



**The Children's Institute**

Amazing Kids. Amazing Place.

## The PWS Care Coordination Program at The Center for Prader-Willi Syndrome

The Prader-Willi Syndrome Care Coordination Program is a new service at The Children's Institute of Pittsburgh. This service will assist with advocacy for children and adults with Prader-Willi syndrome (PWS). Based on patient need, services for patients with PWS may be offered for up to six months.



### What PWS Care Coordination is:

PWS Care Coordination is provided by a team of professionals including a registered nurse. Additionally, the consulting team may consist of a physical therapist, occupational therapist, speech and language therapist, registered dietician, and a special education teacher. This team of professionals can assist with:

- Identifying community and other supports
- Providing PWS-specific education and resources to your family, medical team and community providers
- Scheduling of wellness and other medical appointments
- Identifying resources and following through on recommendations from medical and other providers
- Training of school staff
- Creating a care plan to support overall health and wellness



### What PWS Care Coordination is not:

PWS Care Coordination does not provide medical advice, diagnosis, treatment, or prescriptions, either through this service or in any other way. This service is not a substitute for professional medical advice, diagnosis, or treatment. If you think you may have a medical emergency, please call your healthcare provider or 911 immediately.

### How the PWS Care Coordination Program works:

Medical professionals in all areas can refer a patient, or a caregiver can refer their own loved one.

A PWS Care Coordinator will then schedule an intake phone call with the family or schedule to meet the family in person. During this meeting, patient and family needs are discussed, goals are established, and a plan of care is created.

The PWS Care Coordinator partners with the patient's physicians and other healthcare providers. During this process, support from the PWS Care Coordinator and the PWS expert team at The Children's Institute are provided and services related to PWS for the patient in their local area are organized.



For more information about the [PWS Care Coordination Program](#), please contact 412.420.2113 or visit [amazingkids.org](http://amazingkids.org).



### **Outcomes will be tracked and are expected to include:**

- Better health care through an increase in the number of patients receiving appropriate medical and community-based services
- Assistance with identification of and registration with local developmental disability services
- Decreased stress reported by caregivers
- Decreased emergency room visits and hospitalizations
- Stabilization of weight or continued weight loss
- Assistance with assembling a core healthcare team
- Decreased number of reported school, day program, and work absences for patients and caregivers

### **Eligibility for the PWS Care Coordination Program:**

All children and adults with PWS are eligible. It is not a requirement to have been admitted as an inpatient at the Center for Prader-Willi Syndrome at The Children's Institute of Pittsburgh to participate in this service. Caring for children and adults with PWS involves the understanding and management of this complex medical condition. It is essential to work with multiple physicians, other providers, schools, and payers that support persons with PWS in order to increase the quality of life and overall health for the person with Prader-Willi syndrome.