

# CHERUBS

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



## The Silver Lining

Fall 2000

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

Dear Members,

I hope this issue finds you all doing well. All is well, but busy, at CHERUBS. Our membership is now over 700 and includes all 50 states and 28 countries. Our web site is growing by leaps and bounds, with dozens of support activities for members and over 60,000 visitors to our site. Our volunteers are busy helping families and our professional membership has more than tripled this year. Our office has moved into a "real office" with regular 9-5 hours, thanks to the help and support of Chudy International who also donates the space for our web site, and who donates our shared office space. Our contact information has not changed. Our on-line store had a few problems when the company we were using dropped us without notice, but we are now up and running again with a new company. Next year's conference planning is under way and several State and International Representatives are planning future conferences for their areas. Our 5<sup>th</sup> year has been quite a landmark year for us, with more to come in research, lobbying for better pre-natal care, and more activities and conferences! This is all due to the amazing help of our volunteers and the support of you, our members. Together, we have made a difference in the lives of CDH families and we will continue until CDH is wiped off the face of the earth.

Thank you all!

Dawn M. Torrence, President and Founder

## Non-Survivor Get-Together



Our First Non-Survivor Get-Together was small, but it was great to make new friends and see old friends. We talked, cried, and laughed and had the opportunity to discuss emotions and problems that are hard to talk about with others who haven't lost a child. We hope to make this annual event. Thank you to Judi Toth for all her help! Pictured above are (from left to right); Elizabeth Doyle-Propst, Brian Propst, Judi Toth, Amy Rademaker, Brenda Slavin, Jeremy Torrence, and Dawn Torrence.

## After I've Lost My Child Please....

Author Unknown

Don't Ignore me... Because you are uncomfortable with the subject of death, it makes me wonder if what happened means nothing to you.

Acknowledge my pain...and please don't expect it to be over in a month or maybe even in a year or two. Losing a child is one of the most difficult of all of life's experiences and the depth of my grief will shock even me as it returns in waves over and over and over again, long after everyone else may have forgotten.

Be Aware...that holidays and the time around the anniversaries of my child's birth and death may be particularly difficult and painful for me to cope with.

If you haven't been able to call...for a long time tell me that you are sorry, and that you haven't known what to say, but don't say that you've been too busy. This has been a momentous event in my life and it hurts to hear that it has been so low on your priority list that you couldn't even spare me a 5 or 10 minute call.

If you invite me for a meal...( and please do) in the midst of my grief expect me to talk about my loss. It's all that I am thinking about anyway, and I need to talk about it. Small talk neither interests me or helps me.

Don't change the subject...If I should start crying don't change the subject. Tears and talking about my child's death are the healthiest ways for me to release this intense emotion.

Telling me that...so and so situation must have been harder to bear won't make mine any easier. It only makes me feel that you don't understand or can't acknowledge the extent of my pain.

Don't expect...that since my child is in the presence of the Lord that it is all that should matter and that I should not be hurting. I may believe that and be thankful for that, but my arms ache to hold my child here. I miss the physical contact so much.

Telling me...that I must be a special person for God to send me such a heavy burden and that God's will is best implies that God did this purposely. I may believe that his will is best too. But I don't believe that everything (including my child's death or anyone else being killed by drunk drivers for example) is God's will.

Don't remind me...that I am so lucky to have another child or children. I am and I know it, but my pain is excruciating for this child, and having others doesn't seem to take the pain away.

No matter...how bad I look please don't say "You look terrible." I feel like a total failure right now, so I don't need to be told that I look awful too!

Remember...my child, to me, is a very special and unique person, who can never be replaced.

Don't say..."I know how you feel, I lost my Mother." It is not the same. We all expect our parents to die one day, after they have had a full life, but I am grieving for the Might-Have-Been of my child's short life.

When you ask my husband...How I am doing, don't forget to ask him how he is doing. He has also lost a child and if you ignore his hurt it says to him that his hurt and pain doesn't exist or that it doesn't matter.

Don't ignore...any surviving kids. Remember, they are hurting as well but may not be able to express their feelings.

If I snap at you...for saying any of these things, please forgive me and try to understand that it comes from my intense pain and hurt.

Hug me...and tell me you care and that you are sorry this happened, even if you don't understand the depth of my pain.

Be Available to me...to listen and let me cry. My feelings are a part of the grief process, and I will work through them more quickly and easier if you do not judge me when I need to get do this.

Just Love Me...and I will always remember you as a TRUE FRIEND! A wife who loses a Husband is called a widow A Husband who loses a wife is called a widower A child who loses a parent is called an orphan But in Yiddish they say There is NO word for a Parent who has lost a child. That is how awful the loss is.

## Can We Ever Move On?

by Brenda Slavin (reprinted from 1998)

Moving on is something everyone expects you to do after losing a child. They expect you to be instantly healed and move forward as if nothing has happened. As Bob and I, our family, and our friends, and employers learned it just doesn't happen like that. I remember part of me wishing I would just wake up one day and be able to do just that. The other part was too worried of letting go. What if I lose those precious memories I have left? What if I forget the way they felt, the way they smiled, the way they smelled. This hurdle really hit us when we decided to have another baby. Would we forget our old family being so busy with the new family? We made a decision before Stephen was born that Amanda and Nicholas would be a part of our family forever. Each year at Christmas I hang their stocking up with ours. Their pictures and their urns are in our home openly. They will always be our children. They will always be Stephen's brother and sister.

With Amanda having lived a year, I had a lot baby items and clothes. I am now (5 years later) having to face the dilemma of what do I do with all her things. The clothes I decided to keep in the event we have a baby girl. But there are so many other things that just sit in the attic I haven't had the heart to throw away or give away. It's almost as if I did either of those things I would be giving part of her away. (I didn't have a lot for Nicholas because we knew he wasn't going to live very long.) After much thought I decided I would give her things to other children in need. I know if she lived long enough to say so she would love to share her things with others. So I'm not giving her memories away I'm sharing them with other children. A few times a year (quite a few still) I look at their photo albums, the funeral tape, their clothing (which still has their precious scent after all this time) and their hospital bracelets. I feel so drawn to go get the box even though I know it will be painful all over again. After at least an hour of sobbing I always feel a sense of peace. Almost as if they were with me. I talk to them openly and freely as if they were standing right next to me. I only wish I could hug and kiss them. I know when I talk to them and tell them how much I love them they hear me. Somehow, somehow I know they hear me. I pray every night for God to let them know how much I love and miss them. I often pray to God to have Amanda and Nicholas wrap their angel wings around someone who needs them. I feel so certain Amanda and Nicholas were part of our lives as part of God's glorious plan. As painful and wonderful the experience has been I couldn't be more grateful to God for giving us these beautiful gifts. The impact these two precious angels made on so many lives is unbelievable. Both of our pastor's could feel what we felt around them. You couldn't be more alive, feel any closer to Jesus than when they were around you. Their spirits were so strong all you could feel was love and peace. All of these are cherubs. Not because it's a cute name to give a baby for an angel. They were chosen to be in your life. They are true angels. Even as they fight for their lives in the NICU they are giving so much to so many. They give you, the parents, so much love you can feel your heart overflow. They give you the strength to keep moving on no matter how bad it seems. Maybe it's a very subtle sign. Like a smile through the intubation tube or a squeeze of your finger. They are telling you "Mom and Dad I'm OK and I love you so much." Sometimes I felt they were stronger than I was. But each day they gave me more and more. And I find even though they have been gone 4 years and 2 years, they continue to give me so much. I still feel their undying love and their strength while I'm praying. These angels touch your souls forever. So as you begin to "move on" don't ever fear losing your angel. They will always be a part of you. Everyday they will be there unheard, unseen, untouchable but always filling your heart with their love and ever so precious footprints...

## New Arrivals

(\*siblings of Cherubs)

Caitlin L. Blair  
 Jenna Marie Bonser\*  
 Brendan Carroll\*  
 Courtney Stavis Gabbett  
 Kylee Freedom Green  
 Kristen German Guadarrama Ballesteros  
 Dylan Isaiah Houck  
 Blake Austin Jones\*  
 Joshua Kelly  
 Gabriel Joseph Kolacia  
 Darragh Edward Lennon  
 Quenton L. Lewis  
 Jane Olivia Lignana  
 Ryan Patrick Morrison  
 Toby Oakley\*  
 Matthew Ryan Peterson  
 Madeline Rose Premru  
 Alexis Angel Lynn Riggs  
 Lauren Anee Runion-Hintzman\*  
 Abigail Dawn Sentner\*  
 Devon Dean Stevenson  
 Mitchell Vallins\*  
 Trevor Vallins\*  
 Allison Brooke Weldon

## This Newsletter Is Dedicated To the Memories of:

Mackenzie Helena Collis  
 Kylee Freedom Green  
 Dylan Isaiah Houck  
 Destin Constantine Dennis Jaworski  
 Joshua Kelly  
 Gabriel Joseph Kolacia  
 Kayla A. Lee  
 Haines Becca Leighann  
 Darragh Edward Lennon  
 Jane Olivia Lignana  
 Ryan Patrick Morrison  
 Samantha J. A. Mulcahy  
 Zachary Roger Nickerson  
 Matthew Ryan Peterson  
 Kristen Rose Quintal  
 Casey Charles Spiezio  
 Devon Dean Stevenson  
 Stephen Andrew Tomes  
 Georgina Kay Townsend  
 Cade Andrew Turner

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 (our web site)  
 dawntorrence@cherubs-cdh.org (Dawn)  
 info@cherubs-cdh.org (information)  
 membership@cherubs-cdh.org (membership)  
 volunteer@cherubs-cdh.org (volunteering)  
 donations@cherubs-cdh.org (donations)

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

Niall Christian Ashburner  
 Dominick Aaron Beach  
 Caitlin L. Blair  
 John Brodsky  
 Mackenzie Helena Collis  
 Samuel Anthony Congro  
 Carter J. Conway  
 Alexander B. Cottam  
 Baby Girl Crump  
 Baby Curlock  
 Baby Boy Dewberry  
 Sara Lareigh Dobrick  
 Jeffery Ronald Durrigan  
 Tysen Rick Fausett  
 Karl A. Fiebelkorn  
 James Bradley Foster  
 Courtney Stavis Gabbett  
 Louise Marie Gallagher  
 Baby Boy Gardner  
 Robert Charles Garnett  
 Kristen German Guadarrama Ballesteros  
 Gary John Hargadon  
 Baby Girl Holmes  
 Dylan Isaiah Houck  
 Sarah Brianne Howerton  
 Destin Constantine Dennis Jaworski  
 Madi R Johnson  
 Joshua Kelly  
 Gabriel Joseph Kolacia  
 Jorgen Kavlie Lawrence

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

Kathleen Burch  
 Chudy International  
 Lea Donahue  
 Elizabeth Doyle-Propst  
 Jennifer Dumas  
 Stacy Dinay Everett  
 Michael Garrett  
 Susan Grubb  
 Renata Hoskins

Kayla A. Lee  
 Haines Becca Leighann  
 Darragh Edward Lennon  
 Quenton L. Lewis  
 Jane Olivia Lignana  
 Joshua Scott Low  
 Ian Miles McCants  
 Truman Patrick McHargue  
 Ryan Patrick Morris on  
 Samantha J. A. Mulcahy  
 John Matthew Mulhern  
 Amelia Rose Neill  
 Zachary Roger Nickerson  
 Elliot Harrison Nye  
 Baby Girl Pattee  
 Matthew Ryan Peterson  
 Madeline Rose Premru  
 Alexis Angel Lynn Riggs  
 Sydney Grace Roberts  
 Samuel James Rossiters  
 Parker Seery  
 Casey Charles Spiezio  
 Devon Dean Stevenson  
 Connor Ryan Stevenson  
 Jacqui Taylor-Jackson  
 Stephen Andrew Tomes  
 Georgina Kay Townsend  
 Cade Andrew Turner  
 Megas Christina Vegas

Danielle Kessner  
 Elaine Moats  
 Kathleen Rogula  
 Margaret Rowe  
 Darlene Silverman  
 Jeremy Torrence  
 Judi Toth  
 Barbara Wagner

## Congenital Diaphragmatic Hernia Research Survey

It's almost that time again; time to tally up the results of our annual CDH Research Survey. If your cherub is a non-survivor or a survivor over 1-year-old and you have not filled out your CDH Survey (the 10-page survey), please get that in to us by January 31, 2000 so it can be counted in our 2000 Results. If you have not received your CDH Survey you will shortly after your cherub's first birthday.

We also have inserted a Parent Worksheet (membership form) into this newsletter. If your cherub or family has any new updates since you last filled out your form, please fill this out once again and mail it in. We try to make our Results as accurate as possible and in order to do so, we need updates on our members so if your cherub has had more surgeries, new diagnoses, more complications, etc or if you have had more children or a change in your family medical history, please re-fill out the membership form. This is especially needed if you joined CHERUBS before your cherub was born. You may also use the on-line membership forms.

