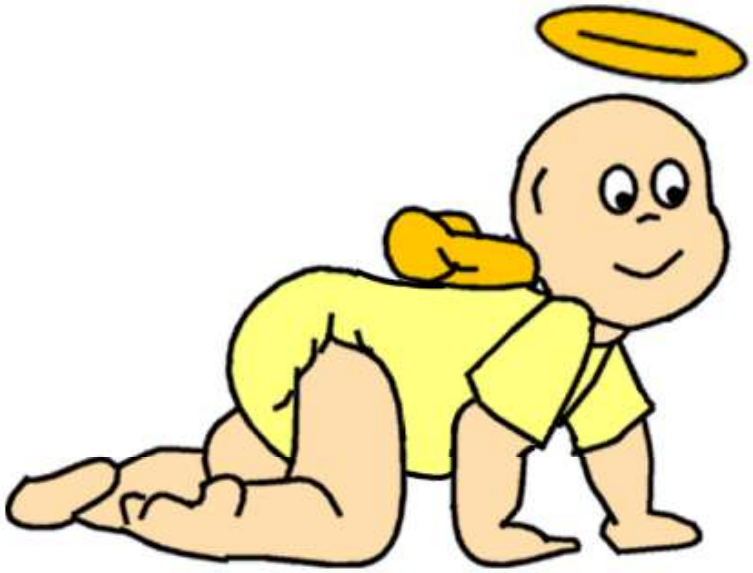

Our Cherub

Bought to you by CHERUBS - The Association of Congenital Diaphragmatic Hernia Research, Awareness and Support

CHERUBS - The Association of Congenital Diaphragmatic Hernia Research, Awareness, and Support

Dawn M. Williamson, President & Founder
3550 Rodgers Rd, #290
Wake Forest, NC 27587
(919) 610-0129
(815) 425-9155 Fax
e-mail: dawn.williamson@cdhsupport.org
web site: www.cdhsupport.org

Dear Parent,

We would like to take this opportunity to welcome you to CHERUBS. We understand that having a sick child is one of the hardest things that someone can go through. Your world is turning upside down, but you are not alone.

Because we know how hard it is to deal with CDH, we have put together this bag for you. Included, you will find the "Our Cherub Baby Book", as well as some items for you and the baby to help you get through the hospitalization. And you will find a crib sign for the hospital with your cherub's name on it.

In the Baby Book, you will find several different sections. We hope that you will read over them and learn as much as you can about Congenital Diaphragmatic Hernia. We also hope that you will use the personalized sections to record information and to journal. Please feel free to make copies of any pages if you need more room to write. And feel free to make copies of any pages for family or friends.

In the back of the book you will find a folder of additional pages. These pages are to be read in the event that your cherub may not survive. We realize that many parents do not like to think about this possibility so we have kept it separate from the other, more positive pages. But please do keep the folder with you just in case you need the information or support.

Please keep us updated on you and your baby's progress. When things have settled down after the birth, please take the time to update your member profile on the site.

If you have any questions or need to talk, please don't hesitate to contact us.

Sincerely,

Dawn M. Williamson

President and Founder

This gift bag is a project sponsored by the following:

- CHERUBS – The Association of Congenital Diaphragmatic Hernia Research, Awareness and Support
- John and Mary Smith, in memory of Jessie Smith
- Bob and Betty Jones, in honor of Billy Jones
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If you would like to make a tax-deductible sponsorship donation, please contact us at donations@cdhsupport.org

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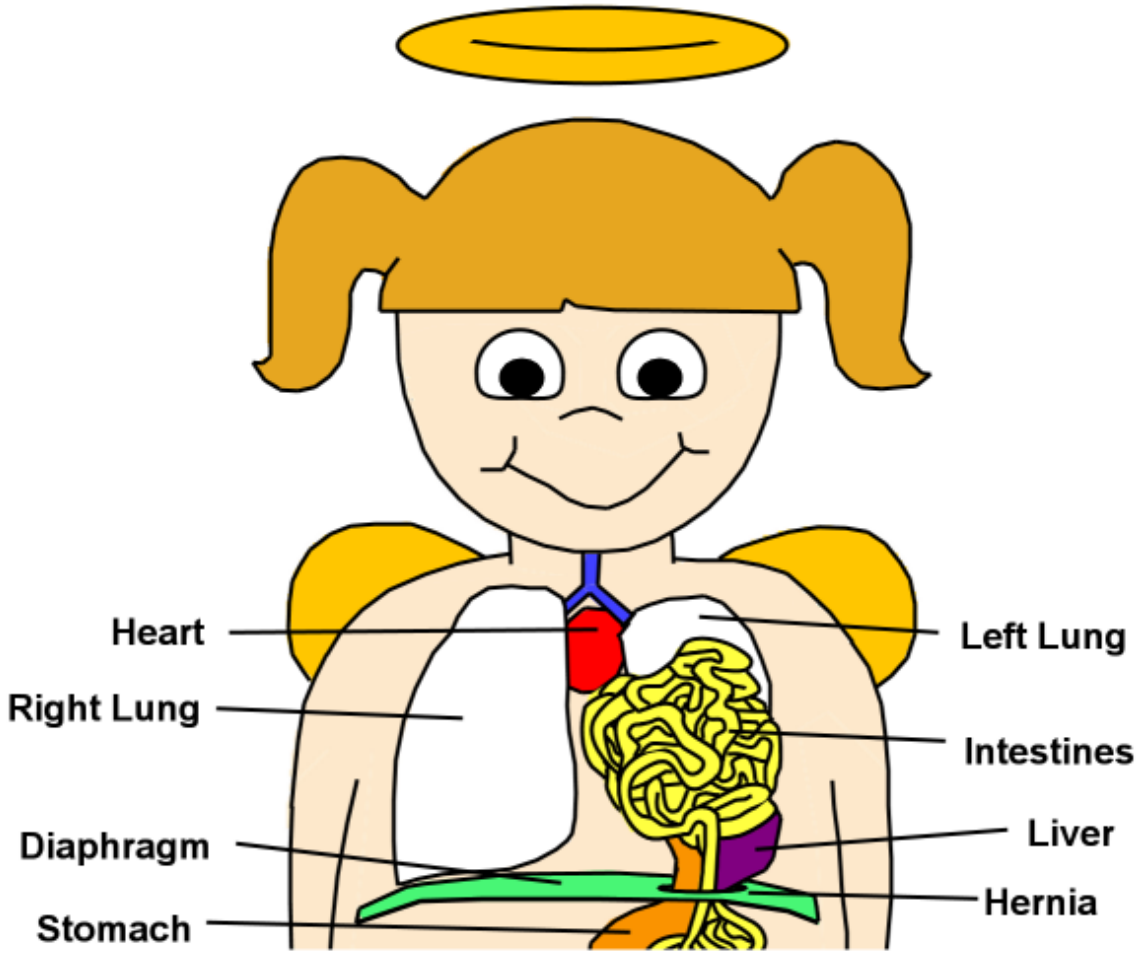
Congenital Diaphragmatic Hernia



What Is Congenital Diaphragmatic Hernia?

Congenital Diaphragmatic Hernia (CDH) is a birth defect that occurs when the diaphragm does not fully form, allowing organs to enter the chest cavity preventing lung growth. CDH strikes 1 in every 2500 babies, of all races, religious backgrounds, and financial status - no matter how well the prenatal care.

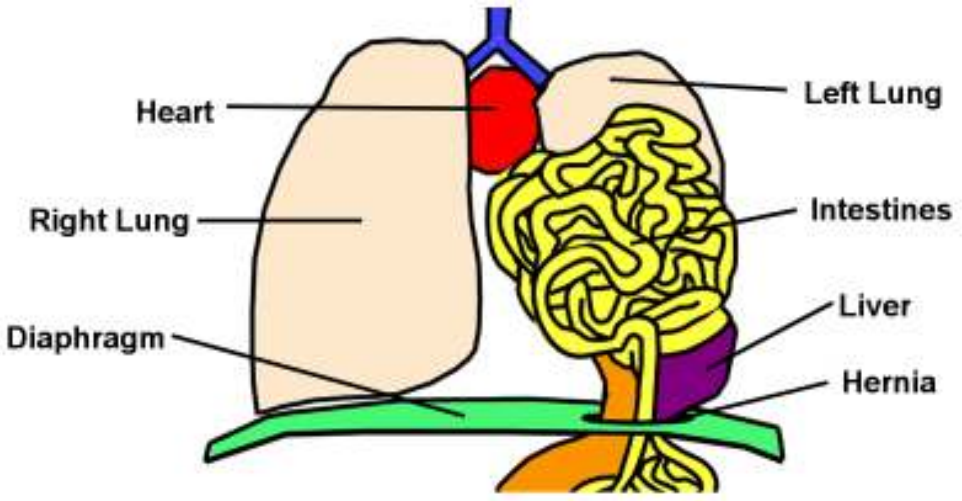
Nearly 4 million babies are born in the United States each year. This means that approximately **1600 babies are born with CDH each year** - in the U.S. alone! Over a half million babies around the world have been affected by CDH since 2000.

There are more babies born with CDH than with Cystic Fibrosis (1 in 3900) and it's almost as common as Spina Bifida (7 in 10,000) - yet, *unless you've been personally affected by CDH, you probably have never heard of it*. CHERUBS is working hard to raise CDH Awareness!

The cause of Congenital Diaphragmatic Hernia is not yet known.

50% of babies born with CDH do not survive and sometimes the remaining 50% have to overcome very difficult medical complications. Many CDH babies have minor lasting health problems such as feeding aversions, asthma, scoliosis, or short-term oxygen dependency. A small number have major lasting health problems such as ventilator dependency, brain damage, or hearing problems. Many patients have no long-lasting medical problems at all other than a scar from the CDH repair. CDH can occur alone or with other birth defects, and rarely, it occurs as part of a syndrome.

Every CDH baby is different, there is no way to predict the outcome of any patient. Some babies with no diaphragm and little lung growth have survived, while some babies with full lungs do not. These children are very different, requiring different treatments, and varying amounts of medical support.



Congenital Diaphragmatic Hernia

What is a congenital diaphragmatic hernia?

Courtesy of Boston Children's Hospital

"Congenital" means "born with." The diaphragm is the breathing muscle that separates the chest cavity and the abdominal cavity. The diaphragm develops when the fetus is about two months old.

Congenital diaphragmatic hernia (CDH) is the absence of the diaphragm, or a hole in the diaphragm. This can occur on either the left or right side, but is most common on the left.

The contents of the abdomen, including the stomach, intestines, liver and spleen, may go through the hole and into the chest. The contents prevent the normal development of the lung (pulmonary hypoplasia) on that side, and may affect the growth of the other lung. After birth the infant will have difficulty breathing if the lungs are not developed enough.

There are two types of diaphragmatic hernia:

- **Bochdalek hernia:** This type involves an opening on the back side of the diaphragm. The stomach, intestines and liver or spleen usually move up into the chest cavity.
- **Morgagni hernia**: This type is rare and involves an opening in the front of the diaphragm, just behind the breast bone. The liver or intestines may move up into the chest cavity.

What causes a diaphragmatic hernia?

As a fetus grows in its mother's uterus before birth, different organ systems are developing and maturing. The diaphragm forms between the 7th and 10th week of pregnancy. The esophagus (the tube that leads from the throat to the stomach), the stomach, and the intestines are also developing at this time.

In a Bochdalek hernia, the diaphragm may not develop properly, or the intestine may become trapped in the chest cavity as the diaphragm is forming. At times, the tendon that should develop in the middle of the diaphragm does not develop properly. In both cases, normal development of the diaphragm and the digestive tract does not occur.

Diaphragmatic hernia is a multifactorial condition, which means that "many factors," both genetic and environmental, are involved. It is thought that multiple genes from both parents, as well as a number of environmental factors that scientists do not yet fully understand, contribute to diaphragmatic hernia.

How often does a diaphragmatic hernia occur?

CDH occurs in about 1 in every 2,500 births. Bochdalek hernias make up about ninety percent of all cases.

Why is a diaphragmatic hernia of concern?

The lungs are developing at the same time as the diaphragm and the digestive system. A diaphragmatic hernia allows abdominal organs to move into the chest cavity, instead of remaining in the abdomen as they are developing. With the heart, lungs, and abdominal organs all taking up space in the chest cavity, the lungs do not have space to develop properly. This underdevelopment of the lungs is called pulmonary hypoplasia.

A diaphragmatic hernia is a life-threatening illness. When the lungs do not develop properly during pregnancy, it can be difficult for the baby to breathe after birth. Healthy lungs have millions of small air sacs (alveoli), which resemble a balloon filled with air. With pulmonary hypoplasia:

- There are fewer air sacs than normal.
- The air sacs that are present are only able to partially fill with air.
- The air sacs deflate easily due to a lack of a lubricating fluid called surfactant.

