was born on March 8, 2000, on Ash Wednesday, at 6:45am, in San Antonio, Texas. I had been in the labor room with my daughter until it was time for Reese to make her arrival. I excitedly awaited just outside of the delivery room for my beautiful granddaughter to be gently placed in my arms; but I, like so many other stories which I have read here, never got that opportunity. I heard them calling 'code blue' on the intercom, and saw nurses, doctors, technicians, and everyone else, it seemed, in the world running into the delivery room. I

kept asking everyone what was happening, but no one seemed to hear. Suddenly, I saw a baby cart being whisked away to the nursery with 6 hospital staff surrounding it and running it down to the nursery. I began to run after the crowd, knowing that my grandchild was the baby in the cart and I kept asking everyone what was wrong. No one would hear me. I peered in through the blinds to try to see my precious baby, but every window I would go to, a nurse would run to close the blinds. My son-in-law came down to the nursery area, but neither he nor my daughter knew what was wrong.

Finally, the OB came into the hallway and tried to explain that they had discovered that Reese had CDH. We knew nothing about this, and the Dr. drew a little diagram to try to show us what had happened. He told us about ECMO - that 2 hospitals in SA had the machines. He told us that she had a 50/50 chance of survival, but that the specialists over at Wilford Hall Medical Hospital were very experienced. We agreed to have Reese transferred by ambulance to Wilford Hall; while my daughter would have to stay behind and my son-in-law and I would follow in the car. When we arrived at the neonatal area of the hospital, we found Reese up on a little pedestal with a team of Drs. and nurses working on her. After several hours of tests, X-rays, tubes, breathing apparatus, etc., the lead Dr. told us that Reese also had a heart defect which was called transpiration of the great vessels. They informed us that she would need to be transferred to a different hospital for heart surgery before they could put Reese on ECMO to be able to do the surgeries for the CDH. My precious angel never made it to Methodist Hospital. My son-in-law left to get my daughter so she could be with her baby. I stayed with Reese and tried to sponge bathe her as best as I could before her mother got her first real chance to be with her baby. I told them to keep Reese on oxygen – I wanted her mother to get to hold her while she was still with us. The staff kept asking me if the parents were coming, but it took about 2 hrs. since the hospital was about 45 minutes away and my daughter had to be released. When they finally got to the hospital, the staff gave the family some time to be with Reese. We were able to hold her while she was still on oxygen; and then we let her fly to be with the other little angels in heaven. My daughter and husband stayed behind to bathe Reese, dress her up, take pictures, and hold her; while I rushed home to take down the crib, and throw all of the baby items into bags and closets to be out of view.

The death certificate lists the time of death as 3:45 PM, on March 8, 2000; although I never saw her move or open her eyes since my sprint down the hallway trying to catch up with the baby cart before they pushed her into the nursery. It's all still a 'fog' to me, as if it were a dream, as if it wasn't real; but I know that Reese is real! Many people would say that I don't really understand - I'm just a grandmother; but the hole in my heart aches and I know that I will never have another beautiful angel like Reese Gabrielle Eisele-Elizondo. She will always be my most special and precious grandchild. I love you, Reese!!!!!

Barbara Eisele (grandmother of Reese Gabrielle Eisele-Elizondo, 3/8/00-3/8/00, 4340 Southeast Dr., San Antonio, TX 78222, 210-337-1705, baeisele@www.com)

My son, Bryan, was born on March 7, 1998 with CDH. He was full-termed and never diagnosed in utero. Which was shocking because my last ultrasound was done at 28 weeks to find out the sex of the baby and the obstetrician said, "Everything looked just fine"! So, my husband and I were very excited because the baby was going to be healthy and he was a boy. My daughter was also excited that she was going to have a baby brother. As the due date came near, we registered with Phoenix Children Hospital thinking if something should happened he would be in the right place. Then on March 7 my contractions started and I started having second doubts about driving 25 mins. to Phx. Children's and the closest hospital was only ten mins away from our place. But my husband and I figured since I had already pre-registered that we should go to PCH. By 4am on March 8, I was admitted and by 1:50pm my beautiful son was born. That was one of my happiest moments until they cut the cord, and that's when our lives was turned upside down. The obstetrician put Bryan on my stomach and I thought it was strange that he only made one small whimper and never did anything after that. A couple of minutes passed when I asked the doctor, "why was he a gray-ish blue and not crying?" She then tried suctioned him and tried to rub him to stimulate so he could let out a big cry but nothing happened. So she took Bryan off me and took him to the little nursery bed and began bagging him. That is when she realized that something was out of the ordinary and called for more help. And a couple of more mins. passed until the NICU team arrived.

