

Our Mission

To enhance the quality of life and empower 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


Prader-Willi
SYNDROME ASSOCIATION | USA
SAVING AND TRANSFORMING LIVES

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*