



The Center for
Prader-Willi Syndrome
Treating Children & Adults

Professional Education and Consultation Services at The Center for Prader-Willi Syndrome

The Center for Prader-Willi Syndrome now offers professional education and consultation services for a variety of audiences including group homes, residential facilities, school districts and others who are caring for individuals with Prader-Willi syndrome.

The Center for Prader-Willi Syndrome at The Children's Institute is the only hospital-based program of its kind in the world. Our medically supervised, individualized treatment program is unique, and has changed the lives of nearly 1,500 children and adults with Prader-Willi syndrome over the past 20 years.

Our treatment teams are comprised of experts in various disciplines that possess in-depth knowledge and experience with this rare genetic condition. Education sessions and consultations are delivered by the following Center for Prader-Willi Syndrome team members:

- Behavioral Specialist
- Registered Dietitian
- Physical Therapist
- Occupational Therapist
- Speech/Language Pathologist
- Psychologist
- Special Education Teacher



Education Sessions

Most training sessions are three hours in length, and are comprised of various modules depending on your organization's needs. The sessions can be delivered via videoconference or in-person at our facility in Pittsburgh, Pennsylvania.

Consultations

One-on-One consultations are available to support other professionals who are in need of specific guidance for a patient, client or student. Consultations are typically delivered via phone, and are provided on an hourly basis.

To learn more about Professional Education and Consultation Services, please call 412.420.2535.

Education Sessions

The Center for Prader-Willi Syndrome can tailor an education package that aligns with your organization's specific needs. You can choose one or more of the education sessions below to be delivered via videoconference or in-person at our facility in Pittsburgh, Pennsylvania.

1. Introduction to Prader-Willi Syndrome

Provides an overview of the genetic disorder including prevalence, symptoms, physical and behavioral characteristics, and treatment program and outcomes at The Center for Prader-Willi Syndrome.

2. Behavioral Supports for People with Prader-Willi Syndrome

Reviews common behaviors exhibited by people with PWS and various behavior management techniques and best practices to reduce anxiety.

3. Everyday Activities to Improve Quality of Life for People with Prader-Willi Syndrome

Discusses the therapeutic use of everyday activities to promote independence and participation in life for people with PWS including the exploration of leisure activities, practicing skills for community, school, or volunteer settings, and sample daily schedules.

4. The School Setting for People with Prader-Willi Syndrome

Examines common cognition characteristics in students with PWS, suggests best practices for writing IEPs and providing accommodations and modifications in the school setting.

5. Nutrition for People with Prader-Willi Syndrome

Describes the metabolic factors impacting people with PWS and how diet management and food security can result in weight loss and improved overall health. The Red Yellow Green Diet is highlighted.

6. Exercise for People with Prader-Willi Syndrome

Explores the physical differences seen in people with PWS, the reason these differences require a modified approach to exercise, and provides tips and suggested activities for improving stamina, strength and health in these individuals.

7. Understanding Speech, Articulation, and Swallowing in People with Prader-Willi Syndrome

Defines the fundamentals of receptive, expressive, and pragmatic language, dysphagia, examines possible clinical implications, and provides communication tips when interacting with people with PWS.

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**