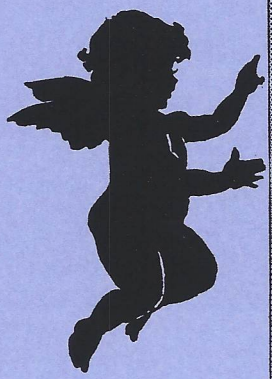
FALL/WINTER NEWSLETTER 1995-96

CHERUBS

THE ASSOCIATION OF CONGENITAL DIAPHRAGMATIC HERNIA RESEARCH, ADVOCACY, AND SUPPORT



Since our summer newsletter, so much has happened to CHERUBS. We have acheived Non-Profit Status; now all donations are tax-deductable. We have also joined such organizations as NORD (National Organizations for Rare Disorders, Inc.) and the Alliance of Genetic Support Groups. Our membership is growing with both families and professionals. A parent reference guide has been printed and will be of particular interest for new or expectant parents of children born with CDH. As you have noticed, this newsletter is our fall and winter issue. It has been combined to help us set a permanent schedule of issuing newsletters in the future. Our newsletters will be printed in March (Spring Issues), June (Summer Issues), September (Fall Issues), and December (Winter Issues). Of course, as we progress, issues will likely be printed every two months or even more often as our financial status changes. I am hoping that this newsletter will set a precedent of how our future newsletters will be set up. If any of you have opinions or ideas, please let me know. This isn't my newsletter; it's OUR newsletter. For those of you who asked how you could help; tell your child's doctors about CHERUBS, along with any other parents of CDH children that you know. Happy Thanksgiving, Merry Christmas, Happy Hanukkah, and Happy New Year!

Sincerely, *Dawn M. Torrence, President*

CHERUBS Would Like To Thank The Following People For Their Help and Support:

Joan Burns-President, Alliance of Genetic Support Groups
Kathleen O. Carder, MS-Genetic Counselor, Sharp/Children's Prenatal Diagnostic Center
Frank and Delores Feidor
Ms. Lisa Thaxton
John A. Harris, MD, MPH-Cheif, California Birth Defects Monitoring Program
Michael R. Harrison, MD-Pediatric Surgery, The University of California at San Francisco
Elissa T. Kopf, LSW-Social Worker, The Children's Hospital of Philadelphia
Maria LaFond Visscher-Abiding Hearts
Melissa LePage, RN
Patrick Leurquin, MD-European Registration of Congenital Anomalies
Measurement Incorporated Printing Services
Betty Mekdeci-Executive Director, Association of Birth Defect Children, Inc.
Jane Rybar-Administrator, Genetic Interest Group (Great Britain)
Joe M. Sanders, Jr, MD-Executive Director, American Academy of Pediatrics
Liz Shannon-Children in the Highlands Information Point (Scotland)
Lesli A. Taylor, MD- Assistant Professor of Pediatric Surgery, University of North Carolina, Chapel Hill
Mr. James Torrence
Mrs. Jeanette Torrence
Claudine P. Torfs, Ph.D.-Epidemiologist, California Birth Defects Monitoring Program
Martha Walker, MS-Genetic Counselor, Children's Hospital Medical Center (Ohio)
Robert Wood, MD-Pediatric Pulmonary, University of North Carolina, Chapel Hill

CHERUBS Would Like To Thank The Following For Their Generous Contributions:

Vincent Adolph, MD–Pediatric Surgeon, Ochsner Clinic
Aviva Katz, MD–Pediatric Surgeon, Alfred I. DuPont Institute
Measurement Inc. Printing
Mary Mitchell–in memory of Harold Jennings Mitchell, III
Elaine Moats–in honor of Kristin Marie Moats
Nurse's House Call
Karla Riley–in memory of Andrew Christian Riley
Beth Zimmermon, RN–Pediatric Surgery, University of Chicago

CHERUBS is an international organization for families and care-givers of children and adults who are diagnosed with Congenital Diaphragmatic Hernias (CDH). CHERUBS provides information,support, and parent-to-parent matches. There is no cost to parents for services provided by CHERUBS. We are a volunteer organization founded in February of 1995 and an Internal Renevue Service recognized Non-Profit Association. Donations are very welcomed and tax-deductible. Checks can be made out to CHERUBS. The opinions shared in this newsletter do not necessarily represent the opinions of all members or staff. The information in this newsletter is by no means to be substituted for proper medical advice. Remember, every child is different. You can't compare the progress of another CDH child to the progress of your own Child. They are all little angels.....CHERUBS

CHERUBS' MEMBERS' UPDATES

I wanted to include this section to let members update us on their child's progress and to allow our members who have lost their children to let us know how they are coping and what their plans for the future are. I'm going to start this section by updating my son's progress. As though of you who read our first newsletter know, Shane has had quite a few problems; left-sided CDH, Atrial Septal Defect, Pulmonary Hypertension, Lung Sequestration, Chronic Lung Disease, Lung Hypoplasia, Brain Damage (causing temporary blindness and deafness-1 year), Hypospadius, Undescended Testicles, Trachomalacia, Trach, Developmental Delays, NG-tube, Feeding Problems, 3 Diaphragmatic Hernia Repairs, Vent-Dependencey (28 months), and Oxygen-Dependency (30 months). He now wears glasses and hearing aids. He is slowly catching up developmentally, but his sight impairment is a major cause of his delay. He is crawling now and "tearing up the house". In July, he had his 4th repair, using Gortex. In October, he had his 5th repair, using Gortex again. No one knows why Shane's diaphragm keeps reherniating; with his odds, I can't wait until he's old enough to buy a lottery ticket. He now has a G-tube, in hopes it will help his feeding problems and help to "anchor" his stomach to keep it where it belongs. He also had a Nissen and an appendectomy (as a preventive measure against appendecitis; which could kill him if he ever had it and knowing Shane, he would). Eating by mouth is still a major problem, especially with all his allergies. Of course all this is very stressful to my husband and I, emotionally and financially. Shane's medical bills are over $4 million and we are average people. With a sick child, you can never get ahead, of course most of you know this. Maybe someday the government will come up with a solution and maybe someday our lives would be normal. But then maybe we wouldn't appreciate all the miracles God has given us.

LETTERS TO CHERUBS

August 28, 1995

Dear Ms. Torrence

Thank you for your recent letter describing the organization you have founded to support the families of children born with congenital diaphragmatic hernia. Your organizational goals are extraordinary laudable, and we certainly wish you every success in meeting your goals and objectives.

The American Academy of Pediatrics is also a 501 (c)III organization which "is committed to the attainment of optimal physical, mental, and social health for all infants, children, adolescents, and young adults". We are pleased to include nearly 50,000 board certified pediatricians throughout the United States and Canada among our members.

...Perhaps we can provide "in-kind" assistance by letting other pediatricians know about the organization you have founded. To this end, I have forwarded the materials you sent me to the editor of our monthly newspaper for consideration of an article describing your work.

I again commend you for your efforts in providing these much needed resources and services.

Sincerely,
Joe M. Sanders, Jr, MD
Executive Director,
American Academy of Pediatrics

August 28, 1995

Dear Ms. Torrence

Thank you for your note of August 1 along with copies of the CHERUBS newsletter. I am sorry to hear that your son required furthur surgery and I hope that it went well.

I have spoken to the current president of the American Pediatric Surgical Association about the possibility of having CHERUBS man a booth at our next meeting. He wished to discuss it at the board level, and said that he would get back to me. I think that there is some concern over setting a precedent but I was encouraged by his positive response to the suggestion. I will certainly let you know as soon as I hear anything further.

