A Parents Guide to
Congenital Diaphragmatic Hernia (CDH)

Shawn Studdard
http://thestuddardfamily.blogspot.com

"Never lose hope, but don't let it cloud the reality of the situation."
- Shawn and Stephanie Studdard

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About this document…

If you are a parent or family who has recently found out that your child has CDH, let me first say how sorry I am. I know firsthand the shock you are dealing with right now and the overwhelming questions with which you are struggling to find answers. Dealing with all of the doctor appointments, terminology, statistics and measurements around CDH can be overwhelming. Each week and month my wife and I would gather one more piece of the puzzle and then have to wait what seemed like years before the next appointment. I have tried to consolidate much of what we have learned to better prepare other CDH families when speaking with their Healthcare professionals. The information below comes from studies, websites, hospitals, doctors, and then my attempt to simplify it. I can't guarantee the accuracy of the information contained below since I am not a doctor. Unfortunately, I spent more evenings at parties than at the library during college. It is also quite possible that some of this information has been proven inaccurate by more recent studies. Use this to build a foundation and then be open to new possibilities as the newer research presents itself.

My intention with this document is to put together the information that helped us in plain English along with some of my opinions and advice. As you go through this journey, there is a balancing act between hope and remaining realistic. My advice is to never lose that hope while not allowing it to cloud reality. You will soon learn that all of these babies are nothing short of miraculous, but not all of them come home.

Before getting into the details below, my advice is to find support through the blogs or CDH Forums. First, access the CHERUBS website (www.cdhsupport.org) and register so that you can get into the forums. I suggest CHERUBS for the forum because I think it is the easiest to use. At the bottom of this document I have listed the major organizations and foundations for CDH and would suggest visiting all of them. You will find some of the most amazing people on these forums that will both inspire you and keep you grounded.

Next, I would start getting to know some of the families currently going through this journey by visiting their blogs. These are the three types of families we found and stayed very connected to:

1) Find families that have made it through this journey with either a baby or a baby angel. These families will carry you through this journey and can answer so many of the questions you have right now.

2) Find families that are going through this that are due around the same time as you are. These are the families that "get it" when you're not sure your family or friends do.

3) As you get further along and make it through this journey, support and encourage families that have recently found out they are in the same boat as you. They will need your guidance and support during this difficult journey.

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CDH Overview

Congenital diaphragmatic hernia (CDH) refers to a defect in the diaphragm that allows the abdominal organs (stomach, intestine, liver, bowel, and spleen) to migrate into the chest cavity. The diaphragm is a thin dome-shaped skeletal muscle that separates the chest and abdominal cavities. The diaphragm plays an important role in breathing: it contracts with each inspiration, becoming flattened downward and increasing the volume of the chest cavity so that air is drawn into the respiratory tract, and then, with expiration, it relaxes and is restored to its dome shape. Diaphragmatic hernia results from the failure of the diaphragm to close or to form at approximately eight weeks' gestation. CDH allows the abdominal organs to move up into the chest cavity and this prevents the lungs from developing properly. Babies who have CDH suffer from small and underdeveloped lungs. This is termed **pulmonary hypoplasia**. Although hypoplastic lungs have created this situation, the critical nature of the condition at birth is due to **pulmonary hypertension** or **persistent pulmonary hypertension in newborns (PPHN)** which I will discuss in detail later. Since this condition will be present "at birth", it is referred to as Congenital Diaphragmatic Hernia as opposed to Diaphragmatic Hernia.

It is important to understand that you didn't do anything to cause this defect in your child. When they told us this condition started in utero, we immediately started to wonder if my wife ate something she shouldn't have, took medicine she shouldn't have, or that maybe something hit her tummy that caused it. These initial thoughts are totally natural, but as we discovered, absolutely unfounded. It is honestly not known why the situation occurs. The occurrence of CDH is somewhere between 1 and 2000 to 5000 live births. While you have probably never heard of CDH until now, the reality is it occurs about as frequently as Cystic Fibrosis which I am not only confident you have heard about, but may have some general knowledge about the condition.

When we left the appointment that first suggested CDH was a possibility, we were probably a bit in denial about the severity of the situation. We both assumed that once our daughter was born, they would just move everything down during an operation, and we would go home in about a week without any issues. One of the most critical hurdles a new CDH family has to get over is the reality that CDH is a life-threatening illness. Currently, overall survival rates of all CDH babies are around 50%. The next hurdle is to understand that there really are not two identical CDH babies. There are so many variables and degrees of herniation that it is impossible to compare these babies or confidently correlate an outcome. This is further compounded by the baby itself and how strong he/she can fight.

If we can prepare you for anything, it would have to be the frustration of not knowing the outcome or even having the ability to determine a reasonably confident survival percentage for your child. You simply won't know the true outcome of your baby until he/she is born, and even then it will be a balancing act for a while. During the pregnancy, each appointment you go to will give you one more piece of the puzzle, but it is just one piece to what feels like a 1,000 piece puzzle. When your doctors say they don't know what the outcome will be, they aren't hiding anything or dodging the question. They truly don't know and I began to realize they are also frustrated. As your appointments and tests progress, they can give you estimates of survival, but they are truly

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estimates. You will find babies that were given a 30% chance of survival go home with few to no complications, and you will hear of babies with an 80-90% chance of survival that do not make it and get their angel wings. I wanted to include this because I think our journey would have been easier if we truly understood this in the beginning. It's not that we weren't told numerous times, but it took a while to sink in. It is important to go through this situation with eyes wide open. Let's begin with the two most common types of diaphragmatic hernias.

A Bochdalek hernia is a hole in the back of the diaphragm and is the most common type of congenital diaphragmatic hernia. The left side of the diaphragm is affected approximately 85% of the time. The left chest can contain the stomach, intestines, liver, bowel, and the spleen causing severe left lung hypoplasia. When it occurs on the right side of the diaphragm, a significant amount of the liver may end up in the right chest causing right lung hypoplasia and affecting the function of the heart due to increased compression. Regardless of which side the hernia is on, most babies will experience some degree of pulmonary hypoplasia in one, if not both, of the lungs.

A less common type of diaphragmatic hernia is called the Morgagni hernia. This defect involves a hole in the front portion of the diaphragm, just behind the sternum. Sometimes the intestines or a piece of liver may move up through this defect in between the heart and the sternum, but this usually does not cause pulmonary hypoplasia.

Clearly, having organs in the chest cavity is not normal and definitely not good, but that alone isn't the biggest challenge these babies might have to overcome. Before birth, the size of a baby's lungs is not important because mommy takes care of oxygenating the blood and removing carbon dioxide. Once delivered, a baby takes over this process and a critical situation of respiratory distress can exist is the lungs are smaller than normal. Normal lungs at birth have millions of small alveoli, which can best be thought of as many clusters of grapes where the exchange of oxygen and carbon dioxide takes place. Unfortunately, the lungs of babies born with CDH are hypoplastic or underdeveloped and have far fewer alveoli present. The alveoli that are present are much more fragile and are missing surfactant which is a protein that decreases the surface tension on the lungs to allow them to become less stiff and operate as they normally would. When babies are born with CDH and hypoplastic lungs, the decreased alveoli and lung function does not produce enough oxygen in the blood, or get rid of enough carbon dioxide from the body without medical intervention. When this occurs, the lack of oxygen leads to severe illness requiring very aggressive support measures.

While lung development will likely be one of the toughest challenges, CDH is also known to have associated birth defects which can complicate the situation and directly impact survival. It is possible to have structural defects within the heart along with chromosomal abnormalities such as trisomy 21, 18, and 13. These chromosomal abnormalities appear in 10% - 30% of babies with CDH.

In addition to chromosomal abnormalities, proper function of some organs can be compromised due to compression and altered location. In most all cases, the function of the contra-lateral lung (lung opposite of the defect) will be greatly compromised. The heart will likely be shifted to the right (in left sided CDH) and in severe cases can affect its function. Some of the abdominal organs will be out of place after moving into the

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chest cavity, and this altered location can cause the gastrointestinal tract to not function properly. Less common are kidney and central nervous system defects, but have been reported to occur in babies with CDH.

There is very little information about long-term lung growth with CDH. It is anticipated that there will be some growth in the years after birth, but how much is difficult to pinpoint. What happens at the alveolar (the tiny air sacs in the lungs that exchange oxygen and carbon dioxide) level is even less clear. In fact, what happens even in premature infants with respect to alveolar development is also not clear - we know that there is an arrest of alveolar development, but whether there is some alveolar growth over time is not known. Animal models suggest that there may be a critical period for alveoli to form, but what happens in humans is not completely understood. With respect to long-term lung function, that depends on how much damage the lungs are exposed to in the neonatal period, as well as, the degree of hypoplasia and the amount of lung growth over time. There are other factors that will also determine long-term lung growth. Survival odds and long-term outcome can be better the later the baby is born. The less lung injury (barotrauma/pneumothorax/etc) the baby sustains while on the ventilator the better. Unfortunately, these and other variables are impossible to factor into the equation in utero which will make predictions all the more difficult. The outcome includes a wide spectrum of normal lung function to long term requirement for oxygen and sometimes a home ventilator.

While the research on lung growth is far from complete, some babies with CDH can and do live a normal life with regards to breathing, although most probably won't go on to be marathon runners.

In summary, CDH is a hole in the diaphragm that allows some of the abdominal contents to move into the chest area. The major threat to survival is underdevelopment of the lungs because these organs are taking up the space where the lung would typically be allowed to grow and develop. These smaller than normal lungs have fewer alveoli than normal and are stiff due to a lack of the protein surfactant which does not allow the blood to become oxygenated like it normally would. To complicate the situation, most CDH babies suffer from pulmonary hypertension which is an increased amount of pressure in the arteries that supply blood to the lungs. Because of this pressure, some of the blood is diverted away from the lungs and doesn't participate in proper gas exchange of oxygen and carbon dioxide. There could also be other abnormalities or conditions that complicate survival once they are born. Once a CDH baby is delivered, he/she will typically present with some level of respiratory distress and will need immediate medical intervention. The goal at this point will be to stabilize the baby which will likely include some type of ventilation technique, but could also include a heart/lung bypass machine called ECMO for the sickest babies. The baby will have to undergo at least one surgery to put the organs in their proper place, but this typically won't happen for days or weeks after delivery. A CDH baby will spend time in the a Neonatal Intensive Care Unit once he/she is born, and this could last from a few weeks for the best case scenario to a few months for very sick babies. A lot of these babies will go home, but unfortunately, some of them won't and will get their angel wings after a very courageous fight.

I am confident you are searching for answers relating to procedures that can be done to "fix" this problem before birth or guidance on likely outcomes for your baby. Before I can discuss those topics, it is important to understand some key terms that will create a foundation of knowledge to better understand the remainder of this document.

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Definitions

LCDH and RCDH:

Bochdalek Congenital Diaphragmatic Hernias can happen on either the left or right side of the diaphragm (actually, the entire diaphragm could be missing, but typically it is more pronounced on one side or the other). When it happens on the left side, it is abbreviated LCDH, and when it is on the right side it is referred to as RCDH.

Mortality:

Mortality is just what it sounds like, the condition of being mortal, or susceptible to death. When you hear mortality, it refers to the possibility or likelihood of the newborn surviving.

Morbidity:

Morbidity is a condition requiring treatment and/or hospitalization over time. When you hear of morbidity, the discussion will deal with possible long-term complications from CDH such as the need for a feeding tube, hearing loss, developmental delays, etc.

Pulmonary Hypoplasia:

Pulmonary Hypoplasia is underdevelopment of one or both lungs. Typically the lung on the side of the defect will have severe hypoplasia, while the opposite lung could be mild to moderate. The vessels and conducting airways of the lungs grow and become established in proportion to the size of the lung. When this growth is inhibited, so is the development of the vessels and conducting airways of the lung. The vascular bed present at birth will be in close relation to the size of the lung resulting in variable amounts of pulmonary hypertension in CDH babies. Pulmonary hypoplasia is the underlying cause of the respiratory challenges, but pulmonary hypertension is the resulting condition that primarily threatens the survival of these babies and is explained below.

Pulmonary Hypertension:

Pulmonary Hypertension is an increased pressure in the arteries supplying blood to the lungs. At a very high level, this increased pressure shunts (diverts) blood away from the lungs and decreases the supply of oxygen to the body. This shunting of blood away from the lungs is normal while the baby is inside the uterus because the baby is not breathing on his/her own. However, once a baby is born, these arteries in the lungs need to relax so that blood can flow through the lungs and exchange gases. These gases are exchanged when the blood rids itself of carbon dioxide and picks up oxygen to supply the body. Pulmonary hypertension is a life-threatening complication, and most CDH babies suffer from some degree of this condition.

Hypoxia:

Hypoxia is a deficiency in the amount of oxygen reaching body tissues. This is a common condition for a CDH baby due to the shunting or diverting of blood away from the lungs and this blood not participating in the gas exchange process to become oxygenated.

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Hypercarbia:

Hypercarbia is the physical condition of having the presence of an abnormally high level of carbon dioxide in the circulating blood. It is believed that this condition is likely caused by the hypoplastic lung condition rather than the state of pulmonary hypertension.

Amniocentesis:

Amniocentesis is a procedure used to diagnose fetal defects in the early second trimester of pregnancy. A sample of the amniotic fluid, which surrounds a fetus in the womb, is collected through a pregnant woman's abdomen using a needle and syringe. Tests performed on fetal cells found in the amniotic fluid can reveal the presence of many types of genetic disorders. Early diagnosis allows doctors and prospective parents to make important decisions about treatment and intervention prior to birth.

Remember, additional abnormalities have a 10-30% incidence rate with CDH babies so this is a procedure your doctor will likely request you have. There are risks to the fetus with this procedure, but they are pretty minimal. The procedure will be a bit uncomfortable, but it is manageable without any anesthetic. Using ultrasound to visualize the location of the baby and amniotic sac, the doctor will push a 22 gauge needle through the stomach and into the sac while avoiding contact with the baby. Using a syringe attached to the needle, he/she will draw fluid out of the sac which takes about 15 to 30 seconds. The test will tell you if there are any chromosomal abnormalities like Down's syndrome. After the fluid is sent off, you will get an initial test result back in about 1-2 days. This will be the preliminary results followed by the final results about 4 days later.

I should discuss something here that you will likely be confronted with, and you should be prepared to address. From speaking with numerous families about their experience with CDH, a number have expressed to me that they were encouraged to terminate the pregnancy especially if additional chromosomal abnormalities were found by their healthcare providers. For us, the topic was only mentioned as an option, and it wasn't discussed again after our decision was made. For those of you who have very strong feelings against pregnancy termination, I simply want you to be prepared that it will likely come up if you are diagnosed before your States legal timeline for the procedure, and I want you to be prepared to address it.

Surfactant:

Pulmonary surfactant is a phospholipid–protein complex synthesized and secreted exclusively by alveolar cells that lowers surface-tension forces at the alveolar air-liquid interface, thereby increasing lung compliance. CDH babies typically have a surfactant deficiency. Basically, this surfactant deficiency causes poor gas exchange and doesn't allow the lungs to expand as much as they should so they remain "stiff". There are a number of studies, conflicting of course, about the success of surfactant therapy once CDH babies are born in an effort to decrease the surface tension of the lungs. It appears that surfactant therapy can help if delivered before the baby takes his/her first breathe, but poor results have been found if administered afterwards.

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Polyhydramnios:

Polyhydramnios is simply too much amniotic fluid, and your OB or Maternal Fetal Medicine doctor will check this at each visit during the sonogram. With twins (our case), they measure fluid by the DVP (deepest vertical pocket of fluid) or MVP (maximum vertical pocket) with 2-8 cm being an acceptable range. In singletons, they measure the DVP in four quadrants defined by the mom's belly button. This is called the AFI or amniotic fluid index. You can do this with twins, but it is a little harder to interpret so they simply check the DVP. Doctors will use these measurements as a base, but will also look subjectively at the fluid, abdominal distention (swelling), and cervix together to make a final determination as to whether polyhydramnios is a concern. For instance, fluid level could be outside of the normal range, but the cervix length and appearance acceptable. In this case they might just monitor the situation and talk you through additional symptoms to be cautious of and would indicate the need to re-check before your next scheduled appointment.

Polyhydramnios can and does exist at times whether or not CDH is involved, but the risk of it happening does increase with CDH so it will be an important measurement at each visit. Basically, your baby is helping to keep amniotic fluid in check by swallowing and breathing in the amniotic fluid and then releasing it through fetal urination. When CDH is involved and the organs are not in their correct location, swallowing could be more difficult for the baby, and therefore this cycle can be interrupted causing polyhydramnios. Too much amniotic fluid can lead to a ruptured sac and/or early delivery which would add an additional hurdle to an already challenging situation.

NICU:

Neonatal Intensive Care Unit. This is where your baby will go after being born and typically to a level 3 unit where the ratios of nurses to babies are 1:1 or 1:2. If your baby survives and does well, it is possible he/she will be moved to a level 2 unit where the ratios will be a bit larger since not as much oversight is needed.

Doctors:

There will be a number of doctors involved in the care of you and your baby. This is just a basic list of who you can expect to meet and consult with:

> **O/B:** This is pretty straight forward, and you will likely continue to see him/her just as you would if there were no problems with your pregnancy.
>
> **Maternal Fetal Medicine Specialist:** This refers to an O/B who has further training in high risk pregnancies and the diagnosis of abnormalities. This is the doctor who found our CDH condition, and we continued to see him every 1-3 weeks throughout our pregnancy. They can also be involved in the delivery. Our MFM was also involved with the coordination of care and scheduling tests and consults.
>
> **Pediatric Cardiologist:** He/she will be involved to conduct echoes of the heart to ensure there are no additional abnormalities with the baby's heart. There is a higher incidence of these defects in CDH babies and having them only complicates a very serious condition. The cardiologist will look at both the structural integrity of the heart and how well it is functioning. Typically this is done fairly early, and ours was scheduled at 19 weeks. An echo will also be completed after birth.

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Pediatric Surgeon: This doctor will be involved to help determine the need for ECMO, complete the procedure for starting/stopping the baby on ECMO if necessary and to conduct the surgery to repair the hernia.

Neonatologist: These doctors will be very involved in the day-to-day decision-making once the baby is born. Their responsibility is to implement the protocols for ventilation and assess and respond to any other issues that arise while your baby is stabilizing and hopefully getting better.

Radiologist: Primary responsibility of this doctor is to oversee the MRI process and interpret the results. He/she will use a special high-speed MRI machine, and the process takes about 30-40 minutes.

Speech Therapist: Speech therapists are critical when it comes to feeding your baby with a bottle. They will help determine the rate at which your baby transitions from tube feeding to bottle or breast feeding.

