People With Strength
Newsletter for parents by parents

Volume 18 Issue 3 **QUO VADIS?** November 2015

Prader-Willi Syndrome Association of South Africa Non-profit Organisation No. 035-837-NPO, PBO Exemption No. 930 016 853, PO Box 2399 Brooklyn Square 0075, www.praderwilli.org.za

This newsletter contains important information on the future of the Association.
Hierdie nuusbrief bevat belangrike inligting oor die toekoms van die Vereniging.

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WHAT IS PRADER-WILLI SYNDROME?

- Genetic disorder
- Floppy baby (low muscle tone)
- Feeding difficulties
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- Increased appetite
- Obesity
- Food related behaviour problems
- Obsessive-compulsive features

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FROM THE CHAIRPERSON

Rika and Wilmien.
Wilmien wears her "Hope – Prader-Willi syndrome" T-shirt

Dear Readers

The end of the year is here and so too the end of the 25 year era of PWSA (SA). It is heart-breaking that we have reached this point. Members of PWSA (SA) are aware that a decision has been reached to dissolve the Association. In order to manage a formal association, a strong and motivated team is necessary, which unfortunately is not the case at this moment in time. Please peruse this newsletter for important information with regard to the way forward. A task team was selected at the Annual General Meeting in August 2015 to manage this process.

My thanks to the committee members of the task team who will be managing the dissolution process, in particular Johan Basson for his valuable contribution. My thanks also to Dawid Basson, who deals with the 'behind the scenes' operation of the website and Facebook. The dissolution process of PWSA (SA) should be completed by mid 2016. More important information elsewhere.

In this newsletter, we meet Wilmien Dormehl through the eyes of her 15 year old sister, Marelie. The Dormehls attended the AGM and Marelie efficiently assisted in keeping everyone busy. Also read about Wilmien's needlework. The Dormehl family also wear T-shirts which they have had specially made to promote awareness of the syndrome. The pictures elsewhere in this edition speak volumes.

Research is currently being carried out in the USA with Oxytocin. A big drive is being made in the USA to raise sufficient funding for the second phase of this study. The PWS community have put their hearts into this fundraising project and are achieving wonderful results. The possibility exists that Oxytocin may assist people with PWS in improving their lifestyle by alleviating anxiety and fear, improving social interaction as well as reducing anxiety with food related matters. Kindly read the summary of the webinar presented by Dr Jennifer Miller. The results of this research are awaited with enthusiasm.

And then there is an article specifically targeted at the professional behind the desk! Parents may identify with the feeling of uncertainty and anxiety when you have no idea what may be wrong with your child. Liza Graziano writes specifically about the emotional experience of the parent and how the professional may assist in making matters more bearable.

Relevant to this, Michele Shingleton (USA) gave her thoughts about how to refer to the individual with PWS. She touches on an important point for parents and others to observe. This is not only relevant to people with PWS, but how any person with a disability should be referred to.

From the USA a manual is available which was put together containing information exclusively from the perspective of people who've lived the experience of being students with PWS. They share their experiences in a school situation to the benefit of parents and educators. This is obviously relevant to the American situation but I am certain that there

are ideas that South African parents and educators will find helpful. Please contact Evan Farrar to receive School Times via email. Interested parties will find the contact details elsewhere in the newsletter.

From the IPWSO blog is an article which is sure to make you smile and join in the joy of this mother.

As usual, we have tips by Patrice Carroll of Latham Centers. I am certain that parents of children with PWS will quickly turn to the tips about *The messy room*. There are also tips for holiday travelling. Whether you are travelling by air, staying over in hotels or driving, please plan ahead. Very handy, take this to heart!

Please note the support which is offered by IPWSO. Also, in *IPWSO News,* important educational articles which are available on their website. They may also be requested from: chairperson@praderwilli.org.za.

The photo gallery contains more about the Annual General Meeting which was held in August. It is a pity that it was not possible for everyone to attend. We appreciate the input by Dr Engela Honey, Molelekeng Sethuntsa and Maryke van der Hoogt, who by their presence offered support to parents.

This will be the last newsletter in this format. Over the years it has been a privilege for me to make contact with members and other parties by means of the newsletter. A greater responsibility now rests with parents and others to make use of other channels to acquire information, but be assured that assistance is but a telephone call or an email away! The website and Facebook have the contact details of people who are willing to assist.

I wish everyone a well-deserved summer holiday. May the togetherness with family and friends be a blessed time. Love and prosperity for 2016 to all of you.

Sincere greetings
Rika du Plooy.

Thanks to Greg Deegan who assisted with the translation

The information in this newsletter regarding the dissolution of the Association is not only of interest to members, but also to anyone with an interest in Prader-Willi syndrome.

PWSA (SA) IS NOW ON FACEBOOK!!!!

PLEASE LIKE OUR PAGE AT www.facebook.com/pwsasa

PLEASE BE PART OF THE FACEBOOK FAMILY OF THE PWS COMMUNITY OF SOUTH AFRICA

In a changing Association, that's the place to meet, share and support! JOIN TODAY!

For your convenience, Dawid Basson drafted a 'Facebook Guide' to assist you with the process to obtain a Facebook profile and to start interacting with the Facebook page.

For this information contact Rika du Plooy: chairperson@praderwilli.org.za

VAN DIE VOORSITTER

Liewe Lesers

Die einde van die jaar is hier en so-ook die einde van ‘n tydperk van 25 jaar in die bestaan van die PWSV (SA). Dit is hartseer dat ons tot hierdie punt moes kom. Lede van die PWSV (SA) is bewus daarvan dat daar besluit is dat die Vereniging ontbind moet word. Om ‘n formele Vereniging suksesvol te bestuur is ‘n gemotiveerde en sterk span nodig, wat daar tans nie is nie. Lees asseblief in hierdie nuusbrief baie belangrike inligting oor hoe die pad vorentoe bestuur gaan word. Op die Algemene Jaarvergadering 2015 is ‘n taakspan verkies om hierdie proses deur te voer.