When these conditions are present, the baby is unable to take in enough oxygen to stay healthy. The intestines, when relocated in the chest, also may not develop properly, especially if they are not receiving enough blood supply while they are developing. A good blood supply is necessary for the intestines to develop correctly, and to be healthy and function properly.

CDH is also of concern due to possible associated anomalies, which in some cases may include heart, genitourinary, gastrointestinal, central nervous system or chromosomal anomalies.

What if a diaphragmatic hernia is suspected during pregnancy?

During routine prenatal care at around 18 weeks, an ultrasound may reveal the existence of a diaphragmatic hernia, or what is suspected to be CDH. A more detailed diagnosis, using more sophisticated testing including fetal MRI, is essential to confirm the presence of CDH, and to show more specifically the details of its severity.

The Advanced Fetal Care Center team at Children's Hospital Boston provides comprehensive diagnosis of CDH as a first important step in determining treatment options. As part of the process, the team also strives to identify any associated anomalies, and screens to determine how much assistance with breathing a baby is likely to need at delivery and to develop the most appropriate delivery care plan.

What are the symptoms of a diaphragmatic hernia in babies?

When CDH is not diagnosed prenatally, the symptoms of a Bochdalek diaphragmatic hernia are often observable soon after the baby is born. The following are the most common symptoms of a Bochdalek diaphragmatic hernia. However, each child may experience symptoms differently. Symptoms may include:

- difficulty breathing
- fast breathing
- fast heart rate
- cyanosis (blue color of the skin)
- abnormal chest development, with one side being larger than the other
- abdomen that appears caved in (concave).

A baby born with a Morgagni hernia may or may not show any symptoms.

The symptoms of diaphragmatic hernia may resemble other conditions or medical problems. Always consult your baby's physician with concerns.

How is congenital diaphragmatic hernia diagnosed after birth?

After birth, your baby's physician will perform a physical examination. A chest X-ray is done to look at the abnormalities of the lungs, diaphragm, and intestine. A blood test known as an arterial blood gas is often performed to evaluate the baby's breathing ability.

Other tests that may be performed include:

- blood test for chromosomes (to determine if there is a genetic problem)
- ultrasound of the heart (echocardiogram).

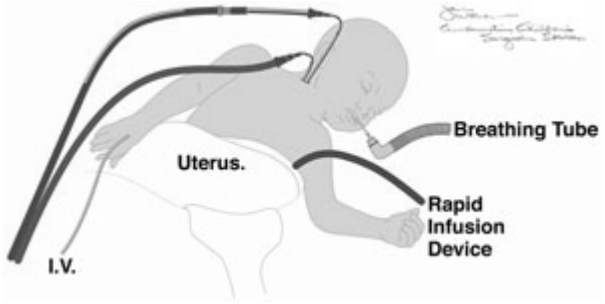
Who is at risk for developing a diaphragmatic hernia?

Parents who have had one child with a diaphragmatic hernia are at increased risk to have another child with the same problem. In cases where it is the only health problem in a baby, the chance for diaphragmatic hernia to happen again in a future pregnancy is 2 percent, or two in 100 chances.

Morgagni hernia is more common in girls than boys, whereas Bochdalek hernia is slightly more common in boys than girls. Babies with the Bochdalek type of diaphragmatic hernia are more likely to have another birth defect. Almost twenty percent have a congenital heart defect. Between 5 to 16 percent have a chromosomal abnormality

What are the Fetal Interventions for Congenital Diaphragmatic Hernia?*

*Courtesy of the Fetal Care Center of Cincinnati



The majority of babies with Congenital Diaphragmatic Hernia will do very well with postnatal treatment in tertiary centers skilled in the management of Congenital Diaphragmatic Hernia.

In select cases, fetal intervention is available for the most severely affected fetuses with very large hernias that have a poor prognosis.

Depending on the nature of the Congenital Diaphragmatic Hernia, the fetus may be a candidate for reversible balloon tracheal occlusion or EXIT-to-ECMO (ex utero intrapartum treatment to extracorporeal membrane oxygenation) procedures, both of which are types of fetal surgical intervention.

Insert ECMO photo & CDH Scar Photo

Recent CDH Research News

In utero repair of CDH is now being replaced by Tracheal Occlusion, which has a higher success rate and a lower rate of premature labor.

EXIT to ECMO is becoming more common. It is a procedure that places the baby on ECMO immediately after birth before the baby can take a breath of his or her own. This procedure utilizes the baby's umbilical cord to avoid the more invasive insertion of the ECMO tube through the carotid artery.

Gentle Ventilation is now more often used in replace of more invasive High Frequency Oscillation ventilation.

At least 7 hospitals in the United States now have clinics for children born with CDH; Boston Children's Hospital, Philadelphia Children's Hospital, Shands in Gainesville, Fetal Care Center of Cincinnati, Vanderbilt University Medical Center, and Women & Infants' Hospital Of Rhode Island

Some expectant moms are now given steroids in order to help fetal lung growth. Betamethazone Steroid Treatments are now used to help stimulate fetal lung growth by administering injections to expectant CDH moms.

ECMO is still largely used among CDH patients, although in some cases patients are being treated with Nitric Oxide instead (depending on individual patient status).

A CDH study group was formed in 1995 to collect data from multiple institutions in North America, Europe, and Australia.

A new tiny transmitter has been invented in order to help monitor uterine activity after fetal surgery and for high risks labor to help diagnose fetal distress.

A study has shown a possible link between vitamin A deficiency and CDH.

The combination of CDH and ECMO may be a strong predictor of hearing loss.

There is a promising new method in tracheal occlusion (also called "tracheal ligation"- it involved clamping off the unborn baby's trachea, forcing the lungs to grow and organs to move down) involving injected collagen. This procedure would eliminate surgery for mom and remove the threat of preterm labor.

Tracheal ligation has been shown to cause lung growth, but may also delay lung maturity due to a decrease in surfactant protein.

In an effort to more accurately monitor preterm labor after fetal surgery, doctors at UCSF are working with NASA to develop techniques for monitoring labor very precisely. The most promising idea is a small capsule that remains in the amniotic space continuously transmitting the intrauterine pressure.

With the help of "Liquid Ventilation," (Perflubron), doctors hope to improve the outcome of CDH babies so critically ill that they require prolonged mechanical ventilation and or ECMO.

In a recent study, it has been found that diaphragmatic agenesis (absence of the diaphragm) was inherited in an autosomal recessive manner.

ECMO remains a common therapy among CDH patients. A study to analyze these patients requiring preoperative ECMO was conducted. The findings suggest that the main pathology of these patients was a high degree of pulmonary hypoplasia.

Recurrent herniation is a problem for many CDH patients. In a recent study, factors shown to attribute to this problem were large-patch repaired defects and right-sided defects.

A new ventilator that improves C02 removal in fetal lambs with CDH is now being tested on humans.

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.
- AFP Test- (alpha-fetoprotein) a blood test performed on pregnant women that can possibly identify fetal abnormalities by measuring the maternal serum level; usually performed at 16-18 weeks of gestation.
- Agenesis- absence.
- Agenesis of the Diaphragm- complete absence of the diaphragm.
- Amniocentesis- a medical procedure performed on pregnant women that can identify possible fetal abnormalities by running lab tests on amniotic fluid. It involves inserting a needle through the woman's abdomen and into the amniotic sac and then removing an amount of amniotic fluid for testing.
- Analgesic- (pain killer) medication that relieves pain and discomfort (Tylenol, Acetaminophen, Aspirin, Tegretol, ect).
- Antibiotic- a medication that prohibits growth of or destroys microorganisms that cause infections (Amoxicilline, Amphotericin, Erythromycin, Gentamicin, Azapen, Staphcillin, Vancomycin, Tetracycline, etc.)
- Artery- a blood vessel that carries blood from 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 needs.
- 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.
- Bochdaleck Hernia- (Foramen of Bochdaleck) an opening through the left diaphragm between the chest cavity and abdominal cavity toward the back of the body. It is the most common form of diaphragmatic hernia.
- Bradycardia- abnormally low heart rate.
- 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- gas exhaled by the lungs after oxygen is absorbed. Insufficient exchange of oxygen and carbon dioxide can cause serious problems for the 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.
- Cental Line- a more permanent type of I.V., surgically placed in an artery or vein, yet less evasive than a broviac.
- 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 beside.
- Chest P.T.- physical therapy that involves "beating" on the patient's chest. Though it may be noisy and alarming to you, it is an essential part of care to help 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 cavity.
- Chronic- any long-term medical problem.
- Chronic Care Facility- a facility that provides long-term care for patients that cannot receive necessary medical care in their own homes.
- Congenital Abnormality- a defect present at birth.
- CPAP- Continuous Positive Airway Pressure which helps a patient to maintain the necessary pressure needed to keep his/her lungs inflated.
- Culture- a sample of blood, secretions, stool, urine, or other physical matter taken from the patient and sent to a 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.
- Diuretics- medications that increase the amount of urination; used to avoid or decrease large amounts of fluid build-up or edema; patients may need extra potassium chloride while on diuretics (Edecrine, Diurel, Lasix, Spirolactone, Hydrochlorothiazide etc.)
- 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 an artery in the patient's neck. Blood is then removed from the patient's body, oxygenated, and returned to the patient. The term ECLS (Extracorporeal Life Support) is sometimes also used.
- EXIT to ECMO – a procedure that places the baby on ECMO immediately after birth before the baby can take a breath of his or her own. This procedure utilizes the baby's umbilical cord to avoid the more invasive insertion of the ECMO tube through the carotid artery.
- Edema- swelling
- Endotracheal Tube- (E.T.-Tube) a tube placed through the patient's nose or mouth to help provide mechanical or manual ventilation.
- Epinephrine- a medication that can be used to restore cardiac rhythm during cardiac arrest.
- Familial Abnormalities- birth defects that occur in two or more family members.
- Fellow- a doctor training to become a specialist in a given field of medicine.
- Femoral Line- a central line placed in an artery near the patient's groin.
- Folley Catheter- a plastic tube inserted into a patient's ureter to aid in urination and taking "clean" urine cultures.
- FTO - (Fetal Tracheal Occlusion) in the list. A surgery that is performed in utero helps stimulate fetal lung growth and remedy pulmonary hypoplasia by closing the trachea, thus preventing fluid from leaving the lungs and causing them to be stretched.
- Gastointestinal Reflux- an illness that occurs when the stomach contents "backup" into the esophagus, where they can possibly be aspirated (inhaled) into the lungs. This is a common problem for babies born with CDH that can be controlled with medications and/or surgery (Nissen fundoplication).

- Genetic Counseling- counseling that involves providing information to at-risk parents who are expecting a child or planning a pregnancy or who have a child with birth defects or chromosomal abnormalities. It informs parents of their risks of fetal abnormalities in present or future pregnancies. It is advised for couples who are older or who have family histories of birth defects or chromosomal abnormalities.
- Geneticist- a specialist in the study of genetic abnormalities and birth defects.
- 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.
- In-Utero Repair- procedure in which the diaphragm is repaired while the mother is still pregnant. It is experimental, done in only a few hospitals, and certain guidelines have to apply.
- Kilogram- (kg) 1kg = 2.2 pounds.
- Lab Technician- an individual trained on how to draw and analyze blood and other body 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.
- Morgagni Hernia- (Foramen of Morgagni) diaphragmatic hernia occurring near the front of the body, near the breastbone.
- Narcotics- medications that cause the patient to sleep; highly addictive and must be weaned slowly (Fentynal, Methadone, Codeine, Morphine, etc.)
- Nitric Oxide- a gas that is used as an inhalant in order to try to enhance lung growth and recovery
- Nissen Fundoplication- a surgical procedure where the opening between the lower end of the esophagus and the top part of the stomach is narrowed to prevent stomach contents from flowing backward into the esophagus.
- NG-Tube- (nasogastric tube)-a plastic tube inserted through the patient's nose into the patient's stomach or intestines to aid in digestion when the patient cannot eat by mouth.
- 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, giving medications, inserting IV's, and recording medical information.
- Nutritionists- trained professionals with special knowledge about the necessary nutrients needed for a patient's growth and development.
- Pavulon- a medication that temporarily paralyzes the patient's muscles to keep him/her still when their condition can be threatened by movement (as when on ECMO). It should not be given without a sedative or the patient's mind will still be awake.
- P.I.C.U.- (Pediatric Intensive Care Unit) a hospital ward for critically ill children.
- Physical Therapists- individuals who help patients recover muscle-tone lost during their illnesses.
- PILG- (Perfluorcarbon-Induced Lung Growth) Perflubron is a liquid that can exchange oxygen and carbon dioxide in the lungs.
- Pneumonia- illness caused by bacteria which causes fluid buid-up in the patient's lungs.
- Polyhydramnios- excess amount of amniotic fluid; usually an indicator of possible fetal problems or abnormalities.
- Psychologist- an individual with training in human behavior and development who can asses a patient's development and assist the patient's 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 normal, healthy people would breathe; 21%.
- Sedative- a medication that calms and/or puts the patient to sleep so that he/she will not feel pain or discomfort (Versed, Ativan, Valium, Chloral Hydrate, etc.)
- Sepsis- infection (septic-infected).
- Social Worker- an individual who helps families deal with their reactions to having a sick child and helps 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- high calorie I.V. fluids used for long-term nutrition.
- Tracheal Ligation/Occlusion- a new procedure that like in-utero repair, involves an operation on the mother during pregnancy. Rather than correcting the diaphragm, this procedure clamps off the baby's trachea, causing the lungs to grow and push the organs back into the abdominal cavity. Also see FTO.
- Vein- a blood vessel that carries unoxygenated blood to the lungs from the body's other organs.

