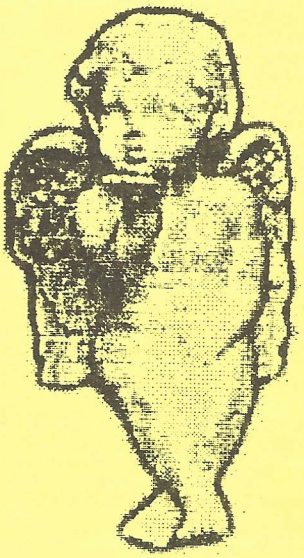
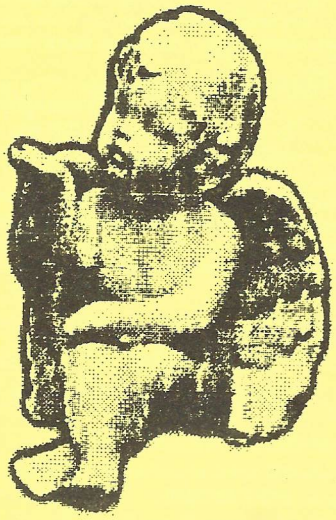
Summer 1996

CHERUBS

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





CHERUBS
C/O Dawn M. Torrence
3671 Bruce Garner Rd.
Franklinton, NC 27525

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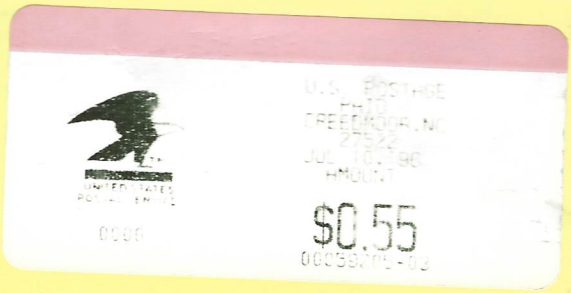

Rhonda Moser
[redacted]
Lemon Grove, CA 91945
Please Forward

Dear Members,

Since our spring newsletter, we have added a few new members; including medical professionals. I urge all of you to take a copy of one of our newsletters and your Parent Reference Guide with you to your child's doctor's appointments (especially surgical and genetic appointments). By introducing your child's doctors to CHERUBS, you may help these doctors to refer other families who also need support!!!!

Many of you sent donations, postage stamps, and office supplies. Thank you!!!! Glaxo Wellcome, the drug company that produces Zantac, donated a computer and many other companies made donations to help fund our trip to the American Pediatric Surgical Convention. Thank you also to all the members who sent pictures for conference! There will be an article in the fall newsletter about our trip. Keep your fingers crossed that we will recruit more pediatric surgeons! We still need donations, so please keep your eyes open for office equipment and supplies especially.

How many of you watch the television show "Chicago Hope"? How many of you saw the episode this past fall about the baby diagnosed in utero with CDH? After the "doctors" on the show told the parents that there was no chance for the baby's survival unless in utero surgery was performed, they opted for the procedure. I won't tell you how it ends, but I will say heaven help those real parents of prenatally diagnosed CDH who were watching this episode! The producers and writers could have educated their viewers a little more on CDH. I urge all of you to keep your eyes open for the rerun of this episode, and please write us with your opinions. I would love to get enough letters from our members to send to CBS. Maybe we can get them do another story on CDH.

Only 10% of our CDH Research Surveys have been returned. So far there are a few similarities, but it would be premature of us to release findings before we have at least a 50% return. So please, all of you who would like to participate in this study, we need those surveys!

Please keep those letters, pictures, and updates coming. We love to hear how our cherubs and their families are doing! I hope you all have safe summers and for those of us in the U.S., Happy 4th of July and let's please remember our bereaved families this Mother's Day and Father's Day.

Sincerely, Dawn

CHERUBS would like to thank the following people for their help and support:

American Association of Pediatric Surgeons
Butner-Creedmoor News (Creedmoor, North Carolina)
Jacob C. Langer, MD, FRACS(C)
Ms. Marilyn Thomas- Alpha World Travel, Raleigh, North Carolina
Prem Puri, MS, MBBS
Mrs. Brenda Slavin

CHERUBS Would Like To Thank The Following People for Their Generous Contributions:

Vincent Adolph, MD- Ochsner Clinic, New Orleans, Louisiana
Mrs. Wendy Barkley, in honor of her son, Jack Barkley
Mrs. Diana Cox, in honor of her son, Dallas Cox
Glaxo Wellcome, Research Triangle Park, NC
Herbs 4U, herbal therapy store, Creedmoor, N.C.
Michael Harrison, MD-University of California, San Francisco
Lori Howell, MS - The Children's Hospital of Philadelphia
Chryl Hundertmark, in honor of her granddaughter, Laura Beth Snyder
Mr. Jeff Jenkins
Mrs. Alice Johnston, in honor of her great-nephew, Jeremy Shane Torrence
Mrs Connie Lee, in honor of her son, Tony Lee
Mr. and Mrs. William McKellar, Jr., R.P.H.
Jennings and Mary Mitchell, in memory of their son, Harold Jennings Mitchell, III
Quality Drugs, Inc., Butner, NC
Ruth Keith Reality, Creedmoor, N.C.
Sportsman's Hut, sporting goods store, Creedmoor, NC
Lesli A. Taylor, MD- University of North Carolina at Chapel Hill, Chapel Hill, NC
University of North Carolina, Chapel Hill Holiday Card Project Fund
Frances VanderSchaaf, in honor of her son, Ryan VanderSchaaf