My dank aan die komiteelede van die taakspan wat die Vereniging tot ontbinding moet lei. Ek noem graag Johan Basson wat met sy insig ‘n belangrike rol speel. My dank ook aan Dawid Basson wat agter die skerms Facebook en die webwerf hanteer. Die ontbinding van PWSV (SA) behoort middel 2016 afgehandel te wees.

In hierdie nuusbrief ontmoet ons vir Wilmien Dormehl deurdie oë van haar vyftienjarige sussie Marelie. Die Dormehls het die Algemene Jaarvergadering bygewoon en Marelie het fluks gehelp om almal besig te hou. Lees gerus van die naaldwerk wat Wilmien doen en hierdie gesin dra ook T-hemde wat hulle spesiaal laat maak het om bewusmaking van die sindroom te bevorder. Die foto’s elders in hierdie uitgawe vertel meer.

Navorsing in die VSA word tans oor die middel Oxytocin gedoen. ‘n Groot veldtog is in die VSA aan die gang om genoegsame fondse vir die tweede fase van hierdie studie in te samel. Die PWS gemeenskap het hulle hart in hierdie projek gestort en behaal wonderlike resultate. Die vermoede bestaan dat hiedie middel die lewe van persone met PWS kan verbeter deur angstigheid en vrese te verminder, sosiale interaksie te verbeter en behoort ook die anstigheid rondom kos verwante sake te verminder. Lees gerus die opsomming van die webinaar wat deur dr. Jennifer Miller aangebied is. Die resultate van hierdie navorsing word met opgewondenheid dopgehou.

Dan is daar ‘n artikel wat spesifiek aan die professionele persoon wat aan die anderkant van die lessenaar sit, gerig is. Ouers kan identifiseer met daardie onsekerhede en angstigheid as jy nie weet wat met jou kind fout is nie. Liza Graziano skryf spesifiek oor die ouer se emosionele ervaring en hoe die professionele persoon kan help om dit makliker te maak.

Aansluitend hierby, skryf Michele Shingleton (VSA) oor die gebruik van Prader-Willi-sindroom wanneer daar na persone met PWS verwys word. Sy raak ‘n baie belangrike punt aan en dit is vir ouers en ander om toe te pas. Dit is ook nie net van toepasing op die persoon met PWS nie, maar hoe daar na alle persone met ‘n gestremdheid verwys moet word.

Vanaf die VSA ‘n handleiding wat saamgestel is uit inligting wat bekom is van jongmense met PWS. Hulle gee raad uit eie ervaring op die skoolbanke en ouers en onderwysers in Suid-Afrika kan ook hieruit leer. PWSA (USA) stuur ook ‘n epos genaamd *School Times* uit. Enigeen kan hiervoor vra. Evan Farrar se eposadres is elders in die nuusbrief.

Van IPWSO se Blog is daar ‘n stukkie wat jou sal laat glimlag en jou in hierdie mamma se vreugde laat deel! Lees dit gerus.

Soos gewoonlik is daar wenke deur Patrice Carroll van Latham Centers. Ek is seker elke ouer met 'n kind met PWS in die huis gaan vinnig blaai na die wenke vir *The messy room*. Ook vakansiewenke vir die ouers wat beplan om te vlieg, in 'n hotel gaan oorbly of met die motor gaan ry. Baie handig, neem dit ter harte.

Neem ook kennis van die ondersteuning wat IPWSO kan bied. Onder *IPWSO News* is daar opvoedkundige artikels wat beskibaar is op hul webwerf. Kan ook aangevra word van: chairperson@praderwilli.org.za.

In die foto-album meer oor die Algemene Jaarvergadering wat in Augustus gehou is. Jammer dat hierdie geleentheid nie vir almal bereikbaar is nie. Ons het waardering vir dr. Engela Honey, Molelekeng Sethuntsa and Maryke van der Hoogt wat met hulle teenwoordigheid steun aan ouers gebied het.

Hierdie is die laaste nuusbrief in hierdie formaat. Vir my was dit 'n voorreg om oor baie jare deurdie nuusbrief met lede en ander betrokkenes te kon kontak hê. 'n Groter verantwoordelikheid lê nou by ouers en ander om deur ander kanale hulself toe te rus met inligting. Wees verseker dat hulp 'n telefoonoproep of epos ver is. In hierdie nuusbrief, op die webwerf en Facebook is die kontakbesonderhede van persone wat gewillig is om te help.

Aan almal 'n welverdiende somervakansie. Mag die samesyn met familie en vriende 'n geseënde tyd wees. Liefde en voorspoed toegewens vir 2016

Opregte groete
Rika du Plooy.

Die inligting in hierdie nuusbrief oor die ontbinding van die Vereniging is nie net vir lede van belang nie, maar vir alle betrokkenes wat om een of ander rede in die Prader-Willi-sindroom belangstel.

PWSV (SA) IS NOU OOK DEEL VAN FACEBOOK!!!!

GAAN NA www.facebook.com/pwsasa

WEES DEEL VAN DIE FACEBOOK FAMILIE VAN DIE PWS GEMEENSKAP VAN SUID-AFRIKA

Die Vereniging is besig om te verander en FACEBOOK gaan die plek wees om te kuier, te deel en te ondersteun! REGISTREER VANDAG! As jy nie weet hoe om hierdie uitdaging te hanteer nie, Dawid Basson het vir jou gerief riglyne saamgestel om deel van FACEBOOK te word.
Vir hierdie inligting via epos kontak Rika du Plooy: chairperson@praderwilli.org.za

ONTMOET MY SUSSIE

Geskryf deur Marelie Dormehl

My naam is Marelie Dormehl. Ek is 15 jaar oud en is twee jaar ouer as my sussie Wilmien. My sussie is gediagnoseer met Prader-Willi-sindroom toe sy vyf jaar oud was. Als het begin verander toe ons van die diagnose uitgevind het. Dit was 'n groot aanpassing vir almal in die huis. Ek kon nie meer net eet wat en wanneer ek wil nie. Ons moet altyd vir Wilmien in ag neem. Sy kan my so kwaad maak en irriteer, maar ons bly steeds sussies. Partykeer baklei ons soos kat en hond en dan speel ons weer saam.

