

# CDH Parent Reference Guide

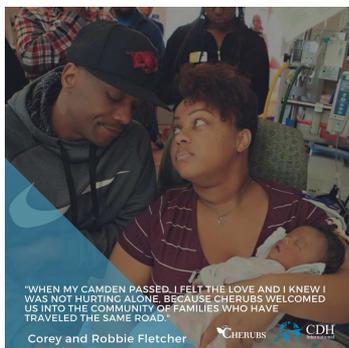
The handbook to understanding Congenital Diaphragmatic Hernia  
2020 Edition



**CDH**  
International

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# WELCOME TO THE UNEXPECTED

## CDH APP

CONGENITAL  
DIAPHRAGMATIC  
HERNIA INFO  
AT YOUR  
FINGERTIPS

CDH  
INTERNATIONAL  
IN THE  
APPLE AND  
GOOGLE PLAY  
STORES



"Each baby has their own story to tell... our job is to help them share that story." - Heidi Forney, mom of Sean

"Every CDH baby is unique and no textbook can tell us what they can or can't do."

- Nicki Young, mom of Anderson

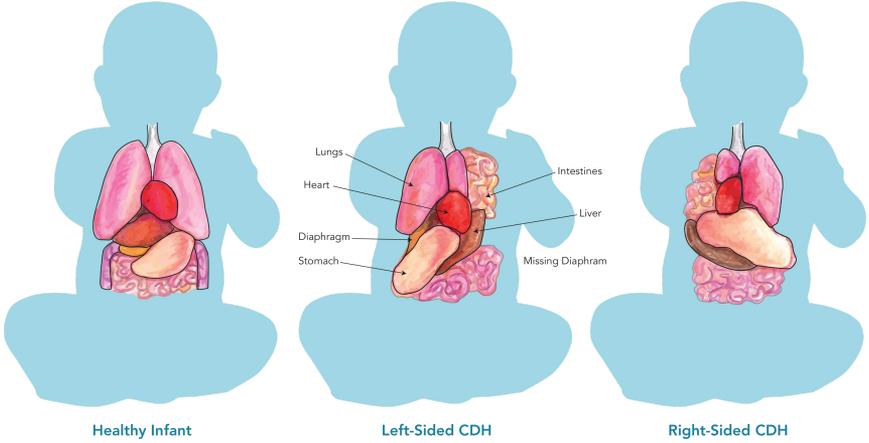
"When all you can do, has already been done, rest in the arms of God." - Julie King, mom of Caroline

"EXPECT THE UNEXPECTED. CDH IS A ROLLERCOASTER RIDE THAT NEVER ENDS"  
- TARA HALL, MOM OF BRANDON

"You made the best decisions you could, with the information you had, at the time you made them." - Karen Myers, mom of Kaleigh



# Congenital Diaphragmatic Hernia



## What is CDH?

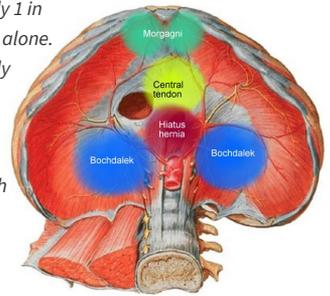
CDH stands for Congenital Diaphragmatic Hernia, which is a birth defect that occurs when a baby's diaphragm (a thin sheet of muscle that separates the abdomen from the chest) fails to fully form, allowing abdominal organs to enter the chest cavity and prevent lung growth. CDH occurs in approximately 1 in 2500 births, with over 1600 babies diagnosed each year in the United States alone. There is currently no known cause, but studies have suggested that it is likely due to a number of genetic and environmental factors.

The diaphragm typically forms during the first eight weeks of pregnancy. In CDH patients, the size of the hole in the diaphragm will determine how much a baby's lungs, heart, and other internal organs will be affected.

There are two different types of CDH: left-sided and right-sided (Bochdalek), and bi-lateral (Morgagni). Left-sided CDH is by far the most common, and may affect the small and large bowel, stomach, spleen, and liver. Right-sided hernias typically only affect the large bowel and/or liver. Bi-lateral CDH affects both sides of the diaphragm and is quite uncommon (2%).

Approximately 40% of CDH cases are associated with other birth defects, most commonly of the heart. These are often difficult to diagnose and confirm until after the baby is born. A diagnosis of CDH also typically occurs alongside various degrees of lung hypoplasia and pulmonary hypertension.

The prognosis for babies diagnosed with CDH remains statistically at 50%. Unfortunately, there is no reliable indicator to predict the outlook of each case. Sometimes, babies with no diaphragm and very small lungs can fare very well, while sometimes babies with two full lungs may not survive. A measurement called head-to-lung ratio is sometimes used to determine whether to intervene prenatally through in-utero treatments, but it does not indicate a true survival rate. Lung function is also not a viable indicator since many other factors determine the health of CDH children, such as kidney function, brain function, other birth defects, and other possible complications. Every baby with CDH is different - like a snowflake, no two are alike.





# I NEED ANSWERS

## WHAT CAUSED THIS?

*Though there is no known cause for CDH, it has been associated with several genetic anomalies such as Fryns Syndrome, Cornelia deLange Syndrome, and Trisomy 18, 21, and 22. Excessive Vitamin-A and deficiency is known to cause CDH in lab rats. It has also been suggested in some medical journals (but not definitively proven) that thalidomide, quinine, phenmetrazine, and nitrofen may also cause CDH.*

## WILL ALL MY CHILDREN HAVE THIS?

*Without a family history of CDH or known genetic abnormalities in a baby's DNA, the chances are roughly 2%. We encourage all of our members to seek a genetic counselor to discuss your odds of having another CDH baby.*

## WILL MY CHILD HAVE LONG TERM HEALTH COMPLICATIONS?

*That is a difficult question to answer. If your child has accompanying genetic anomalies the chances of having long term complications increases. If your child only has CDH there can be many outcomes. Every case is different and every child will face unique circumstances. However, the most common issues experienced by CDH patients are asthma, scoliosis, acid reflux, developmental delays, longer hospital stays, feeding aversions or other feeding issues, and physical scars. There may be other problems your child faces and it is best to continue to follow up with your pediatrician to monitor any other issues that may arise. Trust your parental intuition and ask your doctors if you have concerns.*



# Welcome to Holland

by Emily Perl Kingsley

I am often asked to describe the experience of raising a child with a disability – to try to help people 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 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.

# What to Expect During Pregnancy



CDH is typically diagnosed during a routine ultrasound. Once your baby is diagnosed with CDH, you can expect to be more closely monitored throughout the remainder of your pregnancy. Below are some of the things you may expect:

- A referral to maternal-fetal specialists for further care and evaluation of the pregnancy and your baby's development, which will likely include additional appointments and tests.
- More detailed ultrasounds to examine the defect, a fetal MRI to evaluate your baby's defect, determine which organs are in the chest cavity, and to obtain the size and volume of the baby's lungs, and a fetal echocardiogram to check the baby's heart function and structure.
- Genetic testing and/or an amniocentesis to check for chromosomal abnormalities as CDH can sometimes be associated with other syndromes.
- Several measurements will likely be taken to best anticipate the baby's condition: lung-to-head ratio (LHR), liver position, total lung volume, and the response of the lungs to oxygen.
- The opportunity to meet with the medical team who will be caring for you and your baby, which may include a pediatric surgeon, a geneticist, a radiologist, neonatologist and a fetal medicine specialist.
- Your pregnancy should progress normally from a physical and general health point of view. There is a small chance that you could develop polyhydramnios during your pregnancy, which is an increase in amniotic fluid around the baby. If this occurs, your condition will be monitored closely by your doctor. Depending on the severity, interventions such as medication or drainage of excess fluid may be taken to reduce the chance that complications will occur.

