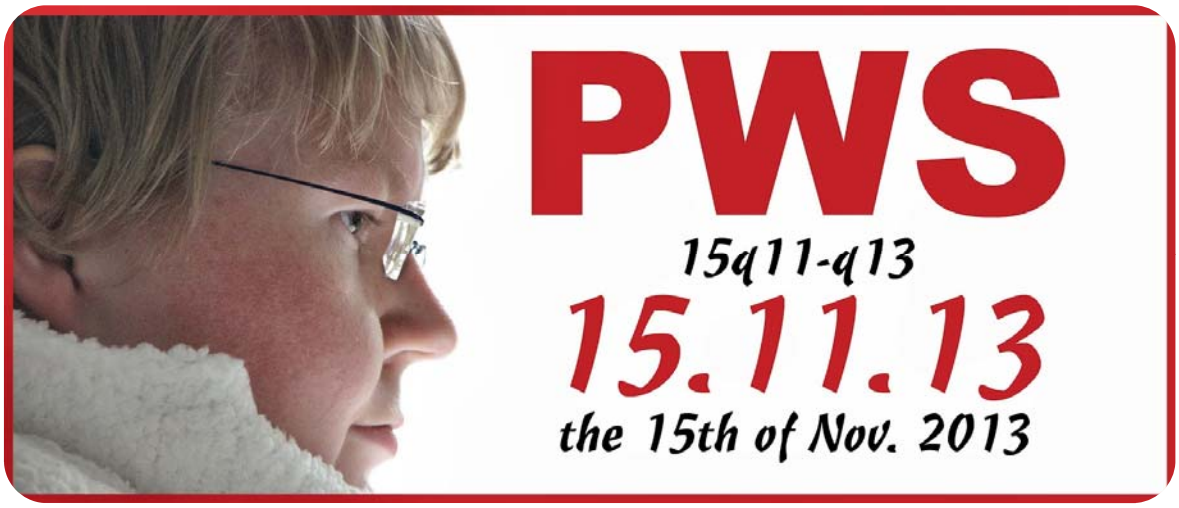
People With Strength

Newsletter for parents by parents

Volume 16 Issue 3 **MISCELLANEOUS** November 2013

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



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What is the link between Prader-Willi Syndrome and the date 15 November 2013?

Please read FROM THE CHAIRPERSON, page 2

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WHAT IS PRADER-WILLI SYNDROME?

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

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FROM THE CHAIRPERSON

Dear Readers

Welcome to the last edition for 2013. The jacaranda trees in Pretoria are in full bloom which, alas, is also an indication of a year running out.

On the front page a banner in which PWS is connected with 15 November 2013. This date can also be read as 15.11.13. This set of numbers as described by the geneticists as **15**q**11**-q**13,** is the code used for the chromosome deletion that marks out Prader-Willi syndrome. Two other syndromes, namely Angelman syndrome and Delq15 syndrome are related to the same area, but caused by different genetic variations within the q11-q13 region of the 15th chromosome. The three related disorders share overlapping symptoms, and each disorder is commonly misdiagnosed with another disorder due to lack of awareness. Therefore, 15.11.13 is a very special date for individuals affected by these three syndromes and their families. This date occurs only once in a century. IPWSO in combination with the US associations of the two other syndromes has decided to use this date to advance awareness. Read more about this on the website of IPWSO, www.ipwso.org. Graphics illustrate the genetic variations that cause Angelman, Prader-Willi and Dup15q syndromes, and the symptoms that each disorder share.

You would have noticed that the theme of this newsletter is *MISCELLANEOUS.* Some information is directed specific on Prader-Willi syndrome and others are more of a general nature, but also applicable. Read about a well known scientist in PWS circles in the USA who tackled a bicycle tour to raise awareness of Prader-Willi syndrome and to raise much needed funding for PWS research. The initiative of Rob gives us a warm feeling. All the best, Rob Nicholls!

Nicoleen Weimann takes us to all the places worldwide where they have stayed since Uwe was 4 years old. Uwe was subjected to many changes and Nicoleen shared their experiences and what they believe are the reasons for Uwe's positive behaviour. We wish them well and it is indeed a pleasure to be in contact with them.

Another article by the Famcare committee of IPWSO addresses the two most important issues for a healthy life style for the person with PWS. This committee supports parents of adults with PWS who are still living at home with their parents. However, parents of younger children should also take note of the valuable hints given by this committee. It is imperative that the correct behaviour must be learned from a very young age.

Janalee Heinemann is the Director of Research & Medical Affairs at PWSA (USA). She often gets calls or reports of concern from parents on the causes of death among persons with PWS. The reality is that most PWS deaths are still obesity-related. She expanded in the article on the causes of death and she stresses the importance of giving all the necessary information to doctors as explained in the *IPWSO Medical Alert Booklet.* This booklet can be obtained from the PWSA (SA) free of charge.

A mother mentioned that her child, for whom all things are going well, does not know that he was diagnosed with PWS. She does not really know how to break the news to him. The

website of Latham Centres contains numerous hints. Please read their hint applicable to this subject. We would like to know how other parents are dealing with this issue.

PWSA (SA) receives on regular basis information from the Department of Women, Children and People with Disabilities. What is a disability? Please read the definition by the United Nations. Furthermore, how to explain to a ten year old what a disability is, is also given.

Please take note of the following:

- Information contained in *IPWSO News*
- Educational material which are available free of charge
- Ronèl wrote on behalf of the Lettie Fouchè School
- A few photographs of the AGM in the photo gallery
- Feedback on *Huis Henri* – an invitation to parents
- This newsletter is also available electronically in A4 format

I trust that you have enjoyed reading this newsletter. You are invited to participate and make it a resolution for the New Year. The management committee would like to have the readers on board.

Enjoy the summer holidays! Best wishes for the festive season.

Sincere greetings
Rika du Plooy

"Too often we underestimate the power of a touch, a smile, a listening ear, an honest compliment, or the smallest act of caring, all of which have the potential to turn a life around." - Leo Bascaglia

VAN DIE VOORSITTER

Liewe Lesers

Welkom by die laaste uitgawe van die nuusbrief vir 2013. Dit is weer daardie mooi tyd in Pretoria waar die jakarandas in volle blom is. Ook ‘n seker teken dat die einde van die jaar naby is.

