CHERUBS

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

The Silver Lining

Winter 2001

CHERUBS
1109 Williamsboro St
Oxford, NC 27565

Dear Members,

We have so much going on at CHERUBS this quarter- we now have over 750 members in all 50 states and 27 countries and our web site has had over 66,000 visitors. Happy 6th birthday CHERUBS!

We also have many projects in the works; our 2000 Congenital Diaphragmatic Hernia Research Survey Results will be published by February 29th. Also out on February 29th is our On-Line Congenital Diaphragmatic Hernia Research Library. We have expanded our web site to over 300 pages of stories, pictures, medical information, and support services. Our 2nd annual CHERUBS' International Member Conference is planned for May in Minneapolis and by the end of the year, we will be producing our first CHERUBS' CDH Informational Video. And all on a shoe-string budget made possible from donations. We hope to have grant funding by the end of the year also, to hire a full-time staff and to conduct more research. Thank you all, our wonderful members, for helping us grown in the fight against CDH!

Dawn M. Torrence, President

New Arrivals

(*siblings of Cherubs)

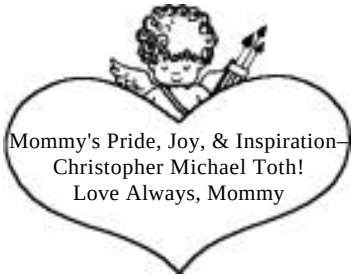
Spencer James Bean
Garrett Reid Benedict
Carsan Blue*
Benjamin James Bogdanovic
Taitlyn Reann Chapman
Matthew Christopher Cheney*
Eileen Francis Dunn*
Abbie G. Edwards
Bridgette Elysabeth Ernst
Courtney Stavis Gabbett
Dylan Isaiah Houck
Lucas Danial Huether
Megan Marie Kayser*
Gabriel Joseph Kolacia
Quenton L. Lewis
Carsen Edward Manfull
Pete Marti, Jr*
Liam Lloyd Nosek
Caden James Robilliard*
Harrison Gregory Schrand
Devon Dean Stevenson
Meghan Hope Swartz*
Colin Joseph Verwiel
Drew Warner
Katie Elizabeth Yerger

This Newsletter Is Dedicated To the Memories of:

Garrett Reid Benedict
Niall Martin Curry
Grace Caroline Dill
Abbie G. Edwards
Colin W. Lansdon
Sydney Isabella Lund
Carsen Edward Manfull
Liam Lloyd Nosek
Brandy Michelle Rogers
Kaylee Ann Rynders
Haley Rose Saunders
Harrison Gregory Schrand
Damien Smith
Leslie Nicole Taylor
Alexander Francis Thalmann
Colin Joseph Verwiel
Katie Elizabeth Yerger

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

Lea Donahue
Ray Donahue
Danielle Kessner
Elaine Moats
Jeremy Torrence



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

Mackenzie Renee Aldridge
Emily G. Archambault
Spencer James Bean
Garrett Reid Benedict
Benjamin James Bogdanovic
Baby Brewer
Samantha L. Burchart
Jordanna Liberty Byleveld
Caroline Harpur Cassese
Taitlyn Reann Chapman
David Christopher Chubb
Laura Ann Condry McFatter
Darrien Jeffrey Cook
Charles Steven Cronin
Jaxon Eli Culwell
Niall Martin Curry
Baby Boy Dewberry
Grace Caroline Dill
Abbie G. Edwards
Bridgette Elysabeth Ernst
Sher Mohammed Hamid
Coleman Allen Hamilton
Mariah Hope Haveman
Daniel James Haughian
Rebecca Breana Higgins
Joshua T. Hill
Lucas Danial Huether
Baby Girl Kneebone
Colin W. Lansdon
Alexis S. Lawson
Sydney Isabella Lund
Sybil M. V. Lyon
Baby Boy Maganti
Carsen Edward Manfull
Keone Zachary McEachern
James Atilano Mejia
Baby Monet
Henry Henry Nancarrow
Liam Lloyd Nosek
Andrew J. Pacan
Rhia Alexandra Pillay
Brandy Michelle Rogers
Kaylee Ann Rynders
Haley Rose Saunders
Harrison Gregory Schrand
Madison Lillian Schultz
Bram Stephen Sewell
Manisha Sharma
Kyle David Simon
Damien Smith
Jaret Paul Spelich
Samantha Grace Stengel
Raquel Marie Stockwell
Danielle Nicole Swank
Leslie Nicole Taylor
Alexander Francis Thalmann
Gerald Ross Vosburg
Drew Warner
Baby West
Katie Elizabeth Yerger

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

- Brian and Denise Bean- in honor of their son, Spencer James Bean
- Martin Bloes- in memory of Colin Joseph Verwiel
- Charles and Kathleen Breen- in honor of their daughter, Caitlin Breen
- George and Kim Byleveld- in honor of their daughter, Jordanna Liberty Byleveld
- John and Charlene Cassese- in honor of their daughter, Caroline Harpur Cassese
- Denise Terzigni-Cox
- Diana Cox-in honor of her son, Dallas Cox
- Samantha and Thad Cummins- in memory of Colin Joseph Verwiel
- Mark and Randi De Wit- in memory of Colin Joseph Verwiel
- Mark and Lise Dill- in memory of their daughter, Grace Caroline Dill
- Rex and Barbara Durington- memory of Matthew Ryan Peterson
- Patrick and Frances Dwyer- in honor of their grandson, Max Kastner
- Barbara Eisele, Danielle Eisele, Teira Eisele, and Salvador Elizondo- in memory of Reese Gabrielle Eisele-Elizondo
- James and Betty Embree- in memory of Colin Verwiel
- Albert and Claudia Faraldi- in memory of Christopher Faraldi
- Albert and Claudia Faraldi- in memory of Anthony Pompeo
- Albert and Claudia Faraldi- in memory of Baby Marino
- Albert and Claudia Faraldi- in memory of Kayla Childress
- Albert and Claudia Faraldi- in memory of Shane Torrence
- Craige Flater and Gregory Brorby- in memory of Colin Joseph Verwiel
- Marion Griffin and Callie Fowler- in memory of Colin Joseph Verwiel
- Geomatrix Consultants, Inc. - in memory of Colin Joseph Verwiel
- Joseph and Freedom Green- in memory of thier daughter Kylee Freedom Green
- Colette Hartigan- in honor of her son,Thomas Hartigan
- Doretha O. Hawkins- in honor of her granddaughter, Allison Lane Pruitt
- Chris and Craig Hester- in memory of Morgan Avery McClintock
- Paul and Jean Hill- in memory of Zachary Barbar
- R. Patricia Hoemke- in memory of her great-grandson, Cade Andrew Turner
- Mary Holbrow- in memory of Colin Joseph Verwiel

- Maureen Holbrow- in memory of Connor Ellis McLuckie
- Hurley Family- in honor of Kyle John Hurley
- Andrew and Jessica Jarrett- in honor of their daughter, Hayley Jarrett
- Kurt and Anne Marie Kastner-in honor of their son, Max Kastner
- Isabelle Kennedy- in memory of Kylee Freedom Green
- Maya Kurz- in honor of her son, Matthew Harry Kurz
- Dr. and Mrs. Joseph Kibler- in memory of Michael Wolfe
- Karen Lignana- in memory of her daughter Jane Olivia Lignana
- Karen Lignana- in memory of Connor Ellis McLuckie
- Natalie Maxfield- in memory of Connor Ellis McLuckie
- McLuckie Family- in memory of Connor Ellis McLuckie
- McLuckie Family- in memory of Jane Olivia Lignana
- Moya Melody- in memory of Colin Joseph Verwiel
- Brett and Elaine Moats- in honor of Kristin Moats
- Donna Morrison- in honor of her daughter, Jodi Morrison
- Mortar Net USA, Ltd- in honor of Michael Patrick Lee
- Robert, Kim & Jeremy Mota- in memory of Colin Joseph Verwiel
- Debbie Mourtsen- in honor of her son, Alex Mourtsen
- Mike and Sany Opsomer- in memory of Colin Joseph Verwiel
- Pete and Amy Rademaker- in memory of their son, Jonathan Luke Radmaker
- Jennalee Rascoe
- Dave and Clare Retterer- in honor of their son, Sammy Retterer
- Holly Ross- in memory of Connor Ellis McLuckie
- Keri and Greg Schrand- in memory of their son, Harrison Gregory Schrand
- John Egan and Cynthia Shaw- in memory of Colin Joseph Verwiel
- Joanne and Jeff Smith- in memory of Colin Joseph Verwiel
- James Somma and Camille Cucita- in honor of their nephew, Max Kastner
- Jane M. Stockwell- in honor of her daughter, Raquel Marie Stockwell
- Timothy and Kim Strong- in honor of their daughter, Karina Strong
- Mark Tachman and Beth Seyda- in memory of their son, Dylan Seyda Tachman
- Thompson Marketing
- Jeremy and Dawn Torrence- in memory of their son, Shane Torrence
- Mr. and Mrs. Gary Tyler- in memory of Michael Wolfe
- Mr. and Mrs. Gary Tyler-in honor of their grandson, Will Kibler
- Paul & Lisa Vallins- in memory of their daughter, Anastasia Vallins
- M.C. VanderSchaaf- in honor of her nephew, Ryan VanderSchaaf
- Lori Verwiel and Michael Crupi- in memory of Colin Joseph Verwiel
- Barbara Vosburg- in honor of her son, Ross Vosburg
- Amy Weldon- in honor of her daughter, Brook Sue Weldon
- Donald and Elizabeth Wells- in memory of Colin Joseph Verwiel
- Daniel and Linda West- in honor of their of their child, Baby West
- Connor Yost- in memory of Colton Ray Saylor

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, Israel, Italy, Mexico, The Netherlands, Oman, Pakistan, Papau New Guinea, Romania, Scotland, Spain, South Africa,Turkey, 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 Dawn for more details.