You may contact us to a request another 10-page CDH Survey if you need to update that also, but please write "Update" on it and repeat something from your old survey so that we can figure out which one it is that needs updating. The information on both forms is 100% confidential and we do not even list your name on the CDH Survey. If you have any questions or concerns, please feel free to contact us. To find the cause and prevention of CDH, we need your help!

## My Two Sides

Author Unknown

Why did this have to happen to us?

You may never know the answer to that.

Am I being punished?

How could you think of anything so precious as being a punishment?  
 I feel so empty.

Yes, but this was not always so.

Remember how long you had her with you.

I don't know if I can bear this pain.

It is tremendous, but you chose to take your pain - and hers.

Would it have been better if I had not known you at all?

No. You are so blessed to have been touched by this life.

I wanted you so badly.

Oh, but she wanted you too.

You were chosen from all the others.

I had so much love to give.

And you did. She knew nothing but your love.

I would have been a good mother to you.

You were. You made the decision only a good mother could.

I wanted to protect you from the world.

You did. She experienced only the comfort and safety of your womb.

I wanted to have you with me forever.

She will always be with you. To love, time does not exist.

I would give anything to hold you once more.

You will hold her in your heart forever.

taking it one day at a time and thanking God we have that day.

We lost my mother on Nov. 29, 1999, and this has been hard on all of us. My mother was very involved in Angel's life and Angel thought of her as another mother. She was there day in and day out. Angel has started asking a lot of questions about her scars and things that happened over the years and I just try to be as honest as possible. My mom was better at that than I am. We are moving into our new house the first of Oct. and hopefully we will turn a new corner and things will get better. Good luck to all the CHERUBS out there and may we all have a happy life.

Janice Crawford (mom of Angelia Crawford, 22606 NC Hwy 902, Bennett, NC 27208, 336-581-3332)

It has taken me weeks to write this letter. After receiving the "Summer 2000" newsletter with the dedication to my son, I felt like it was time to tell my story. I also have a very special "Cherub" in heaven. His name is Parker Daniel. He was born on Monday, May 29, 2000, and he was called home on Thursday, June 22, 2000.

At 32 weeks, I was sent for an ultrasound because I was measuring to big. That is when they found the problem. My doctor sent us to Lynchburg VA for a level 2 ultrasound and CDH was confirmed.

The doctors in Lynchburg recommended that we go to Duke Medical Center. So 3 days later, we headed for Durham, NC. It was such a long day. We had so many tests done and met so many people. The surgeon recommended that I take steroid injections to help with the development of the baby's lungs. So I did. They let me bring the medication home, so my doctor could give me the 2<sup>nd</sup> injection. I saw my doctor on Tuesdays and we went to the hospital on Fridays. On Friday, May 26<sup>th</sup>, after the ultrasound showed that my amniotic fluid was very low. We were told that I was going to be induced that day. So we called our families. At 3:30, the doctor came in and said they wanted to wait until Monday. My emotions were running wild! At this point I had dilated to 2 on my own. The weekend was very long, I had to stay in the hospital. In my mind I was not ready for the baby to be born, but in my heart I knew he had to be. Before they started the IV, I had dilated to 3. Parker was born at 6:16pm. He weighed 7 lbs. 15 oz. He let out 2 small sounds and then they took him away. I did not get to see him until 11:00 the next day. He was in the NICU. It was very hard seeing him with all the wires and machines. He looked so big next to the other baby's. He was stable and would have surgery on Thursday or Friday. But on Thursday morning they took an x-ray to check his chest tube and found that he had an infection in his intestines. Surgery was canceled. He was given more antibiotics. On day 10, Parker got worst. He was moved to the PICU to be placed on ECMO. On day 24, after 14 days on ECMO, Parker was ready for surgery. When the surgeon started on Parker, he realized his intestines had ruptured in his chest cavity from the infection. It was much worse than we thought. To fix the hernia, was the easy part. It was the rest that made it so hard. When the surgeon came to talk to us, we knew it was just a matter of hours. He told us Parker was a fighter, he did not know how he was still alive. We were able to spend a few hours with him before the machines were cut off. After 24 days, I finally got to hold my son.

We know that God does not make mistakes. Parker Daniel was a true blessing to my husband and I. In his short life, he touched so many people. Each day I think God for Parker-my special angel.

Paula Setliff (mom of Parker Daniel Setliff, 5/29/00-6/22/00, 141 Third Ave, Danville, VA 24540, 804-799-5814, swat201@mindspring.com)



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

Bernadette Agüero- in memory of Ryan Patrick Morrison  
 Jocelyn Argain- in memory of Ryan Patrick Morrison  
 Andrea Atwood- in honor of her daughter, Caitlyn Kraft  
 Mary Avery- in memory of Shane Torrence  
 Patrick and Irene Bartels- in memory of Ryan Patrick Morrison  
 Joe Battiato- in memory of Ryan Patrick Morrison  
 Nancy Beim- in memory of Ryan Patrick Morrison  
 Robert and Mary Benedetti- in memory of Ryan Patrick Morrison  
 Gina, Kevin, Kyle, and Kelsey Berta- in memory of Ryan Patrick Morrison  
 Amy Blackstock- in memory of Parker Daniel Setliff  
 Nancy E. Boyd- in memory of Morgan "MoMo" Avery McClintock  
 Kira Brady- in memory of Ryan Patrick Morrison  
 Mr. and Mrs. Carlo Busceme, Jr.- in memory of Kylee Freedom Green  
 Greg Carbone- in memory of Ryan Patrick Morrison  
 Gary and Diane Checchio- in memory of Ryan Patrick Morrison  
 Warren and Lee Cowley- in memory of Morgan "MoMo" Avery McClintock  
 Leslie M. Coughlin- in honor of the Riggs family  
 Diana Cox- in honor of her son, Dallas Cox  
 Donald and Tiffany Craven- in memory of Morgan "MoMo" Avery McClintock  
 Michael and Sally Curci- in memory of Ryan Patrick Morrison  
 Annette Depaola- in memory of Ryan Patrick Morrison  
 Kimberly Austin, Jeffrey Austin, and Barbara and Frank Dolan in memory of Morgan "MoMo" Avery McClintock  
 Wayne and Sabrina Durrigan- in honor of their son, Jeffery Ronald Durrigan  
 Ellen- in memory of Ryan Patrick Morrison  
 Antoinette Everett- in memory of her grandson, Nicholas Alexander Kaulana Everett  
 John and Jacqueline Falconieri- in memory of Ryan Patrick Morrison  
 Suzy L. Freeny- in memory of Morgan "MoMo" Avery McClintock  
 Heather Fresco- in memory of Ryan Patrick Morrison  
 Leonard and Kathleen Gigantino- in memory of Ryan Patrick Morrison  
 Margaret and Ed Green- in memory of Kylee Freedom Green  
 Doretha O. Hawkins- in honor of her granddaughter, Allison Lane Pruitt  
 Renata Hoskins- in honor of her son, Kilian Roberts  
 Rona Korman- in memory of Ryan Patrick Morrison  
 John Kuhn- in memory of Ryan Patrick Morrison  
 Cynthia S. Layman- in memory of Ryan Patrick Morrison  
 Annette Lichtenstein- in honor of her son, Ivan Lichtenstein  
 Manny and Francine Lopez- in memory of Ryan Patrick Morrison  
 Ericka Lorezen- in memory of Ryan Patrick Morrison  
 Kelly and Eric Maurer- in memory of Ryan Patrick Morrison  
 Jerome and Erin McElroy- in memory of Ryan Patrick Morrison  
 Laura Ann McFatter  
 Joy McHargue- in honor of her son, Truman Patrick McHargue  
 Faye Merolla- in honor of Felicia Marti's pregnancy

Faye Merolla- in memory of her niece, Kala Marti  
 Marilyn Merolla-Nalewaik- in memory of Kala Marti  
 Thomas and Michelle Morgan- in honor of their daughter, Michelle Avery Morgan  
 Todd and Mary Beth Morgan- in memory of Ryan Patrick Morrison  
 Meryl Nathan-Goldberg- in memory of Ryan Patrick Morrison  
 Sandra Nunes- in memory of Ryan Patrick Morrison  
 William O'Toole & Antoinette Bouza- in memory of Ryan Patrick Morrison  
 Judith and Laurence Piretra- in memory of Patrick Ryan Morrison  
 Debbie Petronstry- in memory of Ryan Patrick Morrison  
 Randy and Lee Pisane- in memory of Ryan Patrick Morrison  
 Cathy Price- in honor of her daughter, Sydney Price  
 Elizabeth Doyle and Brian Propst- in memory of their daughter, Cecilia Winn Propst  
 John and Andrea Quigley- in memory of Kylee Freedom Green  
 Pat, Cindy, Annie and Jacob Reid- in memory of Connor McLuckie  
 Richard and Heather Reiner- in memory of Ryan Patrick Morrison  
 Patterson Robertson- in memory of Morgan "MoMo" Avery McClintock  
 Ronald and Linda Sadler- in memory of their grandson, Connor Ellis McLuckie  
 San Marcos Baptist Academy Employees- in memory of Morgan "MoMo" Avery McClintock  
 Barry and Edie Saunders- in memory of their grandson, Cade Andrew Turner  
 Fides and Peter Scalici- in memory of Ryan Patrick Morrison  
 Olivia F. Serio- in memory of Kylee Freedom Green  
 Paula Setliff- in memory of her son, Parker Daniel Setliff  
 Andrew and Deborah Skibitsky- in memory of Ryan Patrick Morrison  
 R.H. and Mary Smith- in memory of Morgan "MoMo" Avery McClintock  
 Jeremy and Dawn Torrence- in memory of their son, Jeremy "Shane" Torrence  
 Judith Toth- in memory of her on, Christopher Toth  
 Anthony and Jeni Tubbs- in memory of Morgan "MoMo" Avery McClintock  
 Barbara Turner- in memory of Ryan Patrick Morrison  
 Sharon M. Varriale- in memory of Ryan Patrick Morrison  
 Joe Vidivich- in memory of Ryan Patrick Morrison  
 Bruce and Sally Wagner- in memory of Morgan "MoMo" Avery McClintock  
 Kevin and Barbara Wagner- in honor of their son, Logan Wagner  
 Kenneth and Becky Welch- in honor of their granddaughter, Adrienne Dale Dumas  
 Kenneth and Becky Welch- in memory of Shirley Carmel Loewy  
 Travis and Sherri West- in memory of Morgan "MoMo" Avery McClintock  
 William H. Yoes- in memory of Kylee Freedom Green

## Did You Know?

Stonewall Jackson was born with CDH, but it was never repaired and not severe enough to prevent him from becoming a part of history.

You are more likely to have a child with CDH than to be struck by lightning, be in a plane crash, killed in tornado, killed in an earthquake, win the lottery, become a Senator or Congressman, get high jacked, or win a Grammy award- combined.

Ultrasound technicians in the United States do not have to be licensed.

Over 1500 babies are born with CDH in United States every year.

CDH is as common as Cystic Fibrosis (1:2500), Congenital HIV (1:2700), Spina Bifida (1:2000), Metabolic Disorders (1:3500), and SIDS (1:2000)

We did not get along at all. I knew that Angel had severe scaring and that this next surgery would be long one. He didn't agree and told me that there was nothing in her charts to say otherwise and this surgery would last about 4 hours so I finally said, whatever. Within 1 hour of surgery they came to tell me that he had cancelled all other surgeries for the day and it would be awhile (8 hours) when he was done. It was a different story- all the sudden I knew what I was talking about. We were there for 5 days and then discharged (he didn't believe in keeping patients for 5 days). Well a day before discharge Angel started having severe loose stools, which I knew wasn't good but I was wrong again in his opinion, so home we went. At this time before we left, standing in the hall talking to one of the nurses who was eating potato chips, Angel reached over and took one and put it in her mouth chewed and swallowed. A first for her; she had never put anything in her mouth, not toys, fingers, nothing. I was a little freaked because we were told coming out of surgery nothing by mouth for 4 weeks. Well for the next 5 days we were in the pediatricians office every other day for dehydration. Finally when I started getting very upset, Dr. Novack called the hospital and was informed that Angel had a stool sample done the day we were discharged and it came back the next day with rotovirus. None of the staff had bothered to call. So back we went for 3 weeks (with one very mad mom). When we finally got that worked out she had turned 1 year old so the next step was off formula and onto pediasure. Pediasure at this time was hard to get and it took me 2 weeks before the order came in at my home this was also on a Friday and so at 1:00pm when I finally got it in my hands I called Dr. Novack and asked how to switch. Just change it over at the next feed he said. So at 5:00 that day I did and as soon as I put it in the feeding tube she started screaming so I called the hospital. Dr. Novack was gone for the weekend and I ended up with a doctor from the NICU, who promptly told me that nothing was wrong. I was overreacting and Angel proceeded to code. So I gave him a few choice words and called an ambulance. When the first responder got there and took one look at her foley cath coming out of her stomach and all these scars he panicked and told me he didn't know what to do. I panicked and told him to ignore everything except that she was wasn't breathing and had no heartbeat, which he did. They took her downstairs and put her on the back of a pick up until the ambulance got there and off to a different Hospital we went. When we got there they panicked, which made me worse and wanted to air flight her back to the first hospital. For the next hour the hospital and I argued with them and finally after being told that they could get here before they could get the helicopter there (not to mention I couldn't ride) they agreed to put her on the ambulance and sent her. The ambulance driver had never been to this hospital and didn't even know how to get there. With directions from mom and 3 nurses we finally got on the road. Angel coded 4 times in the ambulance. When we got there a strange kind of peace came over me (being home I guess). After a rough night with 5 more codes, the next morning she was fine. After 4 weeks we were sent home with no explanation as to what happened. My opinion; vegal nerve reaction.

