CHERUBS

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

The Silver Lining

Summer 2001

CHERUBS
1109 Williamsboro St
Oxford, NC 27565

Dear Members,

Many events and projects are happening this fall. Our first Australian Get-Together is taking place in November, our Ohio Get-Together is September 15th, and our Grieving Parents Get-Together is happening in October. Unfortunately, our New England Get-Together has been cancelled until we find a new volunteer to pull it together.

I would also like to welcome Laura Edminston Kelley as CHERUBS' new Secretary. I'm sure Laura will help become a lot more efficient and quicker in our replies to e-mail, phone calls, and letters. Thank you, Laura!

We lost a lot of volunteers over the summer due to many reasons. If you have some spare time and would like to help out other parents, please consider volunteering.

Please make note of our new mailing address. It was just getting too hard to drive 20 minutes one way to pick up the mail constantly from our post office box in another town, so we are changing our mailing address to:

CHERUBS
1109 Williamsboro St
Oxford, NC 27565

We have a new volunteer role for all members that any of you can do with little time and you don't even have to sign up as a volunteer. By becoming a CHERUBS' Hospital Ambassador, all you have to do is go to your local copy store and make copies of our Parent Reference Guide, brochure, newsletters and other items you have received from us. Slip them into folders and drop them off at local hospitals. You can even put a sticker on the front of the folders that say, "This information packet created in loving honor/memory of (your cherub's name)". This is a great way to honor or memorialize your cherub and help out other parents!

Our petition drive is quite pitiful so far, please get those petitions filled out! We can't make a difference without your help!

Dawn M. Torrence
President and Founder

New Arrivals

(*siblings of Cherubs)

Madeline Scout Braxton*
Tara'mais J. L. Brown
Kayci Ann Bunselmeyer
Casey Benjamin Carrow
Noah Adan Chavez
Nathaneil Shane Cheney
Chloe Emma Taylor Childress*
Joshua Shaun Cranston*
Noah Thomas Cranston*
Cameron Faith Gallegos
Nicholas Jacob Gang
Baby Hanabe
Thomas James Hedrick
Hannah Rae Holland
Darren A. W. Honsinger
Gage Inan Hoskins
Achyut Yogeswar Maganti
Maria Lynn Mascary
Emma Beverly McLuckie*
Aaron Matthew Miller*
Phoebe Rose Murray
Kaiya Marie Nuas
Joshua D. Prado
Tyler Seyda Tachman*
Briana Schafer
Madison Lillian Schultz
Michaela Shawn Slavin*
Tyler Jane Smith*
Maya Delaney Sisco
McKayla Lynn Weaver

This Newsletter Is Dedicated To the Memories of:

Kayci Ann Bunselmeyer
Casey Benjamin Carrow
Noah Adan Chavez
Amanda Leigh Durbin
Cameron Faith Gallegos
Nicholas Jacob Gang
Baby Hanabe
Thomas James Hedrick
Hannah Rae Holland
Darren A. W. Honsinger
Achyut Yogeswar Maganti
Kaiya Marie Nuas
Hunter Blake Perry
Joshua D. Prado
Madison Lillian Schultz
Maya Delaney Sisco
James Garry Townsend
Tegan James Walls
Dorothy Sariah Woods

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

Corinne Emily Alexander
Michael J. Bailey
Chloe' Gabrielle Barbee
Baby Boy Bennett
Christopher Michael Boren
Christopher Michael Bowers
Tara'mais J. L. Brown
Mason Evan Bryant
Kayci Ann Bunselmeyer
Kayla N. Byrd
Kevin Matthew Callihan
Casey Benjamin Carrow
Noah Adan Chavez
Jacob Michael Crowley
Amanda Leigh Durbin
Bryce Stephen Eckhardt
Logan D. Edwards
Anna T. Fogarty
Cameron Faith Gallegos
Nicholas Jacob Gang
Baby Hanabe
Thomas James Hedrick
Baby Boy Hoewing
Hannah Rae Holland
Trevor Hoots
Gage Inan Hoskins
Darren A. W. Honsinger
Christian O. Hudson
Hope B. Kuykendall
Baby Girl Langan
Seth David Lewis
Baby Marchesseault
Pietra Agnelli Martinelli
Maria Lynn Mascary
Sydney Olivia Matthews
Emily Grace McConnell
Adam Joseph Donald McLaughlin
Dallas Ann Lynn Miller
Baby Motts
Phoebe Rose Murray
Kaiya Marie Nuas
Baby Boy Oakes
Jarom Isaac Olvera
Hunter Blake Perry
Joshua D. Prado
Nina Heather Prime
Baby Richer
Adrian Alex Ryzak
Braedon Hart Salinas
Maya Delaney Sisco
Michael S. Spencer
Devaron Wes Airen Stanfel
Justin M. Stromberg
Matthew Warren Van Koeverden
McKayla Lynn Weaver
Emily C. Wenig
Samuel Austin Wiggs
Max Anthony Wyatt
Baby Boy Yocum

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

- Adame, Julio Adrian - in memory of his sister, Aileen Iris Adame
- Berta, Kevin, Gina, Kyle & Kelsey - in memory of Ryan Morrison
- Callahan, Ed and Anne - in memory of Bridget Hope Jussaume
- Chancellor Walworth Lodge No. 27 - in memory of Max Kastner
- Chavez, Henry and Monica - in memory of their son, Noah Aden Chavez
- Chow, Mary and Raymond - in memory of Emily Nicole Clark
- Clark, Jason and Melissa - in memory of their daughter, Emily Nicole Clark
- Curlock, Bruce, Pam, Hannah, & Abby - in memory of their daughter and sister, Sydney Elise Curlock
- Dill, Lise - in memory of her daughter, Grace Caroline Dill
- Doades, Kim and Brian - in memory of their son, Nicholas Robert Doades
- Foley, Brian and Joanne - in memory of Bridget Hope Jussaume
- Gomez, Ricardo & Cindy McKernan - in honor of Raquel Stockwell
- Hall, Jeff and Tara - in honor of their son, Brandon James Hall and in memory of all cherubs lost
- Hanabe, Murali and Malini Rao - in memory of their son, Baby Hanabe
- Hawkins, Doretha O. - in honor of her granddaughter, Allison Lane Pruitt
- Henshaw, Mr. and Mrs. Gary - in memory of Max Kastner
- Huber, Lance and Kristin - in honor of their friend's unborn cherub
- Kinkella, Kristen, Kellie Harris, Cynthia Gonzalez, Andrew Degenholtz, Eric Sodorff, and Jennifer Medley – in memory of Jenna Rose Dayton
- Lee, Charles and Judy Yum - in honor of their daughter, Sophie Lee
- Lockhart, Kevin and Vicki - in memory of their daughter, Jane Elin Lockhart
- Manos, Anthony and Amanda - in honor of Raquel Stockwell
- Parker, William and Cyndy - in memory of Madison Anna Thurston
- Rademaker, Pete and Amy - in memory of Curtis Liesmaki, great uncle to CHERUB, Jonathan Luke Rademaker
- Rodriguez, Jimmy - in memory of his niece, Aileen Iris Adame
- Sadler, Linda - in memory of her grandson, Connor Ellis McLuckie
- Skoorka, Grandpa Steve and "Bubbe" Ilene - in memory of Max Kastner
- Southside Hospital, Patient Financial Service Dept. - in honor of Vincent Steven D'Ulisse
- Turner, Suzie and Mike - in memory of Kimberly White-Perez
- Wright, Trina, Randy, and Jacob - in memory of Grace Ellen Wright

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

Laura Edmiston Kelley
Faith Evangelical Methodist Church
Christy Stevenson
James Torrence
Jeannette Torrence
Jeremy Torrence
Tami Torrence

Volunteering at CHERUBS

CHERUBS has recently lost many, many volunteers and we need members to fill those positions! If you have just a few minutes or a few hours a week and want to help other CDH parents, please contact our Volunteer Coordinator, Barbara Wagner at 810-249-5279 or barb@cherubs-cdh.org.

On-Call Volunteers for Non-Survivors

On-Call Volunteer	Phone Number	E-Mail Address
Danielle Kessner	(03) 5135 6999	danielle@cherubs-cdh.org
Michelle Huether	618-853-4157	huether@cherubs-cdh.org
Marion Lansdon	360-882-5502	marion@cherubs-cdh.org
Laurelle Lehmann	250-838-2250	laurelle@cherubs-cdh.org
Amy Rademaker	616-844-4156	amy@cherubs-cdh.org
Amanda McLuckie	214-821-7128	amanda@cherubs-cdh.org

On-Call Volunteers for Survivors

On-Call Volunteer	Phone Number	E-Mail Address
Deeshia Partin	770-919-2162	deeshia@cherubs-cdh.org
Grace Ore	814-833-6421	grace@cherubs-cdh.org
Tara Hall	614-777-4906	tara@cherubs-cdh.org
Ann Peterson	509-735-7208	ann@cherubs-cdh.org
Jeannette Davis	405-670-9937	jeannette@cherubs-cdh.org
Elaine Moats	406-232-5038	elaine@cherubs-cdh.org

On-Call For Families Considering In Utero Procedures

On-Call Volunteer	Phone Number	E-Mail Address
Kimberly Doades	503-625-7343	kimd@cherubs-cdh.org

DISCLAIMER: The information on all pages of this newsletter and on all of our publications is for education only. It is not meant to be used in place of proper medical care and advice. CHERUBS does not encourage or discourage any medical treatments or procedures. Our purpose is to educate families and medical care providers so that they may make the best decisions for the patients' interests. You can not compare your child to other children born with CDH, they are all different. The opinions aired by members are not necessarily the views of all members, staff, or of CHERUBS.

CHERUBS State and International Representatives

Our members are encouraged to contact our Representatives. For your Representative's e-mail address, please visit our web site. Our Representatives are helping members, encouraging new families to join, contacting local hospitals and medical professionals, and conducting such activities as get-togethers, newsletters, parent matching, web sites, on-line chats, and more. We still need volunteers for states that are not listed, states that have "*" by them (we have temporary Representatives for those states), and the following countries; Belgium, Chile, Denmark, France, Greece, Hong Kong, India, Ireland, Israel, Italy, Japan, Mexico, The Netherlands, New Zealand, Norway, 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 our Volunteer Coordinator for more details.