STATE/COUNTRY	REPRESENTATIVE	PHONE#
Australia	Danielle Kessner	(03) 5135 6999
Canada	Dawna Haines	905-852-4255
Canada	Karen Jenkins	905-852-9410
Canada	Laurelle Lehmann	(250) 838-2250
Germany*	Renata Hoskins	907-245-8817
Great Britain	Kevin & Brenda Lane	01553 762884
New Zealand	Nikki Hodson	0064 4 9731333
Northern Ireland	Martin & Sinead Beare	01232 621486
Norway	Victoria Serkland	47-359-41284
AK	Renata Hoskins	907-245-8817
AL	Alicia O'Malley	256-389-8110
CA	Jill Coon	530-582-1261
CA	Shirley DiMercurio	925-439-8382
CO	Amanda Owen	970-246-3337
CT	Laura Webster	203-284-2199
DE	Susan Guariano	302-731-1922
FL	Tammy Warr	850-235-9004
GA	Annette Lichtenstein	404-325-2368
ID	Heidi Forney	208-584-3708
KY*	Leigh Cheney	615-907-1301
LA	Sheila Ezernack	318-645-9361
MA	Heidi Cadwell	603-878-2283
MD	Brenda Slavin	410-956-4406
ME	Teri Morse	207-538-4049
MI	Barbara Wagner	810-249-5279
MS	Marsha McInnis	601-856-2831
MT	Elaine Moats	406-232-5038
NC	Jeremy Torrence	919-692-1270
ND*	Elaine Moats	406-232-5038
NH	Heidi Cadwell	603-878-2283
NH	Lea Donahue	603-425-2639
NJ	Jeff & Sandy Vanesko	570-388-6113
NV	Heidi Forney	208-584-3708
OH	Tara Hall	614-777-4906
OK	Jeannette Davis	405-670-9937
OR*	Heidi Forney	208-584-3708
PA	Tammy Sincavage	610-796-7324
SC	Susan Grubb	864-877-1446
SC	Vanessa Hutchinson	843-770-0109
SD*	Elaine Moats	406-232-5038
TN	Leigh Cheney	615-907-1301
TX	Shelly Evans	254-793-3039
TX	Monica Nedrow	817-329-2402
VA	Elizabeth Doyle-Propst	804-293-4602
WA	Grace Massie	360-933-0411
WI	Karen Nuthals	608-845-3167
WV	Sharon Munson	304-947-7162
WY*	Elaine Moats	406-232-5038

On-Call Volunteers for Non-Survivors

On-Call Volunteer	Phone Number	E-Mail Address
Danielle Kessner	(03) 5135 6999	kessam@bigfoot.com
Laurelle Lehmann	(250) 838-2250	tlm-mathias@telus.net
Amy Rademaker	616-844-4156	rademakeramypete@novagate.com
Kate Rogula	313-565-8722	Alugor@worldnet.att.net

On-Call Volunteers for Survivors

On-Call Volunteer	Phone Number	E-Mail Address
Jill Coon	530-582-1261	JLC835@aol.com
Lea Donahue	603-425-2639	leamd@mail.com
Heidi Forney	208-584-3708	hforney@bigskytel.com
Tara Hall	614-777-4906	TARAJEFF@aol.com
Elaine Moats	406-232-5038	bmoats@midrivers.com
Grace Ore	814-833-6421	n/a
Ann Peterson	509-735-7208	petersonzoo@msn.com
Jeff & Sandy Vanesko	570-388-6113	vaneskoj@aol.com

CHERUBS' 2001 Conference

Our 2nd annual CHERUBS' International Member Conference will take place over Labor Day Weekend in Minneapolis, Minnesota. Located near the Mall of America and many other tourist attractions, our conference will include educational lectures, discussions, and support group sessions for parents, as well as fun for the kids. We are still in desperate need of conference sponsors and volunteers.

We estimate it will take $10,000 to fund this event and we are about $7,000 shy of our goal. To fulfill this goal, we need to sell more t-shirts and cookbooks and find sponsors to help us pay for the hotel costs, conference room costs, food, and materials. If your business can donate $500.00 or more, we will advertise our appreciation on our conference t-shirts and on our web site.

We also need volunteers desperately to help us organize, prepare food, babysit, lead discussions, transport families to and from the airport, and run errands. This year it will be mandatory for all conference attendees to volunteer for at least one conference volunteer position, but we still need more volunteers.

If you plan to attend, PLEASE let us know by February 29th so that we can reserve hotel rooms and food. If you can attend, are thinking about attending, or want to volunteer to help, please fill out the form below or contact Lea Donahue, our Conference Coordinator, at 603-425-2639 or leamd@mail.com. If you would like to sponsor this conference, please contact Dawn at 919-693-8158 or dawntorrence@cherubs-cdh.org. Without more help, we cannot make this conference possible!

CHERUBS' 2001 Conference

_____I am interested in attending, please send me a flyer when they are printed.

_____I am a medical professional who is interested in speaking on CDH and/or the complications that may arise because of CDH.

_____I would like to volunteer to help solicit sponsors for the conference.

_____I would like to help volunteer at the conference by babysitting during lectures and speeches, passing out refreshments, or doing whatever CHERUBS needs me to do.

_____I live in Minnesota and would like to volunteer to help transport families to and from the airport and/or to help make lodging and service arrangements.

Your Name: _____

Mail to CHERUBS, 1109 Williamsboro St, Oxford, NC 27565

Stories of CHERUBS

I found out I was pregnant with my second child 3 days before Christmas after 6 long months of trying. My husband and I were so excited. We waited the 3 days to tell our families on Christmas day. I began having horrible morning sickness just a couple weeks later and that lasted until the end of April. I had been hospitalized on 3 different occasions with severe morning sickness/dehydration in March alone. I was scheduled for my first ultrasound on April 6, 2000. I was beginning to feel better from the morning sickness and my husband and I were expecting to go in there and find out what the sex was. What a shock when we found out something was wrong. The ultrasound technician told us he was going to get the doctor to come take a look and at that time I wasn't worried because they did that with my first daughter. Well, the doctor came in and started looking and looking and looking. She finally said "I know you know I was looking at something so I'm not going to just let you leave and pretend nothing's wrong." She told us she saw something wrong with the heart and lungs and she was going to call my ob to let him know about it. They didn't know it was CDH at that time. My OB called me later that evening and told me that he didn't know the significance of what the other doctor had seen and he was going to refer me to a perinatologist. I got an appointment with the perinatologist on April 10 and had a level 2 ultrasound. That was the day we received the worst news I have ever received. Our daughter had a Congenital Diaphragmatic Hernia. We had no idea what CDH was and the doctor explained it and also told us that it had a high mortality rate. He advised us to get a second opinion , so we got an appointment for the next day with a group of perinatologists in Atlanta, 2 hours away from our home. I saw Dr. Korotkin in Atlanta, and he confirmed the CDH, but he gave me more hope than the first doctor did. I went to Atlanta every 2 weeks for ultrasounds. They decided I needed to deliver up there because the hospital where Allison would be is up there. In May, we flew to San Francisco, CA to look into having fetal surgery. We were turned down because Allison also had a growth on her lung and that disqualified us.

Allison was born on August 22, 2000 in Atlanta, GA. I was scheduled for an induction that morning, but Allison was ready before then. My first contraction was at 3:45 am and Allison was born at 8:45 am. All throughout my pregnancy the doctors never came right out and said it, but I knew that they didn't expect Allison to even survive. But once again, Allison had other plans. She was born in one hospital and transported to the children's hospital. The NICU team where she was born told me that she would definitely need ECMO. But the NICU at the children's hospital called us that night and said she was doing great and did not need ECMO. That was the first of the good news that just seemed to keep on coming. Don't get me wrong, she had her ups and downs, but we had expected much worse than what really happened. They had to put in a central line because she wasn't very easy to get IVs in (like her mommy!). The first obstacle was her pulmonary hypertension. They had to wait for her blood pressure to stabilize before they could do the repair. Finally, at 3 days old, Allison had her surgery to repair the diaphragm. She had her stomach, liver, intestines, and spleen up in her chest, yet she had 1/3 of a left lung! She sailed right through the surgery. She came off her ventilator at 2 weeks. The only problem she had was when they started feeding her my breast milk, it caused her chyloducts (whatever that is) to leak and her chest to fill up with fluid.

So they stopped feeding her for 2 weeks (except for her IV fluids). She had to be put on an NG tube because she couldn't suck from a bottle. Oh, when she came off the ventilator, she was what they called tachypneia, meaning she breathed really fast, like 100 breaths per minute (normal newborn rate is 40-60 bpm). That's one reason why she couldn't drink from the bottle because she couldn't get the hang of suck-swallow-breath. After about a week of trying the bottle, she started to slow down her breathing rate and she would drink a little from the bottle, but we had to put the rest through the tube. She finally came home on October 4, when she was 6 weeks, 1 day old. She came home with the NG tube, on a monitor, a feeding pump, and meds - reglan (for reflux) and prilosec (for the acid). When she had been home for 2 weeks, I stopped using the NG tube in the daytime, and just used it at night when she was on the feeding pump. I stopped using the feeding pump (and the NG tube) altogether when she was 2 1/2 months old. She had some feeding problems where she would only drink about 1 or 2 ounces at each bottle feeding when she should have been taking about 5 ounces. She is slowly working her way up to it, especially since we stopped using the NG tube. She is doing fine now, and not a day goes by that I don't thank God for allowing us to keep her. She is truly our miracle baby.

