

Orthopedic Issues Specific to PWS

Orthopedic issues are common in children with PWS. Recurrent evaluations with an orthopedic surgeon for the purpose of monitoring the known risks in PWS is highly recommended. With low muscle mass and muscle tone, there can be hip dysplasia, when the leg bone is not completely positioned in the socket, at birth. Foot pronation, where the foot or feet turn in, is due to low muscle tone and is often treated with orthotic supports called Ankle & Foot Orthotics (AFOs) or Dynamic Foot & Ankle Orthotics (DAFOs). Scoliosis (sideways “S” or “C” curve of the spine) can occur in infancy and in later childhood. Kyphosis (rounding of the back) can occur later in childhood or adulthood. Curvatures of the spine in infants with PWS are unlikely to develop prior to the influence of gravity across the spine. Monitoring of spine should begin when the child first sits independently. Thereafter, in addition to a clinical examination, yearly x-ray screenings of the seated or standing spine should be taken to closely monitor and detect any developing problems. The earlier a curve is detected the better the outcome for treating the curve with casting or bracing. The incidence is not increased by the use of growth hormone. Some specialists use braces or casting to minimize the need for surgical correction

There are two peak ages for scoliosis in children with PWS. Under the age of 4 years, most of the curves are C-shaped, and are most likely related to the hypotonia. The second peak, around 10 years of age, typically is the more common S-shaped curve. Persons with PWS should be encouraged to be as active as possible, participating in activities that build and strengthen the core abdominal (stomach) and back muscles. In addition to sports and recreational activities, focused physical therapy and hippotherapy (therapeutic horseback riding), emphasizing core muscle strengthening may help improve a hypotonic curve in a young child. If a scoliosis or kyphosis curve is noted to develop, a physical therapy regimen should be included with specific exercises to strengthen the back extension muscles. A number of parents have also found Pilates to be beneficial.