

# Let's walk this journey together.

We understand what you're going through, and what you're about to go through, because we've been through it ourselves.

We at the Prader-Willi Syndrome Association of Victoria (PWSA Victoria) know all too well that when you first hear the words Prader-Willi Syndrome you may be left feeling heart broken and overwhelmed with a myriad of questions. Perhaps even blaming yourself, and wondering how could it happen. "What did I do wrong?" "Why?" "How do we explain this to our other children and our family?"

The impact that this news may have on a family, physically, emotionally and mentally, is a lot to take in.

For many, Google is a very powerful tool, but for a family of a newly diagnosed child, it can often leave you feeling even more saddened by the diagnosis.

You can be very quickly overwhelmed by the abundance of images and information you find. Much of it could be outdated, and leave you with the feeling that your child will not be able to achieve anything in their lifetime. Nothing could be further from the truth. For this reason we encourage you to look to the sites that offer support, such as PWSA Victoria, that can connect you with the most up-to-date resources.

At PWSA Victoria, we see our role in your journey, to be one that provides support and hope.

## CONTACT US:

The Prader-Willi Syndrome Association of Victoria Inc. Ltd.

PO. Box 92,  
Kew, Victoria 3101  
Australia

### PWSA Victoria Support Line

24 hours call: 0451 797 284

E: [info@pwsavic.org.au](mailto:info@pwsavic.org.au)

W: [pwsavic.org.au](http://pwsavic.org.au)



**pwsa** VICTORIA

prader-willi syndrome association



**PWS**  
**Hand-in-hand**



## In the early stages...

Families don't know where to turn and are unaware of the services that they will need in order for their loved ones to have the best outcomes and live a fulfilled life.

*We're here to help you through this and arm you with the right tools, services and supports to enable you and your loved one to reach their full potential.*



We do our best to assist families in navigating the medical system and NDIS, ensuring that your child receives optimal care and assistance throughout their life.

We know and understand that your journey will be challenging for both you and your family. But we can tell you, it will also be unbelievably rewarding, and one filled with love, determination, gratitude, courage, strength and many celebrated achievements. We look forward to sharing this journey with you and helping you along the way.

With love, support and care, children with Prader-Willi Syndrome can lead a full and inclusive life and they have the ability to achieve amazing things.

*Your child was born with PWS because a tiny piece of their Chromosome 15 is imperfect. We all possess 23 sets of chromosomes encoded with an infinite amount of information.*



*Our children may have PWS, but they are so much more than a syndrome. They may inherit your mother's nose, your strange big toe or the sense of humour that runs in the family.*

*However, they will be themselves first and foremost.*

**Your child is wonderfully UNIQUE.**

## PWS will change your life.

To watch your child work at their own pace, with determination and resilience to reach their goals is awe inspiring. You will value all those small achievements that often go unnoticed with other children and will be buoyed through the more difficult times by the love you have for your child — and the love they will return is tenfold.

## We are also here to support your family and friends.

It takes a Village to raise a family. These words could not resonate more true — especially for parents of a child with Prader-Willi Syndrome.

In the beginning, we know that it can be difficult to share your child's diagnosis with your friends and family. It may take some time to build up the courage to speak openly about your child's condition with those around you. Our families have found that talking to other families who have been through what they are going through, helps them to work through and accept their feelings.

*If you feel like you would like to talk to one of our families, please feel free to contact us at anytime on either of the contact options provided in this brochure.*



Our community is one of the most wonderful things about becoming a member of the PWSA Vic, as the support that families provide to each other is beyond anything that you'll find elsewhere.

Once you are ready to talk to your friends and family about PWS, we're here to help you through. Our aim is to always deliver information about PWS in a positive, compassionate and professional way. This will ensure you can provide them with the tools to understand the condition and how they can best support you and your loved one.

## RESOURCES

### Prader-Willi Syndrome Helpline

Call us 24 hours on 0451 797 284



### Prader-Willi Syndrome Association of Victoria (PWSA Victoria) website [www.pwsavic.org.au](http://www.pwsavic.org.au)

This website provides a range of information to help you navigate your PWS journey. The site includes contact details, printable resources and details of useful services.

### Prader-Willi Syndrome Association of Victoria (PWSA Victoria) Facebook Page

<https://www.facebook.com/pws.asn.au>

This Facebook page allows the PWSA Victoria to communicate with their members and others outside of our community about all that they are working on.

The site also allows for PWSA Victoria to share PWS information from various other relevant sites and social media pages.

### PWS Support for Aussies Facebook Group

<https://www.facebook.com/groups/306711946098463/>

This private Facebook group provides parents and carers of those living with PWS a safe forum to discuss everything and anything PWS related. At times this group can become quite personal, therefore the group only allows parents and carers to join.