

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.

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 muscle tone*)
 - Hyperphagia (*uncontrollable hunger*)
 - Hypogonadism (*underdeveloped sex organs*)
 - Cognitive impairment
 - Difficult 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.

The Prader-Willi Syndrome Association (USA) was formed in 1975 to provide a vehicle of communication for parents, professionals and other interested citizens. It is an organization dedicated to the sharing of experiences in how to cope and work with the syndrome. Chapters of PWSA (USA) are located in most states and are available for support, education and advocacy.

An annual national conference, a bimonthly newsletter entitled *The Gathered View*, which incorporates contributions from members as well as professional advice, and a wealth of other written materials and publications on Prader-Willi syndrome are all part of the PWSA (USA)'s effort to carry out its mission.

PWSA (USA) is supported solely by membership fees and donations. Our agency has made a difference in the lives of many families and individuals affected by this unique syndrome.

YOU TOO CAN HELP. Donations and membership applications may be sent to the address below.

PWSA (USA) gratefully acknowledges printing of this brochure is funded by a grant from the Gerald J. and Dorothy R. Friedman New York Foundation in honor of Sophie Grace Coggeshall.

Prader-Willi Syndrome Association (USA)

8588 Potter Park Drive, Suite 500
Sarasota, FL 34238

Tel: 800.926.4797 or 941.312.0400

Fax: 941.312.0142

E-mail: info@pwsausa.org or

Web: www.pwsausa.org

*Contributions to PWSA (USA), a 501(c)(3) non-profit organization, 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 Web site, www.pwsausa.org.

Someone You Know Has PWS



Kirsten

An introduction to
Prader-Willi syndrome
especially for babysitters,
neighbors, extended family,
friends, play-date occasions,
and the community

U S A
PRADE-R-WILLI
SYNDROME
ASSOCIATION Still hungry
for a cure.

Did You Know...



Madilyn

Prader-Willi syndrome (PWS), pronounced PRAH-der-WILL-ee, is a birth defect. This means that a person is born with the syndrome and cannot outgrow it. Doctors don't know why it happens and there is no cure for it.

People who have PWS like to do the same things as other children and adults. They like to go to movies, have parties, play outside, and have hobbies, like putting puzzles together or making bracelets.

Some of the characteristics of children and adults who have PWS are:

■ Babies born with PWS are usually weak from lack of muscle tone and have a hard time sucking. It takes a long time for them to learn to walk and to talk clearly. They get stronger as they grow, but have poor balance and are not well coordinated. Toddlers can have a food drive, but this usually occurs after 3 years of age.



Sebastian



Leslie

- Children and adults have a compulsion to eat that they cannot control. They never feel full and always feel very hungry. The certainty that food is not available frees them up to work and play.
- Children and adults cannot eat as much as everyone else because they will gain LOTS of weight on considerably fewer calories.
- Children and adults who have PWS are usually friendly, pleasant and mild mannered. If they become anxious or distraught, it's very hard for them to settle down. They do not have control over their behavior.
- Some adolescents do not reach full physical maturity. They can be shorter than normal and look younger than they really are.
- Children and adults with PWS are generally concrete thinkers. Terms like, "Hop to it!" may not be understood to mean "Begin the task immediately" and may cause confusion, anxiety, and result in an unwanted behavior.
- People with PWS have a delay in processing the information you give them. Most children will take between 3-5 seconds to understand what you say. If too many instructions are given or the instructions are generalized, they can miss the middle part of what you said and misunderstandings can occur.

YOU CAN HELP BY:

- Never make fun of the child or adult with Prader-Willi syndrome.
- Resist your temptation to give him or her any food, even one cookie or a piece of candy.
- Be aware of their need and ability to tell you made-up stories so that they can have more food.
- Keep food out of sight, out of reach, and never leave the person in a room that has food. The best way is to keep all food locked up. Food can harm and even kill a person who has PWS. Remember, the hand of someone with PWS is quicker than the eye!
- Substitute diet soda, diet gum, or raw fruits and vegetables for foods that have higher calories.
- Understand that a person with PWS cannot resist trying to get food; if they are slim, it is because the family has worked very hard to control their food and weight.
- When someone with PWS becomes upset, allow time and space for them to settle down. Looking at them or trying to talk to them usually only makes them feel worse. Ask their parents or caretaker for tips on what helps them.