



Stage: Pregnancy

Questions to ask medical professionals

- Will I have a fetal MRI?
- Will I need to have an amniocentesis? What are the risks?
- How often will I have appointments during the rest of the pregnancy?
- What are other potential pregnancy complications due to the CDH diagnosis?
- How often will I have ultrasounds?
- What are you looking for when you take ultrasounds throughout pregnancy?
- Why do you measure lung to head ratio? What does this measurement mean and indicate?
- What is the best hospital for me to be at? Does this hospital have doctors who have treated CDH pregnancies?
- Can I get photos from each ultrasound?
- Can we watch our baby in 4D for a while at some of the ultrasounds?
- When will I meet the neonatologists?
- Who are the surgeons and when will I meet them?
- Is there any advice for anything I should/shouldn't do during pregnancy?
- What are the next steps?

Advice from parents

- Get second opinions; have someone else with you at appointments; talk to other families affected by CDH and research as much as you can so you can go in armed with knowledge so it's not so scary and foreign.
- Try not to let a CDH diagnosis takeover your pregnancy or your bond with your baby. It is a stressful and scary diagnosis to receive, but remember you are still allowed to enjoy carrying your baby and being pregnant!
- When you think of questions write them down straight away (for example on your phone) and make sure you ask them at your next appointment.
- Do not feel rushed into making any decisions. Do what you feel is best and right for you and your little one.
- Talk to your baby while they are inside you. Connect and give them little daily pep talks, or perhaps talk them through what will happen after they are born. Tell them you will always be there with them; loving them.