Marelie is 'n Bulls ondersteuner.

Wilmien het die hemp wat sy aan het, self gemaak. Mooi so, Wilmien!

Die laaste jaar het dinge baie verander. Ek is hoërskool en koshuis toe en is net naweke en vakansies by die huis. Daar is baie tye wat ek haar nie kan verstaan nie. Ek verstaan nie hoe sy vir ure net kan sit en kaarte sorteer of speletjies op die tablet speel nie. Ek begin haar nou meer betrek as ek buite iets doen om dit saam met my te doen. Ons het 'n groentetuin begin sodat ons vars groente in die huis kan hê.

Dis belangrik om te weet hoe om iemand met Pader-Willi-sindroom te hanteer. Hulle is altyd honger en kan maklik kwaad word. Sodra ek sien sy is omgekrap, praat ek net mooi met haar of probeer haar aandag heeltemal aflei sodat sy vergeet waaroor sy omgekrap was. Dit vat n sterk en goeie familie om so iemand soos my sussie te hanteer. Jy moet probeer om hulle te laat verstaan, al is hulle honger, gaan dit nie help om meer te eet nie. Ek voel om slotte aan alles te sit, gaan hulle net kwaad maak. Dit was nog nie vir ons nodig om slotte aan kaste en die yskaste te sit nie. Tot sover gaan dit goed.

Wilmien het die laaste ruk op n dieët gegaan en 5kg verloor. Sy en mamma is saam op die nuwe eetplan, sodat hulle albei gewig kan verloor. Dit is vir Wilmien makliker as iemand dit saam met haar doen. Hulle albei verloor goed gewig en hou mekaar gemotiveerd. Mamma en Wilmien gaan nog aan met die eetplan, maar vat dit maar dag vir dag. Dit is glad nie maklik vir Wilmien om uit te hou nie, maar ons is trots op haar. As sy haar kop op iets sit doen sy dit. Sy is baie hardkoppig en volg net wat haar eie kop vir haar sê, maar dis maar net wie sy is. Ek kon regtig nie glo dat my sussie op 'n dieët kon gaan nie, maar sy het. Sy het deur gedruk en goed gewig verloor.

My sussie het elke Vrydag naaldwerkklasse. Sy kom dan uit die huis en leer nuwe vaardighede aan. Sy het nou al 'n hemp en broek vir haarself gemaak, 'n romp vir ouma, 'n kort broek vir my en sy gaan nou 'n bloes vir mamma maak.

Dit is nie gesond om heeldag in die huis te sit nie. Sy ry partykeer ook perd. Sy kry perdrylesse by mamma en pappa se werk by 'n tannie wat elke week soontoe kom. Nou dat dit warm word swem sy graag, wat ook baie goeie oefening is. Mamma en pappa het verlede Desember vir ons 'n opslaanswembad gekoop om in te swem. Wilmien kom mooi reg met die swem. Sy swem onder water met haar "goggles" en sy besef nie eers sy oefen terwyl sy in die swembad is nie.

Al maak my sussie my somtyds radeloos, sal ek altyd lief wees vir haar. My wens vir my sussie is dat sy gelukkig moet wees en dat ons haar kan help om gemotiveerd te wees om enige iets aan te pak.

The Dormehl family started their own awareness campaign. Here is Marelie, Hester and grandma with their awareness T-Shirts. We congratulate them with their initiative.

Wilmien is a PUMA supporter

MEET MY SISTER

Written by Marelie Dormehl

Thanks to Johan Basson who was responsible for the translation.

My name is Marelie Dormehl. I am 15 years old and two years older than my sister Wilmien. My sister was diagnosed with Prader-Willi syndrome at age five. Everything started changing when the diagnosis was made. It was a major adjustment for everyone at home. I could not eat what and when I wanted to. We always had to take Wilmien into consideration. She tends to infuriate and irritate me, but we remain sisters. Sometimes we fight like cats and dogs, but afterwards we play together.

Over the last year things changed a lot. I went to high school and became a hostel dweller, and am only at home over weekends and during holidays. There are often occasions that I don't understand her. I cannot understand how she can spend hours sorting cards or playing games on her tablet. I try to involve her when I have outside activities. We also started a vegetable garden in order to have fresh vegetables for the house.

It is important to know how to handle someone with Prader-Willi syndrome. They are always hungry and get angry easily. When she gets agitated, I speak to her nicely or try to divert her attention away from the source of her agitation. It takes a strong and sound family to handle someone like my sister. One has to make them understand that, even if they are hungry, it will not help to keep on eating. I feel that to lock everything will only infuriate them. So far it has not been necessary to lock our cupboards and fridges and so far it works well.

Wilmien has recently gone on a diet and lost 5kg. She and mummy are on a new eating plan together in order for both to lose weight. It is easier for Wilmien if someone supports and joins her. They are both losing weight and keep each other motivated. Mummy and Wilmien are still on the eating plan, but handle it on a day by day basis. It is not easy for Wilmien to persevere and we are proud of her. It she puts her mind to something, she goes for it. She is very stubborn and follows her own head, but that is who she is. I could hardly believe that my sister would go on a diet, but she did. She persevered and has lost substantial weight.

Wilmien het die romp gemaak wat haar ouma aan het. Wilmien is proud of the skirt she made her grandmother.

My sister has needle working classes on Fridays. It allows her to get out of the house and to learn new skills. She has already made her own shirt and trousers, as well as a skirt for grandma, pair of short pants for me and is busy with a blouse for mummy.