An experimental in-utero procedure called FETO (Fetal Endoscopic Tracheal Occlusion) may be offered in very severe cases of CDH. This involves the placement of a balloon in your baby's airway, which allows fluid to build and the lungs to grow. Your doctor will be able to give you more information about this procedure, including whether or not your baby meets the eligibility criteria.

## Detailed Birth Plan

You and your doctor will create a detailed birth plan based on the severity of your baby's CDH. The level of care provided at the time of delivery can be critical to a baby's outcome. It is essential that delivery of a CDH baby occurs in a hospital that is well prepared to handle the intensive care of a CDH baby. The delivery day will be scheduled in advance in most cases and will likely occur via C-section or induction. All required NICU staff, doctors, and any additional personnel will plan on being present for the birth. Your doctor will be able to detail what you can expect on the delivery day and what options you'll have for pain relief, if desired. Your baby may decide to come before your planned date or due date. If this was to happen, go to the nearest hospital as soon as possible and they will help arrange for a transfer to your hospital of choice or they will deliver the baby and then transfer your baby to a hospital equipped in caring for a CDH baby. Transfers could take place by ambulance, helicopter or airplane.



# 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."



# Questions to Ask Your Doctor

- What is the average length of stay for a CDH baby in your facility?
- How many CDH patients does your medical team treat in a year?
- How many babies does your medical team actually operate on yearly (vs. the number that don't survive until surgery)?
- What is the survival rate for CDH babies at your hospital?
- How many CDH babies end up on ECMO?
- How long does the surgeon like to wait until surgery? If the baby is on ECMO, will the surgeons do surgery while baby is on ECMO or will they wait until baby comes off ECMO?
- Is the Exit to ECMO procedure an option in a severe CDH case?
- What do you use to determine when a patient goes on ECMO? How long can a baby remain on ECMO and can they go back on once they are off?
- What is your survival rate of babies who required ECMO?
- If my child needs ECMO, will he/she stay in the NICU or have to go elsewhere?
- How does the surgeon perform the CDH repair surgery? Procedures used? If a doctor performs the surgery using the scope and a smaller incision, what is the chance of reherniation?
- What type of material is typically used in the surgical repair of the diaphragm hole?
- What is your re-herniation rate? If a patch was used during the repair, will that ever have to be replaced?
- What is the hospital's infection rate in the NICU?
- What is the hospital's rate of medical mistakes/errors in the NICU?
- What is the hospital's stand on allowing breast milk if you want to use it in feeding your baby?
- Will the hospital allow my other children to visit baby in the NICU?
- How do the surgeon(s), fellows, neonatologists, specialists, nurses, etc., work? Is it a team approach? Are there shifting attending surgeons or is there one surgeon in charge per case?
- Can I tour the hospital before my child is born?
- Can I meet the team(s) who will be caring for my child/tour the NICU?
- How will I as a parent be able to communicate to the doctors once my baby is in the NICU and get answers to questions or concerns?
- Will my baby have to be transferred for care or will they receive NICU care at this facility?
- What will happen on the delivery day, will my pregnancy be induced or will a C-section be planned? Will I be able to deliver vaginally?
- What is the doctor's guidelines for deciding that comfort care should be given in lieu of stabilization? How will you work with us as parents if we don't agree with the decisions being made?
- What is the medical team's approach with feeding issues and discharge? Will my child be able to go home with an NG tube or G-Tube? What can be done in cases of severe reflux?
- What type of follow-up program is provided to CDH babies once they leave the hospital?
- Does your hospital participate in any type of CDH research?
- What type of facilities and support do you offer moms who want to pump breast milk and store it?
- What is the hospital and/or doctors readmission rate for CDH patients within 30 days of discharge?
- Add your additional questions below:



# Hospital Checklist

1. Journal\*
2. Paper, pens, and pencils
3. Cell phone, phone charger, and address book
4. Hand sanitizer\*
5. Hand lotion\*
6. Baby socks (for hands to leave IVs alone)\*
7. Healthy snacks
8. Water bottle and juices - especially for moms that are planning to breastfeed
9. Tylenol or other non-aspirin, over-the-counter pain killers
10. Camera and battery charger
11. Disposable camera to be left at bedside for staff to use
12. Books, magazines, ipad, etc... things to help pass time
13. Extra change of clothes for emergencies
14. Personal items such as makeup, hairbrush, nursing pads, and hygiene products
15. Recordings of parents and family members singing or reading to the baby
16. Stuffed animal or toy for the baby (check hospital rules first)\*
17. Portable breast pump if you plan to nurse (ask the hospital if they supply pumps)
18. Photo ID, insurance information, hospital forms (if required)
19. Chapstick / lip balm\*
20. Nonskid socks / slippers and a comfy pair of shoes
21. Comfortable discharge home clothes
22. Maternity bras and nursing pads (if not nursing, these are good for support and leakage)
23. CDH Parent Reference Guide\*
24. CDH Baby Book\*
25. Small, magnetic dry erase board to leave notes to staff
26. Newborn outfit\* and blanket\* - just in case you were to have to say goodbye, you could dress your baby and wrap them in a blanket from home

\* Items included in the CDH HOPE Totebag

..... *Your Notes Here:* .....



# What to Expect After Birth

## Stabilization

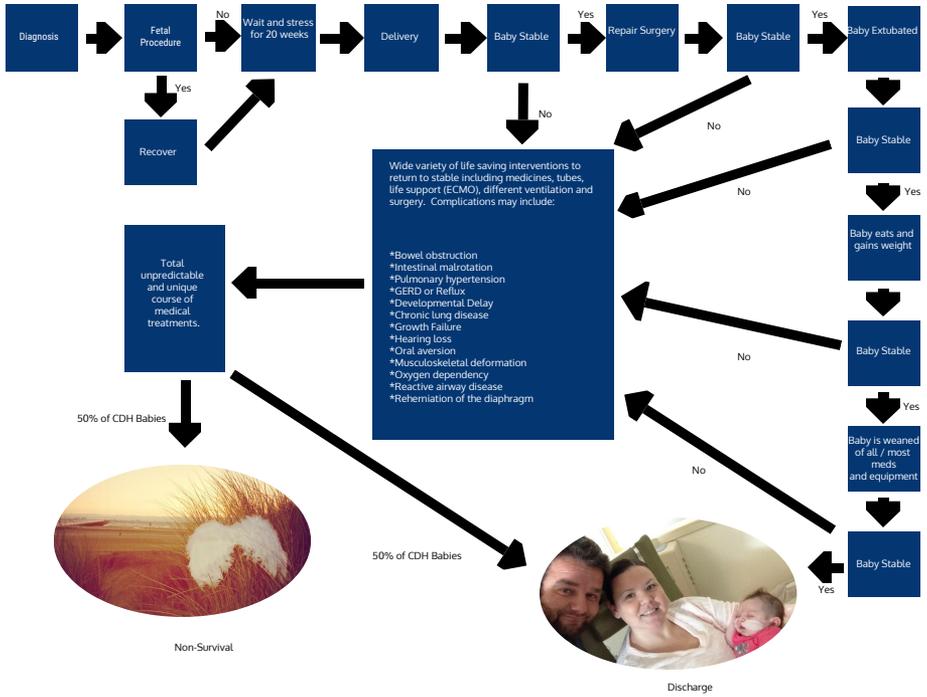
The first 24 hours in the NICU will be a critical time for your baby as the doctors and nurses work to keep him/her stabilized. Your baby will be intubated immediately. Doctors prefer the baby not cry and use their underdeveloped lungs. Some parents may quickly get to hold their baby, but the majority of parents will not get to hold their baby until days, weeks, or months later. This is where your baby will undergo blood tests, X-rays, and be put on any additional equipment for ventilation or life support. There are different ventilation and treatment methods that may be used depending on your baby's condition. Some of these are:

- Mechanical Ventilation: A breathing machine that takes some of the stress off your baby's lungs. This is sometimes called "conventional ventilation."
- Gentle Ventilation: Patient-initiated settings on a conventional ventilator that can cause less lung damage.
- HVOF (High-Frequency Oscillation Ventilation): A gentler form of ventilation that is less likely to damage residual lung tissue .
- Nitric Oxide: An inhaled treatment that assists in the treatment of respiratory failure.
- ECMO (Extracorporeal Membrane Oxygenation): A lung-heart bypass machine for patients failing on ventilation.

Because the dedicated stabilization period may vary, it may be a few hours before you get to see your baby. Most hospitals allow a family member to follow the baby, they just need to ask. This can be distressing, but rest assured that this is in your baby's best interest and you will be allowed to see your baby as soon as possible.



# CDH Flow Chart



..... *Your Notes Here:* .....



# The Repair

Once the doctors feel that your baby is fully stabilized, he/she will undergo surgery to repair the hernia. There is no set time table for this and it varies from patient to patient.

The repair procedure is typically fairly straightforward. The surgeon will make an incision in the baby's abdomen on the side of the hernia, move any abdominal contents back to their proper locations, and repair the hole in the diaphragm.

The surgeon will decide based on the size of the hernia whether to stitch the hole closed or to use a patch to repair the hole. The most commonly used material for these patches is called Gore-tex®, which is made from a specialty biomaterial designed for soft tissue repairs. The baby's own muscle tissue may also be taken from another area to be used to repair the hole. The surgeon should also be able to correct any other problems he/she finds during this repair surgery.

Your baby will be returned to the NICU to be closely monitored while recovering from the operation, and you will be fully informed of the how the operation went and if there were any complications. In some cases, a baby's surgery may take place in the NICU. If a baby is hooked up to ECMO or is too fragile to move, surgery will take place in the NICU and not in an OR.

It is not uncommon for babies to deteriorate after repair surgery, doctors will closely monitor your baby for complications.



# The Hospital Stay

## Dealing with Hospital Staff

On top of dealing with a relatively unknown birth defect in your child, many parents may feel uneducated and intimidated around medical professionals. You do not need to feel this way—do not be afraid to speak up and ask questions. You have a right to know everything about your child's care, from choosing doctors to seeing medical records.

Although times are hard, remember that staff members are also people. Treat them with the same respect you expect to be given—parents who remain calm without losing their tempers earn more respect than demanding, overly-aggressive parents. Educate yourself on medical terminology and your child's diagnosis. It will improve your child's care and your relationship with his/her caregivers.

Most hospitals assign "primary nurses" to patients. These are nurses who agree to tend to your baby every time they are on shift. Get to know your primary nurses, for they will advocate for your baby, cheer on your baby, and get to know your baby very well during their NICU stay.

NICU life is stressful, social workers will often be assigned to your child's case. They are very knowledgeable in resources you may need with having a child in the NICU. They can help answer questions, gather a care conference with your medical team if needed at anytime, and help find you resources during and after a NICU stay.

*"Respect and courtesy go a long way! But don't be afraid to speak up if there are concerns, sometimes staff mess up, aren't taking proper care, and if you see something that worries you, don't be afraid to ask about it. If necessary, go to the charge nurse for further explanation or assistance."* - Heidi Forney, mom of Sean

## Dealing with Family Members and Friends

You may find that many of your family members and friends will be uncomfortable with your situation. Some may unintentionally minimize the severity of CDH. This does not mean that they do not care, they simply have a hard time understanding what you are going through. Some may distance themselves, while others may practically smother you. Some may cry, some may make jokes, and 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 trusted person as a "go-between" for all other family members and friends. This way you only have to update one person, and you will spend less time explaining and updating everyone separately. With technology, many parents chose to create a blog, Facebook page or group, or CaringBridge site to share updates with family and friends.

## Dealing with Physical Changes in Your Child

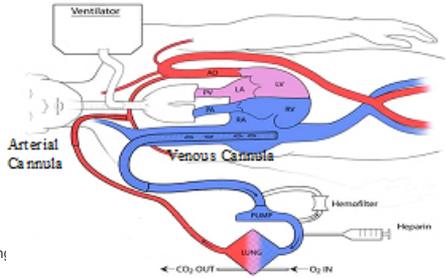
It may be difficult to accept the physical changes that your child will go through. After surgery, swelling is exceptionally hard for many parents to deal with, but your child will return to his/her normal size and the swelling will dissipate without leaving behind stretch marks. The bandages from surgeries will eventually disappear, along with the IVs and other tubes. 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 to.



# ECMO

## ECMO stands for ExtraCorporeal Membrane Oxygenation.

You may also hear it called ECLS, which stands for ExtraCorporeal Life Support. It is a treatment that uses a man-made heart and lung to support the body when a person's own organs are too sick to do the job. ECMO may support the body for a long period of time (days to weeks) to allow the heart and/or lungs time to rest. Although ECMO itself will not cure your loved one, it gives him or her the time needed to heal. ECMO may be an option only after the care team has tried all other treatments such as a breathing machine (called a ventilator or "vent"), medicines to support the heart and lungs, and/or special gases to relax the blood vessels between the heart and the lung.



## How Does ECMO Work?

Similar to the machine used in open-heart surgery, ECMO uses a pump to take over the work of the heart and an oxygenator (artificial lung) to take over the work of the lungs. First, one or two cannulas (large tubes placed in arteries or veins) are placed in the patient's neck and/or groin(s). Based on the patient's illness, the ECMO team will decide what type of ECMO to use, the number of cannulas needed, and where they will be placed. The cannulas are like really large IV's that allow blood to be taken out of the body and pushed through the ECMO circuit (tubing). Once the blood leaves the body and enters the ECMO tubing, it is pumped through an oxygenator, or artificial "lung," where oxygen (good air) is added to the blood and carbon dioxide (bad/waste air) is removed. The treated blood is then warmed before returning to the patient's body.

