



2021 ANNUAL REPORT

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pwsa

VICTORIA

prader-willi syndrome association

People with Prader-Willi Syndrome (PWS) have aspirations for life like we all do and appreciate the support from those around them to help them strive for their goals safely and productively. They are an absolute joy to be around and are some of the most charismatic, friendly and caring people you will meet.

Since 1979, the Prader-Willi Syndrome Association of Victoria Inc. (PWSA Victoria) has been providing vital on the ground support to families, professionals and community organisations in the southern states of Australia.

With a birth rate of 1 in 15,000, we estimate that around 1,500 people live with PWS in Australia and around 300 in Victoria.

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 education, support, advocacy and awareness.

Our role is to work closely with organisations around the world, whose vision and purpose align with ours, to ensure the entire PWS community is well supported while researchers worldwide work hard to find a cure and viable treatments.

Our vision is to ensure that every member living with PWS receives optimal care and assistance from the beginning of life. 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 providing information on how best to care for someone PWS.

Our Vision

We want to create a world where people with Prader-Willi Syndrome lead a Full and Inclusive Life

Our Mission

To empower those living with Prader-Willi Syndrome through support, education, advocacy and awareness



OUR MEMBERS

We encourage anyone who lives/cares for and advocates for someone living with Prader-Willi Syndrome in Australia to [become a Prader-Willi Syndrome Association of Victoria \(PWSA Victoria\) Inc. member](#). By becoming a member of the Association, this helps the Prader-Willi Syndrome Association of Victoria meet the needs of our growing community and build on services and supports for a better and brighter future for those living with Prader-Willi Syndrome. Membership to the PWSA Victoria was free in 2020/2021 and will continue to be.

The PWSA Victoria offers several different membership types:

- **Friends of the Association**
Person with PWS who wish to join as an individual and personally receive up-to-date information on events and news.
- **PWS Family**
Parents/Primary Carers of a person with PWS, and their Siblings (under 18yo).
- **Extended Family and Friends**
Relatives such as Siblings (over 18), Grandparents, Aunt Uncles, Siblings with children of their own, and any friends who wish to show their support to the family by becoming a member of the PWSA Victoria.
- **Professional Organisations**
Professional Organisations who want to support the PWSA Victoria and be kept up to date regarding information, workshops, training opportunities, events, and news.
- **Supporters of PWS and PWSA Victoria**
Anyone (including Professionals) wishing to lend their voice and show their support of PWS and the PWSA Victoria Community

With a birth rate of 1 in 15,000, we estimate that around 1,500 people live with PWS in Australia and around 300 in Victoria. Therefore we were pleased to see that many families living with Prader-Willi Syndrome around Victoria had found the Association and joined as members.

MEMBERSHIP NUMBERS FOR THE 2020/2021 TERM

2020/2021	Adults	Children
People with PWS	21	71
Parents / carers	163	
Friends of the Association	4	
Extended family and friends	26	
Professionals and Professional Organisations	7	
Supporters of PWSA Vic	2	
Total (294)	223	71



PRESIDENTS REPORT

It certainly has been a year like no other and one that we could never have foreseen. The COVID-19 pandemic introduced another challenge into the mix, on top of the many challenges we already face as a charity organisation. However, despite a challenging year, the Prader-Willi Syndrome Association of Victoria Inc. (PWSA Victoria) have achieved a great deal over the past twelve months.

Over the past 12-18 months, we have continued to build our digital capacity internally and externally, thanks to our new IT platform. This platform allowed the board and its volunteers to adjust quickly and work remotely whilst still collaborating in a workspace that supported our needs, and allowing us to communicate with our members.

Our greatest challenge this year was finding new ways to support our members in an environment where we could no longer interact socially. As the PWSA Victoria has always been proud of the strong focus on connecting people, we found it challenging to keep our members engaged as many of our events were cancelled or postponed. COVID-19 restrictions and their impact have accelerated changes in ways of working. These are innovative and beneficial. However, we know that

nothing can replace face-to-face support for our families living with Prader-Willi Syndrome. We hope these services will resume as soon as it is possible to do so safely.

Around this time last year, we refreshed our brand and marketing to distinguish ourselves from the national organisation and connect better with our supporters, partners, and, ultimately, the public. We are committed to being an adaptive organisation that responds to the changing needs of those we support.

In the coming year, our principal focus (among other things) will continue to be to:

- Increase and maintain membership by understanding what people living with PWS want while implementing improvements in our annual programming
- Expand our Professional presenter numbers to provide education and critical up to date information to and on behalf of the PWS Community
- Recover face-to-face community engagement
- Engage more volunteers to assist with projects of interest

Today, the PWSA Victoria is confident of our mission and proud of our achievements. However, this upcoming year will be critical as we refresh our organisational strategy and set out how we will do everything in our power to ensure that we continue to create a world where people with Prader-Willi Syndrome can live a full and inclusive life.

Personally, reflecting over the past 12 months on where we have come from makes me more determined to help create change for people living with Prader-Willi Syndrome. I am also greatly encouraged by the resilience, innovation and commitment of our board, who navigated the ever-changing landscape so delicately and were able to achieve some great things.

I want to thank our board, volunteers, members, partners and supporters for their dedication and contribution. We rely on the whole PWSA Victoria family to ensure we keep those living with PWS at the heart of everything we do, and we wouldn't be the organisation we are today without you.

Renee Di Genova | President



Renee pictured with her son Harvey who has Prader-Willi Syndrome

FINANCIAL REPORT

The 2021 financial year was another challenging one for the Prader-Willi Syndrome Association of Victoria ('PWSA Victoria') and the NFP sector in general due to the ongoing impact of COVID-19. The Association pursued a strong focus on marketing and awareness of both the PWSA Victoria and PWS globally, particularly through online channels. This culminated in May 2021 with the most successful 15 for 15 campaign to date.

The overwhelming generosity of our community once again shone through despite the difficult circumstances, with over \$58,000 donated, \$43,000 of which came from the bumper PWS 15 for 15 campaign.

In addition to this, over \$27,000 was received during the financial year for two significant grants from the NDIA and the Rotary Club of Box Hill Central and Blackburn South branch of Bendigo Community Bank. These funds are committed to projects currently underway that will likely wrap up in FY2022.

