

Spina Bifida

Spina bifida (spī-nə-'bi-fə-də) is a birth anomaly in which the layers of skin, muscles, and bone that normally cover the spinal cord are not all closed together to cover the spinal cord. The spinal cord is the bundle of nerves that come down from the brain to control and to send signals back from the entire body. Spina bifida can occur anywhere on the back from the upper neck to the tailbone area. The effect on the child depends upon if the spinal cord itself is formed correctly. It also depends upon where the spina bifida opening is on the neck or back, how long it is, and whether all or only some of the layers have an opening. For more information about spina bifida, see tinyurl.com/ya4eowbo.

Resources for families

Northwest support resources

- Oregon Family to Family Health Information Center
tinyurl.com/ycwhffwc
- Washington Parent to Parent (P2P) Programs
tinyurl.com/yaucv2mk
- Spina Bifida Association of Oregon [Facebook]
tinyurl.com/y9rujabd

National/international/online resources

- Spina Bifida Association
spinabifidaassociation.org
- Online parent support
tinyurl.com/ybrje9j4
- Online support for parents and people living with Spina Bifida
tinyurl.com/yctjguzb
- Spina Bifida Parents Facebook Groups:
tinyurl.com/ybn64wcv
tinyurl.com/y9pj2wwx
- Bowel Management for Spina Bifida
tinyurl.com/ycjv8lxs
- Baby Center's Spina Bifida Kids group
tinyurl.com/yalmwgc6

Clinical trial information

- Children and Clinical Studies
tinyurl.com/y75s4twm
- Find an approved clinical trial
tinyurl.com/zp3jesq

Information for you and your care team.

- Spina Bifida Association - Info sheets
tinyurl.com/ybqwk2xc
- Centers for Disease Control (CDC) Spina Bifida research
tinyurl.com/yaxfcooz
- CDC - National Spina Bifida Patient Registry
tinyurl.com/y7fkyhgh
- CDC - articles and key findings
tinyurl.com/yc6o8k89
- CDC - "Living with Spina Bifida" by age group infant-young adults
tinyurl.com/y894hvc5

Family stories

- CDC - Spina Bifida family stories
tinyurl.com/y8nonkjz
- Videos of families talking about living with Spina Bifida
tinyurl.com/y8k7rx45

Insurance information and help

- Getting insurance for children (OR)
tinyurl.com/ydfaeeoy
- Getting insurance for children (WA)
tinyurl.com/yca9lkey
- Understand your health insurance
tinyurl.com/ychy6qnz
- General/Oregon Health Plan Questions: 855-323-6744

Other resources

- Toolkit for educators and parents about Spina Bifida
tinyurl.com/y76jm395
- Transition Toolkit for youth with Spina Bifida
tinyurl.com/y7lhymu5
- Camp Attitude:
campattitude.org
- Camp Korey
campkorey.org
- Mobility Assistance Dogs Information
tinyurl.com/y8hm8rot
- Adaptive Sports NW
adaptivesportsnw.org
- Oregon Adaptive Sports
tinyurl.com/y7y65ouu
- Youth Rally Camp
tinyurl.com/y92ng7b3
- On-line children's book about SB
tinyurl.com/yd4ph6v7
- Another Way to Go
tinyurl.com/yb7jp82f

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