I also noticed in the newsletter that you have mentioned the work of the San Francisco group in treating diaphragmatic hernia in utero. I thought you should also know (and perhaps also publish in your newsletter) that there are two other centers which have recently developed programs for fetal therapy. One is the group at Wayne's State University in Detroit, and the other is our center at Washington University in St. Louis.

Best of luck and I will be in touch as soon as I hear anything further about APSA.

Sincerely,
Jacob C. Langer, MD, FRCS(C)
Division of Pediatric Surgery
Washington University in St. Louis

August 17, 1995

Dear Mrs. Torrence:

We thank you for your kind letter of August 1, 1995 and CHERUBS' newsletter, both of which we read with great interest. We shall attempt to answer your questions to the best of our knowledge.

First, there is no available information on the association of any birth defect with the presence of a parent in the Gulf War. The appropriate research has not yet been conducted and may never be, because of small numbers of births to that group (one needs large numbers of infants at risk for epidemiological studies).

...Third, in the descriptive study of CDH which we conducted here, we noted a higher prevalence at birth of CDH in rural areas than in urban areas. For your information, we are enclosing a copy of this study. The rural preponderance we observed needs confirmation by additional studies.

Forth, at this time we know of no particular study which shows a connection between CDH and scoliosis. If we happen upon one, we will let you know.

Fifth, there are provincial data bases for birth defects in Canada (Dr. P.A. Baird of Vancouver, British Columbia) and in European counties (EUROCAT....).

I hope we have answered most of your questions to your satisfaction. It is always a pleasure to be able to communicate with concerned parents.

Sincerely,
John A. Harris, MD, MPH, Chief
Claudine P. Torfs, PhD, Epidemiologist
California Birth Defects Monitoring Program

October 16, 1995

Dear Ms. Torrence:

We are pleased to send you information on EUROCAT. You will find enclosed the latest EUROCAT Report (N'6); a set of newsletters and several publications. You have been put on our mailing list and regularly you will receive EUROCAT newsletters.

...We have circulated a copy of your letter to the members of the EUROCAT network and invited them to send relevant information to your organization.

Sincerely,
Dr. Patrick Leurquin
EUROCAT - European Registration
Congenital Anamilies;
A European Union Project
Brussels, Belgium

Letters From Members

Brittney Landry
August 25, 1989

Dear Dawn,

Thank you for sending me your Cherub newsletter. I was thrilled to discover your organization after six long years of looking. I'd like to tell you about my Cherub. Her name is Brittney. She is living proof that no matter how grim the situation seems to be, with hard work and determination you and your child can prevail. Brittney's first three years were a nightmare. She was in NICU from birth to 5 months of age. Fourteen days on ECMO, and vent dependent for 4 months. Once home she spent the next 2 and half years connected to oxygen. She had a trach until the age of 3, and she continuesto have a G-button, although she's now eating baby foods and some pureed table food by mouth. Of course she's developmentally delayed, but that seems very minor when I think about how far she's come. Her medical status has improved almost 100% which is unbelievable. She has the most incredible personality, always happy and very loving. For me I think this proves that you must never give up hope. It isn't easy, especially in the beginning, but you have to except the responsibility and never give up. If I could pass along some advice to new parents who are struggling I would say, live every day one day at a time. Try not to look into the future or to make comparisons. Every child is different and every CDH case is different. Learn as much as you can. Seek out the resources that will help you to get through it. The more you know the better you can help your Cherub!

Sincerely, Lynn Landry
4623 Hwy 308, Napoleonville, LA 70390
(right-sided Morgagni CDH, developmental delay, G-button, ECMO)

Dear Dawn,

I just finished reading Cherubs and had to write to you to say Thank You! Although I am involved in several support groups I haven't been able to find one devoted to CDH. I read the letters from the other parents (in your newsletter) and cried. It was exactly what I went through. My son John Lee is now 2 and a half and is spastic diaplegia, Cerebral Palsy. The surgeon told us our son was a "very determined little fighter" to have survived his first months of life and I can tell you even now, everyday, his determination is inspiring. Please let me know if there is something I can do to help in the continuation of this successful newsletter and project. In particular, I would like to see pre-natal diagnosis- as I feel this knowledge would have helped us greatly in the medical and emotional crisis that we have gone through. Once again, thank you for taking the initiative and doing something to help so many of us. I look forward to hearing from you and Cherubs in the future.

Very truly yours, Margaret Thompson
10-14 Oxford Dr., Valley Cottage, NY 10989
(left-sided CDH, cerebral palsy, delayed motor skills, spastic diaplegia, reflux, ECMO)

Casey Starks
October 29, 1994

Dear Shane (my son):

Hi there! My name is Casey Richard Starks. I was born on October 29, 1994. I was taken by ambulance to Ann Arbor, Michigan. My diagnosis is the same as yours, Diaphragmatic Hernia. I have all of my right lung but my left is short a lobe so I have a lobe and a nub on the left side. I ended up with a G-tube and have been fed with it for the 1st 5 months, we are gradually weaning from it to where these last few weeks we haven't used it. We got the G-tube because when the diaphragm was repaired and the stomach, bowels, and liver were moved down where they should have been the stomach decided to flip the 1st time which they went back in after a month and tried to straighten it when it moved again curving around itself which wouldn't let food pass through the stomach. So they did the 1st major surgery and ended up going back 2 more times to get the stomach to behave. We were flat on our back 56 days in the hospital. We came home Christmas Eve day. What a blessing! From the sounds of it this is pretty common.....What's going on to cause this?? I sure wish I knew!! Our biggest problem seems to be sucking. Casey doesn't take 4 oz. at a time yet. I think his stomach is too small or something (maybe too much pressure from the move). We are blessed he had a much easier time than most, but trying to feed him all day is real tiring sometimes. He eats best at night. Doctors want him to gain more weight....He does eat spoon foods so we're lucky in that respect...He's our first baby and he's very special no matter what we have to deal with. My sister has 2 girls and she's done- and I beleive I'm done too!! I'd hate to see another baby possibly go through any of this and I don't think I could take it either, it was hard on our whole family. Love, Casey Starks (and mom, Lori)

749 Dutch School Rd, Bronson, MI 49028-9764
(left-sided CDH, G-tube, developmentally delayed)

Dear Ms Torrence,

I received your newsletter in August. I would like to begin by thanking you for founding such an important organization. There have been so many times I had wished for an organization like Cherubs. I am writing a personal letter because I feel our family's story may be of interest to families of children born with CDH. After a pregnancy complicated with hyperemisis our daughter Sara was born on Aug. 7, 1989. At one-day-old she was diagnosed with CDH. She had surgery when she was 2 days old and did very well. A week and a half later she came home from the hospital with oxygen. She remained on oxygen until she was 2 months old. The day after she was removed from oxygen she received her 2 month shots and had a serious reaction. She cried so hard for so long, she reopened the hernia. Two days later she had a second surgery which required the use of a Gortex patch to repair the hernia. She came home a week and a half later without oxygen! She has experienced a minor kidney defect and slow growth but otherwise she's happy and healthy. It would be nice if our story ended here, but five years after our daughter was born, another family member was diagnosed with CDH. In December, 1994, my husband was diagnosed with an atrial septal defect (ASD) which is a defect between the atrium of the heart. The cardiologist also suspected a second problem which they thought was a tumor prior to surgery. My husband underwent open heart surgery to repair the ASD in January, 1995. Mid-way through the surgery, I was informed that what they thought was a tumor was really a Morgagni diaphragmatic hernia. The same as our daughter's! Both his ASD and CDH were repaired without the use of Gortex. He came home five days after his surgery and is in excellent health. When both my husband and my daughter had their surgeries, I tried to obtain as much information as I could. Unfortunately, the medical staff was not of much help. When asked if this defect was hereditary because two family members had it, I was told-"yes", "no" "maybe", and "I don't know"! Incidentally, our second daughter was born without CDH, but she has been diagnosed with Golden hars Syndrome, a cranio-facial syndrome. We have been told by a geneticist that her problems are not related to our others child's. We still have questions as to if our daughters could have children of their own with CDH. Any information you have would be helpful. Best of luck with your work in this wonderful organization.