For the first time in several years, external consultants were engaged to manage the media campaign and social media channels throughout the year. A significant investment yielded a great return with penetration across mainstream print, radio and television media during May 2021. In addition to this, a specialist social media consultant ensured Facebook posts reached a growing group of followers. In total, \$34,000 was spent across the year to boost the awareness of the 15 for 15 campaign, PWSA Victoria's work within the community and Prader-Willi Syndrome more broadly.

Once expenditure was normalised for the marketing and consultant spend overall, the Association ran quite lean with expenses at their lowest mark for at least five years. This was primarily driven by the inability to hold large events and the cancellation of the time out camp.

The strengthening of PWSA Victoria's online presence has continued throughout FY2021. Last year's significant investment in technology continues to ensure functional software is in place to 'run' the Association and to allow for information to be provided to members in an efficient manner.

The PWSA Victoria on-site training has continued throughout the year, with many service providers seeking online sessions to grow their ability to care for those with PWS. While this is not a key revenue driver for the Association, educating our community is an

integral part of the associations offering. It is hoped this will grow through FY2022 and beyond.

The financial position of PWSA Victoria remains strong with a significant surplus after accounting for committed grant monies. The PWSA Victoria board will look to use this strength to drive several big initiatives next year to ensure awareness is spread to an ever-growing audience. Further, there are funds committed to the resumption of several events to ensure our community re-connects, and the wonderful support the PWSA Victoria provides can recommence after the various COVID interruptions.

Another key focus for the first half of FY2022 will be the next time out camp. With grants received to fund several key aspects of the camp, it is hoped the 2021 Time Out camp will be the biggest to date.

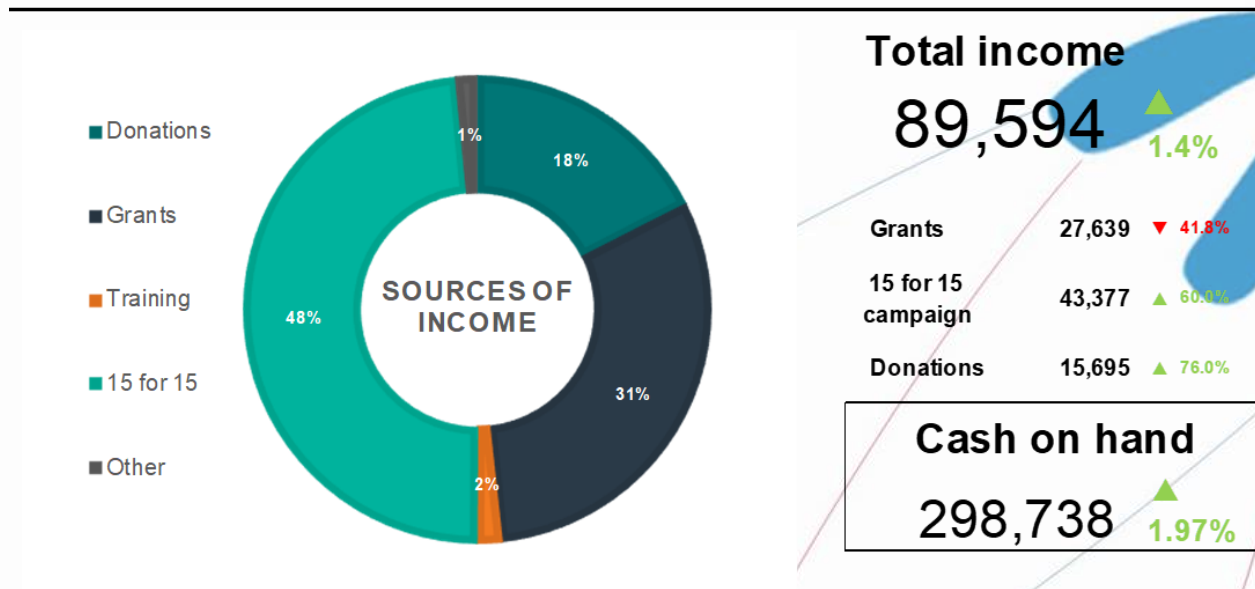
Personally, I would like to thank the committee and the band of volunteers within our community for their tireless hard work and look forward to reconnecting with everyone in the coming twelve months.