Op die voorblad ‘n bannier waarin die Prader-Willi-sindroom met 15 November 2013 in verband gebring word. Die datum kan ook gelees word as 15.11.13. Die kode 15q11-q13. word deur genetici gebruik om daardie verandering op chromosoom 15 wat verantwoordlik is vir die PWS uit te druk. Twee ander sindrome, naamlik Angelman-sindroom en Delq15-sindroom word aan dieselfde area gekoppel. Hierdie drie verwante genetiese afwykings het oorvleuelende eienskappe en kan verwar word as gevolg van ‘n gebrek aan kennis. Hierdie datum, 15.11.13 is gevolglik ‘n baie spesiale datum vir daardie persone en hul families, wat deur hierdie sindrome geraak is. Ons kry hierdie datum dan ook net elke 100 jaar. IPWSO in samewerking met die verenigings in die VSA van die ander twee sindrome, het besluit om hierdie datum te gebruik om bewuswording te bevorder. Meer hieroor op die webwerf van IPWSO, www.ipwso.org.Twee diagramme dui die genetiese variasies wat die sindrome veroorsaak aan, asook die ooreenkomste in simptome.

Hierdie nuusbrief het nie ‘n spesifieke tema nie, maar dit bevat ‘n verskeidenheid inligting. Sommige spesifiek op PWS gerig en ander meer van algemene aard. Lees gerus hoe ‘n

bekende wetenskaplike in die PWS kringe in die VSA op sy fiets ‘n tog aanpak met die oog op bewusmaking en fondsinsameling. Die stukkie nuus gee ‘n warm gevoel om die hart en ons wens Rob Nicholls alle sukses toe.

Nicoleen Weimann neem ons amper op ‘n wêreldreis na al die plekke waar hulle as gesin al gebly het en vertel hoe Uwe op al die veranderinge gereageer het. Lees gerus die redes wat Nicoleen gee vir Uwe se positiewe gedrag. Voorspoed vir die Weimanns en dit bly steeds lekker om met julle kontak te hê.

Die Famcare komitee van IPWSO het ‘n volgende artikel gereed wat twee belangrike aspekte van ‘n gesonde leefstyl by die persoon met PWS aanspreek. Alhoewel die werk van hierdie komitee gerig is op ouers van volwassenes met PWS wat in die huis woon, kan ouers van jonger kinders gerus die wenke wat gegee word ter harte neem. Dit kan nie genoeg beklemtoon word dat die regte gewoontes van kleinsaf aangeleer moet word nie.

Janalee Heinemann, wat verantwoordelik is vir mediese sake en navorsing by PWSA (USA) kry dikwels vrae oor die oorsake van dood by persone met PWS. Die realiteit is dat die hoofoorsaak steeds verband hou met oorgewig. Sy benadruk die belang van inligting aan medici soos vervat in die *IPWSO Medical Alert booklet.* Hierdie boekie kan van die PWSV (SA) gratis aangevra word.

Onlangs het ‘n mamma genoem dat haar kind met wie dit goed gaan, nog nie bewus is van die feit dat hy gediagnoseer is met PWS nie en dat sy regtig nie weet hoe om dit aan hom oor te dra nie. Die webwerf van *Latham Centres* het ‘n verskeidenheid wenke, waarvan twee geplaas word. Ek sal graag van ander ouers wil hoor hoe hulle aan hul kind verduidelik dat hy of sy ‘n persoon met PWS is.

PWSV (SA) ontvang gereeld inligting vanaf die *Department of Woman, Children and People with Disabilities*. Wat is ‘n gestremdheid? Lees gerus die definisie soos deur die Verenigde Volke gegee en ook hoe jy gestremdheid aan ‘n 10 jarige kan verduidelik.

Neem ook asseblief kennis van die volgende:

- Inligting wat onder IPWSO Nuus verskyn
- Opvoedkundige materiaal wat gratis beskikbaar is
- Ronèl skryf namens die Lettie Fouchèskool
- In die foto-album ‘n paar foto’s van die AJV
- Terugvoer oor Huis Henri – ‘n uitnodiging word aan ouers gerig
- Hierdie nuusbrief is ook elektronies in A4-formaat beskikbaar.

Ek vertrou dat almal hierdie uitgawe geniet het. Lesers word uitgenooi om deel te neem – maak dit ‘n voorneme vir 2014.

Aan almal ‘n welverdiende somervakansie. Mag die kerstyd ‘n geseënde tyd wees.

Opregte groete

Rika du Plooy.

Please contribute to ***People with Strength.*** Whether you are a parent, medical practitioner, therapist or relation, please send your contributions, questions or suggestions to: PWSA (SA), PO Box 2399, Brooklyn, 0075 or email: chairperson@praderwilli.org.za

MEET UWE WEIMANN

Written by his mother, Nicoleen

Uwe, as with most persons with PWS, entered the world facing lots of complications and as parents and family that surrounded him we also had to face the tremendous emotional burden that accompanies these traumatic events, especially as a first born. Uwe spent the first eight weeks of his life in intensive care and pediatric wards and for the next three years we would seek answers by visiting specialist upon specialist, hospitals and laboratories, every time leaving with unanswered questions. However, it was only shortly before his 4th birthday that he was eventually diagnosed with PWS.

In 1998 at age three, still with many unanswered questions (almost at the point of giving up) we unknowingly submitted Uwe to probably the biggest challenge for a child with Prader-Willi syndrome, CHANGE. This is a pattern that would become a part of his life, even today.....

When Uwe was three we uprooted ourselves and traded a secure and comfortable lifestyle in Mosselbay for an expatriate life in Qatar. We left behind our county, friends, family and a fantastic support structure to face life, as a very small family unit. We were on our own and in a very different culture. We had to make new friends, get used to a completely new lifestyle in a Muslim country where our experiences ranged from the strange to wonderful. Above all of this Uwe had also to adapt to a new language environment and had to learn to speak English, which he amazingly picked up within six months after we have decided to place him in a nursery.

At age four, yet another set of changes occurred; he became a brother and was diagnosed with Prader-Willi syndrome resulting in strict diets and growth hormone treatment. Within a very short timeframe Uwe changed from severely obese into a normal looking, healthy, active little boy. As a result of the PWS diagnosis our knowledge of the challenges associated with the syndrome increased exponentially and we became much more aware of certain behaviour patterns. However, we remained determined that this would not define the person Uwe should and would be. Hope and faith being our driving force, we have decided not to give up the expatriate lifestyle and had a sense of comfort with the fact that as a result of our decision there would be many challenges along the way but knowing that we would receive the strength and wisdom to manage and overcome these. We continued living the unpredictable ever-changing expatriate life we knew, with Uwe's diet and a diligence to administer the growth hormone the only significant adjustments we had to make.