STATE/COUNTRY	REPRESENTATIVE	PHONE#	E-MAIL ADDRESS
Australia	Danielle Kessner	(03) 5135 6999	danielle@cherubs-cdh.org
Canada	Laurelle Lehmann	250-838-2250	laurelle@cherubs-cdh.org
Germany*	Renata Hoskins	907-245-8817	renata@cherubs-cdh.org
Great Britain	Kevin & Brenda Lane	01553 762884	lane@cherubs-cdh.org
India	Shankari Murali	6164934	shankari@cherubs-cdh.org
AK	Renata Hoskins	907-245-8817	renata@cherubs-cdh.org
CA	Sherry Franklin Amlin	916-428-2738	sherry@cherubs-cdh.org
GA	Annette Lichtenstein	404-325-2368	annette@cherubs-cdh.org
IA	Tami Logsdon	-	tami@cherubs-cdh.org
IL	Rachele Alessandrini	708-283-9006	rachele@cherubs-cdh.org
LA	Sheila Ezernack	318-645-9361	sheila@cherubs-cdh.org
MA	Heidi Cadwell	603-878-2283	heidi@cherubs-cdh.org
MD	Brenda Slavin	410-956-4406	brenda@cherubs-cdh.org
MI	Barbara Wagner	810-249-5279	barb@cherubs-cdh.org
MT	Elaine Moats	406-232-5038	elaine@cherubs-cdh.org
NC	Jeremy Torrence	919-692-1270	jeremy@cherubs-cdh.org
ND*	Elaine Moats	406-232-5038	elaine@cherubs-cdh.org
NH	Heidi Cadwell	603-878-2283	heidi@cherubs-cdh.org
OH	Tara Hall	614-777-4906	tara@cherubs-cdh.org
OK	Jeannette Davis	405-670-9937	jeannette@cherubs-cdh.org
OR	Kimberly Doades	503-625-7343	kimd@cherubs-cdh.org
OR	Marion Lansdon	360-882-5502	marion@cherubs-cdh.org
PA	Tammy Sincavage	610-796-7324	tammys@cherubs-cdh.org
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SC	Susan Grubb	864-877-1446	susie@cherubs-cdh.org
SD*	Elaine Moats	406-232-5038	elaine@cherubs-cdh.org
TX	Monica Nedrow	817-329-2402	monica@cherubs-cdh.org
VA	Elizabeth Doyle-Propst	804-293-4602	elizabeth@cherubs-cdh.org
WA	Marion Lansdon	360-882-5502	marion@cherubs-cdh.org
WA	Grace Massie	360-933-0411	grace@cherubs-cdh.org
WV	Sharon Munson	304-947-7162	sharon@cherubs-cdh.org
WY	Kathy Browning	307-332-4759	kathy@cherubs-cdh.org

Grieving Parents Get-Together

October 20, 2001
North Carolina

Our annual get-together for bereaved parents will take place in North Carolina this year (location to be decided, either Raleigh or Charlotte). This event is for grieving parents or grandparents only. This gives our members a chance to talk about their cherubs, share pictures, and meet and talk to other families who know exactly what it is like to lose a child and how it is coping with grief, family members, and friends. For more information, please contact Dawn Torrence at 919-693-8158 or dawntorrence@cherubs-cdh.org.

Stories of CHERUBS

Logan James Roberts was born 3 weeks early on 5 February 1999, at Timory Hospital here in New Zealand, at 6 lbs 1 oz after a short 5-hour labour. A healthy, perfect baby, so everyone thought. He needed oxygen, but so do many newborn babies. I had had two scans during my pregnancy, one at 20 weeks, which was normal, and another at 28 weeks, as my doctor was concerned the baby was not growing properly as I was not very big, (I am only a small frame person), but everything went normally.

It was not until mid-afternoon the next day that the doctors thought something may be wrong. Logan was not feeding. Whatever we tried, he would not suck. So he was taken down to ICU, where he remained until 10:30 p.m. where he was then loaded on to the rescue helicopter, which had been sent down for him from Christchurch, a major city in the South Island, New Zealand, a 2-hour drive north of Timory. We were told what Logan had, but what the heck was that? Why, how?– millions of questions, and as usual, no answers until we reached Christchurch Women's Hospital at 12:30 a.m. Logan was comfortable; we said goodnight to our little boy. I was just a wreck; I did not know what to think or do.

Sunday we met with the top surgeon in Australia who was going to operate or Logan that afternoon. An hour and a half later, Logan was back in ICU. He did really well through the surgery, all of his stomach contents back in the correct place. I could not believe our little baby boy, who was 2 days old, had just had major surgery. He had wires and tubes and a couple of machines all hooked to him.

Then days later we were able to be transferred back down to Timory Children's Hospital, where we spent another 4 days until was feeding properly. With the feeding tube removed, we came home. Finally we were able to be a family.

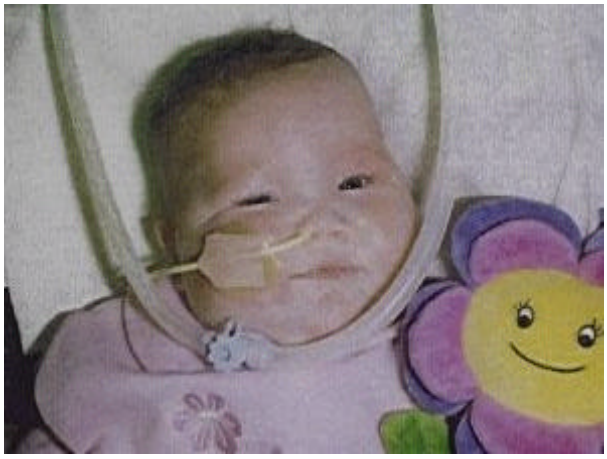
Logan was gaining every week, but he was a fussy feeder. I was feeding him all the time. He was also very unsettled and unhappy. He would not sleep, just scream all the time. It was not until nearly 3 months later that it all made sense. Logan was in so much pain because the scar tissue from his wound had come away, and it was blocking up his bowel.

So we took another trip up to Christchurch Hospital, where the same surgeon performed the same operation. The second time around did not make it any easier on me. But nine days later we were coming home again, hoping never to return, as the same thing happening again is very uncertain.

Well, Logan is now 28 months old. A very active, bright, happy child, not to mention head-strong and determined, but that is why he is here today. A big boy, he often gets mistaken for a 3– 3 ½ year old. He has not looked back since that second operation.

We have had the usual problems with food, but he is not underweight. I know that James and I were very fortunate with Logan, and I feel that we had a very small diaphragmatic hernia experience, compared to most of the other stories I read through CHERUBS. Not that it felt that way all the time. My heart goes out to all the parents who have to live through this terrible experience.

Sharyn Roberts (mom of Logan Roberts, 2/5/99, Elmslie Road, 22 Rd. Orari, Geraldine, New Zealand, 63 6939535)



To our special princess, Hope- After 6 long years of trying and fertility treatment, you were born, Hope. You were a wanted baby. At a 20-week scan, we were told there was a problem, and you were diagnosed with a right-sided diaphragmatic hernia. At 28 weeks, we were told you were a little girl, so that's when we decided to call you Hope. Doctors told us you were rare, as only 1 in 10 babies get right-sided hernias, and you were even rarer because usually only little boys get these sort of congenital defects. At 30 weeks, I had 4 pints of fluid drained from my stomach, as there was too much around you. Three weeks later the fluid had returned, and I went into labour. We were rushed from our home in Seaham, County Durham to the Royal Victoria Infirmary in Newcastle.

On 6th July 2000, at 3:57 a.m., you were born, weighing 5 lbs 7 ½ oz. You were rushed straight to the Special Care Unit, where you were put on a ventilator, then transferred to Ward 3 Intensive Care. Your first 24 hours were the scariest of our lives. We were advised to get you baptized, as they didn't think you would survive the night. We didn't want to tempt fate. Doctors were doing everything they could, but they didn't hold out much hope. It was amazing seeing you improving hour after hour. I don't think anyone could believe how quickly you seemed to improve. After 6 days and many sleepless nights, you were operated on. They brought down your liver, intestines and gall bladder from your chest and repaired your diaphragm. Your operation lasted 3 hours, the longest 3 hours of our lives. Five days after your operation, they tried you off the ventilator but you only managed 1 hour; you just weren't ready. Doctors put you back on the ventilator. On 28th July, doctors tried you off the ventilator again, one hour led to another, then another.

After 4 weeks and 6 days, you were transferred to Sunderland Neo-Natal Unit, to be nearer to home. Then on 26th August, you were allowed home on oxygen. It was only when you were transferred to Sunderland, were we told how lucky we were to have you with us and that you were aptly named. Unfortunately, after 4 weeks at home, you were admitted onto a Paediatric ward, with what doctors thought was probable viral pneumonia. After a couple of weeks, you were transferred back to the Neo-natal unit because your carbon dioxide levels were up. Doctors decided to put you back on the ventilator as you weren't managing to exchange your gases. You had a scan done, which showed your lungs were small. We knew your right lung was damaged, but we never knew your left one had been damaged, too. Over the next 4 weeks, you'd been on and off the ventilator twice. Then on 16th November, your CO2 was really high and you were put back on the ventilator. You needed help to exchange the gases, as you weren't managing to do it by yourself, and your lungs were beginning to collapse.

On 7th December, you were really poorly. Your right lung had collapsed, and doctors were very worried about you. We got you baptized that day. The same afternoon we met the Queen. She came to officially open the new wing you were in. She asked about your lungs, and the doctor told her that you were very poorly and that your lungs needed time to grow. On 13th December, you had a tracheostomy done. Over Christmas you seemed to improve; we had some wonderful times, smiles and giggles and cuddles. Mind you, we had our ups and downs too, infections, your lungs collapsing and those teeth. I think you suffered more with those teeth than anything. Everything else you took in your stride-- needles, injections, blood being taken from you, x-rays, and having to have tubes replaced.

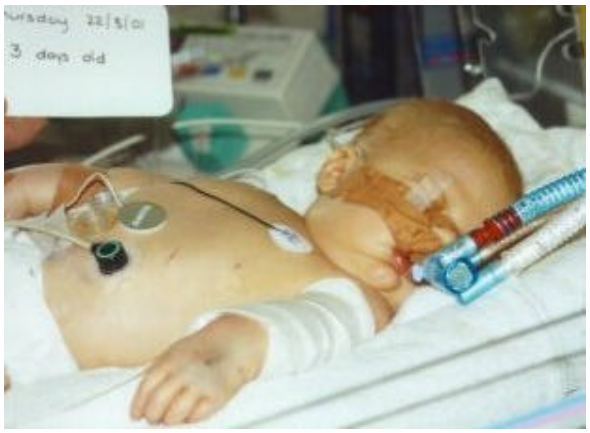
Then on 28th February, you had another bronchoscopy done. It showed no improvement in your lungs. The specialist decided to put your details on the Internet to see if any other doctors had any different treatments to try on you. They couldn't give you a transplant, as you were too young. You had another CT scan on 2nd March, but the results were sent to the specialist at Newcastle.

Then on 9th March, you took a turn for the worse, for all you were being helped with your breathing, you still weren't managing very well. Over the next 2 days, you gradually deteriorated. Doctors did everything they could for you until there was nothing else they could do. At 5:35 p.m., on 11th March 2001, doctors switched off your ventilator, and you peacefully passed away. You were 8 months old; you grew but your lungs didn't.

