

Our Mission

Prader-Willi Syndrome Association (USA) is 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.

Our Vision

- We will provide **emotional support** to families and caregivers, and nurture hope, strength and connection as we strive together to improve the quality of life of individuals with Prader-Willi syndrome.
- We will take a leadership role in **supporting and stimulating research**, which will ultimately lead to a cure.
- We will provide **education and resources** to **improve the quality of life** for everyone with the syndrome as well as the people who support them.
- We will instill a sense of **compassion and understanding** through our dedication to providing **awareness** and enlightened **knowledge** about the syndrome.
- We will **secure the resources** necessary to accomplish our goals.

Furthermore, **we believe research findings** related to PWS will significantly **impact the understanding** of obesity and appetite regulation in the general population.

Prader-Willi Syndrome is:

- A non-hereditary birth defect resulting from a disorder of chromosome 15
- A serious, life-long, and life-threatening medical condition
- Occurs in 1:12,000 to 1:15,000 births; both sexes, all races
- Characterized by
 - Hypotonia (*low tone*)
 - Hypogonadism (*underdeveloped sex organs*)
 - Hyperphagia (*uncontrollable hunger*)
 - Cognitive impairment
 - Challenging behaviors
- One of the most common conditions seen in genetic clinics
- The most common genetic cause of obesity

A major medical concern is morbid obesity, however with early diagnosis and early intervention, many children can maintain a healthy weight.

Prader-Willi Syndrome Association (USA)

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**PWSA (USA), a 501(c)(3) non-profit organization, is very grateful to our donors and invites support of our organization. All contributions are tax deductible to the extent allowed by law.*

We hope you find these materials helpful and that you consider a donation to PWSA (USA) to assist in developing more good work(s) like this. Please see our website, www.pwsausa.org.

Helping All Families and Professionals



A Reference to PWSA (USA) Support and Services

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

We Offer



Family Support Program

Parent Mentoring

- Parent to Parent support with a trained parent mentor
- Extensive age-appropriate materials provided at no cost
- Free packet for physicians which includes a medical overview of PWS (DVD) and a Growth Hormone booklet.

Crisis Support

- Counseling with trained staff with advanced degrees
- Support for medical, behavioral, legal, school and placement crises
- Information and referral services

Advocacy

- Special education advocacy on behalf of students with PWS including information about IEPs, PWS-specific school strategies, and a DVD for educators.
- Advocacy to help people and families living with PWS connect with needed benefits and services including SSI and essential therapies.
- Support for public policies that increase services and opportunities for people with PWS and their families.

State Chapters

- Chapters offer local advocacy, resources and family connections. To find a chapter in your state, visit: www.pwsausa.org/links/chapter.htm
- A State Leader's Team coordinates partnership with national support services.



Medical and Research Program

- Scientific and Clinical Advisory Boards - all members have extensive PWS experience
- Consultation with PWSA (USA) medical board members available to all physicians
- Scientific conference at the annual national PWSA (USA) conference
- Publishing of Medical Alert booklets and medical handouts that are PWS-expert physician authored
- New Third Edition of "Management of PWS" book for professionals
- Research grants awarded annually
- Research advocacy - PWSA (USA) was instrumental in acquiring FDA approval for the use of growth hormone for individuals with PWS

Publications and Website

- Extensive website information with downloadable publications
- Bi-monthly educational newsletter for all members, including the latest in medical information, research and treatment
- Educational, supportive, and medical publications including DVDs available
- Moderated PWSA (USA) e-mail support groups



Awareness/PR/Development

- Booths/Presentations at medical conferences nationally and internationally
- Annual national PWSA (USA) Conference for families and professionals
- Extensive work with national and local media
- "Grass roots" fundraising and chapter efforts
- Annual national PWS Awareness Month
- Support individual awareness efforts
- Awareness merchandise

Bereavement Support and Study of Deaths

- Bereavement support by phone and mailings
- Sponsorship of largest study of PWS deaths

International Support

- Educational materials donated to developing countries
- Reproduction of our extensive education materials in their own languages encouraged
- Parents and professionals worldwide linked to our international organization, International Prader-Willi Syndrome Organization

Opportunity to Contribute

- Volunteers host local fundraisers
- Planned Giving, Corporate Matching and CFC opportunities
- Donations are tax deductible*