After eight years in Qatar it was time to move with our sights set on the USA where we settled in Houston for four years. Again we all had to adapt from living in a Muslim country to a normal western lifestyle. Different school, friends, church, food, culture..... At age 10 Uwe handled this change well and we were fortunate that Uwe had great teachers who were keen to understand, support and manage the challenges that PWS presented to them. He participated in all school events and activities and at age 11 went on his first school trip spending three nights away from home. After anxious three days, we were eager to have

feedback from the teaching staff, and the only complaint was that Uwe only ate salad for the four days, because "the food looked too fatty" according to him.

At age 13 another opportunity for a school trip away from home, visiting New York and Washington and which involved flights, hotels, trains and busses and a week away from home. As usual Uwe participated in and completed all the hikes and physical activities, although challenging at times, never complaining, never giving up and always returning home with the wonderful feedback: "Uwe is so well behaved and so enthusiastic!"

It was also during these four years that we became much aware of the realities PWS will present us as Uwe matures to teenager and adult, since we now had access to the PWSA (USA) and through events, functions and clinics met many persons with PWS from a diverse age and cultural perspective.

We moved again after four years, this time to South Africa due to a new work assignment, where we found ourselves back in a wonderful support structure surrounded by family and friends, but with dad now working away for a month and staying home for a month. A significant change that Uwe had to cope with and which we believe did at times have an emotional affect on him, especially noticeable during school. This was managed via informing teaching staff of the recurring changes at home and had a positive outcome.

After three wonderful years on home soil and close to family our lives changed again when we moved to Australia. This time Uwe has been the one that coped best with the change and at seventeen he settled into a new school and country without a hitch and made us proud again by being regularly rewarded or recognised at school for his perseverance, positive attitude and enthusiasm on numerous occasions.

As parents our priority focus has been on Uwe's social behaviour and acceptance in the community rather than his academic excellence. The goal has and still is to always challenge him to do his best but ensuring that acceptable and appropriate behaviour is an overriding factor. We have to remind ourselves that eventually Uwe will leave the protective environment of home and school and has to be prepared to face the realities of life, fit into a community and make a positive contribution. Having the appearance of a normal teenager, we did not feel the need to introduce any other types of hormonal treatment and thanks to growth hormone we are today blessed with an 18 year old of average height with fluff on his cheeks and eager to finish school to pursue his dreams of becoming a veterinarian assistant or animal attendant. Thanks to a wonderful inclusive educational system in Australia, Uwe will start to attend college in 2014.

We are very fortunate not to have serious behavioural issues with Uwe and it is still fresh in our memories when as a toddler his worst tantrum would be lying on the floor, flat on his back, arms stretched out and completely silent. Today, at 18 years of age, it is a very different scenario. He talks back and can be really stubborn at times. Engaging in an argument to convince him to change his mind takes effort, skill and a lot of wit and over the years we have acquired the tools and techniques to assist us in managing these situations to avoid escalation. Humour has been one of the best strategies of all to resolve or defuse a tense situation and sometimes by just keeping quiet when Uwe is adamant to be right, also worked really well.

We believe there are a number of reasons for Uwe's positive behaviour; one being the exposure to significant change from a young age, but always surrounded by a small family

unit to support. Secondly would be the opportunity to follow his passions, sports and fishing, whether actively engaged or watching on TV. Nothing beats a good rugby match or a few hours on the beach to restore his focus and puts a smile back on his face.
Thirdly, we always try to present Uwe with a choice, and mostly he will make the right choice whether it is from a menu or chores around the house. Fourthly, we believe his positive outlook on life is one of the biggest contributors towards good behaviour. Keeping him focused on his goal to work with animals after school gives him something to be proud of and a topic to discuss with others that gives him that much needed interaction. Fifthly, friends, family and teaching staff that understand the syndrome and have compassion make a huge difference and help to manage challenging situations. We are again fortunate to have the support and patience of wonderful people that will make a great effort to listen to Uwe, explaining in simplistic terms and follow the rhythm of his conversation. He is very aware of the fact that those around him know about Prader-Willi syndrome and realises that he cannot take any liberties regarding food or behaviour. Their authority is just as powerful as ours when it comes to his well-being. We know who can deal with the situation and will always try to make use of their help, rather than creating an insecure environment for Uwe, which will lead to trouble.

Last, but not least, our faith gives us courage and hope to live happy and full lives! God has blessed us with a wonderful, intriguing and special boy. There is power in prayer!

GENETICS FROM A DIFFERENT CORNER

One man. One bike.
One ride across America for a cure.

from Gathered View, September – October 2013, PWSA (USA)

Did you know?
… that if your child was diagnosed with the maternal uniparental disomy (UPD) type of PWS, it is thanks to Dr Rob Nicholls?

Did you know?
… that this discovery by Dr Nicholls and his fellow researchers was a major breakthrough in the field of genetics by showing for the first time that there was genetic imprinting in humans (meaning that some of our genes have to come from a particular parent to work normally)

Who is Rob Nicholls?
Dr Rob Nicholls is a talented researcher and Director of the Birth Defects Laboratories at the Children's Hospital of Pittsburgh at the University of Pittsburgh School of Medicine. Rob has focused on Prader-Willi syndrome since 1987 and was the first to describe genomic imprinting in humans and in PWS. Rob has decided to ride his bicycle over 3,000 miles to raise awareness of Prader-Willi syndrome and much needed funding for PWS research! Research funds in the USA have significantly decreased and Rob has decided to think outside the box and look for alternate forms of funding. Monies raised will go to PWSA (USA) and will be used to fund PWS and obesity research.

The bike route will start on 10 October 2013 in San Diego, California and will end in Orlando, Florida on 6 November 2013 the day before the start of the **32nd Prader-Willi Syndrome Association (USA)'s National Conference** (www.pwsausa.conference. com)
You can follow Rob's journey at www.robsrideforresearch.com.

From the left, Dr Rob Nicholls, Dr Brenda Louw (communication pathologist) and Dr Arnold Christianson (Human Geneticist) at a PWS Conference, held in Pretoria, South Africa in 1999. Rob Nicholls was a guest of the University of the Witwatersrand and agreed to lecture at the conference organised by the PWSA (SA).

THE BASICS OF A HEALTHY ADULT LIFE

Famcare is a project of IPWSO: famcare@ipwso.org

An early childhood diagnosis of Prader-Willi syndrome (PWS) usually provides parents with the opportunity to learn strategies to manage potentially difficult behaviour and obesity. Despite variable intellectual and physical abilities, it must be remembered that a cognitive disability, hunger and reduced satiety remain with the person with PWS throughout their lives. The ability to make appropriate independent decisions regarding energy intake and choices of life rarely eventuates, even as the child with PWS becomes an adult. It will always remain the responsibility of their parent or carer to make healthy choices and maintain firm boundaries around food, money, exercise and lifestyle.

