A guide to communicating with your child’s care team
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.

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**Suggested Hospital Pack List**

**MOM & DAD**

- SBH Tote Bag/Care Package
- Journal/Pen (might want to bring 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 cord (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
- Lasinoh (nipple cream for pumping moms)
- Personal Breast Pump
- Toiletries
- Dry Shampoo
- Extra sanitary pads
- Tylenol/Ibuprofen
- Chapstick
- Hand Lotion
- 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 6pm/7am
- Pillow or own pillow cases (hospital usually provides pillows/blankets)
- Cord blood collecting kit

**PATIENT**

- Boppy Pillow (and extra cover)
- Pictures and special things to hang on their warming bed/crib
- Baby legs (leg warmers)
- Sids snap onies
- Hats/beanies
- baby socks/booties
- baby nail clippers or baby mittons
- Lovey/Tooby/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)
- Webbanub binky
- crib sheets/blankets/swaddlers
  (hospitals supplies these but it’s nice to have your own too to make it extra cozy for your baby)
- 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/sister’s 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/Dinkist that don’t need to be refrigerated
- A special gift for them (new teddy bear/doll)
- Extra clothes/slippers/pjs
- Blankets
- Sweatsuit
Discovering your child has a heart defect is shocking...
Words of Wisdom we’d like to share.

**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?
17.  What can I expect for the next few years as my child develops and grows? Can he or she play sports? Are there potential life-long complications my child may experience?

18.  Developmentally and socially, what can I expect for my child as a preschooler, school-age child, a teenager, and as an adult? Do you have a neuro-developmental program my child can participate in?

19.  Do you have a plan for transitioning my child from pediatric to adult care?