She was still refluxing some and so we started playing with her feeds and finally ended up with no more bolus feeds. Instead we went on a pump over night. This worked perfectly and she quit refluxing. We started seeing an OT for feeding. The first thing was fluid, after this we started solid foods (chips and fries), junk food slowly she started eating. The whole process took 1 ½ years. I wouldn't pull the G-tube until we had gone without it for a year. She has never been on the scale as far as her weight- always under and she still is.

She had her feet operated on when she was 1 and learned to walk with a 5 pound cast on both legs. This has never seemed to make any difference to her. She just got up and went. We still have splints and probably always will, even though these are just inside her shoes and not noticeable. She doesn't jump and run as much as the other kids, but she does her share. We see the ortho doctor every 2 years and he is very pleased with her progress.

She had to have her eyes operated on in 1999. They roll and she can't focus without seeing double and when she tries to focus, they turn. That drives me crazy and now that we are a year out, it seems to be happening again. So we will probably have to have it done again.

Now we are up to the present and I just found out July 6<sup>th</sup> 2000 that she has a severe hearing loss in both ears at high frequency sounds, so now we are going to get hearing aids. Her pediatrician has confirmed that the antibiotics she was on as a baby has caused this. We are still

Well he finally came and told me nothing was wrong but he would do a blood crit and, low and behold, she had to have a blood transfusion. Last time that resident was allowed in my room. We had another nissen within 2 weeks because she was still refluxing. At this time they also put in a feeding tube. Angel had a central line until this point and we were finally able to leave the room without dragging a pole with us. This was heaven. We had never been allowed to leave the hall in front of her room until this point. I noticed that Angel was looking really yellow and we did some blood work to find out that she had a very rare form of hepatitis J or K. Something they didn't even know how to treat. Her billerium soared at this point and she turned an ugly shade of green. Some of the nurses thought that the central line and her hepatitis were the main culprit. I really wondered about the last blood transfusion at this point. By this time I had been at the hospital for 5 months and didn't know when we would be allowed to go home. This had taken its toll on everyone in my family. My son not only had a sister who was very sick but he had lost his mother for 5 months. I never left the hospital for more than 4 weekends at this time. I was so tired of the hospital, I couldn't stand it. I would call my family and cry because I just wanted to go home and I didn't feel anyone was telling me anything. As I became more depressed her surgeon (unknown to me) had requested that I be reserved a room at South because they thought I would be having a nervous breakdown. I didn't just learn that I could go over to the library and do all the research I wanted, I was pulling up case files and then going back and asking all kinds of questions. When the doctors found out what I was doing they had all the medlines restricted to medical personnel only but by then it was too late I really started pushing to go home on my birthday, which was June 25<sup>th</sup>.

By this time I was, and had been doing, all of Angel's care for at least 3 months. I was finally released on July 1st, only because Angels liver was so bad that she was on top of the liver transplant list and her surgeon decided that I should be able to go home because within 3 or 4 weeks she would have to be readmitted to wait for a transplant. He wanted me to say that I had been able to take her home. After 2 days, one of the nurses who had been taking care of her came to visit and we went to the NC Zoo, which was about 10 miles from my home. We went and got everything so I could feed Angel, except her formula, and of course she got hungry. She cried for about 45 minutes until we got home and fed her. Then she started refluxing again. Patricia, her nurse from the hospital, cried as much as I did and told me to call the hospital because she would have to go back. I did call all I could get was a resident who didn't know what to do so I stayed home and just dealt with the reflux. There was nothing they could do I couldn't, so when they called back 2 days later to tell me to bring her back, I refused. After 3 weeks she went back for a checkup and her billerium had dropped just 1 point but it was enough for me and I refused to have her readmitted. Her second checkup in 2 weeks showed it had dropped another point so we came off the transplant list and did a lot of praying. She still had reflux after every feed so I discussed options and was told there was none. Angel refluxed a lot when she was 9 months old and turned blue so we were back in the hospital for 1 month. This time I had a pediatric resident who came to my room and begged me to bring her to him. At this point she didn't have a pediatrician because none in my hometown knew what her condition was so therefore they wouldn't see her as a patient. So I finally got a pediatrician even though he was over an hour away.

Dr. Steve Novack was a Godsend. He was willing to help me make adjustments with Angel's feeds and go through a lot of questions about what would be normal for her. At 10 months, Angel got chicken pox. For 3 days I didn't sleep- nothing but try to make her comfortable. Finally I called Steve and was told to bring her to the ER (for my sake not hers). When we got there, we were put in isolation in the ER and then a whole herd of residents came in to see her. When Steve finally got down to see her he admitted her (worse case he had ever seen). Once in an isolation room on the 5<sup>th</sup> floor they started her on Aclyvir, a miracle drug in my opinion (used for herpes outbreaks). That night I could tell it was helping. We finally went home after 5 days.

Angel was still refluxing seriously and so finally when she was 11 months and 2 weeks we were readmitted for a 3<sup>rd</sup> or 4<sup>th</sup> nissen. I can't keep count. My original surgeon, Dr. Shomer, had left the hospital and gone to Dartmouth (our loss their gain) and we had a new surgeon.

## CHERUBS International Conference

The dates and location for next year's annual CHERUBS International Member Conference have been set for Minneapolis, MN. We also have inducted a new Conference Coordinator; CHERUBS member and CDH mom, Lea Donahue. We desperately need sponsors and more volunteers for next year's conference to pull it off. If you can help, please contact our main office or Lea at 603-425-2639 or leamd@mail.com. If you are interested in attending next year's conference and would like a copy of the conference brochure that will be published in early spring, please fill out the form in the fundraiser insert of this newsletter.

We have also planned the locations for 2002 (Phoenix, AZ) and 2003 (Boston, MA). We want to "skip around" the country to give more members the opportunity to attend. Conferences around the world will hopefully be planned soon.

Last year's conference was a great success and we learned so much- we hope everyone will be able to attend in 2001!

## CHERUBS Volunteer Coordinators

We still need Representatives for many states and countries and volunteers for many positions. Volunteer positions can involve as little time as a few hours a month to a few hours a day. CHERUBS has 78 volunteers at present, all organized and coordinated by our wonderful Volunteer Coordinators. We would like to take this opportunity to welcome our new Co-Coordinator, Danielle Kessner, and to thank our other Co-Coordinator, Barbara Wagner for doing such great work at a very hard job. If you would like to volunteer here at CHERUBS or have a question about volunteering, please feel free to contact Barb at (810) 249-5279 or PURPHAZE19@aol.com and Danielle at (03) 5135 6999 (Australia) or kessam@bigfoot.com.

## National Children's Memorial Day

Sunday, December 10, 2000



Candles will be lit at 7:00pm in all time zones so that there will be constant light around the world in memory of our children in Heaven.

CHERUBS' web site is offering free e-cards to commemorate this special day. Here you can invite family members and friends to light a candle in memory of your cherub or send cards to grieving members. Even if you are blessed to still have your children, please light a candle to remember those who are no longer with us.

## Cooking With CHERUBS Volume 2

As this newsletter goes to print, we await the arrival of the second edition of our cookbook, "Cooking With CHERUBS". A huge thank-you goes out to Elaine Moats and Judi Toth who chaired the cookbook committee and to all those members, family, and friends who contributed delicious recipes. You can order your cookbooks by filling out the form in the Fundraiser Insert of this newsletter.

## CHERUBS T-Shirts

Because our Conference TShirts sold so well, we have decided to order CHERUBS member TShirts. We have a variety of tshirts available in pink or blue with several different logos for cherubs, members, doctors, and nurses in sizes ranging from Infant to XXX-Large. You can view the various logos and order your t-shirts by filling out the form in the Fundraiser Insert of this newsletter.

## Valentine Tributes



Last year's Valentine Tribute Fundraiser was so successful that we decided to try it again this year. Valentine Tributes are memorials and tributes in our newsletter issue around February (the next issue will be published in late January). Not only are they tax-deductible, but also they are a wonderful way to honor your cherubs. For more details, please look at the Fundraiser insert in this issue of our newsletter.



Our September, 2000 Ebay Auction was successful, though not quite as successful as our January, 2000 auction. We hope to make our January, 2001 auction even more successful.

A huge thanks goes out to Annette Lichtenstein, Andrea Atwood, Barbara Wagner, Judi Toth, and Mary Avery for donating items for auction. At least 50% of all items auctioned when to CHERUBS. If you would like to hold an auction in January or donate items, please contact Dawn at our main office.

## End of the Year Tax-Deductible Donations

It's that time of year again; to look forward to next year's tax preparation. Why not think ahead and donate to CHERUBS and add to next year's tax deductions? CHERUBS is an IRS 501(c)(3) recognized non-profit organization and all donations are tax-deductible. You can use the Fundraiser insert in this newsletter to make your donation, or use your credit at our secure on-line store on our web site.

more pictures out and left the room again. Only this time when she returned she told me that I needed to have a seat and see the doctor I knew something was wrong. After 10 minutes of waiting I was taken to the doctors office to 4 or 5 books on his desk and hear that he didn't know how to start with what was wrong and had to do some digging before telling me that my daughter had a Diaphragmatic Hernia (like I new what that was). I was also told that I wouldn't be seen at this office anymore because they were not prepared to deal with a condition they knew nothing about. I was seen at The hospital the Monday after Thanksgiving and went through more ultrasounds and a amniocentesis at the end of a very long day with more tests than I can remember I was told that if the amniocentesis showed any other defects that they would refuse to do anything to save the baby. Her hernia was so severe that they didn't think she had any lung at all on her right side and her heart was pushed into her back. At this time she was given a 10% survival rate. For the next 2 1/2 months I went to the hospital 3 times a week for stress test and more ultrasounds.

I guess I went through the normal stress and strain wondering if I had done something to cause this to happen to my baby. After 2 months of soul searching and finally believing the doctors I finally decided it wasn't my fault after all. Me and Shane (my son) decided that we needed to pick a name. After a lot of looking and listening, we heard a song and decided that it was our name so we finally had Angelia Danielle Crawford named after Richard Marx's "Angelia". I decided that if nothing else it would look nice on a head stone. At this point we were being told that her chances were now at 2%. Finally on January 23<sup>rd</sup> we were admitted into the hospital to have a c-section (my choice after already having one and not wanting to add stress) for the next morning. So on January 24, 1991, at 11:36am, Angelia was born. My mother got to see her first since I was under. I was awakened in the recovery room and tried to get up, only to be sedated again. I woke up in my room and found a picture taped to my bed. All the tubes and wires were hard to take. I went to see her about 3:00pm and was totally unprepared for the sight even though I had been in the NICU unit when I was about 8 1/2 months along. She was huge compared to my first child and it was hard to believe she was as sick as they said. On the foot of her bed was a sign that read ANGEL. I asked her nurse, Amy Vining, (my angel) who had told them her name. She said no one, they just decided as she was brought into the unit that she looked like an angel. I wonder sometimes if that was their way of telling me that they didn't think she would make it. As I went in to see her for the first time, I noticed that her feet were laying the wrong way. She also had clubfeet. At The hospital, up till this point, the surgery was done as soon as possible after birth, but her doctor, Dr. Shomer, (as close to God as anyone on this earth in my eyes) decided to wait for 3 days to give her a chance to gain her strength. So for 3 days we hoped and prayed that she would make it till her scheduled surgery date and then we prayed she would make it through surgery. She did, and thank God we never had to put her on ECMO. She was vent dependent for 2 weeks. Since I had her at the hospital and a c-section, I was a patient for 7 days. After I was discharged, I stayed with a Aunt and some cousins until she was moved into a room on the 5<sup>th</sup> floor. I moved into her room on February 4<sup>th</sup> and our siege began. As soon as she was put in a room her feet were cast up to her thighs and she started refluxing. Of course her doctors residents really didn't think she was so when they checked her cast because her toes were turning blue, she promptly refluxed in his face. Case closed about reflux. When Angel was 5 weeks old, I went back to the clinic and was told that I had cervical cancer and had to make some choices. Freeze the cervix and have it checked out every 6 months or I could have everything taken out. My choice was not to deal, so I had it taken out. At 2 months Angel had her 1<sup>st</sup> nissen and no help, well maybe for one week, then back to reflux. Angel had never nursed or had a bottle. As soon as you get in front of her face she would start refluxing. Actually she had projectile reflux with this. We were told not to handle her as every time she was moved (and even when she wasn't), she would start refluxing. In April I came down with a massive infection and was readmitted. She came down with pneumonia in May of 91 and at the same time one of the other babies on the floor beside us died. Stevie's mom, Denise, and I had become very close and this was hard on all of us. The day Stevie was viewed at the funeral home Angel had a night where she threw up blood and we called the resident on call to come check her and he was to busy in the PICU unit taking care of sick kids so I had a fit and insisted that her surgeon be called since his resident was to busy.

slowly came out of the depression and started to focus on my pregnancy. I was having problems. I had already started having contractions in my 5th month. I was, again, put on medication and semi-bedrest. July 31, 1996, 5 1/2 weeks early, Lacey Denise Evans was born weighing 5 lbs. 6 oz. She had some problems due to prematurity and she had to stay in the hospital a couple of weeks. We were so scared. The minute she was born, I said over and over, "please make her cry, please make her cry." I just knew that she was going to die. But, she did cry! She had to stay on a heart and breathing monitor for 6 months because she had apnea, but today she is a spoiled rotten, healthy 4 year old!