Questions And Facts About CDH

1. How did this happen?
CDH is caused by the diaphragm not closing or forming at around 8 weeks gestation. Organs that would should have been in the abdominal cavity then float freely into the chest cavity, taking up valuable lung space. Why is happens is not known.

2. What caused this?
The cause isn't yet known. We do know that sometimes it tends to run in families, primarily with genetic problems and other families. Studies also show that certain environmental factors might cause CDH; such as exposure to chemicals like Nitrofen or pesticides, excessive Vitamin A and Folic Acid. We conduct our CDH Research Survey to help study these common factors so that maybe someday other babies will be spared this birth defect.

3. What did I do?
There is nothing that you could have done to cause this on purpose. Until we know the cause of CDH, we really can't answer this question yet, but you cannot blame yourself for something we do not know the cause of yet.

4. Could this have been prevented?
Until we find a cure or a cause, this can't be prevented. Taking pre-natal vitamins is a plus- but taking too much can be harmful. There is just no way of knowing how to prevent CDH right away and parents can't blame themselves for not knowing how to prevent it.

5. How often does this happen?
CDH occurs in about 1 in every 2500 babies- this is more common than being struck by lightening or a tornado. It has close to the same occurrence rate as Cystic Fibrosis and Spina Bifida.

6. Has anyone else near me had this same thing happen?
By joining CHERUBS we can help you find other families who have been through this and we will give you information about families near you. Also, ask your doctor to put you in touch with some of his former patients- that is your best bet to find another family in your town.

7. Is there someone I can talk to who knows what this is?
Everyone at CHERUBS knows exactly how you feel. We have parents on-call to listen to you when you need to talk. You are no longer alone.

8. Could this happen again to me? Will all my children have this?
Without a family history of CDH or genetic abnormality in the baby, the chances are given as 2%. We encourage all of our members to seek a genetic counselor to talk about your odds of having another CDH baby.

9. Could this have been detected?
With today's technology CDH is being detected as early as 16 weeks gestation by ultrasound. Unfortunately, the United States does not have a national guideline or require licensing to perform an ultrasound. Make sure the person performing your ultrasound is fully trained.

10. Did the doctors/hospital do something wrong?
CDH is a birth defect, caused during fetal development. There is nothing that the doctors/hospital did that could have caused CDH.

11. How long will my baby be in the hospital?
There is no "normal" recovery time. It could be days or months. Be prepared for anything and hopeful for a quick and smooth recovery.

12. Do I have to give up my plans for breastfeeding?
Absolutely not. Most hospitals will provide breast pumps so that your baby can receive your milk. Your baby needs your milk more than ever. Keep the pump sterile and pump regularly to avoid mastitis.

13. Is there anything that I could have done during my pregnancy to help my baby?
Educating yourself greatly helps, also some moms are now receiving steroids to help with lung development and there is the option of fetal surgery. Rest, staying away from drugs, alcohol, and cigarettes and eating a good diet are the best things you could do for your baby. Also ask your doctor about taking steroids that may help your baby's lung growth.

14. Would things have been different if I had delivered at a larger hospital?

If your child is diagnosed in utero we encourage you to deliver at a large hospital, with experienced pediatric surgeons and an available ECMO machine in case ECMO is needed.

15. Do I have to have a C-Section?

Unless there is a medical need to have an ultrasound because of other complications involving your health or your baby's health, there is no reason to have a C-Section because the baby has CDH. Studies have shown that a vaginal delivery actually helps the baby's lungs because it stimulates surfactant (the secretions that line the lungs).

16. Do I really need to see a genetic counselor?

No matter what the outcome, it is always wise to speak to a genetic counselor. The genetic counselor will go over your child's records and your family's histories to see if there is a genetic abnormality that caused the CDH and to let you know your odds on having another baby with CDH.

17. My doctor says that my baby will not survive, what advice can you give me on keepsakes and what to do at the time of death?

Hold your baby. Many families regret not holding their babies, but none ever regret holding them. Take pictures and video. Take footprints and handprints and a lock of hair. Make plaster molds of footprints and handprints. Ask to keep your babies blankets, clothing, etc and store them in an air-tight, acid-free container. Hold your baby, sing to your baby, tell him/her that you love them and though you will miss them very much, it is ok to go. Take your time and don't let anyone rush you. Don't be afraid to cry, yell, scream, or whatever you feel you need to do. There is no emotion that isn't ok to feel.

18. Could my child have survived with surgery if we had known?

Each child is different. Babies with small defects sometimes don't make it while babies with large defects survive. Even after surgery, some babies don't survive.

19. What is life like with a child who survives CDH?

Again, each child is different. About 95% of our cherubs have feeding problems; 75% have asthma, 75% have reflux- though many cherubs do have "normal lives", some have complications such as hearing problems, cerebral palsy, developmental delay and a few have more severe problems. Many of our cherubs are doing so well that they play sports, go to college and a few are now parents themselves.

20. How will I know if I should let go?

You will know it in your heart when/if it's time to say goodbye. Don't let anyone tell you otherwise, because you will be the one who will be grieving. When/if you feel this, there will be no doubt that you are doing the right thing.

21. How can I help my baby while he/she is in the hospital?

You can read to them, talk to them, make tapes of your voice for when you're not there. Put chapstick on their lips, lotion on their dry skin (with doctor's permission), make sure everyone who comes into contact with your baby washes their hands and keep away visitors who are sick or who have been exposed to people who are sick. Most importantly – ask questions, educate yourself and just love your child.

22. Is there a prenatal indicator on how well a baby will do?

A baby with more lung development may do better than a baby with little lung development but there are many other variables that determine who a baby will do after birth. The baby's size will determine whether he/she is an ECMO candidate, should it be needed. Other organs displaced in the hernia should be checked for damage. Liver displacement is often noted on research studies as having a higher mortality rate with CDH. Most importantly – each child is different and there is no set rules or path for any CDH child.

23. Is it true that lung function is the deciding factor on whether my child will survive?

No. Good lung function certainly helps a baby recuperate more quickly but there are many factors that can come into play. More babies lose their fights from infections and pneumonia than from poor lung function.

24. Can organs move up and down through the diaphragm?

Yes. It is rather common for organs to move up and down the hole in the baby's diaphragm. During one ultrasound you might see more or less herniated organs than in another ultrasound.

25. Do I have to deliver at an ECMO center? What is ECMO?

It is highly recommended that all CDH babies are delivered at ECMO centers. Not all CDH babies will need ECMO but those that do are often too unstable to be moved from one facility to another and delivering at an ECMO center can spare them the needless trauma of a move. 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 an artery in the patient's neck. Blood is then removed from the patient's body, oxygenated, and returned to the patient. The term ECLS (Extracorporeal Life Support) is sometimes also used. ECMO Centers are recommended also to those who wish to use the EXIT to ECMO procedure, a procedure that places the baby on ECMO immediately after birth before the baby can take a breath of his or her own. This procedure utilizes the baby's umbilical cord to avoid the more invasive insertion of the ECMO tube through the carotid artery.

26. What type of in utero procedures are available?

There is a promising new method in tracheal occlusion (also called "tracheal ligation"- it involved clamping off the unborn baby's trachea, forcing the lungs to grow and organs to move down) involving injected collagen. This procedure would eliminate surgery for mom and remove the threat of preterm labor.

27. How can I help avoid feeding issues?

First, it's very important to follow all medical advice given in your child's specific best interests. Every CDH patient is different and timing is very important on all therapies so ask before trying anything new. Many doctors often intubate patients through their noses so that the baby can use a pacifier.

28. How can I help my family and friends to understand that CDH is serious?

Sometimes it is hard to explain that CDH is much more serious than a general "hernia". Sometimes it helps to give them the address to our web site or to print off some brochures from our site to distribute to family members and friends.

29. Where I can find more information on CDH?

CHERUBS web site maintains an on-line CDH Research Library and encourages all parents to learn as much as possible about CDH.

Getting Ready For Your Cherub

WELCOME TO HOLLAND

I am often asked to describe the experience of raising a child with a disability - to try to help people who have not shared that unique experience to 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 guide books and make your 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 guide books. 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....and 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, ever, ever go away... because the loss of that dream is a very 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.

Preparing For the Birth

- ✓ Learn as much as you can. Read, read, read!
- ✓ Talk to your baby and read to him/her, even though you're still pregnant.
- ✓ Keep a diary or start a blog.
- ✓ Prepare a nursery and have a baby shower, just as you would if the baby was healthy.
- ✓ Take pictures of your expanding belly.
- ✓ Talk about how you feel, cry, scream- do whatever you need to do to cope.
- ✓ Visit the hospital's NICU/PICU so that you can prepare yourself for what you will see.
- ✓ Make sure to plan delivery at a hospital with ECMO.
- ✓ Pack a bag (we have a list here in our Parent Reference Guide of suggested items to pack).
- ✓ Designate one family member or friend to keep everyone informed before and after the birth so that you're not overwhelmed with visitors and phone calls.
- ✓ Prepare other children for a long hospitalization for the baby and what will happen.
- ✓ Ask your doctor about steroid treatments to help the baby's lung growth.
- ✓ Talk to your partner about what is going on and might happen. You both need to be on the same page and to be a team for your baby.
- ✓ Try to get as much rest as you can.

For Parents Who Are Expecting Children With CDH:

There are a few procedures that may help your child before he/she is even born. The least evasive and most promising is the used of betamethazone steroids injected into you to stimulate the baby's lungs to grow. This is the same treatment offered to moms who experience premature labor. There are also surgical procedures that can be done. The following hospitals offer in utero surgery and/or tracheal ligation for fetuses diagnosed with congenital diaphragmatic hernia. They are radical and fairly new procedures that come with various possible side effects. We do not advocate for these or any other specific procedures- we support your decision to make the best medical choices for your child. Certain conditions must apply (the liver can not be involved in the herniation, no other birth defects or genetic anomalies, maternal health, etc.). Transportation, housing, and medical cost grants may be provided (ask when you call). For more information or to be considered for an in utero procedure, you can contact:

- Fetal Treatment Center, Univ. of California at San Francisco- 800-RX-FETUS
- Washington University in St. Louis- (314) 454-6022
- Florida Institute For Fetal Diagnosis and Therapy (Tampa, FL)
- Children's Hospital of Philadelphia- (800) IN-UTERO
- Vanderbilt University in Nashville- (615) 936-1050
- Women & Infants' Hospital Of Rhode Island Fetal Treatment Center - (401) 228-0559
- Fetal Care Center of Cincinnati, Ohio – 888-338-2559
- Children's Hospital Boston and Harvard Medical School's Advanced Fetal Care Center - (617) 355-6000

Baby Showers!

Date: _____

Host: _____

Location: _____

Notes: _____

_____

_____


Add Photo Here


Add Photo Here


Add Photo Here


Add Photo Here

Shower Attendees

Guest	Date	Notes

Don't Become A Martyr

Live one day at a time. Even though studies show that 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. Tape record your voice for nurses to play for your child while you leave to eat, sleep, or rest. No one expects you to become a saint, and you shouldn't expect that of yourself either. If you are tired, your baby will sense it, so take shifts with other people to stay at the bedside. When you are tired, you can't make clear decisions about your baby's health care. After all, what is a martyr? A martyr is someone who dies or gives up something irreplaceable like their health or sanity- and your baby needs you to be 100%.

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. Any dime store notebook will do. If your child makes it, it will be an invaluable tool to help educate your child about his/her traumatic entrance into the world and how special he/she is. If you lose your child, it will be a keepsake that, unlike memories, will not fade with time. Make sure to include pictures, of good and bad times, and have both parents and other family members and friends write entries also.

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 the swelling does go away without any stretch marks and your child will return to his/her normal size. The bandages will someday disappear, along with the IVs and other tubes. Of course there will be some scarring, but someday hopefully your child will proudly display his/her "badges of courage", and you will be blessed that they are able.