Sincerely, Sue DeHart

8308 Waverly Dr. Northwest, Alburquerque, New Mexico 87120
(Morgagni CDH, kidney-extra renal pelvis, improper rotation, family history of CDH, 2 repairs)

Kaylee Lyne Bentz
June 20, 1994

Dear Ms. Torrence:

Denver's Children's Hospital gave me a copy of the Cherubs Spring '95 newsletter. We would like to belong and tell you our baby's story. When my husband and I found out I was pregnant we were excited. We had a two year old son and hoped for a girl. I went through my whole pregnancy being sick almost constantly. But my doctor was not alarmed because the prenatal visits were normal. My insurance company would only cover ultrasounds when medically necessary, I never had one because my baby's heartbeat was normal. Finally the day arrives, three days after my due date, I go into labor and twelve hours later I gave birth to a beautiful baby girl. My doctor wipes her down and her little eyes open, look at me and she gives out a small cry. My heart leaps, we got our girl! The umbilical cord is cut and all of a sudden my doctor takes her over to the baby bed next to the wall that contains medical supplies. I look over to my husband and say that something is wrong with out baby. He reassures me and says that they're probably doing some of her reflex tests. Unsure if that was the case, I repeated myself to him three times. He shrugged his shoulders and we both focused on the commotion by our baby. All of a sudden I heard my doctor yell "Come on baby, BREATHE!" My whole world ended I thought I was dreaming. I started crying and tried pinching myself thinking I would wake up from this horrible dream. Intensive Care nurses rush in, take our baby and rush out. I can't remember much of the next two hours except for thinking how could this happen to us, we have a healthy son at home. Two hours later, a neonatologist and a pediatric surgeon walk into my birthing suite and sit next to my bed. They say that our baby has a severe left-sided diaphragmatic hernia. This is very serious and her chances of surviving are very slim. I went into shock. The doctors said there was nothing I did to cause this, but I laid there blaming myself. Doctors would come in and let us know how she was doing and were talking about transferring her to another hospital. Now Kaylee is seven hours old and being prepared to be flown to a more advanced hospital 675 miles away. They let us visit her before she leaves. Her small body laid there covered with tubes, wires, and her body shaking from the ventilator. This could not be the same baby I saw when I gave birth, this one was limp and did not make a sound. We baptized her in the Intensive Care Nursery, despite all my thoughts about why I was being punished. As Kaylee was being transferred, one of the doctors called us on the phone in my hospital room and explained a new gas they're trying on babies with small lungs. Because it is not FDA approved, I had to give permission to the doctors to give my daughter nitric oxide. Twenty-four hours after birth, Kaylee had surgery to correct her diaphragm. Kaylee stayed in their hospital for 24 days and was transferred back to our hometown hospital. She was taken off nitric oxide at 21-days-old, amazingly off of oxygen at 37-days-old, and came home at 69-days-old. Our worries for the next few months was to get Kaylee to eat and gain weight. Kaylee is now fifteen-months-old. She fought off five colds without any help from over the counter cold medicines, had a sinus infection, and now weighs over 17lbs. Eats table food and drinks 2% milk by mouth. She has no tubes and no monitors. We never had to admit Kaylee back into the hospital yet and sometimes find it hard to believe she was born with a defect. We had never heard of a diaphragmatic hernia until Kaylee was born. When we hear about it now, most of the stories are the same and are not as fortunate as ours. We hope our story can give some parents the hope that we have found through our misfortune. We now know God is by our side.

Jeff and Melissa Bentz
105 N. Lowell. Sioux Falls, SD 57103
(left-sided CDH, pulmonary hypertension, Atrial Septal Defect, nitric oxide)

Kristin Marie Moats
August 24, 1992

Dear Dawn,

Thank you so much for starting CHERUBS. Brett, Kristin and I live in a rural community in SE Montana with the population of 8500 people. Sometimes we feel we are the only ones going through this journey. Before Kristin was born we had never heard of CDH. We have learned a lot in 3 years and are thankful each day that Kristin is with us. Having a child with a disability sure puts your life into the proper perspective. There is a need for more information to be available about CDH. In the many hours we spent in The Childrens Hospital library reading up on CDH we came away thinking Kristin would only live to the age of 10 or 12. But as we found out the medical technology to save CDH children is only that old. Research needs to continue. Since Kristin was the first CDH to ever have have nitric oxide and it worked so well I wish all CDH children had that option over ECMO even though that procedure has been a life saver for many CDH kids. Nitric oxide has far less complications and these CDH children can use all the help they can get. My pregnancy was pretty uneventful. Had 3 ultrasounds in the first trimester because the doctor had trouble finding a heart beat. After that things went smoothly until my 8th month and my blood pressure would not stay under control so at 37 weeks gestation the doctor induced labor. Like everyone we were anxious to hold our new baby, count toes, fingers, and give kisses. Baby Kristin started having distress in the birth canal. They had no time for a C-Section so it was "Hang on Elaine" and life has not been the same since. The nurses were cleaning Kristin up and the doctor was sewing me up when he said "Do you need any help?" and the nurses said (as they ran out the door) "We're going to the nursery, What is her name?" Next thing I knew I was alone wondering what was wrong. Since we live in a small community the transport team from Denver, Colorado was called. Kristin was born at 4:10 pm and by 10:00 pm we were the jet to Denver. We would of been gone sooner but the team had trouble stabilizing Kristin. Kristin had no diaphragm at all on her left side and was fully paralyzed with drugs and intubated at 6 minutes of age. She was born with CDH, pulmonary hypoplasia, severe pulmonary hypertension, and Atrial Septal Defect. Kristin was not expected to live. The nurses told my parents to say goodbye to her and my doctor let me go with the team to Denver. Kristin had her surgery to fix her diaphragm at 9 am the next morning. They performed it in the Newborn Center because she was too ill to be moved to the operating room. This is where our story is a little different than others. At that time Children's Hospital of Denver was in the process of doing research on the effects of nitric oxide on different breathing problems. They had used it on 9 other children. Kristin was the first CDH child to ever have this treatment. It took the place of ECMO. Nitric oxide is much less evasive. The nitric oxide gas is introduced along with the high frequency oscillatory ventilation. For 2 weeks the doctors kept telling us to be prepared for Kristin not to make it. But she proved them wrong and I got to finally hold my precious daughter at 2 and a half weeks old. What a wonderful day!! After a month at The Children's Hospital we were flown home to our local hospital. In the next 3 months we were in the hospital more than home. We could not keep Kristin's right lung clear and her oxygen needs were increasing. Back on the plane to Denver we went. What a relief to be going back to Denver where they have dealt with children with CDH. Don't get me wrong we had good care from the doctors at home but they knew when they had reached their limit as far as Kristin was concerned. Kristin is the only one with her condition in our town. The nursing staff was afraid of Kristin and made sure I was there at all times. So it was nice to see The Children's Hospital again. They found out Kristin had been refluxing and that had caused all the infections in her lung. Back to surgery she went. She had a Thal Fundoplication and a G-tube was placed. It didn't take long for her lung to clear and Kristin to stop nippling and become G-tube dependant. At 1 year of age Kristin had her ASD in heart closed in hopes that she would come off oxygen. No such luck. That took another 13 months. Kristin is 3 years old and the only hurdle now is the G-tube feedings. But that will come with time. Each day is a joy with Kristin. Krisitin knows her alphabet, can count to 15, will start dance class soon and of course is the boss around our house. She has pretty much been calling the shots since birth. Now when her temper shows itself I sorta giggle to myself and think that this is what got her this far.