Dean McIntyre | Treasurer

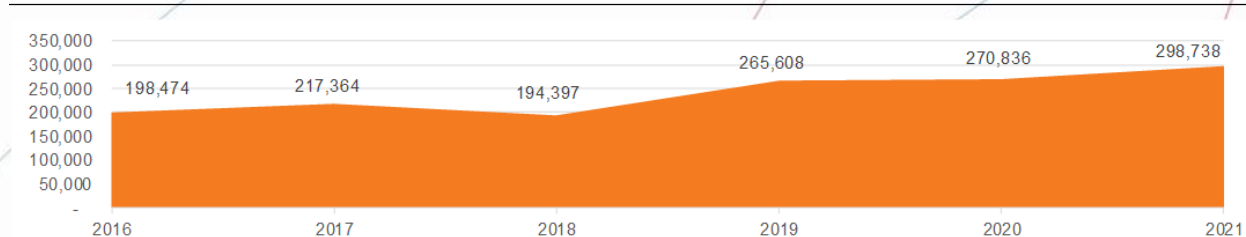


Dean pictured with his son Zac who has Prader-Willi Syndrome

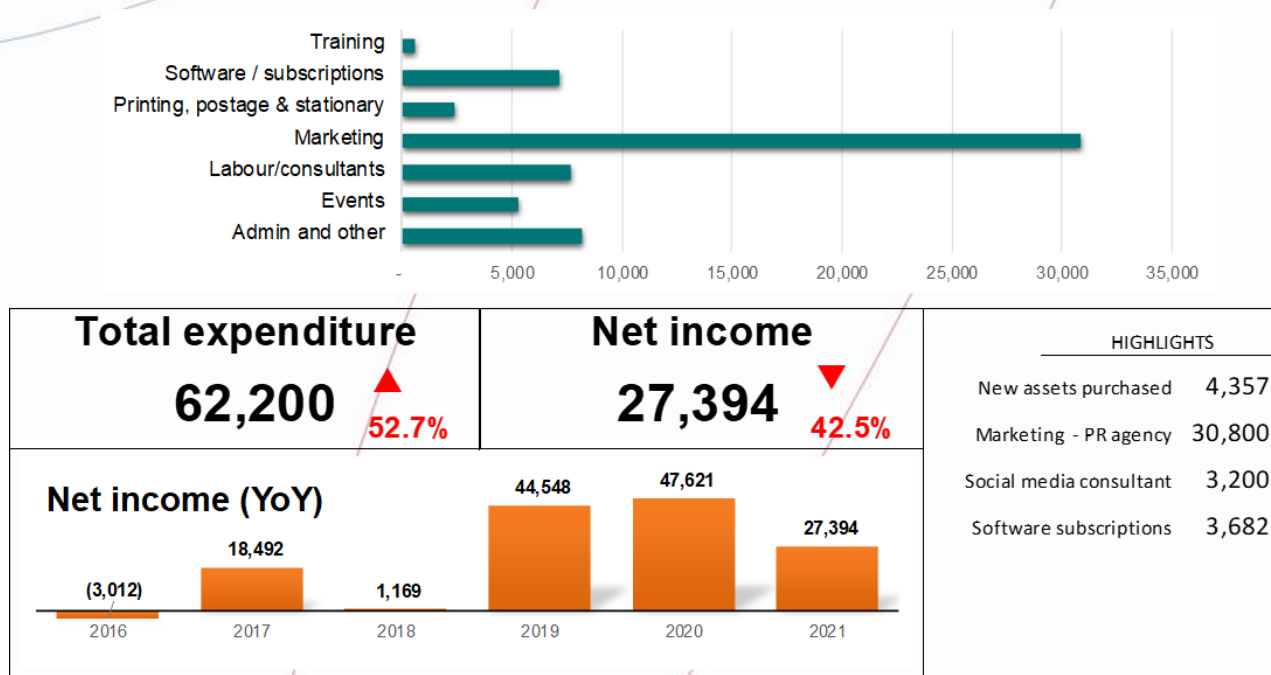
Income



Historical cash balance



Expenditure



HOW DO WE SUPPORT OUR COMMUNITY?

At the Prader-Willi Syndrome Association of Victoria Inc (PWSA Victoria), we aim to support those living with Prader-Willi Syndrome through support, education, advocacy and awareness.

We ensure families and professionals have the right tools to help those that they care for have every opportunity to live a full and inclusive life. We do this because life for many families that we first meet is overwhelming, challenging, confusing and wrought with grief.

This past year, our board and volunteers have worked tirelessly to give people with Prader-Willi Syndrome the support that they need



We helped **31%** of Families estimated to be living with Prader-Willi Syndrome in Victoria in 2020/2021



We supported **86** people seeking support and information through our Support Line



Provided in-service training to **16** organisations to help them better understand Prader-Willi Syndrome and how best to care for people with Prader-Willi Syndrome



We reached **36,000** people via our social media to create awareness and advocate for change for people living with Prader-Willi

TRAINING AND SUPPORT

The Prader-Willi Syndrome Association of Victoria (PWSA Victoria) offers access to [on-site training](#) and visits to creches, schools, kindergartens, workplaces and adult centres primarily in the southern states of Australia. Training programs are tailored to specific requests and the environment in which they are presented. We also offer a support line where people can call for information and support.

TRAINING

The PWSA Victoria has continued to provide Training sessions despite the COVID 19 restrictions. We have continued to be innovative, and a combination of zoom and phone conferences have become our primary delivery methods for training.

Our training programs have continued to be requested by members of the Prader-Willi Syndrome community and disability providers both in metropolitan and regional areas in Victoria and in the other Australian States.

We have received increased interest in Prader-Willi Syndrome specific training from allied health and medical professionals in the past year.

Earlier this year, Dietitians Australia extended an invitation to the Prader-Willi Syndrome Association of Victoria to participate in their Webinar "PWS & Collaborative Support Teams". This information and training session was a standout highlight as over 150 dietitians around Australia subscribed to the webinar. Feedback from participants reinforced the value of these endeavours to improve awareness and understanding of Prader-Willi Syndrome.

Based on requests for Training
and Education

over the past twelve months increasingly, disability providers around Australia requesting information about ways to develop support networks with allied health and medical professionals involved in the support and care of people with Prader-Willi Syndrome.

PHONE SUPPORT

The original purpose of the PWS Phone support line was to facilitate the organisation of the Prader-Willi Syndrome Association of Victoria training sessions.

It quickly became apparent that the need for the Phone support line went far and beyond the need to organise training sessions.

NDIS service providers are increasingly using the PWS phone line to source information and links to other support providers. The line is also increasingly used by medical professionals and allied health professionals to source information about Prader-Willi Syndrome.

Families, carers, and people with Prader-Willi Syndrome are using the Support number to find information, links to services, or someone they can talk to about Prader-Willi Syndrome.

The PWS support line is a very valuable support that we provide members of the Prader-Willi Syndrome community, their families and those who support people who live with Prader-Willi Syndrome.

We appreciate the magnificent work undertaken by Kate de Josselin (Training Co-Ordinator) and Anne Sakaris (Trainer). They volunteer their time delivering Prader-Willi Syndrome training and information sessions for parents, disability providers and allied health professionals around Australia.

The PWSA Victoria is looking forward to further developing its training and education programs to better support those living in Victoria, Tasmania, and South Australia



Kate pictured with her son Brent who has Prader-Willi Syndrome

LOOKING AT THE NUMBERS

Over the past 12 months, the Prader-Willi Syndrome Association of Victoria has prepared and facilitated 11 training sessions in regional and metropolitan areas of Victoria. In addition, we provided a workshop training session in Queensland for a Disability Provider and Prader-Willi Syndrome parent group. The requests for Prader-Willi Syndrome Training sessions were predominantly requested by disability support providers who supported adults with PWS

	Total	Rural Victoria	Metropolitan Areas Melbourne	Interstate
Number of sessions	16	4	8	4

The most requested sessions were the "Understanding PWS Behaviour", Behaviour Management Planning and Strategies for Working adults who have Prader-Willi Syndrome.