Learning How To Deal With The 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 and to see your child's medical records. Remember, staff members are also people. Treat them with the same respect you expect to be given. Parents who remain calm, and do not lose their tempers during stressful times earn more respect from the staff than demanding, overly aggressive parents. Of course we all want our children to receive the best medical care possible. Educate yourself on your child's diagnosis and medical terminology. It will better your child's care and your relationship with his/her care-givers.

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 do not care. Some may distance themselves with others may practically smother you. Some may cry, some may make jokes. Some with healthy children may feel guilty. While you may not understand these feelings, they are all natural and normal. Talk about your feelings and keep your family and friends informed. The easiest way to do this is to appoint one person as a "go between" for all other family members and friends. This way you only have to update one person, and will spend less valuable time explaining and updating.

Questions to Ask The Doctor About Our Cherub

Today's Date _____

Music To Listen To

- "To Where You Are" by Josh Groban
- "Forever" by Vertical Horizon
- "Can You Hear Me When I Talk To You" by Ashley Gearing
- "You Raise Me Up" by Josh Groban
- "I Dont Wanna Miss A Thing" Aerosmith
- "Untitled Hymn" by Chris Rice
- "One of These Days" by FFH
- "Another Time and Another Place" by Wayne Watson, Sandi Patti
- "Glory Baby" by Watermark
- "He's My Son" by Mark Shultz
- "Far Away" by Nickelback
- "Far Different Places" by Janice Kapp Perry
- "Say Goodnight" by Beth Nielsen Chapman
- "For Baby (For Bobbie)" by John Denver
- "God Only Cries" by Diamond Rio
- "Blessed" by Martina McBride
- "Wonder" by Natalie Merchant
- "The Promise" by Tracy Chapman
- "Can't Cry Hard Enough" by Victoria Williams
- "Blessed Be" by Alison Krauss
- "Angel Standing By" by Jewel
- "Child of Mine" by Emmylou Harris
- "A Living Prayer" by Alison Krauss
- "Underneath the Stars" by Kate Rusby
- "You Are My Sunshine" by Norman Blake
- "Godspeed" (Sweet Dreams) by the Dixie Chicks
- "If Heaven Was Needing A Hero" by Jo Dee Messina
- "I Believe" by Diamond Rio
- "Held" by Natalie Grant
- "Close to you" by Carpenters
- "Who You'd Be Today" by Kenny Chesney
- "Mary's Song- Breath of Heaven" by Amy Grant
- "Sometimes Miracles Hide" by Bruce Carrol
- "Love Is Sacrifice" by Rob Frazier
- "The Dance" by Garth Brooks
- "Standing Outside The Fire" by Garth Brooks
- "In This Life I Was Loved By You" by Colin Raye
- "Momma" by Julia McCarl and Pat Schwiebert
- "How Can I Help You Say Goodbye" by Patty Loveless
- "A Visitor From Heaven" by Twila Paris
- "Hero" by Mariah Carey
- "Heaven" by Bryan Adams
- "Down On My Knees" by Trisha Yearwood
- "You Don't Have To Move That Mountain" by Trisha Yearwood
- "How Do I Live" by Trisha Yearwood/LeAnn Rimes
- "Fly" by Celine Dion
- "Because You Loved Me" by Celine Dion
- "One Sweet Day" by Mariah Carey (with Boyz II Men)
- "Safe In The Arms Of Love" by Martina McBride
- "It's Your Love" by Tim McGraw (with Faith Hill)
- "Baby Mine" by Alison Krauss
- "Angels Among Us" by Alabama
- "Earth Angel" by The Penguins
- "Tears In Heaven" by Eric Clapton

Composed by CHERUBS with help of Jeff & Tara Hall, Iris Adame, Kim Richards, Amy Rademaker, Amy Atkins, Judi Toth, Denise Richer, Kim Switzer, Darcy Miller, Danielle Kessner, Dawn Williamson, Tammy Spohr and Denise Dunfee. *suggestions taken from an Abiding Hearts leaflet, compiled by Maria LaFond Visscher

Sources Of Financial Help

*Federal Help- Social Security Disability (SSI) checks, Katie Beckett Grants, and other financial assistance. Contact your local Social Security Office and Social Services.

*Ronald McDonald Houses- housing for families of critically ill children. Ask the hospital if there is one close by.

*Transport Services- many hospitals provide free transportation from Ronald McDonald Houses and nearby hotels.

*Churches- your church of synagogue can provide religious support and possibly offer some financial assistance.

*State Programs- many states offer medical insurance assistance with programs such as Medicaid/Medical, The Crippled Children's Fund, and other programs for handicapped children.

*Member Advice – several members offer the following advice:

Amy Rademaker – "Local chapters of organizations like: Rotary, Kiwanais, Lions Clubs, Shriners etc."

Corin Nava – “Check to see what programs the hospital has available. Mass General had parent rooms to sleep in, a shower facility, a kitchenette for parents to use, a laundry facility, free parking passes for the local garages if your child was there longer than 30 days, free meal trays to breastfeeding moms, and meal tickets for the hospital cafeteria. However, these things weren't mentioned upfront. A lot of it would be mentioned weeks after we were there as an afterthought. I would ask the social worker to look into what services they offer parents ASAP.”

Judi Toth – “In addition to the Federal and State Programs mentioned already, here are a few additional programs and assistance available for financially strapped families, especially if you have a sick child, spouse or family member at home:

SSI - Keep on appealing if you get turned down!!!! Request a hearing in front of an Appealant Administrative Judge from SSA. I can't emphasize this enough as I, myself, was turned down 3 times (for 28 separate disabilities, already receiving 90% VA disability and 100% OPM disability) and finally requested a hearing in front of a judge where I was deemed immediately disabled retroactive 3 years! If your child has a learning disability, hearing loss, medical problems that persists after birth, the CHILDREN ARE ELIGIBLE!!!? Even ADHD & HDD are considered disabilities. Your child upon receiving SSI automatically becomes enrolled in Medicare and while you may not think you need this now, if you or your spouse were to ever lose your jobs and insurance, or switch jobs, some insurance companies may not pick up your child due to pre-existing conditions and the Medicare is a God-send then. If you say you have insurance now, Medicare actually becomes the Primary and the your other insurance becomes secondary and will cover all those co-pays to the different doctors. Some States have no-cost insurance for low/working class people and their children - but you are limited with where you can go, whereas, if you have the Medicare in addition to the State Insurance, you are not quite as limited and don't have to pay quite as much out of pocket expenses. Not all States will allow you both Medicare and their State insurance but some do.

Local Programs, either on the County or City level: WIC (Women, Infant & Children) to help out with formula, milk, protein sources for both mother and children; Food Stamps - don't be afraid of the stigma of going on food stamps! These days food stamps are issued on a debit type card and you pay for the food stamp items on that and your non-food items can be paid for using cash, debit card, etc. The only person knowing you are using the food stamp debit card is the cashier.

Military: You can go to Army/Air Force/Navy?Emergency Relief which can assist in grants, especially when faced with the death of a child; and/or grants or low cost loans to help pay bills. You can't use this on a monthly basis but the counselors can assist you with your bills by referring you to a debt consolidator, so that your bills are consolidated into one smaller payment and they can also help with reducing your high-paying interest credit cards and loans at the same time paying that smaller amount. Military members should automatically head straight to their base's hospital counselor and enroll yourself in the Exceptional Family Member Program. This program ensures that the active duty member and family is stationed at a military base that can handle their child's health problem. Many overseas locations have exceptional medical hospitals and DoD schools. Sometimes, during early enrollment in the program, the deployed Active Duty member can return home or be prevented from deploying to war until the child stabilizes while enrolled in the EFMP.

Red Cross: The Red Cross can assist families that are facing medical emergencies during times of natural or other disasters (fires, power outages, floods, etc.) to ANY family, especially if you have a medical emergency. The Red Cross is also the organization to contact IMMEDIATELY if you have a medical emergency and if your spouse or child's parent is at another location than you and your child. They can cut through some of the red tape to get the spouse/parent of a child in a medical emergency to get them in touch with you and possibly assistance in getting them on emergency leave to be with you and your child.

Utility Companies: If your child (or other family member you reside with) is on life-sustaining medical equipment, i.e., oxygen, respirator, etc., contact your utility companies (including phone company) to be placed on their emergency medical list. Normally, what this means is that during a power outage, they will respond to your area first. It also means that if you are facing financial difficulties, they cannot shut off your service. In case of an power outage, ALWAYS make sure you have an old-fashioned telephone (not cordless type) because you can use these phones during a power outage, whereas the cordless phones cannot be used. Also, even if you cannot afford a cell phone, if you have an old cell phone that's service is disconnected or if you have a family member or friend that has an old cell phone (with charger of course), you can still dial 911 from any old cell phone.

Credit Cards - if you have high interest credit cards, call the creditor and explain your medical situation with your child and ask if they can lower your credit card interest if it's high (some card's APRs are up to 29.9%!!! Check your monthly statements for your APR and you may find that what started out as a low interest card was only for 6 months and then jumped up high after that initial 6 months. Most credit card companies will reduce your rate vs. not getting a payment, even if your credit is messed up, especially for medical reasons. Also, check to see if you were enrolled in their insurance program where if you got sick, lost your job, etc., that particular insurance program will pay your monthly credit card payment. It's better to try to work with the creditors directly sometimes and you won't screw up your credit. Some of these suggestions are also good to know even if your cherub is healthy. You never know when something pops up that can cause chaos in your life!?”

Tammy Spohr – “I'm not sure about other states but in California there is:

Medi-Cal=even with a PPO or HMO you can qualify for Medi-Cal as a second insurance. Sometimes there is a share of cost.

California Children's Services (CCS)=they usually pick up as a third party (after your insurance and Medi-Cal are billed). You have to have Medi-Cal to qualify. They were really helpful when it came to getting Bryston his RSV shots.

In Home Support Services (IHSS)=when you are home with your CDH babe, they will pay you to take care of them, when the care is beyond normal care. They rather pay the parents than hire nurses to do the job. (you have to have SSI to qualify).

The state and system is there to help you. Contact your hospitals Social Worker and ask for help."

Kara Hess – "Ohio offers BCMH (Bureau for Children with Medical Handicaps). It is a supplemental insurance. If you don't qualify for it they also offer a cost share program. It's a lot of paperwork to fill out, but worth it.

Family Self Sufficiency (FSS) funding is also available usually through your county health department or board of mental retardation and developmental disabilities. They give out coupon vouchers that can be used for things such as therapy required toys, tools, cups, spoons, etc. It can also be used for thickeners, supplemental food, and therapeutic services. Here in Ohio, one can qualify for up to $400 every 6 months."

Currently, CHERUBS cannot offer financial assistance but we have created a new fund, our CHERUBS Family Assistance Fund, to hopefully assist families in the near future.

Advice For Family And Friends

- **Listen. You don't have to say anything, just lend an ear and a shoulder.**
- **Learn about the child's problems and how to help take care of him/her. The parents will need trained babysitters that they can trust.**
- **Avoid saying things like "I understand", "It's God's will", "You just have to accept it an move on", and other cliches and "words of wisdom". Stay positive and respect the parents' decisions and feelings.**
- **Offer rides to the hospital, babysitting siblings, doing laundry, cooking meals, cleaning, picking up mail, making phone calls, etc.**
- **Encourage the parents to talk about how they feel, but don't push them too hard.**
- **Realize that the parents will need support, comfort, and help for many years, not weeks.**
- **Ask questions, find information, seek support for the parents- but realize that there are certain boundaries.**
- **Bring food, books, and magazines to the hospital.**
- **Take pictures, videos, and help the parents to accumulate mementos.**
- **Throw baby showers, help decorate the nursery, buy the baby gifts- just as you would if the baby was healthy.**
- **Don't be afraid to cry too. The parents know that their family and friends are hurting too.**
- **Don't expect everything to be "normal" someday- accept the child for who he/she is, an individual.**
- **Call the baby by name, not "John and Mary's baby" or other such references.**
- **Talk to your children about the baby and about what is going on in words that they can understand so that they won't be scared of the baby.**
- **Let the parents grieve in their own ways- even parents of survivors need to grieve.**
- **Ask the parents what they need and make them feel comfortable enough to let you know.**
- **Don't criticize the parents if their child is developmentally behind or not eating with words like "Isn't that baby eating yet?", "Why isn't he/she gaining weight", "A year old and not crawling yet?".**
- **These children cannot be compared to healthy children or even other CDH children. They have their own paths to follow and reminding the parents that their child isn't "normal" is very painful.**
- **Something that really bothered me that a relative did was to suggest in her own words to terminate the pregnancy. She felt she had to say something, even if it was just to let us know that we had a choice. The thing is, that every doctor, nurse or specialist we spoke to also told us. The last place we wanted to here it was from those close to us.**
- **Don't try to cheer up the parents if they break down crying in front of you...sometimes we need to cry and be sad. Sometimes trying to cheer us up just makes us feel worse.**

Suggestions by Danielle Kessner, Theresa Wellman, Dawn Williamson, and Tammy Spohr

EARNING TRUE GIFT OF MOTHERHOOD

Written by Erma Bombeck in 1980

Most women become mothers by accident, some by 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.

