

Hypoplastic Left Heart Syndrome

Hypoplastic (hī-pō-'pla-stik) left heart syndrome, or HLHS, is a congenital heart defect (the baby is born with it) in which the left side of the heart, which normally pumps oxygen-rich blood to the whole body, is very underdeveloped. The Centers for Disease Control and Prevention (CDC) estimates that about 1 out of every 4,300 babies born in the United States each year is born with hypoplastic left heart syndrome. The cause is unknown. For more information on HLHS, see the CDC's website tinyurl.com/ycdlyawu.

Resources for families

Northwest support resources

- Linked by Heart - Northwest Region Group [Facebook]
tinyurl.com/yb5luxlf
- Children's Heart Foundation (OR)
tinyurl.com/yckmhgr
- Pediatric Congenital Heart Assoc. (WA)
tinyurl.com/yba3yhlw
- Mended Little Hearts - Portland [Facebook]
tinyurl.com/y9zskzl1

National/international/online resources

- Sisters by Heart - Support Group for HLHS
tinyurl.com/yabezwsu
- American Heart Association (AHA) Support Network for Congenital Heart Defects (CHD)
tinyurl.com/y5bxh3z3
- Mended Hearts
tinyurl.com/7wppot4
- Little Hearts - Parent Matching Program
tinyurl.com/y7wuh4yc
- Children's Heart Foundation (CHF)
tinyurl.com/ptkqdj
- Congenital Heart Info Network [Facebook]
tinyurl.com/y8oxl67t

Information for you and your care team

- Cincinnati Children's Hospital Hypoplastic Left Heart Syndrome
tinyurl.com/y8o29x5j

- AHA - Fact sheets and other tools
tinyurl.com/kex96bk
- AHA - Portable medical information [PDF]
tinyurl.com/ydye5u4s
- NIH Library of Medicine
tinyurl.com/aot8rx

Family stories

- CDC - Nick, Ryan, Teagan, and Caden's Stories
tinyurl.com/ydhq6zsr
- AHA Family Stories
tinyurl.com/y8j578ny
- Little Hearts Stories of Hope
tinyurl.com/y8cze7em

Clinical trial information

- Children and Clinical Studies
tinyurl.com/y75s4twm
- Find an approved clinical trial
tinyurl.com/zp3jesq

Insurance information and help

- Getting insurance for children (OR)
tinyurl.com/ydfaeeoy
- Understand your health insurance
tinyurl.com/y46h8nvx
- Learn about coverage
tinyurl.com/y4639rz6
- Road map to health
tinyurl.com/yysc6kv7
- General/Oregon Health Plan Questions: 855-323-6744

Other resources

- CHF - *It's My Heart* - free resource book
tinyurl.com/ybyp9goh
- AHA Web Booklet - *If Your Child Has a Congenital Heart Defect*
tinyurl.com/yctu5mzw
- Q&A: A guide to communicating with your child's care team
tinyurl.com/ybxt7fjz
- Merry Heart Children's Camp
tinyurl.com/yaml6cma
- Summer camps for kids with CHD (outside OR)
tinyurl.com/y9awy2gy
- NIH - Miscellaneous tip sheets for children, teens and families
tinyurl.com/y86ofx4e
- CDC - Five Things you Need to Know about CHD [PDF]
tinyurl.com/yav6fn2

Books for parents and children

- Bibliography available by calling the Oregon Family to Family Health Information Center at 855-323-6744
- Swindells' online library search
tinyurl.com/y9t2jwcx