Amy Weldon (mom of Allison Brooke Weldon, 8/22/00, 812 Eden Street, Columbus, GA 31904, 706-321-9976, JAWeldon@msn.com)

In October 1995, I was 41 weeks pregnant with no sign of change. My doctor induced and it was an almost text book delivery. Instead of us being able to rejoice, it became the beginning of many emotions with much uncertainty.

My son Coleman Allen Hamilton came into this world unable to take his first breath. The delivery room was filled with specialist within seconds, he was rushed to emergency surgery. We were told he had a diaphragmatic hernia on the left side with his intestines filling the chest cavity leaving no room for the left lung to develop. At the time, his condition was described as minute to minute.

After the surgery, he was oxygenating in the 30 percent range even on a ventilator. It was then we were told he might need to go on a machine called ECMO (a heart-lung bypass to re-route his blood to oxygenate it and return it to his body). The problem was, the closest one was an hour and a half away and they were not sure if he would even survive the trip. They knew a helicopter would be too rough and even contemplated on what road to take just to get to the highway.

Well, he survived the trip and 24 hours later was placed on ECMO. While on ECMO, he had a couple set backs and they had to change the machine out, along with re-routing the cannulas (which had to be sutured to his face so they wouldn't move).

On the ninth day, the Doctors decided he needed to go off ECMO, or it would be even more dangerous. The surgery to remove the ECMO took longer than expected, but he finally made it through. The next 2 ½ months brought many moments of joy and sadness... I got to hold him for the first time...on the ventilator...off the ventilator just to go back on again.

Next, Cole developed a condition called Chylothorax. When described to me by the doctor, I asked what is usually done about it and he stated, "most babies die". I'll never forget those words.

For the next few days, the doctor came in and "tapped" his chest to drain the fluid accumulated in his chest cavity. Miraculously, it cleared up on it's own.

When it came time for us to leave the neonatal unit, the doctors were saying "we don't know what to tell you, we've never had a baby leave this hospital with as severe problems as your son". We transported Cole by ambulance to our home 3 days before Christmas. What better way to celebrate the birth of Christ! He was still on oxygen, monitors, NG feedings, and lots of medications, but he was finally home where he belonged.

After some developmental delays and reflux issues, he became a pretty healthy toddler. He is now 5 years old and is a wonderful big brother. While his future is uncertain, we love him very much and cherish every day we are blessed to have him in our lives.

Lori Hamilton (mom of Coleman Allen Hamilton, 10/11/95, 1029 Savanna Lane, Cedar Park, TX, 78613, 512-260-8650, kevinh2000@netzero.net)

This is the story of our daughter Katie Elizabeth. She was diagnosed with a CDH moments after her birth, and then eventually with Fryn's Syndrome. We had no idea she was so sick. We'd had the AFP and the ultrasound. Her heartbeat had always been good and strong. She was an active baby.

Katie was conceived in March 2000. We were extremely happy to learn we were expecting. Our oldest daughter, age 6 at the time, was excited to learn she would be having a brother or a sister. I had awful morning sickness. It wasn't just in the morning, it was morning, noon and night! I was sick for about 2 1/2 months. I hated the seasick feeling, but I loved knowing that it was a good sign of a healthy pregnancy.

At around my 3rd month, I started feeling uneasy. I was convinced that *something* was wrong. I expressed my concerns. My doctor assured me that everything was fine. I still couldn't shake my feelings. About my 4th month of pregnancy, I started feeling uncomfortable. I seemed to hurt more than I remembered with my first pregnancy. My family and I had gone on a quick family vacation to our favorite amusement part and I knew the walking was going to be tiresome, but several times during the day I would start hurting terribly, almost to the point it hurt to walk. I later realized that I could no longer feel when I had to use the bathroom. Emptying my bladder every hour or so would became my routine until I delivered Katie.

Shortly after we returned from our mini family vacation, I went in for an ultrasound. My husband was so excited to see her on the screen. It was confirmed that she was a girl! My husband was in awe when he saw her little heart, beating so strongly. The tech said everything looked good.

Looking back, I would have to say that there would have been 2 maybe three red flags: I insisted that I saw her *hand* clenched; she was laying on her other hand/arm; and the fact that even though she was an active baby, she seemed non-responsive to our pokes and prods to my belly, it would almost seem as if she was trying to run away from them. My OB confirmed that my ultrasound looked fine. There was no indication that she even had a CDH. He did mention that I had a mild case of placenta previa. Nothing was ever mentioned about this since.

Shortly after my ultrasound, around my 6th month, my husband and myself started to notice that I was getting big. I was big with my first daughter, but this time, I felt & looked bigger than normal. Even my OB commented how big I had become since my last visit. He didn't seem concerned about it. By the last 3 or 4 weeks of my pregnancy, I had to stop driving because I couldn't fit behind the wheel, nor could I sit comfortably to drive safely. It also hurt to walk. I couldn't get comfortable to sleep; I felt like I was a balloon and I was about to pop at any moment. I had strangers asking me if we were sure there was only one baby in there.

During the last week of my pregnancy, I saw records that indicated that I was measuring over 2 weeks larger than what I was. We took Katie 11 days early, making me 38 weeks pregnant, I remember reading a document that I was measuring at 41 weeks.

November 28 came very quickly. We arrived at the hospital for the scheduled c-section. I was prepped and wheeled down to the OR. I chose to be completely sedated for the procedure.

When I started to wake up in the recovery room, I just had that feeling that something wasn't right. Sure enough, when I started asking for my baby, the recovery room nurse told me that my baby was having problems breathing. My heart broke into about a million pieces. I remember thinking no, not again! My first daughter had some mild complications after her birth and I just couldn't handle going through this again. Unfortunately, that was nothing compared to what I was about to encounter.

I was back in my hospital room when the meds started to wear off. I remember asking for my baby and that I needed to see my baby. Immediately, people started telling me that they were working on her and that we'd know something soon.

I have to stop and mention that shortly after I had Katie, a nurse for some reason felt it was necessary to mention to me that I had an enormous amount of amniotic fluid. Had I known then what I know now, I would have insisted my doctor do a more extensive ultrasound.

Katie's doctor came in and started to tell us that she had a CDH. He was confident that it was a minor tear in her diaphragm, and that he was almost confident that her lungs were fully developed and that this was something that happened when she took her first breath. He life flighted her to Children's Mercy hospital in Kansas City, MO. There, we learned that she had, in addition to her CDH, several other anomalies, hence leading to the tentative diagnosis of Fryns Syndrome...we're still waiting confirmation through the autopsy report. We also learned that her lungs were not completely developed; in fact, one was almost nonexistent and the other was significantly under developed. Once we learned the severity of her medical condition, we decided to disconnect her life support November 29, 2000. Katie died in my arms.

She looked absolutely perfect. She was beautiful. It's so hard to understand why this happened to her. I never heard her cry, I never saw her open her eyes to look at me. Fryn's Syndrome cannot be detected in an amnio because they have not found the DNA link yet; and as we're all too familiar with, detecting a CDH on an ultrasound is difficult. There are other anomalies that could be detected on an ultrasound if the tech is trained well and knows what to look for, but unfortunately the outcome doesn't change. Fryns Syndrome is a rare genetic disorder. Majority of the babies born with Fryn's are stillborn, and the few that are born alive are on life support and will be mentally challenged.

My husband, my daughter and I sat and held Katie for a long time. Shortly afterward, my daughter dressed Katie and helped present her to our families. And, then shortly after that, they brought her back to me and I continued to hold her for several more hours. I stroked her little head, smelled her hair, patted her back and just rocked her. I told her how much I loved her and how much I wanted her. I sang to her, I looked at every inch of her body. I had to cram a lifetime into a few hours. I just held her. I sat there and cried for her, my tears spilled over her little head. I wanted to take her home with me so badly. I was her mamma, why couldn't I make everything all better. I just didn't understand. My husband and I held her and held each other, together we cried. It just wasn't supposed to happen that way.

We had Katie cremated and we brought her home. Katie's signature color is purple. It also happens to be my favorite color. When I see the color purple, I feel comforted in knowing that even though I only knew my daughter for such a short time, we had something in common. If you have been affected by Fryn's Syndrome, you are welcome to contact me.

