

History & Prevalence

Prevalence of Prader-Willi syndrome

Prader-Willi syndrome is a rare genetic disorder that affects males and females and all ethnicities equally. At present it is estimated that in England, one birth in 20,000 to 25,000 is affected by the syndrome.

History

The syndrome is named after endocrinologists Andrea Prader, Alexis Labhart and Heinrich Willi who were the first to report the pattern of abnormalities that are now known to be symptoms of the syndrome.

These observations were further developed in the late 1960s and further characteristics were identified to allow for differential diagnosis of Prader-Willi syndrome.

During this time, the syndrome was also recognised to have two distinct phases during development. During Phase I the fetal activity is said to decrease, and poor muscle tone and a failure to thrive emerges after birth. Phase II is associated with an increase in weight, hyperphagia (excessive eating) and never feeling full.

The 1970s and 1980s saw the beginning of the discussion of <u>behavioural</u>, personality and <u>medical</u> issues that are common in Prader-Willi syndrome.

The 1980s and 1990s saw the confirmation of the <u>genetic cause</u> of the syndrome and the development of genetic tests for Prader-Willi syndrome and the genetic subtypes.