Tetralogy of Fallot (TOF)

OHSU

Tetralogy of Fallot (te-'tral-ə-jē-əv-fä-'lō) is a rare congenital heart defect (the baby is born with it) that affects normal blood flow through the heart. It causes the amount of oxygen in the blood to be reduced. Tetralogy of Fallot is considered a critical congenital heart defect, as most babies need surgery or other procedures soon after birth. The Centers for Disease Control and Prevention (CDC) estimates that about 1 in every 2,500 babies born each year in the United States is born with Tetralogy of Fallot. For more information on this condition, go to the Center for Disease Control and Prevention's website tinyurl.com/y8vvp9fw.

Resources for families

Northwest support resources

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

National/international/online resources

- American Heart Association (AHA) Support Network for Congenital Heart Defects (CHD) <u>tinyurl.com/y5bxh3z3</u>
- Mended Hearts tinyurl.com/7wppot4
- Little Hearts Parent Matching Program <u>tinyurl.com/y7wuh4yc</u>
- Children's Heart Foundation (CHF) tinyurl.com/ptkqdj
- Congenital Heart Info Network [Facebook] tinyurl.com/y8ox167t

Information for you and your care team

- Cincinnati children's Hospital Tetralogy of Fallot tinyurl.com/y9j2j4ht
- AHA Tetralogy of Fallot fact sheet [PDF] tinyurl.com/ya649dvu
- AHA Fact sheets and other tools tinyurl.com/kex96bk

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

Family stories

- Portland Tribune Lucy balances heart with a full life tinyurl.com/y9lb63rq
- CDC Asha, Ken, William and Luke's stories tinyurl.com/ybaqeurh
- AHA Family Stories
 <u>tinyurl.com/y8j578ny</u>
- Little Hearts Stories of Hope tinyurl.com/y8cze7em

Clinical trial information

- Children and Clinical Studies
 <u>tinyurl.com/y75s4twm</u>
- 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 tinyurl.com/ybyp9goh
- AHA Web Booklet If Your Child Has a Congenital Heart Defect tinyurl.com/ycgu5mzw
- 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 <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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