



Orange glow over Savannah

June 1, 2016

By Esther Lauaki - Melbourne

Pentland Primary School pupils wore orange last week in support of one of their classmates.

Eight-year-old Savannah was born with the rare genetic disorder Prader Willi syndrome, which affects development and growth as well as causing an excessive appetite which can lead to obesity.

Acting assistant principal at the Darley school, Sue Collinson said pupils wore bright orange T-shirts and took part in activities, arts and crafts to raise awareness of the syndrome.

They also made donations to raise money for Prader Willi research.

Ms Collinson said the day helped the pupils learn about diversity.

It's important for them to know about Prader Willi because this syndrome affects one of their classmates and they'll come across other people that have it.

You don't realise Savannah has it when you first meet her but she does have some learning and speech difficulties because of it.

It also makes the children aware of what they can do to help Savannah in her daily life.



Savannah (front), with fellow Pentland Primary School pupils Evie, Campbell and Lachie. Picture: Shawn Smits

Article Source – Star Weekly

Up coming events

Family Day
Sunday 18th
September
venue tbc

Christmas Party
Sunday 4th
December
venue tbc



Go Orange - St Kilda Primary School



President's message



Bern Walker
PWSA VIC
President

It's been a very busy couple of months here at the Association. Kate undertook a very successful training tour of Tasmania and James attended some training sessions on the NDIS, both of which you can read more about in this issue. We've been planning our Christmas party and organising our Family Day and Annual General Meeting. We continue to apply for grants to implement programs and activities identified during our Strategic Planning process. Fingers crossed we can see further success in this area so we can bring you some great new offerings.

We are very excited to let you know that we have been fortunate enough to secure Dr Janice Forster from the Pittsburgh Partnership to undertake an Australian and New Zealand tour, presenting on Behaviour Management in November. This is a topic that we receive the majority of requests about and we are wrapped to have Dr Forster agree to come and present. Many of you will remember her from the APPWS conference where her segments were among the most popular and highly reviewed. More information regarding the date and location will be forwarded once the details have been finalised.

We have been working closely with PWSA Australia on developing a new National website, thanks to an NDIS grant. The team have been working flat out developing content to assist families and

service providers in becoming NDIS ready, they have been fantastic. This will eventually become the platform for a new combined national website.

Furthermore discussions have been underway with the PWSAA and PWSA NSW and QLD on collaborating to become one National Association. This is a very important step for us and there are a number of reasons as to why it would be in our interests. In addition to sharing resources and effort, combined fundraising and grant seeking, the larger goal of becoming a stronger voice for PWS with the introduction of the NDIS is crucial. We will be raising an In-Principle motion for you all to vote on at the AGM and I will send you further information on this before then.

Until then, please enjoy our offering this month.

A final note that we are still operating without a newsletter editor. We love to provide this regular publication in addition to our other activities and would really love some extra help to make that happen. If you've been thinking about it, wait no longer! We would be so very appreciative.

Regards,

Bern

Behaviour Management workshop

Dr Janice Forster will be running a workshop here in Melbourne. Details TBC.



Dr Janice Forster



Rotary Changeover Dinner

Our great friend and loyal supporter of PWSAV Greg King was inducted as the President of the Rotary Club of Doncaster for the year 2016-2017 on 29 th June. We had a large contingent at the dinner to how our support for Greg who has been a supporter, advocate and campaigner for our cause and has helped raise a significant amount of money for our Association. He was also instrumental in us receiving two grants for iPads over the past five years. We wish Greg an amazing year ahead and continued relationship with him and the Rotary Club of Doncaster.

**Congratulations
Greg, new
President of Rotary
Club of Doncaster**



Reminder !!

**PWSAV
Memberships
Renewals for
2016-2017 are
now due.**

Membership renewals time!

Don't forget to complete and return your PWSAV membership renewals that were sent out to you in July. If you didn't receive it or need a copy please email Tessa at info@pws.asn.au



PWS Training Sessions in Tasmania

by Kate de Josslin

The PWSA is very grateful to the Endeavour Challenge Foundation and the William Buckland Foundation for their support for the PWSA "Training Without Borders" initiative. This enabled us to respond to the request for onsite training for our PWSA members in Tasmania.

Following the initial request from "Possability" a Tasmanian disability provider we explored the feasibility of running a series of PWS training sessions in several venues in Tasmania. I contacted the Department of Disability and Community Services, the Department of Education and the NDIS in Tasmania. Anne Sakaris contacted the PWSA members in Tasmania to ascertain the level of interest if we were to run a series of information sessions about PWS in Tasmania.

