People With Strength

Newsletter for parents by parents

Volume 17 Issue 1 **FOR RELATIVES & FRIENDS** March 2014

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Courtesy of PWSA (UK) - newsletter Issue number 117, October 2013

Relatives and friends - do not underestimate how important your support is.

Info in this newsletter is to help you on the way

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VAN DIE VOORSITTER

Liewe Lesers

Dit is ons eerste nuusbrief vir 2014 en soos die voorblad aandui is dit gerig op ons familie en vriende. Die doel van hierdie nuusbrief is om familie en vriende in te lig oor die Prader-Willi-sindroom (PWS) en hulle te help om effektief deel te word van ‘n netwerk wat ondersteuning aan ouers bied. Die kind of volwassene met PWS word groot in ‘n sosiale omgewing en daarom is dit belangrik om die persoon te verstaan en om ook begrip vir die behoeftes van die ouers te hê.

Kos speel ‘n belangrike rol in die wêreld van die kind en volwassene met PWS. Die realiteit is dat kos altyd vrylik beskibaar is. ’n Beheerde omgewing met beperkte toegang tot kos is uiters belangrik vir die welstand van die persoon met PWS. Dit mag selfs beteken dat kos weggesluit moet word. Wanneer dit nie gebeur nie, kan dit lei tot ernstige vetsug en gevolglike siektetoestande wat tot die dood kan lei.

Ek doen ‘n beroep op almal wat met ‘n kind of volwassene met PWS kontak het, om die inhoud van hierdie nuusbrief ter harte te neem. Dit mag help om te weet dat die 15de chromosoom, wat in die geval van die Prader-Willi-sindroom geaffekteer is, lei tot die wanfunksionering van die hipothalamus. Die spesifieke gedrag wat ons dus by die persoon met PWS waarneem, is as gevolg van die wanfunksionering van ‘n belangrike deel in die brein. Elders in die nuusbrief word lesersvriendelike inligting oor die sindroom gegee.

Hoe kan jy dus betrokke wees? Lees gerus hoe jy moet optree wanneer ouers met ‘n kind met PWS kom kuier. Met tye soos kersfees, verjaarsdae en alle vorme van sosiale verkeer is eetgoed altyd vrylik bekikbaar. Sulke geleenthede kan vir ouers baie spanning inhou en dikwels is dit vir die ouer makliker om die situasie bloot te vermy. ‘n Skoolvakansie is op hande, belangrike wenke word gegee oor hoe om vakansietye te benader.

Lees verder oor ‘n oupa se gevoelens en wat hy doen om sy kinders en kleinkinders te ondersteun.

Hoe kan ouers ook die ander kinders in die huisgesin by die spesiale behoeftes van die kind met PWS betrek? So dikwels voel die ander kinders dat hulle nie regverdig behandel word nie. Linda Thornton gee raad en benadruk dat dit ook belangrik is dat die vriende van die ander kinders oor PWS ingelig moet word.

Ouers word versoek om hierdie nuusbrief aan alles betrokkenes te versprei. Deel hierdie inligting met ander en moenie huiwer om hulp te vra nie. Daar is geen waarde daarin om die werklikheid van die sindroom te ignoreer nie – dit sal nie weggaan nie. Begin vroegtydig en bou op ‘n oop- en eerlike verhouding met almal om jou.

Kate Beaver gee interessante inligting oor die kommunikasieproses by kinders met PWS. Hulle het tyd nodig om inligting te prosesseer en as ouers en ander dit verstaan, kan dit hulle baie irritasie en ongeduld spaar. My eie volwasse dogter sal vra om net eers een opdrag uit te voer, voordat ek ‘n volgende opdrag gee. Sy het ‘n baie goeie geheue, maar gee nie maklik uitvoering aan ‘n klomp opdragte nie.

Latham Centers gee op hulle webwerf verskeie praktiese wenke. Lees die wenk wat gegee word oor hoe ouers moeilike vrae wat 'n kind met PWS somtyds vra, kan beantwoord. Dit is gewoonlik sensitiewe vrae oor hulself en ons wil hulle nie met antwoorde seermaak nie.

Navorsers wêreldwyd werk hard om die kompleksiteit van die Prader-Willi-sindroom te verstaan. Navorsing in die VSA word aktief deur die PWSA (USA) en die Foundation of Prader-Willi Research (FPWR) geinisieer en befonds. Navorsingsmoontlikhede word ondersoek en tans word terapeutiese middele wat die kwaliteit van lewe van die persoon met PWS sal verbeter, nagevors. Een so 'n middel waar opwindende resultate verkry is, is Beloranib. Hierdie middel het liggaamsvet verminder en kosverwante gedrag by die persoon met PWS het verbeter. Meer oor hierdie navorsing deur Zafgen in die nuusbrief.

Cara Lee Klootwyk het met haar 40ste verjaarsdag die jaar op 'n hoë noot begin. Baie geluk aan Cara en lees gerus hoe sy met ondersteuning, gewig verloor het. Die gevolg is dat sy goeie gesondheid geniet.

Die Famcare komitee van IPWSO het 'n volgende artikel gereed wat algemene gesondheidsprobleme by die persoon met PWS uitlig. Alhoewel die werk van hierdie komitee gerig is op ouers van volwassenes met PWS wat in die huis woon, kan ouers van jonger kinders ook van hierdie inligting kennis neem.

Neem ook asseblief kennis van die volgende:

- 'n Vriendelike uitnodiging……wie gaan vir die Junie uitgawe 'n stukkie oor hulle gesin skryf? Dit kan 'n ouer wees, broer of suster of dalk 'n oupa of ouma.
- Besoek van Dr Janice Foster aan die Wes-Kaap op Vrydag 3 Oktober 2014.
- Onder IPWSO News - besoek gerus die blog van IPWSO. 'n Ma skryf oor die verloop van haar seun se kinderpartytjie sonder die tradisionele verjaardagkoek
- In die foto-album is daar drie foto's wat elk 'n storie vertel
- Vincent en Portia Moatshe het Januarie 2014 by PWSV (SA) aangesluit.
- Hierdie nuusbrief is ook elektronies in A4-formaat beskikbaar.

Dit is dan ook met hartseer dat ons verneem het van die afsterwe van Sammy Robbertze en Werner van Zyl. Ons innige meegevoel aan die families wat deur die dood van hierdie twee jongmense geraak is.

Tot ons weer gesels wanneer die volgende nuusbrief einde Junie 2014 verskyn.

Goeie wense vir die jaar wat voorlê,

Rika du Plooy.

