

Prader-Willi Syndrome

TIPS AND RESOURCES FOR FAMILIES



What causes Prader-Willi syndrome?

Most individuals with Prader-Willi syndrome (PWS) have a deletion of several genes on chromosome 15. The deletion occurs in the chromosome 15 contributed by the father. If an individual does not have a deletion, he or she may have two chromosome 15s, both of which have been contributed by the mother. PWS occurs in about 1 in 15,000 births. The diagnosis occurs equally in males and females and occurs across all ethnic groups.

What are the effects of PWS?

While everyone with PWS is unique, individuals may share certain characteristics. They may include:

- At birth, hypotonia (low muscle tone) and failure to thrive.
- As infants, delays in motor, cognitive skills, and speech.
- In early childhood, a compulsive eating and obsession with food may develop. This feature

usually begins before age 6. The drive to eat is physiological and overwhelming and is difficult to control.

- Obesity is common though not universal.
- Behavior issues such as repetitive behaviors, anxiety, rigidity to schedules and routines, and temper tantrums are common.
- Skills in solving jigsaw puzzles and word searches.
- Especially nurturing and loving towards animals and babies.
- Great perseverance in finishing tasks that can seem monotonous or routine to others.

Can PWS be treated?

While there is currently no cure for Prader-Willi syndrome, individuals with PWS may benefit by receiving input from geneticists, primary care physicians, endocrinologists, nutritionists, psychologists, psychiatrists, special educators, speech-language therapists, occupational and physical therapists, families, support staff, and other care providers.

Several treatments appear promising for better outcomes in weight management.

- Early diagnosis and intervention
- Growth hormone treatment
- Healthy diet and daily exercise
- Close supervision to prevent access to food

In terms of behavior and psychiatric issues, an early diagnosis, appropriate medications, and implementation of effective behavior management by family, staff, and professionals are key strategies for helping individuals reach their potential. Many of the strengths listed in the Effects section of this fact sheet can be maximized in vocational settings.

With interventions in place and careful monitoring, quality of life can be greatly improved for persons with PWS and their families.

Please see reverse for resources.



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RESOURCES

Who We Are and Who We Serve

The **Vanderbilt Kennedy Center (VKC)** works with and for people with disabilities and their family members, service providers and advocates, researchers and policy makers. It is among only a few centers nationwide to be a University Center for Excellence in Developmental Disabilities, a *Eunice Kennedy Shriver* Intellectual and Developmental Disabilities Research Center, and a Leadership Education in Neurodevelopmental and Related Disabilities Training Program. The following are some of the ways the Center's programs and staff can assist families, educators, and other service providers.

Two Easy Ways to Take Part in Research

The Vanderbilt Kennedy Center serves families through research studies. StudyFinder is a searchable database that lists current VKC studies, including ASD research. Studies seek people of all ages with and without developmental disabilities. See kc.vanderbilt.edu/studyfinder, (615) 936-0448. Research Match is a secure place for volunteers and researchers to connect. Once you sign up and get added to the registry, a researcher will contact you if you're a possible match for the research study. See www.researchmatch.org.

Tennessee Disability Pathfinder

Tennessee Disability Pathfinder is a free statewide phone, web, and print referral service in English and Spanish. It connects the Tennessee disability community with service providers and resources. Its website database has over 3,000 agencies searchable by Tennessee county and service. Pathfinder is a project of the VKC, TN Council on Developmental Disabilities, TN Department of Health, and the TN Department of Intellectual and Developmental Disabilities. Contact www.familypathfinder.org, (615) 322-8529, toll-free (800) 640-4636.

Contact the Vanderbilt Kennedy Center
Nashville (615) 322-8240
Toll-Free (866) 936-VUKC [8852]
www.vkc.vumc.org
kc@vumc.org

Other Resources

- **Prader-Willi Syndrome Association**
An organization of families and professionals working together to raise awareness, offer support, provide education and advocacy, and promote and fund research to enhance the quality of life of those affected by Prader-Willi syndrome. www.pwsausa.org/
- **The Arc US**
The largest national community-based organization advocating for and serving people with intellectual and developmental disabilities and their families. www.thearc.org/
- **The Arc TN**
www.thearctn.org, (800) 835-7077
- **Special Olympics**
An organization providing year-round sports training and athletic competition for children and adults with intellectual disabilities. There are opportunities to develop physical fitness, demonstrate courage, experience joy, and participate in a sharing of gifts, skills, and friendship. www.specialolympics.org
- **Special Olympics Tennessee**
www.specialolympicstn.org, (800) 383-8502
- **TEIS (Tennessee Early Intervention Services)**
A voluntary educational program for families with children ages birth through two years of age with disabilities or developmental delays. (800) 852-7157, www.tn.gov/education/teis/
- **Tennessee Department of Education, Division of Special Education** This department promotes educational services and programs for all Tennessee's children with special education needs. (888) 212-3162 www.tn.gov/education/speced/
- **Family Voices of Tennessee**
A health information resource for families who have children with special health care needs: disability, chronic illness, physical or mental health conditions. (888) 643-7811, www.tndisability.org/familyvoices

