**SPRING 1995** 



# Cherubs

THE

**ASSOCIATION** 

**FOR** 

CONGENITAL

**DIAPHRAGMATIC** 

**HERNIA** 

RESEARCH,

ADVOCACY,

AND

**SUPPORT** 

A country road is not a road until many people have traveled the same path.

- Ancient Oriental Saying

### Why I Founded Cherubs

- 1
- TO HELP PARENTS UNDERSTAND what's happening to their child by cutting through the medical jargon so many doctor's use.
- TO LET PARENTS KNOW that they are not alone.
- TO ADVOCATE for pre-natal diagnosis of CDH.
- TO PROVIDE SUPPORT and friendship in a time of need.
- TO HELP PREVENT COMPLICATIONS by educating parents on potential problems and side-effects.

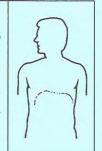
When my son, Shane, was born, I had no one to turn to until I met another mother whose son also had a CDH. She was my rock, but tragically, she lost her son. The friends we make while on this hard journey are the dearest friends that we will ever have. Our families and friends with healthy children may try to understand and support us, but they could never understand our feelings as well as another parent whose child has CDH. This is for Preston, Shane, and all the CHERUBS that have touched our lives.

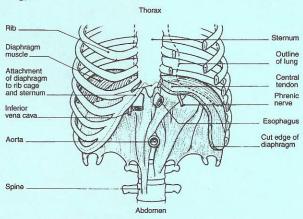
### Cherubs

Cherubs is a national organization for families and care-givers of children who were born with Congenital Diaphragmatic Hernias (CDH). Cherubs provides information, support, and parent-to-parent match-ups. There is no cost to parents for services provided by Cherubs. We are a volunteer organization. Since we are just beginning, donations are badly needed and checks can be made out to Cherubs. We are trying to raise funds to pay for legal fees to obtain Non-Profit status- so unfortunately, donations are not tax-deductible at the moment. Please feel free to share our newsletters with your child's doctors and other parents of CDH children. \*Remember, every child is different. You can't compare the progress of another CDH child to your own child's progress. They are all little angels...CHERUBS.

#### ANATOMY OF THE DIAPHRAGM

The diaphragm is attached to the spine, the lower pairs of ribs, and the lower end of the sternum (breastbone). The muscle fibers of the diaphragm converge on the central tendon, a thick, flat plate of dense fibers. There are openings in the diaphragm for the esophagus, phrenic nerve (which controls diaphragm movements and hence breathing), and the aorta and vena cava blood vessels.





\* From the American Medical Association Home Medical Encyclopedia; 1989; medical editor - Charles B. Clayman, M.D.; Random House; NY, NY

### Goals For The Future Of Cherubs

- Non-profit status
- Providing information to parents immediately following their child's diagnosis
- To advocate for pre-natal diagnosis and research on the causes of CDH
- · To advocate for health-care reform

### Cherubs Would Like To Thank:

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### Earning true gift of motherhood

Editor's note: Erma Bombeck is on vacation. She left behind a few of

the "classics" that are most often requested by readers. This one first appeared in 1980.

Most women become mothers by accident, some be choice, a few by social pressures and a couple by habit.



This year, nearly 100,000 women will become mothers of handicapped children. Did you ever wonder how mothers of handicapped children are chosen?

Somehow, I visualize God hovering over Earth selecting his instruments for propagation with great care and deliberation. As he observes, he instructs his angels to make notes in a giant ledger.

"Armstrong, Beth; son; patron saint, Matthew.

"Forrest, Marjorie; daughter; patron saint, Cecelia.

"Rudledge, Carrie; twins; patron saints . . . give her Gerard. He's used to profanity."

Finally, he passes a name to an angel and smiles, "Give her a handicapped child."

The angel is curious. "Why this one, God? She's so happy."

"Exactly," smiles God. "Could I give a handicapped child a mother who does not know laughter? That would be cruel."

"But has she patience?" asks the angel.

"I don't want her to have too much patience or she will drown in a sea of self-pity and despair. Once the shock and resentment wears off, she'll handle it.

