

## PWSA (USA)

### Mission Statement

PWSA (USA) is an organization of families and professionals working together to promote and fund research, provide education, and offer support to enhance the quality of life of those impacted by Prader-Willi syndrome.

### Vision Statement

- We 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 take a leadership role in supporting and stimulating research, which will ultimately lead to a cure.
- We provide education and resources to improve the quality of life for everyone with the syndrome as well as the people who support them.
- We instill a sense of compassion and understanding through our dedication to providing awareness and enlightened knowledge about the syndrome.
- We secure the resources necessary to accomplish our goals.
- We also 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  
Difficult behaviors
- One of the most common conditions seen in genetics clinics
- The most common genetic cause of obesity

**Major medical concern is morbid obesity.**

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

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**Contributions to PWSA(USA), a 501(c)3 non-profit organization, are tax deductible.**

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**Helping Professionals  
and Families**

**Prader-Willi Syndrome  
Association (USA)**

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## Services Provided

### New Parent Mentor Program

- Counseling with PWSA (USA) experienced staff
- Parent to Parent mentor referral
- Extensive age-appropriate materials sent at no cost
- Free Medical Overview DVD to professionals that refer a new family

### Grandparent Mentor Program

- Grandparent to Grandparent mentor referral
- Grandparent booklet and materials provided

### Crisis Program

- Counseling with trained PWSA (USA) staff with advanced degrees
- Work with medical, behavioral, legal, school, and placement crises
- Advocacy for SSI and needed therapies
- Crisis packets and letters sent as needed
- Pilot 24-hour, 7-day-a-week medical crisis hotline

### School Advocacy Program

- Counseling and advocacy with families and school staff
- Extensive school educational materials provided

### Medical and Research Program

- Scientific and Clinical Advisory Boards — all members have extensive PWS experience
- Consultation with PWSA (USA) medical board members available to 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

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

### Advocacy

- Coordination of public policy advocacy on SSI, insurance, and other public policy issues
- Individual advocacy for affected families

### 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 supported, sponsorships sought
- Annual national PWS Awareness Week

### Bereavement Support and Study of Deaths

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

### International Support

- Educational materials donated to developing countries
- Other countries encouraged to reproduce our extensive education materials in their own languages
- Parents and professionals from other countries supported and connected to our international organization, International Prader-Willi Syndrome Organization

### Opportunity to Contribute

- Volunteers host local fundraisers
- Contributions support all programs



Early Diagnosis



Early Intervention



Support



Education and Advocacy



13 months on Growth Hormone



Weight Management