Sincerely yours, Elaine Moats
2118 Batchelor St, Miles City, MT 59301
(left-sided CDH, Atrial Septal Defect, reflux, G-tube, nitric oxide)

Dear Dawn:

Hi. Thank you for sending me the "Cherubs" newsletter. It was really great to see that someone had started a support group for parents of children born with CDH. I have also been trying to start some kind of support group here in Wisconsin but have been somewhat unsuccessful. (I don't really know why). Although, we have been trying to set up a support group though Children's Hospital of Wisconsin called "ECMO Parent Support Group", it's not quite the same as a group specifically geared toward CDH. I'm glad to hear that your son is improving everyday. He really seems to be a fighter. My son was born on September 22, 1992 and is also doing very well at the time. He was in the hospital for four months and came home on a G-tube with severe gagging reflux. He had the G-tube removed in June, 1994 and is eating very well (sometimes too much). He has a severe hearing impairment but is learning sign language in order to help him communicate, and is slightly physically and cognitively delayed. He also has pulmonary hypertension but seems to be functioning very well with it, although he does need periodic follow-ups. I will send a short story for you to put in the newsletter soon. Anyway, I just wanted to thank you again for including us in your "Cherubs" group and I will be more than happy to help in anyway I can so please just either call me or write me if there is anything you may need help with. I have already given copies of your newsletters to two other moms. (It's wonderful)! Thank you again. Sincerely, Kelly Weber

2884 South Wentworth Avenue, Milwaukee, WI 53207

(left-sided CDH, G-tube, severe reflux, pulmonary hypertension, hearing impaired, ECMO)

Ryan Vanderschaaf
April 22, 1995

Dear Dawn:

Some wishes do come true. Recently I was wishing that there was a support group for CDH, because I desperately need someone to relate to . I am grateful to one of the neonatologists from our Children's Hospital for passing your newsletter along to me. I found the newsletter to be informative and enjoyed the stories of CHERUBS. For me, the stress of our baby's early hospitalization and the dramatic fluctuations in stability effected my ability to understand complex information and unfamiliar terms. I wished I could see something written down about this condition to help with advocacy and decision making. The experiences we have had with the birth and after care of our latest child are extraordinary to most people. To us it is merely reality. The desire to come together with other parents who share the common bond of having a child with CDH is strong. Perhaps someone who is walking ahead of us on this path, and has gone through oxygen, gastostomy tubes, feeding problems and fear of the future. The birth of our first child was a traumatic cesarean, so this time we wanted sedate surroundings for the VBAC (Vaginal Birth After Cesarean) of our second child. Our desire was to have this birth at a stand-alone birth center attended by certified nurse midwives. Instead, my bag of waters broke at 34 weeks, so we would be going to the back up hospital and be attnded by one of the doctors from the birth center. Tests on the amniotic fluid said lung development was minimal and with ultrasound, it was determined that our baby had right side CDH. The baby had to be born for anyone to determine the severity of the CDH. Surgery to repair the hernia was recommended unless the baby was too unstable, and then ECMO was a possibility. this scenario was so diametrically opposed to our original intentions that it was mind boggling. Since the baby was six weeks early and my labor had stalled, it was recommended that the baby remain in utero for approximately one week to encourage furthur lung development. With the luxury of time, we made choices about what level of intervention, if any, we felt was appropriate for our family. We decided to have a normal vaginal birth when I went back into spontaneous labor. This was because the baby would be stimulated by the journey through the birth canal and the baby's lungs would be cleared of fluid, thus maximizing whatever lung development the CDH had allowed. Then, we agreed to intubation at birth followed by a chest x-ray to evaluate the degress of the condition or conditions. We had been reading about ECMO and though a lifesaving device it has risks associated with its use. We hoped it would not come up for serious discussion in our baby's case. We felt that what ever was done to save our baby could exact life long costs and did not want to be blind to the quality of life that would result for our baby and our family. Also, we did not want to know the sex of the baby until birth to retain at least one small, yet precious, surprise. Ten days later, on April 22, 1995, contractions began again, and after many hours of labor and no drugs or interventions Ryan was born. He was alert and looking around. He was immediately intubated and stabilized. I got a moment to see and touch him, and then he was whisked next door to Children's Hospital. When his hernia was repaired he was found to have a right lung that was sequestered, (it had grown to the liver including its vascular structure, and would not have worked), so it was COMPLETELY removed. Fortunately for Ryan ECMO was not necessary. While in NICU for the initial ten weeks, Ryan was also found to have hydrocephalus of unknown origin. He has since received a shunt. In addition, he has two hemi vertebrae which will put him at greater risk for scholiosis. He had problems with reflux and aspiration, and to handle this he received a Nissen Fundoplication. During this surgery a G-tube was placed to help with feedings. I had taken for granted that I would nurse this baby and never thought I would be using a breast pump. I miss that he is not nursing, but I know he is healthier for receiving the milk I continue to pump for him. We have had some ups and downs, and a few nights back in the hospital, but progress also. He continues to gain weight and is recently off of oxygen and doing well. For Ryan, feeding orally again is the next area of focus, but like all else, it will be at his pace. He knows himself best. I feel we are blessed, because, as I write this, Ryan reclines in his bouncer seat kicking his legs, cooing and smiling. It is precious and I hope his future is as bright as this moment.

Frances a. VanderSchaaf

602 Rudd Road, Vista, CA 92084

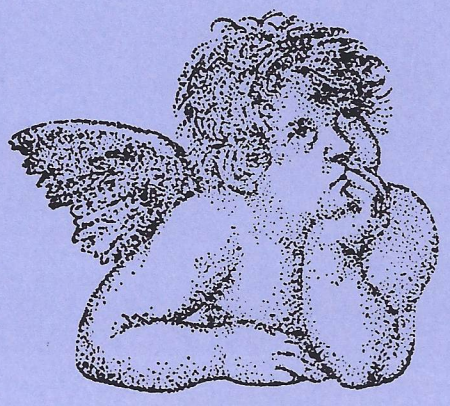
(right-sided CDH, 2 hemi vertebrae, hydrocephalus, reflux, nissen fundoplication, g-tube, Mic-Key button)

This newsletter is dedicated to the memories of:

Andrew Christian Riley
February 14, 1995–June 23, 1995

Amanda Brianne Slavin
November 6, 1993–November 1, 1994

Nicholas Slavin
November 6, 1995



Dear Mrs. Torrence:

I received your newsletter from Contact a Family, based in London, and thought I would like to contact you. We have no voluntary organisations in this country specificalled dealing with congenital diaphragmatic hernia children so you can imagine how interested I am. I have a daughter, Carly aged nearly 14 years, who was born with this defect on 22 June 1981. She had a left sided diaphragmatic hernia and lung hypoplasia, I do not know if she had a lung sequestration. She was operated on at 7 hours old and struggled for life for the next 10 days. I only saw my daughter just after her birth for a couple of minutes because it was quickly realised that she had a problem. They took her to the special care unit on the next floor and sent me to the mother and baby ward saying that I could see her when I felt a little stronger. During the afternoon I dozed but kept waking every 30 minutes or so to ask why Carly had not been brought to my bed. I was told that she 'had a headache' because of forceps birth. This went on for about 3 hours until suddenly a doctor came to my bedside and woke me. She tried to explain what was going on and told me that Carly would be transferred to the Queen Elizabeth Hospital for Sick Children in London, a sister hospital to Great Ormond Street Hospital. I was still very drowsy from drugs but also very frightened. They said I could go up to special care to see her before the trip after I had taken a bath and told me a nurse would be along to give me a hand. A few minutes later, one leg poised over the bath to get in it, a nurse entered and told me that my daughter had already left. I was devastated, I could not believe it. I couldn't even remember what she looked like, and by that time I couldn't even remember what they said was wrong with her. I spent the next 3 days in a mother and baby ward without my darling Carly, not even a potograph of her. After crying in my pillow for most of this time I discharged myself and went to stay with my mother and father. I fought and fought to be taken up to the hospital to be with her but I was told they had no facilities to look after me if I stayed there with her until the midwife gave me the all clear. I was so unhappy that I begged my husband to take me to see her, which he did on the 5th day. When we arrived at the hospital we went straight to the ward. We were shown to a cubicle that had 2 babies laying in incubators. I was extremely distressed when I found I could not identify which baby was mine. They were both girls, both dark in clouring and around the same age. A nurse pointed to the right hand incubator and to my utter disbelief I looked at the most dainty, dark haired, beautiful dark eyed baby I had ever deen. Until that time my view was that most babies looked the same until they were a couple of weeks old but she looked so pretty to me. There were a number of tubes going into her tiny arms, legs and even her head, she also had a large dressing over her stomach. I had expected her to be on a ventilator but we were told that as she had been progressing so very well they had decided to let her try and breathe on her own only an hour beforehand. This she was achieving with a bit of a struggle but she was doing it. I wasn't allowed to hold her on this occasion so I was upset when it was time to leave for home, but contented that even if the worst happened to Carly then I would have a picture in my memory of her, which is something I didn't have until this time. The next time I went to see Carly was when she was 10 days old. This time I took a suitcase and was determined to stay, however long it took. I was given a room within the hospital sharing with the mother of the other baby Carly was sharing with. This child had the same problems as Carly. Her mother and I struck up a remarkable friendship during the next 6 weeks, one that was to last many years. One morning in her 7th week the nurse came to weigh her and as usual we were expecting her to have lost some more weight, but she hadn't, she had put on 1/2 an ounce!! This was the day she was allowed to go home. When Carly was born she weighed 7lbs 1oz, when I took her home she weighed 5lbs 10oz. She had to continutally have a powder added to her milk so that it would stay in her stomach and this also had to be mixed with her baby food, up until she was about 10 months old. Even now she still suffers with heartburn and indigestion but the problem is not severe enough for them to operate. During her early years we had a number of minor problems. She had to keep going back to the hospital for oesophagoscopies to be carried out under anaesthetic, this was to keep an eye on her hiatus hernia. We also had a very scary time when, after a routine outpatients appointment when x rays of her body were taken, we received a phone call at home saying a shadow had been picked up on her head x-ray. She had to go to Great Ormond Street Hospital for a CAT scan, but was given the all clear when it was found that the 'shadow' was just a deformed piece of bone in the back of her head. She also had numerous chest infections and croup on a regular basis and has been admitted in to our local hospital on a few occasions for monitoring during these times. In January 1993, when Carly was 11, she complained of back pain regularly which we put down to her age and the fact that shwe was starting to develop. I decided to take her to the doctor for a general check up as she hadn't been to the hospital in London for a couple of years. The doctor sent Carly for a chest x ray and when we went back for the results he said that he was quite pleased with her but would like her to see a chest specialist. I insisted that she be referred back to the Queen Elizabeth in London as I had complete faith in them. Normally alarm bells would have started ringing but at the time my father was in intensive care and had been for 4 weeks after a life saving operation and my mind was elsewhere for a while. When the appointment came through it was for March 1993. If you knew the NHS system in this country you would know that an appointment so quick after referral is almost unheard of. This is when alarm bells started ringing and my concern for Carly started to increase. The appointment couldn't come quick enough for me but when it did I found that the consultant who operated on Carly at birth had moved on and we saw a new one. Just as I thought the talk was over he told me that our doctor had noticed on the chest x ray that Carly's backbone had a curve in it and that she would need to see an orthopaedic surgeon to check it out. At this appointment a full spine x ray was taken and on comparison with the one which was taken in January we were told that she had a 64' curve of her spine; it looked like a question mark, with the curve inbetween her shoulder blades. The degree had increased 22' since the January x ray. We were told that, in his opinion, she needed operating on immediately to stop her becoming very ill. The condition, if left to progress, would eventually twist her body so badly that her lungs would be restricted and breathing problems could result in a very poor quality of life, even death. After saying she needed immediate treatment costing L22,000, which I will add we could not afford, he told us that there was a two year waiting list on the NHS if we couldn't raise the money. I quickly realised that if we waited that long then all my lovely Carly's struggling over the years for survival would have been in vain. I was not going to let this happen. I learned that my husband had insured the family though work, without my knowledge. After a rushed phone call to my husbands place of work we had confirmation within 24 hours that they would pay for her treatment. You must be able to imagine our joy. Three weeks later, on 7 June 1993, she was in the Princess Grace Hospital in London to have what they call a 2 Stage Spinal Fusion. Eventually I was called to the recovery room and was told that she had vomited during the operation and it went back into her lungs. We nearly lost her again that day so every minute with her, as you can imagine, is very precious to us. Her recovery after this major surgery, as when she was a baby, has been amazing. It was explained very thoroughly to us that, had Carly been born a couple of years earlier then the probability was that she would not have survived. Diaphragmatic hernia babies deteriorate very quickly and can still have major complications during the first 10 days after surgery, as well as after, depending on the severity of the condition. Carly happens to be one of the older children who the medical profession can now compile statistics from and it is appearing that these children can have a higher instance of developing scoliosis in later life, although this was not widely known here when she was younger. It is because of the chest abnormality that eventually makes the backbone bend to compensate. Please excuse my explanaiton but I am not in the medical know-how, I can only put in my own words how I perceive this. It was also explained to us that during infant and junior life the development of the chest area is extremely important to diaphragmatic hernia children therefore, even if the scoliosis had been noticed when she was 5 years old the treatment we would have been offered could have been detrimental to her development, and possibly fatal. After the discussion and explanations my husband and I decided to let sleeping dogs lie and just thank our lucky stars that our daughter is still here with us. We also have a son, Aaron, who is 2 and a half years younger than Carly, and we also have regular visits to the hospital with him! The visits consist of a stitch here and a stitch there when he's bumped his head, fallen off a shed roof or his bike; he was even run over by a car 2 weeks before Carly went for surgery on her spine. But thankfully, these are all visits which parents can expect when they are trying to raise a perfectly healthy, nosy, michievious, very robust young boy. Carly has recently had a thorough medical at the Queen Elizabeth and they are extremely happy with her progress. Her lung function is better than average and although she knows she will never win a race on school sports day, at least she can take part, which she always does with a smile on her face.

Yours sincerely, Sharon Cribben
19 Weymouth Road, Cheriton, Folkestone, Kent CT19 4HU, England
(CDH, scoliosis)

The following is the story of Amanda Brianne Slavin. Her parents have recently lost a son, also with CDH. Our prayers and condolences are with Brenda and Bob.