It's amazing how many people's hearts you touched. Doctors and nurses were like uncles and aunties to you. They were your second family. You'd spent 7 months of your short life in hospital, but you never missed out on anything. When you went, a little part of everyone went with you.

We'll never forget the day our Little Princess met the Queen. You left us many memories, good and bad, and made so many new friends. If it wasn't for doctors and nurses at Sunderland, we wouldn't have had you with us for so long. Doctors at Sunderland gave you that chance. They felt they owed it to you to give you the chance to grow new lung tissue. It's really hard not having you with us now, but if you taught us anything it was "whatever life throws at you, you just keep going," just like you always did. Friends and family turned up to wish you "goodbye," as many people did, even your aunties and an uncle from the hospital. We can't thank them enough for all our precious memories of you.

Mark Scott (dad to Hope Natasha Scott, 7/6/00- 3/11/01, 10 Wynyard Street, Dawdon, Seaham, County Durham, SR7 7LT, Great Britian, 01915818498, Mark.Howe2@btinternet.com)



Emma

You showed courage in the face of adversity
Your spirit shone when dark times loomed
You showed bravery beyond your years fighting to the end
Honoring all who loved you
Your great heart was evident though your body so small
An inspiration to all
And you never gave up though your battle was tough
Unfairly taken from the ones who loved you
Your memory will linger forever in the hearts of all who knew

Remembering always with affection
Emma Margaret West
May your precious soul be at peace

By Mathew May
Emma's Godfather

This is the story of our beautiful little girl, Emma. She blessed our lives. My name is Linda, and I am Emma's mum. Her daddy's name is Dan. In June 2000, we found out that we were expecting our first child. We were a bit shocked at first because we had only been trying for three months and had expected it to take a little longer, but we were very pleased. After getting a positive home pregnancy test result, we went off to see my GP to have it confirmed. We were told our little baby was due on 11 March 2001.

Things went pretty well, and at 12 weeks I decided to take the option of having a neuchal translucency scan. I was so excited that I would get to see our baby for the first time. It was still hard to believe that I was pregnant; I had been getting a little bit of morning sickness, but never actually had to throw up so was managing that OK. My GP told me that this scan would check for things such as Down syndrome. Off I went for the scan; it was amazing seeing the little baby on the screen, my heart just swelled with love. It was real! But I went from one almighty high to a horrible low with a thump. The radiologist advised that the thickness of the skin at the base of our baby's neck indicated an increased risk of Down syndrome; my risk went from 1/380 (round about) to 1/188. We were both scared and worried. We were told we should have some invasive tests done to see if the baby did have Down syndrome. We were told that there were two types of tests we could have done, amniocentesis, or chorionic villus sampling with amnio.

My GP recommended we go to talk to an obstetrician for help in making our decision and recommended Dr. Hill to us. We went and saw Dr. Hill, and in our circumstances, he recommended amniocentesis and recommended a doctor to us. We made an appointment for the amnio and then started on the waiting game. It was (or I thought so at the time) the worst 4 weeks of waiting we had ever experienced. At 16 weeks we went and had the amnio done and everything went fine. But a hint of what was to follow was contained in the doctor's report; it mentioned that it "appeared the stomach was partly in the chest." We saw this and wondered what it meant, but as no one had mentioned anything to us, it must not have been serious. Weren't we wrong!

Two days later we got the preliminary results back, and it was good news. So far, it indicated everything was normal, and the baby did not have Down syndrome, but we had to wait another week or so for the final results. We happily went off on our holiday to New Zealand to visit my family feeling fantastic. While we were in New Zealand, we got the final results, which confirmed that our baby did not have Down syndrome; everything with the baby's chromosomes was normal. It was like a load off our shoulders, and we were looking forward to the rest of the pregnancy.

We were booked in to have a 20-week scan when we got back from our holiday. Our world collapsed when we were informed then that the baby had a diaphragmatic hernia. I have never been so scared. What was this "diaphragmatic hernia"? What did it mean? The obstetrician who did our scan and amnio recommended we go straight to hospital to advise them, which we did. Luckily, a nice nurse was on duty at the antenatal clinic that I attended at the Royal Women's Hospital. She arranged for a neonatalogist to speak to us about and explain what was wrong. When we were told that we could not underestimate the seriousness of the condition and that our baby could die, we were absolutely stunned. This was not supposed to happen to us; what had we done wrong! The doctor was very good and drew diagrams and explained in as plain a language as he could what would have to happen. As you can imagine, we were full of questions. We were told that the baby would need to be taken from us immediately after it was born, sedated and intubated, and placed in intensive care; when they were happy the baby was stable, they would look at operating. We could expect our baby to be in hospital for 3 to 4 months. We walked out of there in shock.

We were back at hospital the following week to see an obstetrician and find out more. It was the beginning of what seemed like 1,000 visits to hospital. After not liking the first obstetrician we saw, we switched clinics to Dr. Hill's, the doctor we had seen privately before this diagnosis. We both liked Dr. Hill and were comfortable with him looking after us. We were determined to do everything we could for our little baby. Thankfully, it was around this time I found Cherubs. It answered a lot of questions for me. My way of coping was to find out all I could and be as prepared as I could.

We then began the cycle of monthly appointments, ultrasounds, etc. We had decided not to find out our baby's sex. I had been diagnosed as having polyhydramnios, common with babies with CDH; otherwise, I was feeling okay, getting bigger, feeling lots of movement. We had a meeting with Dr. Kimble who would be performing the surgery. After being on an emotional roller coaster for a couple of months, he instilled some confidence in us, and we felt better; it was not hopeless. He told us that babies who did well usually did really well, and those who did not do very well, didn't. It was up to each individual baby.

At 31 weeks, I ended up in hospital. I had been at work and was having lots of what I thought were Braxton Hicks, but realised they were coming a bit thick and fast for that. I rang hospital, and they said, "Come in; we had better have a look at you." I stayed there for three nights, with two trips to the labour ward, as they thought I was in early labour. I had two steroid shots for the baby's lungs. Fortunately, my cervix remained long and closed, and they managed to stop the contractions and sent me home. My obstetrician advised I had an irritable uterus due to all the extra fluid, and I would have to take it easy and finish work. We were told the baby would probably come early. We had another couple of trips to hospital, which were false alarms, and our baby's due date came and went.

The time before Emma's birth had been tough, but we knew we were in for tougher. I was not very patient before all this, but feel I am a more patient person now. Some things are just beyond our control. We had received lots of support from our families. But I felt some members of the family did not really understand the seriousness of the matter.

I was getting a bit fed up of it all when her due date came and went. I wanted her out! I wanted the next stage to start. I went for my weekly appointment four days before she was due, hoping my doctor would say, "If you have not had it by Monday, come in and we will induce you." But he checked me out and said it was not safe to be induced yet. I was a bit disappointed but realised there was nothing I could do; the baby would come when it was ready and while I was carrying the baby, I knew he or she was safe. The following week when no baby had arrived, he decided that if I had not gone into labour by Sunday, to come in and he would book me in to be induced. It was a bit scary. We had a date and things were going to start happening!

My mum came over from New Zealand about six weeks before our baby was due (as she was supposed to come early!), and then two weeks before she was due, my sister and father arrived. I am so glad they did; they were there when Emma was born and shared her entire life with us. Danny's parents came down for her birth as well.

On Sunday evening, I was admitted to hospital and had the gel placed on my cervix. Danny was with me and stayed for a while but we were told that nothing would happen until the next day so he went home. That was about 10:00 p.m. I tried to get some sleep (fat chance!) and about midnight asked for a sleeping tablet. This did the trick, and I got about 4 hours sleep, waking at 2:30 p.m. I started to get small contractions and had a lot of what felt like bad period pain. It was 3:30 p.m. when I was lying on my side that I moved and felt a "pop." I remembered my mum saying that when she was having my brother she felt a pop before her waters burst. I rolled over and sure enough my waters came gushing out. It was the weirdest feeling. I called the nurse, and she changed my bed, etc. There was no turning back now! About half an hour later, the contractions started to increase in strength and frequency. I rang Danny at 5:00 a.m. asking him to come in. I needed and wanted him with me. At around 6:00 a.m., Danny arrived at hospital with my mum, dad, and sister in tow, all looking a bit bleary-eyed. It was the start of a long day.

About 7:00 a.m. they took me down to the labour ward. I had decided I would have the baby by lunchtime (again WRONG!). I needed pain relief not long after that, so I tried the gas. It did not do much for me, and around 9:00 a.m. I asked for an epidural. At around 12:40 p.m., I was 3-4 cm. dilated. Things were going pretty slowly. I was hooked up to saline, syntocin, and the fetal monitor and was not allowed off the bed. Baby was doing fine. I managed to get a bit of rest in the afternoon, and Danny got to have a snooze on the comfy chair they had in the labour suite at the same time. At 5:40 p.m., I was fully dilated and bubs was in the right position, so the midwife said I would be able to start pushing in an hour or so. I started to push about 7:00 p.m., but after an hour and a half of pushing and getting nowhere, I was exhausted. It had been a long day, and I felt like I was getting nowhere. They'd had to turn my epidural down as my blood pressure dropped. I was starting to get distressed, but bubs was doing ok. I just knew I could not push her out, and I was disappointed with myself. I felt like a wuss, complaining; my back was killing me, and I could not get comfortable. The midwife called the registrar in and she checked me out; they then discovered that she had turned posterior and appeared to be stuck, so they called my obstetrician.

While we were waiting for him, the midwife said I might have to have a caesarian. I was prepared to do whatever they felt was right, but from the start, my doctor had said he wanted me to give birth vaginally. Dr. Hill arrived, checked me out and immediately took

charge. He decided on a vacuum extraction, and they would try to turn her. I was immediately calmer and listened to the instructions they were giving me about what I had to do. Once I knew that I was going to have some help, I felt a lot more confident. Twenty minutes later (at 9:39 p.m.), our beautiful little girl came into the world. She was placed on my chest for a brief minute and then whisked off by the midwife to the resuscitation team waiting outside the door. We never really saw her, just her sore little head from where the vacuum had been, but we heard one cry from outside the door, and we both looked at each other, our hearts filled with love. They were happy with the way she responded to the intubation, and she was taken up to the ICN. They brought down photos of her shortly after; she looked just like her dad.

I did not get out of the labour ward till 1:00 a.m. the next morning, as they were very busy. We all went up straight away to the nursery to see her. They arranged for the chaplain to come in, and we baptised her. I got back to the maternity ward at 2:30 a.m. and was put into bed. Danny, my Mum, Dad and sister Megan then left; we were all exhausted. It had been a long day! I have to say that I would not have made it through without my wonderful husband. He was fantastic. They gave me a tablet so I could sleep, and I woke 4 hours later just relieved that they had not come and woken me during the night, so my little girl must still be alive.

