

Pediatric Congenital Heart Association's GUIDED QUESTIONS TOOL

QUESTIONS TO ASK THE CARDIAC TEAM

It is hard to hear the words “there is something wrong with your baby’s heart.” But, there is hope! Thanks to new and better treatment, your baby’s chance of surviving is better, with the right care.

At the Pediatric Congenital Heart Association (PCHA), we believe that information is important when making decisions about the care of your child.

For this reason, the following questions were designed to help when you talk with the care team. Some of this information may not be familiar or hard to understand. We have included key ideas on the last page to help. Your care team can help you understand, too.

Experts think there are certain care standards that a quality treatment center should meet. Not all centers are the same. Some families may want to contact another center to better understand treatment options. Often, second opinions are reassuring; further building trust between you and the team you are working with.

At any time, if you feel you need help or extra support, please contact PCHA. We do not have all the answers, but we can certainly help guide you.

For more information about congenital heart disease and links to additional resources, please visit our website at conqueringchd.org.



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Information About Your Cardiac Center:

1. How many procedures do you perform each year? How many times have you and your program performed this procedure or ones like it in the last year? Over the last 4 years?
2. What is the survival rate for this type of procedure at the time of hospital discharge? After one year? How do your results compare to other centers' results?
3. What are the most likely complications or things that can go wrong, with this procedure and how often do they happen within one year of this procedure?
4. Do you share your results with national data programs such as the STS Database or Impact Registry to help improve care? Is this information open to the public?
5. Do your surgeons have special training in congenital heart surgery? What other types of special training do your doctors and nurses have?
6. How are family members included in the decision making process? How will the care team give me information, or reports, before, during, and after the procedure?

Information About Your Hospital Stay:

7. How many days do you think my child will be in the hospital, both before and after the procedure?
8. What are my options for when, where and how to deliver my baby? How do you work together with my OB/GYN/Midwife to prepare for my delivery and my care right before and after delivery?
9. How do you work together with my baby's doctor after birth and after the procedure?

10. If my baby needs to stay in the hospital after delivery to prepare for a procedure, where will he/she be? What about after the procedure? Do you have a cardiac intensive care unit (CICU) that cares mainly for children with heart defects?
11. Will I get to hold my baby before or after the procedure? If so, when and how?
12. Will I be able to breastfeed my baby after delivery and again after the operation? Will my baby require a special diet? Should I expect my baby to take a bottle or breast feeding without problems?
13. What do you do to help prepare parents to take their babies home from the hospital?
14. What support is available for me and my family? For example, can I talk to other families that also have children with heart defects? Do you provide financial, nutritional, and mental health support?

Looking Ahead:

15. What are the expected long-term results for this heart defect and its procedure? What is my child's life expectancy or how long is my child expected to live? Are there other possible life-long problems that I need to watch out for?
16. Thinking about how my child will grow and develop, what should I expect from them as a preschooler, school-age child, a teenager and as an adult?
17. As my child gets older, does your medical care provide a plan for transitioning from pediatric to adult care?



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KEY IDEAS

Procedures – These questions can be used to talk about a number of treatment options including surgery or cardiac catheterization. Cardiac catheterization, which is not surgery, can be used to find and treat some heart conditions. During the catheterization the doctor uses a long, thin, flexible tube that is inserted through a blood vessel.

Number of procedures – Total number of procedures performed at a center may be an indicator of quality, with caution given to centers that don't perform many surgeries. However, some heart defects are rare and the number of times a procedure is performed may be small, even at the biggest centers.

Survival Rate – Most babies live through their first 30 days after a procedure, a common measurement of success for surgeons. It is important to ask about survival rates after 30 days, too.

Training – Some doctors have specialty training including certificates for pediatric congenital heart surgery. Make sure your surgeon has this training.

Data sharing – Most centers collect information, or data, such as number of procedures, survival rates and outcomes, using national data programs such as the Society of Thoracic Surgeons (STS) Database or the Impact Registry. Many centers now make this information available to the public. If a center does not give their data to a national data program, or does not share their outcome data publicly, you should ask why.

THE IMPORTANCE OF TRANSPARENCY

At the Pediatric Congenital Heart Association (PCHA), our mission is to “Conquer Congenital Heart Disease.” We believe that patient and family **empowerment** is essential to achieving this mission.

We support informed decision-making that will allow patients and families to get the best care possible. Health information that is patient-centered (about the patient), accurate (correct), accessible (available to every person), and communicated in the right way is all part of patient and family **empowerment**, resulting in improved outcomes in both patient health and family experience.