Minnesota Department of Education

Prader-Willi Syndrome Information System

Prader-Willi syndrome (PWS) is a rare disorder present at birth that results in a number of physical, mental and behavioral issues. A key feature of Prader-Willi (prah-dur VIL-ee) is a constant sense of hunger that usually begins after the first year of life. About 1 in 12,000 to 1 in 15,000 live births result in Prader-Willi Syndrome. Males and females are affected equally and it occurs in all races.

Prader-Willi Syndrome is divided into two distinct clinical stages. Stage one occurs from birth through the ages of two to four years of age. Babies are born with very low muscle tone and may need special nipples or tubes for feeding. They may need to be turned when sleeping and some take longer than typical to reach developmental milestones. During the first year or two of life, infants put on weight slowly. If a diagnosis of PWS has not been made, the infant is labeled as “failure to thrive” producing anxiety for the parents.

The second stage occurs around age two to four years. The child has a sudden increase in appetite and eats accordingly. At the same time, fewer calories are needed to maintain an acceptable weight. Calories are burned more slowly, therefore food intake must be monitored and an exercise program implemented.

Symptoms and Signs

- Food craving and weight gain.
- Poor growth and physical development.
- Small hands and feet.
- Obsessive compulsive behaviors (picking at skin, argumentative, stubborn).
- Lack of eye coordination.
- Speech articulation issues .
- Respiratory difficulty.
- Scoliosis.
- Vomiting (rare with PWS, if vomiting occurs may indicate a life threatening illness).

Treatment

Some studies have suggested that growth hormone treatment in children with Prader-Willi syndrome helps increase growth, improve muscle tone and decrease body fat. A nutritionist may help develop a healthy, reduced-calorie diet to keep the child's weight under control while ensuring proper nutrition. Families often report challenges in supervising food.

Educational Implications

Some students with Prader-Willi Syndrome have learning disabilities that may include issues with attention, short-term memory, reading, receptive language and poor auditory processing.

Children may socialize with adults easily but may be isolated from peers. Concerns, especially at the secondary level, include easy access to food, privacy in changing rooms (especially for boys who are less physically developed as peers), hurtful comments, opportunities to compete in team games and opportunities to make close friends.

Educational Options

Those students whose Prader-Willi syndrome adversely affects their educational performance may benefit from special education under the Individuals with Disabilities Education Act (IDEA). To qualify under IDEA, a student must meet eligibility criteria in one of thirteen specific disability categories. IDEA entitles a student with a disability to a free appropriate public education (FAPE) and an individualized education program, including individual goals, objectives, related services, accommodations and modifications.

Students that do not qualify for services under IDEA may qualify under Section 504 of the Rehabilitation Act. To qualify under Section 504, a student must have a physical or mental impairment that substantially limits one or more major life activities (for example learning, breathing, thinking, concentrating, walking, bodily functions). Under Section 504, a student is entitled to equal opportunity, and may qualify for a Section 504 plan that provides regular or special education and related aids and services.

A student with a health condition who does not require special instruction and related services can receive, as appropriate, a wide range of supports in the general education classroom, including accommodations, individualized health plans (IHP), emergency care plans (ECP) and local education agency supports.