She remained stable for the first day, but was on maximum support. She took a couple of turns for the worse, but managed to work her way back again; she was a real fighter. It was hard seeing her lying there. All we wanted to do was to pick her up and run away with her. We sat with her, talked to her, told her how much we loved her and all the things we were going to do with her when she came home; we also read stories to her.

The surgeon came round to see her, but he was not happy with her condition. She was not making any headway. The doctors advised us that she was on maximum support, and she had to improve before surgery could be considered, as she would need more support after the surgery. This was heartbreaking. The Tuesday I was in euphoria--we were parents. It was the most wonderful feeling, but mixed with this horrible fear we would lose her. On the Wednesday, the tears flowed quite often. I could not sleep on the Wednesday night; I woke up in the middle of the night, and my thoughts were filled with Emma. I asked the nurses for some paper and an envelope, and I sat down and wrote her a letter. When I finished the letter, I went to the nursery. I had to see her. They put the letter in her cot. I wanted it to be with her all the time, as we could not be there every minute of the day. I wanted a part of us with her.

On the Thursday morning, I was up and hoping to be discharged. I went up to the nursery and read her a story. Danny arrived just as she took a turn for the worst. Megan, my sister, was there, too. She managed to improve slightly but not up to what she had been. We spent the morning with her and took more photos. At lunchtime, I went back to my room, saw the doctor and was discharged. We had 1,000 things to do. We went to buy a mobile phone so that when we were not at the hospital they could get hold of us at any time. I rang that afternoon and called to see how she was doing. She was still the same, no improvement. I told her nurse that we would be in around 6:30 p.m. – 7:00 p.m., that we were just going to have some dinner.

We got to the hospital about 7:10 p.m. I was walking in when the nurse came towards me. For some reason, I had hurried ahead of the others; they were washing up as was required. I just had to see her, so I went on ahead of them. One look at her face, and I knew that my little girl had gone. They had tried to call us, but we were on our way in. It had happened so quickly; she died just before we got there. I turned and looked at my husband who was about 20 metres behind me, and he knew as well. That moment was the worst we had ever experienced and will be the worst we ever experience. We ran to her. She looked so beautiful, so peaceful.

They took the respirator out, and we were able to hold her for the first time. The staff at the nursery was fantastic. We held her by her cot for a while, and then they took all the other leads out, and I carried her to a special room they had. We held her, kissed her, cuddled her. My parents and my sister did as well. Danny and I gave her a bath and then dressed her in a little outfit I had bought for her. We then held her, kissed her, cuddled her again. During this time we took lots of photos. This time we spent with her was so special; we will never forget it. She was our most beautiful and special daughter.

The hardest thing was leaving her. We went and saw her again the next day and held her again. I had to because I was having trouble believing what had happened. I had to see her again. We laid her to rest after a beautiful service the following week.

Emma will always be with us in our hearts, until we see her again.

Linda and Daniel West (parents of Emma Margaret West, 3/19/01-3/22/01, 524 Robinson Road, Aspley, QLD 4034, Australia, 07 3263 4203, lwest@powerup.com.au)

My husband John and I spent a year and a half trying to become parents. Finally, with the help of a reproductive endocrinologist, we found ourselves expecting twins. Because of my age and because there were two babies, the high-risk OBs kept watch over our progress with frequent ultrasounds. We found out that our twins were a boy and a girl—perfect!

About 20 weeks into the pregnancy, the doctors swept away the happy blue and pink fog we were living in. They noticed that our son's heart was on the right side of his chest rather than on the left. After a couple of weeks of observation and speculation, they informed us that he had a left-sided congenital diaphragmatic hernia (CDH), and that some of the contents of his abdominal cavity were protruding into his chest and pushing his heart over. The literature they gave us on CDH, (pages photocopied from a medical textbook), described the surgical repair and estimated a 50% chance of survival. It also gave a long list of possible complications and after-effects, some of which could last a lifetime.

Next, the doctors began closely examining Richard's tiny heart. They thought they could see a hole in the ventricle separating the two lower chambers, or a ventricular septal defect (VSD). They explained that a VSD can be quite serious, but that it is at least a birth defect with a longstanding solution. Successful surgical repairs have been done for decades. Provided the hole is not

too large or awkwardly located, and provided the surgery is done well, the baby usually gets well quickly and has few to no long-term problems.

The senior OB had just returned from a conference where he had seen a presentation by a pediatric surgeon who claimed to have a high survival rate with CDH babies. Luckily, this surgeon was at Shands Hospital in Gainesville, Florida, only 75 miles south of where we live in Jacksonville. The OB also explained that many CDH babies need a bypass machine called ECMO, which they have in the NICU3 at Shands but do not have at any of the hospitals in Jacksonville.

Shortly thereafter we visited Dr. David Kays in Gainesville. He impressed us with his confidence and energy and with his record when it comes to diaphragmatic hernia kids. He has a 92% survival rate with CDH babies, as opposed to the usual 50-60% rate. Dr. Kays attributes his success not so much to the way he performs the surgery—many good pediatric surgeons can repair a diaphragm—but to the timing of the surgery, the timing and administration of other treatments both before and after the surgery, and especially to the "gentle" ventilation he uses to avoid damaging delicate, neonate lung tissue.

The delivery of the twins is a story in itself--suffice it to say that at 34 weeks gestation, both babies were delivered in Gainesville via C-section at 12:04 and 12:05 A.M. October 17, 1998. Isabel weighed 3'14" to Richard's 4'13". As the OB lifted him out and swooped him over for me to give a quick kiss, Richard gave one hoarse cry. I had been told he wouldn't be able to make a sound. Dr. Kays, who had been called at his home at 11:30 P.M., was in the delivery room. He and a respiratory therapist ventilated Ricky immediately.

After birth, we found out that Richard had a considerable amount of bowel in his chest cavity along with his spleen. The heart defect stopped being a possibility and became a certainty. He had a medium-sized hole in his septum. Each defect was bad enough to be considered serious on its own, which made the combination grave.

Dr. Kays literally spent days at Ricky's bedside in the beginning. He used a patch to repair Ricky's diaphragm when he was about 34 hours old. The surgery went well, but the pulmonary hypertension that is usual with CDH kids set in with a vengeance. Within hours of the surgery, Dr. Kays had to hook Ricky up to VA ECMO to give his lungs a chance to rest.

The dangers of ECMO had been described to us, especially the potential for brain damage. The nurses relieved our anxieties a bit on this score, because we could see that they were extraordinarily careful. Around the clock they checked equipment, looked for clots in tubes with a flashlight and, when Dr. Kays wasn't in the unit, phoned blood gas numbers to his beeper. He read them, day and night, and phoned back with adjustments for ECMO and/or ventilator settings. Ricky never had a problem. ECMO looks intimidating with its garden hose-sized, blood-filled tubes, especially to someone unused to hospital sights. We became grateful for it anyway, because it definitely helped save our son's life.

Towards the end of Ricky's third week on ECMO, Dr. Kays left to speak at an out-of-town conference, and another pediatric surgeon took over our baby's care. Dr. Langham had just returned from the same conference to which Dr. Kays was going. On his Friday evening round, I told him that we were eager for Ricky to get off of ECMO.

Earnestly, Dr. Langham told me that he had presented Ricky's case at a roundtable discussion at the conference, and that the pediatric surgeons there had said "to a man" that they would "withdraw therapy" and let him die. He wanted to let me know that we "shouldn't necessarily expect a positive outcome." Ricky's CDH problem was serious on its own, and few babies with an additional heart defect had ever survived.

I was distraught at first, especially with Dr. Kays out of town. When I told my husband what Dr. Langham had said, we commiserated, then pulled ourselves together a bit and decided that, for some reason, we both still believed that Ricky would get well. Dr. Kays had said before he left that he thought Ricky was getting stronger and could make it, and we thought so too—we just wished we could know for sure. We were concerned, however, about having a doctor who felt pessimistic about our son's outcome in charge of his care.

Dr. Langham may have thought Ricky was losing the battle, but to his credit he did not stop helping Ricky fight. Over that weekend, he managed to get Ricky off of ECMO. Instead of reducing the flow of blood, he reduced the amount of oxygen going into the blood. (I may have that backwards.) After 21 days of dependence, Ricky hung in there and got rid of the machine. Gone were our reservations about Dr. Langham!

Ricky's next achievement was supposed to be getting off the ventilator. Everybody hoped he would be able to breathe on his own before he had surgery to repair the hole in his heart. He could not do it. The VSD caused his heart to shunt extra blood to his struggling lungs, which made them too wet and heavy for him to breath unassisted for any length of time. This meant that Dr. Kays had to lobby the cardiac surgeons to go ahead with the VSD repair as quickly as possible.

Like most organizations, hospitals are endowed with a certain measure of politics, a pecking order, territories, etc. The two cardiac surgeons who helped Ricky, Dr. Knopf and Dr. Alexander, are wonderful people and fantastic doctors, but they did not relish having a pediatric surgeon telling them when to perform a surgery on a patient, nor did they want him managing that patient's ventilator settings during and after the procedure. It took delicate persuasion and persistence—Dr. Alexander informed me that "if Dr. Kays tells me one more time about that baby's lungs, I'm going to throw him out that window over there"—but Dr. Kays convinced them to go ahead when Ricky was about six weeks old.

The heart surgery went well. It left Ricky wiped out, of course, and there were niggling issues about keeping his heart in rhythm, but Dr. Knopf (another of Ricky's saviors!) had done an excellent job, and within a month Ricky got off of the ventilator for good. He grew stronger, more alert, and gained weight. We thought it would be smooth sailing from there, and in many ways it has been--he has never been in danger again--but we never reckoned on the feeding problems.

Like many CDH babies, Ricky had gastroesophogeal reflux. Because he had been on a ventilator during his first two-and-a-half months of life, he hadn't had a chance to suck and swallow at a crucial time. In fact, he had been on IVs and had never even had anything in his stomach until after he got off of the ventilator. To make an extremely long, frustrating story short, we tried everything to get him to eat on his own. He did eat, badly, reluctantly, but he didn't gain weight.

The solution offered to us was another surgery, a Nissen Fundoplication, which would prevent him from vomiting. This would not only help to make him more willing to eat, but would protect his lungs from damage caused by stomach acid. During this procedure, Dr. Kays would also insert a G-tube into Ricky's abdomen that would enable us to put formula and/or breast milk directly into his stomach.

The Nissen sounded like mutilation to me. Occasionally, during a lifetime, a person needs to throw up and frequently needs to burp. I wanted my son to be able to do both of these things on an as-needed basis. The G-tube didn't sound so bad because it was a measure to temporary help him grow and make up for lost time.

After six weeks of nurses, occupational therapists, and us trying to feed Ricky enough, John and I finally agreed to the surgery. Dr. Kays

gave him the Nissen, inserted a G-tube, and circumcised him to boot.