CHERUBS WISH LIST

* A copy machine, capable of dual-sided copying on 11"x17" paper
* A fax/modem for our computer system
* A computer scanner
* A CD-ROM drive
* A 3.5" disk drive
* A telephone answering machine
* Computer paper (9 and a half inch x 11")
* Envelopes
* 19 and 32 cent postage stamps
* Cherub postcards
* Colored index cards
* An office phone
* 11"x17" colored paper
* Files
* Computer Software; MS Windows '95, MS Encarta '96, Desktop Publishing, Clip art (especially cherubs and angels)

MEET OUR BOARD MEMBERS

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Parent, Franklinton, North Carolina

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Assistant Professor of Surgery and Pediatrics
University of North Carolina At Chapel Hill

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Pediatric Intensive Care Unit
Duke University Medical Center, Durham, North Carolina

Jeremy D. Torrence- Board Member
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Ochsner Clinic, New Orleans, Louisiana

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University of California, San Francisco
Director, Fetal Treatment Center

Aviva Katz, MD- Medical Advisor
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Alfred I. du Pont Institute, Philadelphia, Pennsylvania

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Washington University in St. Louis, Missouri

Prem Puri, MS, FACS- Medical Advisor
Consultant Paediatric Surgeon
Children's Research Centre
Our Lady's Hospital for Sick Children
Crumlin, Dublin, Ireland

Jay Mark Wilson, MD- Medical Advisor
Assistant Professor of Surgery, Harvard Medical School
Associate in Surgery, Director, E.C.M.O. Program
Boston's Children's Hospital, Massachusetts

Beth Zimmerman, RN, MS- Medical Advisor
Clinical Nurse Specialist, Section of Pediatric Surgery
Wyler Children's Hospital, University of Chicago, Illinois

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 provides by CHERUBS. We are a volunteer organization founded in February of 1995 and an Internal Revenue Service recognized Non-Profit Association. Donations are very welcomed and are tax-deductible. Checks can be made out to CHERUBS. The opinions shared in this newsletter do not necessarily represent the views and 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 not compare the progress of another CDH child to the progress of your own child. They are all little angels.....CHERUBS.

Almost everyone will be faced with tragedy in life. Very few will live without heartache or pain.....

Letters to CHERUBS

March 27, 1996

Dear Dawn:

Thank you for your inquiry about Pen-Parents of Canada. We are a network of grieving moms, dads, and grandparents who have experienced pregnancy loss or the death of a child. Our goals are to provide support to those parents who may not have access to support group meetings, or those who feel uncomfortable sharing in a group setting, or for those who desire additional support through correspondence. Many have discovered that writing is a powerful release of feelings. Sharing these thoughts with someone who has also experienced something similar can be very healing. Please find enclosed a standard packet of information which includes our newsletter, a form letter, brochures, a bibliography of books that I recommend and a release form. I would be happy to exchange newsletters with you and have added your name to our list. I will add CHERUBS to our database of resources. We do have families that have had experience with congenital diaphragmatic hernias--unfortunately they are all bereaved parents. Most would be quite interested in information about recurrence and any studies on the such like. I will feature CHERUBS in our Resource List in the summer newsletter.

If there is anything further that I can assist you with please do not hesitate to contact me.

Sincerely,
Patty Lou Bryant, Director
Pen-Parents of Canada

DEAR MEMBERS, DID YOU KNOW THAT APPROXIMATELY 11,000 BABIES ARE BORN IN THE U.S. EVERY DAY? IF RESEARCHES ARE CORRECT AND 1 IN EVERY 2500 BABIES ARE DIAGNOSED WITH CDH, THEN 3 TO 4 BABIES ARE BORN WITH CDH EVERY DAY! THAT MEANS APPROXIMATELY **1600 BABIES ARE BORN WITH CDH EVERY YEAR**, NOT INCLUDING MISCARRIAGES AND ELECTED ABORTIONS!!!!!!!

March 5, 1996

Dear Ms. Torrence:

I would be delighted to be an advisor to your organization. I have read your newsletters with interest and certainly admire your work. Our Fetal Treatment Team here at UCSF has been struggling with this problem for some time, so we would be happy to share our experience with your members.

I am sorry that I won't have time to write a new article about diaphragmatic hernia, but I will ask Jody Farrell, our nurse coordinator, to send along some recent articles which I think you will find of interest. You certainly have my permission to reproduce whatever part you think would be of interest to your members.

With my best regards.

Sincerely,
Michael R. Harrison, MD
Professor of Surgery and Pediatrics
Director, Fetal Treatment Center
University of California, San Francisco

March 25, 1996

Dear Dawn:

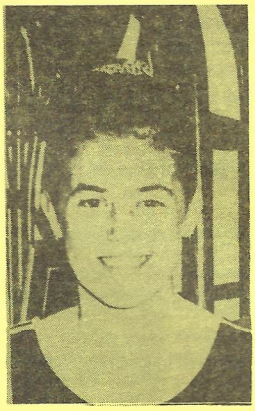
Thanks for your note and the most recent copy of the newsletter. I would be delighted to become a medical advisor for CHERUBS. Just let me know what I would need to do.