Innige meegevoel

Innige meegevoel word namens die lede van PWSV (SA) aan Minke Robbertze en familie oorgedra met die afsterwe van Sammy. Sammy is Augustus 2013 op die ouderdom van 28 jaar oorlede.

Ons innige meegevoel gaan ook aan Elize van Zyl en familie met die heengaan van Werner. Hy is 27 Desember 2013 op die ouderdom van 21 jaar oorlede.

Condolences

The PWSA (SA) announces with great sadness the passing of Sammy Robbertze.
She passed away in August 2013 at the age of 28 years.
Our deepest condolences go to Minke Robbertze and family.

Our deepest condolences also go to Elize van Zyl with the passing of her son Werner. Werner passed away on 27 December 2013 at the age of 21 years.

FROM THE CHAIRPERSON

Dear Readers

This is the first newsletter for 2014. As the front cover indicates this newsletter is aimed at families and friends. We want to inform them about the Prader-Willi syndrome (PWS) and help them to become part of a network to support parents. The child or adult with PWS is part of our daily life and it is therefore important to not only understand the person with PWS but also to show an understanding for the needs of the parents.

Food plays an important role in the life of the person with PWS. The reality is that food is freely available. A controlled environment with limited access to food is extremely important for the person with PWS. It may also happen that food should be kept behind lock and key. If this is left behind, the result can be severe obesity with related illnesses and in some cases eventual death.

I appeal to everybody who has contact with a child or adult with PWS to study this newsletter. It is important to remember that the PWS results from an abnormality on the 15th chromosome which has an effect on the hypothalamus. The specific behaviour of a person with PWS is the result of the malfunctioning of an important part of the brain. A reader's friendly version of more characteristics of PWS is given elsewhere in the newsletter.

How can you become involved? Read how to act when a parent with a child with PWS pays you a visit. During Christmas or birthdays or other social gathering food is freely available – as mentioned before. These gatherings usually create a feeling of anxiety in parents. Most of the time the parents would rather prefer to stay clear of such situations. A school holiday and Easter are around the corner and see how you can plan ahead of time and communicate the importance of food control with all involved.

Also read more about a grandfather's feelings and what he is doing to support his children and grandchildren.

How can parents involve the siblings to assist to manage their brother or sister's special needs? Often the other children feel that they are treated unfairly. It is hard on parents to make sure that each child gets the kind of loving support that they need. Linda Thornton gives some advice and stresses that it is also important that the friends of the siblings should be informed about PWS.

Parents are requested to hand this newsletter to everybody concerned. Share this information with others and do not hesitate to ask for help. It is no use to ignore the reality of PWS. The reality will remain. Start now by building open and honest relationships with everybody around you.

Kate Beaver says interesting things about the communication process of children with PWS. They need time to process information. If parents and everybody else understand this, it can save them much irritation and impatience. My adult daughter asks me to give her one task at a time which she wants to complete before I give her another instruction. She has a very good memory, but finds many commands difficult to perform.

Latham Centers provide many useful hints on their website. Read the hint about how parents can respond to difficult questions asked by a child with PWS. The questions are usually about sensitive personal matters and our answers should not demoralise them.

Researchers worldwide work very hard to understand the complexity of PWS. Research in the USA are initiated and funded by the PWSA (USA) and the Foundation of Prader-Willi Research (FPWR). All research possibilities are being examined. At present therapeutic medicines to improve the quality of life of persons with PWS are being researched. One of the drugs with exciting results is called Beloranib. The drug effectively reduces body fat content and improves hunger related behaviours. Read more about this research by Zafgen elsewhere in the newsletter.

Cara Lee Klootwyk turned 40 and started the year with a celebration. It is a milestone in Cara's life and she is in very good health. We would like to congratulate Cara with her birthday but also congratulate her with the weight she lost. Read more on Cara elsewhere in the newsletter.

The Famcare Committee of IPWSO has an article ready on the general health problems of a person with PWS. Although the work of this committee is aimed at the parents of adults with PWS who stay at home, the parents of younger children can also take note.

Note the following as well:

- A friendly request: What about an article about your family for our June edition? The volunteer can be a parent, brother or sister or even a grandmother or grandfather.
- Visit by Dr Janice Foster to Western Cape on Friday, 3 October 2014.
- Regarding *IPWSO News* – visit their blog. A mother tells about her son's birthday party without the traditional birthday cake.
- Photo Gallery – see three photo's each telling a story.
- Vincent and Portia Moatshe have joined our association in January 2014.
- This newsletter is also available electronically in A4 format.

We have learned with regret about the deaths of Sammy Robbertze and Werner van Zyl. Our deepest sympathies go to the families of these two young adults. These parents are experiencing a great loss.

Best wishes till we meet again when the next newsletter will be issued at the end of June 2014.

Rika du Plooy

Francis Morrison did the translation. I appreciate the time he spent and his patience.

Welcome

A warm welcome goes to Vincent and Portia Moatshe who joined the association early 2014. Their son, Kele is 10 years old and the family resides in Centurion, Gauteng.

RELATIVES AND FRIENDS

From: the website of the Prader-Willi California Foundation - www.pwcf.org

Your willingness to read the following information is a huge step in helping your friend or relative. Thank you for taking the time to learn more about PWS so you can be a valuable part of your loved one's support network. Remember that food is a constant source of anxiety for the individual with PWS. Holiday meals or meals away from home and the normal routine are very stressful for both the individual with PWS and their families. Anything that you can do to reduce that anxiety is greatly appreciated by the individual and the family.

Friends and extended family are in the unique position to have an immediate, positive impact on the life of the person with Prader-Willi syndrome and their family. Do not underestimate how important your support is. In a recent study comparing parents with children with a variety of disorders and disabilities, parents of children with PWS reported the highest levels of stress of any other participating parents. But that same study found that parents of children with Prader-Willi syndrome listed other family members and friends as their main supporters. Your support really matters, and there are a few rules of thumb you can follow to be the best friends and family you can be.

Picture: Courtesy of David and Karin Clarke

Friends and extended family are in the unique position to have an immediate, positive impact on the life of the person with Prader-Willi syndrome and their family.

What does this mean for extended family? It means that when an individual with PWS is visiting your home, you keep food out of sight in cupboards or in the pantry. It means that before they come over, you've already checked your counters to make sure there weren't any food items out. It also means that you'll help ensure a low-stress family holiday meal by serving food pre-portioned onto individual plates for everyone, rather than a buffet or a self-serve "family-style" dinner. It means creating helpful distractions for the child with PWS if they are struggling with holiday treats; arts and crafts activities in a separate room is one fun way to help keep the child with Prader-Willi syndrome pleasantly occupied away from food. When you, as extended family, take the time to learn about behaviors triggered by the syndrome, you enable yourself to give the parents well-needed respite when they stop by for a visit.