Paula Yerger (mom of Katie Elizabeth Yerger, 11/28/00-11/29/00, 313 N. Stephen, Ponca City, OK 74601, pyerger@poncacity.net)

I am writing this story from the bedside of my son Spencer Bean, who is diagnosed with CDH. Our story begins on April 13th when my husband and I went in for a level II ultrasound. We were thrilled to find out what we were having, is it a boy or a girl? However, our excitement quickly changed when they saw on the ultrasound our baby boy's heart was shifted to the right of his chest and his stomach and bowels were up in his chest as well. My husband and I were sick. I sobbed and was so afraid. The doctor said he had a 40% chance of survival. When we left the doctors that day we were numb, they gave us literature to read about the illness. My husband immediately got on the internet and began to research all options. That same day another mother's baby was diagnosed with CDH. From that day forward our grieving began. My husband was strong for me. At 23 weeks my husband and I flew to Philadelphia to see if we would qualify for in utero surgery. The date was May 5th. The day was full of ultrasounds, from having a fetal echo to an MRI, at the end of the day we met with Dr. Adzick and he said our

baby did not qualify for in utero surgery. Our baby had a 1.25 LHR (.9 LHR chances of survival 0, 1.35 LHR chances of survival 70%). I was almost relieved to find out I did not qualify for such a surgery. For the next several months my time was busy at Dr.'s offices. I had level II ultrasounds every 2 weeks. At around 30 weeks my amniotic fluid was on the rise. The reason for that was Spencer was not swallowing fluid like he should because his stomach was in his chest. I also had several non-stress tests done just to make sure that Spencer was not under stress. My husband and I decided to have Spencer delivered at Iowa City, IA. After interviewing several doctors they seemed best qualified for our baby. At 34 weeks I started to go into labor. They put me into the hospital and put me on magnesium. I became so ill, not to mention afraid for Spencer. My goal was not to deliver him until at least 36 weeks. Well, Spencer decided he was ready to join our world at 35 weeks. My second premature baby. My delivery went smoothly. I had Spencer vaginally. All the doctors were present for immediate care. Spencer's honeymoon period was brief. He remained consistant therefore the surgeons decided to do surgery on day 3 of his life. His surgery lasted only an hour. They found he had his stomach, bowel, spleen, pancreas and small and large intestines in his chest. Spencer had a fairly large right lung and a compressed left lung. After surgery, Spencer remained on a high frequency vent. But the good news was he never required nitric oxide. We were so pleased. Surgery went well. One week after surgery, Spencer was put on a c-pap already. He was not on a high frequency vent or even a regular vent any longer. Spencer was being so strong. It seemed he was even stronger than his mother. I was so tired and stressed, not to mention worried. I missed my 20-month-old son so desperately. My heart just ached. On day 8 of Spencer's life they began feeding him, not by mouth, but a tube to the stomach. He was taking 80cc a day. Such a hungry guy. I also played music for him, that is, after he was taken off "PV" restriction. (PV restriction means you can not stimulate the baby in any way, no touching, no high level talking, in any way) It seems when you go through this you always are waiting for the next day to arrive because it is then you know you made it through one more day. Spencer was released from the hospital at 24 days old. I breastfed for 8 weeks. It was difficult the first few months. It seemed Spencer could not relax, he was very easily upset, hard to put at ease, they said it is because of what he went through. Spencer is 5 ½ months old now and weighs 17 lbs and loves to eat and laugh at his big brother. Remember that other mother who was diagnosed at the same time I was, his name was Gabriel, he passed away 3 beds away from my son Spencer while in the NICU. I can't help but to think part of Gabriel will live on in Spencer!

Each day I worry if I hear a cough or a sneeze, I automatically think Spencer is going to catch it and be put back in the hospital. But then again, anybody who ever is a mother knows the worry! We are blessed as is any parent who has the privilege of raising God's children. Remember this "our children are on loan from God!" So feel blessed with as little or as much time as you have with them, they are miracles even those that go on to become angels right away, like Gabriel.

As I write my story there are a few people I would like to thank. First, is God, without him I would not have my blue eyed miracle, secondly my husband for his compassion, kindness and for being the father of my children. Also, thank you to Dr. Bell, Dr. Mike and for Spencer's special nurse, Hope!

Denise Bean (mom of Spencer James Bean, 7/30/00, 1335 Herold Ave, Des Moines, IA 50315, 515-287-5213)

This is the story about Jonah Michael, who has shown us how valuable life is and what a blessing a child can be. Jonah was born with a birth defect known as congenital diaphragmatic hernia which is simply a hole in the diaphragm. The diaphragm begins to develop during the 8th week of pregnancy. Jonah's diaphragmatic hernia was not easily diagnosed during my pregnancy, although my OB/GYN physician did determine during a routine ultrasound that something was wrong with Jonah's development due to not seeing his stomach, which should have been easily seen during this 18th week.

My physician referred me to a specialist, a neonatologist at the Charleston Area Medical Center (CMAC) in Charleston, West Virginia. Upon my first visit with the neonatologist, it was discovered that Jonah had a bronchopulmonary sequestration on his left lung. So, on a subsequent visit to my neonatologist, he was monitoring Jonah's sequestration to see if it was in proportion to his body growth. Each visit we were reassured that everything was in order with Jonah's growth and that the sequestration had not increased or decreased in size.

Due to my husband graduating from medical school in May 2000 and starting his Family Medicine residency program in June 2000, my prenatal care was transferred to Washington, PA. Before our move, my initial OB/GYN scheduled me an appointment with a maternal/fetal specialist at the Physician's Office Center in Morgantown, WV near our home in Washington. There I had several ultrasounds with my sister by my side. I was blessed to have her there provided she is OB/GYN physician and intensely watched my ultrasounds and even performed one on me herself. She spent the time showing me parts of the ultrasound that were alarming. The stomach was still not present at this time. Possible diagnoses from observing the ultrasound were: bronchopulmonary sequestration, congenital cystic adenomatoid malformation (C-CAM), splenic cyst, and diaphragmatic hernia. Ultrasounds were not conclusive; therefore, a fetal MRI was scheduled.

The day of my fetal MRI, I was so nervous. I knew I would have to lie down inside an empty tube and claustrophobia began to foster inside me. It was a little scary, but somehow I managed to get through it. My films from the MRI would be looked at by a pediatric surgeon and an appointment was already set up for 2 days later. The day of my appointment I met the pediatric surgeon and he had not even looked at my films. So, needless to say, my appointment that day was useless. He knew nothing about my case. I was really upset that day after the appointment and when I told my husband, he was fuming. We did not think I should have gone to a scheduled appointment to learn nothing about Our Little One, Jonah Michael. A day later, my husband was on the phone trying to get in touch with the pediatric surgeon. And finally the surgeon called back and gave us the results of his findings. Jonah had a left-sided diaphragmatic hernia which was allowing his abdominal cavity to go into his chest cavity. This is why the doctors could not see the stomach.

Due to Jonah having a diaphragmatic hernia, he would have to have surgery to close his diaphragm. This surgery was to be performed by the pediatric surgeon sometime after Jonah had been stabilized. Our plan was to have this done in Morgantown where both of our families lived; however, we learned that this hospital did not have a machine known as ECMO (extracorporeal membrane oxygenation). We felt Jonah may need this machine after delivery or surgery and so, we chose to go to a hospital which had this machine. We transferred all my records to the high risk ob clinic at Magee-Women's Hospital in Pittsburgh, PA. and we changed our course to having my delivery at Magee-Women's and then having Jonah stay at the NICU in Children's Hospital of Pittsburgh, where the ECMO machine was available.

We, as parents, were to prepare ourselves for a NICU stay after delivering our little boy. Jonah would be delivered, incubated, and sent to NICU after stabilization. Since my husband did not have flexibility of getting time off from his residency program and this delivery was a crucial time in which he would want to be there, an induction was scheduled for Monday, August 7th, 2000.

I labored for two days starting from the morning of August 7th. We wanted to try to deliver Jonah VBAC instead of having a repeat c-section. First day I only dilated to 2cm, so they decided to take me off pitocin and let me sleep through the night without contractions! I started on Tuesday at 5:00 am with pitocin and cervical gel in hopes of making my contractions stronger and labor faster. My labor did go faster and by the end of the day I had progressed to 9 cm. However, it was at 9 cm I stayed. After 4+ hours I progressed no longer. It was at this time that my OB said we should strongly consider a repeat C-Section. And so we did. I went into the operating room approximately 2:30 am, and delivered Jonah Michael Phares at 4:20 am. Jonah weighed in at 8 pounds, 3 ounces.

As Jonah was taken from the room, I was being sewn back together. After surgery I was taken back to my L&D room waiting to see Jonah one last time before he would be transferred to Children's Hospital. They brought Jonah in an incubator which scared me as I wasn't prepared to see him in it. Bob and I said hello to Jonah and told him to be good for the nurses. As I recovered in a private room, Bob rested awhile and then got ready to go over to Children's Hospital to check on Jonah. I didn't like being in a different hospital than Jonah, but that's the way it had to be. Bob told me how beautiful Jonah was and how healthy he looked. In fact, Jonah did so well that day, the pediatric surgical team decided to perform Jonah's surgery as an "add-on" the next day, Thursday, August 10th.

Jonah had surgery on Thursday at 2:15pm. His hole was as large as a half dollar and he had 3 sutures to close it. When surgery was performed, the stomach was not above the diaphragm, rather the colon (large intestine) and the bowel (small intestine) were. The stomach, spleen and liver were all in normal positions. Before closing Jonah's incision, the doctors observed another interesting finding, which they removed and sent to pathology. Weeks later we were informed that the finding was a foregut duplication with gastric and lung tissue. We are unsure if this is related to his primary birth defect.

Jonah stayed in the NICU for 4 days and in the Observation Room/10 South for 2 days. He spent the night with his mommy in a private room on Monday, August 14th and came home on Tuesday, August 15th. This is a day we shall never forget. Jonah was a mild case of diaphragmatic hernia; however, the doctors could not determine the severity of his hernia until they actually started operating. The doctors called Jonah a miracle and superstar patient. They were so proud of his accomplishments in such a short amount of time! The doctors were leery about letting Jonah go home so early, but there was not a good reason to keep him there for his birth weight was fine, his stats were wonderful, and his feeding was terrific. Since the doctors were hesitant to let Jonah leave, they felt they had to give him/us something 'just in case'. So, Jonah left with an Apnea monitor to wear at night or at our discretion. We took the monitor, he wore it once, and never used it again. Bob and I did not think he needed it.