I look forward to seeing you at APSA. I am very pleased that this has worked out. I hope that other groups representing the patients that we deal with will take your lead and involve themselves at our meetings in the future.

Keep up the good work and I look forward to seeing you in San Diego.

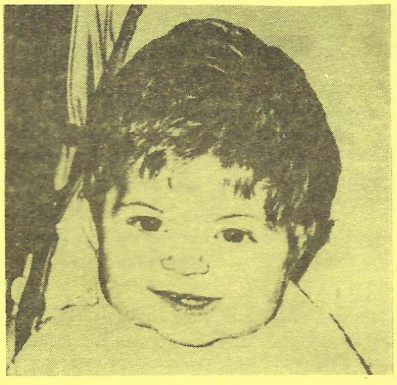
Sincerely,
Jacob C. Langer, MD, FRCS(C)
Division of Pediatric Surgery
Washington University in St. Louis

Pictures of CHERUBS



Carly Anne Cribben
born June 23, 1961
Kent, Great Britain

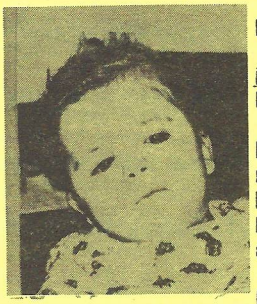
Jessica Tunnel
born April 17, 1994
Columbus, Ohio



Ryan Michael VanderSchaaf
born April 22, 1995
Vista, California

LETTERS FROM MEMBERS

March 26, 1996



Karson Hocker
born August 1, 1995

Dear Dawn,

I was given your address from NPPSIS c/o Kathleen Judd in Blue Ridge, Georgia. I have been searching for a parent group to join. I would love to have copies of your past newsletters. I would be glad to send money to offset the costs just let me know how much you need for the copies.

My son Karson was born August 1, 1995 with CDH at South Bend, Indiana and was driven 4 hours south to Riley Children's Hospital Indianapolis, Indiana for ECMO treatment and complications. I would like a parent-to-parent match-up. Karson is now 8 months old, is off oxygen, had poor vision, developmental delays, low muscle town, poor head control, unable to roll or sit up, had a brain bleed- right occipital lobe at 24 hours old, brain atrophy, closed head fontanels (soft spots are hard and fused together), new hernia developed, and undescended testes. Our son is a true joy, his smiles are infectious, his is always happy. He is our long awaited angel after 2 previous losses prior to Karson. The answer to our prayer for a miracle.

We have seen progress in the past 2 months with Karson. Seems all his therapy has helped. There is no local support group here and the success rate for ECMO is this part of the US isn't very good overall.

I would like to join your CHERUBS group. The name is perfect. All these children are special CHERUBS. I'm interested in current research material too.

Katherine Hocker
2806 Portage Ave., South Bend, Indiana 46628
(left-sided CDH, monosomal chromosomal disorder yet unnamed, brain atrophy, sight impaired, low muscle tone, ECMO, many more complications)

March 22, 1996

Dear Dawn,

Gail Wilson (ECMO Moms and Dads International) called and gave me your address. She told me about your newsletter.

Zachariah was born with left-sided diaphragmatic hernia in September 1992. To make a long story short - Zachariah is on a ventilator with oxygen. He has a G-tube and VP Shunt. He's been in the hospital 25 times and has had surgery on many different parts of his body. God has promised me - "This sickness is not unto death but for the glory of God that the Son of God may be glorified by it". John 11:4.

We have 2 other children- Vanessa, 9 years and Elijah, 6 years. God has used all of this to change our lives, dramatically, and we are truly grateful.

My husband, Rhy, is in the Coast Guard. Zachariah was born in Detroit, MI. We just moved here in April 95. It was pretty hectic moving a child on a ventilator from Michigan to California, but God's grace was more than sufficient! The Elks Club here just purchased a wheelchair lift for our van- isn't God sweet? Zach's chair with ventilator, battery, and oxygen tanks weigh 100 lbs! We had been pushing it by hand, up a wooden ramp into our van.

Anyway, do you have any other "vent moms" you can hook me up with? Everything is going great. Zachariah is such a happy boy. If I can be an encouragement to any other parents, it would be my pleasure.

Jeri Payne
2110 B Santa Rosa Circle, Alameda, CA 94501
(left-sided CDH, vent and oxygen dependent, ECMO)

February 2, 1996

Jack Barkley
born April 25, 1995

Dear Dawn,

We have received 3 of the CHERUBS newsletters so far since our son was born in April, 1995. What a help. They are very informative and I appreciate the fact that you have taken the initiative to do this. It helps so many of us.

Jack has done very well these first nine months. Just one cold with some asthma type symptoms and 4 days of albuterol cleared it up. The most significant that has happened is a small bowel obstruction requiring surgery. The operation showed that it was scar tissue that had grown from the hernia repair. There was just a small amount around the bowel with most of it up around the organs. I guess when it's around the organs it's harmless. He had a very smooth recovery.

Anyways, I'm wondering if other parents have had this happen? I think whether or not scar tissue grows like this is very individual. It's pretty scary to think that just 7 months after his first surgery it had grown that much. The surgeon told us it could very well happen again. The thought of repeated surgeries really scares me.