"I watched her today. She has that feeling of self and independence that is so rare and so necessary in a mother. You see, the child I'm going to give her has his own world. She has to make it live in her world and that's not going to be easy."

"But, Lord, I don't think she even believes in you."

God smiles. "No matter. I can fix that. This one is perfect. She has just enough selfishness."

The angel gasps, "Selfishness? Is that a virtue?"

God nods. "If she can't separate herself from the child occasionally, she'll never survive. Yes, there is a woman whom I will bless with a child less than perfect. She doesn't realize it yet, but she is to be envied. She will never take for granted a 'spoken word.' She will never consider 'step' ordinary. When her child says 'Momma' for the first time, she will be present at a miracle and know it! When she describes a tree or a sunset to her blind child, she will see it as few people ever see my creations.

"I will permit her to see clearly the things I see—ignorance, cruelty, prejudice — and allow her to rise above them. She will never be alone. I will be at her side every minute of every day of her life because she is doing my work as surely as she is here by my side."

"And what about her patron saint?" asks the angel, his pen poised in midair.

God smiles. "A mirror will suffice."

## Learning How To Deal With Hospital Staff

Dealing with your child's illness is hard. Many of us feel uneducated and intimidated around medical professionals. We should not and need not feel this way. Speak up! Ask questions. You have a right to know everything about your child's care. You have a right to choose your child's doctors. Remember, staff members are also people. Treat them with the same respect you expect to be given. In my personal experience, parents who remain calm, and do not lose their tempers during stressful times get more respect from the staff than demanding, overly aggressive parents. Of course we all want our children to receive the best medical care possible. We can achieve this through good parent-doctor relations.

**Cherubs** would be proud to hear and publish the experiences that you've had with your CDH child. We also need case histories and pictures. Your pictures will be returned. Send your stories and pictures to:

#### Cherubs

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

hen I found out that I was pregnant, my husband and I were ecstatic. We were also very young and very naive. I had had a miscarriage six months earlier and I wanted this baby so badly. We went to a small country hospital for pre-natal visits and everything was fine until the end of my first trimester. I almost miscarried again but an ultrasound confirmed the baby was fine. Five months into my pregnancy, I asked my OB/GYN when I would have another ultrasound but he told me that since I had already had one there was no need. After months and many visits, I kept telling my doctors that something was wrong. They all told me that I was a nervous first-time mother. After making a big fuss, I finally got another ultrasound at eight months. During the hour-long procedure, they found nothing wrong. Two weeks before my due date, and after 13 hours of labor, I gave birth and lived the nightmare that I had been dreaming every night for eight months. Shane coded minutes after the umbilical cord was cut. The doctors and nurses rushed off with my baby and left me screaming and threatening on the delivery table for two hours. Finally, the only pediatrician on duty came and told me that my baby boy was going to die. Shane had a severe left-sided Diaphragmatic Hernia, lung hypoplasia, a lung sequestration, an atrial septal defect, and a hypospadias. The hospital called the nearest trauma center and a helicopter was on its way. At six-hours-old, my tiny little boy was wheeled into my room in an incubator by helicopter nurses. I'll never forget how he looked at me, out of a room full of people. Those dark blue eyes asking me for help broke my heart.

Twelve hours later, I was on my way to a different hospital in a different state. The first time I walked into the P.I.C.U., I was overwhelmed. The beds were lined up against the walls, each holding a critically ill child surrounded by family members, equipment and medical staff. I almost lost my balance – I could barely



stand, overcome with the effects of the painkillers I was taking, the pain and discomfort of just giving birth, and the sight of my baby being so ill. Shane was so little, I could barely see him under the tape, bandages, broviac, and I.V.s in every limb – not to mention the ventilator tubing. We were able to get a room at the local Ronald McDonald House - I don't know what we would have done without it.

Shane had corrective surgery done on his diaphragm two days later. It was touch-and-go for weeks. His tiny body was bloated with fluid. It was hard to believe that this was the same baby that I gave birth to. For the next few months, Shane battled pneumonia five times, dozens of blood infections, and intolerance to formulas and breastmilk fed to him via a naso-gastric tube. At three months old, Shane underwent another diaphragm replacement surgery. The patch that the surgeon made from tissue from his lung sequestration during the first surgery came loose. This time, the surgeons decided to use a Gortex patch, even though I asked them to try to use a part of his abdominal wall (I spent a lot of time in the medical library). A month

later, Shane was still ventilator dependent, so at age four months, he received a tracheostomy. Soon after, Shane came down with pneumonia again.