However, in my mind it felt more like an eternity. Then the NICU team was in my room huddling around my baby which I could no longer see. The neonatologist finally was able to intubated him and rushed him to the NICU nursery. His apgar scores were 1 at 1 min., 1 at 5 min., and 8 at 10 min. They did an immediate x-ray and diagnosed him with a left-sided diaphragmatic hernia. My husband and I were in shocked and never heard of CDH and we were also devastated when they gave him a 30% chance of survival. He was so small and looked so perfect on the outside, that we couldn't understand why he was a sick baby. By 7:30pm the surgeon felt Bryan was doing very well and decided to operate on his diaphragm, and did very well throughout the 2 hour surgery. He did fine after the honeymoon period and continued to be on the jet ventilator because of his pulmonary hypertension. It took 2 1/2 weeks to wean him off the jet to a regular ventilator. Then it took another week to wean him off the regular vent because his pulmonary hypertension finally resolved. He was then able to receive regular oxygen via nasal. However, the doctors felt it would be difficult for him to handle a large amount of breast milk and continued to feed him 1cc every hour and only increased it by 1cc every hour. So they could slowly introduce the feeding amount to his stomach.

Then they wanted to insert a broviac line only because he didn't have any more IV sites, but the original surgeon didn't feel the same way and ordered to give Bryan a bolus feed to see what would happened. Miraculous he did just fine and was able to come home and was discharged on April 3, only with an apnea monitor. They discontinued the apnea monitor because there were no episodes. To this day he still has problems. Especially when he gets the common cold it could easily wipe him out for several weeks. My husband and I still feel strongly that he may have a reflux problem because he's always vomiting. However, they don't think he has reflux because his only symptom is when he coughs to a certain point then he'll start vomiting. But other than that he's able to keep his food down. If any other parents have any suggestions or answers please contact me about this feeding issue. When he was 12 months old he needed physical therapy for severe delay in motor skills. Then when he was 18 months old he had to have another surgery to correct his left testicle because it still didn't descend naturally. Now he is 29 months old and goes to speech therapy because he's not talking. The only words he knows is Mama, Dada, and milk, which that's the only words he needs to know for the time being. But I'm trying to do a preventive step so he won't be delayed in any areas when it comes time for school.

To this day I thank God for each and everyday I can spend one more day with Bryan. Plus giving me another chance of having another perfect little girl that was born in March 1999, with no birth defects.

**I just wanted to let the CDH parents know is that this battle is a long and tedious one. My husband and I only advice is to you is that take one day at a time and always have hope because no one can ever take that away from you. May God bless each and everyone that reads this story.

Jennifer Doan (mom of Bryan Shawn Doan, 3/7/98, 877 South Ash Street, Gilbert, AZ 85233, 480-632-5753, jdoan_00@yahoo.com)

Natalie was born in Hospital at 10.05 p.m.; my labor only took 1½ hours as they say your second child comes out quicker. This one came quicker than I thought it would be. I had a normal pregnancy with no problems, they did not pick this birth defect up in the ultra sound that I had when I was pregnant. When Natalie was born she was the colour PURPLE. The midwife saw that she needed oxygen straight away so she cut the umbilical cord and put her straight into the crib where she was given oxygen. I went and had a shower not thinking much of this. When I came out of the shower my husband told me there was more wrong then just lack of oxygen she was breathing funny and the doctor took a chest x ray and found that she had a Diaphragmatic Hernia (an abnormal opening in the diaphragm that allows part of the abdominal organs to migrate into the chest cavity, occurring before birth.) I thought she wasn't