I was told by a doctor I was probably infertile. Bob and I decided that we would adopt in the fall of 1993. We were just newleyweds when I found out I was pregnant. Both of our families were as excited as we were. On my sixteenth week of pregnancy I went for my first ultrasound. At first I couldn't stop smiling. Then as time dragged on I noticed the technician was staying on one particular spot for a long time. I began to feel panic. They informed me by baby had an enlarged kidney. Later that day I went to my OB appointment in a total state of shock. The resident covering for my doctor informed me I should probably have an abortion. She felt this was a life-threatening situation for the baby. I bluntly informed her I would not have an abortion and I was going to give this baby every chance I could. No matter what birth defects or disabilities this child has I would have this baby. (Later I found out the kidney problem was not life-threatening). I received my medical care at Bethesda Naval Hospital in Maryland because my husband was in the military. They are a research hospital so I became the highlight in the Prenatal Assessment Center for my weekly sonograms. I requested an amniocentesis. The chromosomes came back normal and showed we were having a little girl. Around my thirty-second week an ultrasound came back nomal and showed "a mass" in her chest cavity. I was informed I would have to switch hospitals. I had to go to Walter Reed Army Medical Center in Washington, D.C. because Bethesda did not have a pediatric surgical team. (My husband was in California for a week for the military when they told me this news.) I read as much as I could on diaphragmatic hernias. The more I read, the more scared I got. In my thirty-forth week I went into pre-term labor due to excessive amniotic fluid. They were able to stop labor. On November 6, 1993 (thirty-eight weeks) I delivered Amanda after seventeen very physically and emotionally tiring hours. I remember as I was pushing her out thinking I really don't want her to be born yet. She was safer inside me. I was afraid of what was going to happen when her life was in the hands of someone else. I think right after birth I passed out. I woke up at 3 am to my pastor calling my name. All I could think was Amanda is dead. They assured me she was on the ventilator doing well. They told me she had a cleft palate, diaphragmatic hernia, hydronethrosis, and clubbed fingers with hypoplastic nails. On the second day of life they fixed the hole in her diaphragm. Her spleen and intestines were placed back into her abdomen. She did very well. She was completely off the ventilator within one week and acting like a normal newborn. Then they noticed she wasn't stooling properly. She had a biopsy of her intestines to prove she did have Hirschsprungs Disease. At one month of age she had surgery done to perform a colostomy. After the surgery she developed candida sepsis. We were certain we were going to lose her. She was on full life support for two weeks. At two months of age they noticed she had gastroesophageal reflux. They performed another surgery to fix the reflux and gave her a G-tube for feedings. (She could not suck well with the cleft palate) Finally January 18, 1994, we brought her home. In March I asked Amanda's nurse if she had stooled that day. She lied to me and said yes. Her stomach was distended. We went through the trash and only two diapers were found and neither with stool. We took her to the hospital. They tried several enemas. Finally the next day one of the enemas worked. She began spiking fevers. They thought she had osteomyelitis (which later was unfounded). She was in the pediatric ward on antibiotics for a month. I kept telling them the problem was her colostomy. Later in April at home Amanda went into septic shock. She had stooled earlier during the day but stopped in the evening. This time we ended up in the PICU on the respirator for a collapsed airway for five weeks. (Her fever shot up to 104.8 and trying to breath heavy she collapsed her airway) The doctors checked her intestines again and found her surgery wasn't performed properly. She was sent home on oxygen. She was weaned within two weeks. I had to give her an enema after each feeding everday. (Five times per day) In the end of June she began refluxing again. She vomited everything she ate. The surgeons refused to do anything for her until the end of August. It was frustrating calling them every day listening to them denying her medical care. In September she had surgery to fix her vomiting, fix her colostomy, and put tubes in her ears. She was admitted a few times in September and October for infections of her surgical wound. On Friday, October 28 Amanda developed a cold. That day I had taken her to a civilian hospital to start treatment. (I felt the military hospital did more harm than good). On Saturday they took an x-ray of her lungs and ruled out pneumonia. They put her on antibiotics and said they thought it was a virus and they would keep and eye on it. On Monday (Halloween) we bought her into the doctor at 9:00 pm. We got home around 11:30 pm and I put her to bed as usual. On Tuesday November 1 (All Saints Day) I got up at 6:50 am and instead of going to the kitchen to get a cup of coffee, I felt drawn to her room. When i went to pick her up I noticed her legs and arms were ice cold. In the light I noticed she was bluish gray but conscious. She was breathing very shallow. I ran to turn her oxygen up. When I came back Bob was performing CPR. I took over CPR while he called 911. Amanda took her last breath in our living room while her eyes were locked on us. As difficult as it was, we were glad Amanda died at home. No tubes, no hospital, no doctors. She deserved to die in peace after all she had gone through. We found out from her autopsy she died of pneumonia. The x-ray done at the hospital did show pneumona. Here pediatrician overlooked it. The last few years have been the most difficult and most precious years of our lives. We're currently in therapy to deal with anger we have against the doctors and the military. (We're angry with the military because Amanda was a Gulf War Baby). Amanda will always be a part of our family. She taught everyone around her that Jesus is a big part of all of our lives and miracles do come true.

Written by Brenda Slavin (7751 B Olsen Loop, Ft. Meade, MD 20755)

THE GIVING ANGEL

(written by Brenda Slavin for her daughter Amanda)

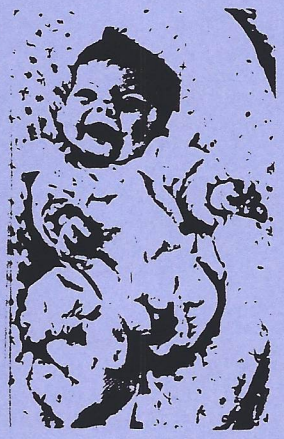
Not a minute goes by without a thought of you
My special little angel so small and brand new
How often my heart crumbles in just one day
Missing your smile since you were taken away

You still are the reason for every breath I take
As hard as it is to go on. I must for your sake
There are many things God is planning for me to do
To love, to understand, and to teach a few

There are many children you watch over every day
There's Casey and Katelin you protect while they lay
They know you are near for they feel your love
That is being sent to them from the heaven's above

Although you are gone one thing is clear
The love you still give shows in all of my tears
For now I must start over while we are apart
But each day I hold my little angel deep in my heart

Love,
Mommy



Amanda Brianne Slavin
November 6, 1993
November 1, 1994

AS WE WAIT

(written by Brenda Slavin for her son, Nicholas)

How scared we were we learned of you
As we patiently our nightmare came true
The doctors said you were a sick little boy
The tears that fell from our eyes were no longer from joy
For we know first hand what a miracle it would be
For you to have a first breath and the world to see
We live each day trusting in the Lord above
We know we'll get through this from all of His love
It was only 2 years now that we once rode this ride
We know how to trust Him and let Him be our guide
We felt the miracle the day your sister was born
We loved and cared for her a year, but now we mourn
For the Lord took Amanda and made her an angel in the sky
She no longer suffers, she's able to fly
I know you see her every day and night
and someday you'll be together, two angels in flight
But for now we pray each day for a miracle to come true
We want you to be with us as long as He wants you to
Always know Nicholas no matter how long you are here
A minute, an hour, a day, or a year
You'll forever have all the love in our hearts
And one day the four of us will never be apart

The following is the story of Andrew Christian Riley, who underwent in-utero repair of CDH. Our hearts go out to his family. I want to remind other parents that every CDH child is different.