Ricky recovered rapidly, and all four of us went home as a family when he was 4½ months old, March 6, 1999. He weighed 8 pounds 4 ounces.

Thanks to Dr. Kays' gentle ventilation, Ricky's lungs are in good shape. He never needed oxygen at home. Although it takes him about a day longer than his sister to recover from a cold with a cough, he's never had any serious respiratory complications and has no asthma. At 33 months of age, he does not appear to have any brain damage, neurological damage or hearing loss as a result of being on ECMO for such a long time.

Ricky's eating has slowly improved, and his G-tube was removed in November of 2000. He now enjoys food. In fact, he samples new things with more eagerness than does his sister. Unfortunately, he still doesn't like to eat the quantities he should, so he remains thin. However, he is gaining weight (26 pounds and some change now) and growing (36 inches tall) without a G-tube.

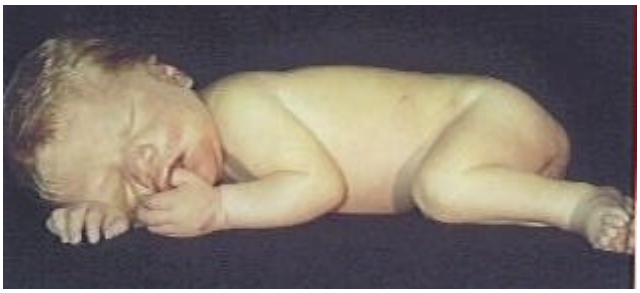
He has had some mild developmental delays but is catching up rapidly. At two-and-a-half he was discharged from speech therapy and will finish physical therapy and occupational therapy when he's three. He's mostly where he should be or even ahead of himself, but there are small gaps here and there in what he knows and in what he is able to do.

I was afraid that all that time in the hospital, three surgeries, needles, tubes, etc. so early in his life would make him mistrustful and withdrawn, but he's just the opposite. He's an affectionate kid who loves to cuddle, likes to meet new people and talk to them, and who even gets along with his sister most of the time. He tells jokes. Last week he turned to me after watching a movie and, as slyly as is possible for a 33-month old, said "Mary Poppins changed my diaper!"

Ricky had the following strikes against him in addition to his CDH; he had a serious heart defect, he was six weeks premature, he was a twin.

Our son was terribly, terribly sick, but he isn't now. The care he received in Gainesville certainly saved his life. John and I thank God every day that we found Dr. Kays. Our hope is that the techniques Dr. Kays uses at Shands will soon become more widely understood and accepted so that more CDH babies can go home with their families.

Catherine Snow (mom of Richard Carl Snow, 10/17/98, 8443 Sanchez Road, Jacksonville, FL 32217, 904-731-9183)



The day I found out I was pregnant with Grace, our fourth child, I went to my dad's house and asked him to tell me the story of Sarah and Abraham (in the Bible). As he recanted the story, he yelled "YOU'RE PREGNANT?!" He asked, just like he did with my other children, what I felt this baby was. I said, "A girl, but I just have a feeling she is going to have problems." I was 6 weeks along and what I felt was doom. At almost 4 months, I was lying in bed on my back. I noticed that it lumped below my belly button. I said to my husband that that wasn't normal. The next week after my AFP came back, my doctor informed me that the baby had CDH. I was alone with my 4 year-old. He had never bothered to call me to tell me to bring in my husband. The ride home was long and torturous. I arrived home, crying and went right to the Internet. It was then that I found CHERUBS and that our daughter's chance of living was 20%. As I progressed in the pregnancy, my daughter lay transverse always and never really moved at all. I never felt her above my belly button, even at 8 months.

Our world was about to get much worse. At 6 months, I had an amnio. When the doctor left to prepare the vials, Mark asked me if there was anything he should ask the doctor. I said, "Ask him if we have to bury our daughter." And with that, all the pain just escaped. I had wanted and prayed for this child for four years. We had to deliver the fluid to the lab. We walked in, gave the vials and left with nothing. It was all too fate-like. I knew then that we wouldn't be taking our daughter home from the hospital. A few weeks later, we had the results back that said Grace had Trisomy-9, rare as can be, with 200 people worldwide possessing it. We had no idea what her facial features would look like. They showed us a picture of babies with half their skull caved in, just gruesome. I now know 1 in 4,000,000 get it. Someone said that it was like hitting the lottery. I didn't feel that way at all.

When we arrived home and called the insurance co., we found out that they would pay for practically nothing. We had 3 other children to think about. We both decided to terminate. I wrote to CHERUBS for support. For 3 days, I cried my heart out. After talking to my doctor, who is a Christian and praying, I called Mark and said I just couldn't do it. He agreed. I hated every minute of the pregnancy. I hated seeing other moms rubbing their stomachs. Knowing she was destined to go to her Creator was too much for me to bear. I knew exactly what we would be missing: her first smile, her beautiful head of wavy hair, the eyes that would turn a brilliant blue, her 1st birthday.

She was born, via C-section, Oct. 19th at 11 a.m. She was covered in yellow goop. They told me to look to my right, and I'd see her. She was perfect but not breathing. Mark went with her, and I lay there crying. The nurse at my head wiped my tears, telling me it was OK to cry. They wheeled her to me, and I stared at her. After she left, I said to Mark, "Why is she so ugly?" Mark said, "She isn't! She's beautiful." As I was wheeled into recovery, everyone including my children, were there. They all said Grace was pretty. The doctor came in later and said, "You have a very sick little girl..." I don't remember anymore. I asked her why she was being so grim; my daughter WOULD live. They wheeled me to see her. Grace opened her eyes. I *wish* I stared back. She never opened them again. I don't remember all the drugs they gave her. She hung on for 33 hours. At 7 p.m. Friday night, I was in my room alone, crying and reading a Bible. My pastor walked in. I took him to go see Grace. He prayed over her. Her body was shutting down, and they said she was probably in a coma. Mark showed up then, as did my dad. I held her as she died in my arms. I cried to Mark that I never got to comb her beautiful hair. They had us carry her to a room, and we spent some time passing Grace around.

We buried Grace naked. The first thing I want to touch when I get to heaven is her skin. My children constantly let go of balloons we get

for their sister and her cherub friends in Heaven. We hear the name Grace everywhere.

We did manage to conceive again within 6 weeks. It was a surprise because it took us 4 years and IVF treatment to conceive Grace. We are due in 10 weeks with a very healthy boy we named Joshua, which means salvation.

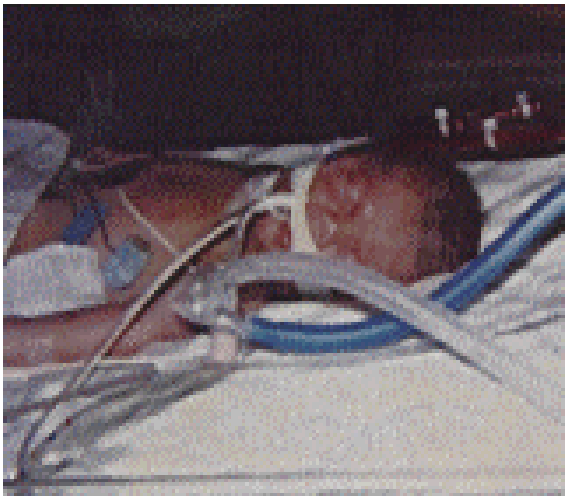
Lise, Mark, Jason, Victoria, and Nick Dill (family to Grace Caroline Dill, 11/19/00-11/20/00, 7919 E. 87th St, Tulsa, OK 74133, mdill12@juno.com)

Samuel Austin Wiggs was born on January 11, 2000. He was due to arrive on February 2, 2000. My labor lasted about 21 hours. When he was born, he didn't cry like most babies do. He sounded like a kitten; then he just stopped. The nurse handed him to me, and I held him, not knowing that anything was wrong. He was so beautiful. After a few minutes, he started turning blue and grunting, so the nurse rushed him to the nursery. I was alarmed, but did not expect it to be anything serious. Four hours later, the pediatrician came in and told me I had a very sick little boy. My heart sank to the floor. He went on to explain the birth defect, but I don't remember his words, only that I thought my baby would not make it through the day. They were sending him to a children's hospital, so the transport team brought him in to see me. I thought it would be the last time I saw him. I cried and held his hand, telling him to please be strong for me. I don't ever remember a time when I was so broken-hearted, to see my child hooked up to tubes and scared.

The next day I left my hospital to see him. I walked in the NICU, not knowing what to expect. To tell the truth, it sounds horrible but I didn't want to see him, because I was so scared. I walked in and a group of doctors, social workers, etc., came up to me. I looked at him lying on his little bed, and I just wanted to hold him. The doctors explained that he was sedated and could not feel any pain. They were going to wait until he was stable to do surgery. Every night we called to check on him. One morning the hospital called and told us to hurry, that he might not make it through the day. I went and held him, thinking it would be my last time holding him. I have never cried so hard. I went into a room by myself. I wanted to be alone. I thought to myself that it was meant to be, so I had to accept it. I somehow found peace and went back in to see him. Much to my surprise, his oxygen levels went back up. The doctors told us he could not go on ECMO because he had a level 4 bleed to the brain. So the vent was his only option. We were just happy that he was alive. He had his surgery; that went great. He was extubated on Valentine's Day. Because of his bleed to his brain, he got hydrocephalus and had a shunt put in. Samuel came home on March 6th, 5 days after my birthday.

He is now 16 months old. He has cerebral palsy due to the brain damage. Also, he has seizures and cortical blindness. He is the light of our lives; he is such a blessing. He has the biggest smile that will warm anyone's heart. Seeing him now, you would never think he was so sick at one time. I learned to never underestimate a baby.

Elizabeth Gwaltney (mom of Samuel Austin Wiggs, 1/11/00, 17372 Woodland Dr., Windsor, VA 23487, 757-255-2190, luvbbyaustin@aol.com)



My name is Lisa Coleman. I'm 26 years old, a mother of 3 children, one of which was born with a left-sided CDH. My daughter's name was Trinity A. Coleman. She is a non-survivor. She was born 9/29/99 and passed away 10/15/99. She lived a hard 16 days. It's taken almost 2 years to write this letter. Also, I want to spend a moment to send a special thanks to one of your On-Call Volunteers. She stayed in touch with me during my pregnancy. I was one that found out in utero. She also spent time in Columbus, OH with me and my family. She was there for support every step of the way. She was there the day Trinity passed away, also the day of her funeral. Her name is Dawn Halley. Something happened in her life that I haven't heard from her again. Her daughter, Ashley, is a survivor of CDH. But I send her my love and thanks everyday in my prayers.