Energy needs
Throughout this article the term "energy" refers to the kilocalories - kcal (or kilojoules - kJ) obtained from the food and beverages consumed.

Adults with PWS still need a limited energy intake - of about 60% of the daily recommended energy intake for non-PWS adults. Remember the caloric intake guide: 29 kJ *or* 7/kcal per centimetre of height (75.5 kJ *or* 18 kcal/inch) if they need to lose weight or (33.5-46 kJ *or* 8-11 kcal per centimetre of height (84-117.6 kJ *or* 20-28 kcal/inch) for weight maintenance. This does not change and applies to people with PWS of all ages.

How is this energy intake achieved?
Restricting energy consumed requires a consistent balance of meals and snacks. This means all extra food sources need to remain inaccessible to the person with PWS. Kitchens, pantries, refrigerators, food cupboards, fruit bowls, garbage bins, shops, relatives' homes, friends' homes, neighbours' homes, work places, day programmes, food courts, shops,

church functions, sporting events and independent travel all provide the opportunity for "extra" energy intake. Most people with PWS will take food or money to buy food, or eat leftover food or scraps from garbage bins, if given the opportunity. This is because they are constantly thinking about food and not satisfied by the amount they consume. This is a trait of PWS, not a personality trait of the person with PWS. A consistently secure environment coupled with psychological 'food security' is essential to achieve emotional and behavioural stability.

People with PWS certainly need choice and variety in the food they eat and what they drink but the calorie content must be determined according to their needs. The more constant the restrictions are, the better the person with PWS will adapt to the restrictions. Also, it is extremely important to maintain restrictions once they are in place. This is not only to maintain a healthy weight but also to avoid over-consumption that could lead to severe gastric health problems.

Calorie Bargaining

This practice involves reducing the usual energy intake for a few days prior to a party or similar irregular or special event, where higher energy food will be consumed. It is a useful strategy that enables greater "socialising" while managing the extra calories to avoid weight gain. For example: reduce the quantity of meat or remove the carbohydrate from the evening meal for 2-3 days prior to an event to allow for the extra calories consumed at the party. Even if the reduction in calories does not equate exactly to what is consumed at the event – the strategy implies an energy control. Offer the person the choice to attend the event and "calorie bargain" or avoid the event. He/she may choose not to go to the event so they don't have to reduce their usual intake. Calorie bargaining gives them a choice, while retaining a constant energy input. It also helps to keep in place "mental security". It requires prior explanation and discussion with your person with PWS and does not suit everyone.

Whether you practise calorie bargaining or not, remember, it is always best if energy consumed out-of-home is discussed, planned for and chosen, before the event, wherever possible.

A parent writes: *in our home we follow the practice of "food or portion bargaining". Our daughter with PWS eats what we eat and we concentrate on low fat, low carbohydrate meals with lots of vegetables and adequate fruit. When our daughter asks for another serving of food – she is happy with my response of "no, I will keep it for you to have tomorrow." When we eat out, if possible, we discuss what food will be served and she is reminded that "I'll dish it up for you." She has a small portion of dessert, if it is served, and if she asks for more our strategy is to ask the host for a portion to take home with us for her to have the next day or later in the week, as a treat.*
She is also prepared to reduce her next meal that follows the outing meal.

The above strategies work well as a result of consistently practising them in the same way each time, so trust is established between the person with PWS and his/her family member. In many cases something that is stored for later, is not even asked for again.

Another parent writes: *when we eat out our "rule" is that she will ask for a take home box when she orders her food, and then I put half of the food into the box before she starts to eat. She knows that the other half will go home with us and she can have it the next night for dinner. For her, this is like eating out two nights in a row. We have not had any problems with this and it works beautifully for her.*

People outside the family unit also need to know about PWS so they can support and assist you in the healthy strategies you practise for your person with PWS. When people you have

contact with are well-informed they can often feel less apprehensive about being with the person with PWS. The knowledge can empower them to understand the nature of PWS a little better.

Exercise – energy output

All people with PWS require regular effective exercise, as much as energy restriction, throughout their lives. People with PWS have more fat and less muscle. Their muscles have reduced tone and are weaker, which reduces joint stability, agility and bone strength. Exercise is the key to weight management, cardio-respiratory fitness, muscle strength and joint stability, bone health, mental health and the prevention of diabetes for all people but so important for people with PWS. Exercise also provides a distraction from focusing on food, develops emotional well-being, boosts self esteem and improves behaviour.

If your person with PWS is not exercising - now is the time for them to start. It is never too late! If they are only able to walk short distances then this is their starting point. Walking 10 minutes twice a day is a great start! The secret is to manage their routine to include some physical activity every day. The aim is to eventually have them doing 30-40 minutes of aerobic type exercise 5-6 days per week. Examples of exercise include: walking, swimming, cycling, dancing, rowing and similar continual exercise. When first introducing a new activity or exercise, a small reward for the completion of a planned exercise can be a good incentive. A planned meal or snack can be used as a routine reward for completed exercise. Exercising before eating or waiting for one hour after eating is recommended except when the person is known to have delayed gastric emptying. Then it's best to exercise immediately after eating to assist digestion. When introducing exercise explain that as the exercise becomes easy the intensity will gradually be increased to make them stronger. To improve fitness, the intensity or duration of the exercise should be increased very gradually. Also remember to warm-up and cool-down. Exercising in the morning has additional benefits: increased alertness, it's done and out of the way, the person is not as tired as at the end of the day.

Incidental or purposeful activity is also important. Household chores like making the bed, hanging out washing, collecting mail and helping with domestic responsibilities not only keeps them active but may also improve their self esteem as you entrust them with family jobs. Adults like to be needed and given responsibilities to prove their ability. Mastery and praise can work wonders!

Where possible, it's even better if family members can join in the exercise so it is seen to be good for everyone, not just the person with PWS. Once exercise is a regular part of their day, less encouragement is required as it becomes a part of their consistent routine.

Outdoor activities are a wonderful way to combine energy expenditure and the many benefits gained from being outside. Sunshine is the essential source of Vitamin D! Walking on different terrains or surfaces also increases muscle strength. Taking in the sights and sounds of nature when in parks, forests or country areas can be educational and stimulating to the senses and mind.

Walking is one of the best activities for sensory motor stimulation in adults with PWS!