It took me 3 1/2 years to go through the grieving stages and come to acceptance. It took Shane a little longer than that, but he has made it. It was a lot of hard work and sometimes it seemed like I was going backwards. It was two steps forward, one step back! I still have bad days every now and then, but they are not as bad as they used to be. I thought that after so much time I would be OVER it by now. I now know that you NEVER get over it! You only learn how to live WITH it. You will never HEAL and it will never go away, you only learn to look at it from a different point of view. I am truly thankful for Shelton being born AND him dying. He taught me more in that short time than most people learn in their entire life. I wondered one day how someone knows if they have reached acceptance. I asked myself... if I could go back to that day and snap my fingers and Shelton would've lived, would I? The answer was "NO"! I later asked Shane the same question and he replied the same. I would still be taking life for granted, I would still be afraid of death, I would not know the true meaning of life and love and most importantly, I would not have the glorious, personal relationship with God that I have now. I wouldn't trade that for anything in the world! I no longer have the sense of loss. I know and feel that Shelton is with me everyday. He is not gone! He lives within ME! I had a video made of Shelton with the song 'The Dance' by Garth Brooks on it. It sums it up perfectly for me. 'I could've missed the pain but then I would've had to miss the dance'. And what a painfully beautiful dance it was!!! If you are reading this and you have lost a child- my heart goes out to you! I truly feel your pain. My prayer is that one day you will find peace and see the light within the darkness!

Shelly Evans (mom of Shelton Earl Evans, 9/16/95-9/17/95, Rt. 2 Box S-31, Killeen, TX 76542, 254-793-3039, SSPSLR@HOTMAIL.COM)

It was nice to hear from you again and see how much CHERUBS has grown since I last talked to you. So let's begin with Angel's story. First I guess that it is important to know that I am a single mother of two very special children. My first child Shane was born October 6 1991, other than being a preemie and only weighing 4 pounds 4 ounces he was normal and was in the hospital 5 days.

For my 31<sup>st</sup> birthday in June of 1990 I was delighted and hurt at the same time. I had developed blood poisoning and went to the local hospital ER room to be treated and before they started the treatment they did a pregnancy test. Much to my surprise with a 9 year old son and now very single I learned that we should expect a new baby probably in January to start a new year. My first visit to the doctor at less than 6 weeks to confirm the pregnancy I had a ultrasound there wasn't even a baby at this point just a yolk sack but I was very much pregnant and a little scared. One child at this point I thought was enough and Shane (my son) wasn't sure if he wanted a new baby brother or sister. All of my doctor's visits were normal and things were going great. I was getting very excited about having a new baby.

One week before Thanksgiving I had a ultrasound done at my request to try and determine what the sex of the baby would be. On the day of the ultrasound my mother and son were present and we were very excited about finding out what the baby would be. My son was amazed at the "railroad tracks" (spine) and then as the baby started turning and moving he was even more the only downfall was it's a girl. As the test progressed the technician finally stopped and spit out a roll of pictures and left the room. Thinking the test was done I proceeded to get dressed only to be told a few minutes later that in the excitement of showing my son and mother the baby that she had gotten the test in the wrong order. So we tried again and she spit

## 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, Greece, Hong Kong, India, Ireland, Israel, Italy, Mexico, The Netherlands, Norway, Oman, Pakistan, Papua New Guinea, Romania, 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. You do not have to be on-line to be a Representative. If you are interested, please contact our Volunteer Co-Coordinator for more details.

AREA	REPRESENTATIVE	PHONE#	AREA	REPRESENTATIVE	PHONE#
AL	Alicia O'Malley	(256) 389-8110	ND*	Elaine Moats	(406) 232-5038
AK	Renata Hoskins	(907) 245-8817	OH	Tara Hall	(614) 777-4906
AR*	Barb Wagner	(810) 249-5279	OK	Jeannette Davis	(405) 670-9937
CA	Jill Coon	(530) 582-1261	OR*	Heidi Forney	(208) 584-3708
CA	Shirley DeMercurio	(925) 439-8382	PA	Tammy Sincavage	(610) 796-7324
CO	Amanda Owen	(970) 246-3337	SC	Susan Grubb	(864) 877-1446
CT	Laura Webster	(203) 284-2199	SC	Vanessa Hutchinson	(843) 770-0109
DE	Susan Guariano	(302) 731-1922	SD*	Elaine Moats	(406) 232-5038
FL	Tammy Warr	(850) 235-9004	TN	Leigh Cheney	(615) 907-1301
GA	Annette Lichtenstein	(404) 325-2368	TX	Shelly Evans	(254) 793-3039
ID	Heidi Forney	(208) 584-3708	TX	Monica Nedrow	(817) 329-2402
KY*	Leigh Cheney	(615) 907-1301	VA	Elizabeth Doyle-Propst	(804) 293-4602
LA	Sheila Ezernack	(318) 645-9361	WA	Grace Massie	(360) 380-1266
ME	Teri Morse	(207) 538-4049	WV	Sharon Munson	(304) 947-7162
MD	Brenda Slavín	(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) 5135 6999
MS	Marsha McInnis	(601) 856-2831	Canada	Dawna Haines	(905) 852-4255
MO*	Barb Wagner	(810) 249-5279	Canada	Karen Jenkins	(905) 852-9410
MT	Elaine Moats	(406) 232-5038	Canada	Laurelle Lehmann	(250)-838-2250
NE*	Heidi Forney	(208) 584-3708	Germany*	Renata Hoskins	08123/990229
NH	Heidi Cadwell	(603) 878-2283	Great Britain	Kevin & Brenda Lane	01553 762884
NH	Lea Donahue	(603) 425-2639	New Zealand	Nikki Hodson	0064 4 5641333
NJ	Sophia Tucker	(908) 684-8701	Northern Ireland	Martin & Sinead Bear	01232 621486
NC*	Jeremy Torrence	(919) 692-1270	Norway	Victoria Serkland	47-359-41284

### On-Call Volunteers for Non-Survivors

On-Call Volunteer	Phone Number
Danielle Kessner (Australia)	(03) 9437 6778
Laurelle Lehmann (Canada)	(250) 838-2250
Amy Rademaker	(616) 844-4156
Kate Rogula	(313) 565-8722

### On-Call Volunteers for Survivors

On-Call Volunteer	Phone Number
Ann Peterson	(509) 735-7208
Grace Ore	(814) 833-6421
Lea Donahue	(219) 289-5746
Heidi Forney	(208) 584-3708
Jill Coon	(530) 582-1261
Tara Hall	(614) 777-4906
Elaine Moats	(406) 232-5038

## Stories of Cherubs

Amanda is getting ready to celebrate her 12th birthday on September 20. It is hard to believe that she will be 12! Amanda was a full term baby. I had no problems with my pregnancy. I had an ultrasound at 9 weeks only. At that time, there was only one ultrasound done unless complications arose. When I delivered my 8lb 2oz baby girl, she did not breathe the way the doctor expected. She was removed immediately and placed on a table where I watched the nurses and doctors do CPR. She was taken to the intensive care unit. Two hours later, we received the news.....Amanda had a hernia in her diaphragm.....My husband broke the news to me. He had spent the last two hours in the intensive care unit watching her closely. I laid in the recovery room with my mother. All I could do was pray. Prayer saved her life. Being Christian, we decided to have her baptized that night. It was so important to me that she receive that sacrament, as I felt this would help pull her through. She was given a 10% chance of survival. She was taken to Children's hospital. We were told that she had to be stabilized prior to her surgery. My husband went with her to the hospital and made sure she was ok. She did well once on oxygen, and IV's. I was given a Polaroid picture of her which did not leave my side. I remember hearing other babies in the hospital crying. I would cringe at the sound. I wanted so badly to be with her and hear her cry. When I was discharged, I went immediately to her. Her surgeon was pleased with her birth weight, and was hopeful that this would pull her through. She had surgery to repair the hernia, which took about 2 hours. This was the longest 2 hours. The pain I felt knowing my baby was fighting for her life was unbearable. The doctor said she did well, and had that "piece" of a lung, which is what she needed to survive. I visited her constantly. I cherished the time I could hold her hand and sing to her. I reassured her every minute I could that I loved her. My sister gave me a tape recording of her piano music. I kept it with Amanda and the nurses would play the music throughout the days. There was no "night" on the unit.....it was always the same. We got to know many of the other parents on the unit, and watched each one take their baby home. We longed to take her home. She was progressing well at the hospital, and after a small "back slide", she was discharged in 3 weeks. About 3 days prior to her discharge, I became worried about nursing her. I had diligently prepared myself for this gift of love, but was realistic that she possibly would not latch on. After one "not so pleasant" try, she latched on, and nursed successfully for several months.

I remember the nurses telling me that most of the children with this birth defect are lucky to survive, and they were amazed that she was discharged so healthy only 3 weeks later. I was just glad to have her home. I remember getting up all night long and making sure she was still breathing. After she was older, we put her in her bedroom with a baby monitor. I would lay there in bed with the monitor next to my ear, listening at her every breath. I would wake up out of a dead sleep if she coughed or took a long breath. She had several episodes of wheezing which landed her in the hospital frequently, but seemed to be doing well. Her development initially was delayed. She had problems with sitting up on her own. The doctor said this was because of the nerves and muscles that were injured during the surgery. However, at her 1st birthday, she was beginning to stand and walk. She was precious and the joy of our life.

Her next 3 years were rough. At her checkup when she was 2 1/2 years old, the doctor was concerned that her reflux was too active. She had several tests done, and 6 months later, and 7 hospitalizations later, she was admitted to Children's for a surgery called a Nissen. This surgery was far more complicated and required a longer recuperation time, but we noticed a significant difference in her about 2 months after the surgery. The doctor informed us that sometimes with a diaphragmatic hernia, there is problems with the reflux muscle, and that is why she needed the surgery. By the time she was 3 1/2 years old, and 6 months into recovery, she was successfully putting on weight, and looked the healthiest ever. She had 10 hospitalizations during the first 3 years of her young life. Most of these were related to the asthma that took over as a reaction to the weak left lung, and the damage from the reflux acid.

These 7 years in school have not been problem free. It is hard for her to ignore the comments about the scars that children have seen over the years at gym class, swimming pools, slumber parties, etc. I did every thing I could to prevent these things from happening, but they do. She also has a very active bowel. When she has to go, don't have her wait until recess is over!! All the teachers