Jonah currently is doing everything little babies do. We are enjoying his energy. He kicks all the time. He loves to talk to us and smile. And we know his lungs work well for he cries loud when he needs us! Jonah's incision is healing well and is getting flatter each day. We massage his incision every day to help the tissue to heal well. We feel blessed to have such a wonderful little boy who began his life on such a bumpy road. We are eternally grateful that God has brought us Our Little *Superstar*, Jonah Michael, into our lives.

Christy Phares (mom of Jonah Michael Phares, 8/9/00, 430 Leonard Avenue, Washington, PA 15301, faithnhope2000@yahoo.com)

After trying to get pregnant for 3 years it finally happened. We were so excited. I thought after the first trimester you were in the clear. And I¹m sure the rest of you know that¹s not true. I delivered my son by C-Section on May 10th 2000 - Tysen Rick Fausett. He was 9lb. 5oz. 20" long and 3 weeks early. And here is his story.

I was having a great pregnancy and all, no morning sickness, nothing. And then it started. At 20 weeks I started bleeding, went home from work called the doctor and he immediately said come in. I went in and they did an ultrasound, and as soon as that probe hit my stomach I knew what I was having. A Boy! He was not shy in the least bit. The doctor looked me over and told me he thinks it is probably Placenta Previa. He sent me to the hospital to have a more extensive ultrasound done to double check his diagnosis. When I went in for the ultrasound at 18 weeks I was diagnosed with placenta previa but everything looked good with the baby. Everything was where it was supposed to be. At 26 weeks I went in for my regular month check up and my doctor checked my stomach and it measured big. He suspected polyhydramnios, so he sent me to a perinatologist in Salt Lake City (300 miles away from home) so he could check it out. The doctor did an ultrasound and looked at everything to make sure there weren't any problems. He found that the baby's heart was shifted to the right side. He looked more closely and then went and had another doctor double check him. He then talked to me about why his heart was shifted. He saw one of his lungs enlarged and he thought it was a mass in his lung. I immediately asked is my baby going to live. The doctor didn't give me much hope at all. He only gave the baby a 10% chance of survival. He wanted a more trained perinatologist to look at me, so he asked me if I wanted to stay in town until Thursday because that was the only day he was in, (this was a Tuesday) but I didn't have my husband with me because he had work deadlines he had to meet. So, I told him I would have to make it the next Thursday. That was the longest 10 Days of my life! I cried more than I've ever cried before. I pretty much told myself my baby wasn't going to live. Everyone else was the opposite, telling me everything was going to be OK. Well the next Thursday rolled around. We traveled up to Salt Lake to see the perinatologist. He did an ultrasound and he looked at everything and I do mean everything. I think I laid on that table for an hour. He finally came to a conclusion. He could see bowel in the chest cavity. He then told us he was 99% positive it was a diaphragmatic hernia. All I wanted to know is my baby going to live? He couldn't tell me one way or another (of course) but he was very optimistic which made me feel better. He had me get dressed and meet him in his office, where he told us all about the condition. He did not sugar coat it, he was very straight up with us. He told us of a chromosome problem, Trisomy 18, that can occur with this condition, but he didn't seem to think the baby had it. He asked if I wanted to get a amniocentesis done and seems how I didn't have maternity insurance we couldn't really afford it, so we decided against it. Not to mention I wasn't too hot on the idea of a big needle being shoved into my stomach. Needless to say I did a lot of traveling back and forth from home to Salt Lake because the doctor wanted to see me every month until 36 weeks and then he wanted me up there for good until I delivered. I had a lot of ultrasounds, and weekly non-stress tests done.

I wanted to deliver my baby up in Salt Lake so he would be close to Primary Children's Medical Center where he would undergo everything. I moved up to Salt Lake on the 3rd of May and I argued with the doctor on why I had to be up there so early because nothing was happening. They were checking my cervix once a week to see if I was thinning or dilating. I almost went back home until the next week, but it's a good thing I didn't because 4 days later on Monday, May 8th my water broke. At that time I immediately called my husband at 11:00pm and told him. I was shaking uncontrollably and very scared. My husband assured me everything was going to be OK. I told him to go back to sleep and I will call him when I get there and find out what's going on. He called me on my cell phone on our way to the hospital and said "if your water broke your going to have this baby, so I am heading up". He had to drive 3 and 1/2 hours to get there so he left immediately.

We got to the hospital, they started me on the drip and a antibiotic and I was so scared that no one knew what was going on with my baby. I told them to call Dr. Ball, my perinatologist in. She told me she would call in the morning, that they knew what was going on. In the mean time Rick got there about 2:00 in the morning, and I was very happy to see him. I felt like everything would be OK now. When I finally dilated to a 10 and 100% effaced I started pushing and nothing was happening. I pushed for 4 hours and the baby just wasn't coming down. The doctor came in and started giving me options. I told him stop right there I don't need my options, just take this baby. I've had enough! 30 hours of labor was about long enough. They got me prepped and ready to go but had to wait a half an hour because of all the medicine that was injected into me. Once the half an hour was up they wheeled me into the surgery room and gave me my spinal block. It was only supposed to numb me from the waist down, but because of all the epidural medicine, it numbed me from head to toe. They laid me back on the metal surgery table and instantly I felt like I couldn't breath. I started freaking out. Swinging my arm trying to grab something, which at the time it was the doctor. The anesthesiologist told me your breathing just fine. I was hooked up to heart monitors so they could see I was breathing just fine. But they put an oxygen mask on me and pumped oxygen into me to help me breath a little easier. He told me to relax and don't fight it. The next thing I knew I passed out. The nurses and anesthesiologist kept waking me to see if I was still coherent. I would immediately go back out. The next thing I knew I woke up. My husband was holding my hand and said "you had our baby". I asked if everything was OK. They told me so far so good.

When they wheeled me into my recovery room on the way there they wheeled me into the NICU unit to see my baby. That was the first time I'd seen him. He was so cute. I was happy he was alive and doing good. It was hard not having a normal baby though. Hearing all the other baby¹s cry and knowing mine was not with me. Having to pump rather that be breastfeeding. But I knew he was where he needed to be. He was in good hands.

At 2:59 AM on Wednesday our baby was born, lots of black hair, and then it all began, the next 5 and 1/2 weeks of recuperating and worrying. Our little boy was a fighter right from the get go. They had a hard time intubating him because he was so (as they put it) "wild". But they finally succeeded. I tried to get up that day and go over to see my baby, but I was very weak, so I didn't get to see my baby that day. My husband brought me back a picture that one of the nurses took of him. I couldn't put it down, That's all I had of my baby for the time being. I showed everyone the picture. Proud mama I guess. My uncle and cousin came up and blessed Tysen for us. My mom came back to my room after they blessed him and she told me that Uncle Russ said everything is going to be OK. This great peace of mind came over me. It was a wonderful feeling. I felt if everything was going to be OK.

The next morning my husband came up to the hospital, and helped me get out of bed to go see my baby. When my husband got there he told me that he got a call from Primary Children's at 10:30 at night and his heart dropped. But all they wanted was to get permission to give Tysen blood if they needed to, to replace what they take out for the blood gases. My husband wheeled me over to the hospital to see our baby. After we scrubbed, we walked into the room, and there laid my son. He looked so lifeless. I began to cry. It was very difficult to see my baby laying there with tubes, wires, and IV's coming out of every part of his body. I don¹t think that there was much of his body that didn't have something or another on it. I just stood there holding his hand, and crying. The nurses told me that he was doing really good. We held his hand, letting him know we were there. The nurses told me that he could tell when we were there, he was content. We gave him kisses and then back to my room. I just slept the rest of the day, between visitors.

On Tuesday, May 16th, Tysen went in for surgery. It went very well, things couldn't have gone better the doctor said. On Friday he opened his eyes and looked at me. I smiled at him and told him that I loved him. I finally got to see my baby's eyes open. They didn¹t stay open very long, he was still drugged up pretty good. On Monday they decided to try taking him off the jet ventilator and just have him on the regular vent. He did excellent! On Wednesday the doctors said they might try him off the ventilator tomorrow. I wanted to be there when they did this so I went up to the hospital the next day and just as I got there, they were getting the stuff ready to take him off the ventilator. They pulled all the tubes from his mouth, he began to cry. I think I cried just as hard as him. But I had to calm down so that I could keep my baby as calm as I could. After about 45minutes his airway was too swollen and his blood gas was too high so they had to put nasal prongs in his nose (C-PAP). That made me cry the hardest. Not to mention he didn't like it at all himself. I came back later that night and they moved him to a different room. IMPROVEMENT!! Friday, May 26th, my due date. I got to hold my baby today. I was in complete heaven!! I actually felt as if I had a baby. On Saturday they took him off the C-PAP and put a nosal cannula on him. He was on oxygen only now. We were so excited! We did get a call from the nurse practitioner that day though, saying that a CBC test they gave Tysen came back abnormal so they wanted to run a spinal tap to test for spinal meningitis. I panicked thinking we just had a major set back. But his test came back negative.

The rest of the two weeks we were there was just getting Tysen to gain weight because of the reflux. Tysen finally was moved out of NICU. As soon as we got to the new room, Tysen's new doctor said let's watch him today and tomorrow and then you can go home. I was ecstatic!!! I was finally going home after 5 1/2 very long weeks. This was the best news I'd had in a long time. It was also a good Father's Day present. On June 16th, Tysen was discharged and I was finally going home with my baby.