What does this mean for a family friend? It means that when you invite them over to your house, you don't have food on the counter. It means that when you want to spend time together with the family, you look for food-controlled environments. Good places for this include going to the zoo, taking a stroll in a local park, or visiting a museum or historical site. When the family doesn't have to devote their energy to preventing food-seeking behavior, they can actually relax with you. Time with you, as a family friend, keeps the fun in life and is rejuvenating for the whole family.

If you're having someone with Prader-Willi syndrome visit your house:

- Remove all candy, mint, and nut dishes that you may typically have out.
- To the extent possible remove food from kitchen counters. Out of sight is not necessarily out of mind for the person with PWS, but it definitely helps.
- Discuss food to be served at meals/parties ahead of time with the parent/caretaker. This allows the parent to prepare by:
  Bringing an alternative for their child
  Cutting calories elsewhere in the day to allow for a treat/higher calorie meal
  Letting the child know what to expect
  Helping you chose good options for the individual
- Let your friend know what time you plan to serve meals or snacks.

- Avoid talking about food in front of the individual with PWS. For example "Who wants pie?" after Thanksgiving dinner can be very stressful. Perhaps your family member was going to leave before pie was served, or maybe they were going to allow a small piece as snack but it's not time yet.
- Avoid eating in front of the individual with PWS if it is not also time for them to eat.
- Do not offer the individual with PWS any food or beverages without asking (away from the person with PWS) their parent/caretaker first.
- Defer questions about food to the parent/caregiver (or to the plan provided if left in your care).
- If someone with PWS is left in your care, follow their food plan exactly.
- Remember that for the individual with PWS "just one", or "just a little bit" does hurt.

If you're out (restaurant, amusement park, etc.) with someone who has Prader-Willi syndrome:

- Discreetly discuss when to eat if a set time has not been decided beforehand.
- Avoid eating in front of the individual with PWS if it is not also time for them to eat.
- Do not offer the individual with PWS any food or beverages without asking (away from the person with PWS) their parent/caretaker first.
- Defer questions about food to the parent/caregiver (or to the plan provided if left in your care).
- If you or your child want a treat (cookie, ice cream, etc.) find a time to do that away from the individual with PWS.

As family and family friends, you should also know the following:

Tantrum behaviour is a normal, expected phase of human development. Though other children grow out of the "terrible twos", people with PWS generally don't pass beyond that developmental stage, regardless of development of intellectual, language, and motor abilities. If you see tantrum behaviour, it is not because the person has been "spoiled". However, don't reinforce the behaviour by giving in. Maintaining a cool head and calm voice will do much to help the individual get control of their own emotions again.

Food seeking behaviour ranges in severity, but in all cases the brain acts as though it is in "starvation mode". Their metabolism is lower, lean muscle mass is down, individuals tend to be less active, and the food drive is heightened. Maintaining a healthy weight requires both a low-calorie diet and regular physical activity. In addition, their brain doesn't register satiety. As a result, food seeking is unrelated to hunger in the normal sense: they may food seek even if they've just finished Thanksgiving Dinner.

Stubbornness is a way of saying NO to changes that might cause stress or anxiousness. Many individuals with Prader-Willi syndrome display some level of cognitive rigidity, getting "caught" on one thought or concern. It is not malicious or learned – it is a part of the syndrome. Redirecting the individual who is stuck on a thought (by introducing a new conversational subject, for example) is one way to help the individual around their own rigidity.

Judgment is impaired. Learning via negative consequences *does not work*. For example, if you or I decided not to bring umbrella one cloudy day and were rained on, we'd remember the unpleasantness and be more likely to bring an umbrella next time it was cloudy. In the same situation, an individual with PWS may continue to leave the umbrella behind in spite of past experience. Fortunately, people with PWS do respond well to positive incentives and rewards. Your praise means the world to them.

Behaviour Tips and Social Skills for Family & Friends

Behaviour Tips

People with Prader-Willi syndrome are generally loving, sweet, kind individuals however their emotions tend to be heightened which can sometimes present problems. Additionally structure and routine are extremely important and unexpected events, no matter how small, can turn into meltdowns. Keeping the follow tips in mind will help you, your friend or family member, and most importantly, the individual with PWS.

- Speak in concrete terms; people who have PWS have difficulty with abstract terms
- Let the individual who has PWS know what to expect – what time an activity will take place, what will happen, etc.
- It's ok to set limits on repeated questions; i.e. "I've already answered that question, so I will only answer it one more time"
- Keep your promises; if you say you're going to do something, do it
- Reasoning with someone when they're in the midst of a meltdown, will not work
- Re-directing the individual to a new or desired activity will often be successful, however there are times when you may need to just give the person time to calm down
- Allow your friend to manage a meltdown or behavioral issue in their own way; it may not be how you manage your children, but they deal with this every day and know the best way to handle their child
- If someone with PWS is left in your care be sure to follow their parents instructions for dealing with behavioral issues and stick to the schedule

Social Skills

People who have Prader-Willi syndrome typically have deficits in their ability to deal with others. They may stand too close, miss social cues, and struggle with what to say. However, if you take a little time you will be rewarded with some very delightful interactions. Children with PWS particularly struggle with peer relationships. The following tips are ways you can help:

- Allow extra time for the individual to respond; it may take them a little longer to collect their thoughts
- Keep in mind that people with PWS take things very literally; they may have problems if you use sarcasm or idioms
- Include the individual with PWS in games, outings, etc.
- Facilitate interactions with other children
- Games or structured activities work better than open play activities
- Teach your children to be patient and encourage them to play with the child who has PWS

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MEMBERS IN THE WESTERN CAPE - PLEASE DIARIES THIS DATE

Dr Janice Forster, a Child & Adolescent Psychiatrist who is part of the Pittsburgh Partnership (USA), specialists in Prader-Willi Syndrome, will visit Cape Town on Friday 3 October 2014. Dr Foster will address professionals as well as parents at the Red Cross Children's Hospital, Cape Town. More detailed information to follow

LOOKING AHEAD TO THE HOLIDAYS

By Janalee Heinemann Director of Research & Medical Affairs and also the mother of an adult son. PWSA (USA) E-news December 2013

The holidays are typically a food fest in many countries - and can be a time of stress for our PWS families. With good planning, it is possible to make it a happy holiday for all.
If you will be with relatives, carefully plan ahead of time and communicate the importance of food control with all involved. Make sure all attending know the "rules of engagement" and agree to cooperate.

