



RESOURCES

For Health Providers

Caring for a Child or Adult with

Prader-Willi Syndrome



Prader-Willi syndrome (PWS) is a complex genetic developmental disability affecting approximately 1:12,000 persons. Because of a defect on the 15th chromosome, these individuals may have a variety of health challenges primarily as a result of a malfunction in the hypothalamus. Ongoing research continues to reveal more health issues and concerns that impact the management and care of these individuals by health care providers. Stay informed. Use the health resources available to you.

Prader-Willi Syndrome Association (USA) is a national organization dedicated to serving individuals affected by Prader-Willi syndrome (PWS), their families, and interested professionals. They provide a wide variety of services including information about health issues, consultation with medical experts in the field of PWS as well as support to families and caregivers.

WEBSITE: www.pwsausa.org

TOLL FREE NUMBER: 1-800-926-4797

- **CLINICAL ADVISORY BOARD:** A network of health professionals located nationwide that provides professional-to-professional consultation. These professionals can be reached through the Triage Support Specialist at the toll-free number. Phone numbers and contacts are only shared between professionals – not through parents and/or caregivers.
- **YOUNG PARENT MENTORING PROGRAM:** This is a program, which connects parents of newly diagnosed infants and children with other parents who provide support and accurate information about the many aspects of becoming the parent of a child with PWS. Professionals and/or parents can be connected to this program by contacting the toll free number.

Prader-Willi Syndrome Association of Wisconsin is a statewide organization dedicated to the support, education and advocacy of persons with PWS as well as those who support them. They are a chapter of PWSA (USA). They provide social, support and educational opportunities through newsletters, trainings, emails and a toll free phone number. They can provide consultative services to parents, schools, vocational and residential providers.

WEBSITE: www.pwsausa.org/WI

TOLL FREE NUMBER: 1-866-797-2947

EMAIL: Wisconsin@pwsausa.org

**Contact Information: PWSA of WI, Inc.
2701 N Alexander
Appleton, WI 54911**