Number of Requests for PWS Training Sessions	Training modules
2	"Understanding PWS Behaviour"
11	"Understanding Communication, Behaviour Management Planning and strategies for supporting adults with PWS"
2	Full-Day Workshop on PWS Behaviour Management
0	"Introduction to PWS "and PWS Health and Wellbeing
1	Learning with PWS and Understanding PWS Behaviour
0	Introduction to PWS

EXTERNAL EDUCATION

The PWSA Victoria collaborated with the Victorian Advocacy League for Individuals with a Disability (VALID) to help the PWS community around Australia understand NDIS in the Parents and Planning Partners workshop which was delivered via Zoom over 4 weeks.

Moore was also invited to speak to our community about Estate Planning: Protecting Vulnerable Beneficiaries. This training session was also delivered via Zoom due to COVID restrictions.

Both Training sessions were well received and requests for follow up sessions have been requested by members of the community.

CONCLUSION

By analysing the data captured pertaining to our training program and support line, we can identify focus areas for improving the services we provide and information available to the Prader-Willi Syndrome community.

Kate de Josselin

Ordinary Board Member &
Training Co-ordinator



FUNDRAISING AND AWARENESS



\$15,045

General Donations



\$446

Merchandise Sales

During the month of May, Community organisations, Associations and Foundations, Families and Supporters of people with Prader-Willi Syndrome worldwide do their part in collectively raising awareness of Prader-Willi Syndrome.

May is also an important time for raising funds to help on-the-ground community organisations that provide vital and immediate support to people living with Prader-Willi Syndrome and raise funds for research into this complex and life-threatening condition.

As part of the awareness campaign, each year, the PWSA Victoria produces daily factual posts about Prader-Willi Syndrome to help open up discussions amongst our communities family and friend network. This also allows the broader community to understand Prader-Willi Syndrome's complexity as we believe that 'Awareness leads to Acceptance'.

Outside of May, the PWSA Victoria work tirelessly to raise awareness of Prader-Willi Syndrome via their social media platforms, commercial media and networking opportunities. We also have a range of [merchandise](#) available throughout the year for purchase.

THE 2021 PWS 15 FOR 15 CHALLENGE



Since 2019, our generous community has raised funds through the 15 for 15 Challenge for several projects that are now coming to fruition. The most significant and most impactful to come from our fundraising efforts over the years is the current collaboration between the Prader-Willi Syndrome Association of Victoria, Monash Children's Hospital, The Royal Children's Hospital and Monash Partners Academic and Health Science Centre to develop a State-wide standard of care for children with Prader-Willi Syndrome.

[This years 15 for 15 Challenge](#) and Awareness campaign saw David Rhys-Jones lend his voice to our cause. His celebrity standing in the Sporting arena saw us accomplish a new level of awareness that we would never have achieved without his ambassadorship. This year we also employed the services of Tyrrell Publicity and Promotions, who assisted us in raising awareness of Prader-Willi Syndrome via various media outlets.

- Herald Sun – Rhys Banks on mate
- [3AW 693 – Breakfast with Ross and Russell](#)
- SEN 1116 – The Sporting Capital
- [The Front Bar – 15 for 15 Challenge David Rhys-Jones interview](#)

We were grateful to see AAMI Park, Melbourne Star Observation Wheel and the Victorian Arts Centre Spire lighting up in the colour Orange over the last weekend in May to support people living with Prader-Willi Syndrome.

This year's campaign saw Vibe Hotel Gold Coast and Squires Winery provide generous donations of prizes to help boost the campaign and get people involved and donate.

Overall, the 2021 15 for 15 Challenge was a huge success

Neil Gumley | Ordinary Board Member and Fundraising Co-ordinator



\$43,377

15 for 15 Donations



\$898

15 for 15
Merchandise Sales

PROMOTION AND MARKETING

Media Opportunities



Sunday Herald Sun

Rhys banks on mate
May 23, 2021



3AW693 News Talk

*3AW Breakfast with Ross
and Russel - DRJ Interview*
May 18, 2021

SEN 1116

*The Sporting Capital - DRJ
Interview*
May 20, 2021



The Front Bar

*DRJ Interview - 5.30
minutes*
May 20, 2021

This year the PWSA Victoria was supported by Tyrrell Publicity and Promotions to help boost the 15 for 15 Campaign.

This investment helped support our Campaign Ambassador David Rhys-Jones in securing media interviews to raise awareness of Prader-Willi Syndrome, advocate for funding to continue to develop the Prader-Willi Syndrome evidence-based State-Wide Care Plan and increase our social media and website traffic.

Leanne and her team worked tirelessly in May to pull together all the wheels put into motion in the first half of the year to ensure the 2021 PWS 15 for 15 Challenge was a huge success.

DAVID RHYS- JONES FACEBOOK PAGE

- Schedule and post 15 Stars in 15 Days Interviews for David's 15 for 15 Challenge
- Share 15 Stars in 15 Days interview through Carlton Fan Groups

SPONSORSHIP AND PARTNERS

- Send medical angle media release to Monash Partners to distribute amongst their intranet, social media accounts and databases

15 FOR 15 CHALLENGE

- Pitch David Rhys-Jones interview to The Front Bar
- Pitch interview with David Rhys-Jones to Sport Regional radio breakfast shows, all SEN programs, Triple M Footy Programs and FM Footy Shows
- Pitch interview with David Rhys-Jones to Regional Victorian Newspapers
- Pitch interview with David Rhys-Jones to 3AW radio shows
- Pitch interview with Renee to all ABC Melbourne and regional radio shows
- Send follow-up pitches to ABC Melbourne and regional radio shows for interview with Renee
- Send out pictorial opportunity to Herald Sun for David and Cooper on Melbourne Star Observation Wheel
- Pitch interview with David to The Project for International PWS Awareness Day
- Pitch Renee interview and story to The Age for International PWS Awareness Day

LIGHT UP IN ORANGE

- Confirm AAMI Park and Melbourne Star Observation Wheel to 'Light Up In Orange'
- Melbourne Star Observation Wheel light up in orange for PWS
- AAMI Park light up in orange for PWS
- Victorian Arts Centre Spire light up in orange for PW

EVENTS

The Prader-Willi Syndrome Association of Victoria prides itself on being able to connect people. The past twelve months has been an extremely challenging time for our Events team as there is no substitute for face-to-face contact and the feeling of belonging and support our events bring to a community of our size. We hope our future scheduled events can proceed, but this unfortunate era of COVID will only mean that we will have to wait to resume our events as soon as possible to do so safely

2020 CHRISTMAS GATHERING

'There are friends, there is family, and then there are friends that become family.' This is our Annual Christmas Gathering motto as it's an event able to be enjoyed by all, no matter their age. The Christmas gathering is where new families find the confidence to meet others in the community and it's a time where our older families can come together in a relaxed environment to catch up with friends they've made over the years.