My other question is bowels! I always feel silly asking about this but part of it is being a first time mom. One of the ECMO nurses at the hospital told me that CDH kids always have a problem with one end of the GI tract. Most have reflux. I think I remember reading where one of the parents had written about a bowel problem.

So- I know you are a busy person but if you have the time, can you drop me a line regarding these 2 things. Just a short note whether positive or negative would be appreciated.

Hope all is well,
Wendy Barkley
116 NE 48th Street, Lawton, OK 73507
(diagnosed in utero with left-sided CDH, bowel adhesion, ECMO)

April 30, 1996

Dear Dawn:

Thank you very much for sending me your information. I really appreciate it. After 5 and a half years of coping with a child with CDH, it's nice to finally hear of an organization that I can learn from. I am anxious to get the newsletters as they come out. I think this is a wonderful organization you have set up. I would like to get involved in anyway that I can. so if you need help with anything feel free to contact me. Again, thank you for sending me the information and your past newsletters. I have really enjoyed reading the information.

Connie L. Lee .(mother of Tony Lee)
P.O. Box 426, Dakota City, NE 68731
(right-sided CDH, hydrocephalus, dextrocardia, dual collection left kidney, ECMO, developmentally delayed)

April 15, 1996

Dear Dawn,

Thank you so much for sending me some copies of your wonderful newsletters! I am sorry that it has taken me so long to respond, but we are truly interested in your organization. I received your newsletters and the next day our son Cole was diagnosed with bilateral profound hearing loss. We have been really busy fitting hearing aids, learning sign language, and reading, reading, reading! I have read and reread the stories and research you published and it all sounds so familiar. It surely is a comfort to know that there are other families successfully dealing with the effects of CDH...we can learn so much from them! Our story sounds strangely familiar to many of the ones I read, but I will share it with you.

In December 1994, we found out that we were expecting twins the following June. I had a previous miscarriage so this news was a wonderful blessing! We live in a small West Texas community and the news and excitement soon spread. Our friends and family were surprised and almost as excited as we were! I had a fairly uneventful pregnancy with the exception of taking maternity leave from my elementary teaching job to rest more at the request of my obstetrician. We had several sonograms and all seemed to be progressing right on schedule...we also found out that we would probably be expecting fraternal twin boys! We busily prepared the nursery and bought "two" of just about everything! On May 14, after our baby shower, my water broke at home and we immediately called the doctor who suggested we come on to the hospital. Once we arrived, the doctor confirmed the fact and admitted me to the hospital where I was restricted to absolute bed rest! They began administering medication to postpone the early delivery and we continued to have two more sonograms which showed the babies doing fine. On the morning of May 18, nature overruled modern medicine and I delivered the boys 6 weeks early. Brett was delivered first and weighed 3 lbs. 14 oz. and about five minutes later, Cole arrived weighing 4 lbs. I knew immediately that something was wrong...Brett was crying and screaming and Cole was not making any sound. They quickly whisked the boys away to the NICU unit with an initial diagnosis that Cole had probably just swallowed some amniotic fluid...I wish it had been that simple. Within the next hour, we had a confirmed diagnosis of a severe left-sided CDH. We had never heard of CDH and certainly never dreamed it would affect one of our children. The doctors informed us that Cole would need emergency surgery in order to survive. The only pediatric surgeon was in another hospital less that a mile away so the doctors and nurses prepared to transport him. The transport team stopped by my room on the way out so that I could see Cole. I couldn't get a very good look through the walls of the transport incubator and I wasn't allowed to touch him, but I could see that he was beautiful! My husband went with Cole and I encouraged our family and friends to go to the other hospital as support during the surgery. I made numerous trips to the NICU to see Brett during what seemed like countless hours as we awaited news on Cole. My heart felt as if it were ripped in pieces...I felt such happiness and relief that Brett was doing well and such sadness and fear that Cole wasn't. The surgical team gave Cole an 2% chance of survival and with the help of God, he beat the odds! Immediately after surgery, Cole was placed on ECMO and we knew that the next few hours and days would be crucial. (Cole is the smallest baby our team had ever placed on ECMO, which made the outcome even more unpredictable.) The next morning, I was allowed a temporary pass from the hospital to go to the neighboring hospital to see Cole. I will never forget the overwhelming feeling of seeing that tiny body being overpowered with so many tubes and such big equipment. I remember the low rumble ..almost vibration.... of the ECMO machine. The room was filled with doctors and nurses monitoring Cole's progress and the operation of the equipment. After five days on ECMO the cannulas were removed and Cole was placed on a high-frequency ventilator under minimal stimulation conditions. He progressed slowly but steadily from that point and after two months in the NICU unit, Cole made his first trip home!