A parent writes: *for my son walking outdoors is a noticeable anti-depressant and mental health aid. Getting sunlight into the eyes, moving around other people, deciding which path to take, hearing birds and seeing insects, having something different to talk about makes being active outdoors all worthwhile. Where possible, involve others in the life of your person with PWS. Positive friends, neighbours and other family members enrich their lives. A simple "hello" or smile or "how are you*

going?" are positive interactions for people with PWS, who generally have difficulties with friendships and community socialisation.

Encourage as wide a range of interests as possible!

Each person will naturally be inclined towards certain interests but "expanding their horizons," when possible and appropriate, has benefits. Encourage reading, writing, craft activities, interest in world events and different sports. Just be mindful of the availability of extra calories at any event attended and discuss the management of this beforehand. Being employed in an active way takes up another opportunity to expend energy in a way that is "part of the working day" rather than an uncomfortable chore. If they are being paid to be active this is even better!

A parent writes: *the only thing that really has worked for our daughter regarding exercise and sticking to it, has been a junk-mail run that is she currently doing. It takes her two hours, and she gets paid a very minimal amount (but anything's better than nothing). Being paid for a "job" has given her not only the encouragement to stick at it, but the ability to say that, yes, she has a job! Amazingly, she goes out in all weathers. Amazingly, she has stuck with it, and amazingly, she has lost 10 kg in 5 months!*

Dressing appropriately

We talk about "dressing for the weather" but must remember that people with PWS do not have this ability. Parents and caregivers are their weather guides and need to encourage their people with PWS to dress appropriately for the weather – regarding clothes and shoes. People with PWS can suffer from hypothermia and hyperthermia when not dressed accordingly for the temperature.

When your person with PWS is exercising or being regularly active, be aware of any injury or pain that may cause greater problems in the future and reduce their ability to exercise. Skin picked sores on the legs or stomach may be exacerbated during exercise if they are rubbed by clothing. They may need to be covered and protected to prevent infections developing. Wearing appropriate shoes for exercise may need to be pre-negotiated. When someone with PWS has favourite shoes and is not keen to wear "joggers" these may prevent the person from exercising safely or adequately. Appropriate exercise shoes don't need to be expensive but do need to be supportive and protective, especially if the person had diabetes. A good shoe for exercising in:

1) has a flexible sole and a good arch support
2) allows for expansion of the feet as they warm up (laces are better than velcro straps)
3) has a good heel support

Be aware as your person with PWS settles into a regular exercise routine
- things may change:
They may have more energy! They may be happier! They may become healthier!

It's never too late to introduce exercise to your person with PWS. It may take some persistence on your part to encourage regular exercise, but if you can add it to their daily routine and make it an enjoyable experience or one that is rewarded in some way the benefits will certainly out way the initial difficulties. Exercise is not an optional extra for people with PWS. It is as important as a restricted energy intake.
A positive experience for all involved can lead to positive results for all involved.

It is exercise alone that supports the spirits and keeps the mind in vigour - Marcus Tullius Cicero

Please note: Parents who would like to know more about *severe gastric health problems* and *delayed gastric emptying* are welcome to contact the chairperson for an article on the subject. Or, search for the article GASTROPARESIS: THE NEWEST THREAT in the June 2013, newsletter.

International PWS Conference, Cambridge: Tiina Silvast, Lesley Robertson and Rika du Plooy, all parents with adult children with PWS and involved in the Famcare project of IPWSO. Georgina Loughnan (right) is the co-ordinator of the project. Georgina is a physiotherapist at the Metabolism & Obesity Services &the Prader-Willi Syndrome Clinic, Camperdown NSW, Australia.

PWS DEATHS-THE FEARS-THE FACTS

By Janalee Heinemann, M.S.W. PWSA (USA) Director of Research & Medical Affairs
Permission is granted by PWSA (USA) and *The Gathered View* to publish this article.
The Gathered View (ISSN 1077-9965), September-October 2013

When word spreads throughout the PWS community about the death of a child or adult with PWS, I often get calls or reports of concern from parents wanting to know the cause of death. I appreciate that not knowing is worse than knowing. Sometimes we can give out more information than others, but no matter what we as an organization say or do, word goes out quickly on the Internet through Facebook and email support groups, etc. So I thought it might be helpful to give a broad perspective.

The reality is that most PWS deaths are still obesity-related. Due to the weak muscle tone, our children/adults who have PWS may even be more at risk from obesity-related complications at a lesser weight than the general population. (The average weight at death for individuals with PWS who appeared to die from obesity-related complications is 257 pounds.) Right-sided heart failure, respiratory problems and diabetes all can happen due to the obesity which makes other illnesses or surgeries more of a risk.

As for the non-obesity related deaths, in the little ones the deaths are typically due to respiratory complications. For an older child or adult, there are a variety of reasons – from

choking and GI perforation to accidents. At PWSA (USA) we do have a committee of doctors that studies the cause of the deaths, and we put out an alert if we see a reasonable risk for which we can warn parents and caregivers. Of course, as a parent you need to keep yourself armed with the Medical Alert booklet at all times and articles from our medical section of the PWSA (USA) website as needed. Every day we are emailing or faxing articles to hospitals, physicians, and psychiatrists at the request of parents.
Our support goes beyond death through bereavement support calls and booklets.
God didn't promise days without pain, laughter without sorrow, sun without rain, but He did promise strength for the day, comfort for the tears, and light for the way.

TIP OF THE WEEK

From: Website of Latham Centres www.lathamcenters.org look for *Latest Blog Posts*

Latham Centres located in Brewster and other towns on Cape Cod and South-eastern Massachusetts, compassionately and creatively helps children and adults with complex special needs, including Prader-Willi Syndrome, to lead meaningful, abundant lives.

How did you explain to your child that he or she is a person with PWS? On what age did you start and how did you handle this issue? Please share your journey with the rest of us

We received several requests for a tip of the week that addresses how to explain PWS to your child. This is an important part of not only your child's growth and understanding of the syndrome, but for yours. PWS is a journey, it is challenging and frightening at times and at other times it is joyous and rewarding. You did not ask to be the parent of a child with PWS but you wouldn't give them back for all of the money in the world! Parents and other family members go through a range of emotions when they receive the diagnoses and you spend years educating doctors, family members and teachers but we sometimes forget the most important person who needs to be educated - the child themselves. There is no right age to start talking to your child about the syndrome as long as you keep in mind your child's ability to process information. You know your child and what information they can understand. Keep it simple and avoid words such as "problem" or "disability". Labels are hard for anyone but especially hurtful to a child.