Hernia Repair:

Years ago, the strategy with CDH was to quickly repair the hernia soon after delivery, but that has changed to favor stabilizing the baby before completing the repair. We tried desperately to find out how complicated the surgery would be, if a patch would be necessary, and would her stomach area have enough skin to stretch and hold all of the organs when they moved them below the diaphragm. Depending on many organs have moved above the diaphragm, your baby's stomach area will possibly be sunken in to some extent because the organs are not there to push against it. Without this pressure, the skin doesn't expand as large as it normally would and when they conduct the surgery, it might be difficult for everything to "fit" in the proper place. They have ways of correcting this so don't have anxiety over this situation, but we wanted to know what to expect. Unfortunately, doctors won't be able to provide you with the answers you are searching for. Sonograms and MRI's are fantastic technology, but they don't reveal nearly enough to allow surgeons to give concrete answers. The complexity of the surgery depends a great deal on how much diaphragm is present which is difficult to determine with current technologies. In some cases, doctors can use the existing tissue and stretch it to close the hole. This is preferred because it typically results in a lesser chance of re-herniation. Unfortunately, if there isn't a great deal of tissue, a Gore-tex patch will be used to repair the diaphragm after moving the abdominal contents to where they belong. From what I understand, re-herniation occurs more frequently if a patch is used requiring an additional surgery.

If a patch is used and there is no re-hernation, the patch repair can be permanent. Over time, tissue growth will occur as it normally would with age around the patch.

ECMO (extra corporeal membrane oxygenation):

"ECMO is a type of heart-lung bypass machine that is used in roughly 30% - 40% of CDH cases. ECMO is used when other treatment options fail. While on ECMO the heart and lungs are rested as the machine is now doing their work. This rest will sometimes allow time for resolution of pulmonary hypertension. A baby can stay on ECMO for only a brief period of time, usually 3 to 21 days. Vessels in the neck are used to take the

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unoxygenated blood out of the body (by a large vein). This blood is put through the ECMO machine and returned to the body via another vessel (an artery) in the baby's neck. A surgical procedure to place cannulas (large intravenous type tubing) into the vessels is performed at the bedside. The blood is heparinized, (heparin, a blood thinner, is put into the blood) to keep it from clotting. ECMO treatment does have risks. The major risk is bleeding. Because of the need to use heparin to thin the blood, there is a risk for bleeding in various parts of the body. The most serious is when bleeding occurs in the brain. Other potential complications can include infection and mechanical failure. If a baby is so sick that they require ECMO, the long-term outlook may include neurologic deficits due to a period of time when he/she was not getting enough oxygen to the brain. These deficits can range from mild mental handicaps and/or chronic lung disease (similar to asthma) to more severe problems such as cerebral palsy and vision and hearing deficits." – Children's Hospital of Wisconsin

It is true that ECMO is typically a last resort to improve lung function to a point where survival is possible. If ECMO is indicated, it does mean your baby is very sick and he/she will not survive with ventilation alone. The suggestion to utilize ECMO will be carefully evaluated and scrutinized by your medical team due to the associated risks. It does not mean hope is lost. If it is suggested, it means your medical team believes there is still hope for you baby to win this battle.

The machine itself may be a little much to take in at first as it is somewhat big and has many tubes carrying blood to and from the baby's body. Additionally, there will likely be a good deal of swelling with your baby as he/she retains fluid. This is normal, but something to be prepared for if your baby does need ECMO.

Unfortunately, there is no way of knowing if your baby will need this machine until they are born. Not all hospitals have ECMO capabilities, and you may hear that it isn't necessary to deliver at a facility with on-site ECMO capabilities. If you deliver in a center without ECMO and your baby ends up needing it, the baby will need to be transported to a center that can handle it. This is something you will need to determine when selecting the facility where delivery will happen. For us, we had a number of hospitals with great NICU's available to us that were close, but we chose a facility that had ECMO to eliminate the transport issue if it was necessary.

Another issue about ECMO is that it probably won't be used unless certain criteria are met. Typically ECMO will be considered if the baby has made it to 34 weeks gestation or 2 kilograms (4.4 pounds), mechanical ventilation methods have been exhausted, and have reversible lung disease. The gestation period and weight requirement is necessary because the baby's circulatory system just won't be able to handle it and the potential for internal bleeding is greatly increased.

Exit-to-ECMO:

This strategy is used in severe CDH cases. With ex utero intrapartum treatment (EXIT), the fetus is partially delivered through C-section, but the umbilical cord is left attached. Doctor's then connect the newborn to extra corporeal membranous oxygenation (ECMO), a heart and lung bypass system that circulates oxygenated blood throughout the body. Once ECMO is functioning, the umbilical cord is cut. This procedure is not real common, but is a possibility for severe cases.

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Nasal Cannula:

A Nasal Cannula is a device for delivering oxygen by way of two small tubes that are inserted into the nostrils.

Feeding Tubes:

As discussed before, there could be complications for CDH babies in regards to feeding both in the hospital and after they are discharged. Remember, these babies are busy fighting to overcome their condition so eating may not be their top priority. Some of them will develop an aversion to eating while some will just simply be too tired to eat. If your baby can't eat, they will likely insert a feeding tube (either NJ or NG) and a brief description of each type is below.

> **NJ-tube, Nasojejunal tube:** a feeding device through which formula, fluids and/or medication can be given directly into the small intestine. The NJ-tube is inserted through the nose, passes down the esophagus, through the stomach and into the small intestine. This tube is usually placed using x-ray guidance.
>
> **NG-tube, Nasogastric tube:** a feeding device through which formula, fluids, and/or medication can be given directly into the stomach. The NG-tube is inserted through the nose, passes down the esophagus and enters into the stomach.

Once your baby comes home, the feeding issue might not be resolved, and he/she will need a more secure type of tube for home use. The G-tube is a likely solution with a brief description below:

> **Gastric feeding tube (or "G-tube," or "button"):** a tube inserted through a small incision in the abdomen into the stomach and is used for long-term nutrition. The most common type is the percutaneous endoscopic gastrostomy (PEG) tube. It is placed endoscopically: the patient is sedated, and an endoscope is passed through the mouth and esophagus into the stomach. The position of the endoscope can be visualized on the outside of the patient's abdomen, because it contains a powerful light source. A needle is inserted through the abdomen, visualized within the stomach by the endoscope, and a suture passed through the needle is grasped by the endoscope and pulled up through the esophagus. The suture is then tied to the end of the PEG tube that will be external and pulled back down through the esophagus, stomach, and out through the abdominal wall. The insertion takes about 20 minutes. The tube is kept within the stomach either by a balloon on its tip (which can be deflated) or by a retention dome which is wider than the tube. Gastric tubes are suitable for long-term use; they last about six months and can be replaced through an existing passage without an additional endoscopic procedure. Overcoming the need for a G-tube can be a slow process and quite frustrating as you begin to mix oral feedings with tube feelings. There are numerous strategies you can use to help with this process and I would suggest contacting other families on the forums who have experienced similar issues to help guide you through these tactics.

Chest Tubes:

It is possible that your baby will need a chest tube inserted, possibly after the hernia repair, to drain excess fluid and air from the chest cavity. An example of when a chest tube would be used is in the case of a

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pnuemothorax (A hole in the lung so that air escapes into the chest space between the lungs and the chest wall. This further compromises lung expansion and blocks cardiac output leading to low BP and severe worsening of the condition).

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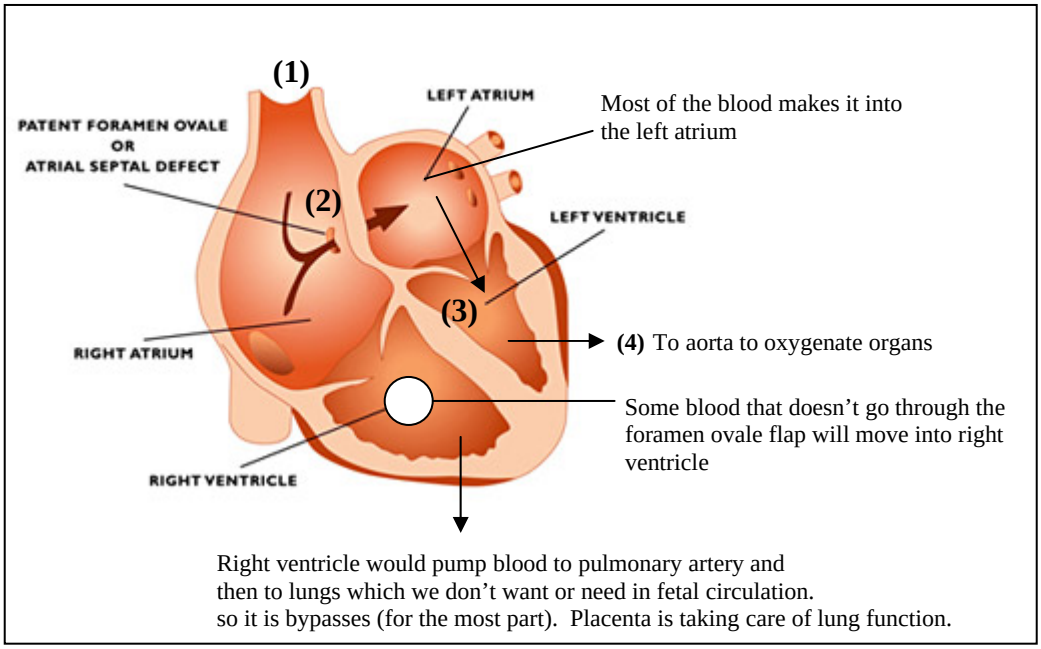
Pulmonary Hypertension

This is typically the most serious aspect in terms of survival with CDH babies and what your medical team will be fighting to overcome. Therefore, a solid understanding of this somewhat complex condition is necessary. To better clarify what will typically happen with your child, it is easier to break this down into three separate discussions: lung function in fetal development, lung function after birth (normal), and lung function with CDH.

Lung Function in Fetal Development

The series of events that take place, in regards to lung development and function in a fetus, is nothing short of amazing. In utero, the lungs of a fetus do not participate in the gas exchange of oxygen and carbon dioxide that is necessary for survival. In reality, there is very little blood flow directed to the lungs because liquid (blood) will tend to take the path of least resistance. The lungs of a fetus are small and have not fully developed or expanded so the vessels within the lungs are compressed. Blood simply has a hard time forcing itself into the lungs through these compressed and immature vessels. If you have ever tried to blow up a very small balloon versus a large balloon you get the idea. This isn't an issue though because the placenta is a very low resistance organ. Going back to the idea of least resistance, blood has a much easier journey if it simply bypasses the lungs and heads straight for the placenta that can perform the gas exchange necessary for survival. In normal fetal circulation, the blood will enter the baby's heart in the right atrium (1). Typically after birth, the right atrium pumps the blood to the right ventricle and then to the pulmonary artery which carries it to the lungs for gas exchange. In fetal circulation, the blood doesn't need to go to the pulmonary artery because it is already oxygenated by the placenta. Therefore, most of the blood bypasses this right side process and diverts to the left atrium through a flap called the foramen ovale (2).



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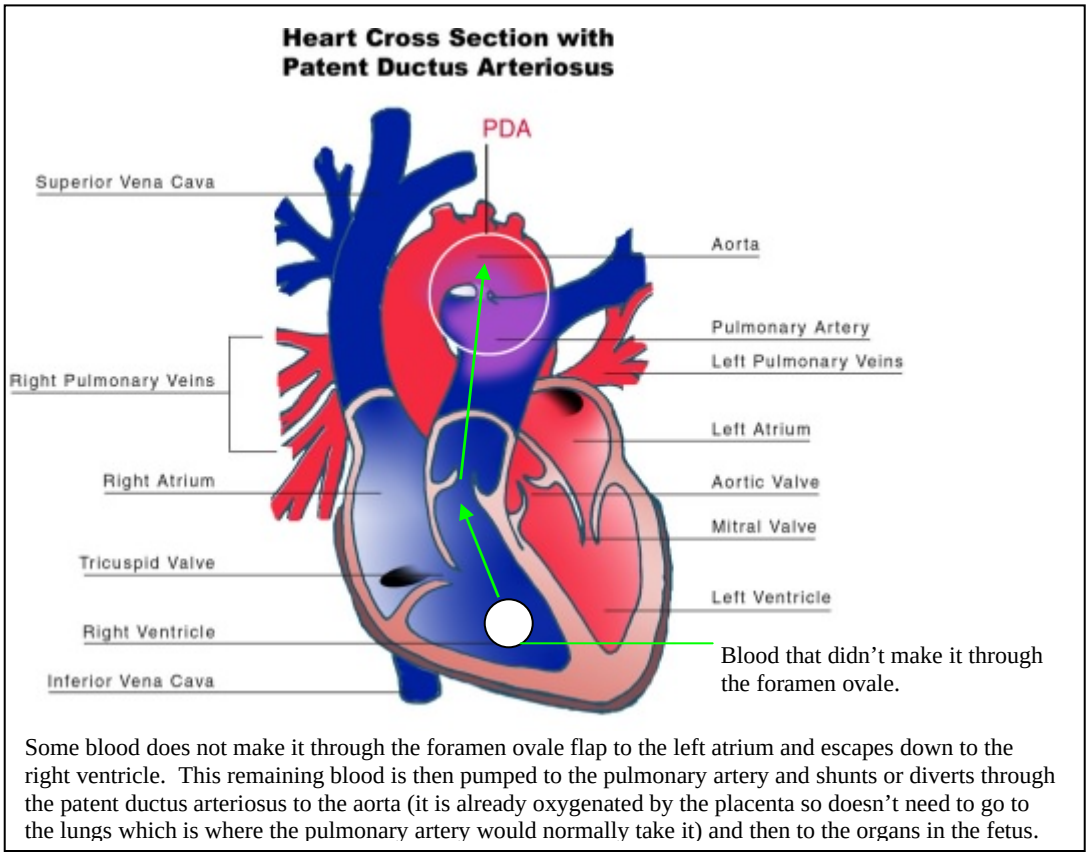
The blood is then pumped to the left ventricle (3) which then pumps it to the aorta (4) for transport through the body. Basically, in fetal circulation, the right side of the heart (which normally pumps blood to the lungs for gas exchange) is bypassed and blood that has already been oxygenated by the placenta is shunted or diverted through the foramen ovale flap into the left side of the heart. While most of the blood is diverted into the left atrium, some will remain in the right atrium and then pumped into the right ventricle. The next stop on the journey would be the pulmonary artery to transport the blood to the lungs. Since the fetal lungs aren't participating in gas exchange at this point, and the blood has already been oxygenated, there is another duct or flap called the patent ductus arteriosis or PDA (patent means open). This flap connects the pulmonary artery (takes blood to the lungs) to the aortic arch (takes oxygenated blood to the organs).



Some blood does not make it through the foramen ovale flap to the left atrium and escapes down to the right ventricle. This remaining blood is then pumped to the pulmonary artery and shunts or diverts through the patent ductus arteriosus to the aorta (it is already oxygenated by the placenta so doesn't need to go to the lungs which is where the pulmonary artery would normally take it) and then to the organs in the fetus.

Instead of blood going to the lungs, it takes a detour through this flap and directly into the aorta to nourish the organs. As long as the fetus is connected to the placenta through the umbilical cord, this process continues throughout pregnancy.

Lung Function after Birth (normal conditions)

At birth, the umbilical cord will be cut and he/she will take their first breathe setting off a chain reaction of processes that allow a baby to become self sufficient with regards to gas exchange under normal circumstances. The ductus arteriosus will close on its own at or within hours of birth while the foramen ovale will permanently close within 3 months after birth. The placenta is no longer the path of least resistance because it is no longer available. At the same time, the baby's entire circulatory

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system becomes much more resistant to blood flow. This in turn causes the left ventricle and atrium of the heart to increase their pressure to overcome the circulatory resistance. This increase in pressure in the left side of the heart (the side that pushes oxygenated blood to the body) pushes against the foramen ovale, and it shuts so that blood no longer escapes through the flap from the right atrium to the left. As a baby inhales, the oxygen in the alveolus and arteries increase causing the pulmonary vessels to relax. This inhalation also forces the lungs to expand and those vessels that were tight and rolled up are allowed to straighten out. These conditions help make the lungs less resistant than the remainder of the baby's circulatory system. Again, blood will take the path of least resistance. At this point it is easier for the blood to go into the lungs than bypass them because a higher resistance is encountered within the circulatory system than within the lungs. The blood becomes oxygenated to regular levels while carbon dioxide is removed and then sent throughout the body. The paths that the blood used to take around the lungs and to the placenta in utero now close as they are no longer necessary.

Lung Function with CDH

What I have described above is how the process normally works, but unfortunately, CDH throws this process a curve ball. If I have done a poor job of explaining how blood flow and lung function should work in utero and after birth, just remember that resistance is the key. Blood will take the path of least resistance and the goal after birth is to have the lungs in a state of least resistance so that the blood will flow easily into them and, as a result, participate in oxygen and carbon dioxide exchange. As discussed earlier, CDH can cause the lungs to be hypoplastic or underdeveloped due to the crowding of abdominal organs in the chest cavity. This crowding happens at the same time as the bronchial and pulmonary arteries begin to branch out and the amount of branching is directly related to how much compression actually occurs. This underdevelopment can result in fewer and tighter pulmonary vessels, decreased number of alveoli that appear to have a closer resemblance to fetal alveoli than mature alveoli, excessive muscle around the pulmonary arteries, and higher surface tension in the lungs due to lack of surfactant which causes the lungs to be tight and doesn't allow for proper gas exchange. These issues result in the resistance of the lungs being greater than the resistance encountered by the remainder of the baby's circulatory system. Some of the blood that can't enter the lungs continues to favor the path of least resistance and will continue to divert through the foramen ovale and into the ductus arteriosus as it did in utero. This process would work fine if the placenta was still available, but since it is not, this diverted blood fails to participate in the gas exchange process inside the lungs. This resistance in the lungs is referred to as pulmonary hypertension and it is life threatening. You might also hear this condition referred to as **Persistent Pulmonary Hypertension in Newborns (PPHN)** or **Persistent Fetal Circulation**. In some cases, pulmonary hypertension is reversible. Your medical team will be focused on keeping your baby alive through assisted ventilation and other measures so that time, which is the cure, can reverse the hypertension. It is important to note that since the lung and entire circulatory system resistance will both be high, the right chambers of the heart will endure a greater load than normal which can result in a number of heart conditions up to and including heart failure.

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In Utero Treatment

Portions of the In Utero Treatment section come directly from The Fetal Care Center of Cincinnati

When we first learned of this condition, we both asked ourselves and our doctor's, "why can't you just do surgery on the fetus and move things where they should be to fix the problem?" At this time, most CDH babies won't be considered for in utero surgery because there is not a remarkable difference in outcome between fetal surgery and current post-natal care protocols. I have taken information from a number of sources and tried to re-write some of it to explain where things stand in regards to in utero treatment.

Years ago, Dr. Harrison and his colleagues pioneered fetal surgery for congenital diaphragmatic hernia / CDH, and new approaches are being developed based on these initial trials. Unfortunately, survival following complete in utero repair was poor, and the failures were associated with babies who had herniation of the left lobe of the liver. Reduction of the liver during repair inevitably resulted in kinking of the umbilical vein, leading to fetal bradycardia (very low heart rate) and cardiac arrest. If herniation of the left liver was present, babies were no longer considered for complete in utero repair of congenital diaphragmatic hernia / CDH.