"Rudlege, Carrie; twins; patron saints... give her Gerald. 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 to 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 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 a 'step' ordinary. When her child says 'Momma' for the first time, she will 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."

Sources of Information and Support

National Organizations

Abiding Hearts- for expectant parents (406-587-7421)
Alliance of Genetic Support Groups (800-366-GENE)
American Heart Association (800-242-8721)
American Lung Association (800-242-8721)
Association of Birth Defect Children, Inc. (800-313-2232)
Compassionate Friends- for grieving parents (708-990-0010)
Cornelia de Lange Syndrome Foundation (800-753-CdLS)
ECMO Moms and Dads (806-892-3348)
Grandparents United In Moral Support (315-492-0090)
Mommies Enduring Neonatal Death (888-695-MEND)
Mothers In Sympathy and Support (602-979-1000)
Mothers United In Moral Support (414-336-5333)
National Organization of Rare Disorders (800-999-NORD)
Now I Lay Me Down To Sleep (877-834-5667)
Parents Helping Parents (408-727-5775)
Pregnancy and Infant Loss Center (612-473-9372)
Pregnancy Risk Line (801-583-2229)
Sidelines- for expectant parents (949-497-2265)
Special Training of Military Parents (206-588-1741)
Support Organization for Trisomy 18, 13 and Related Disorders (800-716-SOFT)
The Compassionate Friends- for grieving parents (630-990-0010)
The Sibling Support Project (206-297-6368)

International Organizations

Australia- CHERUBS Australia - (03) 5135 6999
Australia- Association of Genetic Support (44 Rawson St., Epping, NSW 2121)
Australia- Stillbirth and Neonatal Death Support (03 9773 0228)
Canada- Parent to Parent Link Programme (416-421-8377)
Europe- EUROCAT (Rue Juliette Wytsman 14, 1050 Brussels, Belgium)
Great Britain- CHERUBS UK - **0800 731 6991**
Great Britain- Contact A Family (0171 383 3555)
Great Britian- In Touch Trust (0161 905 2440)
Holland- Stichting Hernia Diafragmatica (0488 - 452614)
Italy- Famiglie Bambini Ernia Diaframmatica - www.erniadiaframmatica.it
New Zealand- Parent to Parent (011 64 71 827 5530)
Scotland- Children In The Highlands Information Point (01463-711189)

Web site and e-mail addresses to these support groups can be found on our web site at:
www.cdhsupport.org

CHERUBS State & International Representatives

Representatives: http://www.cdhsupport.org/volunteers/reps/

CHERUBS On-Call Volunteers

We have parents on-call who are willing to listen and share their experiences. Please feel free to give them a call, or call our office at (252) 492-6003. You can find updated lists of our On-Call Volunteers and State & International Representatives in our quarterly newsletter, The Silver Lining. You can also visit our website for the most current lists:

On-Call Volunteers: http://www.cdhsupport.org/volunteers/oncall.php

"I Wish Someone Would Have Told Me!"

- Don't give up your dream of breastfeeding. Unless your child has a severe allergy, there is no reason he/she can't be given your breastmilk when the time comes. Don't let a doctor or nurse talk you into using formula just because it's easier to measure and control.
- If you find you are not able to breastfeed don't worry there are alot of other good things you can do for you baby.
- Learn how to take care of your baby from the very beginning. Help out the hospital as much as you can. You don't want to delay release just because you haven't learned everything yet.
- After your child comes home, after the phone calls and visitors stop coming so often and you're home alone with your baby, depression very often sets in. It's normal to feel alone and "strange". Don't be afraid to seek help or accept it.
- Your child's immune system isn't as strong as a healthy child's- take precautions, don't go into crowds until your child is strong, and don't be afraid to "monitor" who enters your home.
- Keep records on hand in case of an emergency.
- Notify your local ambulance service and invite them to meet your child- you may need them someday and it will save time to not have to give them your child's complete medical history.
- If your child needs any medical equipment at home, notify the Power Company so that you can be put their emergency list.
- Don't be afraid to call the doctor if you feel anything is abnormal.
- Don't be afraid to do "normal" things, such as tickling, bouncing, going to visit friends and family, taking them to see Santa (of course monitor everyone for viruses first and see Santa on "off-peak" hours).
- Ask your child's doctor about the Chicken Pox, Flu, and RSV vaccines and especially monitor young children that your child may come into contact with.
- Be aware that having a "disabled" child can cause marital problems and sibling rivalry- pay extra attention to family members and seek counseling if needed.

- Don't be afraid to fire nurses, doctors, therapists, etc. that you are not comfortable with- that is your choice, but just make sure your child receives the services that he/she needs.
- Listening to your inner instincts are important. Once we get our babies home we can tell when something is not right and need to convey that to the health care provider. It is important to have a doctor that will listen to and address your concerns. Each child is different so we need to be their advocate in they health care.
- Keep a home medical chart on your child with the dates of past appointments/hospitalizations and which hospital they were at and what was done/said. A list of all medications current and past and what they are prescribed for, a list of all doctors that he currently sees, so that when an emergency does happen whether you transport or you have paramedics transport they have that record because you are not going to remember what exactly is going on during a time of extremely high stress.
- Keep a journal.
- Build a support system of family, friends, and support groups that can listen, answer questions, offer a hand when you need it.
- Don't be afraid to ask for help!

Suggestions made by Elaine Moats, Dawn Williamson, and Denise Richer

Designating A Cherub Liaison

When your cherubs is born you will be very busy indeed… visiting the hospital, pumping breast milk, making decisions and trying to sleep. Most new parents do not have the time or energy it takes to constantly keep all family members and friends up to date on their cherub's status. We highly recommend that you appoint 1 or 2 people as your Cherub Liaisons to be the go-between you and everyone else. He or she will be kept up to date and then they will notify all family and friends of your cherub's status, make requests, lead prayer circles, update your blog, post photos, etc. This will make your life a little easier and allow for you to get more rest.

Cherub Liaison #1 _____

Home Phone: _____ Cell Phone: _____

E-mail Address: _____

Cherub Liaison #2 _____

Home Phone: _____ Cell Phone: _____

E-mail Address: _____

Our Blog

An easy way to keep a large number of people updated is by using a blog on-line. There are many free blog sites available, such as Blogspot and Wordpress and as a CHERUBS member, you also have a free blog on our web site that you can use. CHERUBS offers a blog webring and free graphics for your blog should you chose to host it elsewhere. Please feel free to post any CDH information from our site or materials.

Our Blog Address: _____

Username: _____

Password: _____

Our Pregnancy

Due Date: _____

How We Found Out We Were Expecting: _____

How Mommy Told Daddy: _____

Notes: _____

_____

How We Found Out About Congenital Diaphragmatic Hernia: _____

_____

Pregnancy Complications: _____

_____

_____

_____


Add Photo Here


Add Photo Here


Add Photo Here


Add Photo Here

Today's Date _____

Location _____

Journal Entry By _____

Today's Date _____

Location _____

Journal Entry By _____

Today's Date _____

Location _____

Journal Entry By _____

Our Cherub

Name: _____

Baby Looks Like: _____

Hair: _____ **Eyes:** _____

Notes: _____

Our Family Tree

Name: _____

Meaning: _____

Named After: _____

Mother: _____

Father: _____

Siblings: _____

Maternal Grandfather: _____

Maternal Grandmother: _____

Paternal Grandmother: _____

Paternal Grandfather: _____

Maternal Great-Grandfather: _____

Maternal Great-Grandmother: _____

Maternal Great-Grandfather: _____

Maternal Great=Grandmother: _____

Paternal Great-Grandfather: _____

Paternal Great-Grandmother: _____

Paternal Great=Grandfather: _____

Paternal Great-Grandmother: _____

Baby's Birth Day

Hospital: _____

Doctor: _____

Town: _____

Date: _____

Time: _____

Weight: _____

Length: _____

Apgar Scores: _____

Notes: _____

_____

_____


Add Photo Here


Add Photo Here


Add Photo Here


Add Photo Here

Our Medical Team

Name	Service	Phone Number

Cherub's Medical History

Type of Congenital Diaphragmatic Hernia: _____

Organs Involved / Amount of Lung: _____

Other Birth Defects or Genetic Issues: _____

_____

Allergies: _____

Blood Type: _____

Other: _____

_____

CDH Repair: _____

_____

_____

Neonatologist: _____

Pediatric Surgeon: _____

Primary Nurse: _____

Pulmonologist: _____

Other Medical Team Members: _____

_____

_____

_____

Important Medical Milestones

Event	Date	Notes

Important Medical Milestones

Event	Date	Notes

Important Medical Milestones

Event	Date	Notes

Today's Date _____

Location _____

Journal Entry By _____

Today's Date _____

Location _____

Journal Entry By _____

Today's Date _____

Location _____

Journal Entry By _____

Today's Date _____

Location _____

Journal Entry By _____

Today's Date _____

Location _____

Journal Entry By _____

Today's Date _____

Location _____

Journal Entry By _____

Small Hands Make Big Imprints Upon The World

Baby's Hand Prints

Baby's Foot Prints

Date: _____

Note s: _____

_____

_____

Holding Baby

The First Day Mommy Held You

Date: _____

Notes: _____

_____

_____

Holding Baby

The First Day Daddy Held You

Date: _____

Notes: _____

_____

_____

Hospital Visitors

Visitor	Date	Notes

Hospital Visitors

Visitor	Date	Notes

Cherub's Firsts

Baby's First Bath

Date: _____

Notes: _____

Baby's First Tube Feeding

Date: _____

Notes: _____

Baby's First Bottle / Breastfeeding

Date: _____

Notes: _____

Baby's First Tooth

Date: _____

Notes: _____

Baby's First Haircut

Date: _____

Notes: _____

Baby's First Book

Date: _____

Notes: _____

Baby's First Surgery

Date: _____

Notes: _____

Baby's First Room

Date: _____

Notes: _____

Baby's Milestones

Milestones	Date	Notes

Baby's Favorite Nurse

Date: _____

Notes: _____

Baby's Favorite Doctor

Date: _____

Notes: _____

Baby's Favorite Toy

Date: _____

Notes: _____

Baby's First Friend

Date: _____

Notes: _____

Baby's Favorites

Item / Person	Date	Notes

Going Home!

Leaving the hospital!

Date: _____

Notes: _____

_____

_____

Our Home Support Team

Whether it's family and friends or home health nurses, everyone needs support once you take your cherub home. It can be extremely overwhelming to take a medically fragile child home and suddenly be without the support of having a nurse or therapist right there. Make sure to build a strong support system for both physical and emotional support.

Name	Service	Phone Number

Medical Appointments

Month_____ Year _____

Sunday	____	____	____	____	____
Monday	____	____	____	____	____
Tuesday	____	____	____	____	____
Wednesday	____	____	____	____	____
Thursday	____	____	____	____	____
Friday	____	____	____	____	____
Saturday	____	____	____	____	____

Medical Appointments

Month_____ Year _____

Sunday	____	____	____	____	____
Monday	____	____	____	____	____
Tuesday	____	____	____	____	____
Wednesday	____	____	____	____	____
Thursday	____	____	____	____	____
Friday	____	____	____	____	____
Saturday	____	____	____	____	____

CHERUBS – The Association of Congenital Diaphragmatic Hernia Research, Awareness and Support

CHERUBS is an international organization for families and care-givers of children who are born with Congenital Diaphragmatic Hernia (CDH). Our membership includes over 3000 families and medical care providers in all 50 states and 38 countries. We are an IRS recognized 501(III)C Non-Profit Organization. All of our employees, board members, other assistants are strictly volunteer-status. We do not charge parents membership fees, though we do ask for an annual $20.00 donation, if affordable. Medical professionals may also join our membership for an annual $30.00 donation. Donations are very much needed and appreciated- and also tax-deductible. You can make your check or money order out to; CHERUBS. The information in this guide and in all materials and services published or furnished by CHERUBS is by no means to be used in substitution for proper medical care and advice. Any personal views represented in CHERUBS' material and services do not necessarily represent the views of all CHERUBS' members and/or staff. Please remember, you cannot compare your child or any child to other CDH patients- they are all different and take different paths. Feel free to share our materials with doctors and other families.

