

HYPOPLASTIC LEFT HEART SYNDROME

(HLHS)

PRENATAL FACTS

What to Know

In the United States

40K
CONGENITAL HEART BIRTH
DEFECTS EVERY YEAR*

1 in 4.3K
LIVE BIRTHS AFFECTED
EVERY YEAR**

What Happens

Structures on the heart's left side fail to develop properly in the womb.

Cause

While there's no known cause, researchers believe there may be a genetic link to the condition.



What to Expect

Treatment

Treating HLHS requires surgery.

3
RECONSTRUCTIVE
OPERATIONS

Three surgeries must be completed within the first 3 years of life.

Maternal HLHS Prenatal Diagnosis

To determine prenatal HLHS, mothers may undergo:

Fetal MRI • Fetal Echocardiogram
Lab Work • Genetic Test



Week 13-28



The Fetal Center at Riley at IU Health works with families to discuss these test results with all the necessary specialists needed to develop a care plan for both you and your baby.

HLHS Prenatal Delivery

At Riley at IU Health, your baby will be transferred to the Cardiovascular Intensive Care Unit (CVICU) after you give birth.

1

Your baby will be evaluated by specialists using different tests that look at the heart's structure.

2

Doctors will discuss a surgery plan with you and your family.

3

Within the first few days after delivery, the first surgery will take place: the Norwood Procedure.

The Procedure



Birth

Your baby will be transferred to the CVICU shortly after delivery and evaluated by the care team at Riley at IU Health.

1 to 7
DAYS

Norwood Procedure

This is the first of the three surgeries your baby will need. This surgery helps control blood flow and prevents damage to the heart and lungs prior to the second surgery, the Glenn or hemi-Fontan Procedure. It will be performed within the first 1-2 weeks of your baby's life.

Post Norwood Procedure

After the procedure, your baby will be transferred to a private room in the CVICU, a part of the Riley Heart Center. Your baby's chest will remain open while he or she rests comfortably. It may be a few days before you and your family are able to hold and feed your baby. However, touching and staying with your baby is encouraged.

10 to 15
DAYS

Recovery

While recovery time varies by patient, the average length of stay in the hospital is around six weeks after birth. During recovery, your baby will work on feedings gradually to eventually get up to a full feeding. Two-thirds of our patients go home with a G-tube – a feeding tube that's placed in the abdomen to ensure your baby is getting necessary nutrients.

6
WEEKS

Future Preparation

Your baby will have follow-up visits with their Riley at IU Health care team after their discharge. The second surgery, the Glenn or hemi-Fontan Procedure, will occur between 4-6 months of age. At 2 to 4 years old, your child will undergo the third and final surgery, the Fontan Procedure.



Recovery

Monitoring

Our Home Monitoring Program sends your baby's vitals and other information directly to the care team at Riley at IU Health. We provide families:



Baby Weight SCALE



iPad
TO SEND THE INFORMATION OVER,
AS WELL AS ASK QUESTIONS,
SEND PHOTOS OR VIDEOS TO THE
CARE TEAM



Home Oxygen MONITOR

Prior to discharge, you will meet with our program's nurse practitioner. They will walk you and your family through how to care for your baby once they are discharged from Riley at IU Health. The nurse practitioner will be your main point of contact until your baby's second surgery, and they are available via cell phone to answer any questions you have about your baby's care and recovery.

Living with HLHS

While surgery is an effective treatment, it is not a cure. Children with HLHS can experience complications, such as:

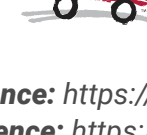
- Heart rhythm disturbances
- Exhaustion after activities
- Blood clots
- Fluid buildup
- Developmental problems
- Feeding issues

Contact

Riley at IU Health is always here for you and your family. If you have any questions or concerns, please contact our team.



317.944.7010



Riley Children's Health
Indiana University Health

*Reference: <https://www.cdc.gov/ncbddd/heartdefects/data.html>
**Reference: <https://www.cdc.gov/ncbddd/heartdefects/hlhs.html>