

One Mom's Hypoplastic Left Heart Syndrome (HLHS) Tips for New Parents

Karla and Derick's son was diagnosed with hypoplastic left heart syndrome (HLHS) before he was born. This meant that after his birth, he would need three cardiac surgeries to help fix his heart defect.

Throughout this experience, Karla found ways to work through the process. For new parents, she shares her own list of tips for handling your child's surgeries, as well as some words of wisdom from her own journey.

Karla's top HLHS tips

1. **Take notes when speaking with your child's doctor to make sure you have the information correct.** The doctor will also provide a packet of information for you to read at home. You will find answers to questions that arise over time and tell you what to expect going forward.
2. **After the Glenn procedure, "Glenn Head" is common.** It is like having a severe headache or migraine, which is caused by your child's new circulatory system. The pain lasts a few weeks. If your child seems uncomfortable, cries often and rubs their head, most likely they are experiencing Glenn Head. The best way to provide relief is with ibuprofen or Tylenol.
3. **After the Fontan procedure, your doctor typically schedules appointments for six-month check-ups.** If you are worried or have a problem prior to that, take your child in for an appointment sooner than the next scheduled check-up. "We only made it through a full six-month period one time; we took him in for check-ups more often if we had a major concern," Karla shares.
4. **Keep a running list of questions for your doctor and make sure you bring that list with you to each appointment.**
5. **Take care of yourself during this process.** While at the hospital with your child, pack a survival kit including snacks, comfortable clothes and a phone charger, for example.

Karla's words of wisdom

1. **Going into each of the surgeries, trust your instincts.** Everyone's instincts are different, so listen to what yours are telling you.
2. **Know that you will have your happy baby back after the procedures are complete.** You may notice your child is even happier after the surgeries than before because they will have more energy.
3. **Remember the rough patches don't last forever.** As your child heals and gets older, they will play with more energy, eat better, and will be more likely to take part in outdoor activities.
4. **Try to avoid daycare, as illnesses at a young age are harder on children with hypoplastic left heart syndrome than on kids without heart defects.**

5. **You can address concerns without going to the emergency room.** You can call the single ventricle coordinator at 720-777-2943 or the main Heart Institute number at 720-777-6820 to speak to one of the doctors or the on-call doctor if it is after hours.
6. **Say yes to any help that your friends and family offer.** Also, ask for specific help if you need something that hasn't been offered.
7. **This journey is hard, but these kids have incredible strength and fight in them.** We call them Heart Warriors for a reason. They will show you true courage and strength, and in turn, they will help you find your own.

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