However, even if babies with left lobe herniation are excluded, the survival rate in the series by Harrison and colleagues was only 41%, which was no better than with conventional postnatal therapy at the time.

A prospective trial sponsored by the National Institutes of Health confirmed these findings; thus, there is currently no indication for complete repair of congenital diaphragmatic hernia / CDH in utero. Basically, if a baby has any part of the liver above the diaphragm, it is unlikely they would survive an in utero surgery and if the liver is down, the surgery doesn't improve the odds of survival over current postnatal therapy.

The shortcomings of in utero repair led to development of a new approach. Known for decades, fetal tracheal occlusion results in accelerated fetal lung growth in animal models. It was not until 1994, however, that tracheal occlusion was applied to the problem of congenital diaphragmatic hernia / CDH. While in the uterus, the fetal lung constantly makes fluid that escapes through its mouth and into the amniotic fluid. When the trachea is blocked with a small balloon, this fluid stays in the lungs. As it builds up, the lung fluid expands the lungs, stimulates their growth, and pushes the abdominal contents (liver, intestine) out of the chest and into the abdomen. The goal of this treatment is to have a baby born with lungs that are big enough that he/she can breathe and provide itself enough oxygen on its own. Originally, this procedure was done by making an incision in the fetus also known as open fetal surgery.

In the animal models of congenital diaphragmatic hernia / CDH, tracheal occlusion induces lung growth, increases alveolar surface area and alveolar number, as well as visceral reduction from the chest. The results of these experiments were so compelling that fetal tracheal occlusion was applied in human fetuses with severe congenital diaphragmatic hernia / CDH.

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Better results have been found with a newer technique called FETENDO. Instead of making an incision in the fetus, a FETENDO uses small endoscopes that are placed into the fetus and can be viewed on a tv monitor. The procedure was named “FETENDO” because the use of the endoscopes is much like playing video games.

Shortly after initiation of the FETENDO trial for congenital diaphragmatic hernia / CDH a group at UCSF developed a less invasive endolumenal balloon tracheal occlusion technique requiring only a single port as opposed to the 5 for the FETENDO approach. This approach, using a detachable balloon, was incorporated into the NIH sponsored trial.

The trial was halted after enrollment and randomization of 24 patients because of an unexpectedly high survival rate with standard postnatal care. The Data and Safety Monitoring Board concluded that further recruitment would not result in significant differences between the groups. Eight of eleven (73%) in the tracheal occlusion group and ten of thirteen (77%) in the group that received standard postnatal care survived.

Basically, performing an operation on the fetus to correct the hernia and moving the organs back to the abdominal area is not promising. If the baby has liver herniation, they likely won’t survive the surgery. If they don’t have liver herniation, the survival is not really better than postponing the surgery although the risk of in utero surgery remains high.

Tracheal occlusion is a technique that has been developed to place a balloon in the fetal trachea to force the liquid that the lungs create to remain in the lungs instead of escaping through the mouth. This increases the pressure in the lungs resulting in the ability of the lungs to grow and provide downward force on the organs that have herniated. Unfortunately, they haven’t shown this technique to provide far better results than the standard postnatal care used today.

I really believe some variation of this treatment will become the standard procedure in the future for CDH babies once it is perfected, but for us, it really wasn’t an option. You would need to contact one of the centers who have substantial experience with this procedure, like UCSF, if you wanted to pursue it.

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Predictors of Mortality and Morbidity

As the gestational age of your baby increases, so will the tests and measurements that you should understand. Up until 23-24 weeks, you probably won't get a lot of measurements specifically in regards to the CDH condition (exception could be echo tests on the heart which likely will happen before 23-24 weeks). The measurements below will likely be calculated using sonogram and MRI.

One word of caution about the studies you will read. There doesn't appear to be a great deal of coordination internationally or even nationally in regards to CDH cases and outcomes across the various centers handling these cases. Most of the studies have relatively low sample sizes which I think is part of the problem, understandably, with gaining confidence in any one of these predictors. When you also throw in the possibility of centers only submitting select cases and using different methods for measurements, it becomes extremely difficult to draw solid conclusions or compare your child's numbers with the studies. All this is to say one of the biggest traps you can fall into when you hear a measurement is to embrace it as a solid predictor for outcome when comparing it to these studies. If your center has experienced a number of these cases, I would generally take their interpretation of the results based on their experience with previous CDH cases.

Liver position:

Liver position (above or below the diaphragm) is an important determination with regards to outcome. There is debate around how much weight to put on liver position and predicted outcome, but there isn't much debate that it does complicate the situation if the liver is above the diaphragm. There are a couple of reasons why this presents a more serious condition. First, the liver is a very large organ that takes up a great deal of space in the chest cavity. When more of the liver is up, it decreases the amount of space that the lungs have in which to grow and mature. Second, the liver is a much more firm organ than the stomach or intestines. Since it doesn't "give" much, the lungs have a much more difficult time growing and expanding. Liver position will be classified as either "up" or "down" regardless of how much is present above or below the diaphragm.

** Refer to the study about % of Liver Up in Predicting Outcome for more information and how they determined 20% of liver herniation was a predictor for ECMO and mortality – this can be found on our blog. **

As your pregnancy advances, sonograms will be utilized to determine the positions of organs above and below the diaphragm, including the liver. In some cases, liver herniation is difficult to determine or it can appear that the liver is down. I would advise you to be cautiously optimistic about liver position until you have an MRI done somewhere between 24 and 28 weeks (typically). Some organs like the heart and stomach will jump off the sonogram screen, and you will easily be able to identify them. That's because these organs are echogenic which simply means they reflect sound waves due to having more liquid in them. The liver unfortunately is not as echogenic so it could have herniated, but not detectable on the sonogram. With an MRI, they will be able to see its position, whether it has herniated, and approximately how much has herniated as long as the images are good and don't have a lot of "noise" in them. The "noise" on the MRI's is a result of movement, and as you can imagine, telling the baby to be still is not a viable option.

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LHR (Lung to Head Ratio):

LHR is a much debated topic in the medical community and is simply the circumference of the baby's head to the size of the contra lateral lung (lung opposite of the defect so in LCDH, it would measure the right lung) represented in a ratio. Using ultrasound, they will locate a view of the chest that clearly shows all four chambers of the heart and the contra lateral lung in the same frame and then freeze the view. They will determine the size of the lung by multiplying the length of the longest diameter by the length of the longest perpendicular diameter. This number is then divided by the head circumference to obtain the ratio. It has been used as a predictor of mortality and most centers will determine this measurement when assessing the severity of the CDH condition. It is important to note that LHR will usually increase with gestational age, but this can be normalized by obtaining the Observed to Expected LHR ratio and/or Observed to Expected Total Fetal Lung Volume % I describe below. Some studies show LHR can be a predictor while others show less correlation between this ratio and outcome.

LHR of less than 1.0	=	Poor prognosis
LHR between 1.0 - 1.4	=	Moderate prognosis
LHR greater than 1.4	=	Good prognosis

The debate typically focuses on the LHR range of 1 to 1.4 or the "moderate" range. It is well documented that survival is not common with baby's who have an LHR less than 1. Likewise, most studies show very good survival rates with babies that have an LHR greater than 1.4. Most babies will fall into the "moderate" range and unfortunately, predicting survival for these babies is far more difficult. You will hear many in the CDH community say to not hang your hat on a LHR, and I would tend to agree, especially if your baby falls into the "moderate" category. We had an LHR above 1.4 throughout most of our pregnancy so I was a little shocked to find out how much ventilator support she actually needed. I think it is important to note two separate issues that I grappled with. First, I think the measurement itself has some fundamental flaws and is a rather crude measurement. The measurement only looks at the lung on a flat plane or one dimensional view. Have you ever seen a house and thought it was a really large house because the front of it was so wide. Your imagination allows to you to believe that the width of that house is in proportion to the depth so you are somewhat disappointed when you find out that while it is very wide, it has very little depth and therefore not a big house after all. LHR can work the same way as it doesn't measure the depth of that tissue and therefore doesn't tell you how much true volume is there. Let's take our case to further explain the "trap". At 29 weeks, our LHR was 2.0. This is a very healthy LHR and we were incredibly happy. We believed she must have a lot of lung tissue for a CDH baby. We were shocked when we reviewed the 2nd MRI at 33 weeks to find that she had 20 cc's of total lung volume. When we compared this to her twin, who had 80 cc's of lung volume, we came to the realization that she only had 25% of the total lung tissue that she should have at 33 weeks. This was extremely small and not what you would expect with an LHR of 2.0.

Second, the LHR predictor is a measure of survival or mortality, not how difficult the road to survival will be for a CDH baby. Again, we held on to the 2.0 finding (it was 1.4 at 26 weeks) and thought she would sail through the treatments and be ready to go home in 3-4 weeks. I wanted to point this out as it became a disappointment for us after placing so much emphasis on the LHR measurement. I firmly believe now that total lung volumes are much better indicators than LHR.

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Observed to Expected Total Fetal Lung Volume % (O/E TFLV %):

This is another indicator that is typically measured using MRI. Again, this is not a predictor to be used alone, but another piece of the puzzle. They will measure the size of each lung in cubic centimeters and total the two (example: Right lung - 8.49cc/Left lung - 5.28cc for a total of 13.77cc). The 13.77cc is the Total Fetal Lung Volume (TFLV).

To determine O/E TFLV %, they will then look at a "normal" fetus at the same gestational age using either FBV (Fetal Body Volume) or the TFLV and divide the actual TFLV by this number. (Example: 13.77 - "actual TFLV" divided by 26.15 - "the TFLV of a normal fetus at the same gestational age when the MRI was done" = 53%). 53% is the O/E TFLV %. ** Studies show that using FBV vs. normal TFLV is a little more accurate as a predictor.

Below are the results of a study of 53 fetuses and survival %:

O/E TFLV %	Survival %
<25%	25%
25-34	50%
35-44	70%
>=45	95%

Percent Predicted Lung Volume (PPLV):

PPLV is determined by subtracting measured mediastinal volume (the central compartment of the thoracic or chest cavity containing the heart, the great vessels of the heart, esophagus, trachea, phrenic nerve, cardiac nerve, thoracic duct, thymus, and lymph nodes of the central chest) from total measured thoracic volume (total area of the chest cavity) using MRI. In one study, the PPLV was significantly associated with extracorporeal membrane oxygenation (ECMO) use, hospital length of stay, and survival. In one study, all patients with a PPLV of less than 15 required prolonged ECMO support and had a 40% survival rate. In contrast, only 11% of patients with a PPLV of greater than 15 required ECMO, and survival was 100%. While this predictor looks promising, it is important to understand that the study size was only 14 liveborn babies which is an incredibly small sample. I'm not confident yet that you can extrapolate this out to make a solid predictor.

Observed to Expected Right Lung LHR Ratio (O/E LHR %):

As discussed, LHR alone is somewhat debatable in regards to predictability of outcome with CDH. To better refine this measurement, some are now looking at O/E LHR % to classify the degree of pulmonary hypoplasia. Basically, this works much like the TFLV % discussed earlier by comparing the measurements of a CDH baby with measurements of a non-CDH baby. The measurements are done on the contralateral lung (opposite of the side of hernia) so with a LCDH, the measurements are taken on the right lung. The observed measurement is taken of the right lung area in a CDH baby (example at 26 wks: 413mm) divided by the observed head circumference (example at 26 wks: 239mm). The result is the observed Right LHR of 1.72. This is compared to the expected Right LHR of a normal baby at the same gestational age which would be 2.57 (staying with the example of 26 weeks). If you take the Observed LHR and divide it by the Expected LHR (1.72/2.57) and then multiply it by 100, you will get the O/E Right LHR % which in this case would be 66%. Below is the table they came up with to classify the degree of pulmonary hypoplasia. In the example used

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above, this baby would be classified as having mild pulmonary hypoplasia, but this doesn't necessarily mean the baby will survive, but the odds are probably in his/her favor. It is important to note that this measurement is difficult because your doctor will have to look up the expected LHR for the exact time your measurement is taken, so this isn't something they will likely do.

<15%	-	Extreme
15% - 25%	-	Severe
25% - 45%	-	Moderate
>45%	-	Mild

All of these predictors focus on pulmonary hypoplasia, but they only give you half of the story and partly the reason it is impossible to gain confidence with any of them. Again, pulmonary hypoplasia refers to small or underdeveloped lungs. The methods above deal with identifying how small the lungs are and in some methods, how much smaller they are from "normal" lungs. Imaging and ultrasound allow for fairly reliable measurements, but they can't determine the other part of the equation which is the development or function. While it is true that there is some correlation between size and function, there is simply no test available or any method possible to test how well the lungs actually function. With isolated CDH cases, I think this is where you find some babies with a low LHR do remarkably well, while others with higher LHR's not do well on occasion. The volume of lung tissue may be on the better side of the spectrum, but the actual function at the alveoli level, the amount of surfactant present, the degree of muscularization of the pulmonary vessels, and the tightness of those vessels may not correlate to the size of the lungs. This is what makes the moderate range of cases so difficult to predict.

Your doctor or facility may use some of these measurements, but not likely all of them. I wanted to include all of them so you would have an idea of what current studies are focusing on. In our case, the lung volume showed around 25% - 50% survival based on one study and the LHR indicated a moderate prognosis.

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Long-term Complications

I know whatever the outcome is for our Baby Kamryn, she is truly a blessing to us and our family. To be completely transparent and honest, I must admit I wanted her to be "normal" when we brought her home. Another harsh reality of this situation is that there is a possibility that she won't be "normal" due to the condition and treatment after she is born. In the best case scenario, she will forever have a scar on her stomach that I know will one day be challenging as her image becomes more important in the teenage years. With the magnitude of everything going on, it seems a little silly that I worry about her avoiding two piece bathing suits or always facing the locker after gym class to not expose her scars. As a father, maybe the two piece bathing suit issue is a good thing. Regardless, those issues are minor compared to other scenarios that can include developmental and growth delays accompanied by hearing loss. Once again, you will find frustration in not knowing what complications will arise if your baby survives, but I have tried to put together the most common issues below.

- **Pulmonary issues** are common in CDH survivors including **chronic lung disease** which has an occurrence rate of 33% to 52% at discharge. In addition, nearly 50% of CDH survivors will experience some degree of impairment on pulmonary function tests. It is possible that your baby could require oxygen and medications, such as bronchodilators or inhaled steroids, when they come home and be more susceptible to conditions like asthma as they grow older. Pneumonia will occur in roughly 7% of CDH survivors within their first year of life. Pulmonary hypertension can continue for months or even years after birth. While some of these issues are a direct result of hypoplastic lungs and/or pulmonary hypertension, unfortunately some can be caused by the treatments they will receive to save their lives such as ventilation or ECMO.
- **Failure to thrive or grow** is very common with CDH and there are numerous CDH babies that are below the 5th percentile for weight even with feeding tube assistance. Babies with CDH require a lot of calories to grow and overcome their illness which can be difficult due to feeding issues. It appears this problem with growth is caused by Gastroesophageal Reflux Disease (GERD) more than the underlying chronic lung disease. This is one of the more common problems with CDH babies after they come home and can lead to a great deal of frustration. Some feeding issues can be overcome quickly, but some babies may take months or years to get over the gastrointestinal complications, vomiting, and aspiration that makes it difficult to get adequate nutrition for growth.
- **Gastroesophageal Reflux Disease (GERD)** is a common problem in CDH babies that is not only frustrating to overcome, but happens in 45% to 90% of CDH survivors and can contribute to other issues such as failure to thrive. This condition results in fluid and acids from the stomach moving up into the esophagus and can cause heartburn, vomiting, and feeding and lung problems. Pulmonary issues discussed earlier can be worsened by GERD due to aspiration. At the bottom of the esophagus is a group of muscles that make up the lower esophageal sphincter (LES) or valve that allows food and drink to enter the stomach, but should close to not allow stomach contents to come back up into the esophagus. These muscles also work in conjunction with the diaphragm. With CDH, the development of the diaphragm has been interrupted and the LES doesn't have the muscle control

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that it normally would to perform its function. Babies can develop an aversion to eating and can come home with a G-tube that was described earlier. GERD can be treated and controlled in most cases through medication although surgery is an option for severe cases.

- Volvulus is the abnormal twisting of the intestine which can cause an obstruction or loss of blood to a portion of the intestine. CDH babies have malrotation or the failure of the intestine to rotate properly in utero which sets them up for possibly having volvulus, most commonly in the small bowel. This condition may not present itself for some time and can cause vomiting of bile, abdominal pains, distention (swelling) of the abdomen, and/or bloody stools. This is a life threatening situation that needs immediate medical intervention. During hernia repair surgery, the surgeons will likely complete a Ladd's procedure which will correct the malrotation and this should keep volvulus from occurring.
- Scoliosis has been found in both young and adult CDH survivors and appears to correlate to the severity of the diaphragmatic defect. It is thought that the more sever the hernia repair is, the greater tension applied to the chest cavity and therefore more asymmetry. Honestly, I haven't heard from parents who have experienced this so I don't think it is common, but the research suggests there is a correlation.
- Developmental problems can also be associated with CDH. Some of these can work themselves out over time and some will be present as they grow into adults. Developmental problems that may be experienced can include a delay in rolling over, sitting up, crawling, and walking when compared to babies without CDH. More extreme issues could be present such as cognitive delays that are a result of the treatments associated with the care of CDH babies. Bleeding in the brain as a result of ECMO, overly aggressive ventilation strategies, and medications used to sedate and paralyze (this is necessary to keep the baby calm and still with all of the tubes they will likely have in the NICU), can contribute to long term effects on brain function.
- Hearing loss can be present in CDH babies, but isn't always evident while in the NICU and could be found months after discharge. It appears to happen in 5%-10% of CDH babies, and the cause is not well defined. The research shows that it is more likely to happen with babies who have received ECMO, but it has been present in babies who required only ventilation.
- Hernia recurrence has been shown to occur in 8% to 50% of CDH survivors with the highest occurrence in survivors with large defects requiring patch repair. While typically not an emergency situation, it will require an additional surgery and it is not uncommon for survivors to reherniate more than once. The opportunity for hernia recurrence is a lifelong risk.

All CDH babies are miracles regardless of the outcome, and survivors of this condition are nothing short of amazing given what they have to overcome. Whether your child has a struggle picking out bathing suits or is forever slower than his/her "normal" peers doesn't really matter in the big picture if they survive. If you ask any CDH parent who has lost a child, they would have taken any and all of the issues I listed above if they could have brought their baby home.

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Ventilation

As you research CDH and talk with your medical team, ventilation will surely be an important topic, and one I found very confusing at first. I truly didn't understand there were different types of ventilators or strategies that are used in CDH cases. The purpose of ventilation, in the simplest terms, is to get oxygen into the lungs to oxygenate the bloodstream and remove carbon dioxide from the system in the gentlest way possible. The information below will hopefully give you a basic understanding of ventilation so that you can further understand your facilities strategy for dealing with the respiratory distress your baby will likely experience soon after birth.

