



Cloacal Exstrophy

A child with cloacal exstrophy is born with part of the large intestine outside of the body and with the two halves of the bladder out on either side of it. In males, the penis is either flat and short or sometimes split. In females, the clitoris is separated into a right half and left half. The intestine may be short and the anus, where normally poop passes out of the body, may not have an opening. With this condition there are often other birth defects, like spina bifida. To learn more about cloacal exstrophy, see the Children's Hospital of Philadelphia website [tinyurl.com/y73fepu9](https://www.chop.edu/conditions-diseases/cloacal-exstrophy).

Resources for families

Northwest support resources

- Oregon Family to Family Health Information Center
[tinyurl.com/ycwhffwc](https://www.oregonfamilytofamilyhealth.org/)
- Washington Parent to Parent (P2P) Programs
[tinyurl.com/yaucv2mk](https://www.p2pwa.org/)

National/international/online resources

- Courage to Shine
[tinyurl.com/yasxyq8u](https://www.couragetoshine.org/)
- Bladder and Cloacal Exstrophy Awareness and Support [Facebook]
[tinyurl.com/ybl7zldc](https://www.facebook.com/bladderandcloacalexstrophy/)
- B.E.S.T Bladder Exstrophy Support Team
[tinyurl.com/yclxqo5f](https://www.bestbladderexstrophy.org/)

Information for you and your care team

- Report - Johns Hopkins Medicine
[tinyurl.com/y97ay57w](https://www.hopkinsmedicine.org/health/conditions-and-diseases/cloacal-exstrophy)
- Report - Urology Care Foundation
[tinyurl.com/yacydzyg](https://www.urologyfoundation.org/)
- Report - Boston Children's Hospital
[tinyurl.com/yannu7jn](https://www.bostonchildrens.org/)
- Fact Sheet - Children's Hospital of Philadelphia
[tinyurl.com/y73fepu9](https://www.chop.edu/conditions-diseases/cloacal-exstrophy)

Family stories

- Bios - Courage to Shine
[tinyurl.com/yasxyq8u](https://www.couragetoshine.org/)
- Tess's Story [YouTube]
[tinyurl.com/yardw64b](https://www.youtube.com/watch?v=yardw64b)

Clinical trial information

- Children and Clinical Studies
[tinyurl.com/y75s4twm](https://www.childrenandclinicalstudies.org/)
- Find an approved clinical trial
[tinyurl.com/zp3jesq](https://www.clinicaltrials.gov/)

Insurance information and help

- Getting insurance for children (OR)
[tinyurl.com/ydfaaey](https://www.oregon.gov/oha/ohcs/insurance/)
- Getting insurance for children (WA)
[tinyurl.com/yca9lkey](https://www.wa.gov/insurance/)
- Understand your health insurance
[tinyurl.com/y46h8nvx](https://www.healthinsurance.gov/)
- Learn about coverage
[tinyurl.com/y4639rz6](https://www.coverage.com/)
- Road map to health
[tinyurl.com/yy5c6kv7](https://www.roadmaptohealth.org/)
- General/Oregon Health Plan Questions:
855-323-6744

Other resources

- Youth Rally
[tinyurl.com/y9jrcvgl](https://www.youthrally.org/)
- Pull through Network
[tinyurl.com/yd25ce8y](https://www.pullthroughnetwork.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](https://www.swindells.com/)