This time, the lack of oxygen to his brain caused complete blindness and deafness. We were told he would never see or hear again.

For the next six months, Shane slowly recovered and my husband, Jeremy, and I started making plans to bring him home - against medical advice (we don't recommend this). We moved closer to the hospital and Jeremy found a new job. After ten months in the P.I.C.U. Shane came home - ventilator dependent, trached, oxygen dependent, NG-tube fed, blind, deaf, and developmentally below newborn level. One month later, at Christmas time, Shane started to watch the Christmas tree lights. He could see!

At 18 months old, the sutures holding the patch in place came loose again. We found a new, wonderful, surgeon who used part of Shane's abdominal wall to create a diaphragm that will grow with him. He's doing really good now. He's been in the hospital a few times for viruses, allergies, and an abscess. He's plugged his trached and even coded at home because of a ventilator valve that was left open. He just turned two and starting to eat by mouth. He is only on his ventilator at night (just because we're still weaning him from it). He is off oxygen and starting to crawl, scoot, and walk in his walker. He can see and hear. He can't talk or cry, yet. He has, hopefully, only one more surgery left to correct damage done to his trachea and vocal cords. He is allergic to everything. He is our miracle baby and even though his progress is slow, we consider ourselves lucky. Instead of only having a baby for a few months like the parents of healthy children do, we've gotten to have a baby for a few years.

Dawy M. Tonence

SPRING 1995

### Dealing With Family Members And Friends

You will find that many of your family members and friends will be uncomfortable with your situation. This does not mean that they don't care. Some may even distance themselves, saying that they "can't handle it". They will come around in time. I have a family member that I haven't spoken to since my son's birth. He has a son two months older than mine and has told other family members that he feels guilty because his is healthy. Of course this is ridiculous, but many people feel this way. I don't think any of us would wish our fates on anyone else. Talk about your feelings and keep your family and friends informed, it will bring you all closer together.

### Dealing with the Physical Changes In Your Child

It can be hard to accept the physical changes that your child will go through. After-surgery swelling is exceptionally hard for some parents to deal with, but believe me, the swelling goes away without any stretch marks and your child will return to his/her normal size.

### **Sources For Financial Help**

Sudden traumatic events can be hard on you and your pocketbook. The following organizations offer shelter and other help for qualifying families:

RONALD McDonald Houses - ask your child's nurse for information

Churches - some can help with your living expenses

Transport services - ask your hospital social worker

SSI - Disability checks for your child contact your local Social Security Office

### I Don't Despair, I Know My Child Knows That I Am There

I was with him even before he was born, I was with him when from my womb, he was born, I was with him in spirit when he was taken away, to a room full of tubes, equipment, and dismay, I love him even though he doesn't know the word yet, I love the cries I haven't heard yet, I was with him after surgery, when fluid added ten more pounds, I love him through the tubes, pumps, and alarming sounds, I fought for him, I prayed for him, I was at his bedside everyday for him, I grieve for my "dream child," I am overwhelmed with love for my "real child," Though at times, he cannot feel, see, or hear, In my heart, I feel he knows that I am here, In times of trauma, I hold on to all the future joys that we will share, I will not despair, for I know my child knows that I am there.

### The Twelve Commandments For Parents Of Children With Disabilities

- I. Thou art thy child's best and most consistent advocate
- **II.** Thou hast valuable information about your child. Professionals need your input.
- III. Thou shalt put it in writing and keep.
- **IV.** Thou shalt try to resolve problems at the lowest level but not hesitate to contact a higher authority if problem is not resolved.
- V. Thou shalt keep records.
- VI. Thou shalt seek information when needed.
- VII. Thou shalt take time to think through information before making a decision.
- VIII. Thou shalt have permission to be less than perfect. Important lessons are learned from both successes and failures.
  - IX. Thou shalt not become a martyr. Decide to take a break now and then.
  - **X.** Thou shalt maintain a sense of humor. It is great for your emotional well being and that of your child.
- **XI.** Thou shalt always remember to tell people when they are doing a good job.
- XII. Thou shalt encourage thy child to make decisions because one day he or she will need to do so.