Ventilators are amazing machines although you will likely form a love and hate relationship with them. The longer your baby is on the vent, the more hate you will likely experience. Ventilators have come a long way over the years and are not nearly as abusive to the lungs as they once were. Actually, the machines themselves can still be terribly abusive, but the strategies used to operate them have evolved with a greater understanding of the culprits behind short and long term lung injury. While the strategies have evolved with a greater appreciation of how lower tidal volumes and low peak pressures can reduce lung injury and barotraumas, the simple truth is there will be some degree of lung damage when subjected to a ventilator of any kind. Part of the problem with ventilation is the process is completely opposite to how we normally breathe. Our lungs work by drawing air in which is also known as negative pressure. A ventilator pushes air in through positive pressure and this causes the damage. The degree of lung damage won't be known until later in life in some cases, but the alternative of not using a ventilator with CDH babies is putting them in a situation where they can't sustain life. In other cases, the resulting lung damage will reveal itself while in the NICU and can result in a critical situation.

The positive pressures that a baby receives on a ventilator can cause a pnuemothorax, which I have already discussed, and can lead to a far worse condition. Another complication that happens less frequently is a **pulmonary hemorrhage**. A pulmonary hemorrhage happens when the blood vessels in the lungs burst and blood fills the airspace. While the incidence is rare and decreases as the ventilator pressures are lowered, it can and does happen even at low ventilator settings. This condition is extremely critical and carries a high mortality rate if it occurs.

This is why there is a love and hate relationship with ventilation. The ventilator can literally save your baby's life, but you know the sacrifice will be some degree of lung damage. With the newer strategies in place, the damage in CDH babies is typically mild up to including asthma later in life. It's one of those aspects you will simply have to accept because there is currently no other option in the care of CDH babies than to use a ventilator, giving their tiny lungs time to grow and mature.

Tidal Volumes:
The volume of air inspired or expired in a single breath during regular breathing. For babies to stay within "gentle ventilation" strategies, these volumes should remain within 3 and 6. If they get higher than 6, the

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possibility of lung injury increases greatly. It is important to ask how tidal volumes are calculated with the vent your baby will be on. When we first started to look at the vent settings, I asked where on the monitor the tidal volumes were represented. It is shown on the Babylog 8000 at VT in ml's. The machine fluctuated every couple of seconds between 9 and 13 and I would flip out. What I didn't understand was that on this vent, true tidal volumes are calculated by the equation TV = VT/kg. The medical team uses grams for weight and our daughter was 2950 grams or 2.95 kilograms. If I divided 9 TV by 2.95 (I used 3 for simplicity), I came up with 3 for tidal volume. On the high side it was 13 divided by 3 which gave me roughly 4 and my heart stopped pumping outside my chest. The lesson I learned and hope to pass on to you is to simply ask before getting anxious. I truly can't count the times that I got freaked out by something I really didn't need to and wouldn't have if I had just asked.

Mechanical Ventilation:

This is artificial ventilation or breathing done using a ventilator (any kind). As discussed earlier, all ventilators operate on what is referred to as positive pressure. This is completely opposite of how normal lungs function (**negative pressure** or drawing air into our lungs) and this **positive pressure** (pushing air into the lungs) is the culprit behind the lung damage associated with ventilation.

Nitric Oxide Therapy:

This is a gas that is normally produced in the lungs to keep the blood vessels dilated. It is often used to dilate the pulmonary blood vessels to decrease the pulmonary hypertension, but there is conflicting evidence that it helps because most of the CDH pulmonary hypertension is structural in nature (fewer blood vessels carrying the same amount of blood or smaller vessels than normal) rather than functional tightening of the blood vessels (which is sometimes reversible). Therefore, Nitric Oxide can be used to relax the walls of the blood vessels of the lungs, but the lack of success is because it doesn't address the underlying problem of fewer blood vessels (Nitric Oxide can't make more blood vessels; it only dilates the ones that are present). Remember, there is additional muscle built up around the lung vessels due to CDH and these muscles sometimes spasm. This twitching can reduce blood flow into the lungs and Nitric Oxide can be used to calm them down. The actual relaxation of the blood vessels will assist with gas exchange (carbon dioxide and oxygen).

Conventional Ventilation:

Uses a combination of high respiratory rates (typically not more than 60 breaths per minute) and modest peak airway pressures (18-22 H2O). Conventional ventilators use positive pressure breaths and allow the baby to exhale passively. Either the pressure can be controlled or the volume delivered can be controlled. The small lungs of a CDH baby sometimes can't handle these aggressive peak pressures, and indications are that it can cause pulmonary damage while not increasing survival odds. The trend is to move to High Frequency Oscillatory Ventilation. While everything I read appears to note a trend in this direction, I want to make sure you understand that there is absolutely nothing wrong with conventional ventilation and it can be used very successfully with CDH. In fact, our daughter's complete ventilator assistance was provided with conventional ventilation using the Draggar Babylog 8000 plus in SIMV mode. There was a point where the positive peak pressures (Also known as PIP) were approaching 30 and they were ready with the HFOV, but she ended up not needing it. Note: A Gentle Ventilation (Gentilation) strategy that is described below can be used on a

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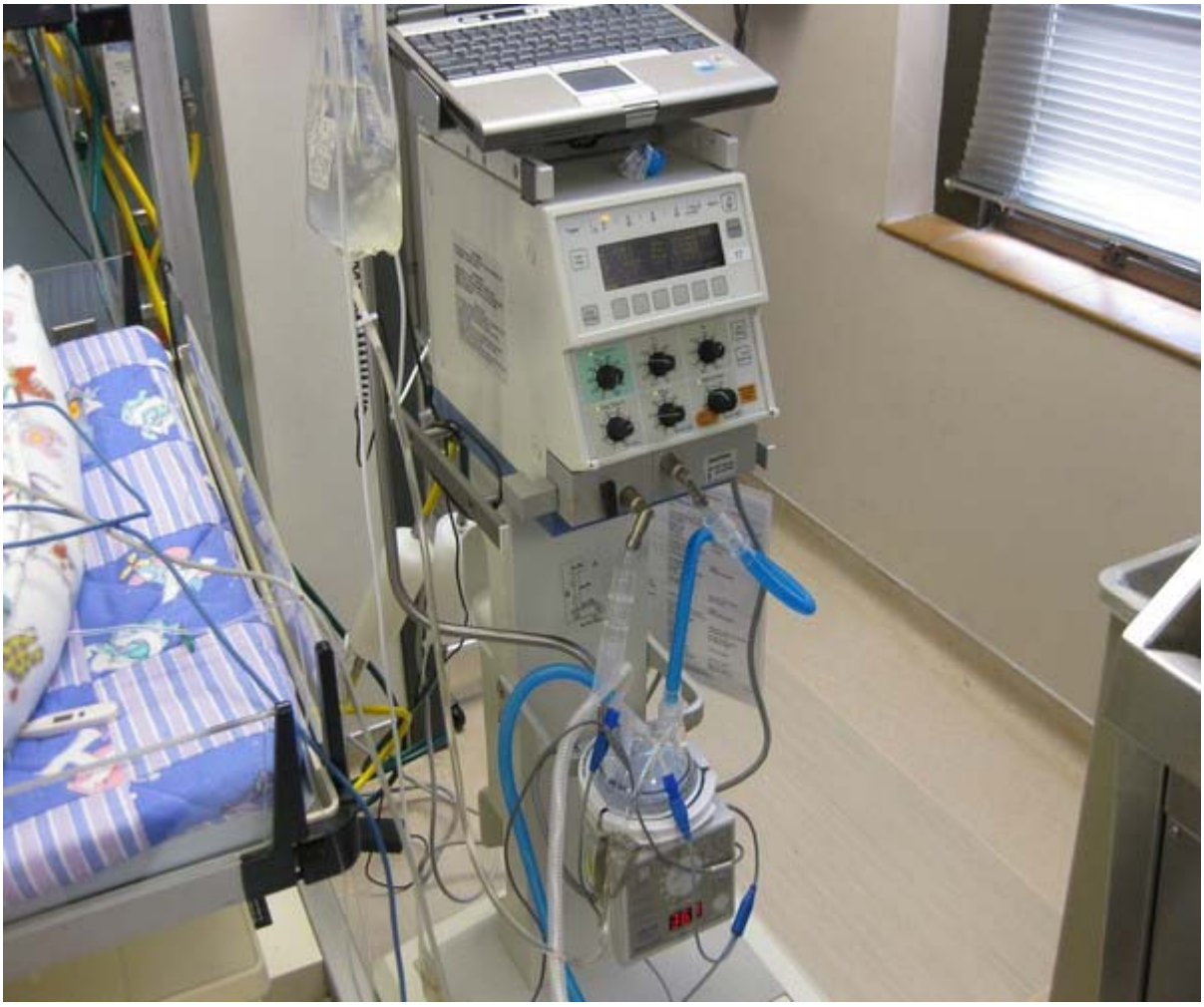
conventional ventilator, as long as, the tidal volumes are kept low. You can measure and control the tidal volumes on this type of ventilator to keep them in the "gentle" range.

Conventional Ventilator



High Frequency Oscillatory Ventilation (HFOV):

High frequency ventilation is a type of mechanical ventilation that employs very high respiratory rates (>60 breaths per minute) and very small tidal volumes (usually below anatomical dead space - dead space is air that is inhaled by the body in breathing, but does not take part in gas exchange). Both the inhalation and exhalation phases of the breaths delivered are active and achieved by a piston that moves actively in and out. The tidal volumes achieved are usually much lower than in conventional ventilation. High frequency ventilation is thought to reduce ventilator-associated lung injury (VALI) found in more aggressive Conventional Ventilation. I want to reiterate that if your child is placed on conventional ventilation, don't be alarmed. They will keep the pressures low to still be considered "gentle". ** HFOV is actually a bigger machine than the conventional ventilator shown above.

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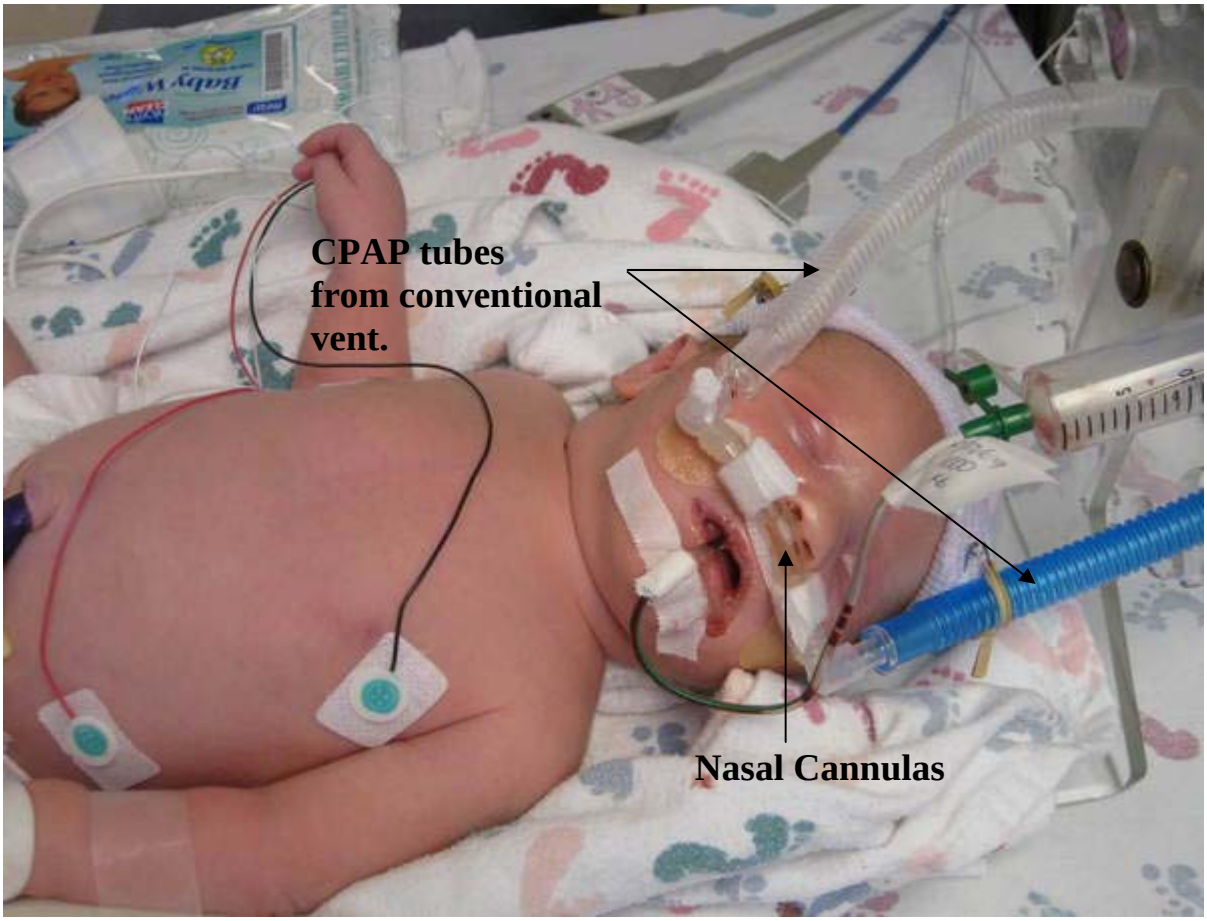
Gentle Ventilation (Gentilation):

First, this is not a specific ventilator, but rather a strategy using a HFOV or Conventional Ventilator. Older therapies ventilated CDH lungs to drop the carbon dioxide to low levels making the baby's blood alkaline in pH (an alkaline pH results in higher oxygen capacity levels and an acidic pH results in lower oxygen capacity levels). This dilated the pulmonary blood vessels. However, as described for nitric oxide above, the blood vessels are not really tight functionally, but are tight by structure. This means that it isn't as much of an issue of the vessels working, but rather the vessels that are there are small and underdeveloped. The higher ventilator settings used to drive the CO2 down causes more lung damage and increases the risk of a pneumothorax (a hole in the lung so that air escapes into the chest space between the lungs and the chest wall). This further compromises lung expansion and blocks cardiac output leading to low BP and severe worsening of the condition). Hence, in more recent years, the blood gases are either kept in the normal range or even allowed to have a higher CO2 to minimize damage to the lungs.

Continuous Positive Airway Pressure (CPAP):

A method of noninvasive or invasive ventilation assisted by a flow of air delivered at a constant pressure throughout the respiratory cycle. It is performed for patients who can initiate their own respirations but who are not able to maintain adequate arterial oxygen levels without assistance. CPAP may be given through a conventional ventilator and endotracheal tube, through a nasal cannula, or into a hood over the patient's head. CPAP may or may not be used after extubating a CDH baby during the weaning process. CPAP can be used as a step down technique from the ventilator or a transition to breathing room air.



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First Steps and the Months Ahead

If you have recently been told that your baby might have or does have CDH, you definitely feel like you hit a brick wall. This wasn't the way you drew it up when you thought about starting or adding to your family. First, if this was diagnosed in utero, your baby is fine right now in the womb. Your baby is not in any pain and he/she isn't struggling to breathe. If it was found in utero, you have time to get prepared and become educated about this condition. This part of the document has been the most difficult for me to put together because the roadmap to your baby's care can go in numerous directions. I only have experience with how ours played out, and I was extremely pleased with it.

The first step is to research as much as you can about the condition, and if you are reading this, you are on your way. The references at the bottom of this document will give you some great resources to learn about this condition, treatments, prognosis, etc. I would encourage you to research some of the leading centers across the country in the care of CDH babies. UCSF, Children's Hospital of Philadelphia, Cincinnati Children's, and Florida Gainesville are just a few of the centers that have a dedicated CDH program. Many families choose to travel and setup a home away from home at these centers because of their expertise. This will be a decision with which you will be faced, and you will need to start thinking about how realistic that is for your situation. We decided to stay in Dallas for a number of reasons, primarily the medical team, and this was the right approach for our family.

The next step is determining if you want someone guiding your care or if you want to seek out the doctors that will be involved on your own. My advice is to find a Maternal Fetal Medicine (MFM) doctor that you trust and feel like can be your advocate. We were blessed by what I feel has to be the best MFM in the country. Your OB/GYN should know of a good one, and this will be the doctor that can coordinate your care and navigate the medical world for you. We were referred to an MFM for our NT Scan (checks for Down's and other abnormalities) due to our age (36 years old) by our OB/GYN. The MFM found the CDH condition during this scan. He then coordinated everything for us (with the exception of us investigating Children's in Houston which we put together). Your MFM can answer most of your questions about CDH, help schedule your testing (amnio, Cardiologist for the heart ECHO, MRI), setup consults with the doctor's at the hospital, and possibly deliver your baby if they have privileges at the hospital where you deliver.

The months ahead will be an appointment, followed by weeks of anxiety, and then another appointment. The schedule below is what we experienced and is just an example. We were diagnosed very early (13 weeks gestation) and this schedule isn't necessarily how it is supposed to happen. If yours maps out differently, don't become alarmed. I am confident there is no single format or order for these appointments. This should just give you a possible scenario (Hi-risk = MFM Doctor):

Date	Appointment	# of Weeks Gestation
12/11	1st OB Appointment	10 weeks
12/29	NT Sonogram– Possible CDH	12 weeks
1/8	Regular OB Appointment	15 weeks

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1/21	CDH Confirmed – Sonogram	17 weeks
2/5	Regular OB Appointment	18 weeks
2/12	Amniocentesis/Pediatric Cardiologist	19 weeks
3/5	Hi-Risk OB Appointment	22 weeks
3/11	Regular OB Appointment	23 weeks
3/20	Children's Houston Consultation MRI/NICU Tour Surgeon/Neonatology Consultation	24 weeks
3/26	Hi-Risk OB Appointment	25 weeks
4/2	Regular OB Appointment	26 weeks
4/3	Children's Dallas Consultation NICU Tour Surgeon/Neonatology Consultation	26 weeks
4/16	Regular OB Appointment	28 weeks
4/17	Hi-Risk OB Appointment	28 weeks
4/24	Pediatric Cardiologist Follow-Up	29 weeks
4/29	Regular OB Appointment	30 weeks
5/7	Hi-Risk OB Appointment	31 weeks
5/11	Regular OB Appointment	32 weeks
5/20	Hi-Risk OB Appointment	33 weeks
5/21	2nd MRI	33 weeks
5/28	Regular OB Appointment	34 weeks
6/2	Hi-Risk OB Appointment	35 weeks
6/7	Admitted to Hospital	36 weeks
6/17	Delivery of twins	37 weeks
6/17	Placed on Conventional Ventilator (SIMV mode)	1 Day
6/19	Initial Hernia Repair	3 Days
7/17	Extubated and off ventilator	31 Days
7/23	Fentanyl (pain med) discontinued	37 Days
7/23	PICC line removed	37 Days
7/23	Methadone therapy started	37 Days
7/28	NG (Feeding tube) removed	42 Days
8/3	Discharged from hospital	48 Days

During the process of deciding which facility you will use for delivery, the option of touring the Labor and Delivery and NICU units should be made available. If they are not, I would strongly suggest requesting this and if you encounter resistance, I would question if this is the best location. You will be dealing with a great deal of emotions and uncertainty at the time of delivery and simply knowing where everything is located can take some of the stress off of you. A tour is also a great opportunity to see the doctors and nurses interacting with other babies and experience the NICU which was a lot for me to take in since I had never experienced this before.

