



What to Ask the Surgeon and Hospital

The surgeon:

- Are you board certified in pediatric cardiothoracic surgery?
- How many pediatric heart surgeries in general do you personally perform each year?
- How many of this particular kind of surgery do you personally perform each year?
- How long have you been at this hospital?
- What surgical and non-surgical options is my child a candidate for? What are the benefits and risks of each?
- Which procedure would you recommend for our baby's condition? (If there is a choice.)
- How long has this particular surgery been performed nationally and locally?
- What is the success rate we can expect for our baby's specific condition? (Short term, after 5 years, 10 years and longer.)
- Which hospitals in the US are considered the most experienced at this type of surgery?
- When would my child have the surgery?
- How long does the surgery take?
- What risks are associated with this surgery?
- What are the risks associated with not having surgery performed?
- Can we donate blood for the surgery?
- Should we consider storing the baby's cord blood in case it can be used in the future to help with heart function? (If a baby)
- What kind of care/special equipment would the child require at home?
- What type of medications are required after surgery and how long would the child be on them? What side effects can these medications cause?

Heart Transplants:

- What is the criteria for being put on the heart transplant list?
- What other surgical or nonsurgical options are there for my child?
- How/when would we get on the list for a donor heart?
- What is the average wait time for a donor heart at this facility for a child my child's age?
- Would we need to stay near the hospital of time after the heart transplant? If so, for how long?
- What medications would be required? What are the possible side effects?

The hospital:

- What is the overall success rate at this medical center for children with my child's specific diagnosis? (Short term, 5 years, 10 years, long term)
- Is this a dedicated Children's Hospital? Is there a dedicated children's unit?
- Does this hospital have a Pediatric Cardiac Intensive Care Unit - (one that is dedicated to children with heart defects.)
- Is there a dedicated unit on the floor for children with heart problems?
- What is the average length of stay in your hospital after each surgery? (How long in the ICU, how long on the general floor.)
- What extra training or expertise does the medical and nursing staff have to deal with children, and to deal with heart defects?

- What is the nurse to patient ratio in the ICU, and on the general floor?
- Are there accommodations for parents to stay at the hospital with the child or nearby?

Delivering the baby:

- Can I have a vaginal delivery? If not, what are the risks of a C-section? How long would I expect to be in the hospital?
- Can I deliver my baby in this hospital?

If yes:

- How many babies with this condition are delivered here annually?
- When would I need to travel to this hospital (if the facility is far from home) to deliver the baby?
- How does the OB staff work with the surgical staff?
- Who is "in charge" of the baby in the delivery room?
- Who do I talk with to get approval to hold my baby after delivery? Do I need to get this approved ahead of time?
- Will I be able to breastfeed the baby? When?

If delivery is NOT an option at this facility:

- Where would I deliver the baby?
- When and how would the baby be transferred to this facility?
- What are the risks of transporting the baby?
- When would I be able to join the baby at this facility? (After a vaginal birth or C-section.)

Hospital Staff:

- Do the anesthesiologists only work with congenital heart patients?
- Do the anesthesiologists only work with infants/children?
- Who else will be interacting with my baby? What will their roles be in my baby's care, and how much experience do they have with this condition?
- Who will be in charge of my child's care throughout the length of his/her stay?
- What role will we have in the decision-making process during our baby's hospitalization?
- Who will be our contact person if we have questions or concerns while our baby is in the hospital? How do we contact him or her?
- Is Physical Therapy (PT) or Occupational Therapy (OT) and feeding help available by those experienced with babies with heart defects?

Other Hospital Services:

- Is there a social worker who can help us with housing, tours of the hospital, sibling programs, etc.?
- What housing options are available? (Ronald McDonald House, hotels, etc.)
- What other services do you provide? (social services, financial assistance, etc.)
- Can you give me the names of other parents whose children were treated for this heart condition at this hospital?
- What other support networks can you refer me to?

After care:

- Will my baby require any special monitoring equipment at home? (oxygen, feeding tube, etc.)
- Will my baby require any medications once we are at home?
- What type of follow up care is recommended (Home Health Care, Physical and/or Occupational Therapy, Pediatric Cardiologist visits, etc.)?
- Can you help us choose a Pediatric Cardiologist in our area for follow up?
- Are there any environmental factors that we would need to eliminate in our household (smoking, pets, etc.)?