

# 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](http://tinyurl.com/ycdlyawu).

## Resources for families

### Northwest support resources

- Linked by Heart - Northwest Region Group [Facebook]  
[tinyurl.com/yb5luxlf](http://tinyurl.com/yb5luxlf)
- Children's Heart Foundation (OR)  
[tinyurl.com/yckmhgr](http://tinyurl.com/yckmhgr)
- Pediatric Congenital Heart Assoc. (WA)  
[tinyurl.com/yba3yhlw](http://tinyurl.com/yba3yhlw)
- Mended Little Hearts - Portland [Facebook]  
[tinyurl.com/y9zskzll](http://tinyurl.com/y9zskzll)

### National/international/online resources

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

### Information for you and your care team

- Cincinnati Children's Hospital Hypoplastic Left Heart Syndrome  
[tinyurl.com/y8o29x5j](http://tinyurl.com/y8o29x5j)

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

### Family stories

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

### Clinical trial information

- Children and Clinical Studies  
[tinyurl.com/y75s4twm](http://tinyurl.com/y75s4twm)
- Find an approved clinical trial  
[tinyurl.com/zp3jesq](http://tinyurl.com/zp3jesq)

### Insurance information and help

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

### Other resources

- CHF - *It's My Heart* - free resource book  
[tinyurl.com/ybyp9goh](http://tinyurl.com/ybyp9goh)
- AHA Web Booklet - *If Your Child Has a Congenital Heart Defect*  
[tinyurl.com/ycg5mzw](http://tinyurl.com/ycg5mzw)
- Q&A: A guide to communicating with your child's care team  
[tinyurl.com/ybxt7fjz](http://tinyurl.com/ybxt7fjz)
- Merry Heart Children's Camp  
[tinyurl.com/yaml6cma](http://tinyurl.com/yaml6cma)
- Summer camps for kids with CHD (outside OR)  
[tinyurl.com/y9awy2gy](http://tinyurl.com/y9awy2gy)
- NIH - Miscellaneous tip sheets for children, teens and families  
[tinyurl.com/y86ofx4e](http://tinyurl.com/y86ofx4e)
- CDC - Five Things you Need to Know about CHD [PDF]  
[tinyurl.com/yavg6fn2](http://tinyurl.com/yavg6fn2)

### 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](http://tinyurl.com/y9t2jwcx)