

About Prader-Willi California Foundation

Prader-Willi California Foundation is a non-profit 501(c)(3) public charity. Established in 1979 by a small group of parents, today we are over 1200 members strong and the only organization dedicated exclusively to serving the day-to-day needs of Californians impacted by PWS.

PWCF is comprised of parents, extended family, supportive friends, and dedicated professionals. We are supported solely by dues and donations.

PWCF proudly maintains an affiliation with the national Prader-Willi Syndrome Association | USA.

Our Mission



Individuals with PWS should have the opportunity to pursue their hopes and dreams to the full extent of their talents and capabilities. The success of people with PWS depends greatly upon the knowledge and support of the community around them. PWCF provides individuals with PWS, their families, and professionals with a state network of information, advocacy and support services.

Our Aims and Objectives

- To provide education and support
- To increase awareness of PWS
- To advocate for families
- To support appropriate and high quality living arrangements
- To support statewide and national PWS research



Our Vision

Our vision is that persons with PWS will live a full life without limits.



Prader-Willi California Foundation and the national Prader-Willi Syndrome Association | USA have an extensive amount of materials available for families, friends, physicians, therapists, caseworkers, residential providers, school staff, and other care providers. Please contact PWCF or PWSA | USA when we may provide information, support, or advocacy services to you, your child, your friend, patient, or student.

To learn more about Prader-Willi syndrome, how we can help you, and how you can help us, please call us or visit www.PWCF.org.



Prader-Willi California Foundation was established in 1979 as a non-profit 501(c)(3) charitable organization. An affiliate of the national Prader-Willi Syndrome Association | USA, PWCF is dedicated to supporting individuals with Prader-Willi syndrome, their families, and the professionals who serve them. TIN #95-3480752.

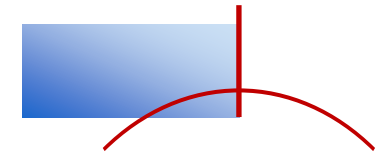


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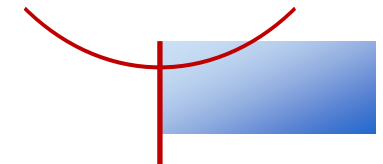


Education and Training Services



for Families and Professionals


Serving Persons with Prader-Willi Syndrome



About Prader-Willi Syndrome

Prader-Willi syndrome (PRAH-der-WILL-ee) is a rare medical disorder and the most common genetic condition that can lead to life-threatening obesity if not properly managed. Children and adults with Prader-Willi syndrome (PWS) experience a multitude of symptoms including growth failure, weak muscles, developmental delays, cognitive deficits, learning problems, orthopedic issues, balance and coordination problems, speech and language problems, and behavioral challenges similar to and often more severe than autism spectrum disorder.

PWS is best known, however, for its hallmark symptom, **hyperphagia, which causes an insatiable drive to eat despite the quantity of food consumed.** Additionally, the metabolic rate is almost half what it should be. If diet is not modified with significantly reduced calories, and access to food is not restricted and supervised, persons with PWS will gain an enormous amount of weight very quickly. In addition to the risk of morbid obesity, persons with PWS are at increased risk for acute stomach and bowel rupture or necrosis.



Often more challenging than the life-threatening hyperphagia are PWS's behavioral symptoms. Fueled by anxiety, impaired impulse control, and executive function deficits, older children and adults with PWS are often easily frustrated, inflexible, argumentative, and prone to verbal and/or physical aggression.

With appropriate education, training, and support many symptoms of PWS can be managed. Individuals with PWS and their families *can* live healthy, happy, and fulfilling lives. PWCF provides state-of-the-art training and support to help families and professionals manage PWS' myriad symptoms.

Contact PWCF today to learn how we can help you.

Parent Education, Training & Support

PWCF helps parents reduce, eliminate, or effectively manage symptoms that occur during various stages of life.

We provide a multitude of education, training, and support services to parents, extended family, and individuals with PWS. Services are provided individually, in group settings, in-person, on-site, online, or in the family home.

- Parent Mentor support to help newly-diagnosed families
- Feeding, nutrition, and dietary education
- PWS Multidisciplinary Clinic referrals and specialty physician referrals
- 24/7 PWS Medical Crisis telephone support
- PWS Behavior Management education and training
- Annual State Conference with topic-specific focus including Special Needs Trust Planning
- Information and Sharing Support Sessions segregated by age for parents of the infant and young child, school age child, or adult
- PWS Camp that exclusively serves children and adults diagnosed with PWS
- Online Physical Activity Program for persons with PWS
- Online Chat Groups for persons with PWS
- Regional Center system support and advocacy services
- School system training, advocacy, and support services
- Residential placement support and advocacy services
- Staff training for providers of care in the residential, vocational work site, day program, and volunteer site
- Production of educational training materials including articles, DVDs, streaming videos
- Training and consultation services provided at hospitals, clinics, universities, and online. Individualized training is available upon request

Professional Education, Training & Support

PWCF provides training to professionals who provide services and supports to individuals with PWS. Since there are an array of professionals who work with or serve persons with PWS, PWCF offers an array of Training Programs and individualized consultative services.



School Training for Educational Staff

Teaching the student with PWS presents unique challenges. PWCF provides training for teachers, aides, nurses, psychologists and counselors, principals, janitorial and cafeteria staff, and all related-service professionals, with special emphasis on PWS behavior management strategies.



Residential Staff Training

The residential needs of persons with PWS are unique and complex. PWS Training for residential service providers is absolutely critical for the health, safety, happiness, and overall well-being of the resident with PWS. PWCF provides training to group home and supported living services providers, with special emphasis on PWS behavior management strategies. PWCF staff is an authorized vendor for the Department of Social Services and offers Continuing Education Units to Adult Residential Providers.



Day Program, Vocational Work Site, and Volunteer Site Staff Training

Quality of life includes meaningful, productive work. The challenges that day program and recreational providers face when working with persons with PWS can feel insurmountable but are often managed with appropriate training and appropriately-trained job coaches. PWCF provides training to providers of care at day programs, vocational work sites, volunteer settings, and private employers, with special emphasis on PWS behavior management strategies.