It quickly became apparent from the numbers of expressions of interest we received that that our "Training without Borders" initiative would be fulfilling an unmet demand for training about PWS. It was decided that we would run four sessions at no charge to the attendees as my services were pro bono and the Foundations support covered both Anne

Sakaris and my travelling expenses. The support we received from the parents, Disability providers, the Department of Disability and Community, Tarremah Steiner School and the Royal Hobart Hospital was invaluable. These organizations not only helped to promote the sessions but also to organize venues and projection equipment and in some cases even the morning teas.

As a result of this on the ground support I was able to present four, two hour sessions involving different topics for the different audiences. Each session included a question/answer/discussion time. I also provided handout material summarizing some of the points covered in the session. We also provided PWS contact details if more information was required.

Following three of the sessions there were opportunities to meet and greet with parents over lunch, giving the parents an opportunity to further discuss information from the sessions.

The session at Tarremah Steiner School and the session organized by the Royal Hobart Hospital were videoed to be uploaded onto the PWSAA website at a future date.

Session 1 – 20/6/2016 at Tarremah Steiner School, South Hobart. This session was hosted by the Tarremah Steiner School. "Understanding PWS –Health, Wellbeing and Behaviour. " This session also included a section on social inclusion strategies in the school setting.

Session 2 - 21/6/2016 at Criterion House. This session was hosted by the Royal Hobart Hospital "Understanding PWS –Health, Wellbeing and Behaviour. "

This session was attended by many from the allied health sector and disability service providers and included a section that focused on effective communication strategies for people providing services to people with PWS.

"Training without Borders" initiative would be fulfilling an unmet demand for training about PWS.





Session 3 - 22/6/2016 at Burnie Yacht Club. This session was hosted by "Possability" - a disability service provider.

"Understanding PWS -Health, Wellbeing and Behaviour. "

This session included more emphasis on understanding PWS behaviours and management strategies.

Session 4 - 23/6/2016 at Drysdale Building. This session was hosted by the Launceston Disability and Advisory team.

"Understanding PWS -Health, Wellbeing and Behaviour. "

This session included more emphasis on understanding PWS behaviours and management strategies.

The overall attendance for the four sessions was 83. Those who attended came from a wide range of areas including psychologists, speech therapists, social workers, occupational therapists, physiotherapists, teachers, adult literacy coordinators, dieticians, disability support workers, residential support workers, day program coordinators, support workers from supported employment work places, representative from NDIA and most importantly parents.



NDIS Planning and Assessment - Assessment of Participants' Needs



Operational Guideline – Planning and Assessment – Assessment of Participants' Needs contains operational information about the process for assessing a participant's needs and prescribes the use of the Support Needs Assessment Tool.

Please [contact us](#) if you need assistance accessing any of the content of this Operational Guideline.

<https://myplace.ndis.gov.au/ndisstorefront/planning-and-assessment-assessment.html>



Prader-Willi syndrome means Brendan Vearing is hungry every minute of every day

by Ellen-Maree Elliot, Quest Newspapers
May 3, 2016 - Queensland

EVERY day, Brendan Vearing is hungry. Not because he does not have enough to eat but because he has a genetic disorder that stops his brain from telling him he has eaten.

Prader-Willi syndrome is a rare, non-inherited genetic disorder in which several genes on the 15th chromosome are deleted or unexpressed. As well as hunger, it also causes intellectual disability and some behavioural issues. "I'm not like everybody else ... it's hard," Mr Vearing said.

He wants to raise awareness for PWS with Go Orange Day on May 27 and he has one thing he wants people to know about himself and others with the disorder: "I'm a person first."



His hunger is constant and overpowering, and he

will eat raw meat left on counters or expired and scrap food out of the rubbish, so the fridge, pantry and bins are kept behind a locked and alarmed door. His mum Donna Vearing said there was "no malice" in his actions — he's not trying to break rules when he sneaks food — he's just -hungry.

"We have a deal with Brendan that it's our duty of care. If he gets (food), it's our fault for not making him safe but he will get into trouble if he lies about it," she said. Mrs Vearing said because no treatment for PWS they focused on their son's quality of life.

The 21-year-old works out six days a week and needs to eat a low-calorie diet — but his mum said they never wanted him to be "the kid who's never had a -chocolate".



Brendan Vearing with his personal trainer and friend Brad Marhsall. Mr Vearing works out six days a week to control his weight. Picture: JOHN GASS

So, he's allowed to have treats, he just has to balance it out. Mr Vearing loves bowling and has a mini-menagerie of animals he cares for at home. He also enjoys going to the movies with his friend and personal trainer, Brad Marshall.