The PWSA Vic Christmas Gathering is the most wonderful event that we host. This is by far our largest and most enjoyed event of the year.

Unfortunately, the 2020 Christmas Gathering was cancelled due to COVID. However, the [PWSA Victoria was not about to cancel Christmas](#) for the PWS community that looks forward to our celebration each year. Therefore we delivered parcels to all PWS Family members.

We felt that the parcels were a reminder to all PWS Family members living in Victoria and interstate that:

- they are important to us,
- we try, where possible, to serve all members and reach members who, for reasons beyond their/our control, are unable to make it to our annual gatherings.

We had again been grateful recipients of Good 360 items. The PWSA Victoria could deliver lego gifts or books to all the children and a vast assortment of various products (incl. socks, makeup, jewellery, hats and personal care items etc.) to the adults.

The response from all, especially the adults with Prader-Willi Syndrome, was highly positive. We are grateful that we were able to bring joy to many during a time when they were feeling isolated and stressed.

2021 TIME OUT CAMP

Each year, the PWSA Victoria host the [Time Out Camp](#), which encourages those living with Prader-Willi Syndrome and their families to develop friendships, build resilience and self-confidence, and understand PWS through education and support programs for Parents and Siblings (Carers) provided by professionals.

Unfortunately, the last camp we were able to host was in 2019, as COVID restrictions have made it impossible for PWS Families around Australia to attend in 2020. There was a brief window of opportunity where we were hopeful that the 2021 Camp would proceed, but last-minute restrictions meant that we had to Postpone until September 2021.

It's difficult to gauge interest in the September camp as this will be hosted during the Grand Final long weekend, and families are still concerned about COVID as those living with PWS are at a higher risk of health issues if exposed. However, our most significant concern for the upcoming camp is that we may be forced into another lockdown and/or heavy restrictions won't allow attendees to travel to regional Victoria, where the camp is held.

Hopefully, our families can enjoy some time away in a Prader-Willi Syndrome friendly environment soon.

PWS AWARENESS GATHERING

To celebrate International Go Orange For PWS Day in May 2021, we planned a special celebration with some great activities for the whole family to enjoy, and we hoped to see everyone wearing the colour orange in support of people living with Prader-Willi Syndrome. This would have been a public event.

If not cancelled by COVID, this event would have been the first event of this kind in Victoria. We have never celebrated the efforts and achievements of our community after a tireless month of advocating, raising awareness and fundraising in May, and we felt that a well-deserved celebration was in order.

PWSA VICTORIA CONNECT DAYS

After close to a year of not gathering for events due to COVID, the Prader-Willi Syndrome Association of Victoria were eager to reconnect with our PWS Community. Providing opportunities for families to once again connect in person and facilitate the peer support that we had all be craving during lockdown was on the top of our agenda.

Our [PWS Connect Days](#) are held on the last Sunday of each month at different public locations all around Victoria; This approach allows our families and members who are unable to attend our larger celebration days an opportunity to meet other families close to home.

Attendees are encouraged to bring their lunch whilst the PWSA Victoria supply tea and coffee.

So far, these days have been a success, and before our most recent lockdown, momentum was gaining, and we were seeing more families come along to these days.

Sarah Rees

Vice President and Events Co-ordinator



Sarah pictured with her Jayden who has Prader-Willi Syndrome

GRANTS

In order for the PWSA Victoria to continue servicing the PWS Community, we apply for grants. As a not for profit organisation, we do not profit from the vital services that we provide, therefore we aim to find funding from outside sources such as secure grants. Grant funding is always applied for to fund direct projects that will benefit the PWS Community and is not seen to be an income to be used on the everyday running of the Association. Whilst there are many projects that require funding, we have limited resources to complete projects therefore we have only applied for grants where resources were available to complete funded projects within required timeframes.

ROTARY CLUB GRANT OCTOBER 2020

This grant round that we applied for was awarded in October 2020 in the amount of \$7,400 to cover the costs of parts of the *Beyond the Diagnosis* series of family and carer resources.

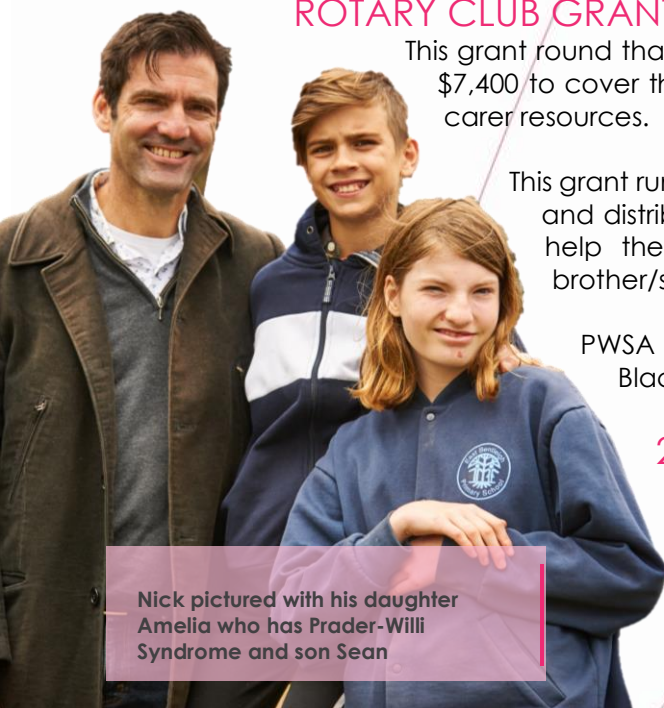
This grant runs over three years and will cover the costs of preparation, printing and distribution of a Sibling booklet. A book written by siblings for sibling to help them understand how to best care for (and keep safe) their brother/sister with PWS and how to best care for themselves.