  \* ECAC Leaflet, By Virginia Richardson

### We Are Our Children's Voices

Our babies cannot speak. They cannot tell you what hurts. They cannot remind doctors to wash their hands. They cannot make choices about their health-care. They cannot remind nurses to turn them over or change their diapers to prevent bedsores and rashes. They did not choose to be born sick. They are helpless against the world. As their parents, we must protect them. we are our children's voices.

### **Statewide Parent-To-Parent Organizations**

(provides 1-to-1 parent matching) Alabama Friends for Life (205) 277-2285 Alaska Parent-to-Parent (800) 478-7678 Arizona Pilot Parents (800) 237-3007

Arkansas (800) 223-1330

California Parents Helping Parents Colorado

(800) 284-0251

Connecticut Parent-to-Parent (203) 667-5288

Parent Information Center (302) 366-0152 Delaware Florida Florida Network on Disabilities (800) 825-5736

Georgia Parent-to-Parent (404) 451-5484

Illinois Network for Genetic Conditions (217) 217-5989

Indiana IPIN (800) 964-4746, (317) 257-8683

Iowa Pilot Parents (800) 952-4777 Families Together (800) 264-6343 Kansas

(800) 525-SPIN Kentucky

Parent-to-Parent (800) 299-9511 ext. 4268 Louisiana

Maine (800) 870-SPIN

Maryland Parent's Place (410) 712-0900

Massachusetts Federation for Children with Special Needs

(800) 331-0688

Family Support Network (800) 359-3722 Michigan

TDD (800) 788-7889

Minnesota Pilot Parents (612) 827-5641 Missouri Parent-to-Parent (800) 743-7634 Montana Parent-to-Parent (800) 222-PLUK Nebraska Parent-to-Parent (800) 284-8520 Parent Network (702) 784-4997 Nevada New Hampshire Parent-to-Parent (800) 698-LINK

New Jersey (800)-654-SPIN

New Mexico Parent-to-Parent (800) 524-5176

New York Parent Network Center (800) 724-7408 North Carolina Family Support Network (800) 852-0042 North Dakota Pathfinder Family Center (800) 245-5840

Ohio (800) 374-2806 Oklahoma (800) 42-OASIS

Pennsylvania Parent-to-Parent (814) 453-7661 ext. 305 South Carolina Parent-to-Parent (800) 922-1107

South Dakota Parent-to-Parent, Inc. (800) 658-5411

Parents Encouraging Parents (615) 741-0361 Tennessee Information and Training Center (800) 468-1160 Utah

Vermont Parent-to-Parent (800) 800-4005 Parent-to-Parent (800) 344-0012 Virginia Parent-to-Parent (800) 821-5927 Washington

Wisconsin MUMS (National Database) (414) 336-5333 Parent Information Center (800) 660-WPIC Wyoming

\*Taken from a MUMS National Parent-to-Parent Network Newsletter-Nov/Dec 1994

### **Letting Go**

Unfortunately, many babies born with congenital diaphragmatic hernias do not survive. I am very blessed in that I still have my son. I have met many parents who have lost their children and they all tell me the same thing; "when the time comes to let go, you instinctively know it in your heart." It is important to give your child permission to stop fighting if that time comes even babies. I pray that you will never have to experience this.

#### Breastfeeding

Breastmilk is the best source of nutrition for your baby. Just because your child cannot receive your milk while he/she is critical, it doesn't mean that you have to give up your plans for breast-feeding! You can pump your breast and store your milk in hospital freezers for future use. It is EXTREMELY important to begin pumping right after delivery Ask your child's nurse for a breast pump kit. Many hospitals have a public, electrical breast pump machine. These machines are safe and sanitary and located in private areas. Though it may be uncomfortable at first, after a while it will become comforting. Remember, you must pump every two to three hours, including at night or your breast may become engorged. If this happens, it is very important that you continue pumping. Besides using a hospital pump, you can use your hands or a small manual pump. Someone bought me a small, electric breast pump at a local drug store for \$35 that I wouldn't trade for anything. With everything that you are going through, it seems like a lot of work, but it is well worth it. If you have any questions you can contact the hospital's lactation nurse or your local branch of Le Leche League. Pumping your breastmilk is something that you can do for your baby that the medical staff can't. When you finally get to nurse your baby, you will know that you made the right decision.