We are very lucky Tysen is with us today. He is truly our miracle baby. We are very glad, and lucky he is here and normal. He is 6 and 1/2 months old and doing excellent. It's like nothing was ever wrong with him. He outgrew his reflux and is developing ahead of schedule. I love him with all of my heart and cherish every moment with him, because he could very well not be here with us today. I Love You Tysen!! Love, Mommy

LaNae Fausett (mom of Tysen Rick Fausett, 5/10/00, P.O. Box 3354, Cedar City, UT 84721, 435-867-5536, fausett@color-country.net)

Ashley was bom on New Year's Day of 1997 and thus began her struggle for life. What is supposed to be a joyous occasion turned into a horrible nightmare. I had a uneventful pregnancy with a sonogram at four months. Nothing was found. I was concerned about birth defects as my last pregnancy resulted in my youngest son having a bilateral cleft palate. The doctor assured me to not worry. Further in my pregnancy Ashley was extremely active. I often wonder if this meant anything in hindsight. When she was born the doctor gave her to me and for about 20 seconds I held my fourth child. I noticed she was struggling to breathe and she was immediately taken away and suddenly many people were in the room. My husband heard one of the doctors say he couldn't hear a heart beat. We later learned he couldn't hear her heartbeat because of her heart being displaced. She was life-flighted to a nearby hospital for surgery, which she had at four hours old. She made it through but was still very sick. We managed to get her transferred to Cardinal Glennen Hospital in St. Louis. What a blessing that was! The doctors and nurses are extra special there. There they were going to try nitric oxide so as to avoid ECMO. Unfortunately it didn't work and at three days old Ashley was placed on ECMO. Ashley did great on ECMO and managed not to have any of the awful side effects that is associated with ECMO. On the sixth day, the surgeons were happy with her blood gases and said she could come off.

Then began the waiting for Ashley to be weaned off the vent. After about six weeks she came off. I never forgot the day she came off. They had put her on C-PAP. She looked like something from outer space! I had a feeling she would take a pacifier. The nurses prepared me for disappointment, but they were the ones surprised! She immediately took it and sucked noisily on it. That was one of the happiest moments in my life! Thankfully my favorite nurse in the world grabbed somebody's camera and took a picture of her sucking on that pacifier. I am forever grateful for that picture. It was then I knew she would make it. Now the next bump in the road was getting Ashley weaned off TPN. It took a little longer than the doctors expected because she kept draining fluid from her chest tube (she had her chest tube in for about seven weeks!). I can't remember exactly the reason why the doctors said she couldn't eat regular formula or breast milk, but she couldn't. That was very disheartening because I had saved a lot of breast milk. Finally she got to have her first bottle at about eight weeks old and of course it came right back up. The doctors put her on Zantac and Cisapride. That worked but it was still difficult to get her to eat much at one time so she was put on high calorie formula. Slowly she took more. You know you are ready to leave the PICU when you get moved around a lot! One night alone, Ashley got moved about three times and she couldn't be moved to other unit on the floor because they were so full! Those poor nurses, they do such a fantastic job and work such long hours. Finally she was moved to a regular floor. Another three weeks of trying to get her to eat and we finally got to go home. That was overwhelming! We came home with oxygen, a pulse-ox machine, and a heart monitor. We have had many ups and downs with two emergency surgeries for bowel obstructions. Because of the initial surgery, scar tissue had formed in Ashley's belly causing adhesions to form. This adhesions cause the bowel to stick together causing her bowel to twist. The first one was terrible. She had diarrhea and I thought she had a bug. But the diarrhea didn't go away and then one night she started to scream in pain. Our local hospital was ill-equipped to deal with Ashley. Unfortunately, we waited til morning to get her to Cardinal Glennon. She was very sick and needed surgery immediately. For the next six months, we dealt with tummy aches and several trips to the local ER. One trip led to an ambulance ride to Cardinal Glennon. I felt like a paranoid mother at this point. Nothing was found. A week later she couldn't keep anything down, so back to the ER. This time a helicopter ride to Cardinal Glennon was in order. She recovered so much faster with this surgery. It was amazing she has gone a whole year without any tummy aches. Yeah! She is a healthy and happy three year old now.

My heart goes out to all parents who lose their cherubs and to those who are just stumbling into this nightmare. Take one day at time and remember these scriptures to get you through the day. Rev.21:1-5, John 5:28, 29, Isaiah 25.8

Susan Nugent (mom of Ashley Nugent, 1/1/97, 603 W.N. 1st St, Shelbyville, IL 62565, 217-774-2459)

My name is Clare. I am writing on behalf of my husband Dave and our precious Cherub, Sammy. I have been meaning to tell his story for over a year but haven't found the time until today.

Dave and I were married for two and a half years when we decided we needed a baby to share all our love with. Our first attempt to get pregnant was successful. I guess standing on your head really does work. My pregnancy went along perfectly. I had an ultrasound at three months. We were told things looked normal. I was supposed to have another ultrasound at five months but since the first one was normal and we wanted the sex of our baby to be a surprise, it didn't happen.

I went into labor 10 days before my due date. The labor and the delivery went smoothly and without a single problem. At 2:50 p.m. on October 9, 1999, Samuel Lee Retterer was born. We fell in love with him the instant we saw him. I wanted desperately to hold him but his color was very poor and the nurse said he wasn't breathing. She told us that he probably just had some fluid in his airway but my gut told me it was something more serious. The longer the doctors worked on him the more worried we became. One minute after he was born his APGAR score was 1. Finally, about 10 minutes later, after they intubated him, I was able to hold my sweet Sammy as a nurse pushed air into his lungs. It lasted less than a minute before he was taken away from me to go to the NICU. I told Dave to stay with Sammy.

Half an hour later, two doctors came to my room to tell us the devastating news. Our son had a severe, right-sided, Congenital Diaphragmatic Hernia. He had a 50/50 chance of survival. I was numb with shock. The first thing we thought to do was pray. We prayed only for the Lord's will for Sammy, no matter what his will was. We felt so helpless. We realized we were dealing with something that was completely out of our hands and we had to rely on doctors, nurses, drugs, technology and most of all, God.

About four hours after the delivery, I was finally able to get out of bed. I was wheeled into the NICU to see my son. I thought he would be hooked up to a couple of tubes but what I saw was totally unexpected. Dozens of monitors, tubes, wires, machines and nurses were helping my baby. I broke down in tears as I saw all the things it was taking to keep my Sammy alive. I had to maneuver through everything just to touch his little hand.

Sammy's doctors decided it was critical that he be moved to a hospital that had an ECMO machine in case he needed it. Children's

Hospital of Denver was just across the street from where Sammy was born. At 14 hours old, they transported him. Fortunately, Sammy never needed ECMO.

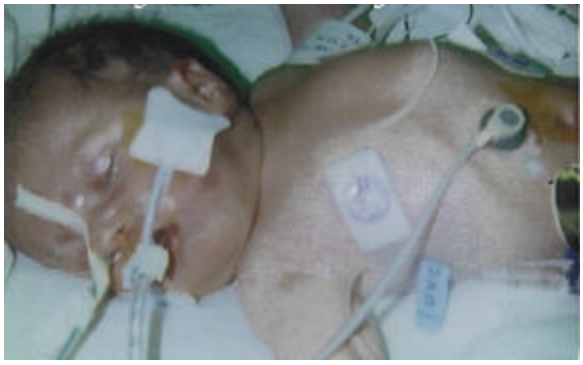
By the time Sammy was four days old, he was stable enough to have surgery to repair the hernia. The surgery was successful but Gore-Tex was needed to patch his diaphragm. Sammy now was on the road to recovery and each day got a little better for him. He was on a high frequency ventilator for about two weeks, then the conventional ventilator for another week and then finally after Sammy extibated himself twice, they put him on oxygen through a nasal canula. He was also on nitric oxide for two weeks along with an assortment of other drugs including several high blood pressure medications. After Sammy proved he could nurse and gain weight we were told he could go home.

Finally, after 34 days in the hospital, we were able to bring Sammy home. We were thrilled! No more crying every time I had to say goodnight to my baby and leave him to the care of others. That was the worst. He left on oxygen. When Sammy was two months old, his lung unexplainably collapsed. His doctors tried several ways to get it open but we have never been successful. We would like to know if any other child with CDH has had a collapsed lung. If so we would like to hear what therapy your child had for it.

Sammy is now 15 months old. He is a very happy and energetic boy. He is a little small for his age but has a big personality. He is walking and has caught up as far as his development goes. He is off all his reflux meds and inhalers but still gets one nebulizor daily for his collapsed lung. Sammy is still on oxygen for about 20 hours a day. We are hoping we will be able to take him off it completely by the spring of 2001. He just battled pneumonia and had to be hospitalized over Christmas. He came through it bravely and quickly. Amazingly, that was the first time Sammy had ever been sick. I am a total germ- a-phobic mother and I guess it paid off.

We want to take this opportunity to thank a few people. Dr. John Kinsella and his team, especially Nancy Wass. Dr. Kinsella is one of the pioneers of Nitric Oxide and was very kind and helpful to us. Dr. Joe Janic who performed Sammy's operation. Dr. Adam Rosenberg and everyone else at the Special Care Clinic who has taken wonderful care of Sammy. The nurses who took care of Sammy when he was born, especially Christy, Brenda, and Amy. Nurses simply do not get all the credit they deserve. We want to thank Dr. Jan Paisley who has been Sammy's primary doctor. Jan has gone out of her way for us and not only been an outstanding physician but a wonderful and loving friend. Finally, we want to thank all of the thousands, literally, of family and friends for their prayers, support and love. There is nothing I can say or write about Sammy to express what a remarkable boy he is. He lights up our days and our lives with his smile. His laugh is music to our ears. His very wet kisses are the reason we get out of bed. We thank the Lord every day for our precious Sammy. I know that He is the reason Sammy is with us. We thank Sammy for coming into our lives. He has brought us so much happiness. He has also brought us closer to God and has made us realize what is really important in this life. We love you Sammy! Thank you for letting us share our story with you and may God bless you and your Cherub always.