Andrew Christian Riley
February 14, 1995 - June 23, 1995

The story of our journey begins in August, 1994 when my husband, Greg, and I discovered that we were expecting our first child. It was such a thrilling time for us. One of our greatest desires in life was to be blessed with children to love, nurture and raise in a happy and loving home. Our joy increased as the size of my pregnant belly grew. We could hardly wait to discover whether our child had "indoor or outdoor plymbing". Finally, when I was 18 weeks pregnant, the day of our ultasound arrived. It didn't take an expert to point out that we were expecting a boy. He was not modest in the least. However, within minutes, our hearts were shattered as we learned that he was in serious trouble. This just had to be a dream. Nothing could possibly be wrong with OUR child. I remember asking the neonatologist several times, "Now, what is the name of this defect?" He would slowly say each syllable clearly, "Diaphragmatic Hernia". We could never begin to imagine just how familiar that term would become. A "hernia" sounded minor and so easy to fix. Certainly it wasn't as serious as this doctor was building it up to be. That day remains so vivid in my memory, as the doctor sat down with Greg and me, informing us that basically there just wasn't much hope. He told us of three options: 1) abortion; 2) try to carry the baby to full term and hope for enough lung growth to sustain him; or 3) experimental fetal surgery. It seemed to us that this doctor's recommendation at this point, was to abort our child. However, to us, this was not an option to consider. It's amazing to think about how much our life had changed within an hour's time. We went home in shock. I remember going to our bedroom, shutting the door, and just lying in bed all day, crying, praying, and just lying there in disbelief. The next day we began seeking out as much information as possible. We went to the local library and I was able to fiind a couple of articles on an experimental procedure beging performed in San Francisco. I was amazed to read that the Pediatric Surgeons there were repairing Diaphragmatic Hernias in utero. We immediately contacted UCSF to see if we would qualify as candidates for Fetal Surgery. Within a very short time, we were on a plane flying from our home in Orlando all the way to San Francisco to meet with the doctors there and to see if this would even be a possibility for us. We met with the Fetal Treatment team headed up by Dr. Michael Harrison. They informed us that we would be candidates for the surgery. However, they would not be able to perform the full repair on our child due to the fact that his liver was herniated up into his chest. We learned that the umbilical cord is connected with the liver. In earlier cases, the team found that when they attempted to bring the liver down into the abdomen, the umbilical cord would kink, and consequently the child would die. If we decided on the surgery, they would keep the lung fluid from escaping. The lungs would have a chance to grow, due to the expansion of fluid in the lungs. The lung growth could even cause the abdominal organs to move into the abdomen. We flew home to Orlando, knowing in our hearts that this was the right option for us. We wanted to give our son every possible chance for life. We knew that if we didn't have the Fetal Surgery and our son died, we would always regret not having the surgery. We believed that if we had the Fetal Surgery and our child still died, we would have done everything within our power to give this child that we loved a chance. Two and a half weeks later, and 27 weeks pregnant, we were back on a plane, going back to San Francisco. We were ready to start fighting for our son's life. The Fetal Surgery went very well, with no complications. However, the week I spent in the hospital was, by no means, an easy week. I spent a day and a half in complete oblivion while in Intensive Care. The medications used to prevent pre-term labor caused very unpleasant side effects. I developed a mild case of pulmonary edema, which for a short period of time, made it drfficult to breathe. One of the medicaitons made my heart race. I also experienced hallucinations and constant hot flashes. It really annoyed me having to wear a fetal monitor 24 hours a day. After leaving the hospital, my husband and I were very fortunate to be able to stay at the Ronald McDonald House in San Francisco. I was ordered to remain on bed rest until the baby was born. Unfortunately, all babies who undergo Fetal Surgery are born prematurely. I was determined to keep this baby in for as long as possible. The room that we stayed in was very small. Looking at the same four walls every day, all day, became very old. I remember on a couple of occasions Greg rolling me eight blocks in a wheelchair to the nearest movie theatre. We were determined to find some excitement! At times, I was so homesick. I must admit it was difficult being without a car, in a strange city, thousands of miles from home. Feelings of excitement soon replaced feelings of loneliness, as they began to see lung growth on the sonograms. Unfortunately, during one of my sonograms, they found that the two layers of the amniotic sac had separated so they had to admit me back into the hospital so that they could keep an eye on the baby and be ready to deliver him, should an emergency occur. Well, on Valentine's Day, Andrew Christian decided that he was ready to face the world. I was placed under General Anesthesia and Andrew was delivered by C-section, eight weeks early. Andrew was truly a fighter! From the very beginning, his course was extremely difficult. i'll never forget the day after he was born, one of the doctor's came in and told us that there wasn't much hope; that he most likely would not make it through the day. They had tried everything, including an experimental procedure, but Andrew had severe Pulmonary Hypertension and there wasn't much more that they could do. Due to the Fetal Surgery, Andrew's lung growth was very significant. He had almost a full right lung and about a quarter of a left lung, but he was having such a difficult time overcoming the Pulmonary Hypertension. The doctors decided to try to place him on ECMO. Andrew weighed only four and a half pounds and the doctors believed that he would most likely be too small. It was a long shot, but it was our only chance. We were told that even if they were able t get Andrew on ECMO that he would only have about a 10% chance to live. Fortunately, they did get Andrew on ECMO, and would we have known just how many more hurdles that we would have to face, I don't know if we could have possibly taken it. Andrew was on ECMO for a week, and we were fortunate that he did not experience any bleeding in his brain. I could write page after page on the many close calls we had with Andrew, and about all that our son had to go through. I specifically remember one occasion being paged by the hospital. They informed us to come to the hospital immediately; that Andrew was experiencing a pulmonary hemorrhage. I'll never forget standing several feet from his bedside, watching all of the doctors and nurses nodding their heads, as if there was just nothing else they could do. I watched as they suctioned blood from his lungs. The pain was unbearable as I watched his little arms and legs tossing about. I felt so powerless. I was his mother. I was supposed to be able to run and pick him up and make everything okay, but I was completely powerless, unable to even stand close beside him. I remember another time, when Andrew coded, during what was supposed to be a simple surgical procedure. When Andrew was about four weeks old, Dr. Harrison and team performed the repair surgery. After the risky procedure, we were informed that Andrew had the largest defect that they had ever seen. His entire left diaphragm was missing. They repaired the defect with a Gortex patch. The doctors stated that without the Fetal Surgery, Andrew would have never had a chance. Over the next several months, we saw Andrew overcome so many hurdles. He underwent eleven various surgeries. We were so proud of him. Andrew was such a joy! He charmed everyone with his big brown eyes and sweet disposition. Even though he was in the hospital, we tried to enjoy every moment with him; rocking him, singing to him, playing lullaby tapes, bathing him, dressing him in colorful socks and hats, and just making sure he knew exactly who Mom and Dad were. When Andrew was four months old they decided to perform an MRI on him to make sure that his brain was okay. It was normal to perform MRI's on babies who had been through as much as Andrew had. Several days later, we sat down with one of the doctors to go over the results. We were not prepared to hear the doctor's next words, "I'm afraid I do not have good news". Greg and I went into total shock as the doctor proceeded to inform us that Andrew had experienced severe brain underdeveopment due to the drastic measures taken along the way to keep him alive. He would most likely never be able to walk or talk. As incredible of a blow as this was, Greg and I made a decision that if Andrew wanted to live, we would do everything possible to give him a life of quality and happiness. As the days went by, we discovered that it was even much worse than we could have ever imagined. We were informed that Andrew would most likely begin having seizures and would not be able to perceive hearing or

