



People With Strength

Newsletter for parents by parents

Volume 14 Issue 3

SIBLINGS

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“Children are not immune from experiencing the anxieties and stress which their parents are experiencing”

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WHAT IS PRADER-WILLI SYNDROME?

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

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VAN DIE VOORSITTER

Liewe Lesers

Nog 'n jaar is amper verby en ek is besig met die samestelling van die laaste nuusbrieff van 2011!

Verskeie navrae het die afgelope tyd die bestuurskomitee bereik wat weer die eise wat die persoon met die Prader-Willi sindroom aan 'n huishouding stel, na vore gebring het. Ek haal aan uit 'n artikel waarvan die verwysing elders gegee word:

“Families of people with PWS are subject to more stress than those of people with intellectual disabilities of mixed aetiologies and 70% of mothers have high levels of stress needing psychological counselling”.



Vir gesinne waar daar 'n persoon met PWS is, is dit amper 'n normale leefwyse, maar alle betrokkenes sal weet wat dit beteken om altyd die welstand van die persoon met PWS voor op te stel – dat etes altyd op vasgestelde tye is en dat dit voldoen aan die nodige kilojoule-vereistes; die fyn trap tussen skielike veranderinge en teleurstellings wat die appelkar kan omgooi en 'n tantrum tot gevolg kan hê en die obsessief-kompulsiewe gedrag waarvoor daar baie geduld en begrip moet wees. Gesinne is blootgestel aan baie stres wat 'n direkte invloed het op verhoudings tussen die ouers en die ander kinders in die gesin. In hierdie nuusbrieff gaan dit veral oor die 'ander kinders' en lees gerus die insiggewende en interessante artikels. 'n Klompie riglyne word ook vir die hantering van die broers en susters gegee. Die vakansietyd wat voorlê is dalk die ideale tyd om te probeer om spesiale tyd aan die broers en susters te gee en geleentheid te skep vir oopkommunikasie!

'n Gesinslid skryf oor haar broer . . . sy deel komiese insidente, haar bekommernisse, maar ook haar wense vir haar broer. Haar omstandighede het haar geleer dat jy jouself 'n klomp pyn en frustrasie gaan spaar, as jy die lewe soos dit na jou kant toe kom, omhels. Moet hierdie stuk nie mis nie! Broers of susters in ander gesinne is baie welkom om ook hulle stories te vertel.

Baie belangrik is die ope brief wat van Liezl Vlok ontvang is, dit spreek juis die bekommernis van ouers oor die toekoms van die persoon met PWS aan. Liezl en haar familie het 'n groot stap geneem! Lees gerus oor Huis Henri en maak met vrymoedigheid van Liezl se vriendelike uitnodiging gebruik. Hierdie projek staan onafhanklik van die Prader-Willi-Sindroomvereniging, maar die Vereniging wil graag hierdie familie met dit wat hulle beoog, alle sukses en voorspoed toewens.

Van 'n praktiese aard is wenke vir die versorging van die persoon met PWS se tande. Van die inligting in die artikel is van toepassing op die Amerikaanse publiek, maar die wenke is baie bruikbaar. Die produk *Biotene* word aanbeveel . . . die tandepaste en kougom is verkrygbaar by van ons groot apteke, maar is baie duur. 'n Klompie jare terug is die tande van persone met PWS as swak beskryf. Die kinders met PWS wat nie aan soetigheid blootgestel word nie en goeie tandversorging kry, het meeste van die tyd geen probleme nie. Die insette van die ouer is hier weer eens baie belangrik.

Die opkoms tydens die Algemene Jaarvergadering in Augustus was 'n teleurstelling en ons het veral die lede in Gauteng gemis. Die onderwerp van die spreker was in die belang van die meeste lede en tog was die opkoms die swakste in vergelyking met vorige jare. Tydens die AJV is Brian Legemaate as opvolger vir Wilna Basson, wat oor baie jare as sekretaresse gedien het, verkies. Baie welkom aan Brian op die komitee en ons gaan beslis vir Wilna wat vele aspekte hanteer het, mis.

Neem ook asseblief kennis van die volgende:

- Kennisgewings afkomstig van IPWSO. Lees gerus die gedeelte wat Janalee Heinemann geskryf het oor die sukses van IPWSO se bewusmakingsveldtog.
- Hulp met die verspreiding van *IPWSO Medical Alert Booklets*
- DVD: *FOOD, BEHAVIOUR AND BEYOND* wat steeds gratis beskikbaar is
- **Partytjietyd** - kom ons begin om gesonde versnaperinge aan ons kinders voor te sit – nie net ter wille van die persoon met PWS nie, maar sommer ook wille van die hele gesin!
- Baie welkom aan die Clarke en Steenkamp gesinne wat aangesluit het
- Hierdie nuusbrieff is ook elektronies in A4-formaat beskikbaar.

Weer eens 'n vriendelike uitnodiging aan ons lesers om insette te lewer en om ook voorstelle te maak vir moontlike onderwerpe wat in die nuusbrieff geplaas kan word. Deel asseblief behoeftes en vreugdes! As daar 'n behoefte is om betrokke te raak of as jy sekere vaardighede het wat jy wil aanbied, kontak ons gerus.

Mag die vakansietyd vreugdevol en geseënd in die bou van gesinsverhoudinge wees.

Vriendelike groete vanuit 'n warm Pretoria
Rika du Plooy.

FROM THE CHAIRPERSON

Dear Readers

The year is drawing to an end while I am compiling the last newsletter for 2011!