It is not healthy to sit in the house the whole day. Therefore she occasionally rides a horse. She receives horse riding lessons from a lady that comes to my dad and mum's work every week. Now that the summer heat has arrived, she enjoys swimming, which is also

good exercise. Mum and dad bought us an inflatable swimming pool last December for our swimming. Wilmien is coping well with the swimming. She swims under water with her goggles and does not even realise that she is exercising while she is swimming.

Even though my sister makes me desperate sometimes, I will always love her. My wish for my sister is that she must be happy and that we can help her to be motivated to tackle anything.

QUO VADIS –TIME FOR CHANGE

Change is the law of life.
And those who look only to the past or present are certain to miss the future.
John F. Kennedy, 1917-1963,
Thirty-fifth President of the USA

THE PRADER-WILLI SYNDROME ASSOCIATION (SOUTH AFRICA): QUO VADIS?

Drafted by Johan Basson, member of PWSA (SA)

1. After a process of consultation with members, discussion at the Annual General Meeting on 23 August 2015 and due consideration of all the possible alternative routes, including to retain the Association in its present form, the task team elected at the AGM came to the conclusion that the only available route was to dissolve the present PWSA (SA) Non-Profit Organisation.
2. Regardless of the above decision, it was strongly felt to retain structures for the South African PWS community that could provide a platform to provide information, to allow exchange of views and to provide a level of support to those families that don't have adequate access to the internet or social media.
3. The structures decided upon will have three pillars:
   - A PWSA (SA) website that is in the process to be redesigned
   - A PWSA (SA) Facebook page
   - Retention of points of contact. Limited personalised support (such as printed information) will be maintained, mainly focussed on those families that don't have internet access.
4. In practical terms these decisions will encompass the following:
   - The present Association will be dissolved in accordance with its constitution and applicable legislation pertaining to Non-Profit Organisations. In this regard the members will have to approve the dissolution with a two-thirds majority. For practical reasons the approval of an appropriately worded resolution will most probably have to be handled on a round robin basis and not in a special AGM. Furthermore, the financial assets of the Association will have to be dealt with in accordance with the constitution and with due consideration of the wishes of the donors of particular funds. Professional assistance will be utilised to ensure the process is handled correctly and in the best interest of the Association and its donors. It is envisaged that the dissolution process will be completed in the second half of 2016.
   - The present PWSA (SA) website (http://www.praderwilli.org.za) is in the process of being redesigned and will remain the main source of information about PWSA (SA). In order to update the information on the website frequently, we will retain

the services of a webmaster. Nominated persons, who are presently members of PWSA (SA), will probably take joint or rotational responsibility for the updating of the website. The website will also have contact details of a number of contact persons, as well as links to relevant websites and references to assist persons or families in their search for information or assistance.

- The present PWSA (SA) Facebook page (http://www.facebook.com/pwsasa) will be utilised and developed to become the main meeting place for its users (the PWS families in South Africa). In this regard a small number of sub-administrators (say 3-5) will be authorised to edit and post information on the page. The Facebook page will utilise its wide range of functionalities to also display pictures, announcements, reports, newsletters and chat facilities. The Facebook page will also have contact details of a number of contact persons, as well as links to relevant websites and references to assist persons or families in their search for information or assistance. Present members will be guided on the procedure to establish a Facebook profile and how to interact with the Facebook page. Although this may be unknown territory to many present members, and may feel a bit threatening, experienced Facebook participants give the assurance that, once people get used to this facility, the journey will be fruitful and even enjoyable!
- A small group of present members (probably 3-5) will be identified to take up the responsibility to be points of contact, probably preferably on a regional basis. They will replace the key functionaries of the to-be-dissolved Association as contact persons. These contact details will be shown both on the website and Facebook page. These persons will deal with enquiries and will also provide a limited service or personalised support to families that don't have access to the internet. An arrangement will be made to distribute hard copies of interesting articles or information (a scaled down version of the present newsletter) to this group of people at a frequency of approximately twice per annum.
- What will unfortunately fall away is the data base on families with PWS in South Africa. This information will no longer be formalised or centralised. The possibility is not excluded that some voluntary data bases may be held informally on a regional basis.
- The relationship with IPWSO will be maintained by the new more informal structure. The new 'PWSA (SA)' can become an Associate Member and is entitled to nominate a parent delegate, professional delegate and caregiver delegate. Access to IPWSO's e-mail list, as well as assistance from the Clinical Scientific Advisory Board and assistance & support to newly diagnosed families, are all still available to 'PWSA (SA)' and individuals.

In summary:

The replacement structures for the Association have already been introduced and will be fully developed promptly. There is therefore time to ensure these new structures function well before the Association disappears. In the meantime the Association will legally remain in place until the dissolution process has been concluded during the second half of 2016.

It is not possible to replicate the present features and services of the Association. In fact, the dissolution of the Association will result in a substantial net loss of support and personal involvement as presently experienced by members. This is inevitable. However, in its place will be an array of options for PWS families to source information: website, Facebook,

IPWSO, and points of contact. The informality of structures allows voluntary groupings, socialising and interaction. Support is at hand and someone will always be on the other side of the medium to take your hand.

NEW PARTICULARS FOR CONTACT PERSONS

The following members of PWSA(SA) have kindly offered their availability to act as future contact persons on behalf of the Association. Their details will also be available on the website and Facebook site:

1. Liezl Grix (North West). Liezl has a 2 year old daughter.
   liezlg@praderwilli.org.za
2. Karin Clarke (Western Cape). Karin has an 8 year old daughter.
   karinc@praderwilli.org.za
3. Liezl Vlok (Southern Cape). Liezl has a 19 year old son.
   liezlv@praderwilli.org.za
4. Rika du Plooy (Gauteng). Rika has a 32 year old daughter.
   rikadp@praderwilli.org.za
5. Janet Legemaate (KwaZulu-Natal). Janet has a 10 year old son.
   janetl@praderwilli.org.za

Support is an just e-mail away and someone will always be there to take your hand.
Feel free to contact us with your questions or suggestions!

IN A WORLD OF CHANGE - HOW CAN IPWSO ASSIST?

