



# Bladder Exstrophy

Bladder exstrophy 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 exstrophy, 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 exstrophy, see the Children’s Hospital of Philadelphia website [tinyurl.com/yc9dkova](http://tinyurl.com/yc9dkova).

## Resources for families

### Northwest support resources

- Oregon Family to Family Health Information Center  
[tinyurl.com/ycwhffwc](http://tinyurl.com/ycwhffwc)
- Washington Parent to Parent (P2P) Programs  
[tinyurl.com/yaucv2mk](http://tinyurl.com/yaucv2mk)

### National/international/online resources

- Association for the Bladder Exstrophy Community (A-BE-C)  
[tinyurl.com/y8b6ldxc](http://tinyurl.com/y8b6ldxc)
- Courage to Shine  
[tinyurl.com/y7jfwfhu](http://tinyurl.com/y7jfwfhu)
- BEECHAC - support group from Australia  
[tinyurl.com/y7cfarww](http://tinyurl.com/y7cfarww)
- B.E.S.T Bladder Exstrophy Support Team  
[tinyurl.com/yclxqo5f](http://tinyurl.com/yclxqo5f)
- Bladder and Cloacal Exstrophy Awareness and Support [Facebook]  
[tinyurl.com/ybl7zldc](http://tinyurl.com/ybl7zldc)
- Association for the Bladder Exstrophy Community [Facebook]  
[tinyurl.com/y7ytmar7](http://tinyurl.com/y7ytmar7)

### Information for you and your care team

- John’s Hopkins University: Bladder Exstrophy  
[tinyurl.com/y9fah89j](http://tinyurl.com/y9fah89j)
- Report at Boston Children’s Hospital  
[tinyurl.com/yc9qb2zp](http://tinyurl.com/yc9qb2zp)
- Treatment info at Urology Care Foundation  
[tinyurl.com/y7h96jpk](http://tinyurl.com/y7h96jpk)

### Family stories

- See bios at Courage to Shine website  
[tinyurl.com/ybwsozly](http://tinyurl.com/ybwsozly)

### Clinical trial information

- Children and Clinical Studies  
[tinyurl.com/y75s4twm](http://tinyurl.com/y75s4twm)
- Find an approved clinical trial  
[tinyurl.com/zp3jesq](http://tinyurl.com/zp3jesq)

### Insurance information and help

- Getting insurance for children (OR)  
[tinyurl.com/ydfaaeoy](http://tinyurl.com/ydfaaeoy)
- Getting insurance for children (WA)  
[tinyurl.com/yca9lkey](http://tinyurl.com/yca9lkey)
- Understand your health insurance  
[tinyurl.com/y46h8nvx](http://tinyurl.com/y46h8nvx)
- Learn about coverage  
[tinyurl.com/y4639rz6](http://tinyurl.com/y4639rz6)
- Road map to health  
[tinyurl.com/yysc6kv7](http://tinyurl.com/yysc6kv7)
- General/Oregon Health Plan Questions: 855-323-6744

### Other resources

- B.E.S.T. Bladder Exstrophy Support Team family camp outs  
[tinyurl.com/yclxqo5f](http://tinyurl.com/yclxqo5f)
- Youth Rally Camp  
[tinyurl.com/y9jrcvgl](http://tinyurl.com/y9jrcvgl)
- Camp Korey  
[campkorey.org](http://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](http://tinyurl.com/y9t2jwcx)