Now, almost two years later, Cole is doing good. He is developmentally behind, but we have seen slow and steady progress in that area. He did not sit unattended until 12 months, and began crawling at 16 months. He is now pulling up to stand and walking around furniture. Actually he is walking just about anywhere as long as there is something to hang on to! He has been admitted to the hospital with a couple of cases of pneumonia and an occasional bout of bronchitis. He had a Nissen and a Pyloroplasy done at the age of 10 months to repair a severe gastro-esophageal reflux. Cole has a g-tube that was placed during the reflux repair and I regretfully report that he still has it. Cole is NOT a good eater...actually he hardly eats by mouth at all! Many doctors attribute this to "oral defensiveness" and concede that he will eat when is ready, but that is not quite fast enough for me! We battle every day to get him to eat by mouth and we have even scheduled an appointment with a speech therapist for extra help. Cole is under weight and I think that has a lot to do with his slow developmental progress...he doesn't have the strength to be too active. Cole also has a profound hearing impairment that has been attributed to either the ECMO or some of the antibiotics he had to take when he acquired a critical staph infection (Gentomyacin in particular). We are very thankful that Cole did not have any bleeds while on ECMO although a subsequent MRI revealed a small amount of damage probably due to trauma at birth and specifically diagnosed as very mild spastic diplegia. The location of the damage may have an affect on lower body motor skills, although our therapist assures us that Cole will walk, run, jump, and play.

Well, it certainly has been a long road, but not one without many rewards! Cole is a wonderfully happy toddler that brings sunshine into our life everyday! Brett and Cole interact and usually play nicely together... I think their special brotherly bond will be especially beneficial to Cole as he begins to imitate the things that Brett does. Brett may be one of his best teachers and therapists! My advice to the new parents of a CDH child is to (1) ask questions even when they may appear to be stupid, (2) write things down in a journal (3) use your judgment because you know your child better than anyone else, and (4) Love your child unconditionally!

Sincerely,
Sherla and Ben Edwards
RR 1 Box 55, O'Donnell, TX 79351
(left-sided CDH, mild spastic diaplegia, hearing impaired, G-tube, developmental delay, reflux, twin)

Laura Beth Snyder
born October 9, 1993

Dear Dawn,

My granddaughter Laura Beth Snyder was born Oct. 9, 1993 at the University of Florida (Shands) with a right sided CDH. It was patched when she was four days old. She spent her first twenty-two days of life on a respirator. Laura Beth had heart complications probably brought on by the strong drugs given to her. Because of the doctor's fear of her refluxing and damaging her lungs (her right one is small) she was not allowed to suck or feed, but was fed intravenously then by NG-tube. This coupled with the various illnesses she succumbed to at Shands; cardiac arrest, staph, R.S.V., yeast in her central line, abcess in her right leg requiring more surgery, Laura didn't come home until Feb. 7, 1994. She has oral aversion and feeds only through a button. Her stomach is quite small and twisted which necessitates her being fed 24 hours a day.

We live in a rural area. About a year before Laura was born another CDH female was born. She was left-sided with only one lung. This was less than half a mile from us. She has since moved away. I did some research and found out about Nitrofin, a herbicide used for weed control. It caused mainly right-sided CDH in rats. Behind us are acres of blueberries but I have never found out what kind of chemicals they use. My daughter had a previous pregnancy which she and her husband elected to abort because the fetus was a severe hydrocephalic with kidney problems. We didn't know of Laura's condition until birth. Laura's parents both suffered head trauma when they were young and are slightly mentally handicapped. I would appreciate any information and help. I would also be glad to answer any questions.

Chryl Hundertmark
50 NE 120th Ave., Silver Springs, FL 34488
(left-sided CDH, organoaxial twist, G-button, RSV, infections)

Brad Miller (on the left) with his brother, Devin born September 21, 1992

April 11, 1996

Dear Dawn:

It was such a pleasure to talk with you after reading about CHERUBS in the CdLS Newsletter, Reaching Out. I must say that I am truly impressed with the work that you have done on behalf of your son, and all children diagnosed with CDH. Your Parent Reference Guide and Newsletters are outstanding. I sure could have used them back in the summer of 1992 when we learned we were carrying a child with CDH. Reading the letters from other parents and speaking to you on the phone brought back a lot of fear and emotion that I had long since tucked away. Our story pales in comparison to those I read in the newsletters, but I would like to share it with you.

Our second pregnancy was a time filled with nervous anticipation, as our first-born son has Cornelia de Lange Syndrome, a rare non-inherited genetic disorder. Since the likelihood of having a second child born with CdLS is extremely rare, we decided to try again, but the pregnancy was carefully monitored. At the first ultrasound at approximately 12 weeks, everything appeared normal, except that there was a singe umbilical artery. I was assured that this was fairly normal, but could be an indicator of a heart defect. We were sent for a fetal echocardiogram, which was normal. I remember practically skipping out of the hospital, because now we were sure this baby was OK. An ultrasound at 20 weeks again showed everything progressing normally. Then, at my 26- week ultrasound, the technician, after telling us we had another boy, quickly left the room to get the doctor. I began to panic. I thought "Oh no, not again." I already knew something was terribly wrong. The doctor came in and looked at the ultrasound, and then called us into her office. That's when we found out he had a diaphragmatic hernia, and only the intestines were involved at that point. The doctor was very kind and gave us as much information as she could. She had consulted with a surgeon while we were waiting and told us that we were not candidates for prenatal surgery. She made an appointment for us to see the surgeon, and suggested that we do an amniocentesis to be sure there were no chromosomal, abnormalities. We did the amnio that day. Waiting for those results was the longest 3 weeks of my life, but the results were normal. We saw a surgeon at a hospital 50 miles away, and he gave us the entire scoop on CDH. At that time they said the baby's chances of survival were about 80%. We felt they were pretty good odds, and we were encouraged. I had monthly ultrasounds after that, and nothing changed much. That summer is pretty much a blur. I just remember functioning, kind of like being on auto-pilot. We told very few people, only immediate family. I just couldn't deal with having to tell people that there was something wrong again. The doctors could not explain why we had two pregnancies with two such rare, devastating disorders. They said it was like being struck by lightening - twice.