Pinkys Pizza Warrnambool



Archie & Lola



Orange for cure

A rare diagnosis made a family in Melbourne's west campaign for better awareness about a little known syndrome

Tarneit mum Ashley had never heard of Prader-Willi Syndrome when her daughter Makayla now six was diagnosed with the rare genetic condition at eight weeks old. The Syndrome is a non-inherited genetic disorder where genes on the chromosome are missing.

Common characteristics for those with the condition are hypotonic (weak muscles) at birth, small hands and feet, abnormal growth, extreme obesity and intellectual disability.

With no cure the family's hopes better awareness for families and others in similar situation.

Makayla's mum said they hope to make more people aware of the condition to fund future research and perhaps a cure

The Go Orange for PWS hopes to help families deal with the Impact of the disorder.

To support the campaign visit go-orange.org.au



Ashley Hebden with her daughter, Makayla, 6. Picture: MARK WILSON

Source: Wyndham Leader 31st May 2016

Go Orange

We are proud to report that our Go Orange PWS Awareness campaign was a huge success.

Facebook feeds were painted orange with people changing their profile pics, posting orange selfies and liking and sharing our PWS facts all around the world. Many schools and workplaces had an orange day and had some fun while raising a bit of money.

Many 1000's of people now know something about PWS. We have a long way to go but we are educating people one person at a time.

Thank you to all those who participated and contributed to the success of the campaign.



Yew Chung International School Hong Kong



Jax, Jordan & Jules

Go Orange for PWS Day 2016



NDIS – How does it work?

by James O'Brien

I recently had the opportunity to attend NDIS information sessions held specifically for organisations. These were very informative and have provided me with a swathe of information for us as an Association and for you our members.

At our Family Day and AGM, I hope to share with you a brief understanding of how the NDIS works. While I will not be able to assist each person in deciding what should be in their plan, I hope to familiarise you with some of the terms and workings of the new system. The idea is to build your knowledge, thereby assisting you in 'standing strong' during your NDIS planning process.

There will be some huge challenges for us under the new system. The very foundation on which the system is built is the concept that the individual with the disability should have 'choice and control'. Even this most basic of principals can bring huge benefits for our children, but also dire consequences!

All our wonderful guys with PWS are so different, yet in many respects they are also the same. The NDIS will approach each person as an individual, all with different plans, hopes and dreams. The aim of the NDIS is to enable each person to live an 'ordinary life'.

The NDIS is a brave new age. Both individually and collectively I believe that we will be able to shape a future with huge opportunity for our children and adults. Individually because the NDIS views all our children as individuals in charge of their own future and will want to receive us into the NDIS one at a time. Collectively because together, as powerful advocates, we can educate the NDIS and its employees about the intricacies that are uniquely PWS.

'Standing strong' during your NDIS planning process

IPWSO Board

by James O'Brien

Australia now has two seats on the IPWSO Board. Georgina Loughnan was reelected for her second 3 year term as the FamCare representative. FamCare is a sub-committee of IPWSO that focuses primarily on developing materials to assist families of adults with PWS that are living at home. FamCare publications in 7 languages can be found on the IPWSO website at <http://www.ipwso.org/#!famcare/canb>

Our second and new representative on the IPWSO board is James O'Brien. His two areas of focus will be:

1. Gathering information about world best practice that will help Australian families and inform Government as individuals move into the NDIS with a long term focus on expanding accommodation options for adults.
2. Investigating Newborn Bloodspot Screening (NBS) with the medium term view of having PWS included on NBS programs.

Two Australians on the IPWSO



Remember!!

Make sure you downloaded the Easy Diet Diary App before your next dietician appointment.

Easy Diet Diary App

When you have an appointment with a dietician at the Royal Children's Hospital make sure you have downloaded the Easy Diet Diary App from the App-store and complete 3-7 days of a food diary. You can email it directly to the dietetics department a week before your appointment. This will enable the dietician to do a full analysis of the micronutrient composition (carbohydrate, protein and fat percentages) and enable you to utilise the appointment time effectively.

PWS Clinic Dates

Pre-school clinics

Aug 5th 2016
Nov 4th 2015
Feb 3rd 2016
May 5th 2016

School Aged clinics

Aug 12th 2016
Nov 11th 2015
Feb 10th 2016
May 12th 2016

Newborn clinics

Aug 19th 2016
Nov 18th 2015
Feb 17th 2016
May 19th 2016

Note: Please do not attend the clinic without an appointment.

To make appointments contact the clinic coordinator on 9345 4765

Dear Families,

As some of you may be aware RCH has recently moved to an Electronic Medical Record system (EMR), along with this there has been some changes made to the way clinics are now scheduled.

The Prader-Willi clinics will now be booked through the outpatient bookings service. We are currently working with the outpatient service to ensure that all families receive the appointments requested by their Doctors.

