

Tetralogy of Fallot (TOF)

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/ycklmhgr
- Pediatric Congenital Heart Assoc. (WA)
tinyurl.com/yba3yhlw
- Mended Little Hearts - Portland [Facebook]
tinyurl.com/y9zskzll

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
tinyurl.com/y7wuh4yc
- Children's Heart Foundation (CHF)
tinyurl.com/ptkqdj
- Congenital Heart Info Network [Facebook]
tinyurl.com/y8oxl67t

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/ya649dvv
- 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

- 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
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/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
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/y9t2jwcx