Again, this is just an example of what you might see, but it will likely be a little different which doesn't mean it is wrong. I just wanted to give you a sense of what to expect about the number and types of appointments you might see.

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The Birth of your CDH Baby

You will spend many anxious months (not always as some CDH babies are born with CDH that was never detected in utero) wishing for the show to get on the road. As you get close to delivery, you may reach for the emergency brake like I did. Fortunately, there is no emergency brake. I say fortunately, because you are about to bring a precious child into the world and regardless of the outcome, I firmly believe he/she has a purpose and will touch many lives. I was asked at lunch one day before delivery if I was worried about Kamryn dying. It was a fair question and although I hadn't anticipated it, I had no hesitation in replying. I understand and appreciate that I could experience every parent's worst nightmare and lose my child. I choose to approach this situation much like I do when I play sports. Although the stakes are much higher with CDH and it seems ridiculous to compare it to sports, my approach is still the same. I know when the whistle blows at the end of my soccer games there will be a winner and there will be a loser. While I understand I could be the loser, I don't worry about losing until it happens. While I am stretching, warming up, and playing the game I am completely focused on winning and I expect to win until that final whistle blows. We are in a battle against CDH and I expect to win, no matter the up's and down's, until that final whistle blows. While I am scared for Kamryn and what she will have to endure, I'm not scared about her dying because I am focused on, and expect to win this battle.

In parts of this section and the next, I am going to discuss what I love dealing with which are numbers and machines. My wife hates them, but I love them and to say I became fixated on them is an understatement. Looking back, I think it was good to understand them to the level I did, but I wouldn't get as fixated on them as I did. As the days went on, I started to focus on trends, not occasional spikes. Therefore, I hope we can make an agreement at this point. I agree to help you understand the numbers and measurements you will want to see when you are in the NICU so you understand before walking in. I only ask that you agree to 1) realize that these numbers are not set in stone and your facility and doctors may have different ranges 2) you won't become fixated on them in the NICU and freak out if you see a particular number drop and 3) you understand that each week, and possibly each day, your baby will be a different baby and the tolerated ranges of numbers will change. You need to focus on trends, both up and down, not on little blips on the screen that don't really mean anything. You also need to ask what ranges the medical team will tolerate on a somewhat frequent basis. You will drive your doctors and nurses crazy if you don't understand these issues described above and that won't benefit anyone.

Immediately after delivery, the first priority will be to stabilize your baby since he/she will likely present with some level of respiratory distress. The severity of this distress won't be known in most cases until they are born. Immediately after birth, the medical team will place at least two tubes in your baby's mouth. One tube will be placed to intubate them and establish a clear airway for ventilation. The second tube will be the orogastric tube that will run down his/her throat to the stomach and will be used to decompress it by removing air and liquid. Once stabilized, your baby will be transported to the NICU. When your baby makes it to the NICU, the medical team will need to insert a number of lines and prepare them for the upcoming procedures. You will likely need to give them an hour or so before you can be next to your baby.

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Let's first begin with what you will likely see when you make your first trip to the NICU and what the purpose of each device and machine plays to stabilize or monitor your baby.

Intubation:

Newborns with CDH are intubated immediately to avoid bag-mask ventilation that can cause inflation of the bowel that has herniated into the chest. Intubation involves inserting a flexible tube (endotracheal tube – ET tube) down the trachea to secure an airway. The tube can be connected to a number of machines to provide various degrees of breathing assistance including conventional ventilators and high frequency oscillating ventilators (HFOV).

0rogastric Tube:

This tube is placed in the mouth and down into the baby's stomach to decompress it by removing air and liquid from the stomach. The tube is connected to a small collection device which is then connected to a suction pump. At some point, the suction pump will be disconnected and they will allow drainage to be handled by gravity. This will be the first step in preparing for feedings down the road.

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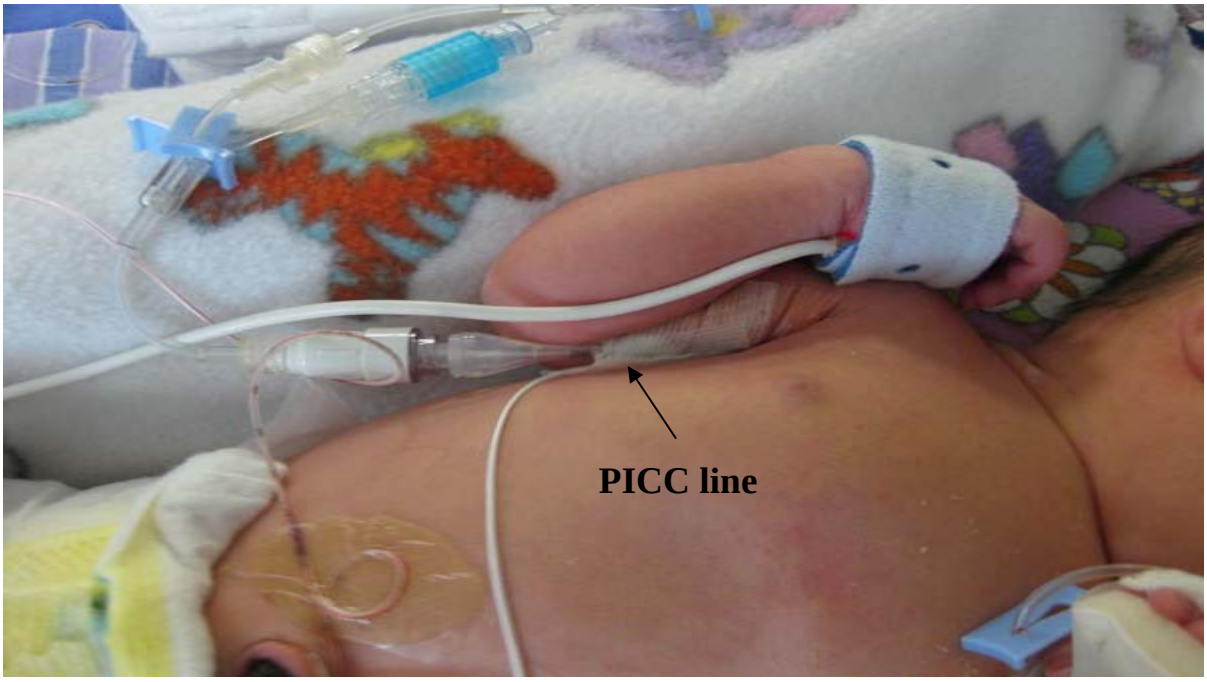
PICC Line:

A peripherally inserted central catheter (PICC) is a type of intravenous line that can be used for an extended period of time, but it is different than what you normally think of in regards to a regular IV. It is inserted into a peripheral vein and then pushed through this vein into gradually larger veins until it rests right next to the heart. This line will typically be inserted into the right arm just below the arm pit, but could be placed in other areas, including the babies head if there is difficulty threading the tube in the arm. To make sure the line is placed in the proper location, the medical team can use ultrasound and chest x-rays.



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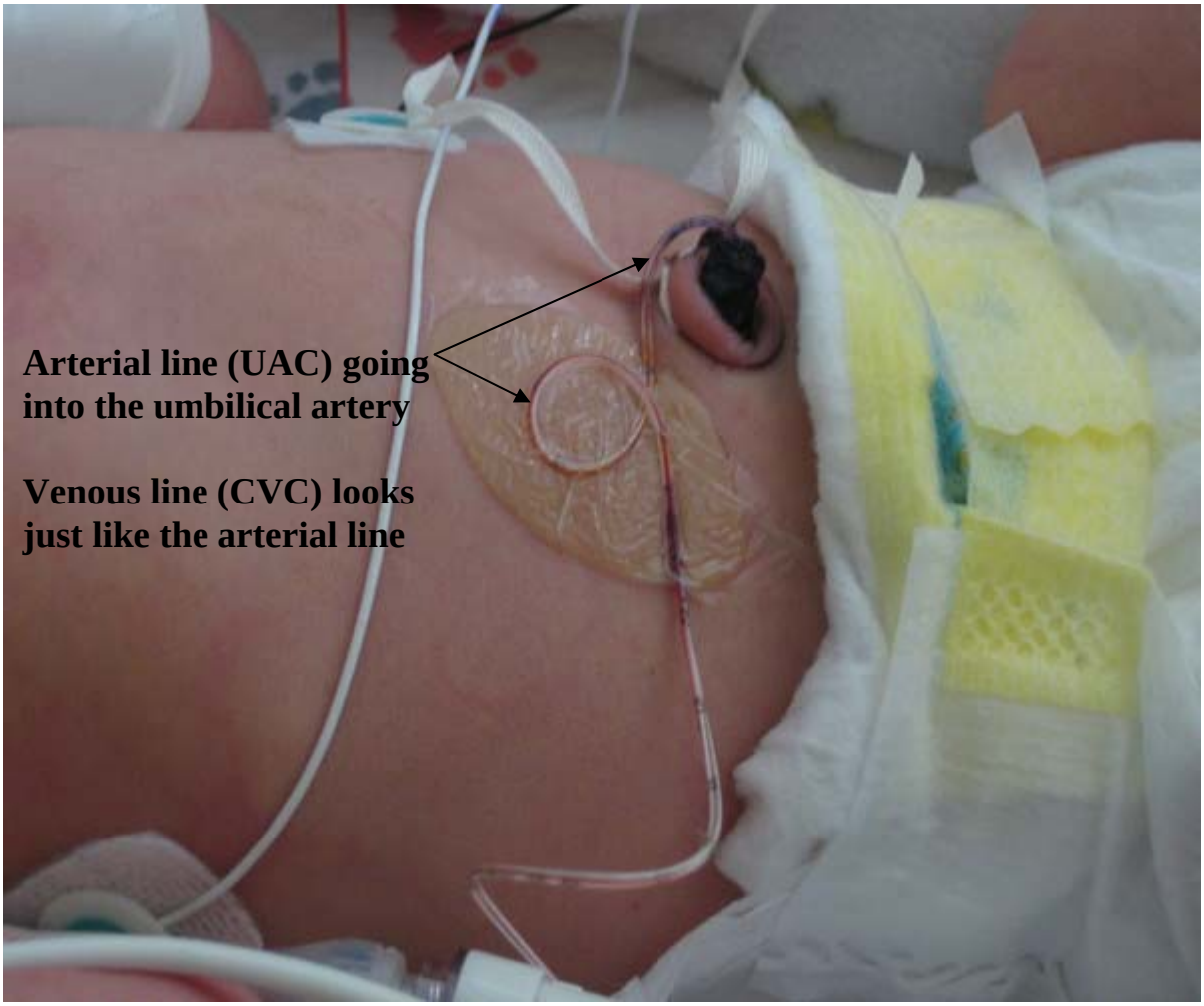
Arterial Lines:

Arterial line or umbilical arterial catheter (UAC) is simply a catheter inserted into an artery which will typically be in the baby's umbilical artery. The line can be used for blood pressure readings and to take arterial blood gas measurements which I will discuss later.

Venous Lines:

A central venous catheter (CVC) is inserted into the baby's umbilical vein and is used to administer medications and fluids while also providing a port to run blood tests. This will likely be placed before the PICC line as it is easier to insert and you don't need ultrasound or x-rays to ensure proper placement.



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One of the issues that your baby might encounter is a drop in hematocrit due to the numerous blood draws that are required to monitor blood gases. In the picture above you can see the port that connects to the UAC and this where they twist on a syringe to draw out blood. Hematocrit (Ht, HCT, or crit) is simply the proportion of blood that is occupied by red blood cells represented by a percentage. Red blood cells are important because they are the primary means of carrying oxygen throughout the body. Actually, it is the hemoglobin within the red blood cells that bind to oxygen and then are released as they are squeezed through the capillaries. If the hematocrit level falls too low, a blood transfusion will be necessary. To minimize the amount of blood drawn from the arterial catheter, a VIA machine might be used. The machine is hooked up to the arterial catheter line and draws just the amount of blood necessary to measure the gases and then pushes the excess back into your baby's system. This is much more efficient and will help the hematocrit levels from dropping too much, but the machine itself is temperamental and doesn't always work right. Below is the machine they used on our daughter with mixed results.

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This is where I should start putting a fair amount of disclaimers. Your baby could have numerous other tubes, lines, and machines in addition to what I have described. The information above is meant to set the stage for what you will most likely see, but doesn't account for additional devices which could be necessary such as a chest tube.

Now that you are prepared for what you will see, let's discuss what the medical team will likely be focused on (Disclaimer: Your baby may have additional issues such as heart defects that they are also working against and I can't possibly account for every situation. The information below is in reference to babies who have isolated CDH.)

The balancing act of keeping your baby oxygenated will soon begin since their lungs will likely not be able to accomplish this on their own. This is where it gets tricky. Your medical team will have to force oxygen into your baby to oxygenate the blood, and in turn the organs, while pushing the carbon dioxide out. Therefore, they will try to find a good combination of oxygen percentage setting and a ventilator setting which is how hard they will push the air in. Too much ventilation into the baby's lungs can cause short and long term injury including a **pnuemothorax** (A hole in the lung so that air escapes into the chest space between the lungs and the chest wall) or **pulmonary hemorrhage**. This can quickly put your baby into a grave condition so a lot of care will be taken to avoid this situation. At the same time, if they don't get enough oxygen into the blood, organs

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can be injured with severe long term complications. The most serious of these organs is the brain and they will monitor the oxygen saturation of the blood to determine if it has sufficient oxygen to nourish the cells within the brain. I say the brain is most critical for obvious reasons, but also for not so obvious reasons. Most other organs in the body have a slightly greater tolerance to oxygen deficiency than the brain does. This is where pre-ductal and post-ductal saturation levels come into play and a basic understanding of the two can be helpful.

I discussed the aortal arch and the ductus (flap) that allowed blood to flow through and bypass the baby's lungs in utero in the pulmonary hypertension section. Just before (pre) this duct or flap there are tubes (tubes – this is another reason I wasn't considered for medical school) taking oxygenated blood to the brain and upper extremities. Just beyond (post) the duct are tubes taking oxygenated blood to the lower organs and lower extremities. Your medical team will still be concerned about post-ductal measurements, but pre-ductal percentages are most critical to ensure damage is not done to the brain. Within a few hours, they would like to see these numbers in the 85% range or higher. As time goes on, they will want the saturation to be in the 90 to 100 percent range.

To get the pre-ductal saturation measurement, they will likely take it from the right finger or ear lobe using a pulse oximeter. It's actually a pretty cool little device and you have likely seen one before. The oximeter will likely be a band that has red LED's on one side and a photodiode on the opposite side. The LED's shoot light through the finger or ear lobe which comes in contact with red blood cells before being detected by the photodiode on the opposite side. The amount of light that does or doesn't reflect off the red blood cells (actually it is looking at hemoglobin which is a protein whose primary purpose is to transport oxygen to organs in the body) and picked up by the photodiode can be converted into a percentage of oxygen saturation in the blood (100% being complete saturation). Normally, this percentage is somewhere between 95% and 100%. The oximeter on the right finger, wrist, or ear lobe is measuring the pre-ductal oxygen saturation (blood going to the upper extremities and the brain).

Post-ductal measurement will also be monitored in the same way although that monitor will be placed on one of the feet. Both of these saturations will hopefully be in the 90 to 100 percent range and also close together, meaning both of them measuring 96 for example. If they are far apart (our baby had measurements that were 10 or more % points a part in the first few hours), then it would indicate some level of persistent hypertension and shunting across the PDA. The first day I watched pre-ductal saturation go from 91% down to 83% and completely freaked. I wanted to shout at someone to crank up the oxygen! This is where you can drive yourself crazy and for no good reason. Remember, the trend is your friend because it will more accurately tell you how your baby is doing. It really isn't a big deal if the saturation falls into the low 80's for a while, unless that becomes the trend. Likewise, you shouldn't scream with excitement if the saturation has been in the 80's and jumps up to 95% for a while, unless that becomes the trend (don't literally jump up and down as they tend to frown on that in the NICU). The picture below shows what a typical pulse oximeter looks like.

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At this point, you know oxygen saturation is important because the lungs will likely have a difficult time doing this on their own. The next issue is blood pressure because we need to move that oxygen around the body. When you think of blood pressure, you likely think of 120/80 being normal. There is actually a third number that we as adults don't use called the mean blood pressure, but it is critical to your baby. The mean blood pressure needs to be above 35 and preferably at or above 40. It's possible, and likely, that this mean pressure will fall below 35. Immediately after surgery, our baby's pressure was down to 31 for a while. It became a trend so they gave her medicine to constrict her vessels which in turn increased her blood pressure. The mean blood pressure is another measurement that you can find on the monitor.

Surgery

Speaking of surgery, this was clearly one of the events that I wasn't completely prepared for. First of all, surgery could be days or weeks after delivery and the medical team will be looking for that window of opportunity when your child is stable and can tolerate it. The surgery itself took about an hour and a half which I expected, but the resulting swelling caught me off guard. Therefore, I thought I should prepare you for what you might encounter. During surgery, your baby will be given a large amount of fluid which they will likely retain for some time. This swelling isn't at all helpful to their situation as it can compress the lungs and make the body work harder to rid itself of the extra fluid. There is a honeymoon period immediately after surgery where things seem to be pretty stable, but our honeymoon period was pretty short. Our daughter was soon so swollen that we couldn't recognize her and she honestly looked like a different baby. She wasn't able to open one of her eyes and they turned her often due to the fluid collecting on the side she was laying on.

Removing this fluid is critical to your child getting better and there is too much to remove for the baby to do it on their own. This is where a diuretic will come into play to get them to "pee" off the excess fluid. They will likely already have a catheter inserted to assist with this and to measure the output. The most common diuretic used is called **Lasix**, but there are others out there that may be used. This process is slow and it literally took a couple weeks for everything to clear up. Interestingly enough, our daughter flipped the switch to getting better just when the fluid was completely gone so I think there is a correlation there. You will soon be asking, "How is he/she peeing?" on a very regular basis. Another interesting situation is the fluid build up that

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takes place in the chest once they move the organs back down below the diaphragm. Due to the space being empty, it fills up with fluid and you can see it clearly on the chest x-rays. This fluid will work itself off and be absorbed over time. As it is worked off, the shifting of the heart to the correct location will occur and the lung on the defect side should begin to take up that empty space. They can tap the chest and drain the fluid, but this procedure can cause other issues so they chose not to do that in our case which seemed to work just fine.

When you walk in to see your baby each time in the NICU you will be focused on that precious baby and the tubes and lines become almost unnoticeable. You will be distracted constantly by the continuous graphs and alarms, trust me you can't help it, on the MONITOR. This is probably a good time to introduce you to daily life in the NICU.