If you do not receive an appointment you believe was required please contact appointments on (03) 9345 6180.

Please remember you must have an appointment to be seen in the PWS clinic and will not be seen in clinic on the day if you do not have one scheduled.

Thank you for your patience and understanding.

PWS Team
Royal Children's Hospital





Eating for good gut health

by Bern Walker

There has been so much research done in recent years on the gut-brain connection and the importance of good gut health. Just Google 'gut-brain connection' or 'how to improve gut health' and you will see how many articles pop up.

Research has shown that your gut microbiome (the millions of bacteria in your gut) not only play a huge part in overall health but are emerging as a huge factor in brain health and mental state.

There are some very simple things that you can include in your diet on a daily basis to help improve gut health. In our house we use:

- Probiotics
- Kefir
- Bone broth

Other things that help improve gut health (among others) are:

- Fibre
- Fermented foods including fermented vegetables

I've been wanting to make some fermented veggies for forever but have not got around to motivating myself to do it.

When you see how ridiculously easy it is in the recipe below you will wonder why I have not done it yet. Good question! I might have to get myself into motivational mode and give it a go this week!

The one thing that I do regularly make is bone broth. It really is so very simple and so very nourishing. If you have a slow cooker it is even easier. You can use left over meat bones or buy some. I put mine on first thing in the morning and let it cook for about 10 hours and strain it at night time and put in mason jars. You can read all about the benefits of bone broth here and I've included a super simple recipe below too.

Enjoy and happy making.



Want to join us?

Have you ever considered joining us and becoming a Board Member? We'd love to have you. We are a small group of committed and passionate parents who share a common thread and who all bring something different to the Association.

We have programs that we would love to implement and much-needed resources to

produce but we can only do so much with the numbers that we have. The bigger the group, the more we can achieve.

If you want to be part of an evolving organisation and reap the rewards that working with a group like this can deliver then put your hand up and join us!



Recipe

Fermented Carrots (from www.wellnourished.com.au)

Ingredients

- 750 gram (approx) carrots, peeled and cut into sticks (if they are little you might like to leave them whole, up to you)
- 1 tablespoon of organic sea salt
- 4 -5 tablespoons of organic whey (you can omit this, see my notes below**)
- Filtered water (I used 200ml, how much depends on the size of the jar you are using)

Note: it is best to invest in organic ingredients as the chemicals on conventional produce may interfere with the fermentation process (good bugs don't grow well with chemicals).

Method

1. Mix the salt and whey if you are using it in water until combined.
2. Wedge the carrots into a mason jar and pour over the water mixture.
3. Place the lid firmly and store undisturbed for 7-21 days (during summer less time is needed to ferment, winter more).
4. Don't open the lid or you will ruin them!
5. After about 7-21 days they are good to go and you can store them in a cool place or on the top shelf of the fridge. They will continue to ferment, but at a much slower rate so don't be too alarmed if the taste changes a little.

Optional extras:

You might like to add some seasoning. Garlic, ginger, peppercorns, chili. Herbs like caraway seeds or cumin seeds, At first, I was really concerned that I might poison myself and my family. However according to Sally Fallon in *Nourishing Traditions*, "Some lacto-fermented products may get bubbly, particularly the chutneys. This is natural and no cause for concern. And do not be dismayed if little spots of white foam appear at the top of the pickling liquid. They are completely harmless and can be lifted off with a spoon. The occasional batch that goes bad presents no danger as the smell will be so awful that nothing could persuade you to eat it."



** Whey is the liquid left remaining when you strain yoghurt. Make labne (cultured cream cheese) and use the whey to ferment vegetables. You can find my whey recipe [here](#). If you don't have whey, add another tablespoon of salt. However, you will have more consistent success lacto-fermenting vegetables if you do use whey.



About us

The Prader-Willi Syndrome Association of Victoria Inc. was set up in 1978 by parents of children affected by the syndrome and is totally run by volunteers. It has a long experience of providing help and information. Our membership focuses on Victoria, Tasmania and South Australia although anyone is welcome to join. Our members include parents and carers, family members, people with PWS, professionals and interested supporters.

To contact us: Prader-Willi Syndrome Association of Victoria
PO Box 92 Kew 3101 Australia
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**PSWA VIC
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tba**

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**Send any articles
to
info@pws.asn.au**

Make a donation

The PWSA VIC welcome donations from individuals and the corporate sector. We are a registered charitable organisation with the Australian Tax Office and all donations over \$2 are tax deductible.



Wanted

The PWSA VIC is looking for a Newsletter Editor to collect information and articles for production each quarter.

If you would like to assist with the Newsletter or have a story you would like to include please email us at info@pws.asn.au