OHSU

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
 <u>tinyurl.com/ycwhffwc</u>
- Washington Parent to Parent (P2P) Programs <u>tinyurl.com/yaucv2mk</u>
- Spina Bifida Association of Oregon [Facebook] <u>tinyurl.com/y9rujabd</u>

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 <u>tinyurl.com/yctjguzb</u>
- Spina Bifida Parents Facebook Groups: <u>tinyurl.com/ybn64wcv</u>

tinyurl.com/y9pj2wwx

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

Clinical trial information

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

Information for you and your care team.

- Spina Bifida Association Info sheets
 <u>tinyurl.com/ybqwk2xc</u>
- 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/yc608k89
- CDC "Living with Spina Bifida" by age group infant-young adults tinyurl.com/y894hv6s

Family stories

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

Insurance information and help

- Getting insurance for children (OR) <u>tinyurl.com/yxqn43kt</u>
- Getting insurance for children (WA) <u>tinyurl.com/yca9lkey</u>
- Learn About Insurance Coverage
 <u>tinyurl.com/y4639rz6</u>
- 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 Physical Differences tinyurl.com/ycthkffr
- Camp Attitude: <u>campattitude.org</u>
- Camp Korey
 <u>campkorey.org</u>
- Mobility Assistance Dogs Information tinyurl.com/y8hm8rot
- Adaptive Sports NW adaptivesportsnw.org
- Oregon Adaptive Sports
 <u>tinyurl.com/y7y65ouu</u>
- Youth Rally Camp <u>tinyurl.com/y92ng7b3</u>
- On-line children's book about SB <u>tinyurl.com/yd4ph6v7</u>

Books for parents and children

- Another Way to Go tinyurl.com/yb7jp82f
- Bibliography available by calling the Oregon Family to Family Health Information Center at 855-323-6744
- Swindells' online library search <u>tinyurl.com/y9t2jwcx</u>

This Family Resource Page was supported by a Cooperative Agreement (#DD004951) funded by the Centers for Disease Control and Prevention to the Oregon Health Authority (OHA) (6NUS0DD004951-01-01). This project is a joint effort of the OHA's Birth Anomalies Surveillance System and the Oregon Center for Children and Youth with Special Health Needs' Family to Family Health Information Center at OHSU. This public domain publication is available in alternative formats by calling 503-494-0865. The contents of this page are solely the responsibility of the authors and do not necessarily represent the official position of the Centers for Disease Control and Prevention, the Department of Health and Human Services, the OHA, or OHSU. The generous support and collaboration of the OHA and Community Partners is appreciated.