International Prader-Willi Syndrome Organisation is the international non-profit support group for all countries where there is even just one person with Prader-Willi syndrome! IPWSO is an international umbrella and supports all PWS Associations. In those countries where there is no formal PWS Association, IPWSO supports the medical and parent delegates. Currently 103 countries worldwide are part of the IPWSO family.

PWSA (SA) is currently a member country of IPWSO. With the changes the status of the Association will change to that of an Associate member country. Delegates from Associate member countries are usually volunteers who agreed to be delegates and will not hold voting rights at the General Assembly of IPWSO, but are openly welcomed to attend. How IPWSO can assist?

- IPWSO's website is a source of valuable information. (www.ipwso.org)
- Anyone who has a keen interest in the Prader-Willi syndrome and wants to be part of the international PWS community is welcome to join their mailing list in order to receive IPWSO's newsletter. You can also contribute to the newsletter.
- Anyone can ask for help from the Clinical Scientific Advisory Board.
- IPWSO is also very supportive to newly diagnosed families.
- Be part of IPWSO's Facebook page and Blog

OXYTOCIN INITIATIVE: A PHASE 2 STUDY IN PWS

A webinar featured Dr. Jennifer Miller, a Paediatric Endocrinologist.
Summary by Denise Servais. ***The Gathered View, PWSA USA, Sept – Oct 2015***

> "I want to make life easier for these kids and I believe this drug, when dosed correctly, has the potential to do that."
> Dr. Jennifer Miller.

On July 8, 2015, PWSA (USA) hosted a webinar called, "Oxytocin Initiative: A Phase 2 study in PWS." The webinar featured Dr. Jennifer Miller, a Paediatric Endocrinologist, from the University of Florida. During the webinar, Dr. Miller discussed exciting information about a drug called oxytocin that she believes has great benefits for people, of all ages, with PWS. Her current research on a Phase 1 study of intranasal oxytocin for treatment of PWS, plus research done on mice, and anecdotal information, all suggests that oxytocin has the potential to improve the lives of people with PWS by decreasing anxiety, reducing fears, improving social interactions, and lessening the anxiety about food and food related issues.

Oxytocin is a hormone, which is synthesized in the hypothalamus. Autopsy studies have shown a deficit in oxytocin-producing neurons in people with PWS. Mice research has shown both social deficits and behavioural rigidity were decreased when administered oxytocin. Human studies have shown an increase in pro-social behaviours and trust when healthy subjects were administered the drug. Currently the drug is off the market in the US.

Withdrawal from the US and Canadian market by the manufacturer of the IN-OT (syntocinon Novartis) in 1997 and 1992 respectively, was not related to any safety issues but was at the request of the manufacturer, for poor market profits. Dr. Miller reported that currently the Phase 1 study is going on now in parts of the US in children with PWS and preliminary results of this pilot study look promising without any major side effects. *The funding for the Phase 1 study came from pilot grant funding from the Rare Disease Clinical Research Center grant studying the natural history of PWS, as well as from PWSA (USA) and a private donor.*

A plea for funding was forwarded by Dr. Miller and Dr. Dan Driscoll. They asked people to help PWSA (USA) to raise the funds necessary so that a Phase 2 study can take place as soon as possible. The goal is to raise one million dollars by the end of 2015. *PWSA (USA) is leading the campaign to make the Phase 2 study a reality. In the first two months, the special campaign led by PWSA (USA) has raised over $250,000. What an incredible response from our supporters.*

The author Denise Servais, also mother to Maya with PWS, shares her thoughts:
There is something that bothers me even more than when my child has meltdowns when she wants to eat. And that's when she looks into my eyes and pleads softly for more food because she is hungry. Maybe it's because deep down inside I am experiencing a mother's innate sense to feed her child or maybe it's because it's just a sad circumstance, I'm not sure. I feel fortunate to have received good advice from very caring professionals. However, I am excited to hear about the positive research that is going on with oxytocin. This could not only

be another tool in our toolbox, but a game-changer. To imagine a world where my child is more social and engaging; less hungry and rigid? Yes, this is the world I would love to imagine for my daughter. To think that it could be a reality makes me hopeful for what's in store for my child with PWS.

WORDS OF HOPE

Janalee Heinemann, Coordinator of Research and International Affairs PWSA (USA)
Email News 25.09.2015

It is an exciting time for research in PWS, and especially in clinical trials. In 30+ years with the Association, I have never seen such interest from pharmaceutical companies regarding working with PWS on clinical trials. I have almost daily contact with various pharmaceutical companies; educating them on the syndrome, advising them, and interacting with their consulting companies. We have seen tremendous advances throughout our son's lifetime, and this next generation will see amazing advances that we cannot even imagine.

PWSA (USA)

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PRADER-WILLI SYNDROME: THE LATER DIAGNOSIS EXPERIENCE

What Parents Want Professionals to Know
By Lisa Graziano, M.A.
Reprinted with kind permission of PWSA (USA), The Gathered View, May-June 2015

Long before our child was born, we dreamt of his or her life and fantasized various futures. None of these dreams included a rare genetic disorder called Prader-Willi syndrome. The first hint that something is wrong with our precious child we experienced a multitude of feelings:

- Confusion
- Fear
- Terror
- Shock
- Helplessness

When specialists are brought in, our fear and panic increase exponentially.

When you present parents with the diagnosis of Prader-Willi syndrome you have the ability to start us off on a more hopeful attitude so that we pursue the support we need. We depend upon you to instil that hope. Liza Graziano

From the moment you first encounter a parent, you influence our feelings and attitude. Where you tell us, **what** you tell us, and **how** you tell us about our child's diagnosis of Prader-Willi syndrome will remain with us the rest of our lives.

When you present parents with the diagnosis of Prader-Willi syndrome you have the ability to start us off on a more hopeful attitude so that we pursue the support we need. We depend upon you to instil that hope.

When giving me the diagnosis:

- Speak with me in person.
- Don't deliver bad news on the phone.

