Bladder Extrophy

Bladder extrophy is a birth anomaly of the bladder and the front bones of the pelvis. In most cases, the baby is born with the bladder outside of the body. Instead of being a normal balloon shape, the bladder can be in two halves that are inside-out. This makes the bladder unable to store urine (pee) made by the kidneys. The pubic bones at the front of the pelvis normally join to protect and support the bladder and the muscles of the outer belly wall. In children with bladder extrophy, the pubic bones do not join, leaving a wide opening between the bones. The urethra, the tube from the bladder that allows urine to leave the body, also does not form properly. This means these babies also need their lower urinary tract and their external genitals repaired by surgery. For more information on bladder extrophy, see the Children's Hospital of Philadelphia website tinyurl.com/y9dk0v.

Resources for families

Northwest support resources
- Oregon Family to Family Health Information Center
tinyurl.com/ycwhfhwcw
- Washington Parent to Parent (P2P) Programs
tinyurl.com/yaucv2mk

National/international/online resources
- Association for the Bladder Exstrophy Community (A-BE-C)
tinyurl.com/y88b6idcx
- Courage to Shine
tinyurl.com/y7jfwhfu
- BEECHAC - support group from Australia
tinyurl.com/y7cfarww
- B.E.S.T Bladder Exstrophy Support Team
tinyurl.com/yclxqo5f
- Bladder and Cloacal Exstrophy Awareness and Support [Facebook]
tinyurl.com/ybl7zldc
- Association for the Bladder Exstrophy Community [Facebook]
tinyurl.com/y7ytmar7

Information for you and your care team
- John's Hopkins University: Bladder Exstrophy
tinyurl.com/y9fah89j
- Report at Boston Children's Hospital
tinyurl.com/yc9qb2zp
- Treatment info at Urology Care Foundation
tinyurl.com/y7h96jpk

Family stories
- See bios at Courage to Shine website
tinyurl.com/ybwsozly

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
- Getting insurance for children (WA) tinyurl.com/yc9ikvey
- Understand your health insurance tinyurl.com/y46h8nvx
- Learn about coverage tinyurl.com/y4639rz6
- Road map to health tinyurl.com/ysyc6kv7
- General/Oregon Health Plan Questions: 855-323-6744

Other resources
- B.E.S.T Bladder Exstrophy Support Team family camp outs tinyurl.com/yclxqo5f
- Youth Rally Camp tinyurl.com/y9jrcvgl
- Camp Korey campkorey.org

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