Emphasize what your child can do and avoid telling him or her that they will never be able to do something, instead talk about what you know they will be able to do. Often when your child meets other kids with PWS it can be eye opening for them. Even if your child has not expressed feeling lonely or different, meeting other kids with PWS can be an opportunity to feel accepted. Most importantly, let the conversation be open and have it as often as your child wants or needs. Some families read stories such as "Michael and Marie" or listen to "I have Prader-Willi but my name's not Willi" every night. Others just answer questions as they come up. No one knows your child better than you do, you are the expert. Trust your judgment and always remember that we are here to help if you need advice or guidance.

Patrice Carroll - Manager of PWS Services

We hope you find the newsletter of the PWSA (SA) interesting and helpful.
If you are not a member of PWSA (SA) please consider a donation to the association.
It will be a great help in supporting families country wide.

WHAT IS A DISABILITY?

From the Department of Woman, Children and People with Disabilities
Website: www.dwcpd.gov.za

What is a disability?
South Africa aligns itself with the definition of disability as articulated in the UN Convention on the Rights of Persons with Disabilities (CRPD), as "an evolving concept resulting from the interaction between persons with impairments and attitudinal and environmental barriers that hinders their full and effective participation in society on an equal basis with others". From: DWCPD Concept Document, Second Draft (June 2013)

Also explained as: *it is not the impairment per se which disables an individual, but the interaction between the person with the impairment and the environment which causes disability when this interaction is negative.*

What is a disability? A child-friendly definition
The Rights of People with Disabilities Unit in the DWCPD has just completed a global brainstorming exercise for UNICEF to develop a child-friendly definition of disability (targeting 10 year olds). This exercise goes to the heart of the new conceptualisation of disability as a social construct. (Information received from the Department of Women, Children and People with Disabilities 6 September 2013).

This is how you could explain to your children what disability is!
All children are different, but this is what makes children so interesting. Some are tall, some are small, some are black, some are white, some have disabilities, and children speak all different kind of languages.

Children with disabilities are children like all other children, but they do things a bit differently.
A child who cannot see, for example read by using her fingers to read dotted letters called Braille.
A child, who cannot hear or speak, uses his hands to sign the words and sentences. Some children move around with crutches, special shoes or wheelchairs, as it is difficult for them to walk and run. Some children take a bit longer to understand, but if we give them time and use simple language, they can learn and do things with other children.
If we remember that each one of us is different, we all will find different ways of playing together.
So it is important for us to find playgrounds where wheelchairs can move around easily. If we all learn to use our hands when we speak, we can all understand each other. And if we explain to children who cannot see or understand what is happening around them and what the rules of our games are, they can also play with us.

3 DECEMBER 2013 – THE INTERNATIONAL DAY FOR PERSONS WITH DISABILITIES

South Africa celebrates National Disability Rights Awareness Month annually between 3 November and 3 December. The month will be celebrated under the theme: "Break barriers, open doors: for an inclusive society for all." 3 December, which is the International Day of Persons with Disabilities, is also celebrated in South Africa as National Disability Rights Awareness Day.

IMPORTANT EDUCATIONAL MATERIAL

Undiagnosed and unmanaged, Prader-Willi Syndrome causes morbid obesity. There are, however, treatment and management strategies that save lives and improve the quality of life of all who are impacted by PWS.

DVD: FOOD, BEHAVIOUR AND BEYOND PWSA (USA)

This comprehensive DVD, a joint project of PWSA (USA) and IPWSO, is being used around the USA and overseas to train staff working with persons with PWS. It is an excellent learning tool for parents. It addresses *Nutritional Basics, Food and Behaviour, The Behaviour Toolbox, Cognitive and Behavioural Traits and To Medicate or Not to Medicate.* Parents will be able to review sections over and over again as needed and share with family, teachers and babysitters. Having years of hands-on intensive experience, Dr Gourash and Dr Forster's lectures on the management of PWS have received rave reviews from both parents and providers. Members, parents and other interested people are welcome to order above mentioned DVD (free of charge) from the PWSA (SA)
Please contact Wilna Basson at 012 991 3399 or e-mail: bassons@iafrica.com

DVD: UNDERSTANDING THE STUDENT WITH PRADER-WILLI SYNDROME PWSA (USA)

This DVD provides teachers with an introduction and overview of the issues associated with PWS and to demonstrate and described pragmatic strategies that school staff can use in supporting the success of a student with PWS in the classroom. Done from an USA view, for upper grade and lower grade students, but contains valuable strategies which can inspire school staff to create their own successful strategies.
Please contact Wilna Basson at 012 991 3399 or e-mail: bassons@iafrica.com

A LETTER FROM RONèL VAN DER RYST

On behalf of the Lettie Fouchè School I wish to thank you for your informative newsletters. It helps our teachers to understand the learners with Prader-Willi syndrome much better and to view them differently.

Ronèl is for 27 years on the staff of a school for Learners with Special Educational Needs in Bloemfontein. She is part of their Support Base Team. In the 27 years at the school, she came across four children with PWS.

Our school accommodates multi-disabled learners. We have a professional nurse, a social worker, two physiotherapists, two occupational therapists, twenty one teachers, hostel staff and assistants on our staff. The disabilities of the learners include the following: Down syndrome and Prader-Willi syndrome, cerebral palsies, e.g. hemiplegics and diplegics, autism, physical disabilities, e.g. amputations, ADHD, and also disabilities caused by diseases, like juvenile rheumatoid arthritis. We also have learners with partial sight and hearing disorders. All the learners in our school have severe intellectual barriers to learning.

We are learning considerably from your newsletters, especially from the new research contained within. We divulge all information to our teachers, therapists and hostel staff. New information is often discussed at the meetings of our Support Base Team. This multi-disciplinary team endeavours to find solutions to problems in our school or at home and it

gives additional assistance to a learner who behaves aggressively or struggles with his or her work.

The DVD, *Food, Behaviour and Beyond,* about the eating program for individuals with PWS was extremely helpful. We can use this information even for other disabilities.

We encourage other schools and institutions to study the newsletters carefully and to share information. In this way everyone who works with learners with PWS can be empowered to do the best for the child and parent.

Kind regards
Ronèl van der Ryst

IPWSO NEWS

PWSA (SA) wants to congratulate PWSA (UK) for hosting an outstanding International PWS Conference in Cambridge, UK, in July 2013. They hosted delegates from over 30 countries and a high light was the wonderful celebration supper with Ceilidh Scottish dancing.