- Please pronounce the syndrome correctly: PRAH-der WILLee
- Please use person-first language: "Your child has PWS"; "People with PWS"; "People who have PWS"
- Know that I may be in shock and may not remember details of what you tell me… unless they scare me and then I may never be able to let go of that image.
- Schedule a follow-up meeting so that I may ask the questions I didn't think to ask during the first meeting or I don't remember you answering.
- Give me current printed material from the national Prader-Willi Syndrome Association (USA) website. www.pwsausa.org.
- Use current information and research to answer my questions. PWSA (USA) is a good resource.
- If you don't know the answer to a question, don't guess.
- Encourage me to call PWSA (USA) as soon as I can so that they may provide me with important, accurate information and ongoing support resources. Provide me with phone numbers.
- Tell me about the genetics of my child's disorder in words I can understand.
- Don't talk at me or over my head.
- Don't try to tell me every genetic fact about PWS, just the highlights.

Things that are helpful for me to know right away are:

- PWS is a genetic disorder but generally not inherited, and that I can receive genetic testing if I consider having more children.
- Tell me that PWS is a part of the human condition and is most often a random genetic event. Tell me there's nothing I or my spouse did or didn't do to cause our child to have PWS.
- Tell me that PWS is a spectrum disorder; not everyone has all of the symptoms, and symptoms vary from person to person.
- Tell me that because my child now has a correct diagnosis I will be able to address and reduce many of the typical symptoms. **This gives me hope.**
- Tell me there are medicines, therapies, and interventions that will help my child grow and develop into a healthy individual.
- Tell me specifically about the benefits of growth hormone therapy.
- Tell me what nutritional phase my child may be in or entering and how I may prepare for that phase. **This gives me hope and empowerment.**
- Tell me there are parents who can mentor me, guide me, help me understand the things I need to know.
- **Reassure me that supports are available.**
- Tell me there is a great deal of research being done in many symptom areas including the hyperphagia and behavioural symptoms.
- Tell me only the facts. Don't predict my child's future even if you think you know it... because you don't know my child's future.
- Let me know you understand my life has been difficult.
- Tell me you know I have been struggling with my child's weight and behaviour.
- Tell me that having a diagnosis now will provide me with a better framework and path and help me get the resources my child and my family need.

Affirm my feelings of:

Validation – because I knew something was wrong and no one would believe me

Relief – that I now have a direction for treatment and interventions for my child
Anger – at not having a diagnosis long before
Resentment – that I have been shamefully blamed for my child's spiralling weight gain and behaviour problems
Sadness – that my child could have benefited from therapies long ago

Don't tell me, "God only gives us what we can handle" or "God chose me to be this child's parent because He knew I could handle it." Right now I may be cursing God or questioning my ability to parent my child.

Tell me that given the right supports, our children and adults with PWS are loving, friendly, outgoing, talented, funny, bright, articulate, generous, brave, amazing human beings.

Parents want you to know that absolutely having a child with PWS challenges us as parents. We need support. We need research breakthroughs. We also need to know that having a child with PWS can broaden us into being more loving, compassionate people.
We need to know we are no longer alone on this journey. Ever.

SUPPORTING STUDENTS WITH PRADER-WILLI SYNDROME:

INFORMATION AND ADVICE FOR SCHOOL PROFESSIONALS

Evan Farrar, PWSA (USA) Family Support Counsellor
Reprinted from a resource of the Prader-Willi Syndrome Association (USA).
www.pwsausa.org

Although the information in this article is shared by individuals in the USA, it will translate into the school situations of students with PWS in other countries.

This is the first handout for schools that contains information exclusively from the perspective of people who've lived the experience of being students with PWS. Therefore, it is an important contribution to literature we provide schools because it is based on the first-hand experience of Advisory Board members. We recommend it to parents and school professionals. I want to say a very special thanks to the Advisory Board members who provided information for this handout: Shawn Cooper, Brooke Fuller, Conor Heybach, Kate Kane, Lauren Lange, and Abbott Philson. Without their willingness to share openly and honestly about their school experiences, this important new resource would not be available to help a new generation of students with PWS.
Evan Farrar, PWSA (USA) Family Support Counsellor

What Works Best For Students with PWS

• Adaptive Physical Education is important for students with PWS. It helps with weight management and improves low muscle tone.
• A positive response to behavioural meltdowns including the following:
  - ✓ Give the student time to recover.
  - ✓ Limit verbal interaction to simple directions.
  - ✓ Allow space.
  - ✓ Avoid restraint and seclusion.
  - ✓ Never making fun of a student in distress.
• Plan for food security – especially managing lunch and any other food-related activities.
• Eliminate easy access to vending machines.

• Provide 1:1 paraprofessional supervision with food security and support during academic activities and transitions. A paraprofessional working with a student with PWS should:

- ✓ Receive training on how to appropriately and effectively support a student with PWS.
- ✓ Enforce food security protocol – including not eating lunch or any other food in front of a student with PWS.
- ✓ Have a sense of humour.
- ✓ Have a coaching or teaching background.
- ✓ Know how to provide support without hovering.

What Accommodations Can Help Students with PWS

- Extend time for tests and assignments.
- Read questions on tests to the student instead of having the student read them.
- Use of assistive technology.
- Utilize fun strategies and teaching methods.
- Adaptive Physical Education
- Supervision as needed to promote academic success and safety.

What School Professionals Should Do To Better Serve Students with PWS

- Instruct other students to put food away so it is not visible or accessible in the classroom or other school environments.
- Remember that students with PWS can't help asking for food especially when it is visible.
- Don't take advantage of a student. Listen so you can understand their point of view.
- Make every effort to put the interests and needs of student with PWS first.
- Don't use food as a reward for any activity at school.
- Understand there is no cure for PWS and it is life threatening.
- Be aware that skin picking is a problem for many. Don't invite embarrassment or shame to this challenging behaviour.
- When possible show a student what to do rather than just tell them.
- Communicate with parents regarding holiday activities at school and create a plan for students with PWS to participate in a safe and appropriate way.
- Know that tantrums can be part of PWS. When we are upset, please do not punish us - help us.

