# Core Therapies
# for the Child with Prader-Willi Syndrome

**Prader-Willi Syndrome (PWS)** is a genetically-based medical disorder that affects multiple systems in the body that create various symptoms. These symptoms vary from person to person, as well as vary within the individual's lifetime. Addressing issues as early in life as possible helps ensure a better outcome. This article provides an outline of the early intervention treatments and supports that help the child with PWS maximize inborn strengths and talents.

## The "Core" Therapeutic Interventions

Early identification and early intervention are critical to ensuring a high quality of life for persons diagnosed with PWS. This article provides a brief overview of the therapeutic interventions that are considered "core" therapies for the child with PWS to help them reach their full potential.

## Growth Hormone Therapy

One of the most prominent issues in infancy and childhood is severe low muscle tone, called hypotonia, which interferes with strength, balance, coordination, and stamina. Hypotonia in PWS is a result of a deficiency in the body's production and/or utilization of growth hormone. Replacing missing growth hormone with growth hormone medication (hGH) as soon as possible after the diagnosis of PWS supports your child's natural growth potential.

A helpful side effects of hGH is that it also improves muscle tone, which helps improve in the infant's ability to feed, improves respiratory function, and accelerates the child's overall progress toward meeting their milestones. Growth hormone therapy is considered standard of care for children with PWS.

hGH is prescribed and monitored by a physician who specializes in endocrinology. PWCF maintains a referral list of endocrinologists who treat patients with PWS, and can provide information about PWS and hGH therapy to any endocrinologist you choose to work with.

## Physical Therapy

Physical therapy should begin in infancy or as early in life as possible to help strengthen large (gross) muscle groups important for the acquisition of gross motor skills, strength, endurance, and the management or reduction of orthopedic issues including foot pronation and scoliosis. Therapy should support not only the acquisition of gross motor skills but also work to improve the *quality* of gross motor movements. Interventions to address these issues is provided by a Physical Therapist. Growth hormone treatment does not replace physical therapy.

## Occupational Therapy

Occupational Therapy should begin as early as possible in infancy and continue throughout childhood.

The focus of Occupational Therapy during infancy is to acquire and refine fine motor skills such as hand-eye coordination, batting, grasping, and pinching. Some Occupational Therapists are trained feeding specialists and can help teach parents special feeding techniques to help babies who, by virtue of weaker muscles and problems coordinating the suck-swallow-breathe skills, have difficulty bottle feeding.

Throughout childhood, Occupational Therapy will focus upon hand and finger strength and dexterity, motor planning and coordination to help the child master such skills as coloring, cutting, tracing and writing. Therapy should also help the child master self-care skills such as buttoning, zipping, snapping, toileting, opening and closing containers.

Hypotonia contributes to problems integrating the body's senses including sight, sound, and touch, as well integrating input from the vestibular system which involves body awareness, movement, balance, and the pull of gravity upon the body; and the proprioceptive system which informs the brain about the body from the input received from joints and muscles.

An Occupational Therapist and/or a Physical Therapist trained in Sensory Integration (SI) Therapy can help improve the ability of the child's brain to process and integrate the input it receives from all of the body's senses. SI Therapy can help decrease any hypersensitivity to light, sound, clothing fabrics, tags, etc., and improve motor planning, sequencing, and organizing the body to perform both fine and gross motor activities.

## Oral Motor Therapy

This early intervention therapy evaluates the baby's oral development, helps them feed more easily, and supports babbling skills which are a precursor skill to the development of clear speech. Oral motor therapy is provided by a specially-trained Feeding Therapist, Occupational Therapist, or Speech and Language Pathologist.

## Speech & Language Therapy

Speech and Language Therapy is important throughout childhood to address weak oral-motor muscles, poor articulation (Dysarthria), and common speech patterns of leaving off ending consonants (Final Consonant Deletion) and other phonological disorders, and global speech and language delays.

Some children with PWS also have a neurological disorder called Apraxia of Speech, or Speech Dyspraxia, that interferes with their ability to sequence and coordinate information in ways necessary to produce clear, smooth speech, and organized pragmatic language.

Speech and language therapy is provided by a Speech and Language Pathologist (SLP). Speech Dyspraxia requires treatment by an SLP who has received specialized training in treating dyspraxia which is essential for the child to make progress.

### Social Skills Therapy

The foundations of social relationships begin in infancy, therefore parents and care providers should focus upon building social skills as early as possible with the help of a professional, such as an Infant Stimulation Therapist, who can facilitate the social exchange between infant and care provider.

For many reasons children with PWS often need extra help learning appropriate social skills. Social Skills Therapy can begin as early as age 2 years to help the child develop and strengthen social and play skills necessary to initiate, develop, and maintain genuine, enjoyable, and long-lasting friendships. Social Skills Therapy can be provided by a Speech & Language Pathologist or a Social Skills Therapist, with best results in a small group setting. There is some research that supports the effectiveness of PWS-specific social skills therapy provided online.

### Behavioral and Psychiatric Intervention

To varying degrees PWS interferes with the individual's ability to manage the intensity, duration, or expression of their emotions. Many people with PWS are hyperreactive to stress, frustration, and disappointment. Some people can have emotional and behavioral reactions that are disproportionate to the situation, and can exhibit rapid mood swings or outbursts.

Incorporating PWS-specific behavior management strategies and interventions as early age 2 years is a crucial component of early intervention and helps reduce behavior problems. PWCF has many helpful resources, and can provide in-person or online training for family members, treating therapists, and school personnel.

For some individuals with PWS, brain chemistry can occasionally impact rational thought and behavior, making brain-based medications necessary. Psychotropic medications, prescribed by a psychiatrist, can help reduce or eliminate these symptoms and restore a higher quality of life. PWCF offers specialized resources to help your psychiatric physician better understand the use of psychotropic medications in persons diagnosed with PWS.

Prader-Willi
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**There are many more helpful interventions, therapies, and resources** available from PWCF and the national Prader-Willi Syndrome Association | USA.

**Contact PWCF when we may be of support or assistance**
**800-400-9994 | info@pwcf.org | www.PWCF.org**