



# Pulmonary Valve Atresia and Stenosis

Pulmonary atresia (ˈpʊl-mə-ner-ē ˈvalv ə-ˈtrē-zhə) is a rare congenital heart defect (the baby is born with it) where the valve that controls blood flow from the heart to the lungs doesn't form at all. In babies with this defect, blood has trouble flowing to the lungs to pick up oxygen for the body. This condition may be diagnosed during pregnancy or soon after a baby is born. For more information about pulmonary atresia, see the Center for Disease Control and Prevention's website [tinyurl.com/y8xnfjmx](https://tinyurl.com/y8xnfjmx).

## Resources for families

### Northwest support resources

- Children's Heart Foundation (OR)  
[tinyurl.com/ycklmhgr](https://tinyurl.com/ycklmhgr)
- Pediatric Congenital Heart Assoc. (WA)  
[tinyurl.com/yba3yhlw](https://tinyurl.com/yba3yhlw)
- Mended Little Hearts - Portland [Facebook]  
[tinyurl.com/y9zskzll](https://tinyurl.com/y9zskzll)

### National/international/online resources

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

### Information for you and your care team

- Cincinnati Children's Hospital Congenital Pulmonary Valve Stenosis  
[tinyurl.com/yc5ozymh](https://tinyurl.com/yc5ozymh)
- AHA - Fact sheets and other tools  
[tinyurl.com/kex96bk](https://tinyurl.com/kex96bk)
- AHA - Portable medical info [PDF]  
[tinyurl.com/ydye5u4s](https://tinyurl.com/ydye5u4s)

- NIH Library of Medicine  
[tinyurl.com/aot8rx](https://tinyurl.com/aot8rx)

### Family stories

- AHA Family Stories  
[tinyurl.com/y8j578ny](https://tinyurl.com/y8j578ny)
- Little Hearts Stories of Hope  
[tinyurl.com/y8cze7em](https://tinyurl.com/y8cze7em)

### Clinical trial information

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

### Insurance information and help

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

### Other resources

- CHF - *It's My Heart* - free resource book  
[tinyurl.com/ybyp9goh](https://tinyurl.com/ybyp9goh)
- AHA Web Booklet - *If Your Child Has a Congenital Heart Defect*  
[tinyurl.com/ycg5mzw](https://tinyurl.com/ycg5mzw)
- Merry Heart Children's Camp  
[tinyurl.com/yaml6cma](https://tinyurl.com/yaml6cma)
- Summer camps for kids with CHD (outside OR)  
[tinyurl.com/y9awy2gy](https://tinyurl.com/y9awy2gy)
- NIH - Miscellaneous tip sheets for children, teens and families  
[tinyurl.com/y86ofx4e](https://tinyurl.com/y86ofx4e)
- CDC - Five Things you Need to Know about CHD [PDF]  
[tinyurl.com/yavg6fn2](https://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](https://tinyurl.com/y9t2jwcx)