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sight. He had also developed severe scoliosis, and one doctor believed that there was a possibiity of him even having Cerebral Palsy. I cannot begin to describe the pain and anguish we experienced as we went in to see our beautiful little boy, after hearing this news. We had such an overwhelming amount of love for this child. Now, we were faced with a decision. Would we - could we - possibly let him go? We would have loved nothing more than to just bring him home and shower him with love! Somehow, though, we knew in our hearts that the right decision for us was to let him go. After much prayer and oceans of tears, we decided to take him off of the antibiotics, and to decline any further drastic measures. We kept him on oxygen and on Morphine to keep him very comfortable. I cannot think of anything more painful or difficult in life, than letting go after so much fighting, and giving your child permission to die. The wonderful staff allowed us to take Andrew out of the Intensive Care Nursery and into a private hospital room with us. We finally had a chance to be a family. How wonderful it was rocking Andrew in total peace and quiet, with no interruptions, and no beeping and buzzing. We knew we didn't have much time left with Andrew, but we were determined to make this time with him valuable and precious. One day, we bundled him up and took him on his first and only outing; to the beach. I could never count how many stares we received, as we walked down to the sand with an oxygen tank, a morphine pump, a stroller, a car seat, a diaper bag, and a little six pound bundle of cuteness in our arms. This was Andrew's last week with us and his absolute best week. We had never seen him so content and peaceful. It was Friday, June 23rd, when Greg looked at me as he was holding Andrew, and said, "I think this is it Karla." It was almost as if he could just feel his spirit going. I took him in my arms and we told him that we loved him with all of our hearts, and that it was okay for him to go. I sang, "Jesus Loves Me," and Andrew smiled his first smile. Actually he smiled three times, and we truly believe that he was beginning to see Heaven. He then took his last little breath and went to be with Jesus. Our lives are forever changed from knowing a little angel named Andrew Christian Riley. To this day, we have no regrets with the many decisions made along the way. Because of the Fetal Surgery, Andrew was given an incredible chance to live. We would have necer had those four and a half months with him had we done things differently. We spect six months in San Francisco. We are grateful that God has opened our eyes to see beauty and purpose throughout this sorrowful time. I could never bear to think that this six months of our lives meant nothing, that our child was just a mistake of nature. Andrew's life was full of meaning! We choose to rejoice in the blessing of knowing him. Let me say also that, because we are human, we have had our times of questioning. No, it's really not fair this happened. I believe that questioning is a natural part of grief. We have also chosen, however, not to let questions consume our lives, but to move on in life, carrying valuable memories of a wonderful little boy who will always be a special part of us. There may be someone reading this who has recently lost a child due to this terrible defect. I just want you to know that I know what you are going through. I know the loss is tremendous. There is consolation in knowing that our children are completely whole and without pain. They are enjoying pleasures that are too incredible to imagine. If you'll listen with your heart, you will hear your child say, "Thanks Mom, Thanks Dad, for believing in me and for loving me. I want you to know that I'm just fine." If you are carrying a child that has been diagnosed with CDH, I encourage you to begin considering and researching your options right away. Whatever the path you choose, it is going to be a difficult journey. I highly suggest that you obtain information on Fetal Surgery. It is not for everyone, but it is a viable opportunity to consider. My prayers are certainly with you as you face the days to come!

Karla and Gregory Riley (3701 Eloise Street, Orlando, FL 32806)

CORRECTION NOTICE: In the summer issue of our newsletter, we incorrectly printed the telephone number of the Association of Birth Defect Children, Inc. The correct phone number is (800) 313-ABDC (24 hours a day). I hope that you will all take the time to join this great organization that conducts research on the causes of birth defects. We also misprinted the name of one of our CHERUBS. To Anna Tijan, please accept my apology.

? QUESTIONS AND ANSWERS ?

I wanted to include another new section in the newsletters to let parents ask questions of our other members. A lot of you have asked me questions about CDH and it's causes. As you know, I am not a doctor and so I can't give you all of the answers; but I will do my best to find the answers for you. Unfortunately, I don't think the doctors have the answers either. As I told one mom, when the cause of CDH is found, it will most likely be discovered my a parent. The medical world just doesn't conduct enough research on the causes of CDH, only the corrections of CDH (though this research is needed and appreciated). So CHERUBS is going to try to conduct our own research by comparing our medical histories. Included with newsletter, for our members, is a questionairre. Though some questions are very personal and you may wonder why we are even asking some of them, they could possible give us valuable insights on any "coincidences" that some or most of us have in common. Maybe this research will catch the eye of the medical profession and force them to take second or third looks at the causes of CDH. The questionairres are confidential and information included in them will only be given out to medical researchers will your permission. CHERUBS does not and will not discriminate against any of it's members or potential members because of the answers to any of the questions included. Race, religion, social or financial status does not matter to us, our common bond is having children with CDH and we need to find out why this bond exists.

Also, this section is included to allow you to ask questions about such things dealing with siblings, family, friends, grief, anger, medical procedures, home health care, and anything that you need another member's advice on. Of course I am glad to give you my opinion on any of these topics (as most of you know!) but by printing your questions, you can help other members who were wondering the same thing!

.Right now I don't have any other children, so I can't imagine how some of you are coping with having other children along with your child with CDH. God Bless You. Below are some pictures of siblings of our members who are miracles in their own rights.

Tabitha Goembel; age 3 (sister of Matthew)

Michael Monaco; age 3 (with his little brother, Anthony)

WELCOME TO HOLLAND

by Emily Perl Kingsley

I am often asked to describe the experience of raising a child with a disability- to try to help people understand it, to imagine how it would feel. It's like this...

When you're going to have a baby, it's like planning a fabulous vacation trip--to Italy. You buy a bunch of guidebooks and make wonderful plans. The Coliseum. The Michelangelo David. The gondolas in Venice. You may learn some handy phrases in Italian. It's all very exciting.

After months of eager anticipation, the day finally arrives. You pack your bags and off you go. Several hours later, the plane lands. The stewardess comes in and says, "Welcome to Holland."

"HOLLAND?!?" you say. "What do you mean, Holland? I signed up for Italy! I'm supposed to be in Italy. All my life I've dreamed of going to Italy."

But there's been a change in the flight plan. They've landed in Holland and there you must stay.

The important thing is that they haven't taken you to a horrible, disgusting, filthy place, full of pestilence, famine and disease. It's just a different place.

So you must go out and buy new guidebooks. And you must learn a whole new language. And you will meet a whole new group of people you would never have met.

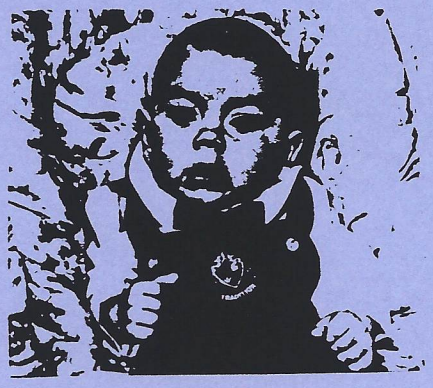
It's just a different place. It's slower-paced than Italy, less flashy than Italy. But after you've been there for a while and you catch your breath, you look around, and you begin to notice that Holland has windmills, Holland has tulips. Holland even has Rembrandts.

But everyone you know is busy coming and going from Italy, and they're all bragging about what a wonderful time they had there. And for the rest of your life, you will say, "Yes, that's where I was supposed to go. That's what I had planned."

And the pain of that will never, ever go away, because the loss of that dream is a very significant loss.

But if you spend your life mourning the fact that you didn't get to Italy, you may never be free to enjoy the very special, the very lovely things about Holland.

PICTURES OF CHERUBS



Anthony Monaco
May 17, 1994
(left-sided CDH, vent-dependent, BPD reflux, Mic-Key Button)
mom- Laura Monaco
4527 Raccoon Dr. Gahanna, OH 43230

Gregory Joseph Jennings
March 4, 1993 - March 14, 1994
(left-sided CDH, G-tube, 2 surgeries, viruses, infections, pneumonia)
mom- Jessie Jennings
118 West Nott St. Tomah, WI 54660

Mattew Goembel
March 19, 1993
(left-sided CDH, J-tube, G-tube, gastointestinal herniated esophagus ulcers) mom-Cindy Goembel
403 E. Pearl, PO Box 462, Danvers, IL 61732

CHERUBS
c/o Dawn M. Torrence
3671 Bruce Garner Rd.
Franklinton, NC 27525