What Students with PWS did not like about School

- Other students not putting food away.
- Vending machines were a constant temptation.
- Use of detention and punishment for seeking food.
- Teachers using food rewards for classroom activities.
- Being bullied, picked on and called names.
- Teachers and classmates not understanding PWS.
- Isolation from peers.
- Being bullied by teachers and staff.

What Students with PWS Liked About School

- Spending time with friends.
- Learning.
- Using a computer.
- Special Olympics.
- Gym class/adaptive physical exercises.

- Graduating with class and participating in graduation activities.
- Special celebrations with classmates and family.
- Senior Prom and other extracurricular activities.
- Learning photography.
- Helping other people/classmates.
- Freedom to have new experiences while meeting new people.
- Changing classes in high school.
- Participating in mainstream and general education classes.
- Working on the school newspaper.
- Graduating from high school.

You are welcome to subscribe to the PWSA (USA) school e-letter, "School Times". To subscribe to "School Times", e-mail Evan Farrar at efarrar@pwsausa.org Note: We encourage all parents of school-age children with PWS, and school professionals who serve them, to subscribe to "School Times" which is the only publication dedicated exclusively to PWS school related issues.

FROM A MOTHER

Michele Shingleton Burlington, CT – a mother of a 13 year old boy.

The Gathered View ~ Prader-Willi Syndrome Association (USA) September – October 2015

I don't know about yours, but my child is not "PWS." He is a person with PWS. He is a person FIRST - a human being with feelings, emotions, likes and dislikes, wants, desires, and needs. He is a child first - who does things and acts in ways much like "typical" children. Not everything he does or that happens to him physically is because of PWS. We don't define our son as PWS, or refer to him as "A PWS," because we refuse to let him be defined by his diagnosis. I implore everyone with a child with PWS to consider this - if you define your child by the symptoms and characteristics of Prader-Willi syndrome, you are setting him up for a lifetime of doubting his ability, and restricting her from realizing her full potential in life. It doesn't take much more time to say or write, "My child with PWS," or, "My child who has PWS." Sometimes, all you need to say is, "My child," "My son," or, "My daughter," and leave out the PWS altogether. I'm not saying to ignore the fact that a child has PWS, or not to tell a child he or she has PWS, just don't make everything about your child relate back to PWS, and don't define your child solely based on what PWS brings to the table. My son is so much more than his diagnosis, and so is a child who has PWS. Respect.

A PERFECT DAY

From IPWSO's Blog August 2015

Some days confound expectations. Today was one of them. My 11 year old son (who has PWS) headed off this morning to spend a day having fun with his grandparents. He does the same thing every summer with varying degrees of success. Some years he returns sullen and anxious, but today came home with a broad smile on his face accompanied by his equally happy grandparents.

There is always the potential for things to go badly wrong on a day like this. Sometimes the excitement is so overwhelming that upset becomes almost impossible to avoid. Sometimes my son's (often unspoken) expectations about what will happen are not met leading to

tears. Sometime the stress and worry prove so exhausting that the outing cannot be enjoyed at all.

But not today...Today, the sun shone!

The pet farm was as he remembered and as he wanted it to be. The amusement park was fully operational and he could enjoy all his favourite rides. His snacks and lunch were as he expected and he was satisfied with them.

Today, my son laughed and sang and talked and joked with his grandparents and glowed with happiness.

Today, my son enjoyed a great deal of independence. He planned the day and decided where they would go and when.

Today, my son willing embraced physical activity. Without having told me of his plan, he decided to bring his grandparents on an unscheduled 7 kilometre (!) walk as part of their day out. I think he was proud that he was able to do so.

Today, there were no signs of hyperphagia or anxiety around food. My son arrived home over an hour after his normal dinner time exhibiting no signs of worry about food or anything else. On days like this it is almost possible to forget about PWS. It is certainly possible to believe that it need not interfere with happiness or fun.

Recognising and taking pleasure in perfect days and remembering that they are possible. It makes harder days so much easier to tolerate.

TIP OF THE WEEK: PWS AND THE MESSY ROOM

Website of Latham Centres - www.lathamcenters.org look for *Tip of the Week*

We all know what this looks like - piles of seemingly disorganized hoard that mean the world to your child. There is hope for order without causing a meltdown!

1. Make sure everything has a place to go and they know what goes where. Simply saying *"clean your room"* will be meaningless in many cases. If you want toys or their collection off the floor then make sure there are labelled bins with words or pictures of what goes in each.
2. Catch it early. Waiting until their room is a fire hazard will only make the process more difficult. Make it part of their daily routine: clothes hung up, floor clear of clutter, etc…
3. Don't expect perfection. Know what you will settle for and stick with it.
4. Be an example. If you don't make your bed every day then asking your child to is futile. They will follow your lead.
5. Make donating unused toys part of their lives. Our kids are typically quite generous and like to bring joy to others. Throwing away toys or clothes may be one of life's greatest challenges but explaining that other kids will benefit from their donation will be a much easier sell.

Whatever you choose to do be sure you stay consistent and positive. Nagging will not work and neither will ignoring the problem hoping it will stay the same or get better. It won't!

Once the routine of tidying up becomes part of their day you will see a calmer and less anxious child and definitely a calmer and less anxious you…

ANOTHER TIP OF THE WEEK: SURVIVING HOLIDAY TRAVEL

Many of you are starting your plans for holiday travelling. Here are some tips for creating the odds for a positive experience

1. Flying. If you are flying home for the holidays be sure to alert your airline that you are travelling with a person with special needs. Many parents simply say that their child has autism because it is more recognizable than having to explain PWS and the needs are similar. You will likely be allowed to board and exit first allowing you to skip the commotion and rush during the boarding and exiting process.
2. Driving. If you are driving be sure to check online for rest stop locations and pack a cooler for meals and snacks so you can avoid having to rely on fast food. Under estimate what you will be able to tolerate as far as distance per day. Pushing it will only lead to frustration and exhaustion on your part which will add to your child's stress.
3. Book a hotel. If at all possible don't try to stay with family, especially if they don't know your child well. Holidays are stressful enough and having your own space to escape to at the end of the day is priceless.