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Daily Monitoring in the NICU

It is truly one day at a time and often it feels like one minute at a time. The rollercoaster will kick into high gear soon after delivery and you should prepare yourself for ups and downs. The important thing to remember is the trend is your friend, whether positive or negative. What I mean is that you can trust the trends far more than you can trust the sporadic ups and downs. For instance, every time the Care Flight helicopter landed, our daughter would get agitated and de-sat (go down on oxygen saturation on the monitors) on us. At first I would get flustered and want to pump the oxygen into her. It's frightening to watch. Our daughter was easily agitated and I had to learn to let go of these minor ups and downs. The trend is what I learned to put faith in.

My wife wasn't concerned with what I am going to talk about in this section and you may not be either. She relied on me to tell her if Kamryn was doing well or not so well and that was my job. To do my job well, I needed to understand everything I could about this condition and about the environment. I could tell her how well Kamryn was doing based on the numbers and relay that information as either "trending positive" or "having a setback". Her job was to nurture our daughter and tell me how Kamryn was really doing just by observing her behaviors each day. I think she could tell if Kamryn was agitated, tired, fighting, etc. We made a great team. Whether you have a desire to understand this section really doesn't matter in the big picture. If you have a solid medical team, they will handle this role for you. My wife (and I to a lessor extent) had the most important role and that was to nurture our little girl through this journey.

I can almost guarantee there will be setbacks. It's just a cruel reality on this rollercoaster and I can't prepare you for them adequately in this document. Just take one day at a time and work with your spouse/partner as a team. My "breakdown" came 12 days after Kamryn was born. I had done well up to that point keeping my gameface on and hadn't shed a tear over the situation. I was too distracted by the numbers, stats, and x-rays to allow the emotional side to take over. That all changed one morning when I was by myself next to Kamryn's bed. They weaned the versed which is a sedative (not a paralytic drug) and it had served to keep Kamryn knocked out for the previous 12 days. Kamryn had also stalled on her progress and we weren't trending positive anymore. With the versed gone, my little girl was active and I could easily observe her discomfort with the tubes and environment surrounding her. For the first time she looked at me completely alert and I swear it felt as if she was asking why her daddy wouldn't help her. She couldn't understand why I, her protector and advocate, wouldn't take the tubes away that she appeared to be gagging on occasionally. I talked to her for hours that morning, probably trying to put my own sense of guilt behind me. My mind told me that it was silly to feel guilty as these tubes were supporting her life, but my heart felt as if I had betrayed her trust of protection. It was then that I simply lost control of my emotions and felt more helpless and sad than I ever had before.

After getting home and posting on the blog, I once again lost control. My wife was there this time to pick me back up and help me get my gameface back on. I wanted to share this because you too will have a breakdown, if not more than one. I don't know when that will be or what the trigger will be. I can't adequately prepare you for the feelings you will go through. My advice is to know it will happen and to be there for each other just as you are for your baby. Ok, let's get to know the machines and first up is the monitor.

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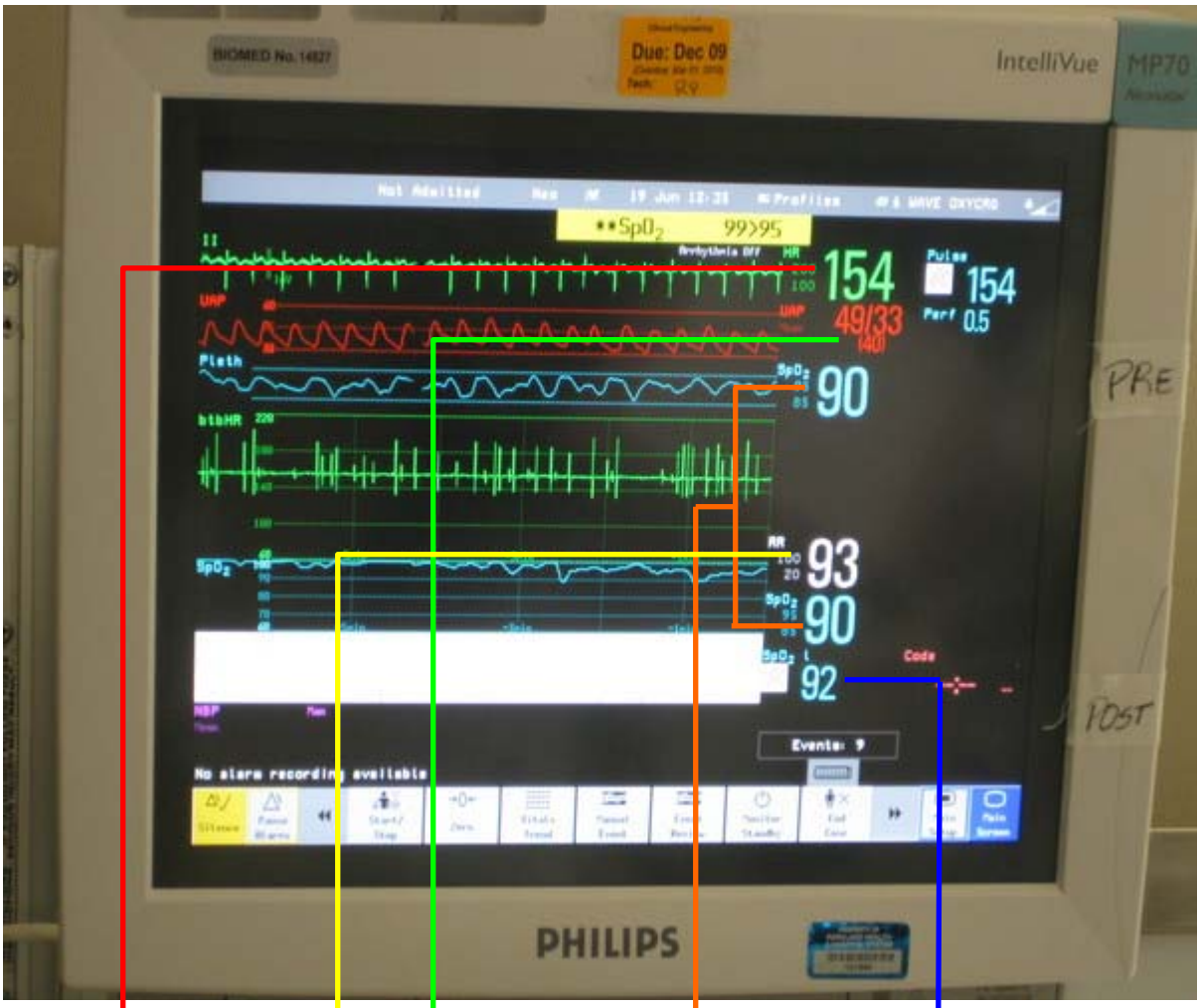
The Monitor



Heart rate
(This can fluxuate between the 130's to 170's and I never paid much attention to it.

Blood pressure
The mean is in (xx) and here it is at 40. This is measured using arterial catheter.

SpO2 or oxygen saturation. There may be just one number or two like there are here. These two numbers are the exact same thing. Notice the tape on the right side of monitor. "Pre" is on top, so the top numbers are pre-ductal sats.

SpO2, but this is on the bottom so it is the post-ductal saturation. Notice the "post" tape on the right of the monitor.

Respirations per minute. We are pretty high here as we would like to see this closer to 60. So many variables can affect this I tried not to fixate on this.

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That is basically the monitor that we peaked at most often and tried to not get fixated on. If I looked at it right now it would tell me a couple things. First, her heart rate is fairly normal. I know based on history that she will go between the 130's and 170's so 154 looks fine. I typically move immediately to the pre-ductal oxygen saturation levels and right now she is at 90%. They would like to see this between 95 and 100 percent, but I wouldn't be alarmed at 90% or even in the low 80% range for brief periods. It needs to be above 85% and this also moves up and down every second. If I would have snapped another picture, it very well could have been at 95%. Next, I look at the post-ductal saturation and she is at 92%. I'm definitely not concerned about this being below 95% because her pre-ductal is at 90%. Actually, I'm happy to see the pre and post-ductal numbers close together. This tells me that there probably isn't a lot of shunting of blood through the PDA going on right now in the heart, which is good. If these numbers were farther apart, like greater than 5 or 10 for a period of time, I would question if we had some shunting going on from increased hypertension (The numbers being close together doesn't mean there isn't hypertension. Trust me, she had hypertension when this picture was taken but it wasn't significant at this point.). If you remember back to the hypertension section, one aspect of fetal circulation is shunting across the PDA (Patent Ductus Arteriosis). If you see the post saturation lower than the pre saturation number by greater than 5 or 10 for an extended period of time, it could indicate this flap still hasn't closed due to the pressures. If this does occur and becomes a trend, they will likely request an echo procedure or ultrasound of the heart. In the example above, the pre is lower than the post which isn't really possible in reality unless there is a heart abnormality. Therefore, I chalk this up to the sat monitors just not being exactly accurate.

Her mean blood pressure is at 40 and just where we want it. Actually, we want to see it above 35, but 40 or higher helps everyone smile much more. Finally, I look at her respirations. This number is actually high right now as we would rather see this in the 50's or 60's. I am not too concerned as this number goes up and down all day and could simply mean she is agitated or stimulated or is too hot or cold in her bed. I also don't put a lot of faith in this reading because it isn't always accurate. If you want to know the true respirations, take a peek at the ventilator monitor which will give you a true reading all of the time.

Every once in a while, your medical team may throw you a curve ball and will keep you on your toes. For example, notice anything different about the monitor on the next page?

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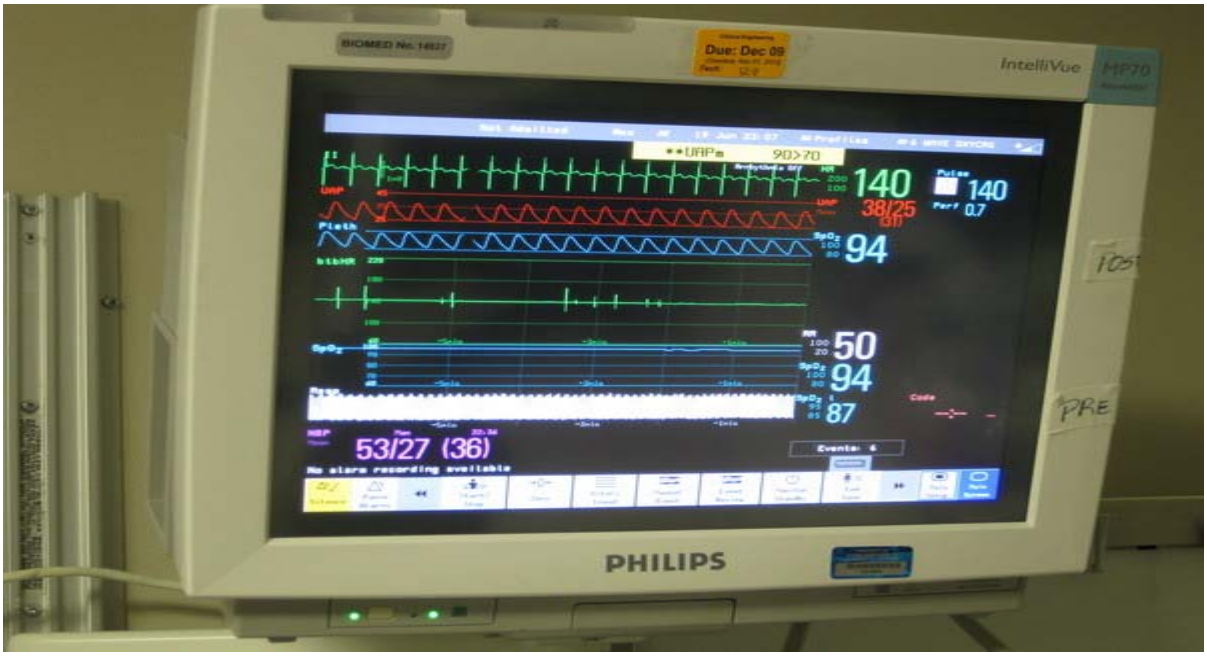

Yes, there is a new number on the monitor in the lower left hand corner and it is actually another blood pressure reading. This picture was taken just after surgery. It's hard to see, but the red numbers in the top right are reading her blood pressure from the umbilical arterial catheter (UAC) and the mean pressure is 31. That is a low reading and could be the actual pressure, but it could also be a small clot in the line throwing off the result. The pink number is a blood pressure cuff they put on her and it is reading 36. We are still on the low side, but they are using this as a second measurement to qualify the UAC reading.

While the additional blood pressure reading is new, that's not the only change. If you look on the right side of the monitor, do you see the pre and post-ductal tape? They are switched and the two large SpO2 numbers are post-ductal readings while the single smaller SpO2 is the pre-ductal reading. Nothing is wrong with the switch, but again, pre-ductal is more important that post-ductal to ensure the brain is nourished with oxygen (the other organs in the body are more tolerable to oxygen deficiency than the brain). The pre-ductal saturation is at 87 while the post-ductal is at 94. Again, the pre-ductal can't physically be lower than the post unless there is a heart abnormality involved. She doesn't have this additional problem so the monitors are simply not picking up accurate readings. If we were to see the pre-ductal at 94 and the post-ductal at 87, it would likely indicate a some amount of shunting continuing to happen across the PDA as a result of significant hypertension taking place. Remember, these numbers are real time and they change every second just like they would in you and me. If the saturations go down to the low 80's for a few seconds, don't become alarmed. If they stay there for some time, your medical team will make adjustments to the ventilator settings (likely increase the oxygen % to get the saturation back up).

Finally, you will walk in one day and just see one saturation number, likely the post-ductal saturation and you shouldn't be alarmed. There comes a point where the shunting should diminish and they will just monitor the post-ductal. Remember, in theory the post-ductal saturation should never be lower than the pre-ductal saturation. If the shunting is gone, they can just monitor this one and know that the pre-ductal is at or above the post.

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Arterial Blood Gas (ABG)

Now that you understand the real time monitors, I'll move on to an area that I think is more important and what will drive a lot of the strategy they use for you child. Before I truly became engaged with all of this, I thought our medical team just needed to push oxygen into our baby's lungs and monitor how well she was saturated with oxygen. They would continue doing this for weeks as her lungs would grow and as long as the monitors showed good saturations, we were fine. I didn't even have half the picture. Arterial blood gases (ABG) are critical in guiding the medical team's decisions on care and strategy, so much more than the monitor I just showed you. ABG's are primarily used to measure acidity, oxygen, and carbon dioxide in the blood. The blood comes from the artery (typically, and especially in the beginning) rather than a vein as you are used to when you have blood drawn. The reason they take the measurements from the arterial line is to measure the acidity, oxygen, and carbon dioxide in the blood after it has left the lungs, but before it has reached any organs. As time goes by, they may lose or choose not to re-do an arterial line and get venous blood instead (heal stick). In the beginning, it will definitely be arterial blood. This test will indicate how well the lungs are able to move oxygen into the blood, carbon dioxide out of the blood, and keep the critical PH level in a very small window.

Understanding ABG's is nothing short of difficult and caused me a lot frustration. Honestly, I finally gave up trying to truly understand how the PH balance in blood works and felt content having a general understanding which I will try to explain here. Basically, for metabolic functions to work correctly within the body and at the cellular level there is a small window that the PH needs to stay within. If the PH gets out of balance, metabolic functions are compromised and left uncorrected, the result can be death. PH can get out of balance due to either metabolic or respiratory factors. Given the CDH condition and to not make this any more complicated than it already is, let's assume that the PH imbalance that your child will have is due to respiratory factors.

Your child's PH will likely be outside the normal window of 7.35 and 7.45 as it is directly related to how much oxygen and carbon dioxide is being transferred within the body. The PH range is actually 1 to 14 with water having a PH of 7 which is completely neutral. If the PH is below 7.35, your child has an acidic PH and if the PH is greater than 7.45 he/she will have an alkalosis condition. Your body, and your baby's body, has natural defenses against this imbalance to keep it in check. One defense is respiratory and the other is renal, or kidney.

When cells metabolize, they give of carbon dioxide which is then transferred to the blood and carried to the lungs where it combines with water to form carbonic acid. The amount of carbonic acid will trigger the blood PH to either rise or fall. This change triggers the lungs to either increase or decrease the ventilation until the carbon dioxide is back to normal. Amazingly, this adjustment happens within 1 to 3 minutes. This is the first natural defense to keep PH in check.

The second attempt to keep PH in check involves the kidneys. When PH levels decrease, the kidneys will retain bicarbonate and when PH increases, the kidneys will excrete bicarbonate through urination. The kidneys are very effective in regulating PH levels but they are slower than the respiratory defense, taking hours to days to correct PH imbalances. For effective stabilization of PH, both systems need to function well and with CDH, the respiratory system isn't able to do its part. When both have engaged and are working to correct the problem, you are in a fully compensated state.

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With CDH, you will typically see a condition of respiratory acidosis. This means the PH level will drop due to increased carbon dioxide in the lungs. If carbon dioxide gets to high, the PH levels will get too far out of balance and if the PH drops below 6.8 for an extended period of time, metabolism will be hindered at the cellular level. The solution to rid the body of carbon dioxide is simple in theory. Your lungs would increase the rate and depth of ventilation to pump the CO2 out. Unfortunately, your baby's lungs won't have the ability to do this job. Plan B is so simple in theory, but incredibly difficult in reality. The ventilator will be used to push the CO2 out and this will do the job, but can have enormous consequences to the lungs in the form of short and long term lung injury. This is where "gentle ventilation" comes into play.

Your medical team needs to accomplish two primary objectives for an extended period of time while the lungs grow and develop to a point where they can fully support life. First, they have to keep the blood oxygenated so that the organs are not damaged and second, they need to keep the blood's PH level in a range where metabolic functions can occur. Keeping the blood oxygenated isn't as difficult as they can simply increase the oxygen percentage pushed into the lungs by the ventilator. The PH balance is a different story. When the PH level drops, they will increase the Peak Airway Pressure (also know as PIP on a conventional ventilator) to drive out the carbon dioxide. This in turn will hopefully cause the PH to rise into an acceptable window (ask your medical team what the window is as it changes daily, but likely will be 7.25 or 7.3 and up to 7.45). If it doesn't, then they will need to increase the pressure, but they can only go so high before they damage the lungs or cause a pneumothorax. Therefore, a gentle ventilation strategy means they will apply just enough pressure to get the PH level into a "tolerable" range, which could be as low as 7.25, while still allowing carbon dioxide levels to remain higher than desired into the 50 and 60 range. With a respiratory disorder like CDH, your child will generally be in a respiratory acidosis state needing correction. In this state, PH and carbon dioxide have an inverse relationship. When the carbon dioxide level rises, the PH will typically drop. If they correct the CO2 problem, the PH will generally return to the tolerable window. This balancing act will go on everyday and there will be constant tweaking on the vent to get this right. I felt at times like we were chasing a rabbit and just when we would corner the rabbit, he would get away and we needed a new strategy. Below I will discuss some ranges that your medical team will likely use, but remember, these ranges change as your baby changes. **Please make sure to discuss tolerated ranges often with your medical team and don't take these numbers as being definitive.**

ABG's will be conducted at different intervals throughout the day and night depending on how your baby is doing. It could be every hour, 2 hours, 4 hours, 6 hours, etc and each day could be different. You will become very focused on these numbers so you should understand what each one means. If you focus on anything, it would be the blood gases far more than the monitor I showed you earlier. Here are the five key measurements that they will take on a regular basis.