was going in that box to be put into the ground. This was inconceivable. Shane was anxious to get home to Peyton. So, we went home and slept. That first night was terrible. I couldn't sleep. I would lay there staring at his cradle with all of his stuff in it, waiting for him. We had everything but the baby! I finally had woke Shane up and told him to take it out of our room and put it in his room. The next day I went "shopping" for the perfect outfit and Shane went "shopping" for the perfect burial plot. I picked out the cutest outfit. It was blue and white and had "Thank Heaven For Little Boys" on it. I got a preemie size so it would fit him. I was so used to buying for Peyton that I immediately picked up the bigger size. Then I realized that he didn't need growing room. The lady at the counter went on and on about how cute and small it was. I wonder what she would've said if she knew that it was to bury my baby in. My sister and I took the outfit to the funeral home. I wanted to see him, but he said that they weren't "done" with him yet. He said that I really needed to get a bonnet for him because he had a bad spot where they tried to put an IV in his head. I told him that we had all seen it and I didn't care. He looked perfect to me. We went back later to see him. Me and Shane went in first. Shane finally broke down. This was too much to bare. The next day we went to the funeral home before the funeral. They told me that it was time to go and I couldn't leave. I laid my head on his chest and cried out to God. I knew that this would be the last time I would see or touch him. I guess it's a good thing that they pulled me away because I would still be there today. The funeral and the days that followed were a complete blur. A week later I met my sister in town to have my niece's pictures taken and to take back some of the baby things that I hadn't opened. I went and looked at all of the baby stuff and when I went to the photo place there was a woman with a newborn baby. I just stood there staring at him. I wanted to take him and run. Just to hold and touch a baby seemed like Heaven. I realized that I was standing there crying and I hoped that woman had not seen me because she would've thought that I was crazy. Maybe I was. My sister was going to come to my house but she had a couple of stops to make first. I went straight to the cemetery. I guess she knew the shape I was in because she came there, too. When she got there I was laying on his grave bawling. I had my hands dug into the fresh dirt and ants were crawling all over me. As she sat there rubbing my back, I realized that this was too much to handle. I stopped crying, stood up and went back to my car. A few weeks later I got a job and kept myself busy. I did really good, too. I could talk about it with no problem. It happened to someone else-not me. I joined a support group at the Ronald McDonald House. All of these parents were so emotional and depressed. I started to feel guilty because I didn't feel like this. Did that mean that I didn't love Shelton as much as they loved their's? Two months later I found out that I was pregnant again. We had been trying. I said the day of Shelton's funeral that I wanted another one. Everyone told me, "You don't know what your doing! You need to wait." I told them that I wanted a baby when Shelton died and just because he died, that didn't mean I didn't still want one. I was so happy. I just knew it was going to be another boy. I had even contemplated naming him Shelton because I loved that name so much. We had our 1st ultrasound with a specialist and they told me that it was a girl. I started crying. I wanted a boy! Then it dawned on me what I was doing. I was unconsciously trying to replace him. I wanted to do it over and pretend that it never happened. After I told my boss that I was pregnant, she fired me. She didn't say that, that was the reason, but I know it was. I was the bookkeeper and she depended on me. I guess she thought that I couldn't do that being pregnant. Depression began to seep in. I didn't have anything to keep me busy anymore. I couldn't run anymore. I didn't want to get out of bed. I didn't eat. I didn't even want to take care of Peyton. He ate hot dogs or cheese, anything he could get himself. I slipped deeper and deeper each day. I wanted to die. I would pray to God everyday not to let me wake up. I didn't care about anything. I just wanted my son back. I would sit for hours holding his clothes, smelling them, trying to go back in time. Shane would come in and get mad because I didn't do anything around the house. He told me that he was going to admit me somewhere if I didn't snap out of it. I had a family to take care of. He didn't like to see me upset because that made him think about it and he didn't want to. He was still running. I finally hit bottom one day and called a therapist. I didn't know what else to do. I felt like I was going crazy. I couldn't control my emotions, I didn't care about anything and I cried continuously. After many weeks of therapy and the support of the Ronald McDonald House, I

start going off. They would tell me not to stimulate him too much. What a strange word for love. I wanted to rip all of those needles and tubes off of him, but instead I had to settle for rubbing his foot, and now I am told that this was too much. Shelton's stability rose and fell through the night. That was the longest night of my life! Shane told me that I needed to prepare myself in case he didn't survive. I told him to "stuff it", he was going to be just fine. Don't you love denial? Shane wouldn't go in to see him anymore. He was preparing himself for the worst. Shelton continued to deteriorate. His Dr. called the Santa Rosa Children's in San Antonio and consulted with the head neonatologist. They have a treatment there called ECMO. (Extra Corporeal Membrane Oxygenation) This machine would oxygenate his blood for him to take the strain off of his lungs and allow them to mature. In order to transfer him there, we had to make sure that he was strong enough to make the move. They performed an ECG and an EEG. His EEG came out fine. No brain damage. But, they thought they saw a problem on his ECG. They called in a specialist to confirm. The specialist arrived around 3am. We went in with Shelton while he performed a more advanced ECG. The Dr. showed no emotion through the procedure. When he was done, he explained to us that the right side of Shelton's heart looked fine. However, on the left side he detected a closure in his aorta. This is called Coarction of the Aorta. While he was going through the medical jargon of this condition, I was staring at my beautiful son. We were in a different world. Just me and him, as it should be. I felt tears begin to stream down my face. Reality was setting in! How could this be? This was not real! This was a nightmare and any minute I would wake up. We returned to the waiting room while the two Dr.'s talked about our options. The neonatologist called Santa Rosa and explained the situation. The head Dr. there said that a baby born with CDH and any associated heart defect had a 100% mortality rate! I will never forget those words. He then told Shane and I our options. We could leave him on the ventilator and he might survive 3 days or we could take him off and let him go. I asked him, "either way, would we be delaying the inevitable?" He said, "yes!". So, we made the hardest decision of our lives. We chose to take him off of the vent. His Dr. asked us if we wanted to be there when he was removed. He said that if it were him, he came into this world with his parents and he would want to leave it with his parents. Shane said that he did not want to be there. I said that I wanted to. I could not pass up the first and last chance to hold my son. They brought in a rocking chair, with a pillow to sit on, in for me and they put up privacy screens up around us. My mom, my sister, my mother-in-law, my sister-in-law and me were there. I sat in the chair and they quickly unhooked him and placed him in my lap. He had been heavily sedated after surgery. There was no movement, no last breath. The nurse checked his vitals to determine a time of death and asked me if we wanted an autopsy done. She said that if we did that they would have to leave the tubes in. I don't know why that is, but I said, "no". I wanted all of the needles and tubes off of him right now. It was very silent and peaceful. I immediately brought him to my face. I wanted to take in every inch of him. I was transported to another place. A place where I had a beautiful, healthy son, a place where I took him home the next day and showed him his room, fed him, bathed him, loved him. A place where babies don't die! I unwrapped him from his blanket. I looked at every inch. I counted his fingers and toes. They were all there. They were all perfect. How could he look so perfect and have so much wrong on the inside? He was beautiful. His hair was brown like his Daddy's and it felt like silk. He had my nose, which I got from my mom. He had my feet and toes. He looked like his Daddy when he was a baby. Everyone took turns holding him. I asked them to find Shane and send him in, but they couldn't. He was doing laps around the hospital. I did learn later that he stood at the NICU door and watched me holding him through the glass. After everyone was done I held him for a few more minutes. I stood up, and handed him to the nurse. She said that she'd clean him up for us. I turned and walked out without looking back. This haunts me to this day. I never turned to get one more look, see where she took him or kiss him one last time. I think I thought, in my mind, that if I turned around I would grab him and run and never look back. We left the hospital with an empty, hopelessness. It was as if he were still at the hospital and we just had to go pick him up later. We went straight to the funeral home to make the arrangements. I did OK until they brought in a casket to show us. I lost it! I will never forget the look on that man's face. He felt awful. He just turned around and took it right back out. There was no way that my baby

were informed each year of her need to be excused to the bathroom at any time. They were cooperative, until a substitute teacher was there. I remember Amanda being humiliated because she needed to go to the bathroom, but had to wait until "time". Well, it didn't work. Another problem she has had is gym class. She was responsible to learn a "back bridge". When she did this, it pulled every muscle in her abdomen. We ended up at the ER, and several days later, after many tests, it was determined that she would be fine. To this day, she does not do this exercise.

I believe that my daughter is a walking miracle, and we have been blessed with her love. She hopes to someday be a teacher for disabled children. I believe that her heart is big enough to handle this challenge. She is nurturing, and loving and patient. The world is lucky to have her in it.

Her name is Amanda, which means "deserving of love".....and that she is.

Theresa Bracher (mom of Amanda Bracher, 9/20/88, 85 Fawn Drive, Harrison, OH 45030, 513-202-0510, tbracher@cinci.rr.com)



My name is Catherine Taylor and I'm a mum. It seems funny to say that when I've never changed a nappy or had to get up in the middle of the night to that all familiar cry, but six months ago I did become a mother for the first time. My baby is a little girl and her name is Mersayd.

We discovered our precious angel had CDH at six months in utero. To say my husband and I were shocked at this diagnosis is an understatement. To be told that your baby has an abnormality is just not something you expect to hear! That happens to other people not us!! My first reaction was guilt – "what have I done?" but we were reassured that it was "just one of those things.". With this diagnoses I was immediately referred to a specialist in Tauranga and then an Obstetrician in Hamilton. The next few months were a blur of more scans and check-ups. We were told that our baby had a 50/50 chance of survival but I was determined to be positive and I did not want Mersayd to feel any bad vibes. I think back now to that time and wonder if I may have been a bit naive but I truly and honestly did not expect Mersayd to die. I bought everything. The nursery was complete. The drawers were full. The crib was ready.

The obstetrician gave us the option of induction or c-section at 38 weeks but Craig and I decided that the less stress on Mersayd the better, so we chose the c-section.

The big day arrived and I was scared. After a sleepless night we arrived at the hospital but were told due to unexpected complications with another newborn, Mersayd's arrival was to be postponed. I felt so relieved.

Craig and I wondered, with this turn of events, what to do next! We decided to have a bit of fun, so the three of us had a trip to the Hamilton Zoo. We had a great day. I have always believed things happen for a reason and I truly believe we were given that extra day to spend with Mersayd. It is a special day I will never forget and I hope we can visit the zoo again on Mersayd's anniversary.

The next morning I was feeling allot more relaxed as I lay on the operating table (maybe it was the drugs!). There were so many doctors and nurses in theatre - some to assist me but most waiting for the big arrival of Mersayd. As soon as she was born I remember her sailing past me and onto the OHIO table. She was immediately intubated and whisked away to the NICU accompanied by her Dad.

I was stitched up and taken back to the recovery room. Craig joined me with Polaroid's of Mersayd. He informed me things weren't good. I refused to believe it.

A couple of hours passed. The Paediatrician came to see me with the bad news. The hernia was far worse than predicted. Mersayd's lungs were tiny nodules and one had ruptured.

Numb with shock I was pumped full of morphine and wheeled up to see my wee fighter for the first time. I know all parents think their babies are beautiful but mine truly was. Except for all the lines and tubes attached to her; Mersayd looked like any other healthy, bonny bundle. She looked peaceful. It was hard to believe she had only moments to live. One of the nurses asked me if I would like to hold Mersayd and I said yes. She was placed gently in my arms. I have never been one for babies but I felt so confident holding her. It felt right.

I didn't cry when Mersayd died. I feel guilty about that but I think I must have been in shock. The reality of the situation didn't really hit me till a few days later.

If someone had told me a year ago I would be planning my baby's funeral I wouldn't have believed it. But here we were sorting out readings and music to be played. We chose 'The Power of Love' by Celine Dion, 'Angel Song' (my favourite) by Sarah MacLaughlan and 'Whenever God Shines His Light' by Van Morrison. We decided to not only have a service to say farewell but to also celebrate a life that although short; touched so many. We also let everyone there release a pink or silver balloon at the cemetery as a final goodbye. It was such a terribly sad day.

So now six months on not a day goes by when I don't think about Mersayd. I wonder does she know how much we all love her and how truly wanted she was? I feel envious when I see other mothers with their babies. I hope they know how lucky they are.

To lose a child, especially one that has not had a chance to experience life is hard. There is no one to tell you why this has happened or when the grief will pass. I have since joined SANDS and that has helped. I have found talking about Mersayd is the best therapy. Craig and I have also had lots of support from our family and close friends. Even strangers have shown genuine concern and great kindness.

But still, I wake up every morning missing my baby and wondering 'what if?' and 'why us?'. But still, tears come to my eyes at the mention of her name. But still, most of all, I can't forget I am a Mother.

Catherine Taylor (mom of Mersayd Margaret Taylor, 3/30/00-3/30/00, 8 Connell Street, Waihi 3061, New Zealand, 64 7 8637334, francesca.l@merseymail.com)



My husband and I were thrilled and giddy when we discovered I was pregnant June 1999. My pregnancy was a fairly kind one—my first trimester, marked by mild nausea and extreme fatigue but no sickness. My second trimester was great, although I never felt my baby move as much as I thought I would. By my third trimester, his lack of major movement was a great concern to my mom, who is also a labor and delivery nurse. I believed he was simply a calm baby, but the soon-to-be grandma wanted me to have non-stress tests every week to monitor my baby boy. The strips were always acceptable but not great, so I went to see a perinatologist. After he did a detailed ultrasound, it appeared that our baby had a double-nuchal cord, meaning his cord was wrapped around his neck twice, so it was decided that I should just be monitored twice a week. At 37 weeks gestation, I had

an amniocentesis test to determine the baby's lung maturity. They were very mature, so the doctor decided to induce me 3 weeks early, just to be safe.

I labored fairly quickly, despite being induced, and the delivery went very well. Surprisingly, the cord was not a problem at all during labor and delivery. When he came out, the cord had loosened itself and was very limply wrapped only once around his neck. He weighed 5 pounds, 9 ounces, and was the most perfect, beautiful baby. We named him Connor Ryan--Ryan after his daddy, and Connor, so he would have his mommy's initials. Already I loved him immensely. As we held our precious, tiny blessing, we wondered what all the fuss had been about. We wouldn't know until a few weeks later, that all the worry and precautions resulting in an early induction, would prove life saving and miraculous.