- See that someone at all times is clearly in charge of your child with PWS. Clearly define when you are "changing guards". As Dr Linda Gourash states, "*When everyone is in charge - no one is in charge*."
- If your child is old enough, rehearse the "rules" before the special day and come to a mutual agreement on what your child will be allowed to eat. You can barter, i.e. "*Do you want a little extra turkey and dressing, or do you want a piece of pie as your special treat?"*
- Ask relatives to discretely check with you first before offering more
- It is okay to request that Grandma and other relatives tuck away tempting items during your visit and to discreetly check with you prior to offering your child a treat.
- Make sure you know what everyone is bringing, so there are no surprises on what the choices will be.
- Grandpa and Grandma, or aunt and uncle may want to bring a special gift toy to compensate for the food they have to deny your child.
- Go over with the hostess or your family the plan to contain accessibility to food. This will help prevent your child from sitting near bowls of food, rolls, or condiments. Many people do not consider how many calories children can consume with the extras - sugar, butter, catsup, etc.
- After eating when people are just visiting make sure food is put away or, if left out, someone is responsible for guarding it.
- Your child must have the security of knowing you will be strong in your commitment to keep them protected from food - in spite of themselves. Giving in, even once, means several battles ahead. Consistency is the key.

Of course, each family must judge their own situation based on their child's food drive and their own regulations on treats. Some families are raising their children to never have any sweets - no exceptions. Others (like ours) just go by calories and the weight of the child, trying to keep the diet less in quantity with more variation of food. Often, the most important thing is to prevent food sneaking or food demands. There is a large variance in the food drive of children with PWS. Some will ask or beg for more food, but make no significant attempts to sneak food. On the other hand, some will go to great extremes to get food, and are incredibly cleaver at doing so.

HOLIDAY WARNING
The holidays have an extra risk factor for our older children and adults with PWS. There have been individuals with PWS who have died of gastric rupture and necrosis. Some of these were over the holidays or special events and due to a food binging episode that led to necrosis (deadening of the tissue) of the stomach wall and a perforation (tear) in the stomach. In most of the deaths, the person with PWS was relatively slim, so there was no

great concern about weight gain. Keep in mind that a person with PWS, who is slim still does not have total food control. When a child or adult with PWS has many opportunities for food ingestion, the lack of feeling full, the high pain threshold, and a weak vomiting reflex - then there is the potential of filling the stomach dangerously full. Because there are many food binging episodes of our children and adults with PWS, most not having such disastrous results, we think there are probably other factors that play into this life-threatening situation, which we are currently researching. One hypothesis is that due to prior food binges, and stomach muscle weakness, certain areas of the stomach wall become thinner putting this area at risk. **Please see that the safety and security that your child deserves is provided.**

FROM A FELLOW GRANDPARENT

Courtesy of PWSA (UK) - newsletter Issue number 117, October 2013

When I first realised that my grandchild had PWS I was very shocked but I soon realised that there were things I could do. First and most importantly, I wanted to support my family and secondly, I wanted to know as much about the syndrome as I could.

Finding Out

It was easy to find out about the syndrome. My daughter belongs to the Prader-Willi Syndrome Association UK, who have published several books and leaflets on the condition and they were only too pleased to let me have some to read. Equipped with all this information, I felt better able to offer help where I could.

Supporting the Family

I quickly decided that I should allow myself to be guided by my daughter as to how I should treat my grandchild, particularly where control was concerned. After all, she lives with these problems every day and I was determined not to sabotage her efforts.

Sweets

Most grandparents find it hard to resist the temptation to slip their grandchild the odd pack of sweets but times change and I had already noticed how the parents of our other grandchildren and great nieces and nephews like to limit this type of treat – knowing nowadays just how bad they are for teeth. I decided to leave the giving of sweets to parents and find other small gifts instead.

Weight Control

Some of us have discovered just how much easier it is to put on weight as we grow older, so this should make us more understanding of the ease with which children with PWS gain weight - weight which, in their case, can be positively dangerous.

Exercise

Diet isn't the only way people who have the syndrome can keep weight at bay. Faced with the fact that they need fewer calories than the rest of us do, exercise has its part to play too. We are told that a little gentle exercise does not come amiss in later years. It can be fun to tone and our well being. Going for a walk is just as good. It seems to me that things that we can encourage our grandchildren with PWS to do, can often be mutually beneficial.

Not Easy

I'm not saying that any of this is particularly easy. For us it's remembering these things when our grandchild comes to visit, for grandchildren popping in and out it must be quite difficult. As a family both we and the children have found the Prader-Willi Syndrome Association (UK)

a great source of support. Always ready to answer the odd question if there's something we don't understand or don't know. Why don't you try a PWS association?

Other family members

Children with PWS will always need support from their families but don't let us forget that the family needs support too. How about taking the other children for a few days to give them the change to enjoy the relaxation of the strict eating rules? Or take the child with PWS just for an afternoon, to allow the mum to go shopping in peace, or for a few days to give the other children a little more of mum and dad's attention?

It may disrupt your routine for a while but it will mean so much to the family.

SIBLINGS

Linda Thornton (New Zealand) IPWSO Communications Coordinator and mother of an adult daughter.

Being part of a family where one of your brothers or sisters has a disability can be really difficult and often stressful. You may also think it's really unfair! At the same time, it can also be rewarding, fun, and a huge source of inspiration. Often it seems as though your parents spend way too much time with your brother or sister with PWS, and not enough with you. Often it seems as though they are getting all the attention and you're getting punished by not being allowed to eat what you want, or always having to watch out for your sister or brother. It doesn't seem fair, and, it's not. So the whole family will have to make adjustments, learn new skills to help support your brother or sister, and that requires lots of patience and understanding.

Your friends will have to learn to understand as well. It all seems so tough to begin with, and it's natural to have a love-hate relationship just as it's natural to have a whole heap of other emotions all jumbled up at the same time. On top of this, you have all the other problems of life-school, growing up, parents, responsibilities, peer pressure and acceptance, and then as you grow older, there's a bucket-full of hormones that need stabilizing! The problem is how can you learn to integrate all this when it just seems impossible?

Parents need to realise that it is a huge task for the sibling as he or she tries to make their own way in the world, just as it is a huge task for parents to oversee and make sure that each child gets the kind of loving support that they need to become the individual they can.

