TINYHERO

Questions To Ask Your Doctor And Your Delivering Hospital **

1. How many CDH patients has your team treated in the last 10 years?

2. How many CDH patients do you treat each year? Would you break down your survival rates (e.g., liver up versus down, left versus right, LHR, and when additional severe birth defects are present)?

3. What is the estimated number of your patients who have required ECMO? If ECMO is required, what is your survival rate (at one week, two weeks, three weeks, four weeks, beyond four weeks)?

4. How many CDH repairs has the pediatric surgeon performed?

5. Do you limit how long you will let my baby stay on ECMO? Do you have a policy that determines the number of days my baby can be on ECMO? *(*Some institutions have been known to set strict timelines for ECMO use*).

6. Irrespective of how my baby appears to be doing at birth, is it your policy to aggressively pursue stabilization? If all standard stabilization techniques fail, do you use ECMO immediately post birth to ensure stabilization of a patient? What are your criteria for deciding that comfort care should be given in lieu of stabilization? What if there is a difference of opinion between us (the parents) and the hospital team? *(*Because a newborn CDH baby's blood gases can look severe at birth, they should not be used to determine that a baby's chances of survival are low).*

7. How do you decide when to perform the hernia repair? Will you do the repair on ECMO if needed? If my baby needs to be put on ECMO before the repair, are you willing to perform surgery within the first day or two? (See the medical journal article at this link regarding the increased survival rates with early repair).

8. How will the CDH repair be performed (open vs. thoracoscopically, anteriorly vs. posteriorly (*i.e., from the back*)). *(*A posterior repair is an old-fashioned repair strategy that can cause problems. Further, a thoracoscopic surgery prevents a surgeon from accurately evaluating and addressing anatomic complications as compared to an open surgery for moderate to severe CDH patients. Lastly, as of this writing patch failure has proven to be significantly higher in thoracoscopic repairs*).

9. What is your hernia recurrence rate? If a patch is required, will it have to be replaced at regular intervals throughout my child's life? *(*The more severe the hernia, the higher the likelihood of a child re-herniating. An experienced practitioner should have a low recurrence rate and should not anticipate that a patch will have to be repeatedly replaced*).

10. Who manages the day-to-day care of our baby during his/her NICU stay (neonatologists, a dedicated surgical team, etc.)? Does the team change daily, weekly, etc?

11. Even if it is a "team effort," is a single practitioner primarily the one responsible for making strategic decisions about my baby's care or are multiple practitioners allowed to make their own independent decisions? *(***The more consistent the continuity of care, the better your baby will do. A lot of changing of hands can cause big problems**).

12. How much experience does the ICU staff have with CDH patients? Do you have designated staff that oversee your CDH patients or do all of your ICU staff care for CDH patients? *(*Like many unique congenital abnormalities, care from staff-persons who are familiar with CDH and who regularly care for CDH patients will be beneficial for your baby).*

13. Is the CDH team familiar with "gentle ventilation," and do they ventilate babies in this manner? ***(If the medical team and doctors are not familiar with gentle ventilation this is a big red flag).***

14. Do you paralyze your CDH patients at any time during their care? **(Paralyzing a CDH baby to force them to be very still can (a) prevent the practitioner from really determining how the child is doing and (b) can inhibit the baby from participating in respiration).*

15. What percentage of your patients over the last 3-5 years required the following in order to discharge: a tracheostomy, an NG tube, ventilator support?

16. How will you support my baby through feeding issues like severe reflux? What do you think about the Nissen Fundoplication and G-Tube as a way to deal with reflux? Is there anything that can be done to minimize the requirement of a Nissen Fundoplication?

17. What is the average length of stay for your CDH patients? *(*Really severe cases should expect 3-4 months*).

18. Can I have my baby vaginally or do you recommend C-section?

19. Will my baby be delivered in the same facility that the NICU is located in, or will he/she have to be transferred to a different facility? *(*CDH babies can be very unstable at birth. The stress of transportation can worsen the condition of a newborn CDH baby. Some birth facilities/hospitals will not transport to the Children's hospital until the baby is "stable").*

20. Does anyone in your hospital do any CDH research?

21. What will follow-up be like after discharge?

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In addition to some of the ECMO questions above, below are some more detailed ECMO questions which will help you appraise the doctor's/facility's experience, practices, and policies should your baby require ECMO.

- How many CDH patients have you managed on ECMO in the last year?
- How do you minimize the bleeding risks when performing surgery on ECMO? Do your patients tend to have bleeding problems as a result of performing surgery on ECMO? *(*Although the blood thinners associated with ECMO increase the risk of bleeding problems during and after surgery, a skilled and experienced surgeon should not experience a lot of bleeding complications*).
- How often do your patients experience brain bleeds and any associated complications while on ECMO? *(*Skilled practitioners should have lower rates of bleeding complications*).
- What is the difference between VA and VV ECMO?
- Are you proficient with both VA *and* VV ECMO? Have you seen that VV ECMO has a tendency to cause an enlarged heart? What complications arise from an enlarged heart?
- Do you have a minimum weight/size requirement for placing a child on VA or VV ECMO? *(*If a facility only offers VV ECMO and your baby is under 6 lbs., then ECMO is generally not offered because the cannulas are too large for their corresponding veins*).
- Would you describe to me how you determine whether a child is ready to be weaned from ECMO?
- Would you describe to me how you wean your patients from ECMO so as to maximize their chances of successfully transitioning to a ventilator?
- How long do you typically take to wean from ECMO? Is it an immediate pause of ECMO or a methodical wean (i.e., taking your time over several days)? *(*Babies will tend to do much better with a methodical and slower wean).*
- Do you afford second or third ECMO runs if needed?
- What is your survival rate for patients that required ECMO?

This list was written by parents who have had personal experience with CDH and have interviewed over six of the top CDH hospitals in the US (hospitals and professionals who have published the most medical journal articles on CDH and have the best survival rates in the country) in order to find the best care for CDH babies. **This list is not a substitute for advice given to you by a licensed medical practitioner. Lastly, as CDH care and management is still fluid within the medical community, the above questions and their related answers regarding "best practices" are subject to change and may not be reflected within these questions.

When "all is said and done," we want you to feel empowered to advocate for your child. We wanted to be thorough, and allow you to take from this information what best fits your situation.

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