

Total Anomalous Pulmonary Venous Return (TAPVR)

Total Anomalous Pulmonary Venous Return (ə-'nä-mə-ləs pùl-mə-ner-ē 'vē-nəs) (TAPVR) is a rare congenital heart defect (the baby is born with it) in which oxygen-rich blood does not return from the lungs to the left atrium. Instead, the oxygen-rich blood returns to the right side of the heart. This causes the baby to get less oxygen than is needed to the body. Read more about TAPVR on the Center for Disease Control and Prevention's website tinyurl.com/y94l7ywd.

Resources for families

Northwest support resources

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

National/international/online resources

- 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 Total Anomalous Pulmonary Venous Return <u>tinyurl.com/ybsk3dea</u>
- AHA TAPVC fact sheet [PDF] tinyurl.com/y8809sj7
- AHA Fact sheets and other tools tinyurl.com/kex96bk

- AHA Portable medical info [PDF] tinyurl.com/ydye5u4s
- NIH Library of Medicine tinyurl.com/aot8rx

Family stories

- AHA Family Stories
 <u>tinyurl.com/y8j578ny</u>
- 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 tinyurl.com/yysc6kv7
- 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
- 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] 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 <u>tinyurl.com/y9t2jwcx</u>