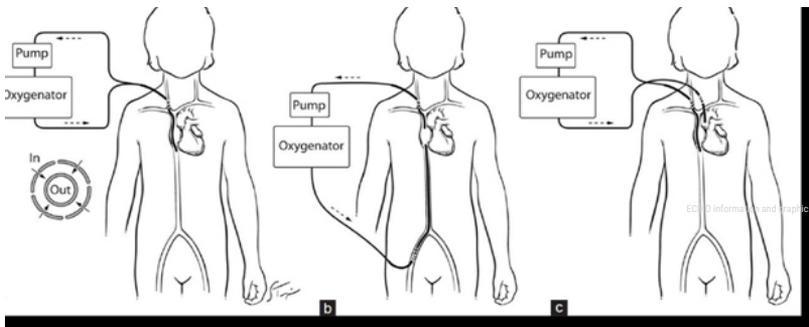
This diagram shows a typical ECMO circuit with blue (without oxygen) blood becoming red (oxygenated) by the artificial lung outside the body. The Pump provides the power to move the blood around. The hemofilter can act as an artificial kidney, and heparin is the drug that helps keep the blood from clotting when it's outside the body.

## Types of ECMO

There are two types of ECMO. Venoarterial (VA) ECMO can be used for heart and lung support, while venovenous (VV) ECMO is used for lung support only. The ECMO team will decide which type will help your loved one the most, based on his or her specific illness.

**Venoarterial (VA) ECMO** provides support for the patient's heart and lungs by allowing most of a patient's blood to move through the circuit without going through the patient's heart. This type of ECMO takes blood out of a large vein and returns it into a large artery, allowing oxygen-rich blood to circulate through the body even if the heart is too weak to pump it. Therefore, two cannulas must be placed in either the neck or the groin(s).

**Venovenous (VV) ECMO** provides lung support only, so the patient's heart must still function well enough to meet the body's needs. Two cannulas are placed into veins in spots close to or inside the heart. With VV ECMO, the surgeon cannulating physician has an option of using a special type of cannula with two lumens (pathways inside the tubing). This allows for blood to leave and return to the body in one place, creating the need for only one entry site instead of two. Blood from the ECMO system returns to the body before the heart, and the patient's own heart pumps the blood throughout the body.



- VV ECMO using special double-lumen cannula
- VV ECMO using two regular cannulas
- VA ECMO

ECMO Information and Graphics provided by:



# CHERUBS

## Why CHERUBS Was Founded

- To help parents understand what's happening to their child by cutting through all the medical jargon that so many doctors use.
- To let parents know that they are not alone and that there are other people who know exactly what they are going through and how they feel.
- To advocate for pre-natal diagnosis of CDH and National Birth Defects Monitoring.
- To provide support in a time of need, through our many services or just by lending an ear.
- To help prevent complications by informing parents of potential problems and side-effects.
- To help doctors better communicate with the parents of their patients.
- To encourage awareness for a birth defect that receives little research funding and virtually no media attention.

CHERUBS was founded in 1995 by Dawn Torrence Ireland, mother of Shane Torrence. Shane was born in 1993 with left-sided CDH and multiple other birth defects. "When my son was born, I was ignorant of the medical world and the terms that his doctors used. I wished someone had explained things to me and emotionally supported me the way that only a parent with experience and hindsight can do. Though I met many parents of children born with CDH and other problems, and made quite a few dear friends, none of us understood everything or could offer each other advice on what to expect. I vowed that if, and when, our lives reached some degree of normalcy, I would help other parents. That's what CHERUBS is all about."

CHERUBS is an international organization for families and care-givers of children who are born with Congenital Diaphragmatic Hernia (CDH). Our membership includes over 6000 families in all 50 states and over 70 countries. Medical professionals may also join our membership, and many have joined. We are an IRS recognized 501(c)(3) Non-Profit Organization. We do not charge parents membership fees, though we do ask for an annual \$20.00 donation, if affordable. Donations are very much needed and appreciated; and are also tax-deductible. You can make your check or money order out to: CDH International.

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. Please feel free to share our materials with doctors and other families.



# CHERUBS Q&A

## **How is CHERUBS different from CDH International?**

CHERUBS is the patient support department of CDH International. There are also departments for Research and Awareness. Because CHERUBS was the original name of the charity in 1995 and was founded for patient and family support, the name and the charity's history is still honored by that department.

## **How do I join CHERUBS?**

You can join by joining our forums at <http://www.cdhboards.org>

## **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, please consider donating or joining the Angel Club to help us continue to support families.

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

You can 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 to [cpab@cherubs.org](mailto:cpab@cherubs.org). 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 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 CDH International has 501(c)(3) status under the United States IRS. Donations in Italy and the UK will be tax-deductible by 2020 and Canada by 2021.

## **Where does my donation go?**

All donations go to directly help the cause. CDH International has a 6% overhead so 94 cents of every dollar goes to research, awareness projects, totebags, events and family services. We are fully transparent and our 990 tax forms and independent audits are posted annually at [Guidestar.com](http://Guidestar.com), where we are a 5-star charity. We also publish annual Financial Reports so you can see closely where funding goes. If you would like your donation to go to a specific fund (research, awareness, support, financial assistance or scholarship), you can allocate that money by check memo or note.

## **Can I help?**

We always love new volunteers! If you would like to volunteer, please contact us at [volunteer@cherubs.org](mailto:volunteer@cherubs.org).

## **Is CHERUBS Online?**

Yes, we have been online since 1997 and offer many different online services such as Facebook pages and groups, forums, listservs, message boards, chatrooms, and much more. Our website address is [www.cherubs.org](http://www.cherubs.org). Our Facebook page is <https://www.facebook.com/cdhsupport/>.

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

CHERUBS / CDH International 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 is the CDH Patient Registry?**

The CDH Patient Registry is the patient history survey now online. All families of non-survivors and families of survivors over one year of age can participate. Your information is completely confidential and HIPAA compliant. De-identified data (with your permission) is shared with other researchers to help find the cause, prevention, and best treatments for CDH. 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, we can offer that information to the research community and push help for these children farther, faster.



# CDH Research Studies

The following hospitals and organizations are currently conducting CDH research studies.

Each has their own set of guidelines. Some studies include blood work on all family members, some include oral swabs. Some studies also include grieving families. There is no cost to families to participate in research studies. We encourage members to participate in as much research as possible so that we can help save babies of the future and their families from suffering from Congenital Diaphragmatic Hernia.

## Identifying Genes Which Cause CDH

Massachusetts General Hospital  
Boston, Massachusetts  
Patricia K. Donahoe, MD, Program Project Director  
Marshall K. Bartlett Professor of Surgery, Harvard Medical School  
Mauro Longoni, MD, Principal Investigator  
Frances High, MD, PhD, Principal Investigator  
Jennifer Lyu, MS - Program Coordinator  
617-355-8780  
CDHResearchStudy@childrens.harvard.edu  
Boston Children's Hospital  
300 Longwood Ave, Fegan 3 (CDH mailbox)  
Boston, MA 02115

Genetic Molecular Basis of CDH

## DHREAMS Study

Columbia University Medical Center  
1150 St. Nicholas Avenue  
New York, NY 10032  
212-305-6987  
info@cdhgenetics.com

## University of Utah

Diaphragm: Development, CDH, and Evolution  
Department of Human Genetics  
University of Utah  
15 North 2030 East  
Salt Lake City, UT 84112  
Contact: Gabrielle Kardon  
801-585-6184 office  
801-585-7365 lab  
gkardon@genetics.utah.edu  
http://www.kardonlab.org/

## RESPIRE program

Stem cell therapy for CDH lungs  
The Hospital for Sick Children  
Zani laboratories - Developmental & Stem Cell Biology (DSCB)  
Peter Gilgan Centre for Research and Learning  
686 Bay Street, Toronto, ON M5G 0A4, Canada

## International CDH Patient Registry

CDH International  
Wake Forest, North Carolina  
www.cdhrefsearch.org  
Full patient information and family history, long term development and complications. A comprehensive look at Congenital Diaphragmatic Hernia, the registry collaborates with other registries and universities to better research CDH.

