The Center for Prader-Willi Syndrome at The Children's Institute of Pittsburgh

When it comes to pediatric and adult inpatient treatment for Prader-Willi syndrome, there is no place like The Center for Prader-Willi Syndrome at The Children's Institute. Our medically supervised, individualized treatment program for children and adults with Prader-Willi syndrome is truly unique. In fact, it is the only hospital-based program of its kind in the world.

The Center for Prader-Willi Syndrome is another example of why The Children's Institute has earned an international reputation for its success in rehabilitation. Our state-of-the art facilities and individualized, family-centered services are provided by an expert treatment team led by highly-experienced physicians.

The Center for Prader-Willi Syndrome provides:

- Absolute food control (often not achieved in general psychiatric or medical units)
- Experienced medical management
- Calm, skilled nursing staff who are extensively experienced with gaining patient cooperation to achieve necessary medical interventions
- Individualized psychiatric and behavioral treatment
- Intervention for cardio-pulmonary deterioration, acute psychiatric decompensation, and behavioral/environmental crises

Program Goals

The Center for Prader-Willi Syndrome's treatment program provides a medically-supervised, individualized program with the goals of:

- Weight loss
 Motor development
- Nutrition awareness
 Physical fitness
- Improved aerobic capacity
 Improved social skills
- Behavioral self-control



Treatment Team

Children and adults with PWS are best treated in a highly specialized environment like The Center for Prader-Willi Sydrome. Our multidisciplinary team may include (a):

- Pediatrician
 Physiatrist
 Psychiatrist
- Psychologist
 Dietitians
 Social Workers
- Speech/language pathologists
 Nurses
- Music Therapist
 Occupational therapists
- Physical therapists
 Recreational therapist

In addition, family members provide essential emotional support and are encouraged to take a hands-on role in the recovery process.

More than 1,200 children and adults with Prader-Willi syndrome have been treated in our inpatient program.

To learn more about the Center for Prader-Willi Syndrome at The Children's Institute, or to make a referral, please contact Christa R. Gross, RN, BSN, MSEd, at 412.420.2113 or cgr@the-institute.org.

Referral and Admission

With the help of our patient care liaison, we ensure that your patient's admission and transition to The Center for Prader-Willi Syndrome is an easy one. After admission, a case manager coordinates your patient's treatment plan, ensuring that his or her individual needs are met.

We consider the referring physician to be part of the treatment team. We understand that you want and need updated information on your patient, progress reports and discharge plans. Our case managers will share this information with you on a regular basis.

Going Home

Upon discharge, continued implementation of structure by family members/caregivers, friends and neighbors is imperative to the ongoing successful management of the syndrome. Once patients with PWS achieve their program goals, our staff works with them, along with their families, to translate the controlled-care environment of The Center for Prader-Willi Syndrome to home, school and social situations.

We Are Here for You

The Center for Prader-Willi Syndrome team encourages families and caregivers to contact the patient care liaison, or treatment team directly with any questions or concerns during the patient's stay, or once he or she returns home. Our goal is to make the transition from hospital to home, school and community as smooth and productive as possible.

Together, we achieve the amazing.

Our program treats the most challenging individuals with PWS — and we get the best results. On average, patients stay with us for 60 days and achieve the following during that time:

- 31% average increase in cardio endurance
- 27 pound average weight loss
- increased compliance with behavioral management

The results continue after completion of the program:

- 97% of patients have no psychiatric admission 9 months post discharge
- 75.5% of patients have no acute or medical inpatient admission related to PWS 18 months post-discharge
- patients continue or sustain weight loss 18 months post-discharge, with an average continued weight loss of 67 pounds