My due date was October 10, but I was scheduled to deliver by C-Section on September 22, if an amniocentesis on the 21st showed that the lungs had matured enough. But my little fighter wasn't waiting; I went into labor early in the morning on September 21. We rushed to the hospital, where I immediately had a C-section. I was given general anesthesia, because my labor had progressed so far there was no time for an epidural. I don't remember much of anything after that, because I was pretty out of it. I do remember the doctor coming in after about 2 hours and saying that the baby was stable and going into surgery. We asked that he be baptized, and we waited for news. When the surgeon returned after surgery, he told us he had made it so far. We then asked about his chances of survival. At that point the surgeon told us only about 20%. I remember, in that fog of anesthesia, thinking we came all this way and I was going to go home without a baby. I had not even seen him. We held our breath and prayed he would continue to fight. I finally got to see him around 10 p.m. that first night. We had been through a lot with our first-born, but nothing prepared me for the sight of that tiny baby hooked up to all those instruments in the NICU. Anyway, we got the miracle that we had prayed so hard for. Not only did he survive, but he recovered and was out of the hospital in record time; off the vent in 10 days and home at 24 days. He does not appear to have any problems related to the CDH, but we still hold our breath. He had surgery several weeks after being discharged for bilateral ingruinal hernias, and surgery again at age 2 for recurring left sided direct ingruinal hernia. These recurring hernias, along with some other minor physical characteristics, prompted the surgeon to suggest we take him for a genetics evaluation to look for a connective tissue disorder. The geneticist felt that he may possibly have a very mild form of a connective tissue disorder and suggested an echocardiogram to rule out mitril valve prolapse and regular eye exams to watch for any eye problems. His echo showed a mild heart murmur, everything else was normal. Chest X-rays show his left lung has grown to normal size. Function has not been tested, as the doctors feel at this point there is no need. He has not had any problems with asthma or bronchitis, as the doctors suggested he might.

So, after a hairy beginning, Brad appears to be very normal, active, healthy 3 and a half year old. I am sure the beginning of my story is much like the others. The ending of that part of the story was nothing short of a miracle. We did not realize that CDH could have such profound medical implications as I read in the letters from parents. We were led to believe that if the child survived, they had few, if any, complications. Maybe that was just Brad's prognosis, as clearly it is not the case for most children with CDH. I hope Brad is an inspiration to parents who are going through this. We are blessed that he is one of the few to survive and have few, if no, complications. I can empathize with families whose CDH children have complications; as I mentioned earlier, our first born, Devin, has Cornelia de Lange Syndrome. He is severely retarded, has upper limb deformities, an unrepaired cleft palate, vision and hearing difficulties, and had a fundoplication for severe reflux. He now has a gastrostomy button which we use for supplemental feeding. He is mobile but does not yet walk and has no speech, nor is he expected to. He is totally dependent on us for his care. We adore both our children and take nothing for granted. Each day is a blessing. I have said in the past that I feel I have the best of both worlds; one child who teaches my life's lessons and pushes me to find myself, and another who lets us feel "normal" once in a while! I have enclosed some photos.

Forgive me for rambling so. As I mentioned, it has been a long time since I even allowed myself to think about that time in our life. I commend you for the work you are doing, and if I could do anything I can to help you continue to reach families who are going through a similar experience. I know how time-consuming a special needs child can be; I admire you for your strength and dedication. Keep up the good work.

Sincerely,

Lynnette Miller
324 S. Cologne Avenue, Cologne, NJ 08213-0877

(left-sided CDH, possible connective tissue disorder, bilateral ingruinal hernias, heart murmur)

Daniel Collett September 3, 1992

February 13, 1996

Dear Mrs. Torrence,

I wanted to say thanks for sending me your newsletter. I only wish someone could have helped when Daniel was born. But now 3 and a half years later I can honestly say that I feel comfortable talking to other CDH parents and I've had a lot of questions I couldn't answer so maybe your newsletter will help lessen the stress of the unknown for new CDH parents!

