

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: <u>tinyurl.com/ybn64wcv</u> tinyurl.com/y9pj2wwx
- Bowel Management for Spina Bifida tinyurl.com/ycjv8lxs
- Baby Center's Spina Bifida Kids group tinyurl.com/yalmwcg6

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/y7fkyhqh
- CDC articles and key findings tinyurl.com/yc6o8k89
- CDC "Living with Spina Bifida" by age group infant-young adults tinyurl.com/y894hv6s

Family stories

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

Insurance information and help

- Getting insurance for children (OR) tinyurl.com/ydfaaeoy
- 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 andparents about Spina Bifida tinyurl.com/y76jm395
- Transition Toolkit for youthwith Spina Bifida tinyurl.com/y7lhymu5
- Camp Attitude: campattitude.org
- Camp Korey campkorey.org
- Mobility Assistance DogsInformation 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

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