You can join CHERUBS at http://www.cdhsupport.org/members

My CHERUBS Username: _____

My CHERUBS Password: _____

Services Offered by CHERUBS:

- Our Web Site – stories of our members, photo albums, member blogs, message boards, chat rooms, medical research, information, and much more.
- Parent Reference Guide – our guide for new and expectant parents.
- Quarterly Newsletters – stories of cherubs, medical updates and updates on our newest projects.
- Parent-to-Parent Matches – matching up families who have the most in common so that parents can truly talk to someone who knows "exactly what they've been through". This is all done now through our web site.
- Congenital Diaphragmatic Hernia Research Survey – our way of helping to find the cause of CDH through comparing similarities and "coincidences" among our members.
- On Call Volunteers – parents ready and willing to lend an ear when you need it most.
- On-Line Chat Meetings – on-line support group meetings that allow our parents to "talk" to other parents and talk or lend an ear. We have several different types of meetings, directed to all members, parents of non-survivors, cherubs and their siblings, dads, and more.
- On-Line Listserv Program – an e-mail program that allows our members to send e-mails to all Listserv members, asking questions and giving support.
- On-Line Message Boards / Forums – our "Questions and Answers" message board that allows members to seek and give advice.
- On-Line Blogs & Albums – Now our members can keep their family and friends updated through their own blogs and photo albums.

Questions About CHERUBS

How do I join CHERUBS?

You can join by filling out one of our membership forms on our family membership page or professional membership page. You can also print your membership form and mail it in through regular postal mail.

Who can join?

Parents, grandparents, adoptive parents, foster parents, and adult survivors can join our family membership. Pediatric surgeons, nurses, neonatologists, epidemiologists, pulmonologists, respiratory therapists, and social workers can join our professional membership.

Does it cost anything to join?

CHERUBS does not charge families membership fees. If you can afford to, you can make annual donations of $20.00, but it is not required and you will not be billed. Professional members are required to pay $30.00 annual membership fees.

If I join, do I have to participate in all the activities?

You participate as little or as much as you'd like. You don't have to participate in any activities, volunteer, or be matched with other families and still join. We realize that each family and parent is different and your lifestyle or emotions might make it hard for you to be involved in some or all of our activities. You can always join in or pull back on your activities in CHERUBS.

How do I send in my child's story?

You can e-mail your story by typing it directly into an e-mail or attaching it as a document. You can also send it through postal mail. We ask that you please type the story (sometimes we have problems deciphering handwriting) and prefer to have it sent through e-mail to save us time on retyping. You can also e-mail your child's picture as a .gif, .jpg, .jpeg., or .bmp file or send it through regular mail.

If I make a donation in honor/memory of a loved one, is it tax-deductible?

Yes, donations are tax-deductible because CHERUBS has 501(C)III status under the United States I.R.S.

Where does my donation go?

All donations go to help us reach and inform families and medical professionals. Funds are used to pay for literature, newsletters, postage, office supplies, phone calls, and other expenses that allow us to send information and to counsel families. No donations are used to pay employees (we are a volunteer-run organization). Currently, CHERUBS does not receive grant funding and our survival depends on donations and membership fees.

Does anyone get paid for working for CHERUBS?

CHERUBS is solely run by volunteers. The number of volunteers that we have frequently changes, but we usually maintain a number of about 50 volunteers in dozens of positions and can always use more.

Can I help?

We always love new volunteers! If you would like to volunteer, please contact us. And now with our Angels for CHERUBS program, family members and friends can help also!

Is CHERUBS On-Line?

Yes, we have been on-line since 1997 and offer many different on-line services such as listservs, message boards, chatrooms and much more. Our web site address is www.cdhsupport.org.

Can you give me information about a certain hospital or doctor?

CHERUBS cannot make referrals or give medical advice on who is the best hospital or doctor. You need to make contact and judge them yourself, based on their amount of experience, success rate, and how comfortable you feel trusting them with your baby's life.

What are CDH Surveys used for?

Data on our surveys is used to help us find the causes and best treatments for CDH. Currently CHERUBS is the only organization actively researching the U.S.'s number of CDH cases. Though many hospitals and organizations research CDH and other birth defects, no one else is questioning the parents and reviewing the entire medical histories. With your help, one day we can and will save babies of the future from the devastating effects of CDH.

God's Loan

(Author unknown)

"I'll lend to you for a little time,
A child of mine," He said,
"For you to love the while she lives
And mourn for when she's dead.

"It may be six or seven years
Or twenty-two or three,
But will you till I call her back,
Take care of her for me?

"She'll bring her charms to gladden you
And should her stay be brief,
You'll have these precious memories
As solace for your grief.

"I cannot promise she will stay
Since all from earth return.
But there are lessons taught down there
I want this child to learn.

"I've looked this world over,
In my search for teachers true.
In the crowds that throng life's land,
I have selected you.

"Now will you give her all your love
Not think the labor vain,
Nor hate me when I come to call
To take her back again?"

It seems to me I heard them say,
"Dear Lord, thy will be done.
For all the joys a child shall bring,
The risk of grief we'll run.

We'll shelter her with tenderness,
We'll love her while we may,
And for the happiness we've known
Forever grateful stay.

"And should the angels call for him
Much sooner than we've planned,
We'll brave the bitter grief that comes
And try to understand."

CHERUBS 5 Funds for CDH Families

CDH Family Support Fund – this fund covers all support services, including our web sites, newsletters, conferences, New Member Packets, get-togethers and other general operating costs. CHERUBS does a lot for CDH families and the CDH community and we incur quite a few costs during so. Just 1 newsletter mailing is now over $3000 for printing and posting with so many members. Our conferences are also expensive. Our monthly expenses are several hundred dollars for ink, postage, web site hosting fees, fax number, etc. It takes a lot to fund an organization with almost 3000 members. Remember , no one at CHERUBS gets paid and we have no office so every penny directly helps CDH families. And all of our services are FREE so we do charge membership fees. Only 2% of our members donate annually so we depend on public donations quite a bit. And the occasional grant as well.

CDH Research Fund – to pay for the $1000 a year cost of research database hosting and to raise money for research organizations such as the International CDH Study Group – unless a request is made to go a specific hospital. The CDH Study Group is a collective group of over 30 hospitals around the world specializing in CDH research. We chose to support groups like this one because we know that every cent will go directly to research on Congenital Diaphragmatic Hernia and research will be brooder and more advanced when collaborating with dozens of hospitals and researchers together.

CDH Family Assistance Fund – A majority of this fund will go to help families with travel expenses such as airline tickets and gas. It will not go to lodging because CHERUBS highly recommends the free lodging available at Ronald McDonald Houses. Families will submit confidential applications to assistance and a committee will consider each request. Our goal is to make sure that all CDH families can afford to get to their cherub's medical center and have a place to stay so that they can concentrate on their children instead of travel worries. We hope to assist a family through this fund by this fall. The remaining small percentage of this fund will go to the gift bag project, a new program that helps new and expectant families by supplying them with items needed. This project will start this summer!

CDH Awareness Fund – this fund will help raise awareness of Congenital Diaphragmatic Hernia through balloon releases, giving away free CDH ribbon buttons and brochures and other items. It will also cover advertising costs, billboards, video production and much more.

CDH Scholarship Fund – for CDH survivors and siblings. Families can raise money to give scholarships in honor / memory of their cherubs. We hope to award our first scholarship in 2010. This will all be funded through donations, grants and fundraisers. Member and the general public will be able to donate directly to a particular fund of their choosing. Donations not allocated to a specific fund will be deposited into the CDH Family Support Fund. We are very excited about all 5 of these new funds!

How You Can Help CHERUBS

- ✓ Make a tax-deductible donation
- ✓ Participate in events
- ✓ Shop and Search through Goodsearch.com with CHERUBS your preferred charity
- ✓ Pay it Forward – help other families by visiting our forums and offering support
- ✓ Volunteer at CHERUBS
- ✓ Submit your cherub's story and photo
- ✓ Wear the CDH Awareness Ribbon button
- ✓ Join in on voting and other events on our forums
- ✓ Ask family and friends to donate in honor of your cherub
- ✓ Donate items for our gift bag project
- ✓ Sponsor events or projects
- ✓ Participate in fundraisers
- ✓ Help us find items for our Wish List
- ✓ Use the following form to increase awareness and raise money for CHERUBS

CHERUBS Wish List

CHERUBS is always on the look out for the following to help us cut costs and to help more families affected by CDH. Items with a * are for our gift bag project.

Monetary Donations
Printing Sponsors
Event Sponsors
Adopt A Hospital Sponsors
Grant Writers
Volunteers
2-pocket folders
Postage Stamps
Printing Paper
CDH Awareness Ribbon Pins
Copies of "Stories of Cherubs"
CDH Education Posters
CDH Awareness Bracelets

1.5" White 3-ring Binders*
Baby Blankets / Quilts*
Journals / Notepads*
White / Natural Cotton Tote Bags*
Chapsticks*
Small bottles of lotion*
Small bottles of hand sanitizer*
Travel Kleenex*
Disposable Cameras*
Pens*
Newborn Button up T-Shirts*
Restaurant Vouchers*
Gas Cards*

It costs $4 - $5 to print and mail each newsletter - per copy in the U.S. - up to $20 per overseas copy. Please help us to cover these costs by donating or opting to not receive our newsletter by mail (you can view them for free on our website at any time). You can do this by logging into the site and editing your Profile. Or you can subscribe to the printed version of our newsletter for $20 a year by checking in the box below and sending in payment.

If you have benefited from our services,, please consider donating so that we can continue to help families affected by Congenital Diaphragmatic Hernia. Donations are tax-deductible.

CHERUBS subsists off of donations. CHERUBS does not charge membership fees. Currently only 2% of our almost 3000 members donate annually. It costs $4 - $5 to print and mail each newsletter - per copy in the U.S. - up to $20 per overseas copy. Please help us to cover these costs by donating or opting to not receive our newsletter by mail (you can view them for free on our website at any time). You can do this by logging into the site and editing your Profile.

If you have benefited from our services over the years, please consider donating so that we can continue to help families affected by Congenital Diaphragmatic Hernia. Donations are tax-deductible.

Make A Tax-Deductible Donation

Name _____

Address _____

_____

_____

E-mail _____

Phone _____

Method of Payment

☐ Bill Me
☐ Check
☐ Visa
☐ MasterCard
☐ American Express

☐ In Honor Of ☐ In Memory Of

_____

Donation:

☐ Newsletter Subscription ($20.00 per year) $_____
☐ Donation to CDH Family Support Fund $_____
☐ Donation to CDH Research Fund $_____
☐ Donation to CDH Family Assistance Fund $_____
☐ Donation to CDH Awareness Fund $_____
☐ Donation to CDH Scholarship Fund $_____