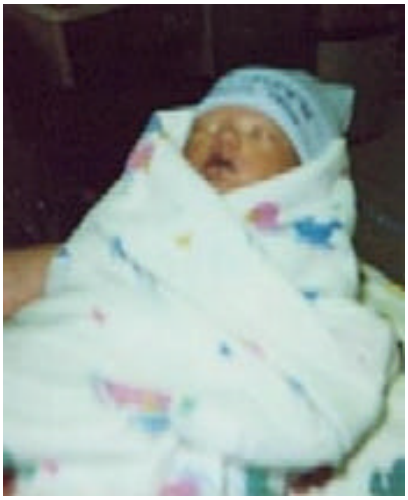
I want to write you in reference to your Spring 2001 newsletter and your story. I don't look down on you for even trying to file a malpractice suit. I tried the same thing. The doctor went and gave Trinity her first surgery after taking her off of ECMO. It was my 25th birthday, October 4, 1999. I was so happy; it was the greatest birthday present a mother could ask for. I thought for sure she was going to make it through all of this OK. But after hours of her surgery and waiting, the doctor came out and told us everything was moved back OK, but he ran into something he had never seen before. Her small intestines were buckled and rotted, so he had to remove that piece of intestine. After they brought her back to the NICU, I saw a sight I was not prepared to see– her intestines in a cone-shaped bag, suspended and tied to the top of her bed. Her intestines were lying outside of her, resting on her stomach. I couldn't believe the sight I saw. I was told that they were too swollen to put back, so we would have to wait for a few days before they could try to put them back. I was so devastated. They were able to put them back, but she had to have a colostomy bag on her. I wasn't sure for how long. Well, as days went on, she started to get worse. Then I was told that she had a form of e-coli, that when the doctor cut her intestines, he let a form of the e-coli out into her bloodstream, and that the doctor didn't wait on her blood test to come back. I was upset at this time, but I quickly turned my attention to Trinity and put this in the back of my head.

On the 15th of October, I went to Children's to see my daughter. Before I could step off of the elevator, my dad was at the doors waiting for me, telling me that the doctors want me to pull the plug. We went into a private room. The doctor told us Trinity's oxygen level was low, that she was in a coma, and she wouldn't survive the night. If by some miracle she would survive, Trinity would have brain damage from lack

of oxygen. So the doctor stepped out of the room so my husband and I could come to a decision. Of course it didn't take long. We decided it wasn't up to us to choose when she should pass away. It would be hers and God's, of course. The doctors and nurses were almost disgusted with our decision, but I didn't care, this wasn't their daughter; she was mine. So that night was very hard. Time went so slowly. When I was finally alone with my baby girl, I put my hand on her head and sung "Jesus Loves You." Then I said something that was so hard for a mother to say. I held her sweet little hand and told her that if she couldn't fight anymore and she had to go, that it was OK and Mommy will always love her. I kissed her on the head and walked out. An hour later, I decided it was time to hold her, so they did what they could do so that I could hold my daughter. That was the first and last time I held her warm body in my arms. She passed away 2 minutes after I held her. Two days before that, I knew it was coming. It's like she let me prepare myself for it. Not every parent is the parent of an angel. That is what I tell myself everyday I wake up.

When I had found out about her defect when I was 5 months pregnant, on the way home from the doctor during my crying, I looked at my husband and said that her name would be Trinity. He asked why. I said, "The Son! The Father! The Holy Ghost! is what that beautiful names stands for." But after Trinity passed, I told my husband that I blame the doctor for letting the e-coli virus through her blood stream. We talked to a lawyer, but he won't touch the case because of CDH. I was going to send all money for CDH research, also buy my daughter a headstone, which she still doesn't have. I feel so guilty about that. I'm having a hard time affording one, but I will one of these days. I learned not to take James, 7, and Dacia, 3, my son and daughter for granted anymore. Every day of their life is precious to me. I also learned not ever to say never. I thought something like this would never happen to me. So I tell everybody I know to don't ever, ever say "never."

Lisa Coleman (mom of Trinity Ann Coleman, 9/29/99-10/15/99, 752 E Wheeling St #Uppr, Lancaster, OH 43130-3210, 740-689-3601, mittys99@yahoo.com)



Hello everyone. My name is Mary Sierra-Hales, 27 years old and a mother of three girls and our darling little boy, Joseph Michael Hales. Joseph Michael Hales was born on April 7th and died April 10th of 2001 from severe birth defects, one of the major ones being a diaphragmatic hernia.

When I first found out I was pregnant, I was a little scared but happy at the same time. I knew in my heart that this baby would be a little boy, the answer to many prayers for my husband and I to have a son. We had longed for a son for a long time, so when the doctor confirmed that I indeed was carrying a boy, we were overjoyed. That joy was to be very brief for us.

My pregnancy went better than expected, for I am considered high-risk for pre-term labor and other problems associated with pregnancy. I kept all of my doctor's appointments, exercised, and ate healthy until the week before he was born. I had gone into the hospital for pre-term labor and complications from the flu. Little Joseph's heartbeat was acting up, so I was sent for a fetal echocardiogram. The doctors assured me that there was probably nothing wrong.

At that appointment, I spent three hours on the table as the doctor checked my son out. After much delay, I was told that my son had a congenital heart disorder that he would survive, barring nothing else was wrong. My heart sank and I felt that God was telling me to prepare because the worst was yet to come.

One week later, I was airlifted to a hospital about three hundred miles away from home. Things had gotten worse, and I could no longer hold our son in. I prayed as I was being flown to Corpus Christi, Texas, where Driscoll Children's Hospital is located. As I delivered him, I prayed for things to go well, but they did not. I remember so clearly as the doctor pulled our son out of my womb that he was squirming and had cracked his little eyes open. He was huge for being only 33 weeks gestational age. He weighed in at 6 pounds and 10 ounces! I saw him, and I hope he saw me too. I cried because he looked so perfect. As soon as they cut him away, he went downhill and soon went into cardiac arrest. The doctors did not know the extent of his disorders. They tried to resuscitate him but blew the only good lung he had. Meanwhile, Joseph, my husband, had arrived at the hospital where I delivered. He did not see our baby and did not know what was going on until he was pulled aside and had to sign forms for life support consent. He did not know how to tell me that our son was very ill. I took one look at my husband's face and cried. My attending nurse in the recovery room, Lori, was there with us as we heard the news of our son's deteriorating condition. She cried with us and tried to comfort us as I was wheeled out into the hallway to look at my son, just in case he died and I did not get the chance to see him alive again. He looked so beautiful despite the tubes and monitors. I wanted to hold him but settled with touching his arm and telling him that I loved him very much. He was then taken to Driscoll.

Those three days were such a blur of activity and sorrow. We got phone calls and visits from family and friends. I had a pass to go see my son for a few hours and spent the time kissing him and telling him that mommy loved him so very much and that mommy would be there for him no matter what. The team that took care of our son was excellent. They were very kind and caring. The head of the team, Dr. Karl Serrao, kept us informed at all times and took care of little Joseph as if he were his own son. He explained to us all the things that were being done to help our son, including the two types of ECMO that were used and why they were keeping him on life support (they were trying to give him every possible avenue of treatment so that he might live).

Finally, on his last day, we went into a conference with the doctors, and they laid it all out for us. Our son, tough as he was, was not going to live. He had the congenital heart disorder aggravated by the diaphragmatic hernia, the total agenesis of his left hemidiaphragm, one non-developed lung, one non-developed kidney, a rare kidney disease, and he had had two strokes the night before. Karl gently told us that it was time for our son to go. Joseph and I had already discussed taking our son off of life support, so we consented to sign the DNR (Do Not Resuscitate) orders and the forms for a full, unrestricted autopsy that they might learn more about his conditions and someday be able to help other babies in similar situations. We could not hold that back from other children; our son was going to help other babies, even in death. We cried as we consented and the doctor (Karl Serrao) did the most amazing thing. He was crying with us and came to us and held us both. He

felt our loss almost as much as we did.

At our son's bedside, we took turns kissing him and touching him. I studied his little face and did my best to learn every inch of his body– his eyes, nose, toes and fingers. He started to go after daddy told him it was okay to go and not to be scared, but then he stopped and kept on fighting. Our son wanted to hang on. Every time he started to go, I went to him and told him I loved him. He would fight on until finally, I leaned down, kissed him and told him that it was alright to go, that Mommy would miss him and not to be scared, that we would see him again someday--as I said this and bent down to kiss his little nose, he died. I think he was waiting for me to tell him that it was okay to die and leave us. My heart broke into a million little fragments that seemed impossible to pick up. My husband and I were devastated at his passing.

Our son was so very ill. He had all of the odds stacked against him. At the *autopsy report conference, we were assured that we did all we could for our brave little boy, but he had not even a fraction of a percent of a chance of survival. Yet with all of these odds, he still held on for three days! He was so brave and so strong. He had the diaphragmatic hernia, severe heart defects (at least three, I believe), Potter's Facies (kidney disorder), one lung, one kidney, virtually no spleen, and the strokes, but still he held on until we told him it was okay to die and not to be scared of what was about to happen to him. All of the congenital disorders combined made his case extremely rare. The doctors learned a lot from doing the autopsy--enough to be able to better handle such a rare case like his. For this, we have a little bit of comfort in knowing that maybe someday, other children will benefit from his loss.

It has been almost two months since our little boy came into our lives and changed it forever. Not a day passes where my husband and I do not cry and think of him. We are trying to adjust to life without him. The emptiness seems almost as deep and as endless as our love for him. We hug our other three children all the more tightly and love them all the more that we can. We are trying to live each day as best as we can, but it has been very hard so far. We realize that the journey on the long road in grieving and some sort of recovery has just begun for us. We have had the support of our family, friends and church ward (we are Mormon) to help us out. We keep in contact with Dr. Serrao and a few of the people that were there for us as we went through this ordeal (the chaplain at the hospital, social coordinator, and the nurse that attended me after my son was born). They have been just wonderful in supporting us and reassuring us that our son is in a better place, with no more pain and lots of love and care while he waits for us to go with him.

It is such a credit to our son's valiant spirit and willingness to live that he held on. He was certainly a strong little boy with a strong spirit and a strong heart. My family and I will miss him and feel grateful to have the opportunity to share our story with other CHERUB families. We now know that we are not alone. Sometimes when we are really having a tough day, all we have to do is think of how beautiful he is and how blessed we were to have him those three days and realize that he is a perfect little angel with God and we feel much better. I want to thank everyone that did all their best for our son, especially the team at Driscoll headed by Dr. Karl Serrao. We love all of you for all that you have done and still do for us. I close this letter with a small saying that we saw in a grief pamphlet that brings us much comfort in this time of need (we love him and miss him so much that it hurts):

Jospeh Michael is a twinkle in our eyes, in our hearts, and now in heaven. Forever loved and missed by his sisters Kristen Lorraine, 10, Amber Jeanne, 8, and Anna Elise 2 1/2 and by mommy and daddy.

