PWSA Victoria

Since 1979, the PWSA Victoria has been providing vital on the ground support to families, professionals and community organisations in the southern states of Australia.

Today, we know more about Prader-Willi Syndrome (PWS) than ever before. The purpose of the PWSA Victoria is to provide vital services to those living and supporting people, with PWS in the areas of education, support, advocacy and awareness.

It is our role to work closely with organisations around the world to ensure the entire PWS community is well supported, while researchers around the world work hard to find a cure and viable treatments.

We provide up to date and relevant information to help guide families through all stages of the PWS journey and help navigate the medical and education system and the National Disability Insurance Scheme (NDIS).

We also assist the wider PWS community—educators, professional service providers, medical and allied health professionals, disability advocacy groups, employers, the research community and the broader community in understanding PWS and provide information on how best to care for someone with PWS.

We aim to continue to break down barriers and create a world where everyone with PWS has access to the right tools, to enable them to live a full and inclusive life.

For parents and carers of children with Prader-Willi Syndrome, there is an Australian online community that can be found on Facebook. The group is called 'PWS Support for Aussies' Facebook group.

The online community is managed by the Prader-Willi Syndrome Association of Victoria (PWSA Victoria) and is made up of parents of those living with Prader-Willi Syndrome from all around Australia.

OUR VISION:

A world where people with Prader-Willi Syndrome lead a full and inclusive life.

OUR MISSION:

Empowering those living with Prader-Willi Syndrome through support, education, advocacy and awareness.

CONTACT US:

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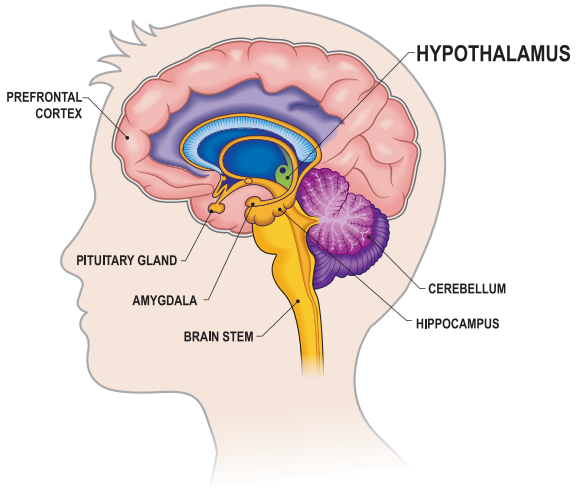
What is Prader-Willi Syndrome (PWS)?

What is PWS?

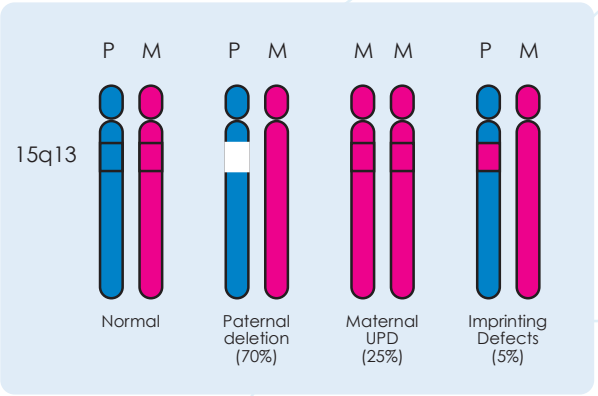
Prader-Willi Syndrome (PWS) is a rare, complex, unique, multistage genetic disorder that affects 1 in 15,000 births.

Prader-Willi Syndrome (PWS) is a multistage spectrum condition. Prader-Willi Syndrome affects the part of their brain called the hypothalamus, which is responsible for the regulation of all the systems in the body and the resultant control of hunger, thirst, temperature regulation, pain and stimulation hormone production amongst others.



Males and females of all races and ethnicities are affected equally. PWS occurs randomly and is a result of an abnormality of the 15th chromosome pair. Currently, PWS is thought to be an utterly accidental occurrence. It is not the fault of either parent and rarely reoccurs in the same family. A small piece of genetic material that is missing or not working on the 15th chromosome is responsible for the characteristics that make up this syndrome.

PWS is a complex neurodevelopmental disorder due to errors in genomic imprinting with the loss of imprinted genes that are paternally expressed from the chromosome 15, which means it is silenced, or not active on the mother's chromosome and the information required is read from the father's copy. If the required section on the father's chromosome is deleted or the entire chromosome is missing, then PWS is the result.



PWS is a spectrum disorder, and symptoms vary in severity and occurrence among individuals.

Research has shown that people with PWS require and benefit immensely from holistic care because of the complexities of the medical condition and their interdependencies between poor physical and mental health, cognitive limitations and other disabling attributes.

There really is no way to predict which symptoms will occur in any particular individual or to what degree. However, we do know that all children with PWS benefit from early intervention, a loving and enriching environment.

Is there a cure for PWS?

Currently, there is no known cure for PWS. Research is finding that the lives of people living with Prader-Willi Syndrome can be improved with early diagnosis and careful management of symptoms.

It can be difficult for families to keep from thinking and worrying about the future, and a lot of information regarding PWS can be daunting and overwhelming. However, while it is sensible to contemplate and make provision for the years ahead, there will be new developments and change, and there are many reasons to be hopeful.

What treatments are available?

People with Prader-Willi Syndrome (PWS) are affected from birth throughout all stages of their life. The challenges they experience change throughout the different stages; however, each stage consistently presents with real, significant and potentially life-threatening issues.

A multi-disciplinary, holistic, coordinated and proactive care team is essential across the lifespan of someone with PWS to ensure quality of life can be achieved. The treatment of PWS is currently based on treating the symptoms of the disorder as they arise.

The use of Growth Hormone Treatment has been one of the most important developments in recent years as it has transformed the physical appearance and development of children and adults with PWS.

More information on Growth Hormone can be found on the PWSA Vic website.