### Keeping A Diary

It is a good idea to keep a diary to help cope with your emotions. Recording your feelings and your Baby's progress can become an important part of your family history later. Any dime store notebook will do and it be an invaluable tool to help educate your child about his/ her traumatic entrance into the world when he/she is older.

#### Don't **Become A Martyr**

Live one day at a time. Even though studies show babies, even sick babies, respond to love, touch, and their mother's voices, it does not mean that you have to be at your child's bedside 24 hours a day. Take breaks, and take care of yourself so you can take better care of your baby.

### **Chronic Sorrow Grief Process**

#### STAGES **FEELINGS** Numb/immobile Shock Denial Helpless/flight Sadness, Self-pity, aggression, anger confusion anxiety How will we survive? Adaption Reorganization Here's how we'll survive!

### **Medical Terms You Need To Know**

**ABG** - (Arterial Blood Gas) a blood gas drawn from an artery; usually from the patient's arm, leg, or central line.

**Artery** - a blood vessel that carries blood form the heart to the body's organs.

**Bagging** - a procedure that uses an Ambu Bag to manually pump air into a patient's lungs.

**Blood Gases** - a measurement of the amount of carbon dioxide, oxygen, and acid in a patient's blood. These measurements are needed to determine the amount of oxygen and ventilator support that a patient should be given.

**Blood Saturation** - the percentage of oxygen contained in the patient's blood. For a healthy person, 100% is ideal.

**Blood Transfusion** - carefully screened blood given to a patient to replace blood lost during a surgical procedure.

**Broviac** - a more permanent type of IV (central line) put in an artery in the patient's chest.

**Capillary** - a blood vessel that carries blood between the smallest arteries and the smallest veins.

**Carbon Dioxide** - (CO<sub>2</sub>) gas exhaled by the lungs after oxygen is absorbed. Not exhaling the normal amount of carbon dioxide can cause serious problems for a patient.

**CBG**- (Capillary Blood Gas) a blood gas drawn from a capillary blood vessel; usually from the patient's toe or finger.

cc - liquid measurement used by many hospitals. 30cc = 1 ounce.

**Chaplain** - trained person who can provide you with religious support. Most hospitals either have or can find a chaplain within your religion. Many can perform dedications and baptisms at a patient's bedside.

**Chest P.T.** - physical therapy that involved "beating" on your child's chest. Though it may be noisy and alarming to you, it is an essential part of care to prevent pneumonia.

**Chest Tube** - a drainage tube surgically placed in the patient's chest and connected to a suctioning device to prevent fluid from collecting in the chest.

**Chronic** - any long-term medical problem.

Congenital Abnormality - a defect present a birth.

**Culture** - a sample of blood, secretions, stool, urine, or other physical matter taken form the patient and sent to the lab to look for disease and infection. If the culture is positive, it will be treated with different medications to find which can kill the bacteria present.

**CPAP**-Continuous Positive Airway Pressure which helps a patient to maintain the necessary pressure needed in his/her lungs.

**DNR** - (Do Not Resuscitate) order given to the medical staff by a patient's next of kin if they decide it would be in the patient's best interests to let he/she die naturally.

**ECMO** - (Extracorpeal Membrane Oxygenation) a very large and complex machine that takes over the work of the patient's heart and lungs. A very large catheter, a plastic tube, is placed in a blood vessel in the patient's neck. Blood is then removed from the patient's body, oxygenated, and returned to the patient.

**Endotracheal Tube** - a tube placed through the patient's nose or mouth to help provide mechanical or manual ventilation.