PWSA Vic would like to thank the Rotary Club of Box Hill Central and Blackburn South branch of Bendigo Community Bank for their support.

2021 VOLUNTEER GRANT

An application to the Morrison Government's Volunteer Grants scheme, through Josh Frydenberg's constituency, was made in May 2021 for \$2000 to cover some of the costs of holding the PWSA Victoria planning day - The application is still under assessment.

Nick Burke | *Ordinary Member and Grant Writing Co-ordinator*



Nick pictured with his daughter Amelia who has Prader-Willi Syndrome and son Sean

SOLUTIONS FOR A MODERN WORLD

While many parts of the country have opened into the post COVID-19 world, Victoria and in particular Melbourne are still facing an enduring hard lockdown which has severely hurt the effectiveness of small organisations such as ours to operate and service our members.

Many organisations, especially ones in the NFP disability sector, are finding this time particularly difficult due to underfunding and a constant struggle to find volunteers willing to provide support and expertise. For many disability service providers, the enforced lockdowns due to COVID-19 are causing regular supports and advocacy exceedingly challenging to provide to their most vulnerable community members

Over recent months, the PWSA Victoria board has led a program of strategic improvements and innovations to increase quality, lower costs, reduce resource time and lower risks associated with committee operations at PWSA Victoria.

The board through these initiatives has actively embraced agile tools, techniques and technologies to maintain at the forefront of emerging trends that have enabled us to continue to collaborate on projects and member services in a locked down community. At the heart of this work is our transition to a centralised, modern IT system that supports team-work and enhanced collaboration in a virtual team environment.

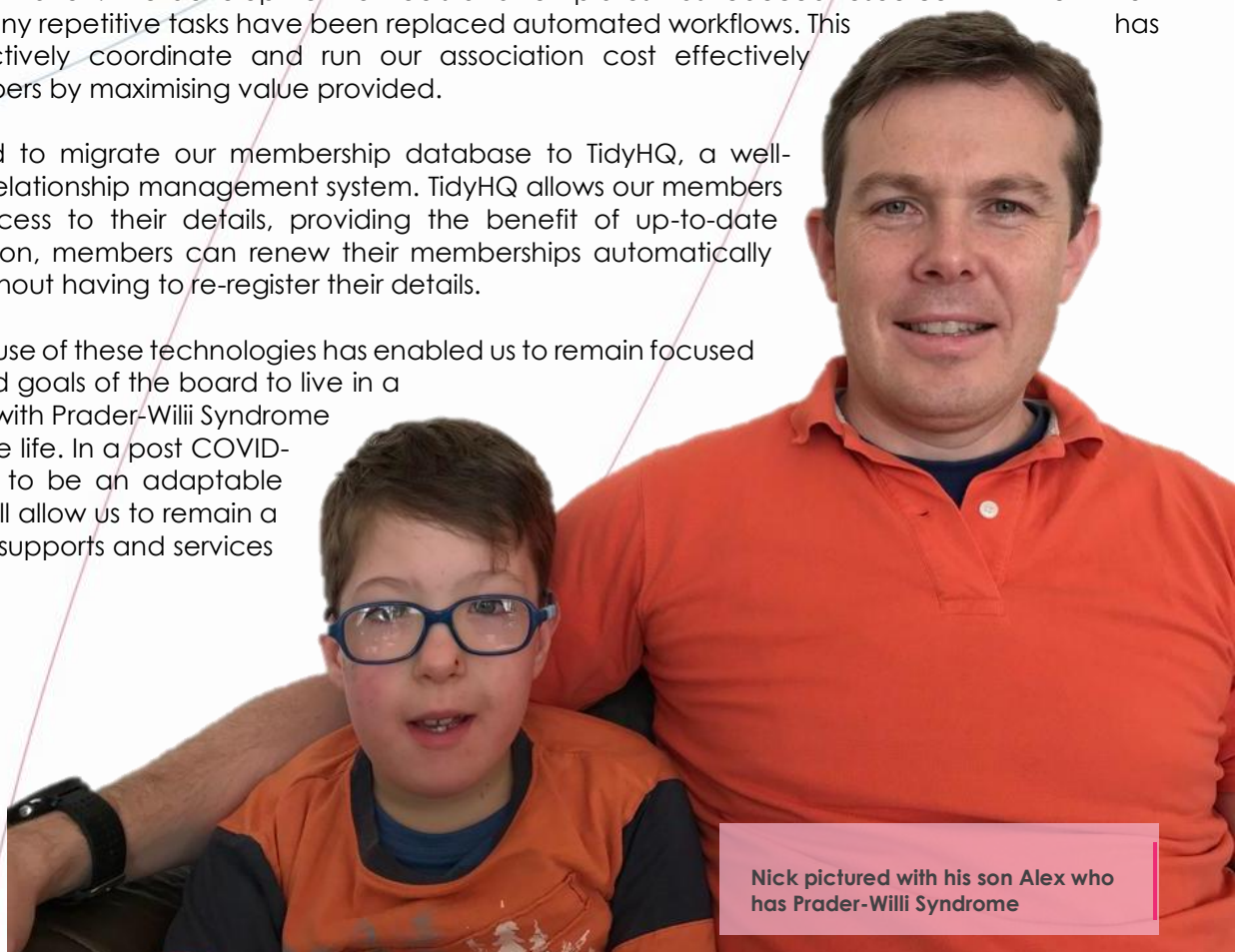
PWSA Victoria has continued to operate through the adoption of online board meetings using Zoom and Teams video technologies. Agile project management tools such as Trello and Microsoft Planner have been adopted to actively manage project work. The board has invested in customised financial spreadsheets to accurately track and manage the spending of project budgets. Using these technologies has allowed us to remain actively engaged with our current collaborating partners in Monash University and the NDIA to continue to progress our vital projects whilst in lockdown.

Central to its operation, the PWSA Victoria board has designed and built from the ground up a customised Microsoft Office 365 environment to securely house all association policies, procedures and other important governance documentation. The development of tools and templates has reduced resource time on manual tasks and many repetitive tasks have been replaced automated workflows. This has allowed us to effectively coordinate and run our association cost effectively benefitting our members by maximising value provided.