Delegates from 30 countries enjoy the Celebration Supper in the marquee at the Holiday Inn

The Auditorium at the Fitzwilliam College, Cambridge

9TH INTERNATIONAL PWS CONFERENCE, 2016

Keegan Johnson the Executive Director, of the Foundation for Prader-Willi Research put a bid in for FPWR Canada to host the next international conference and they won. The result was that the next international conference will be held in Toronto, Canada in three years time. FPWR is well known and has provided more than $3,000,000 in research support since 2003, with more than 60 research projects funded to date. For more info on FPWR and the research they support please visit www.fpwr.org

PLEASE VISIT IPWSO'S BLOG AND BECOME A FRIEND OF IPWSO.

Read the different stories as well as the news and views of IPWSO. Also on the Blog a review, edited by Jackie Waters and Suzanne Cassidy, of topics presented at the PWS International Conference in the UK. You are welcome to communicate directly with the

Communications Director of IPWSO, Linda Thornton. She will welcome your comments. http://ipwso.blogspot.com

PHOTO GALLERY

The AGM was held on Sunday 25 August 2013 at the Vriendekring Bowls Club, Pretoria

It was a sunny day and the children enjoyed themselves

Parents socialised and get to know each other

Lunch together is always an enjoyable occasion

Two couples with adult children: Janet Drysdale, Dave and Joey Edwards, Doug Drysdale

REPORT ON HUIS HENRI

Together we CAN make a difference! Written by Liezl Vlok

Just a few words to bring everyone up to date with the progress made with Huis Henri. After I attended the AGM of the PWSA (SA) on 25 August 2013 in Pretoria, the Henri Warnich Foundation decided to appoint my mother (Marieke Warnich) to help with the research of existing residential care in the Western Cape. On our list were more than 30 places, mostly in and around Cape Town.

We then realised and came to the conclusion that it is necessary to have the HOME close to Oudtshoorn because that is where we live. My mother and I will be responsible and we need to be close to give the necessary assistance and support to the staff and also to the adults with PWS living in the house. We heard about the *Up with Down's* school and hostel for children with Down syndrome in George, who plan to start a home for adults. We contacted Janet Seegmuller, who founded the school 16 years ago and who is still the overall manager of the school, hostel and all the fundraising projects. They need 10 adults with special needs, before they can start the home. At that stage they already had 5 and were very keen for us to get on board with 5 adults with PWS. We had a lengthy discussion and our proposal was submitted to their Board of Trustees. I left information about PWS and also two DVD's to give Janet a better understanding of PWS. www.upwithdowns.co.za

PWSA (SA) has no interests in the Henri Warnich Foundation except that the association supports the initiative of the Foundation to start a HOME for adults with PWS. Liezl Vlok is a member of the PWSA (SA).

A week later we had another meeting and Janet told me that after going through all the information her biggest concern was the management of food. The reason being that they are planning to run a B&B and a Coffee Shop from the Home to generate income and that the residents would also be working there. All the jobs that they have lined up for the adults in town include working with food. At this point it became very clear to us that this setup won't be suitable for adults with PWS and that we are actually left with only one option – and that is to start our own Home exclusively for adults with PWS.

We started to look at houses in Oudtshoorn to rent, with the option to buy.
Oudtshoorn is the logical choice for us. Why?

1. My mother and I live here and will be available 24 hours if needed.
2. Oudtshoorn has a Medic Clinic and more than enough medical expertise.
3. An international airport is only 40 minutes drive away in George.
4. Oudtshoorn already has a school for children with special needs and an institution for adults (Eljada) with special needs. The community of Oudtshoorn is already educated about people with special needs.

We plan to take 5, maximum 6, adults with PWS (18 years and older). My son Ruan, turning 18 in January, will be one of them. We looked for a special place which will satisfy all our needs - enough bedrooms, big living areas, must be fenced, swimming pool and enough outside space for a vegetable and herb garden. The vision is to establish a *home away from home*, we would like to run it as one big family and not as an institution, hence the small numbers. The adults with PWS days will be structured in such a way that there will be time for work, exercise, craft work and skills training. The plan is to appoint and train a couple who will live in with a live in assistant. After looking at quite a few houses we found the perfect house!! We are still working on all the detail concerning the financing, cost and training of the staff. Much homework has already been done, to much to mention here. There are still unanswered questions to be resolved.

Please note: The "perfect house" that we found is in the market to be sold. Currently the house is rented by the same family for the last four years. Their contract is due for renewal by the end of November 2013. The owner needs to have an answer from us before or at the end of November if we want to rent with the option to buy, or not.

Here is where you come in: If you have a serious need for a home for your adult child with PWS, please contact me. We (me and my family who started the Henri Warnich Foundation, solely for the purpose of establishing a Home for adults with PWS) plan to open the doors of *Huis Henri* by 1 June 2014. The bottom line is in order for us to get the process in motion we will urgently need 5 or 6 adults with PWS wanting to be living in the house. We need to know how many parents are prepared to make a commitment to this venture. **We will not be able to start *Huis Henri* if parents are not prepared to get on board.**

We are very excited and motivated to make a success of this dream we have. HUIS HENRI will be a house that will give your child with PWS a home for the rest of his/her life, where he/she will be cared for with much love and understanding, where they will be able to enjoy friendships, healthy meals and make a valuable contribution to the community. **BUT** we will not be able to do this alone!

Contact me either by cell phone or email. If we have enough parents who want to know more and seriously consider getting involved, we plan to meet you on **Friday, 22 November 2013** here in Oudtshoorn. We will give you all the detail and you will have the opportunity to visit the house that we think is the future HUIS HENRI. If you are not able to come to Oudtshoorn, but still want to get involved we can Skype with you during the meeting.
I am looking forward to hear from you.

Liezl Vlok
072 243 5251 or info@mpafa.com

THE PRADER-WILLI SYNDROME ASSOCIATION OF SOUTH AFRICA

The Prader-Willi Syndrome Association (SA) is a support group and was established by a small group of parents in March 1990

FREQUENTLY ASKED QUESTIONS ABOUT PRADER-WILLI SYNDROME

From the website www.pwsausa.org

Q: What is Prader-Willi syndrome (PWS)?
A: PWS is a complex genetic disorder that typically causes low muscle tone, short stature, incomplete sexual development, cognitive disabilities, problem behaviours, and a chronic feeling of hunger that can lead to excessive eating and life-threatening obesity.

Q: Is PWS inherited?
A: Most cases of PWS are attributed to a spontaneous genetic error that occurs at or near the time of conception for unknown reasons. In a very small percentage of cases (2 percent or less), a genetic mutation that does not affect the parent is passed on to the child, and in these families more than one child may be affected. A PWS-like disorder can also be acquired after birth if the hypothalamic portion of the brain is damaged through injury or surgery. All families with a child diagnosed with PWS should see a geneticist for genetic counselling in order to fully understand their chances of having another child with PWS.

