Below you will find selected resources for supporting youth and families with spina bifida (myelodysplasia) compiled by Megan Merrill, DNP, RN.

Feel free to forward this newsletter to others.
Ann Garwick, Center Director

**Spina Bifida Resources for Youth and Families**


- Comprehensive overview for parents expecting a baby or who have just had a baby with spina bifida.

**Minnesota Spina Bifida Association:** [http://mnsba.org](http://mnsba.org)

- Located in Golden Valley, MN this organization aims to increase awareness about spina bifida and enhance the lives of those affected. Offers local activities and social events.
Spina Bifida Association:  [www.spinabifidaassociation.org](http://www.spinabifidaassociation.org)

- A national organization dedicated to enhancing the lives of those with spina bifida and those whose lives are touched by it.
- For Families: New diagnosis education, developmental information, advocacy, online communities, local chapters.
- For Providers: Education module on folic acid and fact sheets on various topics related to managing patients with spina bifida.

Centers for Disease Control and Prevention:

- Offers spina bifida information for expectant parents, including information on treatment, how to find support, a guide to a healthy pregnancy, research, and great videos about the experience of living with spina bifida.

Minnesota Department of Health:
[http://www.health.state.mn.us/divs/cfh/program/cyshn/family.cfm](http://www.health.state.mn.us/divs/cfh/program/cyshn/family.cfm)

- Local information and resources for Minnesota families of children with special healthcare needs including: health history resources, emergency preparedness, financial services, and a list of organizations that support families and children with special health care needs.

---

Copyright © 2016 School of Nursing, University of Minnesota, All rights reserved.
Our mailing address is:
Center for Children with Special Health Care Needs
University of Minnesota, School of Nursing
5-140 Weaver-Densford Hall
308 Harvard Street SE
Minneapolis, MN 55455

e-mail: cshcn@umn.edu
website: www.nursing.umn.edu/CCSHCN