Pulmonary Valve Atresia and Stenosis

Pulmonary atresia (pronounced PUL-mun-air-ee aht-REE-sha) 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/y8xnjmx).

Resources for families

Northwest support resources

- Children’s Heart Foundation (OR) tinyurl.com/ycikmhr
- Pediatric Congenital Heart Association (WA) tinyurl.com/yba3yh1w
- Mended Little Hearts - Portland [Facebook] tinyurl.com/y9zskzd

National/international/online resources

- American Heart Association (AHA) Support Network for Congenital Heart Defects (CHD) tinyurl.com/y9zjth92
- Mended Hearts tinyurl.com/7wppot4
- Little Hearts - Parent Matching Program tinyurl.com/y7wu4yc
- Children’s Heart Foundation (CHF) tinyurl.com/ptkqdd
- Congenital Heart Info Network [Facebook] tinyurl.com/y8oxl67t

Information for you and your care team

- 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

- 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/ydfaaeoy
- Understand your health insurance tinyurl.com/ychy6qnn
- 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/ycg5mz
- 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/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/y9t2jwce