



Prader-Willi Syndrome Program at The Children's Institute

The Prader-Willi Syndrome (PWS) Program at The Children's Institute treats both children and adults and is the only hospital-based program of its kind in North America. Since 1981, more than 1,000 children and adults with Prader-Willi Syndrome have been admitted to The Children's Institute's inpatient program.

Prader-Willi Syndrome is a complex genetic disorder typically diagnosed in newborns and toddlers. A person with PWS experiences insatiable hunger that leads to rapid weight gain and can cause additional health problems, including diabetes and strain on the heart, lungs and joints. It also can result in early death. Symptoms of the syndrome include morbid obesity, decreased muscle tone, obsessive/compulsive behaviors, decreased mental capacity, communication challenges and loss of emotional control, ranging from tears to tantrums to physical aggression.

People with PWS are managed most effectively in a highly specialized environment. At The Children's Institute, a multidisciplinary team, including pediatricians, physiatrists, psychiatrists, dietitians, occupational therapists,

physical therapists, psychologists and speech/language pathologists, coordinates services to provide the most effective, individualized treatment program for each patient.

The Children's Institute provides a medically supervised, individualized program that encourages personal weight control, motor development, nutrition awareness, social skills and self-motivation. Patients learn behavioral self-control in order to minimize tantrums, isolation and oppositional behavior.

Once patients with PWS have achieved their program goals, the staff at The Children's Institute works with them and their families to translate the controlled-care environment of The Children's Institute to home, school and social situations. Continued implementation of structure by family members/caregivers, friends and neighbors is imperative to the ongoing successful management of the syndrome and its related health and behavioral issues.

The Prader-Willi Syndrome Program is another example of why The Children's Institute has earned an international reputation for its success in pediatric rehabilitation.



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FACTS ABOUT PRADER-WILLI SYNDROME*

- Prader-Willi Syndrome (PWS) is a disorder of chromosome 15.
- It is estimated that PWS affects one in every 12,000 – 15,000 births.
- PWS is diagnosed through DNA analysis.
- Newborns with PWS typically have feeding problems and difficulty gaining weight.
- Developmental milestones typically are delayed by one to two years.
- People with PWS are of short stature by age 15 and have small hands and feet for their age.
- Behaviors characteristic of people with PWS include tantrums; violent outbursts; obsessive/compulsive behavior; a tendency to be argumentative, manipulative, possessive and stubborn; stealing and lying.
- PWS puts people at greater risk for developing curvature of the spine, weakened bones, diabetes, hypertension and dental problems, among others.

* Source: www.pwsausa.org



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