## CDH Study Group

University of Texas, Houston  
This study is the collection and collaboration of CDH hospitals and physicians. We encourage you to encourage your hospital to participate



# Services Offered by CHERUBS

- Our Forums – free source of 24 hours a day/7 days a week support in talking to 100s of other CDH families in a safe, supportive, confidential environment
- Our Website – stories of our members, photo albums, member blogs, message boards, chat rooms, medical research, information, and much more
- CDH HOPE Totebags – care packages offered to new and expectant CDH babies
- Parent Reference Guide – our guide for new and expectant parents
- CDH Baby Book – customized for babies born with CDH
- Local Get-Togethers – held by State and International Representatives across the country
- Annual CDH Conference – guest speakers, round table discussions, information and support
- Save the Cherubs – our international CDH awareness campaign
- Newsletters – stories of cherubs, medical updates, and updates on our newest projects
- Social Media – CHERUBS supports families through Facebook, Twitter, Instagram, Pinterest, Google+, MySpace, and other social media sites
- Free Blogs and Photo Albums – included in your membership on our forums
- Free Customized CDH Awareness Ribbons – with your cherub's name on them
- CDH Patient Registry – our way of helping to find the cause of CDH through comparing similarities and "coincidences" among our members by conducting a Natural History Survey of CDH.
- Ambassadors – parents ready and willing to lend an ear when you need it most



## 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%.



# Questions and Facts About CDH

## 1. How did this happen?

CDH is caused by the diaphragm not closing or forming at around eight weeks gestation. Organs that should have been in the abdominal cavity then float freely into the chest cavity, taking up valuable lung space. Why this 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 anomalies. Studies also show that certain environmental factors might cause CDH; such as exposure to chemicals like Nitrofen or pesticides, imbalanced Vitamin A and Folic Acid. We conduct our CDH Patient Registry to help study these common factors so that maybe some day other babies will be spared from this birth defect.

## 3. What did I do?

Unless you took a bath in pesticides or helped clean up a toxic waste site, there is nothing that you could have done to cause this. We can't blame ourselves for not preventing something that does not have a known cause.

## 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 from happening.

## 5. How often does this happen?

CDH occurs in about 1 in every 2500 babies- this is more common than being struck by lightning.

## 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/her 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 of occurrence in another child 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.

## 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. 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.

## 12. What would life have been like if he / she had survived?

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 delays, and a few have more severe problems.



**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 and a good diet are the best things you could do for your baby.

**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.

..... *Your Notes Here:* .....



# 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 and move on," and other clichés 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.
- Babies with compromised lungs, such as CDH patients, are very susceptible to viruses. Parents are encouraged to isolate their children during cold and flu season. Please respect this.
- Please keep away from these children, their parents and siblings, and the hospital if you are showing any signs of illness (rashes, aches, fevers, sore throats, coughs, wheezing, etc.).



# Sources of Financial Help

**CDH International** – When funds are available, we can award financial grants to families who are in financial turmoil to help cover travel expenses to and from the hospital.

**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, synagogue, temple, or other house of worship can provide religious support and possibly offer some financial assistance.

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



## Chronic Sorrow Grief Process

Though different, both families of survivors and non-survivors grieve for the child and life they dreamt for and that is perfectly normal.

### Stages

Shock  
Denial  
Sadness, Anger, Anxiety  
Adaption  
Reorganization

### Feelings

Numb / Immobile  
Helpless / Flight  
Self Pity / Aggression / Confusion  
How will we survive?  
Here's how we'll survive!



# Medical Terms Glossary

**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.

**Agensis** – Absence.

**Agensis of the Diaphragm** – Complete absence of the diaphragm.

**Amniocentesis** – A medical procedure performed on pregnant women to 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 to remove amniotic fluid for testing.

**Analgesic** – Commonly called "painkillers," medications that relieve pain and discomfort (Tylenol, Acetaminophen, Aspirin, Tegretol, etc.).

**Artery** – A blood vessel that carries blood from the heart to the body's organs.

**Artificial Placenta** – A procedure that removes the baby from the uterus in the second trimester, repairs her hernia and then places the baby in an artificial womb for the duration of gestation. The baby is then delivered by "artificial C-Section" from the container. Human trials were not available yet as of early 2019.

**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 a patient's blood, 100% is ideal for a healthy person.

**Blood Transfusion** – Carefully screened blood given to a patient to replace blood lost during a surgical procedure.

**Bochdalek Hernia (Foramen of Bochdalek)** – An opening through the left diaphragm between the chest cavity and abdominal cavity toward the back of the body. This is the most common form of diaphragmatic hernia and is sometimes called Posterolateral CDH.

**Bradycardia** – Abnormally low heart rate.

**Broviac** – A more permanent type of IV 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.

**Central Line** – A more permanent type of IV, surgically placed in an artery or vein, yet less invasive 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 bedside.

**Cherub** – A term of endearment for a patient diagnosed with CDH.

**Chest PT** – 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 screen 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 to increase the amount of urination to avoid or decrease large amounts of fluid build-up or swelling. Patients may need extra potassium chloride while on diuretics (Edecrine, Diurel, Lasix, Spirolactone, Hydrochlorothiazide etc.).

**DNR (Do Not Resuscitate)** – An 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 him or her die naturally.



**ECMO (Extracorporeal Membrane Oxygenation)** – A very large and complex machine that takes over the work of the patient's heart and lungs. A large catheter is placed in an artery in the patient's neck to remove blood, which is then oxygenated and returned to the patient.

**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 (ET 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.

**Extubation** – Removal of a tube which has been placed through the nose or mouth into the trachea.

**FETO (Fetoscopic Endoluminal Tracheal Occlusion)** – A balloon will be placed in your unborn baby's airway. The balloon blocks the baby's airway and remains in place for a few weeks. Fluid builds and the lungs grow. Bigger lungs may improve survival. Several weeks later, the balloon will be removed from your unborn baby's airway in order for her lungs to mature.

**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.

**Foley Catheter** – A plastic tube inserted into a patient's urethra to aid in urination and taking clean urine cultures.

**G-Tube (gastrostomy tube)** – A tube inserted through the abdomen that delivers nutrition directly to the stomach. It's one of the ways doctors can make sure kids with trouble eating get the fluid and calories they need to grow.

**Gastrointestinal Reflux** – An illness that occurs when stomach contents move up 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).

**Gavage Feedings** – Feedings delivered by a small plastic tube placed through the nose or mouth and down into the stomach when the baby is too weak or too premature to suck and swallow.

**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. This informs parents of their risks of fetal abnormalities in present or future pregnancies and is advised for older couples or those who have family histories of birth defects or chromosomal abnormalities.

**Geneticist** – A specialist in the study of genetic abnormalities and birth defects.

**Grams (g)** – 454 grams = 1 pound.

**HFV (high-frequency ventilator)** – A machine that gives hundreds of tiny breaths per minute. Oscillating and jet ventilators are examples of high-frequency ventilators.