**Fellow** - a doctor training to become a specialist in a given field of medicine.

**Femoral Line**-a more permanent type of IV placed in an artery near the patient's groin.

**Grams** - 454 grams = 1 pound.

**Hernia** - a protrusion of an organ or tissue through a weak area in muscle or other tissue that would normally contain it.

Kilogram - (kg) 1 kg = 2.2 pounds.

**Lab Technician** - an individual trained on how to draw and analyze blood and bodily fluids.

**Lung Hypoplasia** - failure of one or both lungs to develop fully. **Medical Student** - a student in medical school training and taking courses to become a doctor.

**Medical Team** - doctor's nurses, technicians, dieticians, and therapists assigned to care for a patient.

**N.I.C.U.**- (Neonatal Intensive Care Unit) a high-tech newborn nursery for critically ill babies.

**Nurses** - individuals trained to take care of a patient's hygienic and medical needs, give medications, insert I.V.'s, and record medical information.

**Nutritionists**-trained professionals with special knowledge about the necessary nutrients needed for a patient's growth and development.

**P.I.C.U.** - (Pediatric Intensive Care Unit) a hospital ward for critically ill children.

**Physical Therapists** - individuals who help patients recover muscletone lost during their illnesses.

**Pneumonia** - illness caused by bacteria which results in fluid build-up in the patient's lungs.

**Psychologist** - an individual with training in human behavior and development who can assess a patient's development and assist a family as they adjust to having a sick child.

**Pulse-Oximeter** - a machine that reads the patient's heart rate and blood saturation levels through a probe taped to the patient's toe or finger.

**Resident** - a doctor in training under the guidance of a more experienced physician.

**Respiratory Therapists** - trained individuals who assist in the operation of ventilators and perform procedures which aid a patient's breathing and oxygen intake.

Room Air - a term used to describe the fact that a patient is breathing the same amount of oxygen that a normal, healthy person would breathe; 21%.

Sepsis-infection - (septic-infected).

**Social Worker** - an individual who helps families deal with their reactions to having a sick child and to help them make necessary housing, transportation, and financial arrangements.

**Suctioning** - a procedure during which a small catheter, attached to a suction machine, is inserted into a patient's trach or endotracheal tube to remove secretions that a patient could not normally cough out. **TPN and Lipids** - I.V. fluids used for long-term nutrition.

**Vein** - a blood vessel that carries unoxygenated blood to the lungs from the body's other organs.

**Ventilator** - a machine that mechanically breathes for a patient unable to do so for themselves.

**X-Ray Technician** - a trained individual who operates both portable and stationary x-ray equipment.

The information in this CHERUBS newsletter is by no means to be used in place of proper medical advice. CHERUBS cannot be held responsible.

The views expressed in this newsletter do not necessarily represent the views of CHERUBS members or staff.

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Cherubs Parent Worksheet	
Your name: Mr. ☐ Mrs. ☐ Miss ☐ Ms. ☐	
Your child's name	Male  Female  Birthdate
Address City	State Zip
Phone number	Number of siblings
Did you, the mother, during your pregnancy, have:  An AFP test?  An ultrasound?  An amniocentesis?	Do you give Cherubs permission to publish your name, your child's name, your address, phone number, or your child's case history, and/or picture?  Do you give Cherubs permission to give out your name, address, and/or phone number
If yes, during what month of gestation? Any abnormal findings? What was your child's birthweight? Was your child early?	to other parents in order to make a parent-to-parent match-up?*Writing does not exclude you from becoming a member of Cherubs.
At what age was your child diagnosed with CDH?	There is no charge for parents to become members of <b>Cherubs</b> . We request that medical professionals donate \$2.00 for each copy of our newsletter.
Was your child ever on ECMO? For how long?  Does your child have a family history of CDH?	No. of newsletters x \$2.00 =
If so, who?For how long did your child receive assistance in breathing?	Name Phone Number detach and mail to:
List any other birth defects or complications:	c/o Dawn M. Torrence 3671 Bruce Garner Road Franklinton, NC 27525

### Cherubs

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

"Two (friends) are better than one . . . for if they fall, one will lift up the other. — Ecclesiastes 4:9,10 NRSV

Bear ye one another's burdens.
- Galatians 6:2 KJV