

What is CDH?

A Handout for Family & Friends



 **cdh UK** The Congenital Diaphragmatic Hernia Charity
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- Congenital Diaphragmatic Hernia (CDH) occurs when the diaphragm fails to fully form, allowing abdominal organs to move into the chest cavity and preventing the lungs from having enough room to grow.
- CDH occurs in 1 in every 2500 babies.
- Babies born with CDH undergo surgeries and long hospitalizations.
- The cause of CDH isn't yet known. Sometimes CDH runs in families.
- Most organizations that work with CDH families recommend couples get genetic testing after having a baby born with CDH so that an expert can tell them if that information provides any information for their specific family.



- Until a specific cause is determined, CDH cannot be prevented.
- Many CDH cases can be detected with an ultrasound, sometimes as early as 16 weeks.
- There are many facilities that treat babies with CDH. The Sensigreen CDH Foundation and other organizations that support CDH families encourage each family to research different treatments and to deliver at a facility with an ECMO team.
- There is no “typical” stay in the hospital. Some babies will be released in weeks, some will be kept in the hospital for months.
- Unfortunately, 50% of babies born with CDH do not survive to their first birthday.

How can I support a CDH family before and after their baby is born?

- Learn as much as you can about CDH so that when they talk about their baby you have some understanding of what they are talking about. The Sensigreen CDH Foundation website has resources that will help you learn more about congenital diaphragmatic hernia.
- Ask before you throw a shower or celebration. CDH parents know there is a chance their baby may not come home. Some couples want to do all of the typical celebrations for expectant parents. Other parents want to wait and know what their prognosis is before a showering of gifts.
- Ask how mom is feeling and ask the parents about their baby. Does he/she have a name? Can I see a sonogram photo? How have your doctor’s appointments gone?
- Remember that a family expecting a CDH baby is going through a lot of emotions and may be very stressed about very high medical bills. Consider dropping a meal off before the baby is born or getting the family restaurant gift cards, quarters for hospital vending machines, paying for a Netflix or Hulu subscription that can be used at the Ronald McDonald House.
- Once the baby is born, ask to see photos if the family is sharing news. There may be tubes from a ventilator, ECMO and IVs, but tell the parents how beautiful their child is.
- Do not share information on social media or in prayer circles unless the family specifically asks. Unfortunately, even with the best of intentions, disseminating information this way can lead to rumors and phone calls and emails to parents and grandparents who do not need the extra stress of taking calls and answering emails.
- Respect the boundaries that parents communicate. Some parents are going to want to see their family and friends at the hospital and at home. Some parents are going to want complete privacy. Please respect the wishes of your friends and family members when they communicate their wishes on visitors.
- Ask how you can support your loved ones. It is ok to say to the person you love, “I want to support you, but I do not know the best way. What do you need right now?”