Finally, if you don't think that your child can handle the travel or the final destination- *stay home*. You know your child better than anyone and it's ultimately your decision. Visiting family can be a wonderful thing as long as you plan realistically.

Patrice Carroll
Manager of PWS Services

IPWSO NEWS

PLEASE VISIT IPWSO's blog and become A FRIEND of IPWSO.
Look for a variety of interesting material on IPWSO's blog.
Please read *A Perfect Day* elsewhere in the newsletter – from IPWSO's Blog, August 2015.
You are welcome to communicate directly with the Communications Director of IPWSO, Linda Thornton. She will welcome your comments. http://ipwso.blogspot.com

CARING FOR YOUR ADULT DAUGHTER OR SON AT HOME? NEED SOME HELP?

Please share these FAMCARE articles with others!

The following articles are available from the FAMCARE page on IPWSO'S website:

- SKIN PICKING IN PEOPLE WITH PRADER-WILLI SYNDROME – MARCH 2013
- COPING WITH CHANGE IN PEOPLE WITH PRADER-WILLI SYNDROME – June 2013
- THE BASICS OF A HEALTHY ADULT LIFE – Nov 2013
- "GOOD HEALTH" CHECKLIST – March 2014
- MANAGING A MELTDOWN – SPECIAL EDITION – SEPTEMBER 2014
- STORY-TELLING – June 2014
- "I WANT THE SAME" – March 2015

- STRENGTH IN BOUNDARIES – June 2015

Articles are also available from the chairperson PWSA (SA): chairperson@praderwilli.org.za

SAVE THE DATE: IPWSO'S 9TH INTERNATIONAL PWS CONFERENCE

Hosted by the Foundation for Prader-Willi Reseach (FPWR) in Toronto, Ontario Canada, July 20 – 24, 2016.

This conference promises to be fantastic with over 600 expected participants! Together, we can eliminate the challenges of PWS through research, support, and advocacy. Mark the dates on your calendar and start making plans to attend. For additional information please visit our 2016 IPWSO Conference page

PHOTO GALLERY

The AGM was held on Sunday 23 August 2015 at the Vriendekring Bowls Club, Pretoria.
It was a successful get together and the children enjoyed the fun and activities.
We thank our volunteers: Mart Booyse with practical matters, Simoné Mulder for keeping the children busy and Francois Theron, our photographer.

CARD GAMES WERE THE HIT OF THE DAY!

Simoné Mulder (volunteer) with Kele, Tshiamo and Wilmien

Marise is excited to take a card

Willemien waits her turn

WE PULLED FACES!

Kele, Metsiatsile and Tshiamo

WE HAD FUN!

Back: Marise, Willemien and Wilmien
Front: Kele, Metsiatsile, and Tshiamo

PARENTS AND PROFESSIONALS

Portia Moatshe (parent), Molelekeng Sethuntsa (psychologist), Rika du Plooy (parent), Dr Engela Honey (paediatrician and PWS medical advisor) and Maryke van der Hoogt (dietician).

MOTHERS AND CHILDREN

Tshiamo and Patricia Chabane with Portia Moatshe and Kele

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Our volunteers who offer their time and dedication:

Elsa Volschenk for her involvement in assisting with the newsletter
Wilna Basson for taking care of the Library and educational material
Karin Clarke and Magdaleen Kloppers for the birthday cards
Johan and Elmaré Mostert for the annually preparation of the financial statements
Dawid Basson, the webmaster of the website and also responsible for Facebook.
Jan Els, chartered accountant for auditing the income and expense accounts
Dr Engela Honey, the medical advisor of the Association, who is always available

Members for your loyalty and support. Thank you for prompt payment of membership fees
All those who contributed to *People With Strength*
Johan Basson and **Greg Deegan** who assisted with the translation of material
IPWSO for continuously forward information regarding important PWS issues
All other **PWS Associations** for assistance and sharing of knowledge
Our donors for your support to our Association
afrihost.com for hosting the Association's website

Members who participated in the questionnaire on the future of the Association
The **task team** who assists with the dissolvement of the Association
Members who kindly offered their availability to act as future contact persons on behalf of the Association.
Dawid Basson, Diederik de Roos en Elsa Volschenk for their involvement in the updating of the website

Genetic Alliance
SOUTH AFRICA

http://www.geneticalliance.org.za

Genetic Alliance South Africa, formerly the Southern African Inherited Disorders Association (SAIDA), was launched in August 2015 at the 16th Southern African Society of Human Genetics Congress, held in Centurion.
Genetic Alliance South Africa (GA-SA) is a non-profit, membership organisation uniting patient support groups, healthcare professionals and other stakeholders relevant to the care and prevention of congenital disorders.

While continuing to focus on the three core aims of support, education and awareness and research as funding becomes available, GA-SA incorporated the new focus area of advocacy. Going forward, the aim of GA-SA is to unite the patient support community in the call to government for improved genetic services.

A FRIENDLY REQUEST

Please contribute to the Facebook page of PWSA (SA). Whether you are a parent, medical practitioner, therapist or relation, please *like* our page or send a comment. You are welcome to send your contribution, questions or suggestions.

YOU ARE INVITED

You are invited to be part of a Global Prader-Willi Syndrome Registry (www.pwsregistry.org). The Foundation for Prader-Willi Research has taken another tremendous leap forward. The Registry allows the secure collection of a wide range of patient-/caregiver-reported information about the clinical and behavioural characteristics of PWS, which will inform our understanding of PWS and facilitate new research and development efforts. The ultimate usefulness of the Registry is directly dependent on the community's participation.