

# Hypoplastic Left Heart Syndrome

Hypoplastic (ˌhī-pō-ˈpla-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]
   <u>tinyurl.com/yb5luxlf</u>
- Children's Heart Foundation (OR) <u>tinyurl.com/yclkmhgr</u>
- Pediatric Congenital Heart Assoc. (WA) tinyurl.com/yba3yhlw
- Mended Little Hearts Portland [Facebook]
   <u>tinyurl.com/y9zskzll</u>

# National/international/online resources

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

# Information for you and your care team

 Cincinnati Children's Hospital Hypoplastic Left Heart Syndrome <u>tinyurl.com/y8o29x5j</u>

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

#### **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) <u>tinyurl.com/ydfaaeoy</u>
- Understand your health insurance tinyurl.com/y46h8nvx
- Learn about coverage tinyurl.com/y4639rz6
- Road map to health
  <u>tinyurl.com/yysc6kv7</u>
- General/Oregon Health Plan Questions: 855-323-6744

# Other resources

- CHF *It's My Heart* free resource book <u>tinyurl.com/ybyp9goh</u>
- AHA Web Booklet If Your Child Has a Congenital Heart Defect tinyurl.com/ycgu5mzw
- Q&A: A guide to communicating with your child's care team <u>tinyurl.com/ybxt7fjz</u>
- Merry Heart Children's Camp <u>tinyurl.com/yaml6cma</u>
- Summer camps for kids with CHD (outside OR) tinyurl.com/y9awy2gy
- NIH Miscellaneous tip sheets for children, teens and families <u>tinyurl.com/y86ofx4e</u>
- CDC Five Things you Need to Know about CHD [PDF] <u>tinyurl.com/yavg6fn2</u>

# 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 <u>tinyurl.com/y9t2jwcx</u>

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