Five years ago, God blessed me with an angel. This is his story! My husband, Shane, and I wanted our children to be 2 years apart. So, after the birth of our first son, Peyton, we waited one year and started trying to conceive. Much to our surprise, I was pregnant within 2 months. I had a very uneventful pregnancy and we assumed that we would have another beautiful, healthy child. We had an ultrasound and found out that we were having another boy. So, we started planning for Peyton's little brother's arrival. Then in my 31st week of pregnancy, I went into premature labor. I really

wasn't too concerned. My doctor seemed more concerned than I was. The third day I was in the hospital, I was using the good old bedpan and I lost my mucus plug. It was then that I realized how serious this was. I didn't really feel like I was in labor. It's a wonder what drugs can do! However, I had dilated to 3 1/2 cm. I was in the hospital for a week and we finally got the contractions stopped. I was sent home on medication and bedrest. My step-mom came to help out with Peyton. Shane works out of state putting in natural gas pipelines. So, I was in desperate need of help. Things clicked along fine and we scheduled my baby shower for September 16, 1995. I went to see my Dr. on the 15th. He said that he thought I'd have to have my shower at the hospital. I said, "Yeah, right!" We took Peyton to McDonald's and when I went to the restroom, I started spotting. We went to tell my sister so that she could come stay the night with me "in case". We stayed up until 2am waiting. Nothing happened. I woke up at 5am to go to the restroom and my water broke. I immediately called Shane and we headed for the hospital. The pain was much worse than with Peyton. I literally thought I was going to die. I remember my nurse making a comment about how much the baby had hiccups when I was in labor. I asked her why unborn babies got hiccups. I had always thought that it was an air bubble in your diaphragm and they don't breathe air. She said that it's not necessarily air, it's just a disruption in your diaphragm. I told her that he had hiccups more than he didn't. He had them 11 times just while I was in labor! At 2:19pm, after much screaming, Shelton Earl Evans was born into this world, weighing 5 lbs. 12 oz. and 18 3/4 in. long. Needless to say, I didn't make my shower. I was in too much pain to notice that he wasn't crying. His nurse gave him a shot to "wake" him up. They thought he might be reacting to the Stadol I had during labor. It didn't work. After what seemed like hours, they began CPR on him. The nurses asked everyone to leave the room. After a few minutes of this, they wheeled him out of the room to the nursery. I really didn't know what was going on. Awhile later, my nurse came into the room crying. She told me that I had a very sick little boy. Then, my Dr. came in to explain to me that they had done a chest x-ray on Shelton and found that he had a condition called Congenital Diaphragmatic Hernia. This is a hole in the diaphragm. During pregnancy, vital organs and intestines slip up through the hole into the chest cavity and this prevents the baby's lungs from developing. He said that they needed to transfer him to Seton Hospital in Austin so that he could have surgery immediately. While he was explaining this, Shane arrived. I'll never forget the look on his face. He thought I had, had the baby but he didn't see him anywhere and I didn't look pregnant anymore. He looked around very confused. Then we explained to him the situation. They let us go in and see Shelton for a couple of minutes before they transferred him. (This was the only time I saw him with his eyes open and for the life of me, I can't remember it.) When we arrived at Seton, the surgeon came out to explain the surgery to us. They would make an incision and put everything back in its place. They were hoping the hole would be small enough to stitch closed, but if it wasn't they would have to use a synthetic patch to close it. He was in surgery for 5 hours. The surgery went well. His intestines and his liver were inside the chest cavity. Needless to say, they had to use a gortex patch to close the hole. When we went in to see him, I couldn't believe my eyes. He had tubes and needles covering every inch of his tiny body. I could only touch his head or his foot. Sometimes when I would go in to see him I would be rubbing his tiny feet and the alarms would

They prepared me nice & early at 6.00am on 20<sup>th</sup> January, 1999 and started me on drip. At 11.30 the waters broke and how!!! The entire room was flooded- maybe 5 litres, maybe more.☺ After a smooth 38 weeks of pregnancy, 5 ultrasounds, I was blessed with a very sick baby boy on 20<sup>th</sup> January, 1999 after an emergency C-section (non-progression of labour and lower segment distention). I was not given the epidural I'd feebly requested so was totally out when this tiny guy got into my life! How I wish I'd insisted on an epidural but then again, that's the way things were on that fine day. He was born 21" and over 8 and ½ pounds and the Apgars were 6 and 8 at 1/5 minutes and I am told that he was a big pink baby - no hint of blueness. He had a whimper of a cry for such a big baby and the heart was heard much better on the right than the left. I was told by other medical professionals that both these factors COULD have been overlooked as the baby 'appeared' healthy. Thank God that they were not! Enter our hero-Dr. Vivek Bagga, the Pediatric Consultant, who immediately rushed out to where my anxious husband and Mother were waiting and shared his fears. He asked for an immediate X-ray. Immediately, he shared the options available with my husband and once the pediatric surgeon was decided upon, he took it upon himself to contact the surgeon and asked him to come over and see whether the child was OK for surgery. Is it any wonder then, that we love that doctor?! In an hour, Dr. B.D. Dwivedi, a highly experienced and skilled Pediatric Surgeon, examined him and gave a fair prognosis. He was taken to the Indraprastha Apollo Hospital in an ambulance by my husband where a team was waiting for him. The immediate problem was the tremendous pulmonary hypertension (PPHN). He also suffered a few internal bleeds, though I'm not too sure if they were spontaneous internal hemorrhages or those triggered by some not so clean aspiration efforts. In addition to the High frequency oscillating ventilation, he received dopamine and dobutamine for the PPHN and antibiotics, morphine and painkillers for infection and pain management. There is, no NO used in India, at least for neonates. ECMO is still considered an exotic thing in India and the cost involved (in terms of the arteries sacrificed) is touted as the medical reason against the use of ECMO by the medical practitioners.

His surgical repair was performed on the morning of 23<sup>rd</sup> January, and he followed a textbook recovery. He was extubated on the 26<sup>th</sup> and was off oxygen on 27<sup>th</sup> night itself. I saw my baby only on the afternoon of the 23<sup>rd</sup> - I realized that I had been lucky enough to witness one of His miracles and that no power on earth could have stopped my son's life as he was divinely blessed! BTW, that's what Anugrah means- a divine blessing! Then came the next battle- of feeding him, warding off post-op infections and ensuring that he put on some weight before being discharged. The neonatologists, Drs. Sushma Kaul, Vidya Gupta and Anjali Kulkarni were extremely positive I moved into the hospital on the 27<sup>th</sup> and was glad that the EBM was being used to feed the baby thru' his NG tube. All through the preceding days I'd been manually expressing and wasting all the precious milk, which was meant for my baby. He tolerated these feeds quite well. Breast-feeding was extremely difficult to establish because my primary engorgement made me hard and holding the baby with a drainage tube, plus scores of other tubes running this way & that was extremely difficult. He would get frustrated with my attempts at feeding him and would cry till his UAC started bleeding. I was extremely helpless and didn't want to continue with what was a torture for all concerned. Thank God, Dr. Gupta intervened and offered a bottle for the EBM. It was an extremely trying time. Once a fungal growth was suspected in a blood sample and they wanted to do a dural tap for CSF. I was asked to sign the form for it and boy o' boy, did I get into the mom from hell mode! (I came upon this perfectly apt phrase much later, thanks to Dawn) The Registrar, Dr. Krishnan (God bless him!) spent an hour trying to reassure me that he would do a clean tap and not fool around with my son's Cerebro-Spinal Fluid. Soon the neonatologists were joking that with his increasing weight he should be in PICU not NICU! To cut a long story short, by the grace of God and thanks to the tremendous faith & support of all those around us, I went back home, with a baby, on 8<sup>th</sup> February, 1999. The major factors for his survival appear to be: full-term growth, good birth weight, late herniation and immediate detection of what was a huge defect. Anugrah is a really happy little kid with no feeding issues or developmental delays. The pectus seems to be resolving and there is no indication of scoliosis in spite of his terrible bowlegs.

Shankura Murali (mom of Anugrah Murali, 1/20/99, 184 Munirka Enclave, New Delhi 110067, India, 6164934, shankari\_murali@hotmail.com)

At almost 3 weeks old, Connor attended his very first Church meeting. We left early because Connor had been spitting up bile that past week and had been doing it again Sunday morning. I had called the doctor earlier in the week when he began spitting up bile, and the doctor said it was normal and not to worry unless he seemed sick in other ways. Connor had also started bobbing his head up and down when he breathed, but not all the time. When I mentioned it to the doctor, he listened to his chest sounds and decided the head bobbing must simply be one of those unusual infant reflexes. But Sunday night, Connor spit up some bile and couldn't stop gagging afterwards. I waited for it to stop as it usually did, but he kept gagging, struggling to catch his breath. Ryan called the doctor-on-call but had to leave our number on his pager. As Connor went paler and looked more and more helpless, I knew we couldn't wait for the doctor to call us back. We rushed to the emergency room.

The triage nurse took him back immediately, and doctors and nurses swarmed to the room, giving him oxygen and calling for tests and x-rays. My mom was at work on the 5<sup>th</sup> floor, so I called her down to be with us. When the chest x-ray returned, we heard the words, "diaphragmatic hernia" and "life-flight to Primary Children's." I saw my mother's face go white and her jaw drop. Suddenly, we realized with dreadful horror how severe the situation was. I began sobbing into my husband's arm. When I pulled away and looked at him, I realized he, too, my non-emotional husband, had tears streaming down his face.

Within the hour, the helicopter from Primary Children's Medical Center had arrived, and we were getting ready to drive up ourselves. By the time we arrived at the hospital, Connor had already been taken into surgery. We had to wait four long hours for the surgery to be complete.

When the surgeon entered the hospice room in which we had been resting, my weary body jumped up and my heavy eyes tried to focus on his words. He said that Connor's diaphragm most likely had a weakness in utero, which after he was born became a hole in the right side of his diaphragm. His intestines, as well as part of his liver, had floated up into the hole, pushing aside the lungs and heart, making it difficult for him to breathe and digest properly. His liver was transverse, and the surgeon wondered if other organs might be flip-flopped. The surgeon explained how he brought down the intestines and liver and placed them back where they belong. He also took some muscle tissue and repaired the hole in his diaphragm. He also noticed Connor had an extra appendix, which he removed along with his regular appendix. The surgeon, like all the other doctors and nurses, was shocked to see a diaphragmatic hernia in a 3-week old infant. We were blessed that Connor came early and was able to expand his lungs before his hernia became a serious problem. Now, Connor faced the recovery process, which we were told could take anywhere from 1 week to 1 month at the hospital.

When we were finally allowed to see Connor, he no longer looked like the picture of a perfect healthy baby we had brought home from the hospital the first time. He had a tube up his nose that went into and emptied his stomach. He had a ventilator tube in his mouth and a chest tube near his surgical site, emptying it. He was bandaged and had a few IVs. He had monitors taped to his body to monitor his breathing, his oxygen intake, and his heart rate. Again, tears streamed down my face to see my angel in this life-threatening condition.

But through all these tears and whirling emotions, I felt an unexplainable peace. I knew my precious baby would recover. Now he is 9 months old and the cutest baby boy. The doctor believes Connor had some developmental problems in utero on the right side only, because he also has an undescended right testicle and a smaller right leg and foot, only noticeable if closely observed. But his smile lights up any room, and we're so grateful to have him in our lives.

Christy Stevenson (mom of Connor Ryan Stevenson, 1/31/00, 139 Danada Dr., Wheaton, IL 60187, 630-462-6714, stvensonfamily96@yahoo.com)

As Rob and I rushed to the hospital I'm sure we were thinking of how hard it would be when we came back home with a newborn. When Candace was born we had no idea how hard.

Candace was born with a right CDH. She was born by C-Section and right off the bat she wasn't breathing on her own. That's when they told us what was wrong. It was explained to us a total of a million times, but we were in a daze. Once she was in the children's hospital things went from bad to worse.

For a week after the hernia surgery she was touch and go. Her lungs looked like a doily. The worst day of our lives came when they told us that she wouldn't live through the day unless they put Candace on ECMO. For two weeks she stayed on ECMO with no residuals.(unbelievable). This was the worst time I think out of everything. Gradually she got stronger and moved up to the ward room where we could actually stay in the room with her overnight. We had our ups and downs over the next 5 months but we eventually got home. This in itself is it's own turmoil, but it is so much nicer. Candace had a feeding tube about a year and a half ago but at three and a half is now eating what we are (a completely different struggle)and going to school. Her doctors are still amazed that this ECMO baby has made it this far. She is an amazing little cherub.

Rob and Leanne Reeves (parents of Candace Reeves 12/20/97, 1 Dean Park Road, Apt.1103, Scarborough, ON, M1B 2W5, Canada, 416-282-6303, Notes\_shortname@ca.ibm.com)

On July 26th, 2000 my son Dominic was born. He was one month early and born by c-section because he was breech. During my pregnancy I had no idea that he had CDH until the doctor had done a chest x-ray because of respiratory distress. Fortunately, he was healthy in spite of the defect. One week later he had his surgery and it was determined that it was on his left side and the hole was small and his left lung was a good size. After the surgery we almost lost him because of pneumonia that had set in. He has been on the road to recovery ever since. The only set back he has had is that he has been intubated 4 times because of swollen vocal cords and trachea. He has been in the hospital for two months now and is progressing at a rapid rate of speed. He's been extubated for almost a week now with the help of steroids and respiratory meds. He's acting like almost any other 2 month old and developing his own personality. He will need physical therapy for his motor skills because of being under sedation for so long and from being in the hospital. We are hoping that he will be home soon in time for his first Halloween.