Clare Retterer (mom of Samuel Lee Retterer, 10/9/99, 2179 S. Lincoln St., Denver, Co. 80210, 720-570-4022, clave5679@msn.com)



Oh where to begin ... I guess our story begins with Michael age 15 and how much we love being his parents. So much so we definitely wanted more children. It took ten years with eight miscarriages and one ectopic pregnancy, but finally Jennifer was born. We were so happy and still wanting to have more children. Try as we might only to have another miscarriage. At this point we pretty much gave up hope and decided we were fortunate just to have our two beautiful children and we would be happy and give up the dream for more. Well... God had another thought in mind. We found out that we were pregnant again. Matthew Ryan or Elizabeth Rue would be expected sometime in June 2000. We were not sure just when because I was not sure when we conceived. I was so happy. I just could not believe it could possibly be true when we reached the 12th week and nothing bad had happened. We are really going to have another baby! Things progressed as normal. I am a diabetic and require insulin. The shots increased to 4 per day. Small inconvenience to pay for such a reward. But this condition required close monitoring so I was scheduled for a level two ultrasound beginning in my 12th week and to continue every month. Everything looked good! It was time for the ultrasound again and I went to the appointment, alone as always, unaware at the news waiting for me. I must say that the technician was terrific, she showed no sign that something was wrong, but I do remember that it was taking a long time. The name would be Matthew Ryan! Then the doctor come in and my world changed forever. CDH what is that? I had never heard of anything like that. Ok.... Now what do I do was my question and what do we do to fix this. My head was spinning and I was there alone and so scared. The doctor left to call Children's Hospital in Philadelphia. She come back and explained they need films and more tests to determine if we would be a candidate for fetal surgery. So on with the testing. As it turned out we were not a candidate. At the time they did not think the hole in the diaphragm was very large. Good news for Matthew and us. The smaller the hole the better the chances for survival. So on I continued with all my appointments. We never told the other two children there was a problem until later in the pregnancy so they would be able to enjoy the thought of a brother. Michael was so happy; he would finally have a brother. Jennifer was not as excited at first, she wanted a sister. She quickly warmed up to the idea when I explained to her how great it would be to have 2 brothers who loved her so much. Since she adored Michael

this was an easy sell. I saw a doctor for some aspect of the pregnancy at least once a week and the last month, 3 times a week. I had the very best prenatal care a woman can get. I really had thought in my mind this child will do just fine. All these terrific doctors and they are all brushing up with all the latest information on CDH and will be ready for Matthew when he is born. I was getting huge. I was measuring at 52 weeks pregnant by the time Matthew was born. I really worked hard to get him to full term. The doctors told me that had to be my main goal so that Matthew had the best chance for a good outcome. I was on bed rest the last 3 months. I was at high risk for premature labor. Even though I was contracting the last 2 months almost consistently. I really never went into active labor. I was induced at 38 weeks and June 27th, at 7:01 p.m., Matthew Ryan was born to a room full of doctors and nurses. Ken and I were overwhelmed at the amount of people, 17 in all. Matthew was intubated and then rushed off to the NICU for evaluation. One hour later I would see my precious baby, gosh was he perfect looking. How could he be so sick? Reality was starting to set in.

Even after all the appointments and everything I had read from CHERUBS, I still was just now realizing the enormity of the situation. The doctors were terrific and kept us informed. When Matthew was just two hours old we had him baptized. I was so glad his Godmother could make it to the hospital in time for the ceremony. I was in a hurry, just in case! All through the night his condition was getting worse. I had heard the term ECMO from CHERUBS, but really didn't understand what it was and now the doctors were mentioning it to each other. Phone calls to Cardinal Glennon were beginning, they have had the best success with their ECMO unit. At 20 hours of life I kiss Matthew goodbye and he was rushed off to the hospital 20 minutes away. Ken and I would follow as soon as I could get dressed and signed out. The nursing staff was terrific. They had me packed and ready to go in 15 minutes and off we were to be with Matthew. By the time we got there Matthew was prepped and ready to go on ECMO. We could see him one more time. He was really looking sick. All went fine but the doctors were very guarded with his chances. They think the hole is larger than originally thought and this means more organs than expected in the chest cavity and less lung growth then had been thought. We would ride the roller coaster. His first night was uneventful. The next day ironically another child from further away would come in for ECMO…Trevor he was born two hours after Matthew with the same condition. The doctors and nurses were surprised, this had never happened before. This was hard, Matthew and Trevor were never on the same timetable for ups and downs. When one was doing well the other was having big problems and so on. Trevor would have his repair first ... he was really doing poor. Matthew's would follow a week later. His hole was larger, he had almost no diaphragm on the left side and required a gortex patch. The intestines, stomach, liver and spleen had been up in the chest cavity. Both would be on ECMO during the operation. Matthew did great and seemed like he would come off ECMO in 2-3 days. Then the other shoe dropped and he starting bleeding from the chest tubes (he had 3 of them). Then he started retaining fluids from all the blood products he was receiving; soon to follow the kidneys failed. They were able to get them functioning again. But then he was having trouble with his blood pressure. Finally Tuesday, the 18th of July, the day we have been waiting for he will come off today. His stats are good, trials were perfect and they were getting ready. Ken had to go to work, but I would keep him updated. Again I was alone, then Matthew's pressure started dropping. More medicine, but nothing was working and his pressure got VERY low. The call went out to Ken and the rest of the family get here quick. The doctors call heart specialists from around the country- what could be wrong. They did an echo and found nothing wrong. The only explanation was he had become too dependent on the ECMO and they turned the machine back up. The pressures got better, but still not great. Several hours later the decision had been made he would come off and we would let him go with the angels. We left the room while the nurses "got him ready" for us to hold. We came back in and he was dressed in "big boy" clothes. This was the first time he wasn't laying there in just a diaper! He looked so cute! Someone had made him a bracelet for his wrist and was wearing it, he also had a hat on to cover up his enormous head. When I delivered him they had to use suction and for this reason the head had swollen far more than usual. The surgeons did not completely take out the cannulas, but clamped them off and disconnected him from the ECMO so that we would be able to hold him. When the doctor placed him in my arms I remember feeling so relieved to get to hold him while he was still alive. I let out a gasp and said "this feels so good" and then the flashes began. The nurses were taking pictures and recording this moment for us. At the time I felt really odd about this. Now I am so thankful. They are wonderful pictures. My greatest fear had been that he would pass away before he would get the chance to be held by his mother. I knew this was the first and last chance for him to feel our arms around him. Ken and I held Matthew 4 hours as he journeyed on to God. Those were the longest, yet shortest, 4 hours of my life. The happiest, yet saddest also. I was finally holding my son. I had waited 22 days for this to happen. But it would be the first and last time. Matthew I love you so much, and we miss you terribly. We had a very nice funeral for Matthew. Family and friends were terrific. After the gravesite ceremony we all let go of blue and white balloons and sent them to Matthew in Heaven. My sister was really a Godsend. She held back all her grieving during the service to get pictures for me. We have some really terrific shots of all the balloons floating off, just as I imagine Matthew floating off to the heavens.

Michael and Jennifer are doing fine. At first Jennifer thought maybe it was her fault because she was not happy about sharing her room, but now I think we have handled that. But I will be watching her closely. I do have Michael in therapy just to make sure he is ok. Being a teenager is hard enough. But losing a brother who was so loved makes everything turn upside down. Love and prayers are with Trevor who is still in the PICU fighting hard. He has many problems, but has Matthew, his roomy watching over him. Now the question is do we try for another miracle? Only time and God will answer this question.

Dawn Peterson (mom of Matthew Ryan Peterson, 6/27/00-7/18/00, 109 Sunshine Drive, Festus, MO 63028, Sunrise35@aol.com)

2000 Congenital Diaphragmatic Hernia Research Survey Results

Our latest CDH Research Survey Results are being tallied and will be published on our web by February 29th. Included, will be the results of almost 700 membership forms and over 100 CDH Research Surveys. CHERUBS boasts the world's largest research database of CDH patients and we hope that our work will lead to then end of this devastating birth defect.

Our next issue of the Silver Lining will include a brief overview of the results. If you would like a complete print out of the results, please send $3.00 (or $5.00 for international orders) to CHERUBS, 1109 Williamsboro St, Oxford, NC 27565, USA. Please make checks or money orders out to CHERUBS. You can also download these results, along with past year's survey results, for free from our web site at: www.cherubs-cdh.org/research/

It's not too early to get your CDH Research Surveys in for next year! Thank you to all our members who, by just joining CHERUBS, have contributed to helping us end CDH and a special thanks to those members who took the time to fill out the 10-page CDH Research Surveys that each of you received if your child is over 1 year old or a non-survivor. On behalf of future cherubs- thank you!

Congenital Diaphragmatic Hernia On-Line Research Library

On February 29th, 2000 we will be unveiling our on-line Congenital Diaphragmatic Hernia- a project that has taken months to complete but a project that will hopefully benefit our members and the medical community by allowing quick and easy access to medical journal articles and abstracts dealing with CDH and associated birth defects, syndromes, and complications. This is a free service to help parents and doctors looking for information on the latest CDH treatments and research.