Total: _____

Credit Card # _____ Exp. date _____

Signature _____

Or Donate On-Line at
www.cdhsupport.org/donate

Resources for Families Dealing With Congenital Diaphragmatic Hernia

- ✓ Our Web Site - more information about CDH than anywhere on the net with 1000's of pages! http://www.cdhsupport.org
- ✓ All About CDH - information, diagrams, videos and more. http://www.cdhsupport.org/cdh/index.php
- ✓ CDH Forums for Families - over 100 posts each day, 100's of topics. Get advice, help, info and support 24/7 from parents who have been in your shoes. Membership is FREE and it is all confidential. http://www.cdhsupport.org/members
- ✓ CDH Parent Reference Guide - simple, easy to understand information on CDH written for parents whose babies were newly diagnosed. http://cdhsupport.org/members/dload.php?action=file&file_id=32
- ✓ CDH Brochure - in 4 different languages http://cdhsupport.org/members/dload.php?action=category&cat_id=10
- ✓ CDH Research - research library, survey results and coming very, very soon an interactive CDH research survey for parents and researchers http://www.cdhresearch.org
- ✓ Newsletters full of stories, news and much more -http://cdhsupport.org/newsletter/
- ✓ International CDH Conference - members from several organizations and CDH researchers coming together http://www.cdhconference.org
- ✓ Congenital Diaphragmatic Hernia Day - May 17, 2009 http://cdhsupport.org/members/portal.php?topic_id=3012
- ✓ CDH Events - tons and tons of events and get-togethers and fundraisers around the world http://cdhsupport.org/members/viewforum.php?f=184
- ✓ State & International Representatives - find local support. http://www.cdhsupport.org/volunteers/reps.php
- ✓ On-Call Parents - need to talk to someone? They are on-call for you. http://www.cdhsupport.org/volunteers/oncall.php
- ✓ Videos of Cherubs - dozens of videos of cherubs, events, and more. http://www.youtube.com/user/cdhsupport
- ✓ CDH Photo Albums - 100's of photos of children and adults born with CDH http://cdhsupport.org/members/album.php
- ✓ CHERUBS Adopt A Hospital Program - help us to help families around the world by adopting a hospital to provide materials to for new CDH families http://cdhsupport.org/members/portal.php?topic_id=3013
- ✓ Our Blog - http://cdhsupport.blogspot.com
- ✓ Free On-Line Albums for CDH Families - http://cdhsupport.org/members/album_personal_index.php
- ✓ Free Blogs for CDH Families - keep your family and friends updated with these free blogs on our CDH informational site so they can also research! http://cdhsupport.org/members/weblogs.php
- ✓ CDH Blog Ring - group of CDH blogs written by parents http://www.ringsworld.com/cdhblogsring/home.html#2
- ✓ CDH Awareness Ticker - drop by and see how many babies have been born with CDH since 2000 as a new baby is diagnosed every 6 minutes somewhere in the world. http://cdhsupport.blogspot.com/2009/04/over-half-million-babies-born-with.html
- ✓ Research Library - add your links or view the links of others to CDH research articles and sites. http://cdhsupport.org/members/links.php
- ✓ Personalized CDH Awareness Ribbon - Order a personalized ribbon with your cherub's name, date(s) and photo - send them to ribbons@cherubs-cdh.org
- ✓ "Stories of Cherubs" Vol. I & II - full of stories of 100's of families who have dealt with CDH http://www.cafepress.com/cherubs/6191951
- ✓ CDH Calender - featuring 100's of faces of children born with CDH http://www.cafepress.com/cherubs.337095355
- ✓ Congenital Diaphragmatic Hernia Awareness Items - including Clothes, Bibs, Maternity Shirts, Totes, Journals, Posters, Hats, and much, much, much more - http://www.cafepress.com/cherubs
- ✓ CDH Awareness Ribbon Car Magnets - http://www.supportourribbons.com/m/160153 Also available in a larger size
- ✓ CDH Awareness Ribbon Buttons - just 18 cents each!!!! http://cdhsupport.org/members/viewtopic.php?t=3001
- ✓ CDH Awareness Bracelets - pink, blue and yellow silicone bracelets that say "CDH Awareness" http://cdhsupport.org/members/viewtopic.php?t=2436&start=165
- ✓ CDH Awareness Postage Stamps - http://www.zazzle.com/cherubs
- ✓ CDH Awareness Mailing Labels - download and print for free! http://cdhsupport.org/members/dload.php?action=category&cat_id=17
- ✓ Random Acts of Kindness CDH Awareness Cards - there is no nicer way to raise awareness! http://cdhsupport.org/members/dload.php?action=file&file_id=85
- ✓ CHERUBS Facebook Group - talk to other CDH parents on Facebook http://apps.facebook.com/causes/44070/11273893?m=6d54c0aa
- ✓ CHERUBS Myspace Page - talk to other CDH parents on Myspace http://www.myspace.com/diaphragmatichernia
- ✓ More Downloadable Info - info on where donations go, our non-profit paperwork, older newsletters, event brochures and more! http://cdhsupport.org/members/dload.php

This is just a small list of what we offer and doesn't even include most of our awareness activities and projects. Drop on by our site and take a look at how CHERUBS has been helping families deal with Congenital Diaphragmatic Hernia for 14 years.

Donate To CHERUBS For Our Cherub!

In honor of our cherub, _____, we ask that you donate to CHERUBS – The Association of Congenital Diaphragmatic Hernia Research, Awareness and Support. CHERUBS helps families like ours by providing support and increasing awareness and research. All donations are tax-deductible and any amount will help CHERUBS to help families affected by CDH!

Name: _____

Mailing Address: _____

_____

Amount Donated: _____

Please mail your donation to CHERUBS, 3650 Rodgers Rd. #290, Wake Forest, NC 27587, USA. Or you can donate on-line at http://www.cdhsupport.org/donate - please make sure to include our cherub's name in the comment section. Thank you for helping support cherubs like ours!

Congenital Diaphragmatic Hernia Awareness

The History of the Official Congenital Diaphragmatic Hernia Awareness Ribbon

The first awareness ribbon or bracelet for CDH was discussed on CHERUBS old listservs in 2004. Because all the colors are taken, we didn't want to impede on any other cause's ribbon or their awareness efforts. Besides, we widely used the "cherub" as our awareness symbol for CDH. We tossed the idea around and talked about it with CHERUBS members but there was no real desire to join in on the awareness ribbon bandwagon.

The very first awareness ribbon for Congenital Diaphragmatic Hernia was a turquoise ribbon created in memory of Drew Lewallen in May, 2006 and posted on Rainbow of Hope. Many of us feel that this is Drew's ribbon - and it is. Permission to use this ribbon on a larger scale for fundraising for 1 organization only and ownership of this ribbon was never given and *copyrights belong to Drew's family*.

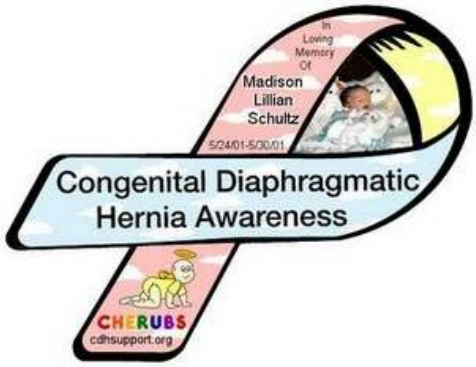
Because of trademark issues now associated with another organization's co-opting of Drew's ribbon and trying to trademark it (twice), most families refrain from using the turquoise ribbon. Most families affected by Congenital Diaphragmatic Hernia view wearing turquoise or a turquoise ribbon as *endorsing the trademark* and helping to fund and encourage a corporation's bid to profit off their babies' pain and suffering and control awareness of this devastating birth defect. Many families do not want to be walking, talking billboards for something that they find morally and ethically wrong.

The Congenital Diaphragmatic Hernia community needed an awareness symbol that was free, not tainted with any ulterior motives, owned by no one and chosen by CDH families. We also wanted something that belonged to just the CDH community and not several other causes. The turquoise ribbon happens to also be used by many organizations and the public for Addiction Recovery, Lymphedema, Native American Reparations, Sexual Assault, Ovarian Cancer, Anxiety Disorders, Mental Health Disorders and more.

We are nothing if not original at CHERUBS and ethically, we could not have used a ribbon color that belonged to another cause or was copywritten by Drew's family. Besides, these CDH babies are so special that they deserve an original awareness ribbon all their own - so we came up with several ideas for an original awareness ribbon.

Members of several organizations voted for many days and a decision was made. The *official* congenital diaphragmatic hernia awareness ribbon, as voted on by CDH parents and survivors, is baby blue, pink and pale yellow with clouds.

This is the Congenital Diaphragmatic Hernia Awareness Ribbon recognized by the members of the Alliance of Congenital Diaphragmatic Diaphragmatic Hernia Organizations. Is it recognized by CHERUBS, the world's first and largest CDH organization with over 2800 members in 38 countries. It is the ribbon associated with the Congenital Diaphragmatic Hernia Research Study.
Wikipedia recognizes this ribbon. There is even a postage stamp with this ribbon, created February 12, 2008. Not to mention 1000's of items with this ribbon available on our stores and various other sites.



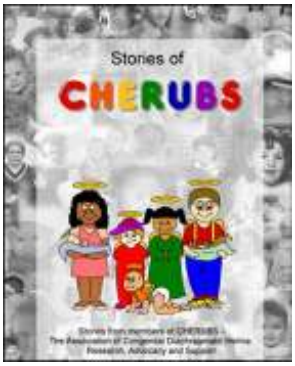
And now, there are personalized Congenital Diaphragmatic Hernia Awareness Ribbons. If you would like one, please e-mail your child's photo, name and date(s) to ribbons@cherubs-cdh.org and Fer and Barb will make your ribbon as soon as possible.

Some parents are even wearing their CDH ribbons as permanent tattoos.

The Official Congenital Diaphragmatic Hernia Awareness Ribbon is on 1000's of web sites, including those belonging to CDH organizations and the CDH Blog Ring.

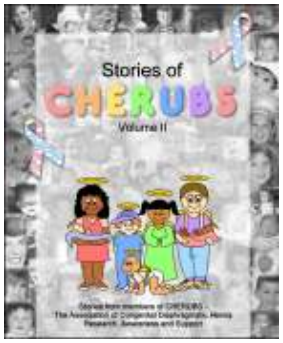
CHERUBS Cafepress Store

CHERUBS has many CDH Awareness Projects Going on. One of the awareness projects that we currently have is our Cafepress Store located at http://www.cafepress.com/cherubs Below are just a few of the 100's of items from our store:








But this isn't all that we offer! We also have cookbooks and t-shirts that we sell from our office, event souvenirs, and items at our zazzle.com shop that include postage stamps, neckties, skateboards and shoes! There are also CDH Awareness car magnets, personalized ribbons and CDH awareness bracelets. Visit our web site to find out more information and to make purchases on-line!

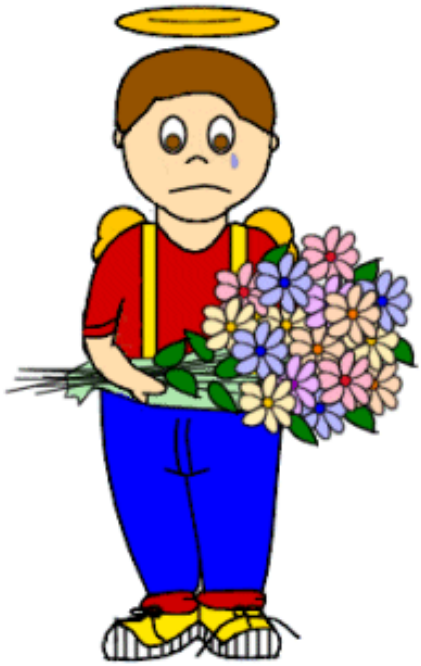


Simple Ways That You Can Raise Awareness

- Wear the CDH Awareness Ribbon Button
- Wear a CDH Awareness Bracelet
- Wear CDH Awareness clothing
- Put a CDH Awareness magnet or bumper sticker on your vehicle
- Post information about CDH on your blog or personal web site
- Tell people about CDH
- Include information about CDH in your church bulleting, club newsletter or other materials
- Give a presentation about CDH at your local school, club or church
- Contact your local media about your story
- Have a blood drive and give out information about CDH
- Hold a fundraiser and give out information about CDH
- Hold a balloon release and give out information about CDH
- Have a birthday or memorial party and give out information about CDH
- Post flyers or posters about CDH
- Participate in CHERUBS events and fundraisers
- Give CDH Awareness items as gifts for birthdays and holidays

Kid's Drawing Here

Kid's Drawing Here



If You Have To Say Goodbye

Bereaved Parent's Wish List

(author unknown)

1. I wish my child hadn't died. I wish I had him back.
2. I wish you wouldn't be afraid to speak my child's name. My child lived and was very important to me. I need to hear that he was important to you also.
3. If I cry and get emotional when you talk about my child I wish you knew that it isn't because you have hurt me. My child's death is the cause of my tears. You have talked about my child, and you have allowed me to share my grief. I thank you for both.
4. I wish you wouldn't "kill" my child again by removing his pictures, artwork, or other remembrances from your home.
5. Being a bereaved parent is not contagious, so I wish you wouldn't shy away from me. I need you now more than ever.
6. I need diversions, so I do want to hear about you, but, I also want you to hear about me. I might be sad and I might cry, but I wish you would let me talk about my child, my favorite topic of the day.
7. I know that you think I also know that my child's death pains you, too. I wish you would let me know those things through a phone call, a card or note, or a real big hug.
8. I wish you wouldn't expect my grief to be over in six months. These first months are traumatic for me, but I wish you could understand that my grief will never be over. I will suffer the death of my child until the day I die.
9. I am working very hard in my recovery, but I wish you could understand that I will never fully recover. I will always miss my child, and I will always grieve that he is dead.
10. I wish you wouldn't expect me "not to think about it" or to "be happy"; Neither will happen for a very long time, so don't frustrate yourself.
11. I don't want to have a "party", but I do wish you would let me grieve. I must hurt before I can heal.
12. I wish you understood how my life has shattered. I know it is miserable for you to be around me when I'm feeling miserable. Please be as patient with me as I am with you.
13. When I say "I'm doing okay," I wish you could understand that I don't "feel" okay and that I struggle daily.
14. I wish you knew that all of the grief reactions I'm having are very normal. Depression, anger, hopelessness and overwhelming sadness are all to be expected. So please excuse me when I'm quiet and withdrawn or irritable and cranky.
15. Your advice to "take one day at a time" is excellent advice. However, a day is too much and too fast for me right now. I wish you could understand that I'm doing good to handle an hour at a time.
16. Please excuse me if I seem rude, certainly not my intent. Sometimes the world around me goes too fast and I need to get off. When I walk away, I wish you would let me find a quiet place to spend time alone.
17. I wish you understood that grief changes people. When my child died, a big part of me died with him. I am not the same person I was before my child died, and I will never be that person again.18. I wish very much that you could understand ---- understand my loss and my grief, my silence and my tears, my void and my pain. BUT, I pray daily that you will never understand.

