

23/08/2017

## **PRADER-WILLI SYNDROME (PWS)**

Prader-Willi Syndrome (**PWS**) was first described in 1956 by Swiss doctors, Prof. A Prader, Dr A Labhart and Dr H Willi, who recognised the condition as having unique and clearly definable features. These features are:-

- Hypotonia: weak muscle tone, and floppiness at birth.
- Hypogonadism: immature development of sexual organs and other sexual characteristics.
- Obesity: caused by excessive appetite and overeating (**hyperphagia**), and a decreased calorific requirement owing to low energy expenditure levels. (**Obesity is not normally a feature of those whose food intake is strictly controlled.**)
- Central nervous system and endocrine gland dysfunction: causing varying degrees of learning disability, short stature, hyperphagia, somnolence, and poor emotional and social development.

Many people with PWS also exhibit characteristic facial and other physical features. These include: almond-shaped eyes, a narrow forehead (**measured across**), a down-turned mouth with a triangular-shaped upper lip, and small hands and feet. People with PWS have poor large muscle strength, often coupled with poor coordination and balance. Muscle tone can be improved with appropriate therapy and exercise. Small muscle strength is usually better.

The sister syndrome, **Angelman Syndrome (AS)**, is caused by a similar loss of paternally-inherited genes. **AS** is named after a British pediatrician, Dr. Harry Angelman, who first described the syndrome in 1965.

### **PRADER-WILLI SYNDROME ASSOCIATION (UK)**

**Helpline: 01332 365676**

The Association was founded in 1981 by a small group of parents and a doctor with an interest in PWS. It became a registered charity on 13 May 1982. Since that time it has grown to include over 750 families and individuals affected by PWS in its membership. We also have over 500 professional members from the fields of health, social services, education, residential and community care. They offer a range of services to help families, people with PWS, and professionals in all fields.

**Website:** [www.pwsa.co.uk](http://www.pwsa.co.uk)

### **ASSERT (Angelman Syndrome Support Education and Research Trust)**

**Helpline: 0300 999 0102**

**Assert** is a United Kingdom based support group. They are all volunteers who have direct contact with people with Angelman Syndrome.

**Website:** [www.angelmanuk.org](http://www.angelmanuk.org)

### **ANGELMAN SYNDROME FOUNDATION**

**Website:** [www.angelman.org](http://www.angelman.org)

### **ANGELMAN PROJECT**

The Angelman Project is the first in a series of multi-media databases on low incidence disorders. Working collaboratively with experts in the disciplines related to the study of Angelman Syndrome in education, medicine, and science.

**Website:** [www.angelmanproject.com](http://www.angelmanproject.com)

**We cannot be held responsible for the level of service provided by the organisations included in this publication.**

All details correct at time of publication, if you find that this info is inaccurate please call us.

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