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

**IMV (intermittent mandatory ventilation)** – A way to help babies breathe using a ventilator to give a set number of breaths per minute.

**Intubation** – Placing an endotracheal tube in the baby's trachea (windpipe). See Endotracheal Tube.

**In-Utero Repair** – A procedure in which the diaphragm is repaired while the mother is still pregnant.

**IV Catheter** – A tiny flexible, hollow plastic tube inserted into a vein over a needle. The needle comes out and the catheter stays in.

**IV Pump** – A machine used to give IV fluids.

**Kilogram (kg)** – 1kg = 2.2 pounds.

**LHR (The Lung-To-Head-Ratio)** - A numeric estimate of the size of the fetal lungs, based on measurement of the amount of visible lung. High LHR values greater than 1.0 are associated with better outcomes in medical research but each patient is different and other variables come into play.

**Lung Hypoplasia** – Failure of one or both lungs to develop fully.

**Mechanical Ventilator** – A machine that helps your baby breathe or breathes for him when he's not breathing on his own. It works by pushing warm air and oxygen into the lungs through a breathing tube called an endotracheal tube. The provider sets the amount of oxygen.

**Morgagni Hernia** - Anteriomedial (middle back) type of CDH, occurs in 2% of cases

**Nitric Oxide** - inhaled gas that allows the lungs to expand. Often a step before ECMO.

**Physical Therapist** – An individual who helps patients recover muscle tone lost during their illnesses.



**Pneumonia** – An illness caused by bacteria, fungi, or virus that causes fluid buildup in the patient’s lungs.

**Polyhydramnios** – Excess amount of amniotic fluid, which is usually an indicator of possible fetal problems or abnormalities.

**Pulmonary Hypertension** - A type of high blood pressure that affects the arteries in the lungs and the right side of the heart.

**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 Therapist** – Trained individual who assists in the operation of ventilators and performs procedures which aid a patient’s breathing and oxygen intake.

**Room Air** – A term used to describe that a patient is breathing the same amount of oxygen that normal, healthy people 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.

**SVT** – supraventricular tachacardia (high heart rate).

**TPN and Lipids** – High-calorie IV fluids used for long-term nutrition.

**Tracheal Ligation/Occlusion** – An in-utero procedure that clamps off the baby’s trachea, causing the lungs to grow and pushing the organs back into the abdominal cavity.

..... *Your Notes Here:* .....



# Normal Lab Ranges:

	<b>ABG</b>	<b>VBG</b>	<b>CBG</b>
<b>pO2:</b>	40-85	30-50	60-70
<b>pCO2:</b>	30-45	38-50	41-51
<b>CO2:</b>	16-21	24-28	18-28
<b>pH:</b>	7.35-7.45	7.33-7.43	7.34-7.43
<b>O2 sat:</b>	95-98%	not applicable	not applicable
<b>base excess:</b>	0-2.3	0-2.3	0-2.3

- *Babies born with CDH will not generally have normal pCO2 levels, but acceptable levels can vary by hospital. In general, pCO2 levels of 50-70 are accepted for babies with CDH, and lower pH levels, to 7.10 may be accepted.*
- *Different hospitals have different parameters for blood gases. Many have different expectations for CDH babies depending on their age. Parameters for blood gases can also be affected by other factors such as cardiac defects. Ask your baby's care team what their expectations are for desired blood gases.*

## Coagulation profile:

Prothrombin time: 13.5-16.4 sec  
 Partial thromboplastin time: 30-42 sec  
 INR: 1.1-1.4  
 Fibrinogen: 283-401 mg/dl  
 Antithrombin III: 60-89%

## Complete blood count (CBC):

WBC: 8.1-14.6  
 RBC: 3.32-4.8  
 Hgb: 10.8-14.6  
 Hct: 32-44.5  
 MCT: 90.1-103  
 MCH: 30.4-35.3  
 MCHC: 33.2-35  
 Platelet: 279-571  
 Rdw: 14.4-16.2  
 MPV: 10-12.2  
 Neutrophils: 16-70%  
 Lymphocytes: 17-59%  
 Monophils: 1-23%  
 Eosinophils: 0-8%  
 Basophils: 0-1%

**Free Hemoglobin:** 0-10 mg/dl

**CK (CPK):** 29-168 U/L

**Lactic acid:** 0.52-2.25 mmol/L

**C reactive protein (CRP):** <2

## Chemistry testing:

Sodium: 137-145 mmol/L  
 Potassium: 3.5-5.1 mmol/L  
 Chloride: 98-107 mmol/L  
 CO2: 22-30  
 Anion Gap: <18  
 BUN: 5-18 mg/dl  
 Creatinine: 0.60-1.00  
 BUN/Creatinine: 12-20 ratio  
 Total protein: 6.3-8.2 g/dl  
 Calcium: 9-11 mg/dl  
 Ionized Calcium: 1.13-1.32  
 Glucose: 60-99 mg/dl  
 Total bilirubin: 0.2-1.2 mg/dl  
 Direct bilirubin: <0.3 mg/dl  
 SGOT (AST): 5-34 U/L  
 SGPT (ALT): 0-55 U/L  
 A/G ratio: 1-2.2  
 Triglycerides: <15020-140 IU/L  
 Alkaline Phosphatase:  
 0-14 days: 83-248 IU/L  
 15 days <1 year: 122-469 IU/L



# Dealing with Emotional Turmoil

We are all individuals who cope with situations and emotions differently, and there is no right or wrong way for you to feel throughout all of this. Below are some of the emotions that you, your family, and even your friends may feel at some point:

- Devastation
- Fear
- Anxiety
- Anger
- Depression
- Numbness
- Confusion
- Impatience
- Helplessness
- Uselessness
- Guilt
- Despair
- Denial
- Hopelessness

All of these feelings are completely normal. Professional help and counseling can be a vital resource for you and your family during this time, so please do not hesitate to seek help if necessary.

If you have other children, you may worry that they are being neglected due to your attention being focused on your baby with CDH. This is also completely normal. It can be very helpful to have family and friends around to help look after them and take them on outings to serve as a distraction until you can spend more time with them.

You can help your children cope and understand what is happening by talking about the new baby, showing them pictures and videos of the baby, and encouraging them to draw pictures or make something special for the new arrival.





## Caring for Children with CDH: Advice from Parents

- "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 breast milk 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."
- "Learn how to take care of your baby from the very beginning. Help out the hospital staff 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."
- "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 your power company so that you can be put on 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 during 'off-peak' hours)."
- Ask your child's doctor about vaccines for Chickenpox, Flu, and RSV, 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. This is ultimately your choice, but make sure your child receives the services that he/she needs."





## Where to Find Support

**CHERUBS** ([www.cherubs.org](http://www.cherubs.org)), the support division of CDH International, has been helping families affected by CDH since 1995. Some of our services include:

- Online Forums – Free source of support with hundreds of other CDH families available 24/7
- Facebook Support Groups – National and statewide support groups for families affected by CDH
- CDHi Ambassadors – Other CDH parents ready and willing to lend an ear when you need it most
- CDH HOPE Totebags – Care packages offered to new and expectant CDH babies
- Local Family Gatherings – Held by our state representatives across the country
- Annual CDH Conference – Guest speakers, round table discussions, information and support
- Weekly Newsletter – Stories of Cherubs, CDH research, new events and fundraisers, and updates on our newest projects
- CDH Research Survey – Our natural history database with over 4,500 participants to help researchers discover the cause of CDH

**ACDHO** ([www.acdho.org](http://www.acdho.org)), the Alliance of CDH Organizations, is an international group of CDH charities and research organizations who are dedicated to the highest standards of patient support and advocacy.