A huge thank you goes out to Darlene Silverman, our Research Coordinator, and to the following members who spent many hours searching for articles and helping us set up the search engine; Kathleen Burch, Elizabeth Doyle-Propst, Susan Grubb, Renata Hoskins, Elaine Moats, Michelle Morgan, Margaret Rowe, Cindy Surgis, and Judi Toth.

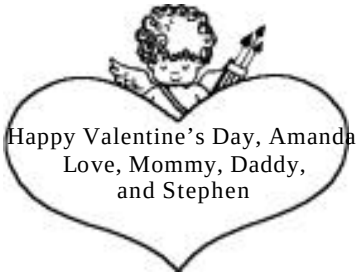
You can search through our library after February 29th by going to www.cherubs-cdh.org

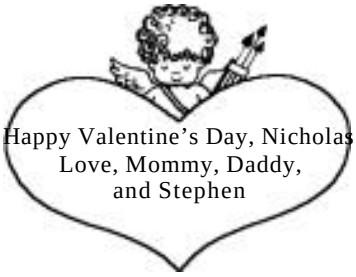
CDH In The Media and Our CDH Informational Video

We are collecting newspaper and magazine articles, as well as videotape of television broadcasts, dealing with CDH and cherubs. The articles will be included in our office photo album, which travels with us to all CHERUBS' conferences and get-togethers and also to medical conferences. We also list them on our web site. Videotapes of television programs featuring cherubs and/or CDH will be used in our new CDH Lending Library, and loaned out to new parents seeking information on this birth defect. If your child has been featured in the media, please send us copies of the articles and let us know how to purchase video tapes of your interview. A big thank-you to Ray Donahue for volunteering to run the lending library for us. Thank you, Ray!

The February issue of Family Circle Magazine is featuring one of our members, Beth Seyda, and tells about her work helping UNC Hospitals in memory of her son, Dylan Seyda Tachman. Be sure to pick up a copy at your local store.

Also, within the next year, we will be creating our own informational video for new parents. We are looking for home videos and professional videos of cherubs in the NICU, on ECMO and other types of support, and present-day videos of cherubs. We are also interested in interviewing parents and surviving cherubs. If you have videotape of your child and would like to be a part of this project, please send those videos in! We cannot return the videos so please do not send in your only copy. We hope to have them ready for distribution to parents and hospitals by the end of the year.





Who Can We Blame?

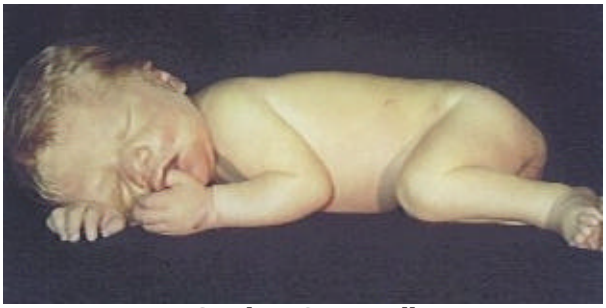
by Brenda Slavin
reprinted from our Spring, 1997 issue

The most difficult part of having a child with CDH is that the cause is still unknown. Is it environmental, medication-related, or genetic? Maybe we won't have that answer soon. Most parents of birth defected children feel somehow they did something to cause it. Some feel maybe they didn't eat right through their pregnancy, or they took medication, or they shouldn't have worked through their pregnancy. I don't think any of these cause CDH. Regardless of what the answer to the cause is, I know it's not our fault. Why would fate deal us such cards? Sometimes the heartache is so overwhelming. I don't think it's a coincidence that we became parents of these children. I view it as an honor from God to be chosen to be the mother of Amanda and Nicholas. Our focus should not be on blaming ourselves rather we should focus on this wonderful gift. That doesn't mean we have to stop researching the cause. But more importantly on surgery and medication and preventative medicine to help those children survive. We are all able to give our children something medicine can never compare to. That is our undying love for them. No matter how long they are here, they know and feel our love. When I was pregnant with our son, Nicholas, we discovered his CDH in utero at 16 weeks. I was not a candidate for the in utero surgery. I continued with the pregnancy with prayer and hope. Although he died 2 and a half hours after birth, I am very grateful for nine moths of bonding and holding him on his way to Heaven. Through a CDH pregnancy, you all know how stressful and confusing it is. Always remember the child inside you can feel your love. And if your cherub is still with us, your love is seen in their precious smiles. It's very easy to be angry in our situation. The problem is, who do we get angry at? Without an answer to the cause, who do we direct it at? Always try to vent your feelings. Talk to a supportive friend or family member. If you don't have that understanding or support close to you, you always have our support, love, and understanding from CHERUBS. You're not a bad parent for feeling overwhelmed. There's a lot of stress and confusion when taking care of these babies. But by remembering how beautiful they are for their strength, courage, and faith gives us our reward… being proud to be given the gift to be their Mommy and Daddy.

CHERUBS' Cookbooks and T-Shirts

We still have a TON of cookbooks and t-shirts for sale. They will make great Mother's Day gifts and the proceeds are going to help us fund our annual International Member Conference. You can purchase them with the order forms that were enclosed in our last newsletter or by ordering them through our web site at www.cherubs-cdh.org/fundraisers/. If you would like another order form, please contact Dawn.

Pictures of Cherubs

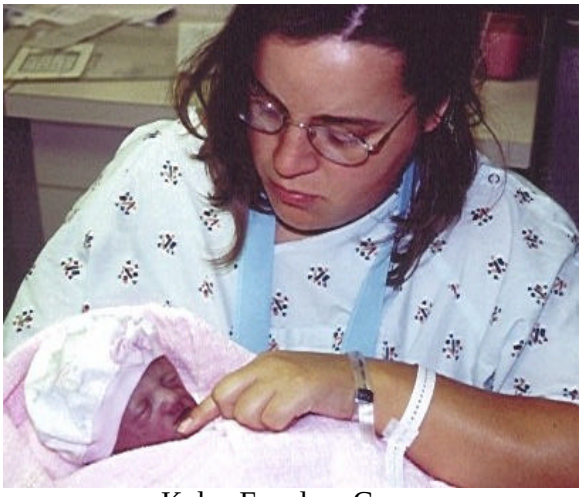


Caroline Grace Dill
10/19/00 - 10/20/00

Raquel Marie Stockwell
4/27/00

Benjamin Aaron Koehler
10/6/97

Laura Ann Condry McFatter
9/12/62



Kylee Freedom Green
10/4/0 0-10/5/00

Cole Matthew Pamula
6/14/97

Dad's Corner

By Jeremy Torrence

Well, it's been a few years since I wrote a Dad's Corner column so I figured I would write another. In case you don't remember what I wrote or you weren't a member then, I'm going to recap on what I had said.

When Shane was born and in the hospital I guess you could say I was kind of the silent partner in our marriage. When it came to making decisions about Shane and his care I didn't know what to say. I was scared of making the wrong decisions. Here was this fragile child who needed his parents to speak out and be his voice, but mommy was the only one speaking. When we had care conferences, bedside meetings or any dealings with the doctors, Dawn was the voice of the family. Here I am the man of the family and I'm scared to death to voice my opinion about the care my son should be getting. I am very, very grateful for a wife like Dawn. She wasn't intimidated by anything, especially doctors. She told them what she thought was the best care for Shane, and she was always right. If she didn't know a solution, she researched enough to make the doctors weigh all the options before they did anything. Why I didn't have the nerve to tell the doctors this I still don't know. I wish I would've been there for Shane and Dawn more while he was in the hospital. I had to go back to work and only saw them on Wednesday nights and on weekends, so I missed a lot.

When Shane finally came home I still relied on Dawn for making decisions about his therapies and doctors appointments. I was like the gopher, if they needed something I made sure they got it. Then I realized that I wasn't being the dad I wanted to be. I started voicing my opinion, doing things I should have been doing all along. When Shane started school, I took him everyday and was learning sign language too. He became my little shadow, everywhere I went, he went. I only wish I would have done all this earlier in his life. He went riding with me, fishing with me, basically everywhere with me except work. You could see a big difference in him and me. I was starting to act like the dad I was supposed to be, the dad I wanted to be. I can't believe I missed out on doing things with him the first 2 years. I don't know why I acted that way, but I'm glad I changed, for my sake and his.

Now I look back and wish I could turn back time to fix what I didn't do, but everyone knows you can't. I'm glad I saw the light and straightened up myself and became an influence on his life and care before it was too late. After losing a child it really makes you look back on his/her life and see all the things you've done whether it be good or bad. Losing a child is hard on both the mom and dad. Being the dad, people always think that you are supposed to be the strong one. Boy, are they wrong. When I'm by myself I think a lot and that's when the emotions normally hit me. When I'm riding home from work, going to the store, or going anywhere by myself. I guess this is because Shane went with me everywhere, the passenger seat in my truck was his. Sometimes I look over and think I see him sitting there, I want to see him there. Dads go through emotional stages too but it seems like everybody consoles the mom. I know that some cases are different but most I've seen this happens too. We are hurting too.

So Dads, if your acting anything like I did the first few years, its time to change, for you and your child. Spend time with them, be involved in there care, voice your opinion. If your child is sick or healthy, please don't take the time you have with them for granted. You may never know how much time you have with them. And if you've lost your cherub, know that it's OK to grieve too and not be afraid to show how much you loved your child.