



Q&A

**SINGLE
VENTRICLE**

*A guide to communicating with
your child's care team*

■ NATIONAL PEDIATRIC CARDIOLOGY
■ Quality Improvement Collaborative

www.jcchdqj.org/parents

Sisters
by heart™

www.sistersbyheart.org

Suggested Hospital Pack List



MOM & DAD

- SBH Tote Bag/Care Package
- Journal/Pen (might want to bring 2 one for you to journal your thoughts/draft blog posts and one to document everything for your HLHSer)
- File Folder for important documents and handouts
- Electronic chargers & USB cords (phone, camera, laptop, iPad, e-reader...)
- Books to read/Kindle
- Camera
- Headphones
- Magazines
- Crossword Puzzles
- Scrapbook kit (papers, glue, scissors, tape)
- Change of clothes
- Flip flops/slippers
- Sweatshirt (it can get cold in the hospital!)
- Sports Bras/Nursing Bras
- Lashinoh (nipple cream for pumping moms)
- Personal Breast Pump
- Toiletries
- Dry Shampoo
- Extra sanitary pads
- Tylenol/Ibuprofen
- Chapstick
- Hand Lotion
(RECOMMENDATION: Gold Bond Hand Sanitizer - the constant use of anti-bac hand gel can dry out your skins so it's nice to have an alternative)
- Insulated Cup (keep hydrated!)
- Team Bags, instant coffee or Starbucks VIA sticks
- Cash for coffee, vending machines...
- Takeout menus/phone numbers for nearby restaurants
- Non-perishable snacks/Gum/Mints
- Pillow or own pillow cases (hosp usually provides pillows/blankets)
- Cord blood collecting kit

PATIENT

- Boppy Pillow (and extra covers)
- Pictures and special things to hang on their warming bed/crib
- Baby legs (leg warmers)
- Side snap onesies
- Hats/beanies
- baby socks/booties
- baby nail clippers or baby mittens
- Lovie/Wooby/special toys that can comfort them & be taken to surgery (it's suggested that mom sleep with these items a few times so they smell like her)
- something that plays soothing music (toy or CD player)
- Wubbanub binky
- Crib sheets/blankets/swaddlers (hospitals supplies these but it's nice to have your own too to make it extra cozy for your babe)
- A bag to keep by their bed for infant items (and dirty clothes/blankets)
- a book/poster board/autograph frame for nurses, docs & visitors to leave well wishes
- Healing Helpers (www.healinghelpers147.com) check out the "Zip-Flight" option where you can send your own plush in "for surgery!"

SIBLINGS

- Books
- Drawing/Coloring supplies (they will love making things for their baby brother/sisters' room!)
- If you have an iPad/iPhone, get some iTunes gift cards to give them once you get to the hospital and throughout your time there. Nice way to reward "good behavior" and keep them from getting bored with their existing apps :)
- Snacks/Lollipops/Drinks that don't need to be refrigerated
- A special gift for them (new teddy bear/doll)
- Extra clothes/slippers/pj's
- Blankets
- Sweatshirt

The National Pediatric Cardiology Quality Improvement Collaborative (NPC-QIC) is a group of parents, physicians, nurses, nurse practitioners, surgeons, and dietitians working to improve care for children needing a three-staged open heart repair (i.e. HLHS).

This booklet was prepared by NPC-QIC and Sisters by Heart, a parent non-profit organization, as a guide for questions to ask the cardiac team and surgeon regarding your child's care.

We hope these questions prepare you for the medical journey ahead and help foster a good, working relationship with your child's medical team.



Discovering your child has a heart defect is shocking...
Words of Wisdom we'd like to share.

- Sometimes you have time to research, sometimes you don't. Remember, not everything you read on the internet is accurate. Discuss findings and concerns with medical professionals.
- Each child is different, each family is different; only you can decide what is best for you and your baby.
- The suggested questions in this booklet may be overwhelming – don't feel pressured to ask them all at once and don't feel you need to ask them all.
- Information regarding your child's care can be confusing, especially numbers and data. Ask your center to explain their numbers and data in a way that you can understand.
- Communication with your child's care team is important. Be open and honest about your feelings and expectations for your child.
- Remember that your child's medical team is there to help you and your child; they care about your family's well-being.
- If you're concerned about the care your child is receiving, you may get a second opinion from another doctor or cardiac center. Ask your child's medical team or Sisters by Heart for guidance on how to obtain a second opinion.

**SUGGESTED QUESTIONS TO ASK THE CARDIAC TEAM
About Your Hospital/Cardiac Center**



1. Can you tell me more about your center? Why is your center the best option for the care of my child? How many Norwoods/Hybrids has your program done in the last year? Over the last 5 years?

2. What are your surgeon's expected survival rates from birth through the second surgery (Glenn)? What are your center's overall survival rates from birth through Glenn? How do your survival rates compare with other centers' survival rates? _____
3. What are the most common complications following a Norwood/Hybrid? At your center, what percentage of babies need re-intervention (cardiac catheterization or surgery) in the 1st year of life?

4. Do your surgeons hold sub-specialty certification in congenital cardiac surgery? When can I meet with the surgeon who will perform my child's surgeries? _____
5. Does your program participate in the National Pediatric Cardiology Quality Improvement Collaborative (NPCQIC), Society of Thoracic Surgeons (STS) Database, and/or Impact Registry?

6. How am I included in decision-making regarding my child? How can I communicate with the surgical team before, during, and after surgery? Who is on my child's care team and what are their roles (i.e. primary cardiologist, surgeon, ICU team, outpatient team, etc.)? _____
7. How do you decide when my child will have each surgery - Norwood, Glenn, and Fontan? Do you have certain criteria (weight, age, etc.) my child must meet prior to each surgery? _____