In the case of your child who is brother or sister to the one with PWS, how much do you tell them? What do they need to know, and how do you support them? Often siblings have very conflicting and confusing feelings about their brother or sister. As they grow older and have more understanding, they may be embarrassed by the abnormal eating behaviours and resent the need for controlled access to food. They may find it difficult or impossible to ask their friends home and this may generate resentment towards their brother or sister.

Children absorb information at different levels - too much at one time and they selectively retain some and ditch some.

The pre-school child doesn't need as much information as the schoolchild, who doesn't need as much as the teenager and so on. Children ask questions, when they feel the time is right, and it is up to us as parents to help them understand the unique needs of PWS. The important thing is that you give them time to question and answers they can understand.

It is important that the family works together to support the child with PWS, especially when he or she starts to be more interested in looking for food. This is when parents need to discuss the importance of managing the dietary needs of PWS with other children in the family (and also their friends, and the whole wider family) and stress the importance of their brother or sister's special needs. If siblings understand about the syndrome, they may be more willing to put up with, and help with, all the limitations on treats, food accessibility etc. that it takes to manage the special dietary needs. Rewarding the other siblings with extra food is not a great idea (unless it's away from the house), but spending time with them is. Letting them do things without their brother or sister with PWS can make them feel valued and important; and at the same time will give one-on-one time with the other child. Keep a good balance between time spent and rewards given.

Although each family will tackle this subject in the way that they feel will work best for them, parents may still need to help their other children to express their feelings in the knowledge that it isn't wrong to feel embarrassed, awkward, resentful, or even guilty towards their sister/brother.

As the brother or sister grows older, the changes and development in their sibling with PWS will become more obvious and good parenting skills will be called on more and more to settle arguments ("it's not fair-you always let Jason get away with everything"), and pour oil on troubled waters.

When everything seems "unfair", it's a good strategy for the parent to go to their child at bedtime, sit on the bed and allow them time to talk about what happened during the day and why it wasn't fair. Often you can ask the sibling what he or she thinks you should have done, or what they might have done if they'd been the parent. You may be surprised at the answers and encouraged by the child's actual understanding of the situation. Making the brother or sister feel special because they are taken into your confidence and asked to help with their sib with PWS can often be the key. It may not work the next time the same situation arises, but continued talking about it will help reinforce the message that both of you are learning to help Jason to grow up in a world that is often strange and uncertain.

So, if you know of a sibling of a person with PWS take a moment today to *thank them* (no matter what age they are!) for the important role they play in supporting people with PWS.
Also visit: www.siblingsupport.org

Evan Farrar, PWSA (USA)
Crisis Intervention and Family Support Counsellor

It is sensible to treat your child with PWS as much as a normal member of your family as possible. Sure they get tired, more irritable, more hungry etc, but they can still help around the place with the chores. Make allowances, but don't make a rod for your own back. Be kind to yourself as a parent, too! Make time for special dates-write them up large on your calendar even if it's just going to the movies, or a coffee with a friend, it is important for your own sense of wellbeing that you do something for yourself. Try to set goals for yourself that are purely your own.

Join an internet group of age-related parents with kids who have PWS (there are plenty on the Net), most of them have been through what you are going through and can give great support and advice. No one said parenting is easy - it's not. It's hard enough for anyone and the extra challenge of raising a child with PWS has its share of bad days. We all know the

feeling of being the constant meat in the sandwich, or 'someone's mum, wife, partner' rather than the person we may have otherwise have been. Dwell on the good days!

COMMUNICATION CONSISTENCY

Kate Beaver, Crisis Intervention Counsellor, PWSA (USA)
The Gathered View ~ Prader-Willi Syndrome Association (USA), January-February 2014

Children who have PWS usually have a processing delay as part of their problems with communication. We have found that working with the school and parents to create a consistent form of communication has helped children at home and at school. One of the reasons that consistent communication helps is that the child doesn't have to struggle with processing directions from different people who have different communication styles. Remember, children with PWS have a delay in processing the information you give them. Most children will take between 3-5 seconds to understand what you say. If too many instructions are given or the instructions are generalized, they can miss the middle part of what you said and misunderstandings occur. Instead of saying "go get ready for bed", or "go get ready to go home", try breaking the process down into steps; It's time to brush your teeth", or "it's time to put your book away", wait 3-5 sec. before repeating the request. If after the second request they do not comply, do the task with them before asking that they do the next step.

Problem-solving skills are also often impaired. This is in part due to the processing problem and not being able to put things in order of how they should be done, which also creates anxiety. Children become frustrated and anxious trying to do what you want them to without being able to know what to do first and what all it entails. Again, having a set of short clear steps for them to follow will help with the child's anxiety and help them to process the information. Working with teachers and parents to come up with common language to use with the child is very helpful. Decide how steps should be broken down and what common words will be used. Decide on how much time the child needs to process a step--is it 3 seconds? 5 seconds? Each child can be different.

EXCITING NEWS ABOUT THE DRUG BELORANIB

PWSA (SA) acknowledge the Prader-Willi Syndrome Association (USA) and the Foundation for Prader-Willi Research (California) for the active role they play in initiating and funding research in the field of Prader-Willi syndrome. It is an exciting time for Prader-Willi syndrome research – it is all about what is best for our children with PWS.

Zafgen Announces Initial Results from Phase 2a Study of Beloranib in Patients with Prader-Willi Syndrome. From the Biotech newsletter http://www.fiercebiotech.com

CAMBRIDGE, Mass., Jan. 15, 2014 /PRNewswire/ -- Zafgen, Inc., a leading biopharmaceutical company dedicated to addressing the unmet needs of severely obese patients, today announced initial results from its Phase 2a study of beloranib, a selective inhibitor of methionine aminopeptidase 2 (MetAP2), in patients with Prader-Willi syndrome (PWS), a severe form of genetic obesity. These results showed improvements in body weight, hunger-related behaviors, and body composition, including reductions in body fat content and preserved lean body mass following four weeks of treatment.

These changes were observed despite the increased caloric intake that was a component of this trial. Known markers of beloranib response including those associated with cardiovascular disease risk were also improved, demonstrating that PWS patients responded to the molecular mechanism of beloranib.

"The results of this short-term proof-of-concept study are very promising and underscore our belief that beloranib has the potential to successfully treat this severe form of obesity. To our knowledge, this study represents the largest placebo-controlled, randomized, multiple dose trial to date for obesity in this patient population, and these results bode well for further study of beloranib in patients with this devastating condition," said Thomas Hughes, Ph.D., President and Chief Executive Officer of Zafgen.

