

About Prader-Willi Syndrome

Prader-Willi Syndrome is a group of symptoms caused by a genetic defect in Chromosome 15. The symptoms include many, although not all of the following:

- **Central Nervous System** malfunctions including impaired body control and mental retardation with an average IQ score of 70. Dysfunction of the hypothalamus affects physical growth, sexual development, appetite, temperature control, and emotional stability.

- **Hypotonia during infancy** with poor motor control, weak cry and poor sucking ability. Although children get stronger as they grow older, muscle tone usually remains lower than normal.

- **Short stature**, with adults reaching about five feet in height. Other physical characteristics include small hands, feet, and a narrow forehead.

- **Insatiable appetite** begins somewhere between age 2 and 5 years. Since individuals with PWS have a metabolism which is only 60% of normal, they require fewer calories to maintain weight. An uncontrollable preoccupation with food usually leads to obesity, serious health problems, and early death unless access to food is strictly controlled. With adequate supervision and careful control of food intake, persons with PWS can maintain healthy weight.

- **Scratching and picking** is common due to increased pain tolerance and decreased sensory input.

- **Behavioral difficulties** usually begin in early childhood and persist throughout adult life. These difficulties include behavioral outbursts, uncooperative behavior, and resistance to transitions.

About Our Programs and Supports Network

People with Prader-Willi Syndrome often have a difficult time at home or in a residential setting. Despite these challenges, Keystone Community Resources has been able to provide individuals with PWS a safe and stable environment to learn, grow, become and stay healthy.

The daily life of Keystone's Prader-Willi Program involves a structured blend of social, recreational and behavioral support in which staff perform therapeutic support services. Activity schedules include planned leisure and recreation, training in activities of daily living, and an emphasis on developing and enhancing appropriate social and behavioral interactions. Homes of 4 to 5 residents each offer individual bedrooms for most residents. The program offers the following:

Specialized training modules on PWS for all direct care staff.

- Nursing services for coordination of health care needs
- Physician services through the community
- Behavioral Specialist
- Therapists

Social and recreational programming at Keystone involves a multitude of in home and community based activities. Since PWS is characterized by obesity and poor muscle tone, activities which require physical exertion, such as walking, swimming, and aerobic exercise, and use of equipment such as treadmills are an integral part of the daily routine.

Professional staff at Keystone are involved in the national and state chapters of the Prader-Willi Association and are regularly represented at conferences to keep abreast of current practices.

In the home, controls have been added to the living environment to assist residents in meeting their needs. Access to both the refrigerator and food cabinets at all PWS homes is secured at all times.

Staff are specially trained to avoid the topic of food and food related subjects and ensure that meals are well presented to make up for a low caloric content.





Measures of Success.....

The emphasis on weight loss/weight control is probably the most evident measure of Keystone's success in responding to persons with Prader-Willi Syndrome.

The average weight loss of participants in the PWS program is 70.23 pounds, with a record of 129.75 pounds lost!



KEYSTONE
COMMUNITY
RESOURCES

100 Abington Executive Park, Suite B
Clarks Summit, PA 18411

Admissions Department

Phone: 570-702-8028

Fax: 570-702-8094

www.keycommres.org



*Prader-Willi
Syndrome*



KEYSTONE
COMMUNITY
RESOURCES