**Ronald McDonald Houses** ([www.rmhc.org](http://www.rmhc.org)) provide housing services for families of critically ill children. Ask your hospital for more information and they can arrange to have you put on the waiting list if there is one nearby.

**Churches** are a valued place of support for many families. Your church, synagogue, temple or other house of worship can provide spiritual support and may be able to offer financial assistance as well.





## Living at Home with CDH

If your baby continues to improve, he or she will eventually be able to come home with you and your family. This can take anywhere from a few weeks to over a year, depending on how quickly your baby's health improves and whether or not complications occur.

Babies born with CDH often need regular follow-up care by different specialists after going home from the hospital. The best-case scenario will be that your baby will have no permanent issues and grow up to be a normal, healthy adult. However, below are some of the difficulties your child may face due to CDH.

- **Breathing Support** – some babies still need oxygen support due to pulmonary hypertension or various other reasons and may come with a nasal cannula and oxygen. In very severe cases, a baby may come with a trach. A tracheostomy is a surgically made hole that goes through the front of the babies neck into the trachea, or windpipe. A breathing tube, called a trach tube, is placed through the hole and directly into the baby's windpipe to help them breathe.
- **Feeding Issues** – Being slow or unable to breast/bottle feed may affect growth and weight gain. Occasionally, an NG tube may be placed into a baby's nose and down into the stomach to administer nutrition and medications. In severe feeding issues, a G-tube may be inserted through the abdomen that delivers nutrition directly to the stomach.
- **Gastro-Esophageal Reflux Disease (GERD)** – Gastric acid coming up into the esophagus from the stomach can be distressing for your baby and is usually treated with medication. In severe cases, a procedure called a Nissen fundoplication is carried out where the surgeon improves the natural barrier between the stomach and the esophagus to prevent the upward flow of acid.
- **Speech and Developmental Issues** – Resulting from artificial ventilation and long periods of hospitalization. Your child will normally be referred to a speech therapist, physical therapist, and / or occupational therapist to deal with these issues.
- **Hearing Loss** – This sometimes happens, although professionals aren't entirely sure why. Your baby will be monitored throughout childhood by an audiologist in regards to his or her hearing.
- **RSV** – This is a sometimes deadly virus that can present itself as a simple cold in older children and adults but is very dangerous for the elderly, newborns, and those with compromised lungs. Please talk to your child's doctors about RSV precautions such as the Synagis shot, isolation, etc during cold and flu season for the first 2 or 3 years.
- **Viruses** – it is imperative to keep your child away from viruses such as the cold, flu, RSV, Chicken Pox, Whooping Cough, etc. The only way to do this is to avoid crowds, limit visitors, and screen everyone your child comes into contact with. We have had several children survive CDH only to be lost to simple viruses.
- **Reherniation** – Recurrence of the hernia is uncommon, but can be very serious. Contact your GP or call an ambulance if your child experiences the following:
  - General unwell feeling (very lethargic, uncontrollable crying)
  - Vomiting (may contain bowel contents and or green bile)
  - Abdominal discomfort or pain
  - Loss of appetite
  - Abdominal distention
  - Difficulty breathing





## If You Have to Say Good-Bye

Sadly, some babies diagnosed with CDH will not make it past their first few hours, days, or weeks of life. The medical personnel will explain the reasons your baby is deteriorating and go over options as far as improving your baby's condition and whether or not ceasing treatment should be considered. This is never an easy decision for parents or medical professionals to consider, and you will be given as much time and support as necessary to make your decision. Some parents can see their baby struggling and will find that the baby lets them know when the time arrives.

**Below are some suggestions for when the decision has been made:**

- Take many photos and videos of your baby. These will always be precious to you.
- Contact Now I Lay Me Down to Sleep to see if there are resources in your area. Their services are free of charge and they will provide remembrance photos of your son and daughter.
- Write down your baby's day-to-day care and any special moments in a journal to keep.
- You may want to invite visitors to see your baby before the time comes. The hospital will try their best to fulfill all of your requests, but please be mindful that many of these units have strict visitor policies to protect other babies and their parents.
- Arrangements to have your baby baptized in the unit may be made if you are interested.
- When the time comes to remove your baby from life support, you may either be present or wait for the nurses to bring your baby to you. This may be the first time you and your partner have been able to hold your baby, and this may be extremely overwhelming.
- You are encouraged to bathe and dress your baby, and to hold them and talk to them for as long as possible. Do not be afraid to hold your baby after they have passed—many parents have regretted not doing so.
- You may also wish to take photographs holding your baby, as well as hand and/or footprint impressions.
- It's a smart idea to make sure that blood is collected by the geneticist for DNA tests in the future as they become available.
- A lock of hair is a precious memento.
- There is no right or wrong way to deal with emotions during these devastating moments. Family and friends are invaluable support, and you may also find it useful to speak with a hospital counselor or chaplain if they are available.
- Finally, tell your baby that it is okay to go. Studies show that people of all ages, even newborns, seem to pass on more peacefully after hearing these words.



# Advice From Other Grieving Parents

“Do not allow anyone to rush you. Take as much time as you need to say goodbyes. 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 goodbyes 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 known as 'Ryan's Box'.” - Cindy Mohr

“Ask for pills to dry up your breast milk or continue pumping until after the funeral. Hugs can be very painful when you're engorged.” - Rhonda Montague

“I am making a shadow box with Thomas' mementos. His little hat and socks and bracelets and some cards, etc. are put into a special frame which will hang on a special wall. This way I can look at Thomas' memories every day without opening a box, and it is such nice decor too. I also had one made for my older son Michael, and he enjoys looking 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 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. 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 a while, but it hasn't really made a difference in the way we have connected. But truly, the two women I met through Cherubs have been the best relationships of all. We give each other strength and support regularly.” - Laurie Stusser-McNeil



## Why My Cherub?... A Letter To Grieving Parents

Dear Grieving Parent,

It is not because you were not worthy of your cherub—you were and are. You are so worthy that you have been entrusted to carry on your life's goals and theirs as well. You are so worthy that your cherub chose you to be his or her mommy and daddy during their short time here. You are so worthy that you were blessed enough to be the parent of a living angel ... a child placed on earth to touch the hearts and lives of so many people. So much love and so many lessons put into such a short time. Not everyone can comprehend that great blessing and that great responsibility—but you were chosen.

It is not because of your faith or doubts. It is not because you didn't pray hard enough or because not enough people prayed for your cherub. There are cherubs who have had 1000's of people around the world praying for them ... and they did not survive. We have had cherubs whose parents do not believe in religion and they have survived. Your prayers for a miracle were not refused. You have received miracles too ... even though they may not be the one you wanted most. Prayers can sustain us through whatever CDH throws at us, helping us to make the right decisions, bringing us peace no matter the outcome ... and they can lift us up and carry us through grief.