Similar to results seen in non-PWS obese patient populations, beloranib treatment in this study reduced body fat content by 8.1% vs. placebo in four weeks of treatment at the highest study dose of 1.8 mg, despite a 50% increased daily caloric allowance. Hunger-related behaviors improved, and a trend towards overall improvement in body weight was seen, although this did not reach statistical significance, in part due to the fact that study was not powered to demonstrate these differences. Key hormones, including adiponectin and leptin, also showed changes characteristic of non-PWS obese patients, demonstrating that the drug was highly active in these patients and had a similar effect to that seen in non-PWS patients.

"These results are very exciting for the treatment of PWS, as most patients showed improvements in body weight, hunger-related behaviours, and body fat content, despite the increased food intake included in the trial design," explained Dr. Jennifer Miller, Associate Professor of Pediatric Endocrinology, University of Florida, and Principal Investigator for the study. "PWS is a complex genetic disease that is difficult to treat and the results of this trial demonstrate that beloranib has a beneficial impact on this underserved patient population. Notably, we were encouraged by reports of fullness, a first-time occurrence for PWS patients who otherwise lack the capacity to feel sated after meals."

"PWS patients remain severely impacted by their disease and are not treatable with other anti-obesity agents," added Janalee Heinemann, Director of Research & Medical Affairs for the Prader-Willi Syndrome Association (USA). "PWS represents one of the most severe forms of genetic obesity and we welcome these results, which are a significant step towards finding a treatment for those suffering from this life threatening condition."

Beloranib, a novel obesity therapy that utilizes a unique mechanism of action, is being studied for its ability to reduce body weight and improve cardiometabolic risk factors in obese patients with and without PWS. This study was a randomized, double-blind, placebo-controlled trial to evaluate the safety and tolerability of a dose range of beloranib administered as twice-weekly subcutaneous injections for four weeks. The randomized treatment part of the study was followed by an additional four weeks of open label treatment, the results of which are not yet available. The trial enrolled 17 patients with genetically confirmed PWS, including 11 women and 6 men, with a mean age of 33.9 years, and mean body mass index (BMI) of 31.4 kg/m2. Beloranib appeared to be safe and very well-tolerated. All 17 patients completed the randomized treatment part of the trial and all opted to continue into and completed the four-week open label extension.

About Prader-Willi syndrome (PWS): Prader-Willi syndrome the most common known genetic cause of life-threatening obesity, causes constant hunger that drives PWS patients to

gain more weight on fewer calories than the average person. As a result, many of those affected become morbidly obese before the age of five. There is currently no cure for this disease. Although the cause is complex, it results from a deletion or loss of function of a cluster of genes on the 15th chromosome. PWS typically causes low muscle mass and function, short stature, incomplete sexual development, and a chronic feeling of hunger that, coupled with a metabolism that utilizes drastically fewer calories than normal, can lead to excessive eating and life-threatening obesity. PWS occurs in males and females equally and in all races, with the same incidence around the world. Prevalence estimates have ranged from 1:8,000 to 1:50,000 with the most likely figure being approximately 1:40,000. To the best of our knowledge, prevalence is about 5,000 - 7,000 people in the United States needing treatment. You can learn more through the Prader-Willi Syndrome Association website at www.pwsausa.org.

About beloranib: Beloranib is the first compound in its class that works by targeting a key enzyme called MetAP2 that controls the production and utilization of fatty acids. Inhibitors of MetAP2 reduce the production of new fatty acid molecules by the liver and help to convert stored fats into useful energy. Beloranib is being developed as a twice-weekly subcutaneous injection for severe obesity. Zafgen holds exclusive worldwide rights (exclusive of Korea) for development and commercialization of beloranib. The company licensed beloranib from CKD Pharma in Korea.

About Zafgen Inc: Zafgen is an innovative company dedicated to addressing the unmet need of severely obese patients and related orphan indications by bringing beloranib, a first-in-class novel medicine, to market. Founded in 2005 as a virtual company, Zafgen brings together leading experts in obesity and metabolic disease to address the underserved and growing population of patients who are severely obese. Zafgen's singular focus is on advancing novel therapeutics for patients suffering from severe obesity and obesity-related disorders including Prader-Willi syndrome and patients with hypothalamic obesity, including obesity resulting from surgical treatment of craniopharyngioma. The company is located in Cambridge, Massachusetts. For more information, visit zafgen.com.

MEET CARA LEE KLOOTWYK

Written by Anthia Lindeque, Cara's mother

Cara Lee celebrated her 40th birthday on 19 January 2014. Thank you for the birthday card she received from the association. She had a happy celebration at home with family and friends. Unfortunately her sisters are both living in the UK and could not be at the party. They sent wonderful emails with some funny memories from their childhood which I read out with the speeches.

Cara's adult years have been an interesting journey to say the least. Cara is in a home which is part of the Challenged Adult Residential Care (CARE) in Somerset West. We have tried many ways to make things work for her well being and

Cara Lee celebrated her 40th birthday earlier this year. With Cara is her mother Anthia. We wish Cara good health and lots of happiness for the future. Cara achieved a lot and can be proud of herself. The Klootwyk family are members of the association since 1994.

for the people who deal with her in the group home. She has been in the group home for the past 14 years or so. We would all have wished for Cara to be included in some way into the community and to enjoy a certain amount of independence. However, we have come to the conclusion that she will always have to have supervision and it is only through this constant supervision that we have managed to get her weight and therefore her health under control. Her weight some years ago reached 126kg and is now down to 72kg. I have to give the main credit to Charmaine Engelbrecht, who runs the group home. Charmaine followed with Cara a diet found on a PWS website.

Another contributing factor has been Topimax (epileptic medication with a weight loss side effect over a period of time). An attempt at the gym, Virgin Active back fired as there wasn't sufficient supervision and Cara was finding all sorts of ways to find food.

As Cara's weight reduced so did her health improve and as a result she is now off all diabetic meds, insulin injection and other oral medication. The one big obstacle we still had to overcome was the smoking habit!! She was down to 5 a day, but that still caused a lot of hassles. The home was very supportive and was all the way behind us to get her to stop. Finally in August last year with much drama, it was achieved!!

Cara's main interest is reading and we are always looking out for second hand book shops and fêtes. She gets the You magazine every week and reads it from front to back. She is very fond of animals and they all seem warm to her to. A pity she can't work with them. She has her own TV and computer in her room but does not write at all unless dictated to. Her hand writing is very immature. She makes Xmas and greetings cards, from recycled stuff, when she's in the mood. On the subject of mood - she is still very up and down even on the bipolar medication. Cara thinks she knows everything, will argue to the death and usually have the last word. This can be very tiring and annoys many people.