PH - The symbol 'pH' is used to represent the acidity or alkalinity level. PH measures the hydrogen ions in the blood. Typically a PH below 7.0 is acidic, while a PH is greater than 7.0 is alkaline. For newborns, the medical team would typically like to see a PH at or above 7.25 (7.25 – 7.35) or slightly alkaline. This is one of the two most important readings on the ABG and will be used to drive decisions and strategy. If this is outside the window, the likely culprit is PCO2.

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PCO2 – This represents the partial pressure of carbon dioxide dissolved in the blood. To understand partial pressure, we can use an example of blowing up a balloon. When you blow air into a balloon, you are increasing the pressure inside the balloon by introducing oxygen, carbon dioxide, and nitrogen from your lungs. If you were to just measure how much pressure was in the balloon from just the oxygen molecules, you would have the partial pressure of oxygen within the balloon. This works the same way within the blood and alveoli. Each molecule in the blood occupies space and puts out pressure. The partial pressure of PCO2 is simply how much pressure the CO2 molecules are exerting in that blood sample which gives you a proportion of how much carbon dioxide is in the sample. With CDH, this will likely have an inverse relationship to PH. Your baby's lungs will have a difficult time getting rid of CO2 on its own and will need a ventilator to push the CO2 out. If they aren't pushing hard enough, CO2 will rise which will drop the PH. They will have to put more pressure through the lungs while trying to keep tidal volumes between 3 and 6 to get rid of the CO2. If successful, the PH will likely return to tolerable ranges. If unsuccessful, they will have to push more air, but being vigilant to not damage the lungs. Outside of PH, this is where the focus will be and what will typically drive ventilator settings. It is important to note that you can't directly affect PH levels. You have to indirectly correct them by dealing with other variables such as PCO2.

PO2 – This represents the partial pressure of oxygen in the blood. Again, this would be the pressure of any one gas on the walls of a container if it were the only gas present. In PO2, it is the oxygen pressure that is being measured. Partial pressure can also be related to dissolved gases, specifically when referring to blood. The partial pressure of a gas dissolved in blood is the partial pressure that the gas would have, if the blood were allowed to equilibrate with a volume of gas. I know, it's a bit confusing. Basically, as the proportion of dissolved oxygen in the blood changes, either more or less, so would the pressure it exerts. The higher the partial pressure of oxygen (PO2), the higher proportion there is in the blood. This works the same for the partial pressure of carbon dioxide (PCO2).

HCO3 – This represents the bicarbonate level in the blood. I didn't pay as much attention to this measurement as I did to the previous three items. Bicarbonate is the main form of carbon dioxide in the body. It is produced when carbon dioxide and water meet in the lungs. HCO3 is not an actual measurement in the blood, but actually calculated using the PH and PCO2 in the sample. Remember, your body is in a constant state of balancing acid and bases to keep the PH within a 7.35 – 7.45 window. When the PH gets out of that window, the respiratory system and kidneys kick in to regulate it. HCO3 is either released by the kidneys or reabsorbed in an effort to maintain proper PH. Therefore, the bicarbonate level in the blood will typically correlate to the PH. As HCO3 rises, so will the PH.

Base Excess – Base Excess is actually not something they measure in the blood, but rather a calculation they compute based on the bicarbonate levels and PH reading. The result is the amount of acid or base that is either added or taken away to return the blood to a neutral level. It is important to understand that this measurement helps determine an acidosis or alkalosis metabolic state, not respiratory like PCO2 does. If the number is negative, your baby likely has a metabolic acidosis while a positive number indicates metabolic alkalosis. As discussed earlier, after a short time your baby's kidneys will begin to compensate for the respiratory acidosis state, raising the bicarbonate level through retention and putting your baby in a metabolic alkalosis state. The Base Excess reading will tell you how much compensation is actually happening and

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loosely tell you how much equivalent base was added or excreted to the blood to get the PH back to neutral. If the Base Excess is 8, the body has 8 equivalents more base (bicarbonate) than acid and therefore alkolotic. The normal range in an adult is -5 to 3, but don't get alarmed if you see a 12 or 14 reading. It will happen as your baby can be in a highly metabolic alkalosis state much of the time combating the primary respiratory acidosis condition.

SaO2 - Oxygen saturation is a measurement to determine the percent of hemoglobin which is fully combined with oxygen. This should actually sound familiar since we covered this in another section on the pulse oxymeter. This measurement is a snapshot in time of what you watch on the screen with either a pre or post-ductal saturation. Typically this number should be above 85% and closer to 95% just as it should on the monitor.

Hematocrit (crit) – This is not a typical measurement that you will see with the regular blood draws, but something that will be monitored to ensure there are sufficient red blood cells in the blood. Hematocrit is the percentage of the blood that is occupied by red blood cells. The medical team can drive oxygen into the lungs all day long, but if there are not enough red blood cells containing hemoglobin for the oxygen to bind to, it won't help. This is absolutely a measurement whose tolerance will change with time and circumstances. After just 2 days of life, our daughter's crit level was at 35 and surgery was right around the corner. They decided she needed a blood transfusion at this point. Just three days later, her crit level was 32 and another transfusion was ordered. It's important to know what hematocrit is, but more important to understand what your medical team's tolerance is at each stage.

Below is a table that compares normal ranges in adults and "tolerable" ranges in your baby with CDH. I have to reiterate, please don't fall into a trap of believing these numbers are absolute. Your baby, circumstances, and conditions will change daily and so will some of the tolerances. It is critical to have frequent conversations with your medical team to fully understand where their tolerances will be.

Measurement	Adult	Your baby
PH	*7.35 – 7.45*	*7.25 – 7.35*
PCO2	*35 – 45*	*Desire 50's or below* *Tolerate 60's* *Assess/action in the 70's* *Likely take action above 80*
PO2	>79	> 41
HCO3 (bicarbonate)	22 to 26	Will likely be 30-45
Base Excess	-5 to +3	Could be +14 or more
SaO2	> 94%	> 85%
Hematocrit (crit)	41% - 50%	> 35%/first month of life

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Our Case Study

If there is a section of this document that I really questioned writing about, it would have to be this one. I hope that I have done a good job in explaining that no two babies will follow the same path and therefore this section won't match up with what you will experience. So why put it in here you may ask? I decided to put it in here because I had a tendency to try and compare my child to other CDH children and their progress even when I knew I shouldn't. I think it is human nature. While I tried to compare, I found out no other baby followed the same path that our daughter went down. I can assure you that your child will not follow this path exactly. So why do I still put it in here? I know some of you still want to know. I get that.

I will take you through day by day of what transpired along with some charts and graphs to give a visual representation. First, it's important to review where we were before Kamryn was born.

Born:	June 17th, 2009 (37 weeks exactly)
LHR:	1.4 (26 weeks)
	2.0 (29 weeks)
Lung Volume:	13cc's (26 weeks)
	20cc's (33 weeks)
O/E Total Lung Volume:	25% (33 weeks) ** her twin had 80cc's of volume at 33 weeks
Birth weight:	6 pounds 6.5 ounces
Liver:	Completely down
CDH:	Left side and large opening requiring a patch
Abnormalities:	**Isolated CDH** with no other issues
Delivery:	C-section

We delivered the twins at 8:00am on June 17th, 2009 and it was an experience. There were 25 people in the room, not including Stef and me. Kamryn was delivered first and was labeled Twin 'A'. I did hear her cry when she was delivered, but only one time. Her apgar score was an 8 which was pretty good.

After they intubated Kamryn, they took her directly to the NICU and it was roughly an hour before I was able to go back there. Our true rollercoaster ride had officially started and I was scared to death even before I ever had my seatbelt secured. Here is how the journey played out.

Day 1

Kamryn placed in isolation room with 1:1 nurse to patient ratio.
Placed on conventional ventilator on SIMV mode.
Starting pressure (24) and rate (45) were very low. We thought we were out of the woods without knowing our ride was going to get much more interesting. PICC line was placed in her arm and they started her on Fentanyl for pain and Versed for sedation. No paralytics used (I don't like the paralytic approach so I was thrilled)

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Day 2

Vent settings remain low and she did great. Medical team was a little surprised about how well things were going. Discussion of surgery the next day was going on. I figured they were being a bit optimistic.

Day 3 - Surgery

I was wrong, surgery scheduled for that afternoon. Amazingly, just before surgery her pressure was down to 20 and rate was 45. The surgery itself last about 1.5 hours total and was uneventful. Our confidence was through the roof and I remember thinking to myself that we would be out of the NICU in 20-25 days. What little did I know….

Day 4 – Honeymoon period

Fairly uneventful day although she seemed a little more swollen than the previous day. She held up well most of the day and the vent settings remained low.

Day 5 – Are the wheels falling of the bus?

Kamryn's swelling was unreal. During surgery they pumped so many fluids through her (this is typical) that she swelled everywhere. The area in her chest where the organs used to be was also filled with fluid (typical). Honestly, she looked like a different baby. They did not want to drain the fluid in her chest as it could cause the heart and other lung to shift too rapidly and cause her to code. At the same time, this pressure caused so many more problems than the original organs did. The medical team spent a lot of time trying to keep her CO2 in check over the next few days. By the end of day 5, her vent settings had gone from a pre-surgery pressure of 20 and rate of 45 to a pressure of 30 and a rate of 60. I'm scared now.

Day 6 through 11 – Panic mode

I thought we were prepared for anything but these days were by far the hardest. Kamryn's CO2 was all over the place and they played with her pressure settings trying to drive it down. Just when they thought they would make progress, her CO2 would jump and so would her vent settings. I truly felt at times we were going to lose the battle.

Day 12 through 15 – Progress is great

Our panic turned to cautious celebration as they were able to bring her settings down over these days and she was doing fantastic. She was getting rid of a lot of fluid and we truly believed we were out of the woods. We were going to bring our daughter home soon! We were down to a rate of 48 and pressure of 22!

Day 16 through 22 – The brick wall

We were honestly exhausted by these days and they tested our patience. Things didn't get worse or better during this time and it was incredibly frustrating. We tried to be optimistic, but even the medical staff was confused and we all begin to think this may be the point where we just can't get over. Once again we were back to questioning whether we would make it through this journey to take our daughter home with us.

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Day 23 through 26 – Some progress

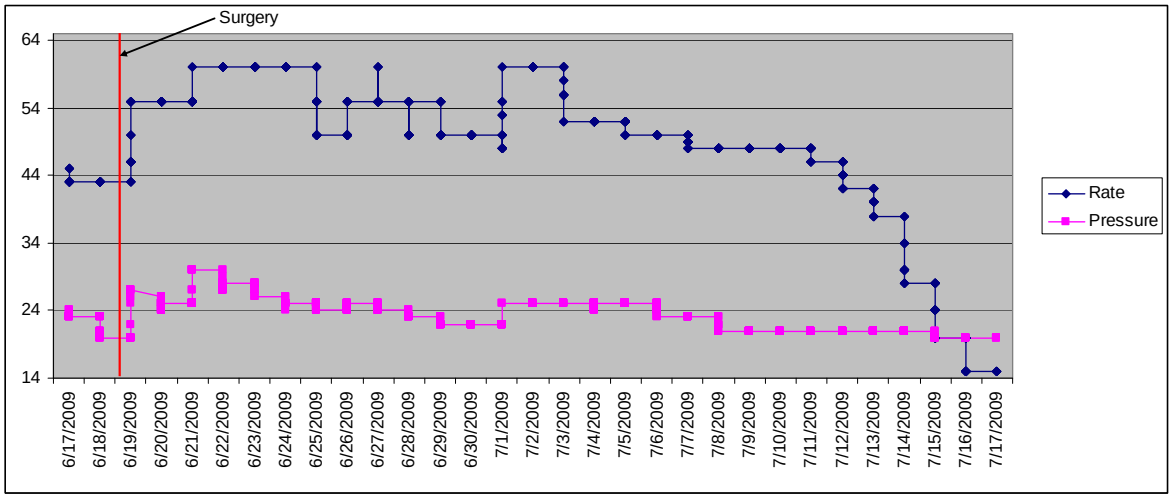
There was some progress during these days which we were thrilled about, but it was small. Just a couple clicks down on the rate, but it was something. Honestly, we were still very scared as we knew 1 or 2 clicks on the rate were not much at all. At the same time, it was something to hold onto.

Day 27 through 31 – Wow

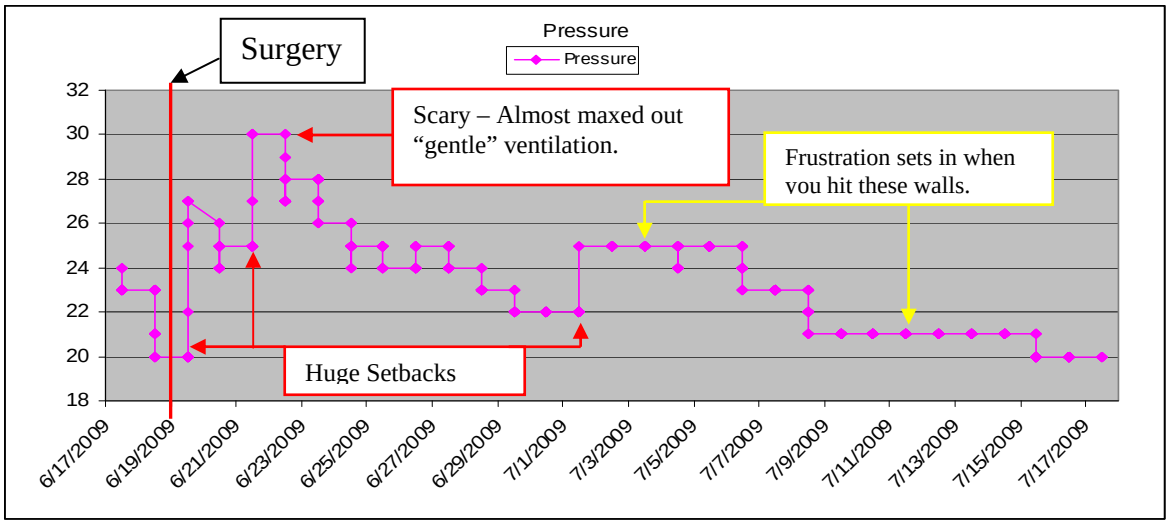
To this day, I can't tell you what happened and neither can the doctors. Our little girl made up her mind that she wanted off the vent and she did it. We ended day 26 at a pressure of 21 and a rate of 42. Over this 5 day period of time, she was down to 20 on her pressure and a rate of 15. It was truly unbelievable. The medical staff didn't try a new procedure or do anything differently. She simply decided it was her time.

You hear about the rollercoaster and I thought a visual representation could help. Here are her pressure and rate settings for the 31 days she was on the ventilator.

This shows her rate and pressure settings on the conventional ventilator. You can see how well she started off and then surgery caused everything to spike, likely as a result of the swelling.



The next chart below shows her pressure readings in more detail than the chart above. Notice how aggressive they had to get immediately after surgery.



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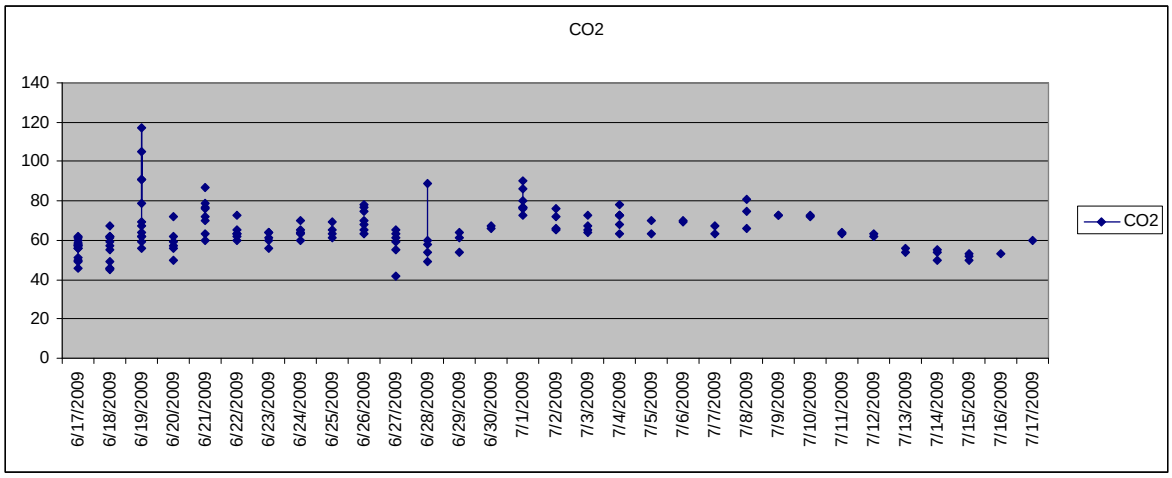
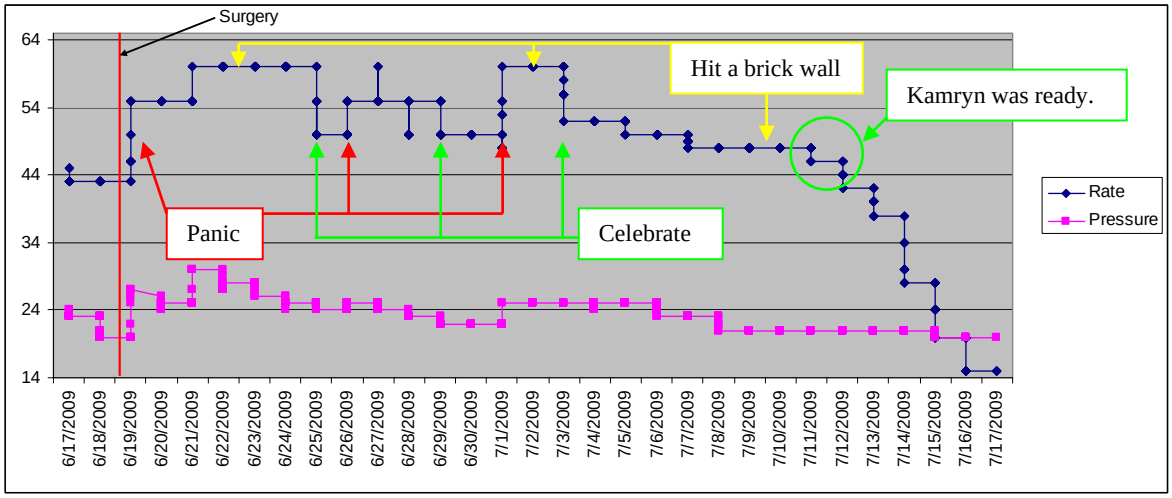
These are the CO2 readings over the 31 days. Notice the constant up and down pattern as they tried to keep it in check with adjustments to the ventilator.