It is not because you made a bad medical decision or did not fight hard enough for your child. Your cherub had a whole medical team fighting for them alongside of you. You made all the best decisions that you could for your cherub. You were and are the best parent to your cherub that you can be. There are 1000's of healthy children who do not have parents who would fight for them. Your cherub was blessed to have you as parents just as you are to have had the opportunity to be a parent to your cherub. If CDH has taught us anything it is that it plays by no rules. Children with no diaphragm and little lung can survive while children with two full lungs might not. It has taught us that lung function is not the deciding factor. It has taught us that sometimes the best care in the world is not enough.

It is not because you couldn't offer your cherub the support or resources needed for a special needs child. It is not because you lack patience or skills. We have grieving members who are doctors, nurses ... we have parents of survivors who were teenagers themselves. We have grieving members who are amazing, amazing parents and we have parents of survivors who have lost custody of their cherubs. We also have many, many parents of survivors who are amazing and prepared and ready to be wonderful parents to their cherubs. CDH does not care who is ready, who is able, who is best qualified to care for a cherub and who is not.

It is not because you didn't love your cherub enough. If love could spare babies from CDH, this horrible birth defect would not claim one more life. CDH shows no favoritism. It shows no prejudice. It truly is the luck of the draw who survives and who does not. It does not mean you are better or worse than anyone else. It is not fair. Your cherub did not choose to leave you. But they did choose to spend their time here with you. They did not choose wings over feet. They did not choose Heaven over staying here with you.

There is no good answer to why your cherub did not survive ... but there are hundreds of answers as to why he or she should have. At CHERUBS, we all know the pain of CDH. The pain and grief of having a child born with a severe birth defect ... some grieve over the loss of a healthy child as they struggle to deal with CDH in their surviving cherub and the loss of a dream. Some grieve a never-ending grief of losing the dream and the life of their cherub. But we all grieve, and we all have questions that we may never get answers to.

We have all lost a lot. So many parents are grieving the losses of their babies right now. The CDH community has lost so many babies that we have all prayed for, loved from afar. But we have gained a lot too. So have the family members, friends, and even strangers. Each cherub has left their mark on this world and left it a little better than they found it. That is more than most people do in lifetimes that last decades. We should all follow such beautiful examples as these children have left for us.

Yours Truly,

Dawn M. Torrence Ireland

President, CDH International



Never trust your phone battery.

# IMPORTANT CONTACTS

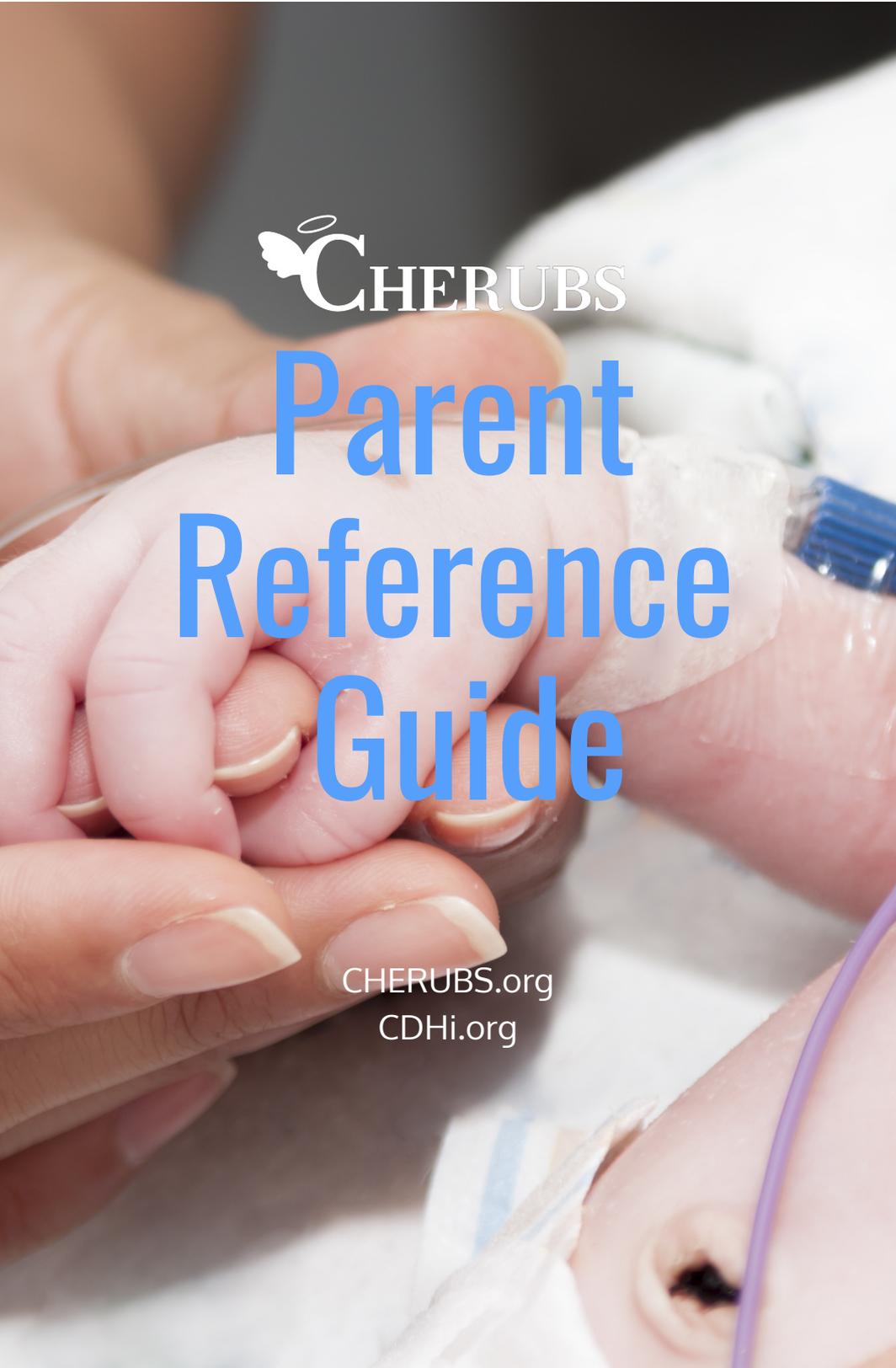
## EMERGENCY AND INFORMATION LIST

Appoint Your Go-Between. The person who will field calls for you, update all your family and friends, update your social media, etc so that you can spend time with your baby and not constantly answer questions from well-meaning family and friends.

Our Appointed Go-Between is \_\_\_\_\_ He/She can be reached at \_\_\_\_\_

	Name:	Number:
Obstetrician	_____	_____
Primary Physician	_____	_____
Mom's Cell	_____	_____
Dad's Cell	_____	_____
Grandparent / Other	_____	_____
Grandparent / Other	_____	_____
Grandparent / Other	_____	_____
Grandparent / Other	_____	_____
Hospital Switchboard	_____	_____
NICU / PICU	_____	_____
Hotel / Ronald McDonald House	_____	_____
CHERUBS / CDHi	Tracy Meats	(919) 610-0129
Local CHERUBS Ambassador	_____	_____
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 CHERUBS

# Parent Reference Guide

[CHERUBS.org](http://CHERUBS.org)  
[CDHi.org](http://CDHi.org)