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

"GOOD HEALTH" CHECKLIST

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

The basics of a healthy adult life for someone with Prader-Willi Syndrome (PWS) include a healthy, appropriate eating plan and regular, effective exercise to avoid obesity, keep the body fit and maintain good mental health. Before any of this can be achieved the people working with the person who has PWS must have a good understanding of the complexities of the syndrome. This

"checklist" is to assist you in maintaining good health for your person with PWS. It is to be shared with professionals and caregivers who are also involved with your person with PWS.

PWS is a genetic disorder which, due to a lack of expression of particular genes on the 15th chromosome. It effects several systems in the body. Below are some common problems seen in people with PWS, what the effect of the problem is on health and how it needs to be monitored or treated. Changes in physical health are often only detected due to changes in general behaviour so it's best to know what to check!

System/organ	Effect	Monitor / Watch / Treat
Appetite regulation	Always wanting to eat / drink Overeating	Food & beverages must be limited Overweight / obesity
Behaviour	Often perceived by others to be mood or mental illness	Requires appropriate management strategies and rarely, medication, unless due to a diagnosed mental illness
Bladder	Poor emptying Obesity may increase infections &/or incontinence	Timed toileting Increase awareness of full bladder feeling Confusion may indicate infection
Body fat - increased	Increased risk of obesity and related complications	Energy intake must be limited Exercise must be a part of life
Bone density (and bone strength)	Often reduced due to reduced hormone production & decreased muscle. Increased risk of fractures.	Maintain adequate calcium & Vitamin D intake and check blood levels. Check bone mineral density every 2 years. Helped by regular weight bearing exercise.
Bowel	Constipation is common and may lead to slow stomach emptying, incontinence, rectal picking	Prevent over-consumption of fibre. Maintain regular fluid intake. May require low dose laxative. Helped by exercising after eating
Diabetes	Develops as a result of obesity. If poorly controlled, will cause undesirable weight (muscle) loss.	Maintain a healthy weight & regular exercise to prevent diabetes. Check fasting blood glucose levels every 6-12 months if overweight to watch for diabetes. If known diabetes exists check HbA1C every 3-6 months.
Ears	Poor speech; lack of concentration	Check with ageing as person with PWS may not be able to express loss of hearing. If acutely impaired check for infection.
Eyes	Strabismus (abnormal alignment of eyes, squint); short/long sightedness	Change in vision with age 2 yearly eye checks
Feet / legs	Can develop oedema and cellulitis when obese or inactive	Maintain a healthy weight Maintain daily activity / exercise

Gut	Distended stomach Loss of appetite Vomiting often indicates serious illness	Slow emptying of stomach may cause constipation and "discomfort" from bloating and dilatation of stomach. *Risk of gastric necrosis* – death of stomach tissue due to reduced blood flow. Requires urgent medical assessment.
Lungs	Obesity, reduced breathing mechanics, scoliosis, and kyphosis can cause reduced oxygen consumption. Obesity & inactivity can lead to pneumonia, lung infections and respiratory failure.	Maintain healthy weight Maintain daily activity /exercise Medical check is required if exercise tolerance is poor or deteriorates.
Mental illness	Depression, psychosis	Requires psychiatric assessment and may need treatment with medication
Mouth	Reduced saliva causes dry, sticky mouth	Poor dental hygiene – dental erosion Requires regular, effective cleaning and regular visits to a dentist.
Muscle - **Reduced strength & tone** **Reduced muscle mass**	Weaker muscles, unstable joints Scoliosis, kyphosis Increased sensitivity to some medications	Poor posture, slower mobilisation, reduced breathing mechanics (worse with obesity) Requires strengthening exercises. Dose of some medications, when newly prescribed, should be lower than usual
Pain tolerance - high	Complaints of real pain are rare Real pain is often indicated by change in behaviour or activity level	Undetected illness or injury from accidents All pain complaints must be investigated to exclude a cause
Sequential processing	Poor personal hygiene can cause infections	Encourage thorough washing of body May require assistance or visual cues
Sex hormones - reduced	Lack of, or reduced sexual maturity Replacement required for bone health	Yearly sex hormone (androgen) blood test from 15 years of age Testosterone replacement (males - start with low dose) / oestrogen replacement (females), as required
Sleep apnoea (pauses in breathing while sleeping)	Daytime sleepiness, lack of concentration, excess irritability	To be assessed by sleep/respiratory specialist - may need positive airway machine or longer sleep time at night
Skin picking	Sores & infections	Cut fingernails every week, keep hands busy to distract from picking.
Water intoxication	Will lead to electrolyte imbalance which may cause seizures	Do not allow unlimited fluid intake
YEARLY MEDICAL CHECKS	**May need to be insisted on by family members *for* their person with PWS**	Check weight, waist measurements, blood pressure, lung function, teeth, andposture. Annual blood tests are recommended from the age of 15 years. Ask for: biochemistry (including calcium, cholesterol, glucose), iron

		studies (including iron), endocrine (including sex hormones, thyroid, Vitamin D)

Do not be afraid to seek a medical assessment for your person with PWS if you are concerned in any way about their health, due to changes in their manner or behaviour.

People with PWS need the ears, eyes and voice of the person with whom they live, to maintain good health and longevity!

TIP OF THE WEEK: THE HARD QUESTIONS

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

Will I get married one day? Will I have my own children? Will I go to college?
Can I become a fire-fighter/pilot/doctor or nurse?
We hear these questions so often and many parents struggle with what to say. Do we take away their dreams by being honest or do we provide them with a false sense of hope?
The answer is somewhere in the middle.

Although we know that our girls will likely never give birth, that does not mean that they won't be a strong presence and role model to a child. We know that many adults with PWS have strong romantic relationships and here at Latham we have an example of how that can be supported. We have two adults, one with PWS who live in their own apartment but it is attached to a home with 24 hour supports. They live as a married couple but because their benefits would have been negatively affected they chose to have a civil union. I know of another couple who live with similar supports and their children are their pets whom they dote over and care for, and they are a family. So the answer to will I get married and have children? – If you want to, yes. It may not be the traditional family but how many of us can claim that we are traditional anymore? We see our kids with passions and interests that start young and seem to grow with age.

Will I become a college professor?
My answer to that is: "I want you to work towards that and if it doesn't happen then I have no doubt that you will work on a college campus."