In 2021, we decided to migrate our membership database to TidyHQ, a well-regarded customer relationship management system. TidyHQ allows our members always to retain access to their details, providing the benefit of up-to-date information. In addition, members can renew their memberships automatically each year simply, without having to re-register their details.

Active and effective use of these technologies has enabled us to remain focused on the objectives and goals of the board to live in a world where people with Prader-Willi Syndrome live a full and inclusive life. In a post COVID-19 world, continuing to be an adaptable nimble association will allow us to remain a leader of Prader Willi supports and services in Victoria.

Nick Healy
Secretary and IT
Solutions Project
Manager



Nick pictured with his son Alex who has Prader-Willi Syndrome

PROJECTS

The Prader-Willi Syndrome Association of Victoria have a dedicated team working through various projects to help support the Prader-Willi Syndrome Community. Currently, we are actively working on four significant projects.

PWS EMERGENCY SERVICES KIT

We are nearing completion of the writing, editing and design of the ILC PWS Emergency Services Kit. It has been a much more complex project than was ever envisioned by project manager Kate de Josselin.

PWSA Victoria collaborated with a Monash University Information Technology Team to investigate developing a technology solution for communicating information about Prader-Willi Syndrome to emergency services.

The first stage of the project involved interviewing parents, disability workers, disability providers, psychologists, and a minimal number of emergency service workers (interstate). Due to COVID, we could not get permission to interview our emergency service workers until much later in the project's development stages. We also tried to involve adults with Prader-Willi Syndrome to participate in the interview process, but only one person accepted our invitation.

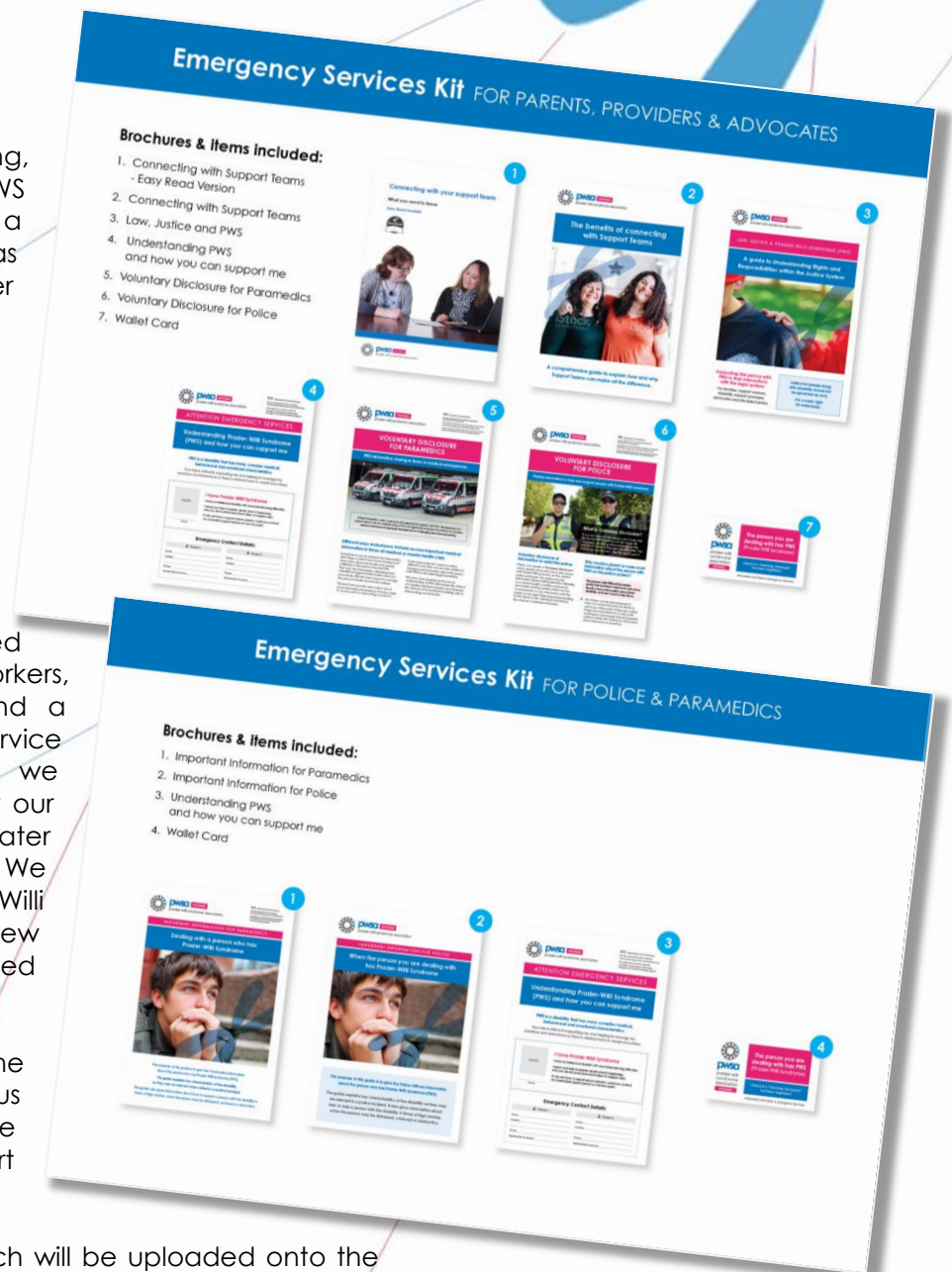
Even with these limitations, the information was invaluable. It guided us to widen the project's scope to include more information about how to support someone with PWS in times of crisis.

We have ended up with two Kits which will be uploaded onto the PWSA Victoria website upon completion. During September/ October, Kate de Josselin will be running some workshops in Regional Victoria with disability providers and parents, focusing on the different ways PWS Emergency Services Kit can help build capacity.

Online zoom workshops will also be provided to promote how the Kit can be used as a tool to build capacity in times of crisis. Details dates and times of the zoom sessions will be posted on the PWSA Vic social media sites and emailed to members.

The main goal of this project was to give the person with PWS and the people who support them the tools to increase their capacity to share personal information and information about PWS in times of crisis.

