

Prader-Willi California Foundation

Prader-Willi California Foundation is a non-profit 501(c)(3) public charity established in 1979 and the *only* organization dedicated *exclusively* to serving the needs of Californians impacted by Prader-Willi syndrome.

PWCF is comprised of parents, extended family and friends as well as dedicated professionals and care providers. The Foundation is supported solely by dues and donations. PWCF Federal Tax Identification Number #95-3480752.

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
- To advocate for families
- To support appropriate and high quality living arrangements
- To support statewide and national research



Our Vision

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

You can make a difference!

With early diagnosis and early and appropriate medical and therapeutic interventions, the future of children with Prader-Willi syndrome can be bright and full of promise. Please help us help them.

- Make a tax-deductible donation to PWCF
- Volunteer your time and/or talents to help people with Prader-Willi syndrome
- Learn more and educate others about PWS



To learn more contact...

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 Redondo Beach, CA 90277
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 800.400.9994 (Toll-free in CA)
 info@pwcf.org • www.PWCF.org

An Affiliate of...

Prader-Willi Syndrome Association (USA)
 800.926.4797
 info@pwsausa.org

USA
PRADER-WILLI SYNDROME ASSOCIATION
Still hungry for a cure.



An Overview of Supports and Services for Families and Loved Ones

Working Together to Create A Full Life Without Limits

Prader-Willi syndrome is but a collection of symptoms.

It is what our children have.

It is not who they are.



We couldn't imagine life without Jacob. I wish I knew in his earlier days that there was nothing to be afraid of. Thankfully, PWS is just something that Jake happens to have and will in no way define him or his quality of life. ~ Laura

The day we got Emily's diagnosis was the darkest day of my life. Looking back, if someone had given us any positive information about Emily's future, it would have helped me and my family so much. My conversation with you was the only thing that got me through those first couple of weeks. Every new family deserves to know that the future of kids with PWS is changing every day. Emily is proof of that. ~ Susie

There is so much to know about the medical aspects of PWS, but because it's so rare we can't always rely on our local doctors for the most current information. Staying connected with PWCF and attending our Support Group meetings helps me stay knowledgeable and feel empowered. I now believe I'll be able to manage whatever comes our way along this PWS journey. ~ Tom



Prader-Willi Syndrome (PWS) is a non-inherited genetic disorder that causes many different symptoms. The hallmark symptom in utero and infancy is hypotonia, severe low muscle tone, which interferes with feeding and causes a "failure to thrive." From childhood and throughout the person's lifetime, additional symptoms interfere with their ability to safely live independently including difficulty managing emotions and behavior, and hyperphagia defined as an insatiable, biochemical drive to eat. While medications can successfully manage some of the symptoms caused by PWS, there is no medication to reduce the symptom of hyperphagia. There are, however, treatment and management strategies that enrich the lives of all persons impacted by PWS. *And there is great hope.*



PWCF's Programs and Services

Education, Information, Resources and Training for families, care providers and professionals including physicians, therapists, case workers, residential and vocational service staff, attorneys and teachers.

Advocacy to secure appropriate medical and therapeutic interventions, Regional Center eligibility and educational supports and services.

Support in the form of organized Support Groups, personal telephone contact and online communication.

Awareness to ensure early diagnosis and appropriate treatment, as well as increased public awareness, understanding and acceptance of persons with PWS.

Research support of studies held in California and throughout the nation.



Prader-Willi California Foundation

(PWCF) serves parents, extended family members, friends, care providers, and all professionals who work with someone who has Prader-Willi syndrome. Please let us know how we may assist or support you.

Please contact PWCF if you suspect your child or loved one may have PWS. Use this form to request that PWCF send you a PWS Information Packet specific for a:

- Parent Extended Family Family Friend
- Therapist: Specialty _____
- Physician: Specialty _____
- Teacher: Grade Level _____
- Other _____

Please print

Name: _____

Address: _____

City: _____

State/Zip: _____

Phone: _____

Email: _____