I was told 5 and a half months into my pregnancy that my child's heart was missing one chamber. Well at 7 months and many doctors later and a lot of high-tech ultrasounds (Doppler) we knew that I had a CDH baby and I met with a neonatologist and he told me hat the mortality rate for CDH babies was 96% and in his own works "I'm sorry Ms. Collett, but most CDH babies never live to see the light outside the delivery room. I think I cried enough to fill the ocean from that point on. I developed toxemia poisoning at 7 and a half months and was hospitalized at 8 months; strict bed rest up once daily 30 minutes in a wheelchair until delivery! I had three amnios to check for lung maturity- No lung maturity. Fetal distress set in and well delivery day came quickly by a c-section on Sept. 3, 1992. Wow, I've never seen so many people fit into one small room! At 6:59 a.m., Daniel was born and my husband was told to leave the room and everyone was running around. My doctor came over while I was being stitched up and said "Jeannie, Daniel isn't doing well. He is now intubated and not doing well, he was taken away being bagged faster than I could imagine anyone pumping". I only saw the top of his head. Four and a half hours later Daniel was brought to my recovery room to say goodbye. I was able to touch his tiny fingers and tell him how much I loved him and to be strong. Then he was taken 26 miles away by Angel II Transport to Egleston Children's Hospital I was called 2 hrs. later only to be told his condition was going down hill and he for sure had a right-sided CDH. The doctor then explained that the last resort was ECMO but he wasn't sure Daniel could qualify for it but he explained it to me and told me the risks involved and how experimental this was. I gave my permission for any and all intervention nessacery to save born his life. I was called 5 hours later and told ECMO was started and his condition went way down hill. Up and down for six and half days. After 4 days I finally was able to see and count my baby's fingers and toes. I cried and cried, he didn't even look like a baby. He looked like something from a sci-fi movie. I was so scared, I was told not to talk or stimulate him; let him rest up for the operation. His eyes finally opened at 9 days of age. September 17th, at 14 days old; time for surgery. Wow, he came up after surgery 9 and a half hours later on lower vent settings than before the surgery! More ups and downs, infection set in. Talk about a scary feeling. There was a lot of talk about what to do with him- his reflux kicked in and everything was upside down! By the grace of God he pulled through - I was able to hold him for the first time at 23 days old. I finally felt like a mother. At age 2 months, 21 days, Daniel was taken off the vent and put on oxygen via nasal cannula which he was to come home on. He started being fed 1cc per hour and switched formula 5 times before we hooked up with Pregestimil. We came home on Dec. 3rd, with 3 lpm of oxygen, a NG-tube, pulse ox, apnea monitor, and 13 types of meds and aerosols every 3 hours. A lot of work. We were home

(continued on next page.....)

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6 hours and admitted to Scottish Rite with RSV. Back on the vent for 2 months. Home 14 hrs, admitted for roto-virus. Home 3 weeks, admitted back with respiratory distress (in for 6 weeks). Back and forth for 15 months. Lots of doctors appointment; ENT, GI, Pediatrics, Pulmonary, Surgery, Speech, PT, OT, ect.. Frequent ER visits, admission. We were off NG feedings which was a true blessing from reflux at age 2 yrs 1 mo.. We were off the apnea monitor at 2 yrs 3 mos. Off the oxygen at 2 yrs 10 mos. We still have the pulse-ox and use it now and then when he gets worked up!

Now age 3 years 6 months, we haven't been hospitalized in almost 2 years. Thank you, Lord. Daniel is healthy and happy. His is down to 2 meds per day, no physical therapy, speech, etc.. He uses the pulse ox through the night. He runs, talks, counts, etc.. A normal 3 and a half year old. No one really knows what the future holds. The doctors predicted surgery before age 2 again for the gortex patch repair. It hasn't happened yet. Thank God. I learned a long time ago that it takes a special person to be given a CDH child. Please no matter how tough it is and how fragile your child is and how much equipment they are on take them out. Your child needs it for development and social skills. I took Daniel grocery shopping and was stopped at least twice. We became friends with clerks there who watched his progress and love him. Treat them as normal as possible. My big problem with Daniel now is discipline. How do you discipline a child who had such a tough start? They can press your buttons just like a normal child. And remember, take time out for yourself and your marriage. Believe me, I almost lost mine. To expectant parents; listen, listen, listen, and learn. The more you listen and learn, the more you know and can help your child. Also speak your peace. Stop your doctor, ask questions, you are your child's best advocate. Speak for them. Here's wishing all of you a lot of love and luck!!!!!! Hug those babies everyday and continue to pray!!

Fondly,

Jeannie L. Collett
218 Walthall Rd #B-7, Marietta, Georgia 30060
(In-utero diagnosed right-sided CDH, ECMO, BPD, RAD, reflux, ear tubes, eyeglasses)

NEWS FROM THE RESEARCH WORLD

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• summaries taken from EUROCAT newsletters.

Dear Members,

I received a call from one of our members who had lost her child from CDH. She wished to be taken off of our mailing list because it was too painful for her to read about the children who had made. She felt that it wasn't fair that her prayers for a miracle were not answered. She needed more support than we could give her. She was right, it is not fair to our members who have lost their children for so much information and so many stories about children who survived to be printed without equal room in the newsletters for families of children who did not survive. To be honest, we just don't have that many members who have lost their children. Most of these parents just want to put this behind them. No one can blame them for their feelings about this. I have talked to so many parents who have lost a child, not just CDH parents, but other parents of children with birth defects. I have the utmost respect for them, I can't pretend to know how they feel. The pain and jealously we have towards other parents of healthy children is nothing compared to how these parents must feel. It is only natural and normal for all of us to feel this way. I would love hear how you feel about this. I have asked Brenda Slavin, one of members who has lost two children to CDH, to write a column for our newsletters, especially for grieving parents. She graciously agreed. I invite all of our members who have lost children to contribute to this article. Just write me and I will forward your letters to Brenda, she will have free reign on this column. My apologies to any parents who may have felt left out, I hope this helps and we will continue to print more stories about babies who are now real cherubs, as they come in.

WE ALL GRIEVE TOGETHER

by Brenda Slavin

Dawn thought it would be a great idea (I couldn't agree more) for the newsletters to include a section on grief for the families that are grieving and the families of the survivors to better understand ourselves as we begin to understand others.....