Rachele Alessandrini (mom of Dominic Joseph Reitz, 7/26/00, 112a Hemlock Court H-12, Park Forest, IL 60466, 708-283-9006, diamondtux@core.com)



My name is Ann Lennon, I am 33 years of age and I am Irish. I had a baby boy called Darragh born with C.D.H. on the 13<sup>th</sup> of May, 00. Unfortunately he died 11 hours after birth. And this is my story.

Well I had been seeing someone for a few months, it was not that serious and we broke up. That was okay but about two months later I realized I had not had my period for a while so I did a test not thinking that I would be pregnant but I was. I had no idea how far on I was, so I went to the doctor and she confirmed it, I was then given an appointment for a scan to determine my due date.

Well I had four weeks to get used to the idea and to tell everyone of my news and slowly I started to get used to the idea. I then decided that I would raise the baby alone with the help of my family; the father of Darragh was from a different area so he did not have to know unless I told him. Well by the time I had my scan I was so happy about my baby, I realised that this was going to be the best thing that ever happened to me. I was very financially secure. And I felt that I did not need anyone, it was just the baby and I all the way. I was so happy.

The day of my scan they took down all my details listened to his heart beat, confirmed that I was 15 weeks pregnant and the baby and I was doing fine. I never had morning sickness or needed to take iron I was so healthy and blooming. And my baby was to be born on the 2<sup>nd</sup> of May 2000. What a brilliant new Millennium.

At 2 years old Jeffery started having problems with his esophagus. He had reflux problems. They put him on medicine, then at 3 years old he had to have an endoscopy. At 4 years old he had a hydrocele, so they operated again. Then at 4 he had another endoscopy and he stayed on medication for his reflux for 2 years.

Jeffery has been on and off medications for his reflux for most of his life. He also uses a nebulizer when he gets colds. At 9 years old he had another endoscopy and another operation to correct cartilage he had protruding out of an area below his chest.

Jeffery has played baseball, basketball and soccer. He does have learning disabilities but he tries real hard at whatever he does. He will be 11 years old November 1, 2000 and we are very proud of him. He has a sister Alyssa who is 5 years old and born very healthy. Alyssa adores her brother. Jeffery also has a very special surgeon who has been in his life since before birth. He now sees Jeffery once a year.

Wayne & Sabrina Durrigan (parents of Jeffery Ronald Durrigan, 11/1/89, 241 N. Sterling Rd, Sterling, CT 06377, 860-564-1226, briway87@aol.com)



Hi! Finally, here I am writing my miraculous cherub, Anugrah's story! As I often find myself saying, this is my miracle baby. The miracle seems to have begun real early. Everything about his birth was miraculous- in that I hadn't even planned on his being born! I was quite upset when I was late. A quick lab-test after two weeks and my fears were confirmed. Amled across to a Doc, and she casually mentioned a MTP. Yes, those of you who may be wondering, a Medical

Termination of Pregnancy is quite a routine method of birth control in India! I was outraged at the terrible suggestion and within moments was determined to go ahead with the pregnancy, whatever it entailed.

Of course, it didn't help that my husband was away for the first 6 weeks of this pregnancy. Those crucial 6<sup>th</sup> to 8<sup>th</sup> weeks of gestation was just when I was trying to come to terms with the fact that there would be another baby. And while I did feel tender and protective about the baby, I was rather embarrassed as I began to show too soon. The terrible nausea did nothing to help! But I was extremely regular about Folic acid and my diet comprised more or less fully of cherries, pears, salads and other such light stuff, which I was able to eat. Being a non-smoker and teetotaler, I had no fears of exposing the foetus to any noxious substance and just wanted to increase my hemoglobin levels, get adequate proteins and calcium and NOT get stressed about anything. By the fifth month I was huge (no polyhydramnios - just BIG) and the movements began. My daughter enjoyed the tiny movements and began looking forward to her sister! In the 38<sup>th</sup> week, I was huge and uncomfortable but going about all my work as usual. I was determined to work till the very last day but was so HUGE that I was making a lot of people quite uncomfortable by going about my work. The routine U/S at the 38<sup>th</sup> week showed a fully developed large breech foetus, head not yet fixed, nearly 4.00 kilograms and suddenly, unusual polyhydramnios. The radiologist appeared quite agitated and felt I needed to be induced IMMEDIATELY. Needless to say, I had high regard for his views. It was late evening and we rushed to my Doc, Dr. Saroj Aron. She is a nice gentle lady and wanted a trial of labour. She asked me to go in for yet another U/S (my fifth) on Monday, the 18<sup>th</sup> January, 2000 to assess the approx. fundal height and weight, to be performed in the hospital where I was registered. The radiologist, a senior and experienced person was very thorough. He was clear that it was a big baby, the breech resolved but brachycephalic and ready to be induced. He also confirmed the polyhydramnios and was warming up to the shadow in the pulmonary region when my Doctor, who was present throughout, intervened and whisked me off. I was very unhappy that this radiologist was seeking some abnormality where none existed (how naïve, I was).

was on his right side of his chest so they took an x-ray. All his intestines were up in his chest cavity, where his lungs were supposed to be. We never got to hold Colton that day. They took him by life flight to Children's Hospital of Pittsburgh. They practiced with ECMO there and that is what he needed. He was on ECMO for a long time. Longer than they like you to be. They did his surgery to repair the diaphragmatic hernia while he was on ECMO.

The surgery went well but his little body was not able to get off ECMO. His left lung was very small and he had significant pulmonary hypertension. August 13<sup>th</sup> 2000 was the worst day of our lives. The risks of ECMO set in and his head ultrasound revealed large bleeds in his brain. They told us they had to take him off ECMO right away or he would suffer a stroke. We knew this was the end because they tried to clamp off the machine a couple of times earlier that week and his numbers would drop. When they were explaining this to us I was in such shock that I didn't realize what this meant. I thought they were going to tell us a new game plan. Then I looked at my husband and he was crying so hard. I never saw my husband cry so hard. There was nothing more they could do. I held Colton for two hours before he went. I sang to him and told him how much we loved him. The 30<sup>th</sup> day of his life I held him for the first time and the last. I will always remember how he felt in my arms and the way he yawned and stretched. I am sure he knew I was holding him. He seemed so content. We held him for five hours after he went home to be with the Lord. I will never forget him and the way he smelled and his facial expressions when we talked to him. We will never get over the loss of our son. He will be with us always. It has been 4 weeks today and my heart still aches like the day we lost him. I don't see how we will ever be the same.

Ryan and Heather Saylor (parents of Colten Saylor, 2874 Brotherton Rd., Berlin, PA 15530, 814-267-6405)



When I was 8 months pregnant they discovered through an ultrasound that our baby had a hole in his diaphragm. The doctors gave us a 15% chance of survival. I had an ultrasound once a week and I was put on the heart monitor too. They did an amniocentesis, but really did not have enough time for all the results to come in. Then 5 days after my due date (November 1, 1989) our son Jeffrey was born. He weighed 8 lbs. 2 oz. and 21 ½ inches long. He was born at Westchester Medical Center in Valhalla, NY. I could not see him, because they had to take him right away. In all my ultrasounds they told us that his heart was on the wrong side. Well, when he was born, they yelled out his heart is on the right side, what a relief!!! Jeffrey was operated on the following morning and did well; on his 8<sup>th</sup> day things did not look so good. His bowels

were backing up, so they operated again on day 9. Thank God he pulled through. Jeffrey was on the respirator for 3 weeks. They told us Jeffrey has 1 full right lung and a small left lung, since most of his body parts were up in his chest when he was born, there was no room for his left lung to grow. Once he was off the respirator he turned blue a couple of times. They had a pulmonologist give him treatments. Jeffrey was in the neo-natal unit for 30 days. Then he graduated to an intermediate unit for 3 days. Then he came home.

Jeffery was home not even two weeks, when his stomach broke the repair. The doctors decided that Jeffrey should get strong before they operate again. He was too weak, so they monitored him. We understood that Jeffrey needed to get strong, but then on the other hand it hindered him from being active. He could not crawl, because every time he tried he was in pain. When Jeffrey was 1 year old and 5 days they operated. This time they put gortex in him and they had to make a few more repairs. They also discovered he had a hole in his pericardium. The day after his surgery, Jeffrey crawled for the first time, what a sight!!!

Well I had no problems what so ever until the last few weeks, I had a lot of fluid and my body weight had increased from 10 stones before I was pregnant to 15 stones. I had very high blood pressure and I was having spells of flashing in my eyes, numbness in one side of my body and migraines. I was taken into hospital over night for my self and my baby to be checked out but they could not find anything wrong with me and the baby as always had a very healthy heart beat and was doing fine. At forty weeks I was given another scan because they thought that the baby was very big and that I might have had trouble delivering him. The scan confirmed that he was about 9lbs and he was doing fine.

At 40 weeks plus 8 days I was taken back into hospital with the same problems only this time I also had 3 parts of protein in my urine, this was a Wednesday and I was booked to be started on the Friday morning. I was started with gel at 10am. Well I had a long labour I was not dilating after about 5 hours, so they put me on a drip, but then I was having drip contractions (false contractions) so I had an epidural and at 4am the following morning I was fully dilated. They told me that I would start pushing in 1 hour, just to let his head move fully down. They also told me that I would only be allowed to push for 30 minutes because of my high blood pressure. So at 5.55 am Saturday 13<sup>th</sup> May 2000 after a vacuum delivery I had a baby son. Weighing in at 7lb13.5oz and I called him Darragh.

The cord was round his neck and when the cut they cord the doctor handed him to me, well I never experienced a feeling like it before. He said Ann you have a beautiful baby boy. He just looked up at me and blinked twice I remember how long he looked and how perfect he was, and his little warm leg against mine. I think I held him for about 1 minute when they rushed over and took him from me, because they had noticed that he had went limp and had not cried at all. They started to revive him and the next day the sister told me that they could not find his heart it was slightly moved to the right, but I did not know at the time. They got him back and he was a beautiful pinkie colour they handed him back to me for another minute and told me they where taking him to special care to be checked over but he was fine. That was the last time I was to hold my baby alive. I taught that he would be okay. Then my after birth broke up inside me which had to be removed manually I lost 1 litre of blood but my worry was with my baby I just felt that they were not telling me something I asked and asked them and after a while they told me that he was having a chest x-ray and that the baby doctors would be along soon to talk to me. He came along about 7.30am and told me that he had a diaphragmatic hernia and that he was been transferred to a hospital in Dublin for sick children. Where he would under go an operation. They took me to see him I stayed for 30 minutes and then I asked to go. I could not stop crying and I felt that I had been stupid because I didn't realize how sick he was. I had my self-done advanced first aid and I knew about Hernia's and I taught that it was only a small operation. The nurses and doctors were really great and took photos of him because he was going to a different hospital. They told me everything but they did not tell me he could die. Although looking back how I think I knew in the back of my mind he could. At 9.30am he left on his journey to Dublin, I prayed to God that they would get him there alive. I went back to the labour ward to be monitored I told them as soon as I was able to get out of the bed I was going to Dublin and they told me I would be going nowhere if my blood pressure did not come down, so they persuaded me to go to sleep. My parents went with Darragh because I did not want him to be on his own. The doctors told me he was going to the best hospital in Ireland and if anyone could do anything for him they could.

Miriam the nurse woke me about 2 pm to tell me that the hospital was on the phone and I taught that they where going to tell me that he was over his operation and doing well. But they told me that they could not stabilize him and that he was gravely ill, they asked me had he been baptised I said no. I think I just keep saying what about his operation, they said his heart had stopped several times and that it didn't look good, I remember saying could he die and she said I think he will. I could not believe this, they where not saying this to me. I dropped the phone and screamed the nurses moved me into a private room where I lived the 2 worst hours of my life. At 4.50pm they phoned back with the news that he had died 10 minutes ago. That his heart had stopped again and that they had to let him go. They told me that they could not believe how beautiful he was when they removed all the tubes and machines. I could not speak I cried and just answered yes and no.

I was asked could they do a post-mortem but I said no because I wanted him back with me. So my dad and my brothers-in-law, took him back to me where we stayed two sad but glorious days together. I had all my family, relatives and friends and we took pictures and enjoyed him. Its been five months now and I love him so much and cherish his memory and I thank my little baby boy Darragh for making me is mammy and for the pleasure of knowing him, even if it was for just a short time in his lovely life and sharing it just with me. I love you my son even though it hurts this much I would not change having you all over again, even if I knew you where going to die.

I also could not have coped without the hospital staff, my family and Cherubs. Thank you all. And thank you Darragh for giving me the pleasure of motherhood and been able to call you my own.

Ann Edward Lennon (mom of Darragh Lennon, 5/13/00-5/13/00, 20 Mountain View, Point Road, Dunalkk, Ireland, 042 9328378, benann@gofree.indigo.ie)

Hello. I am Karli, mother to Austin, 3 years and Cole forever 8 hours old. I wish I would have found CHERUBS sooner. Where do I begin?

