

## 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. PWCF is supported solely by dues and donations. Federal TIN #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 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...

**Prader-Willi California Foundation**  
**1855 First Avenue, Suite 201**  
**San Diego, CA 92101**  
**310.372.5053 • Fax 310.372.4329**  
**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 • www.pwsausa.org



## Helping People with Prader-Willi Syndrome Live A Full Life Without Limits



*Since 1979 Prader-Willi California Foundation, a non-profit public charity, has been serving persons with Prader-Willi syndrome, their parents, and the professionals who serve them*

*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*

*Clint Hurdle, Pittsburgh Pirates Manager, father of Madison who has PWS, and PWSA (USA) national spokesman advises, "Please appreciate your children; they are working hard to get where they are and it may not come as naturally as it does for other children."*

**Prader-Willi syndrome is a life-long, life-threatening medical disorder.**

**Without continuous supervision and specific interventions throughout the duration of their lives, persons with PWS will die prematurely, whether from stomach rupture, choking, or complications related to morbid obesity.**

**Please help us improve the quality of their lives**

**Prader-Willi Syndrome (PWS)** is a non-inherited genetic disorder that causes a multitude of serious and life-threatening symptoms. The hallmark symptom in infancy is **hypotonia**, severe low muscle tone, which interferes with feeding and causes a "failure to thrive." From childhood throughout the person's lifetime, additional symptoms emerge including growth failure, body temperature abnormalities, sleep problems, cognitive impairment, learning disabilities, scoliosis, and incomplete sexual development. The hallmark symptoms of PWS, however, and perhaps the most debilitating, are **emotional dysregulation**, the impaired ability to control emotions and behavior, and **hyperphagia**, an insatiable, unrelenting, biochemical drive to eat no matter how much food is eaten. Unmanaged, PWS leads to morbid obesity and premature death.



Because *there is no known medication to eliminate or even reduce the drive to eat*, persons with PWS cannot live independently without risk of eating themselves to death. There are, however, treatment and management strategies that save lives and improve the quality of life of all persons impacted by PWS. *And there is great hope.*

### PWCF's Programs and Services

PWCF provides **Support, Education, and Advocacy** services to families and professionals. We help families secure appropriate medical and therapeutic interventions, educational supports, and residential services. We help increase **Public Awareness** and acceptance of persons with PWS. We provide **Training**, and support **Research** that seeks to unravel the complexities of PWS in order to identify effective treatments and ultimately find a cure.

### Information Request & Donation Form

PWCF relies upon the generosity of family members, caring friends and professionals. If you would like to make a tax-deductible donation to support the Foundation's vital programs or if you'd like to receive more information about Prader-Willi syndrome, please let us know. With your help, we will make miracles for our children.

I would like more information about Prader-Willi syndrome and Prader-Willi California Foundation.

I would like to make a tax-deductible donation to the Prader-Willi California Foundation.

In honor  In memory of: \_\_\_\_\_

*Provide the address of the honored family and we will notify them of your generous support:*

Address: \_\_\_\_\_

City: \_\_\_\_\_ State \_\_\_\_\_ Zip \_\_\_\_\_

Enclosed is my check made for \$ \_\_\_\_\_

Please charge my credit card \$ \_\_\_\_\_

Card #: \_\_\_\_\_  
Expiration Security Code

Name: \_\_\_\_\_

Address: \_\_\_\_\_

City: \_\_\_\_\_

State/Zip: \_\_\_\_\_

Phone: \_\_\_\_\_

Email: \_\_\_\_\_

