



Ebstein Anomaly

Ebstein's Anomaly is a birth defect of the heart's tricuspid valve. The tricuspid valve separates the right upper chamber (the right atrium) and the right lower chamber (the right ventricle) of the heart. In a normal heart, the tricuspid valve closes all the way when the right ventricle squeezes to push blood to the lungs. Being closed keeps the blood from going backward. With Ebstein's anomaly of the tricuspid valve, some blood "leaks" back into the right atrium because the valve doesn't close completely. The atrium can start getting too big because of the extra volume of blood. Some children with Ebstein's anomaly of the tricuspid valve also have an atrial septal defect (ASD), a hole in the wall between the two upper chambers of the heart, or other heart defects. For more information on Ebstein's anomaly, you can visit the Children's Hospital of Philadelphia website tinyurl.com/y9um3x8f.

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

- Ebstein's Anomaly Foundation
tinyurl.com/y95kcr5p
- 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 Ebstein
Anomaly
tinyurl.com/ya4bn9se
- AHA - Ebstein's Anomaly fact sheet
tinyurl.com/yagagdw6

- AHA - Fact sheets and other tools
tinyurl.com/kex96bk
- AHA - Portable medical information
tinyurl.com/ydye5u4s
- NIH Library of Medicine
tinyurl.com/aot8rx

Family stories

- Arden's Story [YouTube]
tinyurl.com/yb68bv4x
- 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