Will I become a pilot?
My answer is: "Let's research all of the jobs that have to do with planes and then we will have a backup plan."

A goal is a wonderful thing to work towards but it will be helpful down the road to have a number of smaller goals that you are working on as well. We know that the future is brighter than it has ever been for our children and the real truth is that we don't know what the next 20 years will bring. We don't know that our kids won't achieve all that they set out to so let's support them to dream while giving them concrete skills to have full lives regardless of the outcome. I admire their creativity and often unwavering belief in themselves so why take that away? We can help them work towards these goals, support them every step of the way while at the same time, teach them life skills that will provide them with options.

Patrice Carroll - Manager of PWS Services

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.

IPWSO NEWS

PLEASE VISIT IPWSO's blog and become A FRIEND of IPWSO.

Read the different stories as well as the news and views of IPWSO. A mother commented on her son's birthday party without the traditional birthday cake. You are welcome to communicate directly with the Communications Director of IPWSO, Linda Thornton. She will welcome your comments. http://ipwso.blogspot.com

9TH INTERNATIONAL PWS CONFERENCE, 2016

The next international conference will be held in Toronto, Canada in 2016.

PHOTO GALLERY

FRIENDS MEET AGAIN

Kade Gordon (right) and his family emigrated to Australia in 2005. Rogan Donenberg and Kade Gordon meet again in Johannesburg after many years. Here they are, now young adults and happy to see each other again.

THE 64TH SMYTH CUP GOLF DAY

Rika du Plooy, chairperson of the PWSA (SA) received a donation of R5 000 from the Pretoria Country Club Golf Ladies. The presentation was held at the PCC on Friday 29 November 2013. With Rika is Dave Avery, Chairman of PCC, Nancy Blomerus and Rosa Botha who were active involved in the organisation of the traditional Smyth Cup Charity Golf Day.
PWSA (SA) values the support and generosity of the golf ladies of PCC highly.

PAYING A VISIT TO THE USA

Ronél van der Ryst, a teacher at the Lettie Fouché School (LSEN) in Bloemfontein visited Los Angeles, California in December 2013. Ronél (middle) met Lisa Graziano (left) and Katherine Crawford (right) of the Prader-Willi California Foundation.

Ronél wrote: *During our visit to our son in Los Angeles, California (USA), we took the time to visit the Prader-Willi California Foundation in Redondo Beach. We had the pleasure to meet Liza Graziano, Executive Director, as well as Katherine Crawford, Family and Support coordinator of the Foundation.*
It was surely a great privilege to share knowledge and information. It made us realize how important the consistent application of knowledge is and how it benefits the person with PWS. We had meaningful discussions about residential care for young adults with PWS. In the USA, 6-8 adults are accommodated in a house and they do sheltered work during the day.
Our visit to Liza and Katherine was a positive and enriching experience and we extend our sincere thanks to Liza and Katherine. We are greatly encouraged and are proud to be part of the PWS "family".

Visit the website of the Prader-Willi California Foundation (FPWR) on www.fpwr.org

WHAT IS PRADER-WILLI SYNDROME?

From: *First Steps* Foundation of Prader-Willi Research (FPWR)

Prader-Willi syndrome (PWS) is a genetic disorder that occurs in one out of every 15,000-25,000 births. PWS affects males and females with equal frequency and affects all races and ethnicities. The symptoms associated with PWS are caused by a lack of active genetic material in a particular region of chromosome 15, but it remains unclear how inactivation of this region leads to the PWS characteristics.

Early on, PWS is characterized by low muscle tone in infants, with difficulty feeding and risk of failure to thrive. Later, this is replaced by an unregulated appetite and a strong drive to eat. Individuals with PWS lack normal hunger and satiety cues. They usually are not able to control their food intake and will overeat if not closely monitored. Food seeking behaviours are very common. In addition, the metabolic rate of persons with PWS is lower than normal. Without appropriate dietary intervention and constant vigilance, the combination of

One of the earliest signs in PWS is hypotonia. In the infant period developmental milestones such as sitting, crawling and walking are delayed compared to other normal infants.

these problems will lead to early onset childhood obesity and its many complications.

In addition to obesity, a variety of other symptoms are often associated with PWS, including growth hormone deficiency, abnormal body composition, speech impairment, scoliosis, sleep disturbances and learning disorders. Behavioural difficulties may include symptoms of obsessive-compulsive disorder and difficulty controlling emotions. Behaviour and mental health issues can represent some of the most challenging aspects of caring for an individual with PWS.

PWS is a spectrum disorder and symptoms vary in severity and occurrence among individuals. With the benefit of an early diagnosis, access to growth hormone replacement therapy, and a nurturing environment, those with PWS are accomplishing more than ever. Nevertheless, even as many with PWS have the intellectual capacity to live independently, the challenges of the disorder are limiting, and the vast majority of individuals with PWS are not able to live without constant supervision.

Currently there is no cure for Prader-Willi syndrome, but our goal is to change that. For many individuals who are affected by the disorder and their families, the elimination of some of the most difficult aspects of the syndrome, such as curbing the insatiable appetite, has the potential to dramatically improve the quality of life and open up an abundance of new opportunities. Through advancement of FPWR's mission, we intend to do just that.

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.

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

ACTIVITIES OF THE ASSOCIATION:

- The association provides support to parents and others who care for children and adults with PWS.
- The association publishes a newsletter, *People With Strength* to update its members and other interested persons regarding news and the latest developments in the field of the Prader-Willi syndrome.
- The association disseminates important educational material such as information provided by the *International Prader-Willi Syndrome Organisation*, (IPWSO) and other sources to its members and others involved.
- The association organizes workshops, seminars or conferences from time to time on the latest research and effective management of PWS.
- The association organizes an annual general meeting to deal with official matters at which occasion parents are also afforded the opportunity to socialise and share their ideas and experiences with other parents in similar situations

We invite everyone involved with persons with Prader-Willi syndrome, including parents, family members, friends, professionals, caregivers and other interested persons, to become members of the association.

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 chairperson.
chairperson@praderwilli.org.za or 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

PLEASE CONTRIBUTE AND HELP TO MAKE A DIFFERENCE!

Your donation, large or small, provides vital support to individuals with Prader-Willi syndrome, their families and others in the supportive team.
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.

MEMBERSHIP FEES ARE DUE: 1 APRIL 2014

Opinions expressed in *People With Strength* are those of the authors or editors and do not necessarily reflect the views of the management committee of the PWSA (SA).