Q: How common is PWS?
A: It is estimated that one in 12,000 to 15,000 people has PWS. Although considered a "rare" disorder, Prader-Willi syndrome is one of the most common conditions seen in genetics

clinics and is *the* most common genetic cause of obesity that has been identified. PWS is found in people of both sexes and all races.

Q: How is PWS diagnosed?
A: Suspicion of the diagnosis is first assessed clinically and then confirmed by specialized genetic testing on a blood sample. The bottom line: It is both possible and important to confirm the diagnosis of PWS through genetic testing and to find out whether your family carries an increased risk of recurrence.

Q: What is known about the genetic abnormality?
A: Basically, the occurrence of PWS is due to lack of several genes on one of an individual's two chromosome 15s— the one normally contributed by the father. In the majority of cases, there is a *deletion*—the critical genes are somehow lost from the chromosome. In most of the remaining cases, the entire chromosome from the father is missing and there are instead two chromosome 15s from the mother (*uniparental disomy*). The critical paternal genes lacking in people with PWS have a role in the regulation of appetite. This is an area of active research in a number of laboratories around the world, since understanding this defect may be very helpful not only to those with PWS but to understanding obesity in otherwise normal people.

Q: What causes the appetite and obesity problems in PWS?
A: People with PWS have a flaw in the hypothalamus part of their brain, which normally registers feelings of hunger and satiety. While the problem is not yet fully understood, it is apparent that people with this flaw never feel full; they have a continuous urge to eat that they cannot learn to control. To compound this problem, people with PWS need less food than their peers without the syndrome because their bodies have less muscle and tend to burn fewer calories.

Q: Does the overeating associated with PWS begin at birth?
A: No. In fact, newborns with PWS often cannot get enough nourishment because low muscle tone impairs their sucking ability. Many require special feeding techniques or tube feeding for several months after birth, until muscle control improves. Sometime in the following years, usually before school age, children with PWS develop an intense interest in food and can quickly gain excess weight if calories are not restricted.

Q: Do diet medications work for the appetite problem in PWS?
A: Unfortunately, no appetite suppressant has worked consistently for people with PWS. Most require an extremely low-calorie diet all their lives and must have their environment designed so that they have very limited access to food. For example, many families have to lock the kitchen or the cabinets and refrigerator. As adults, most affected individuals can control their weight best in a group home designed specifically for people with PWS, where food access can be restricted without interfering with the rights of those who don't need such restriction.

Q: What kinds of behaviour problems do people with PWS have?
A: In addition to their involuntary focus on food, people with PWS tend to have obsessive/compulsive behaviours that are not related to food, such as repetitive thoughts and verbalizations, collecting and hoarding of possessions, picking at skin irritations, and a strong need for routine and predictability. Frustration or changes in plans can easily set off a loss of emotional control in someone with PWS, ranging from tears to temper tantrums to physical aggression. While psychotropic medications can help some individuals, the essential

strategies for minimizing difficult behaviours in PWS are careful structuring of the person's environment and consistent use of positive behaviour management and supports.

Q: Does early diagnosis help?
A: While there is no medical prevention or cure, early diagnosis of Prader-Willi syndrome gives parents time to learn about and prepare for the challenges that lie ahead and to establish family routines that will support their child's diet and behaviour needs from the start. Knowing the cause of their child's developmental delays can facilitate a family's access to important early intervention services and may help program staff identify areas of specific need or risk. Additionally, a diagnosis of PWS opens the doors to a network of information and support from professionals and other families who are dealing with the syndrome.

Q: What does the future hold for people with PWS?
A: With help, people with PWS can expect to accomplish many of the things their "normal" peers do—complete school, achieve in their outside areas of interest, be successfully employed, even move away from their family home. They do, however, need a significant amount of support from their families and from school, work, and residential service providers to both achieve these goals and avoid obesity and the serious health consequences that accompany it. Even those with IQs in the normal range need lifelong diet supervision and protection from food availability.
Although in the past many people with PWS died in adolescence or young adulthood, prevention of obesity can enable those with the syndrome to live a normal lifespan. New medications, including psychotropic drugs and synthetic growth hormone, are already improving the quality of life for some people with PWS. Ongoing research offers the hope of new discoveries that will enable people affected by this unusual condition to live more independent lives.

Contact a parent support group. Parents of children with the syndrome have experience and understanding of many of the challenges you will face. It implies that you need never face the future alone; there is always somebody who can listen and who can share both in your success and anxieties.

WOULD YOU LIKE TO JOIN THE PWSA (SA)?

Please contact:
Chairperson: chairperson@praderwilli.org.za, tel: 012 344 0241 or
Secretary: secretary@praderwilli.org.za
Visit our website: www.praderwilli.org.za

COST OF MEMBERSHIP

Registration fee R50.00 (once-off payment)
Annual membership fee R200. R220 members outside RSA.
You are welcome to make a direct deposit into the savings account.
Please ensure that your surname is included as reference on the deposit slip.
Please forward proof of payment to the treasurer.
Fax: 012 344 0241

BANK DETAILS OF SAVINGS ACCOUNT

PRADER-WILLI SYNDROME ASSOCIATION (SA)
ABSA BROOKLYN, PRETORIA
Branch number 632005
Acc. no. 11 364 1800
Reference: Your SURNAME

ACKNOWLEDGEMENTS 2013

PWSA (SA) would like to acknowledge with gratitude the goodwill and support of:

Members for prompt payment of 2013 membership fees
afrihost.com for hosting the Association's website
Dawid Basson the webmaster of the website and also responsible for Facebook.
Johan and Elmaré Mostert for the annually preparation of the financial statements
Jan Els, chartered accountant for auditing the income and expense accounts
Elsa Volschenk for her involvement in assisting with the newsletter
Karin Clarke and Magdaleen Kloppers for the birthday cards
Dr Engela Honey, the medical advisor of the Association, who is always available
Wilna Basson for taking care of the Library and educational material
IPWSO for continuously forward information regarding important PWS issues
Famcare committee for valuable educational information

THE CO-WORKERS AND ALL THOSE WHO CONTRIBUTE TO *PEOPLE WITH STRENGTH*

PLEASE CONTRIBUTE AND HELP TO MAKE A DIFFERENCE!

PWSA (SA) is registered as a non-profit organisation (No. 035-837 NPO) as well as a public benefit organisation (PBO Exemption no.930 016 853).
The PBO registration benefits donors and all donations made to PWSA (SA) are exempt from income tax. We will issue an official certificate for donations of R100.00 or more.
You are welcome to make a direct deposit. Please ensure that your surname and cell number are included as reference.

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