As I am writing this my chest is tight and my stomach is aching. Today I am grieving. But today is different that any other day. For today I am not grieving for my two children who have died. Today I grieve for my friend Mary, her husband, and their two beautiful children they have lost. As I physically am aching my heart is breaking twice for them. It's the sadness I know they feel. "Mourning parents" have a bond that only we can share. It's not an envious bond. It is an bond of parents who have only footprints in their hearts for memories of their children. Losing a baby leaves you asking the question "Why did God take my baby?" I don't think we will get an answer in this lifetime. Maybe when we are reunited with our babies Jesus will show us the wonderful things they accomplished in heaven. Or maybe they were a guardian angel for someone who desperately needed them in their life. These babies did not die and go into a world of darkness. They went into light. The beautiful, loving light of heaven. But knowing that doesn't take away our tears, our pain, or our suffering. I can remember picking up the newsletter after my daughter died and reading about all the "little miracles" who have survived. I'll admit I have felt jealous reading how well they are doing. It's hard not to ask "How come they made it and my baby didn't? What makes them the chosen ones?" Deep inside we are happy for them and for their parents. We know how lucky those children and their parents are. We know how grateful and appreciative the parents are for having them. We know how they feel. I am a mother of a daughter Amanda who lived for 11 months and 25 days and a mother of a son who lived 2 hours and 45 minutes. I remember with each surgery Amanda she fought and struggled. I would thank God for each day I had with her. I thanked Him I was not "one of those mothers who weren't so lucky" I always had felt sorry for those parents. I would try to envision their pain but could not. I always wondered what I would even say if I ever met one. Then one day I did. My sister had a stillborn baby that had a heart condition. For the first time in my life, I did not know what to say to her. She refused to answer the phone or return calls. She took two months off work and sat in a rocking chair rocking and crying all day. I still kept trying to call. I refused to believe she didn't want to talk about Arik. When finally I talked to her we really didn't talk. We cried together. I never told her "I know how you feel". Because I knew I didn't. I only told her I would be there for her night or day if she needed me. And now I am a parent who has lost two children. Now I do know how she feels. I only wish everyone knew that it's not important what you say but that you are there for them and you will not give up on them. I've also had people try too hard to "say the right thing". Basically their words were worse than silence. I was told "You'll have another one", "Please don't have any more children because it's too painful for me to go through again", and "You're better off they died now so now they don't have to suffer". The last thing a grieving parent needs is to be told what to do or what to feel. They do not need to question if "by putting my child through intervention methods did I make them suffer more than they had to?" Amanda had eight surgeries. I strongly feel if she didn't want to be with me for 11 months she would've given up a long time ago. When I was pregnant last summer with Nicholas I found out about his diaphragmatic hernia at 16 weeks. My biggest prayer to God was please let me be able to say hello and goodbye. I had several people stop speaking to me or acknowledging my pregnancy. They wanted me to abort him to save pain. First of all I feel abortion is a personal decision. It is not our place to judge each other. Secondly I believe people who abort do grieve. The time spent with a child in-utero or how long a child lives past birth does not make the pain less. We all feel empty. Some of us feel we have nothing left to live for. I want to share a personal part of my life in hopes that if anyone is going through this they can learn from my experience. Three months after Amanda died one I just "snapped". I couldn't go through another fake smile or laugh because others couldn't handle it when I cried. I missed her so much and wanted to be with her more than anything in this world. So I "thought" I found the answer. I told my husband I was taking a nap. After taking 50 pills of a mixture of three medications I fell asleep. (Or so I thought, I actually passed out). I thought I was on my way to heaven to be with Amanda. My husband was an investigator at the time and always paid attention to detail. He had suspicions I would do this. He came in to wake me up for dinner after a few hours. (Later he told me my breathing was very faint). He persisted until I woke up. I ate one bite of food and got very sick. I went back to bed hoping it would be over soon. I woke up the next morning. Not surprised or disappointed. It was almost as if I had dreamt the whole thing. To this day I not know what really happened to me. But I do know something did. I no longer desired to be in a hurry to die and be with Amanda. Three days later I confessed to my husband. Of course he said he already knew and was waiting for me to tell him. I asked him if he would go to therapy with me. I knew I couldn't go through this pain without professional help. We went for eight months. I encourage anyone with these thougts to seek professional help. There is no shame in not being able to handle all of this pain alone. I think it is the worse pain any one person could ever go through. I have learned my children couldn't be in a better place or more loved. To them our lifetime here on earth is a blink of an eye. I know they will be waiting for us whether we die tomorrow or if we die at 100 years old. In the meantime we need to be there for each other loving and supporting each other every step of the way. Our children are with us whether they are in your arms or up in heaven. They love us unconditionally. The one thing we all have in common is our children are in our hearts impressing their little footpritns. May God Bless every one of us.

This newletter is dedicated to the memory of William Thomas Mitchell (May 4, 1996), who is now playing amoung the clouds with his big brother Harold Jennings Mitchell III (April 5, 1995 - April 17, 1995). Though he did not have CDH like Jennings, he is nevertheless a cherub. Let's all remember their parents, Jennings and Mary and all of our other bereaved parents. This and every newsletter is dedicated to all of them.