I tried to visually show you the rollercoaster of emotions that we went through.



I should have labeled the yellow portions above 'frustration' as that was the overwhelming feeling each time we hit a brick wall. These were the times that I allowed my emotions to get the best of me and probably beat the doctors up a little more than they deserved. During the panic and celebration stages, there isn't a lot of time to blow up because you are so overwhelmed. During the 'brick wall' stages, I had time to dwell and it got the best of me on more than one occasion.

It's important to note that this is just one of the many rollercoasters you can experience. You can, and likely will, experience the same rollercoaster with CO2 readings, ability to urinate and work the excess fluid off, feeding, weaning off the narcotics, and a number of other issues. I had heard going into this that it would be a rollercoaster ride, but I didn't know I would be on 5 different rides at the same time! My point here is to simply try and prepare you about the emotions around the ups and downs. Your rollercoaster won't look like ours so there is no sense in preparing your mind to follow the charts above. You can though walk in knowing you will experience ups and downs and prepare coping mechanisms to handle them.

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On June 11th, Kamryn decided she was ready to get off the vent. The medical team didn't do anything differently on this day. There were no new medications or treatments given to Kamryn. I talked before about time being the real cure for this condition and this chart displays that. The medical team's role is to manage the baby's condition until their body decides they are ready.

Day 32 until discharge

I will admit, we were terrified the day they extubated Kamryn. I had prepared myself for it to be unsuccessful as it can take a few tries to work. We were incredibly fortunate that she was successful on her first try and she actually didn't need to step down to CPAP. We were thrilled to say the least and were ready to take her home. Once again, we didn't see the big picture. There were two things standing in the way of hitting the exit door and they were feeding and drug rehab (I'll get to that in a moment).

Kamryn was still getting her feeds from the orogastric tube and the first goal was to see if she could take a pacifier. Oral aversion is a common problem with CDH kids because they can forget how to suck. Fortunately, Kamryn remembered how and took her first bottle 3 days after getting off the vent. I was ready to take the tube out and have all her feedings given with a bottle, but again the process is painfully slow. Our speech therapy team would increase the number of bottles a day from 1 to 2, then 2 to 3, and so on until we reached 8 bottles a day of 2 ounces each time. I thought I was going to lose my mind, but looking back, it was the right thing to do. There is no reason to jeopardize taking a step backwards. It took 11 days after being removed from the ventilator to get the NG tube out.

The more painful process was the drug rehab. I never even thought about it until she was off the vent, but it was a little weird having a six week old infant in drug rehab. From the first day of life, Kamryn had been on Versed and Fentanyl which are highly addictive. Over the course of two weeks, they weaned her meds and replaced them with Methadone. Then, it was time to wean her from Methadone which is also used frequently with heroine addiction. Methadone is easier to wean from, but it does have a rather long half life so it takes a while to get it completely out of her system. Each day they would score her withdrawal symptoms from 0 to 10. Anything under 5, she could be weaned so each day they would take just a little away until she was completely free from the drugs. We were given the option of taking her home while she was on Methadone, but we declined. Just didn't make sense to us to go that route no matter how badly we wanted her home.

On August 3rd we experienced a gift that we had grasped for over the course of 48 days. We were able to bring Kamryn home. Unfortunately, our story and journey isn't typical. I discussed earlier the short and long term issues that exist with CDH such as feeding tubes, supplemental oxygen, home monitors, hearing loss, and oral aversion along with other unpleasant issues. We count our blessings each and every day that the only issue Kamryn brought home was a 4 inch scar across her belly. This isn't typical, but I want to point out that it is possible. We entered into the journey as a 'moderate' case, not a 'good' or 'great' case. There were times when all of us, including the medical team, questioned if she would survive. If you ask the medical team what influenced our daughter's remarkable recovery, they won't be able to say it was any one treatment or strategy. Truth is, the medical team gave her time to work things out and she decided, on her terms, when she was ready. That is why it is important to find a medical team that has experience with CDH. They won't have a magic pill or treatment, but they will have the experience of how best to stabilize these babies and give them

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the gift of time. No matter what stage of this journey you are currently in, don't lose hope, but don't let it cloud the reality of the situation.

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The Daily Rollercoaster

A lot of what I have covered so far is pretty straightforward and much of it you will experience. I wish this section was as straightforward, but it's not. When you hear about life in the NICU with CDH being like a rollercoaster, it truly is. There will be days when the drops are so rough that it will twist your stomach in knots while at other times you make progress and are on top of the world. I don't want to paint a gloomy picture for you, but I want to be completely honest so as to prepare you as best I can. Unfortunately, I can only prepare your mind for what is ahead of you. No one can prepare your heart and stomach for this rollercoaster.

As we prepared for our delivery, I really didn't know what questions to ask about life in the NICU. I knew our daughter would be intubated, but outside of having a tube in her mouth and throat I wasn't sure what that would mean. I didn't know to ask if I would hear her cry when she was uncomfortable and I didn't ask if I would hear her cough as the tube irritated her throat. I wish I would have as it was difficult to watch the first time she cried, but there was no sound. I could see the facial expressions and there was no mistaking her crying, but you never actually heard a sound. Same was true whenever she coughed. I could see every physical sign that she was coughing or gagging, but again, no sounds. I was a bit concerned until I realized the ET tube was preventing air from flowing across her vocal cords. It's the little things like this that will stack up over the days, weeks, and possibly months that will test you. At the same time, you will come to realize in the days, weeks, and possibly months that your baby is an incredible fighter to endure what they have to go through.

As I have put this document together over the months, my compass has been to ask myself along the way what I wished I had known. I like routines as they give me some form of consistency. Our visiting hours are all day and night except for 9am – noon so they can do rounds. After a few days, my routine was to be there at noon to hit that big silver button on the wall that made the doors open automatically to the NICU. After a few more steps I made it to the big sink to wash my hands which you will do more times than you can count. In the beginning, they would ask my last name because they have to call back to the room to make sure it was alright for me to go back. I remember getting frustrated that they continued to ask my name. After a while, I would overhear them asking other families what their name was, but they stopped asking me mine. After washing my hands, they would simply tell me, "You can go back now." I was a regular now unfortunately, and that was the last thing I wanted to be.

Our NICU was huge and could hold 90 babies at one time. To think that my baby was the sickest of them all was an awful reality that I had to come to grips with. As I would walk to the back of the NICU, I wondered what news I would hear today. In the beginning, I would walk down the hall and try to guess how much they weaned her overnight from the vent or how great her CO2 was going to be. I would create images in my mind of how much less swollen she looked because I just knew she was peeing like a champ overnight. I can't count the times that what I imagined was just simply not reality. So many self inflicted missed expectations. At some point I accepted all of it and stopped creating stories in my mind. You see, being in denial about the severity of the situation or having unrealistic expectations about getting out of the NICU in 3 weeks because you heard of

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another CDH baby doing it will only serve to make your time more frustrating and stressful. My advice is to accept it, sooner rather than later, that you have a critically sick baby.

- Accept that he/she could be there for 60, 90, 120 or more days.
- Accept that just because you learned of another family whose baby had an LHR of 1.4 and brought their baby home in 4 weeks, doesn't mean your baby won't be there for 90 days after having an LHR of 1.45.
- Accept that you will likely have one of the sickest, if not the sickest baby, in the NICU for some time.
- Accept it that time, and only time, is the true cure for your baby's condition.
- Accept it that there will be one, but likely many, setbacks coming your way.
- Accept that trends will guide you much more accurately than daily changes.

What I am trying to say is that often times our setbacks are magnified because of unrealistic or overly hopeful expectations about the rollercoaster ride. It is important to keep setbacks in perspective and a bad gas or increase in vent settings doesn't mean the wheels are falling off the bus. Setbacks will happen regardless if there is a good or bad final outcome. There is no quick fix to this condition and everything is about baby steps. Remember when I said to hold on to hope, but don't let it cloud reality? The sooner you embrace this, the smoother ride you will have. I slipped up on this numerous times as you likely will also and that is human nature. If you want proof, below is one of my blog entries where my emotions escalated and I was losing focus.

Tuesday, July 7th

"We still feel so frustrated with the overall progress. We think it has to do with all the predictors I researched before delivery. I was aware going in that we weren't in great shape, but I really felt like we were in pretty good shape. We had an LHR of 1.4 at 26 weeks, 2.0 at 29 weeks, and then LHR's of over 3.0 after 32 weeks (an LHR over 1.4 has been used as a predictor of a good outcome in numerous studies). I know LHR is a predictor of mortality, not necessarily a predictor of days on vent or hospital stay, but having such great LHR measurements really made us feel like we would make good progress quickly. Unfortunately, I didn't rely on what I now believe is a much more important factor to hospital stay which is the total lung volume and then comparing that to a "normal" baby's lungs. When we did that at 34 weeks, Kamryn only had 25% total volume compared to her twin sister Brooke. While the LHR was fantastic, it only measures the one "good" lung on one dimension. When measured 3 dimensionally, there really wasn't much total volume there. I think that is what is now causing her so many problems.

It's hard not to look for some type of comparison to gauge where you are at. The doctors aren't able to even give me a "gut" feeling on where she is headed with all their knowledge and experience. It's hard to prepare your mind and emotions sometimes when you don't see the people who know this better than you showing much optimism or pessimism. It's just a constant, "we don't know". My brain tells me not to, but even now I find myself looking at studies that show total lung volume to the mortality rate and hospital length of stay. In the most recent study, all babies survived with 15% or more total predicted lung volume and Kamryn had 25%. If I look at the graph for hospital stay compared to lung volume and map it out to her 25% volume, she falls at 53 days in the hospital (small study with 14 baby's - hardly enough to draw conclusions). It's been 21 and at the rate we are going, I see us here much longer than 53 total days. You just want to grab onto something,

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anything that will give you a sense of where you might be heading, good or bad. It's frustrating not knowing if you should allow your hopes to get up or brace for a negative outcome. You honestly feel simply lost most of the day. We know we should only focus on today as we can't change yesterday, nor should we try and anticipate tomorrow. Our heads know what we should focus on; just try telling that to your heart and stomach. So many percentages and unknowns with this defect and I know in my mind that none of them really matter. We know in the end there is no middle ground and we will have only one of two numbers to hold on to, 0% or 100%, but you honestly try to find some direction anywhere you can along the way."

That was a tough day, but I soon recovered after taking a step back and friends, family, and our Parkland Hospital primary nurses (who I believe were a gift from God) telling me to chill out.

While you shouldn't let the small setbacks get you down, you also must be careful to not let the wins get you overly excited. Celebrating success with your baby is one of the most wonderful and proud moments a parent can experience and you will likely get to share this experience on numerous occasions. My advice is to celebrate cautiously until you walk out of that main entrance of the hospital with your baby in your arms. While it is true that overcoming the hypertension and hypoplastic lungs is the primary battle, there are other issues that can surface even when everything is going exceptionally well. All of the lines and tubes inserted into your baby to save their life can also complicate the situation and become a threat to their survival. The primary issue is infection and your baby will have many sources of infection while in the NICU. At any time, an infection could present itself and begin an additional battle that complicates the first even if everything is trending exceptionally well. In addition, while on the vent, even at low pressures, your baby's blood vessels in their lungs could burst causing a pulmonary hemorrhage. This would cause the lungs to fill with blood and create a grave situation with a high level of mortality. You could literally be on top of the world with the progress and almost ready to extubate and then within a few hours crash and have your baby hooked up to ECMO. These issues are not common, but they are real and they do happen. Throughout our time in the NICU, we tried to cautiously celebrate the wins while staying grounded. Allow yourself to go through the emotional ups and downs, but try to not let them get exaggerated or out of perspective. Keeping the big picture in play at all times is important.

My point here is to simply take each day as it comes and focus your energy on that. You can't change what happened yesterday (whether good or bad) and you can't anticipate tomorrow without setting yourself up for missed expectations (good or bad). Focus on the present day and what the strategy will be. Let's go back to the routine.

Once I got there and made the long walk to her bedside, I would kiss my daughter. Yes, it is ok to kiss your baby, touch your baby, and lay your hand on your baby. You will likely find the wires, tubes, and machines intimidating and wonder how you can touch your child without disturbing something. You might find yourself concerned that if you hit a wire or tube will it make your baby crash or set off alarms. These thoughts and fears are normal, but try to not be scared of them. I promise, the environment is not nearly as delicate as you perceive it to be. Before long, you will be tossing wires out of the way and won't think twice about touching your baby and moving wires around the bed.

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I would soon get an update from the nurse about the latest blood gas, check the monitors and vent monitor for any changes, and then ask how she did overnight. After asking any questions, I would spend time with my daughter. Much of the day she slept, especially in the beginning. I tried to be very conscious of stimulating her because she could become agitated very easily. Who could blame her? One thing I learned was stroking her on her skin would lead to her becoming agitated. What I found was she preferred if I just laid my hand on her and rested it there. Your child will let you know what he/she likes and dislikes, but the key is to try and minimize their stimulation as much as possible. When she was sleeping, I would talk to her, read her stories, and watch her. I watched her a lot. Other times, I was just there, reading a book or magazine and just being by her side. I would usually spend about 3 to 4 hours each day and then get replaced by my wife. We had to work it out in shifts since we had our baby's twin at home. I think it is important to not feel guilty about not being by their bedside 24/7. It is true that your baby will be fighting for their lives in ways that few of us can imagine and needs your comfort. It is also true that you will be fighting an emotional rollercoaster that not many parents can truly relate to. It is important to take care of yourself during this time whether it is seeing a movie or going out to dinner. There shouldn't be any guilt in having a little time away from the emotional rollercoaster of the NICU.

When we weren't there at the hospital, we called often. One of the first things you need to figure out is the number to call the NICU and the procedure for talking to the nurse caring for your baby. They will also need to verify that it is you, the parent on the phone, so I would find out early how they plan to do that. At our hospital, it was the armband number that my wife had on. You will call a lot, so memorize that number.

We would also spent time getting involved in her care once she was stable. You need to let the nursing staff know you want to be involved. We changed diapers, took her temperature, and cleaned her mouth. One of the problems with ventilation is that there is a lot of saliva that builds up around their mouth so they need to be suctioned and brushed often. I actually enjoyed doing this and we did it often. I would also ask to look at the x-rays and discuss then with the doctor. She had one almost daily during the first couple of weeks. My point here is this is your baby and you can be involved in their care so get in the game early. Some nurses are more comfortable with it than others so just ask.

So, to recap, here are some things that worked well for us and I would do early on.

- Find out the procedure for checking on your baby by phone along with the verification method used.
- Get involved in their daily care as much as you can.
- Kiss your baby.
- Touch your baby.
- Talk to your baby (they will learn your voice).
- Ask to see x-rays and ask for explanations.
- Get a routine down for consistency.
- Learn what time rounds happen each day.
- Ask your doctor what the strategy is for the day.
- Take a lot of pictures until your finger hurts.
- Don't be scared of the wires and tubes. You can touch them – they won't break.

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The rest of the routine will be determined by you. I honestly believe that we, just as you, were chosen to go down this road because we could handle it. It may not be fair, but it is the hand we were dealt and honestly, we don't have much choice but to face it head on.

I feel like I could keep writing for days, but I think I have given you enough to at least get started down this path. I encourage you to keep researching and learning all that you about this condition. I am also available to you if you ever have any questions. I won't promise that I can answer all of them, but I can promise that I know all too well what you are going through. My email address is studdard1@gmail.com

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Final Thoughts…

I know that was a lot to take in and digest, especially with the anxiety and fear you are currently facing. As I began writing and organizing the bulk of this document, I didn't know how our journey would play out as we still had a couple months before delivery. I experienced all of the same fears and anxiety that you do. I have had to learn how to give up control of the outcome and understand that I can't "fix" this like I do so many other things in life. One of our doctors reminds me that our little girl is writing a book that we can't put down. Every couple of weeks she writes us a new chapter, and we read it intently. Unfortunately, we can't turn to the end and read that last chapter. We can only hope that it is a happy ending. It's frustrating. Over the next few months, you will also need to learn how to let go of control and understand that no matter what percentages you hear or how optimistic/pessimistic a healthcare professional is, you and the medical community truly won't know what the outcome is until after your baby is born. The harsh reality is that some of these babies won't survive, but many will.

Regardless, every one of these babies has a purpose and will touch more lives than you currently realize whether they choose feet or angel wings. As I said before, never lose sight of hope, but don't let it cloud reality.

While you won't be able to control the final outcome, I strongly believe all of us have a responsibility to be our child's advocate and find what we feel is the best team to handle the care of our child. We do have control of this aspect and should address it with a passion. We also have a responsibility to educate everyone we know about this terrible condition and get the word out about CDH so that together, we shift the odds in favor of survival.

On behalf of all the families who already walked this journey, we are truly sorry that you are faced with this situation. There is a very large and caring family out there to support and guide you every step of the way. You just need to ask. My wife and I wish only the best for your baby and family.

Shawn
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Additional Support Sites

CHERUBS	**http://www.cdhsupport.org**
Parker Reese Foundation	**http://www.theparkerreesefoundation.com/**
Breath of Hope	**http://www.breathofhopeinc.com/**
Global CDH	**http://www.globalcdh.org**
A Rainbow of Hope	**http://www.arainbowofhope.com/**
Jack Ryan Gillham Foundation	**http://www.jackryangillham.org/**

References

Wikipedia: http://en.wikipedia.org/

(Links to the studies below are on our blog – http://thestuddardfamily.blogspot.com)

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Valérie Datin-Dorriere, MD; Sarah Rouzies, MD; Pierre Taupin, MD; Elizabeth Walter-Nicolet, MD; Alexandra Benachi, MD, PhD; Pascale Sonigo, MD; Delphine Mitanchez, MD, PhD

Liver position and lung-to-head ratio for prediction of extracorporeal membrane oxygenation and survival in isolated left congenital diaphragmatic hernia
Holly L. Hedrick, MD; Enrico Danzer, MD; Aziz Merchant, MD; Michael W. Bebbington, MD; Huaqing Zhao, MA; Alan W. Flake, MD; Mark P. Johnson, MD; Kenneth W. Liechty, MD; Lori J. Howell, RN, MS; R. Douglas Wilson, MD; N. Scott Adzick, MD

Dr. Michael Zaretsky, Assistant Professor, UT Southwestern
Dr. Rashmin Savani, Professor, UT Southwestern

The Children's Hospital of Philidelphia (http://www.chop.edu/consumer/index.jsp)
Cincinnati Children's (http://www.cincinnatichildrens.org)
The Brown Fetal Treatment Center (http://bms.brown.edu/pedisurg/FetalProgram.html)
Children's Hospital of Wisconsin (http://www.chw.org/display/PPF/DocID/12082/router.asp)
University of California, San Francisco (http://fetus.ucsfmedicalcenter.org)
Fetal Care Center of Cincinnati (http://www.fetalcarecenter.org)

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