Chronic Sorrow Grief Process

Stages	Feelings
Shock	Numb/Immobile
Denial	Helpless/Flight
Sadness, Anger, Anxiety	Self Pity, Aggression, Confusion
Adaption	How will we survive?
Reorganization	Here's how we'll survive!

Books To Read

- “Stories of Cherubs” by CHERUBS
- “Room of Marvels” by James Bryan Smith
- “Gone But Not Lost” by David W. Wiersbe
- “When Pregnancy Isn't Perfect” by Laurie Rich
- “When Bad Things Happen To Good People” by Harold Kushner
- “Talking About Death- A Dialogue Between Parent and Child” by Earl A. Grollman
- “A Time To Decide, A Time To Heal” by Molly Minnick
- “Helping People Through Grief” by Delores Kuenning
- “When God Doesn't Make Sense” by Dr. J. Dobson
- “Bittersweet… Hello, Goodbye” by Sr. Mary Jane Lamb (from SHARE, Inc.)
- “I'll Hold You In Heaven” by Jack Hayford
- “Good Grief” by Granger E. Westberg
- “Living Through Grief” by Harold Bauman
- “Angel Unaware” by Dale Evans Rogers
- “See You Later Jeffrey” by Fran Gaffey Sandin
- “Empty Arms” by Sherokee Ilse
- “When Hello Means Goodbye” by Pat Schwiebert, RN & Paul Kirk, MD
- “Empty Cradle, Broken Heart” by Deborah L. Davis, Ph D.
- “A Silent Sorrow” by Ingrid Kohn, MSW & Perry-Lynn Moffitt with Isabelle A. Wilkins, MD
- “What Will Help Me?? 12 Things to Remember When You Have Suffered a Loss” by James E. Miller
- “Surviving the Death of a Child” by John Munday with Frances? Wohlenhaus-Munday
- “Barron's Parenting Keys: Keys to Helping Children Deal With Death and Grief” by Joy Johnson
- “Surviving Holidays, Birthdays & Anniversaries - A Guide for Grieving During Special Occasions” by Brook Noel
- “Holiday Hope - Remembering Loved Ones During Special Times of the Year” - Compiled by the Editors of Fairview Press
- “Tear Soup” by Griefwatch.com
- “Letters to Gabriel” by Karen Garver Santorum
- “Healing a Parent's Grieving Heart: 100 Practical Ideas After Your Child Dies” by Alan D. Wolfelt
- “Help, Comfort and Hope: After Losing Your Baby in Pregnancy or the First Year” by Hannah Lothrop
- “Mommy Please Don't Cry” by DeYmaz

Suggestions by Judi Toth, Dawn Williamson, Lise Dill, Denise Richer, Michelle Towner, Kimberly Switzer, Iris Adame and Heather Southwell

Little Angels

(Author unknown)

When God calls little children to dwell with Him above,
We mortals sometime question the wisdom of His love.
For no heartache compares with the death of one small child,
Who does so much to make our world, seem wonderful and mild.
Perhaps God tires of calling the aged to his fold,
So He picks a rosebud, before it can grow old.
God knows how much we need them, and so He takes but few,
To make the land of Heaven more beautiful to view.
Believing this is difficult still somehow we must try,
The saddest word mankind knows will always be "good bye".
So when a little child departs, we who are left behind,
Must realize God loves children, Angels are hard to find.

Advice To Parents Who Have To Say Good-bye To Their Cherubs

- Tell your baby that it's ok to go- studies show even newborns seem to die more peacefully when hearing those words.
- Take as many mementos as you can- hand and foot prints, plaster castings of hands and feet, lock of hair, clothing, blankets, ID bracelets, pictures, video, blankets, diapers, etc. Keep fabrics in air tight containers with acid-free tissue paper- years later you can smell your baby's scent.
- Hold your baby even after he/she has gone- we've never had a parent say "I wish I hadn't held my baby after he died". We can't count the parents who've said the opposite.
- Take your time. Rock your baby, hold your baby, sing to your baby.
- All hospitals have chaplains who can perform christenings, even after the baby has gone.
- "Do not allow anyone to rush you. Take as much time as one needs to say good byes. I spent about 45 minutes with Ryan before they let us take him to pathology, which is against hospital rules, but we broke the rule. I regret that I didn't hold him more. Also, this sounded weird to me, but the nurse told me about it the day before Ryan died. She told me we'd unhook all the tubes and wires, bathe him, put baby lotion all over, comb his hair (cut a lock of it too!) dress him, wrap him in a blanket and hold him. Take pictures and say our good-byes and explain why God was taking him from us. That part I couldn't figure out to explain--still can't! I kept all the stuff the hospital used on Ryan--scissors, pacifiers, diapers, his toys, clothes, the sign on his bed. For 29 days, he collected quite a bit of stuff. It's all in an air tight box and known as Ryan's box." Cindy Mohr
- "Continue pumping until after the funeral- hugs can be very painful when you're engorged". Rhonda Montague
- "A homeopathic remedy to dry up breastmilk is to put cold cabbage leaves in your bra and change as they become wilted (strange I know, but it helped, after I quit being stubborn and tried it.) If your cherub passed at birth, or shortly after, your milk will probably come in the day of the funeral. This was the worst day of my life, as I was in so much physical pain, and so numb emotionally. I would even go so far, as to print in the funeral bulletin, "We know how much you want to hug us, but please refrain from hugging the recently delivered mother", or something like that". Amy Rademaker
- I am making a "shadow-box" with Thomas' Mementos. His little hat and socks and bracelets and some cards, ect. are put into a special "frame" which I will hang on a special wall. This way I can Look at Thomas' memories everyday without opening a box, and it is such a nice decor too. I also had one made for my older son Michael, and he enjoys to look at it too." Gabi Frietag
- In our case, it wasn't a sudden at-birth death, but after 3 weeks of intensive care. I would suggest having as many visitors as possible--the more people who actually meet your baby before they leave, the better. Makes them more real, helps affirm they were really here! We celebrated his life with a full on funeral, reception back at our house, etc. These events were important, for us and well as friends and family. Many told me it gave them a chance to really focus on what had happened. It has been good for me to gather everything about Fletcher's short life together. I made an album of sorts and have a huge box for all the cards that came in. Now it's all together to take out and "visit" when I'm in the mood. There are many books on infant loss. I related to some of the material, and not to a lot of it. Same with other infant loss sites/boards on the Web. Something for everyone, I suppose. It was helpful to look around and check everything out. It has helped me to reach out to others who have suffered a similar loss. I'm in a support group with wonderful women who all had late or during labor still births. Mine was the only one "here" for awhile, but it hasn't really made a difference in the way we have connected. But truly, the 2 women I met through Cherubs have been the best relationships of all. We give each other strength and support regularly." Laurie Stusser-McNeil
- Hold your precious baby and tell them everything you want them to know, without holding back. Let them know how much you love them and will miss them forever. Take pictures, so you have them. You may want to see them later. Give them a bath, dress them and then have all families members close to you say goodbye. It is important for everyone to say goodbye. This will always be a cherished, yet painful memory that you will reflect on". Brenda Slavin
- "Take as many pictures and momentos and possible. Make sure that siblings are involved, or that you record things so that future siblings can see what you experienced." Amy Rademaker
- "When my son passed away we opted to do things a bit differently. We released 6 Sesame Street balloons (1 for each year he was here) and 100 red, yellow and blue balloons (1 for each year he should have been here). ". Dawn Torrence
- "We asked for donations to CHERUBS in lieu of flowers". Dawn Torrence
- "I designed and printed the funeral programs myself - I didn't want some sad, impersonal booklet written by a stranger. I wanted it to reflect him. It was bright, had cherubs and Sesame Street characters. Letters to him from me and his dad. A poem written by a friend and member". Dawn Torrence
- "His dad and I both wrote letters to him that were read by his Godparents at the funeral". Dawn Torrence
- "I wish had never touched him in the casket. It took me years to get over that, feeling him cold and hard. I held him after he died and I would have rather had that memory". Dawn Torrence
- "We found a casket with cherubs on it. There are casket discount stores out there (I didn't know this at the time) ". Dawn Torrence
- "I wish we had all worn bright colors instead of black, but I didn't think of that either. His Godmother wore a bright yellow dress and it couldn't have been more appropriate - Shane would've loved it.
- "We buried him with letters from us, his favorite stuffed toy, cars, a Bible". Dawn Torrence
- "His headstone has a cherub logo character on it, Big Bird, Elmo, a truck... symbols that were him.
- "On his headstone there is also a Bible verse that if you look it up, it reads. "He flew on the wings of a cherub, Yeah he did fly like the wind" There wasn't room enough and it was too expensive to have all that letter so it was easier to put the verse and chapter info". Dawn Torrence
- "Shane is buried on my parents property in Virginia - their county had no cemetary laws at the time. We didn't have a family cemetery. Now we do". Dawn Torrence
- "After Gabe passed away in the hospital I couldn't bear the thought of planning his funeral, it was all too much for me and my husband and his parents did most of the work for me so there wasn't a whole lot of unique things about the funeral, but it was nice to have. We buried him with pictures of all of us and some toys." Corin Nava

- “After spending so much money in the hospital and not working the cost of the funeral alone was going to be an added stress we couldn't deal with. Fortunately a local funeral home did everything free of charge. There are some funeral homes who will wave their costs and fees for infant funerals as a way to give back to the community. It allowed us to have a proper funeral for our son.” Corin Nava
- "I also would've liked a list of poses for our pictures. I did get alot of pics in our 6 days but there are some I just never thought of doing. Looking back, I wish I had laid down next to him and got a pic but it is too late now. That would've been nice to have...a list of different poses, regardless if baby makes it or not. Also would've been nice to know how important dressing him after he passed was...I didn't and now wish I had. I wish I stayed back and did the hand and footprint but I didn't. I wish I had someone taking pics of all these things but I didn't. I was in shock. My world had ended and I just didn't know..." Theresa Wellman
- “In the state of Michigan, you can actually take a deceased baby home for up to 30 days, but it must be properly buried after that time”. Amy Rademaker
- “Once we got home from the hospital after losing our daughter, we had family members taking care of the funeral. One thing that never enters your mind is what is will mom where to the service. I remember family and friends asking me what would you like to where. Honest 1st thing on my mine was like.. " are you nuts! " I know now they where being very kind and thoughtful. It's just so much is coming at you so fast while you are still in a total state of shock and numbness. The other part is that I had had an emergency
  c-section and then had to be driven home over 4 hours away so I was very swollen. It takes some time for your body to get back to normal after the C-section. Anyway, where I'm getting at is that maybe you can add something in the reference guide for grieving parents to have someone help the mom have or pick out something to wear to the funeral. That alone can become such an overwhelming task.” Freedom Green
- “Now I Lay Me Down To Sleep organization taking photos and something that I wish I would have thought of was to bring a outfit with me for the baby everytime I was there" Kim Richards
- "One thing the nurse did for my husband since I was not able to see our daughter for so long was she let him cut locks of her hair. She has so many wonderful curls. I would of never in a million years thought of this. I'm so happy we did this. My husband later gave me a wonderful locket that I keep her hair in with a tiny pink bow tied to it and in the other side a picture of her. I love, love, love, love this." Freedom Green
- "Ask the hospital to give you all his/ her stuff that they used while in NICU. It will be hard at first to deal with but later on you will be so happy you have all of these items. Like the little beds they have the babies sleeping in”. Freedom Green
- “The hospital we stayed at allowed us to give our daughter her 1st bath and diaper change after she had passed. We then dressed her and wrapped her up in a blanket that was given to us as a gift. We where allowed to rock her and hold her for as long as we needed. They gave us a private spot to do so in the NICU. All family from both sides was aloud to spend time with her. They also allowed my mom to bring her up to my room one time before they took her away. I will never forget that moment”. Freedom Green
- “One thing we did when Joel left us was to have him come home the night before his funeral. It raised lots of eyebrows here from older family members but we felt it was important for Joel to spend sometime here.The coffin was closed. My other children ranging from 2- 18 at the time said they thought it was a wonderful thing to do. It also meant that seeing his coffin wasn't a shock to them on the funeral day. Its lovely knowing that he came home and spent a night here. The children (and David and I) all wrote letters to put in his coffin too and the children also all gave something that was special to them too”. Debbie Blakeley
- “Send out birth announcements, I found a saying in a book and modified it to my liking. …I had a regular birth announcement company do the printing etc”. Amy Rademaker

Information on Now I Lay Me Down To Sleep