Mary Sierra-Hales and Joseph Revelle Hales and Family (family of Joseph Michael Hales, 4/7/01- 4/10/01, RR 11 box 744 Edinburg, TX 78539, 956-386-0568, clueyee@hotmail.com)

My name is Rachel. My first son Harry was born in October 1997 a normal healthy baby. It was a great shock to discover at 32 weeks pregnant with my second child, that there was a problem. My GP had referred me for an extra ultrasound scan at 30 weeks because I was too big for my dates. Nothing seemed wrong except that my baby was big. I was asked to return in two weeks. At the next scan, I could tell from the sonographer's face that something was very wrong. Two consultants were called, and they told me they thought my baby may have a right-sided diaphragmatic hernia, something I had never heard of. I was also told that I had too much amniotic fluid, and in order to stop me from delivering early, I needed to have some of it drained out. I went into hospital the next day for the drainage, and then the day after to University College Hospital London for a second opinion on my baby's condition.

A right-sided CDH was re-confirmed, and I was booked in to have the baby at UCH instead of my local hospital at Milton Keynes (England). They decided to monitor me weekly until about 38 weeks and then consider induction. However, at 35 weeks my waters broke, and I was rushed by ambulance to London. Max Anthony Wyatt came into the world about 36 hours later on 12th November 1999. We had been warned that he would be silent and would be put straight on a ventilator and taken to intensive care. However, to our complete joy, he managed a little cry as he was born, and once he was 'wired up' I was able to hold him for a few minutes before he went to the ICU. It was a wonderful moment after those three terrible weeks of worry to hold my beautiful baby boy - who to our surprise had bright ginger hair. He weighed 5 pounds and 14 ounces - not bad for 5 weeks early!

Max held up very well from the start and was stable enough to be transferred to Great Ormond Street Hospital (London) where he had his surgery at just 3 days old. The worst moment of our lives was when he was wheeled down to theatre - not knowing if we would see him alive again. However, all went very well, and he was back in about two hours -- he had survived.

Max made a very good recovery and 8 days after surgery he was off all breathing aids and transferred to special care. Only two days after that, he was well enough to be transferred to our local hospital, and then only four weeks after his birth, and still one week before he was due, he came home.

Our greatest wish for the Millennium New Year's Eve was to be at home with our two sons – and that wish came true. Max had now at 21 months old been 'signed off' from our local hospital, although he has another check-up next July with his surgeon in London. He is the most wonderful, cheerful, charming toddler you can imagine, and apart from his scar, you would not have any clue that he had once been so poorly.

Rachel, Nigel, and Harry Wyatt (family of Max Wyatt, 11/12/99, 40 Tudor Gardens, Milton Keynes, MK11 1HX, Great Britain, 01908 565574, rachel@magentanetwork.co.uk)

Hello. My name is Tammy Higgins, and my story is about my daughter Rebecca. I didn't find out about Becky's condition until my thirty-sixth week of pregnancy. My pregnancy was typical, so I thought, but I didn't really feel much fetal movement, and my stomach measured much larger than the normal. I was told I was having a ten or eleven pound baby.

When I went for my 20-week ultrasound, the girl doing the ultrasound detected no fluid in the fetus's stomach. I returned the next day, and they said that they did detect some fluid. I was very relieved and ecstatic that I was having a little girl. I had wanted a child for as long as I could remember, and I felt that all of my dreams were becoming a reality.

I didn't really worry anymore because the Ob-gyn kept indicating that all was fine, and I was only twenty-two years old. I went on to have my perfect baby shower, and I received the perfect baby gifts for my perfect baby girl. I went for a second ultrasound just before Halloween because I was measuring so large. The hernia was detected.

The hospital that I had been attending was not able to handle my situation, so they referred me to the Columbia Presbyterian Babies Hospital in NYC. The hospital seemed so big and cold at first but now is my security blanket. They were wonderful to me and my child. Rebecca was born by vaginal birth on November 4, 1998. She was perfect. She weighed six pounds one ounce and was 20 inches long. She was whisked away from me and brought to the NICU. She was placed on a respirator. She was doing well. Her surgery took place when she was two days old, and the surgeon said her hole was the size of a silver dollar. He patched it with gortex and moved her intestines back down, and she was doing well. When we went to see her, her little legs were all dusky blue, and she looked to be in so much pain.

Shortly after the surgery I held her. She was so tiny and so cute. I felt that she and I would fight. And she would live. She had so much gumption. She would pull the IV's out and thrash her arms. She recovered from the surgery, and then it was determined she had reflux. She was released from the hospital the day before Thanksgiving. She was three weeks old.

We battled reflux for approximately a year, and she still will occasionally vomit. She is now a very strong-willed and stubborn two and a half year old. She amazes me everyday. My world would have never been the same without her; she is what I live and breathe for.

Now my husband and I are trying to have a second child, and I have to admit I am very nervous, but I would love nothing more than to make my Becky a big sister. God bless all of the little cherubs wherever they may be.

Tammy Higgins (mom of Rebecca Breana Higgins, 11/4/98, 194 Harding Ave., Clifton, NJ 07011, 973-772-9660, Higg3912@msn.com)

This is the story of my little cherub. Frank and I were married for three and a half years and thought we would never have children. I had a tubal pregnancy 13 years earlier and was told there was only a 30% chance I would ever conceive. After our wedding, we decided to let nature take its course, and if we got pregnant that would be great; if not, that was okay too. Imagine our surprise when after being a week late, I took a test and it was positive. We waited until an ultrasound confirmed the pregnancy was okay before telling the grandparents. They were all thrilled. Franks parents have no other grandchildren. Mine always have love for more.

I developed gestational diabetes after 20 weeks. I was sent to a specialist in the area to be monitored. He performed a sonogram and confirmed that the baby was doing fine. I was told by both doctors that I was carrying a large amount of fluid. They said that was normal for my condition. I controlled my sugar with diet and exercise. I had a total of six sonograms between 20 weeks and up to a few days before delivery. They were done by both doctors. Everything was said to be perfect.

After 12 hours of labor and a perfect delivery, we were told we had a son, 7 lbs 7 oz 22 1/2", and he was having a little trouble breathing. They thought it might be a collapsed lung. The NICU team took him after letting me hold him for his father to take a picture. I was taken to a room and told to wait for the doctors to come and talk to us.

Imagine our shock when the first doctor came in and told us the problem was very serious. We needed to decide where to send our baby for treatment. We were in shock and asked the doctor for his recommendation. He said Rainbow Babies hospital in Cleveland was his first choice. We gave consent, and he said he would make the arrangements for a life-flight helicopter and see if they had a bed available. After an hour, they had Jaret stable enough for us to see him. He was hooked to so many wires and tubes that I could only hold his little hand. I had no idea it was going to get so much worse. The team arrived to take him away and told us he only had a 20% chance of surviving the flight. My heart was breaking as they wheeled him away from me. I could not leave the hospital until the next morning because the other hospital was an hour away.

Many friends and family members came to the hospital to offer their support. My husband and father-in-law left as soon as the helicopter took off so they could be with our son. It was the longest day of my life waiting for the word that he made it. The doctors were waiting for Frank when he arrived. They were so very helpful to him. They told him Jaret had a left congenital diaphragmatic hernia, and it was very severe. The chances he would make it were very slim. They explained the ECMO machine and the surgery he would need. All we could do for the first day was pray. The longer he held on, the better his chances of surviving the surgery would be.

I was released from the hospital at 6 a.m. the next day. I had to stop at home and pack some clothes for my husband and myself. The moment I walked by the nursery, I lost control. I sat on the floor and sobbed. This was not how it was supposed to be. Then I felt a calm come over me; I'll never be able to explain. I knew I had to hold it together for this special little boy. He was born for a reason and would be fine if I could just be there for him. The drive to the hospital seemed to take forever.

The moment we arrived, my father-in-law met me at the door. He took me up to the second floor with tears in his eyes. The nurse who was taking care of Jaret met me at the door and tried to prepare me for the sight of my baby all hooked up to the machines. Nothing can prepare you for that sight. He looked so small and vulnerable. I wanted to pick him up and just hold him tight.

Three days after his birth, we were told he was ready for the surgery. Again, we were given odds that seemed impossible to beat. He

pulled through the surgery with flying colors. The doctors told us the longer he could last before going on ECMO, the better his chances. He lasted 48 hours before his hypertension got too bad, and the decision was made he couldn't wait any longer. Dr. Stork was his EMCO doctor, and she was pleased he had given them that much time. Waiting again for the worst news, he once again surprised everyone. He remained on ECMO for 8 days. The day he came off was the scariest and most hopeful day yet.

Within a few hours, his chest had filled with fluid and was compressing his lungs and shifting his heart over again. He had to have 3 separate chest tubes put in over the next few days. After a week, he was showing signs of being ready to come off the Nitrix Oxide and the vent. I finally got to hold my son when he was 20 days old. The next day, he had a set back and had to go back on the vent. That was a crushing blow. He had to be put back on just after midnight; it was now my birthday. His dad and I sat with him while they reintubated him. The nurses said we could step out, but we just couldn't leave him to go through this alone.

Two days later he came off the vent for good. Daddy finally got to hold his little boy. He was now 24 days old. The progress from there was slow but steady. We moved from the NICU to the step-down unit just before the 4th of July. We could now stay right in the room with him 24 hours a day. It was our home away from home. He slowly came out of the oxygen hood and went to nasal cannulas. Three weeks later, we were finally able to bring our son home. He was sent home with an NG tube for feeding, but free of oxygen. We were thrilled, scared, and very unsure of what to do next.

The next few weeks passed by in a blur of feedings, and replacing NG tubes. Jaret was on medication that made his reflux terrible. After getting his feedings, he would vomit half of what he ate. Our little man didn't like having anything up his nose, so he pulled his tube out daily. After working with several therapists, we could still not get him to drink from a bottle. I started mixing his milk with cereal to thicken it and fed it to him off a spoon. Just little tastes at a time. He loved it. Dr. Stork suggested taking the NG tube out for a week and trying to maintain his weight. We spoon-fed him every 2 hours around the clock for a week. He gained 4 ounces. "Keep going" was all the doctors could say. He has been without the tube ever since. The first month was the hardest, but as his stamina increased, and he grew larger, he could eat larger meals less often. The vomiting stopped when the tube was out, and the solids were much easier for him to hold down.

I am happy to say Jaret is now 11 months old, and we are happily planning his first birthday party. We have been lucky Jaret has not been back in the hospital since we brought him home. We hope to keep it that way. With a little luck and a lot of prayers, he continues to grow stronger every day. I wish everyone could have the happy ending we have, and my heart breaks for all the mothers who lost their little ones. Be sure they are in heaven watching over us all. Thank you for sharing our story.