We are involved in discussions with Queensland Health about a technology information sharing solution called "Julian's Key". Currently, this app is in the trial stage, but due to COVID, the trial is not completed, but we are



optimistic that this app could be tailored to suit the needs of people with PWS and all the Information sharing brochures have been designed with that in mind.

In the course of working on this project, Kate de Josselin (Project Manager) has been supported by some great people and organisations.

Information contained within the two kits is outlined below:

PWS First Responders Kit - for parents, providers, and advocates

Includes the following:

1. Connecting with Support Teams -Easy Read Version
2. Connecting with Support Teams - Original Version
3. Law, Justice and PWS
4. Tell me about PWS -Understanding PWS and how you can support me.
5. Voluntary Disclosure Alerts for Paramedics - How it can help support people with PWS.
6. Voluntary Disclosure Alerts for Police - How it can help support people with PWS.
7. Wallet Card for Police and Emergency services

PWS Information for Emergency Services Kit - for Police & Paramedics

Includes the following:

1. Important Information for Paramedics - with a person with PWS
2. Important Information for Police -dealing with a person with PWS.
3. Tell me about PWS-Understanding PWS and how you can support me.
4. Wallet Card for Police and Emergency services

MENTOR PILOT PROGRAM

The Mentor program aims to provide Adults with Prader-Willi Syndrome an opportunity to become more involved in our community. While assisting and encouraging their younger peers. Participants in the Mentor Program will also build self-esteem.

Teamed with a trusted carer, our pilot group will be guided by a project manager and facilitator who has experience in working with people with Prader-Willi Syndrome. The facilitator and project manager will assist us in creating a program that will take into account the many factors that will be required to build this program that inexperienced individuals may overlook.

The project manager will meet with the group before the camp to introduce each other and explain the program, responsibilities and benefits.

The adults with PWS are an essential part of our community, and through this project, we want to help them discover their true value and benefit to all their peers living with Prader-Willi Syndrome.



BEYOND THE DIAGNOSIS

This project has been a long time in the planning, and with the help of a grant from the Rotary Club of Box Hill Central and Blackburn South branch of Bendigo Community Bank, we were able to start this journey.

The first two parts of the series

1. Birth to three and
2. Kindergarten to Grade 5 is complete.

These sections are sent to members with children aged in these life stages.

Recipients of the first, or first and second parts, will receive a folder, document wallet and dividers to house these, and future parts that will be sent at the appropriate time before the child moves into the next life stages.

As we complete this project, parts will continue to be sent to members until adulthood.

The grant providers have enjoyed watching our progress and when they learnt that we want to continue the series to cover all life stages, they invited us to apply for a second grant.

Due to the number of applicants, we had to divide our next part of the project and have received enough to fund creating a picture book for young siblings to be sent out with the first part of the series where appropriate.

The Beyond the Diagnosis series resources will be available to the PWS Victoria Family members of the PWSA Victoria at no cost and for purchase by the broader community.

Currently, the following resources are either in the 'completed' or the 'in progress' stage:

- Beyond the Diagnosis – part 1. Birth to 3 – complete
- Beyond the Diagnosis – part 2. Kindergarten to Grade 5 – complete

- Sibling picture book – in progress

As this is a whole of life resource, we aim to continue to develop this series with the following future projects:

- Sibling book for over 6.
- Beyond the Diagnosis – part 3. Transitioning into Secondary school and the workforce
- Beyond the Diagnosis – part 4. Adulthood

This project is an ongoing commitment as records of our members, their life stages for forwarding further parts of the series, and continuous fact-checking to maintain the accuracy of the resources is required.

Where information changes or becomes outdated, or where new information is appropriate, replacement pages will be printed and forwarded to members to update their folders.

An information brochure is also currently in development for distribution to all Victorian hospitals with a maternity ward with an adjoining Neonatal intensive care unit or special care nursery. The brochure will also be distributed to geneticists and genetic counsellors to help them direct families, to this vital resource and the support of the PWSA Victoria.



PWS STATE-WIDE CARE PLAN

For the past 12 months, the PWSA Victoria has been working closely with Monash University, Monash Children's Hospital, The Royal Children's Hospital, Melbourne and Monash Partners to piece together an evidence-based state-wide care plan for children living with Prader-Willi Syndrome. The research is being gathered, and the team is on track to deliver the first care plan of this kind in Australia.

The next step in the process is to hear from stakeholders, including families living with Prader-Willi Syndrome. Shortly, we will be inviting families from within the PWS Community to participate and have their say on what they find currently works well within the hospital network and beyond and where they believe improvements can be made. This will be done via an online portal and will allow participants to provide input in their own time easily. The portal will be open for several days. In addition, there will be a separate allocated time for health professionals to provide their feedback in the same manner.

After this feedback is collected, the team can begin to fine-tune the areas to be included in the project's further development.

Eventually, we will develop a smaller focus group to further brainstorm with selected clinicians to refine areas of concern and need.

The State-wide care plan is an ongoing project, and all those involved are pretty excited to see where this initiative will lead.

Once established at the two major children's hospitals, the care plan guides will roll out to all hospitals in Victoria. The aim is for the information to trickle down to all paediatricians and eventually all GP's and health care professionals.

Although each state of Australia has its own health system, and this project can't roll out

nationwide without a plan to do so, it will provide a template allowing other states to implement with a minimum of replicated effort.

Our 2020 and 2021 annual PWS 15 for 15 Challenge fundraisers have successfully funded this project to date and will do so until project completion. This is undoubtedly one of PWSA Victoria's most worthwhile, most needed, and most ambitious projects that we have initiated in quite some time.

We want to take this opportunity to thank the following:

- Prof. Katrina Williams Director of Research & Developmental Paediatrician at Monash Children's Hospital
- Assoc. Prof. Tom Connell Chief of Medicine at the Royal Children's Hospital
- Angela Jones Chief Operating Officer Monash Partners Academic and Health Science Centre
- Cathie Pigott Project Manager Monash Partners Academic and Health Science Centre
- All PWS 15 for 15 Challenge participants
- Each person who has donated to the PWSA Victoria to help establish this project.

Without these people, the opportunity for improvement in our children's care would still just be a dream.



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times a million