When we found out for sure that we were expecting our first child we were ecstatic! It took us almost 2 years. My entire pregnancy was nearly perfect. I had no morning sickness, no odd cravings. My water broke almost 3 weeks early, but he was perfect at 6.10oz and 19 in long.

When we found out we were expecting again, we were overjoyed. Everything was perfect again. Or so we thought. I had my first ultrasound at 9 weeks to check dates. Everything was fine, we were told. I continued with my monthly check-ups until I was 19 weeks.

We went in for the "routine" 20-week ultrasound. We did not think anything of the techs speaking in "code" They did everything not to alarm us. When I think back I can still see the pale, blank looks they had. When I asked if anything was wrong, they just passed it off as being hard to see everything because he was still so small. We went home thinking things were great.

I was not scheduled to see the doctor for 3 more weeks. In that time we did not get a call from the nurse confirming that things were OK like we did with Austin. I thought they must only do that when it is your first baby. Boy was I wrong!

When I went in, I asked my nurse why she had not called. She then told me that the etches had sent my results to the wrong doctor and my doctor has just received the report 2 days prior. She also said there were something's the doctor wanted to discuss with me. My mind was racing, could it be twins....or was my due date way off?.... The time waiting for the doctor seemed like hours. She came in and explained things to me. I was blown out of the water! Like so many others I had never even heard of a diaphragmatic hernia. She also said they were not able to see all the parts of the brain or heart. I was sick. How was I going to tell my husband? This doesn't happen to us, our baby had to be healthy. She must be wrong. I was referred to a perinatologist for a level 2 ultrasound. We could not get in until Monday,(this all happened on Friday afternoon). I explained everything to my husband. We were both just in shock. We spent the weekend praying, reading and wondering. On Monday our nightmare was confirmed. CDH. There was a bright side though. He said the heart and brain looked normal. We had an amnio done to rule out the long list of other defects that go along with CDH (this later came back fine, no other defects). The doctor explained our options: abortion-out of the question, not even an option for us, fetal surgery-we felt this was still to experimental at this time, or carry the baby as close to term as possible and do the surgery after he was born. After many days of praying, more reading and meeting with more doctors, we chose to do the surgery after he was born. We felt that would be our best chance. We even chose to deliver in Minneapolis, 300 miles from our home in South Dakota. We met with all the doctors and nurses, made more trips up to Minneapolis and we thought we had everything in order. I even moved up there my last 2 1/2 weeks. I stayed (alone, Scot stayed home to work) at an accommodation center which had a bed and TV and that was about it. Scot would come up on the weekend and stay for my Monday DR appt. I had bi-weekly non-stress tests and biophys profile. Cole passed every test with flying colors. We thought we had this beat!

went into the triage dept. at the hospital a couple of times but, my doctor did nothing saying that if she drained the fluid it would just prolong the pregnancy and inducing me was illegal. We were so frustrated! We decided that we wanted a second opinion! I knew my rights with the insurance company and insisted on a second opinion. It took a while but, we were finally scheduled for a second opinion in my 29th week.

It only took this wonderful doctor a matter of minutes to tell us that both my condition and the baby's had become very severe. He asked if he could be blunt and then told us that our son had no chance of surviving. He also told us that he was far too large to deliver naturally. His abdomen had become so swollen he was off of the charts and this was only my 29th week. He told us how severe my polyhydramnios was. We immediately signed our care over to him that day. He drained some of my fluid and scheduled me for a c-section 2 days later.

With our families at our side every step of the way, we went into the operating room-my husband holding my hand the entire time. The operation was difficult because of the size of our son. The staff was so understanding and compassionate. They delivered our son and pre-wamed us about the severity of his appearance. The nurses held and cuddled him as they would any other baby. One nurse even asked if she could bless him. They showed us our son. We named him Joshua-meaning saved by God. Although he did not live-we feel that he is alive with God and is therefore, saved. After the surgery, a couple of wonderful nurses brought us our son to touch and hold him. We didn't think that we had the strength for this but, it turned out to be the one thing that I am most thankful for. It did not matter to me what Joshua looked like-he was so beautiful to us. He was our son and we loved him and will always love him! Although he never breathed-he had a slight heart beat for about an hour -it stopped right after they took him away from us. I think that he was holding on to meet us. The nurses made a memory box for us that is my most treasured possession. I look at Joshua's pictures daily and still cry often but, I know that he is with God and my mother in heaven and is in no more pain.

To those of you that may be going through this very difficult time in your life-all that I can say is have faith in God-He will give you courage and strength and He will look after your beautiful baby in the best way that he sees fit. Although, I do not have my baby with me-and this hurts very deeply-I thank God for the precious moments that I did have with him and I thank God that he did not endure any pain. My prayers are with you.

Teresa Kelly (mom of Joshua Kelly, 6/24/00-6/24/00, 1431 Livingston Ave., Chula Vista, CA 91913, 619-482-5085, termkelly@hotmail)



November 1999 my husband and I found out that we're going to have our first baby. We had been trying for seven months to get pregnant and then it happened. We were so excited. We were married five years the year that Colton was to be born. My pregnancy was a normal one. I had two months of morning sickness and was very tired. The baby was always very active and his heart rate was always at 160. I only gained 20 lbs with my little guy, never had any swelling and stayed very active throughout. At every doctor's visit I was told, "sounds like a healthy baby in there". Boy were we wrong! I don't blame them in any way. After all, he did sound healthy because he wasn't relying on his lungs inside my womb. We went to the hospital July 14<sup>th</sup> at 1:30am and delivered Colton Ray Saylor at 6:24am. We had a boy. The look on my husband's face was priceless! Colton looked like a healthy baby boy until my husband cut the umbilical cord. July 14<sup>th</sup> was the happiest and saddest day of our lives. When he cut the cord, Colton started gasping for air. Our Midwife took him over to examine him and started bagging him. Then the nurse listened to his heartbeat. That was when they realized that Colton was not a "healthy baby". His heart

did the sonogram, I knew something was WRONG! She evaded my questions and was very reluctant to give me a picture of the baby. The worst part was that I had taken our 6-year-old daughter with me. She was so excited about finally having a brother or sister. We were hoping to find out the sex of the baby. That, too, was not told to us. I was simply told that my doctor would be contacting me to go over the results. I had the sonogram on a Friday afternoon so, needless to say my doctor had already gone home and wasn't able to tell me anything that day. I went home and worried the whole weekend-knowing in the back of my mind something was wrong. On Monday morning, I called my doctor during my break from work and my worst fears were realized. She informed me that the sonogram showed a great deal of fluid in the baby's abdomen. I asked what this meant and she said she wasn't sure but, would like me to go for a more intense sonogram. I called immediately and tried to schedule an appointment-they tried to tell me that I was going to have to wait for nearly a week-I told them there was NO WAY that I was going to wait a week after hearing this news-so they finally scheduled me the following day. That night I went home and searched all over the internet for these symptoms to see what it could possibly be but, found nothing. I backtracked through my pregnancy a million times to find things that went wrong. In my first trimester, I spotted a couple of times but, it was dismissed by my doctor as nothing major. The pregnancy appeared fine. The second trimester I gained weight very rapidly despite eating right and exercising-I gained very little weight with my daughter. My doctor insisted that I was merely eating too much even though I told her I was NOT.

The next day came and my husband and I went together. We were taken into a room and within minutes the technician had the doctor in the room. He showed us all of the fluid and explained that our baby had CDH and it was very serious. He said another doctor was going to talk with us and explain what this meant and what our options were. We were taken to another room where we sat a while and cried until the doctor came in she explained that our son had CDH and it was very serious. He had liver in his chest area and he was under cardiac arrest from his liver pushing on his heart. She said that I had polyhydramnios with very large amounts of amniotic fluid. She felt that the fluid was going to put me into an early labor and the baby would die at birth or else the baby was going to die in the womb. She did also say that there were some doctors in San Francisco doing experimental surgery and some doctors at Children's Hospital that could tell me more about CDH and the chances for our baby. She felt they were slim to none. We were offered a late termination that would have to be done in the next 3 days-as late as possible. I don't know how I remember any of what she told us because I was in such a state of shock! We left there having decided we could not take the chance with my life and we did not feel we had the strength to bear watching our son die-we were going to L.A. to terminate.

The next 3 days were grueling. I cried continuously, threw up constantly, and prayed God would take my son naturally and not force me to make this decision. I took it upon myself to go to Children's hospital and find a doctor who dealt with babies with CDH. She was such an amazing person. Without ever knowing me-she left what she was doing and talked for nearly an hour to me-she told me of all of the wonderful things that they can do to help these babies-but, she also told me that my case seemed to be very severe-she even cried with me. She even went as far as to give me her home and office number to talk further if I wished. She truly was an angel of mercy. The day came, we went to L.A. with my sister at our side. We went into the clinic and I broke down and lost complete control. There was no way I could abort a baby that I wanted so badly and had PLANNED to have. I loved my baby! We left and I thank God every single day of my life for walking me out of that clinic.

The remainder of the pregnancy was very difficult but, I would never reverse my decision to continue the pregnancy! We had so much love and support from our families, friends, and colleagues. My polyhydramnios got far worse! My care was taken over by specialists. The specialists gave us very little hope but, for the same token would not tell us that there was no hope either. They did nothing to help me with the horrible discomfort from the polyhydramnios-I had gained 60 pounds. The weight was coming on at about 8-10 pounds a week. My legs were so swollen that I could not bend my ankles or knees. I could not sleep-I cried it hurt so bad. I

On Christmas Eve my mother-in-law brought Austin up to see us. It turned out that he had come down with a double ear infection.. So off to the ER in St. Paul, where we were staying with my brother-in-law. To top everything, I started to have contractions. I did not get too alarmed because they were still tolerable. By the time we were discharged from the ER and had the prescription filled I could hardly walk, it felt like my lower pelvic area was going to fall out! I told Scot we needed to go to the hospital NOW! I had nothing along. We tried to call my mother-in-law on the way but we could not reach her.

When we arrived at Abbot NW, I was already at an 8, and I had to push. With the holiday, and Minnesota weather I was just hoping that my doctor was on her way.

I was wheeled into the surgery area. Scot and my ill little Austin were not able to come in so they continued to try to reach my mother-in-law. They did. She came to get Austin. Mean while, they broke my water and I quit having productive contractions. The team from Minneapolis Children's were all there and ready. They went back. I continued to labor until 3 am when I could start to push. The team came back and at 3:19 am on Christmas morning Cole Robert was born. He was beautiful! The team started working on him right away. They put every kind of tube imaginable in him. Before they took him away, I was able to see him and touch him. The doctor told me there was an unforeseen problem; Cole was born without a sternum. His heart was laying just under the skin. I thought, "how could they not see that- they did every test under the sun?" After I was cleaned up my nurse brought me to see Cole. He was on hi freq ventilation, had a chest tube and every other kind of tube in him. He was on medications to keep him from moving. He laid there so helpless and here I am not able to do anything for him. As a mother that was so hard, there was nothing I could do but pray. The nurses told us that he was stable for now and that we should go back and get some rest, by this time it is about 5:30 am. We went back to rest. We did have the camera on him hooked up to the TV in my room so we could keep an eye on him. At 7:30 am we got a call from the NICU saying we need to come right over! The doctor told us Cole is not doing well on the high freq vent and we need to think about ECMO. We wanted to go through with it. They needed to do some ultrasounds of him first. In the mean time we were able to hold and spend time with Cole. While they were getting a scan of his head the doctor came in and said his blood gases' were very low and that there was a pocket of air in his chest they could not control with the chest tube. He also said there was no way to tell how much damage had been done to his brain with the low oxygen levels he was getting. They just could not keep the levels up. He also told us that what ever we do from here on out we would be doing things TO him and not FOR him. Neither Scot nor I wanted that. We needed to make the hardest choice of our lives'. We made the choice to take him off life support. But first we had Cole baptized. We then were able to go into a private room to spend time with Cole until he passed on. Cole was so strong, he just did not have enough lung tissue.....Cole died in my arms at 11:40am on Christmas day. This was the worst day of my life. We left for home the next day, without my baby. I felt so empty inside, it hurt so bad. He was buried on the 29th in my husband's hometown.

Not a day goes by that I don't think of and miss him. We never got to hear him cry or see him open his eyes. BABY COLE WE MISS YOU!!!!

I am Karli, mother of two beautiful boys, Austin is 3yrs and Cole is 8 hours old. Thank you for listening.

Karli Pulse (mom of Cole Robert Pulse, 12/25/99-12/25/99, 900 Magnolia Drive, Brandon, SD 57005, 605-582-2676, skpulse@splitrocktel.net)

I'm not quite sure where to begin. It's now been a little over 3 months since we lost our son to CDH. It's taken me a while to come to some sort of terms with our loss in order to be ready to tell our story. I feel that it's important to tell our story not only to help us heal and to remember our beautiful baby boy but, also to help anyone out there who might be going through what we went through. I know that after our son was diagnosed with CDH, I spent hours daily on this site and it really helped me!

I was 23 weeks pregnant when I went in for my 2nd trimester sonogram. As the technician