Monica Spelich (mom of Jaret Paul Spelich, 6/3/00, 2520 Chestnut St., Girard, OH 44420, WINKY11@PRODIGY.NET)

As with all of the Cherub stories, it is very hard for me to think back and remember those 9 months. It was horrible. My pregnancy went pretty normally, except it seemed that everyone thought that there was something wrong. My first visit to the doctor, the nurse seemed strange about it; my mother-in-law had a bad feeling. I felt unsure. So the way I learned about Anna's CDH was because I was bleeding, and the doctor found that I had placenta previa. So I had to have a second ultrasound done at about 16 weeks, and that is when he found the hernia.

I pretty much fell apart for the next five months. I also learned that day that my husband had a brother who died of CDH at birth. So this was very devastating to the whole family. Besides being on an emotional roller coaster, going to two doctors twice a month, endless ultrasounds and tests, everything went normal. To my doctor's surprise, I delivered a full-term baby. She cried when she was born and had better Apgar scores then any of my two other boys.

But she had this one big problem-- she had almost all of her organs in her chest. She was born with everything "up" except her liver. She had a displaced heart, and her one lung was not fully developed. The way my husband explained to my oldest about what was done during her surgery was that the doctors had to go in and put back all the pieces like in a puzzle. I thought this was a great analogy for a 5 year-old.

Anyway, she had her surgery done when she was 3 days old, was on a vent for about a week and a half, and left with O2 at about a little under a month. She had all of her hospitalization done at the Children's Hospital in Denver, which I am very grateful to. Her doctors and nurses were wonderful. Her one doctor, Dr. Kinsella, has pioneered the NO persidure. I would recommend that hospital for our CDH kids!!

Anna is now 18 months old. She has no problems so far, and she is the most beautiful little girl. She is walking, talking, throwing tantrums, laughing, playing, loving her 2 brothers. She's a daddy's girl, how couldn't she be. But most of all she is my angel. And I am the happiest mom in the world with my 3 little ones. I would not change a thing.

Karen Fuss (mom to Anna, 1/24/00, 5660 Wellington Pkwy, Arvada, CO 80003-5147, 303-426-9477, kfuss@yahoo.com)

My name is Amy. In February 2000, I found out I was carrying a little girl. Not too long after that, my husband and I found out that she had a diaphragmatic hernia. We were devastated. Along with my husband and his mother, I went and checked out some special medical centers. We finally chose Boston Children's Hospital.

On June 16, 2001, baby Briana was born. She had her surgery the very next morning and did a great job. The doctors told us she would not be able to come home until the end of September. She spent two weeks in the NICU and was doing well, so she was then put out on the floor.

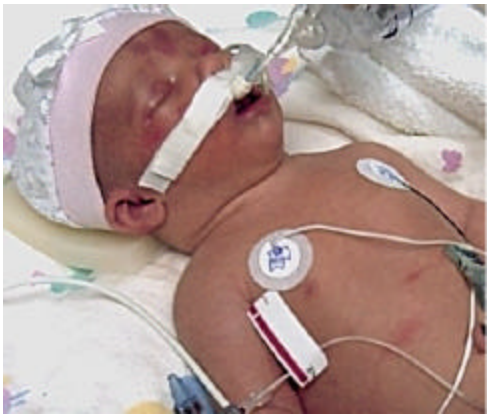
After one day on the floor, the respirator came out. My family and I were so excited. A couple weeks later, the oxygen came off, and it was time to learn how to bottle-feed. It took many nipples and many days, but after only two weeks she did it. It is now August 16, and she has been home for one whole week . She has had her ups and downs, but she is a strong fighter. She has no feeding tubes and is very precious.

I would like to tell all the new and upcoming Cherub parents simply this: Miracles do happen. We were prepared for the worst possible outcome, but we were one of the lucky ones, and you could be one, too. I'd like to thank you for hearing my story, and we pray for all the other little angels that are out there. For anyone that has any questions, or just needs someone to talk to:

Amy Schafer (mom of Briana Schafer, 6/16/01, 22 Diamond St, Naugatuck, CT 06770, 203-723-1245)

P.S.- I would like to thank Cherubs for all the info that was sent when I was still pregnant. Other people's phone numbers and addresses were extremely helpful and gave me people I could talk to at any time. Their stories and children gave us a lot of faith. Thank you so much.

Pictures of Cherubs



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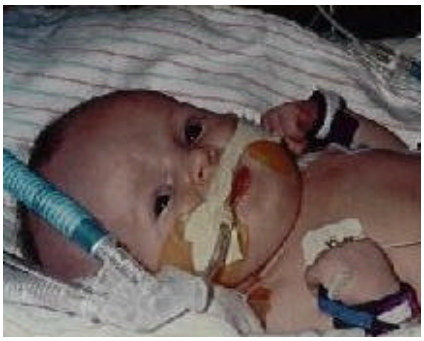

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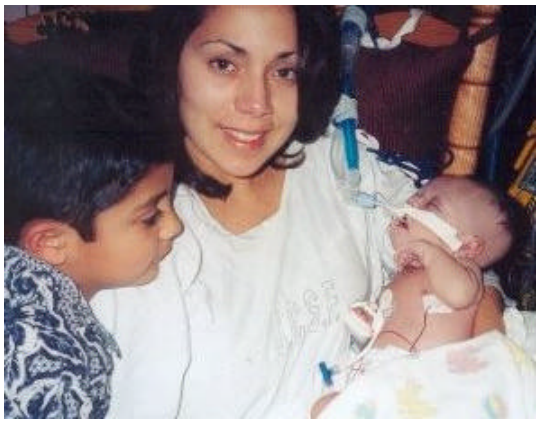

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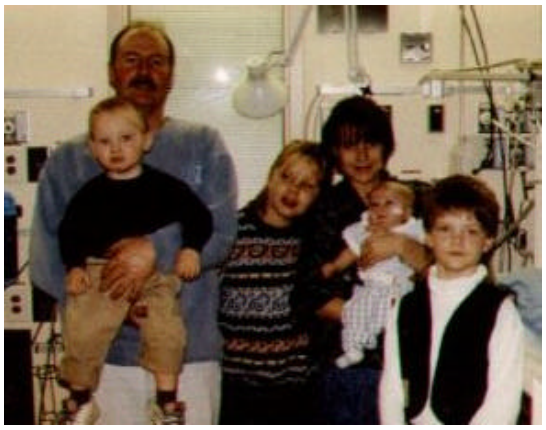
Cody Walker Keeton
10/4/99



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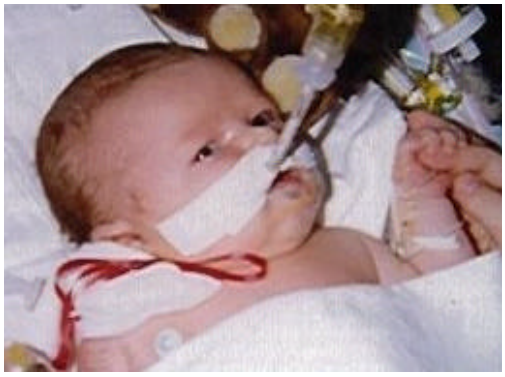

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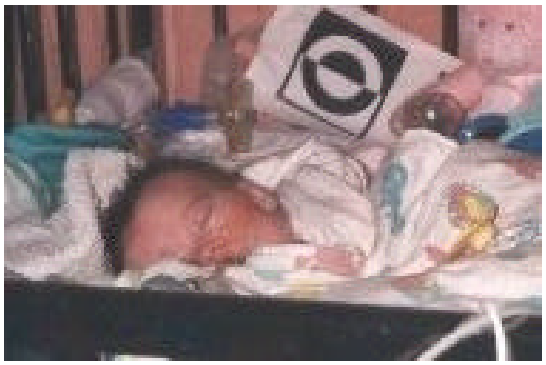
Khyreik Ezra'el Hamlin
8/3/98

Tanina Cadwell
3/6/95



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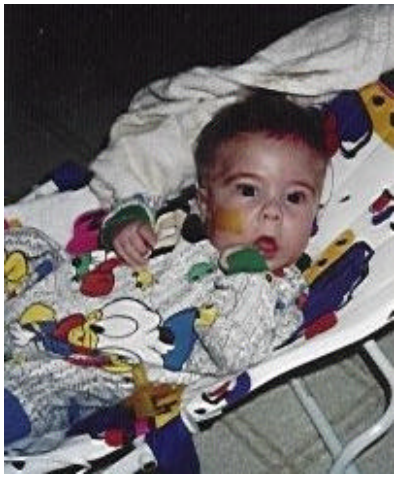
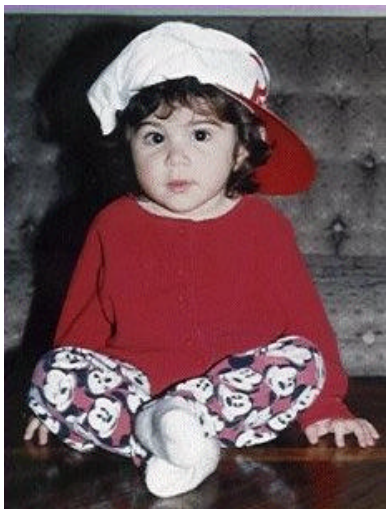


Ryan Matzuka
6/15/96 - 11/29/96

Caitlin Elizabeth Breen
9/9/97

Dylan Seyda Tachman
9/29/97 - 10/13/97

Ivan Oscar Lichtenstein
1/17/97



Megan Hope Burns
8/20/97

Zachary Christian McInnis
11/12/98

Australia Member Get-Together

On Saturday, 10th November 2001
Royal Children's Hospital in Melbourne
10th floor

For more information on details and lodging, please contact our Australia Representative, Danielle Kessner, at 03 5135 6999 or danielle@cherubs-cdh.org. All members are welcome. You can visit the Australian CHERUBS' web site at http://www.geocities.com/aussiecherubs_2000/

i Ohio Get-Together i

September 15, 2001
Holmestead Park, Hilliard, OH
For more information, please contact Tara Hall at 614-777-4906 or TARAJEFF@aol.com.

g North Carolina Get-Together

Saturday, June 2, 2001
Kannapolis, NC

From left to right: Dawn Torrence, Jeremy Torrence, Susan Grubb, Tyler Grubb, Jim Grubb, Courtney Young, Wanda Young, and Barbara Vosburg

For more pictures and details visit the NC CHERUBS' web site at:

www.cherubs-cdh.org/nc

Ebay Auction

Our Celebrity Ebay Auction has been postponed until January 25, 2002. We need many, many more volunteers!!! Our auction volunteers contact celebrities and ask them to donate autographed items to CHERUBS. We have an enormous list of celebrity addresses that will be divided among volunteers. We will also be auctioning off other items, so please send in your items or contact if you would like to hold an auction. If you would like to help, have autographed items to donate, or any items to donate, please contact Dawn at 919-693-8158 or dawntorrence@cherubs-cdh.org.