The management committee has recently received many queries about the demands set by a person with Prader-Willi Syndrome. The following quote may be of interest: “Families of people with PWS are subject to more stress than those of people with intellectual disabilities of mixed aetiologies and 70% of mothers have high levels of stress needing psychological counselling”.

Families caring for a person with PWS regard it as a normal way of living, and those involved know what it means to put the well-being of the person with PWS always as a priority. It is no easy task to serve meals, containing the prescribed amount of kilojoules, always at set times. A sudden change of programme or disappointment will rock the apple cart and resulted in a tantrum and it is hard to always have patience with and insight in the obsessive-compulsive behaviour. Parents and siblings are exposed to a lot of stress which can have a profound influence on the relations between them. The emphasis in this newsletter is on the siblings. Please read the interesting and informative articles on this subject. Some guidelines are also given regarding the handling of the brothers and sisters of a child with PWS. The coming holidays might be the ideal time to give some special attention to the brothers and sisters and to find ways for open communication.

A family member writes about her brother. She shares some comic incidents but also her worries about her brother – what will happen to him? She came to the conclusion that you will save yourself a lot of pain and frustration if you can learn to embrace life exactly in the way it has been given to you. Do read this article! A friendly invitation to all brothers and sisters: you are welcome to share your particular stories with us.

Please take note of Liezl Vlok’s open letter which addresses the need of a HOME for individuals with PWS. Liezl and her family have taken a giant step! Do read about Huis Henri and please respond to Liezl’s friendly invitation. This project is not a project of the Prader-Willi Syndrome Association, but the management committee nevertheless wishes the family who are engaged in this project all the best in their endeavour.

Some practical hints are given regarding the dental care of a person with PWS. It is an American article but the hints can be put to good use in South Africa. Biotene is recommended. The toothpaste and gum can be obtained from the large well known chemists, but it is quite expensive. In earlier literature the dental condition of persons with PWS was usually described as very poor, but if their sugar intake is controlled and they receive good dental care, they should not have any problems with their teeth. The parent’s input is once again of great importance.

The attendance at the General Annual Meeting in August was a disappointment, and we especially missed the members in Gauteng. Notwithstanding the interesting talk by the speaker, the attendance was in comparison with previous years very poor. During this meeting Brian Legemaate was chosen as secretary to succeed Wilna Basson who has served on the management committee for many years.

Please take note of the following:

- Information from IPWSO. Read what Janalee Heinemann writes about the success of IPWSO's awareness campaign.
- Assistance with the distribution of the *IPWSO Medical Alert Booklets*
- DVD: *FOOD, BEHAVIOUR AND BEYOND* – still available free of charge
- **Party time:** let us begin by serving our children healthy snacks – not for the sake of the child with PWS only, but for the whole family!
- Welcome to the Clarke and Steenkamp families who joined our association
- This newsletter is also in A4-format available by e-mail

We are eagerly awaiting feedback from our readers. Also let us know what topics you would like to be published in *People With Strength*. Please communicate your highlights and needs! If you feel like getting involved, or if you have certain skills you would like to contribute, please feel free to offer your help.

Enjoy your well deserved holiday and may you all have the opportunity to treasure family relations.

Greetings from Pretoria
Rika du Plooy.

My appreciation to Francis Morrison who did the translation.

HE AIN'T HEAVY. . . HE'S MY BROTHER

Written by his younger sister

"How much do you love me then...?"

"Umm... a lot"

"A lot?" I laugh, "You're going to have to be more descriptive than that! Try again." I hear a thoughtful sigh coming from the other end of the line. "Ummm, I love you more than all the stars in the sky." He says.

"Wow! That's a lot hey and you must remember, I love you even more than that!" I reply.

My brother is 10 years my senior and he'll be turning 40 this year. Growing up with him has been eventful to say the least.

I'll tell you this much, my brother is not stupid. There is no one that can plan an elaborate scheme like he can. My brother seems to understand the composites on a good symbiotic relationship. He figured out, quite quickly, that wine can be a precious commodity to those less fortunate. So he would get a bottle of wine from the house and trade it for a packed of sweets with the labourer, and I am sure, each one came out of the transaction, feeling that they got the better end of the deal.

Then there was the time, when we moved into town and we had new neighbours. He would go and chat with them and play with their dogs. Somehow the lady thought it a good judgement call to give him a set of her keys in order for him to feed the dogs whilst she was gone for a couple of days. Needless to say, she must've opened the fridge with quite a shock because apparently, he cleaned her out.

When he was 8 years old, he'd hang around the ice-cream cart that occasionally stopped by the school. Then, when one of the other mothers came along to buy their own children some ice-cream, he would stand there looking all sullen and they would feel sorry for him and buy him an ice-cream as well. He scored a lot of ice-creams this way and the ice-cream seller was very happy, as he was pocketing the extra sales.

Sometimes my brother would find himself lucky enough to be in a café of some sort, by himself. Then he would start gathering sweets and drinks, go to the cashier and say that his father will come by shortly to make it right and then walk off triumphantly with his loot. I think the cashiers were so dumbfounded by the whole situation and his size that they let him get away with it. Later on my dad would get a phone call and he would have to go and settle the outstanding bill.

Once we were on a family holiday and there was a seafood restaurant with a special deal on, where you could eat as much as you want for a set price. I think my brother could not believe his luck, he must have thought he had died and gone to heaven with all that food. My mother tried to ask him to slow down, "You can't eat so much" she said to him. He looked up at her with a puzzled expression, perhaps even a little indignant and then looked at the "eat as much as you want" sign and then back at her and simply answered, "Of course I can." That night I think he over indulged even by his standards and was quite ill for the rest of the evening.

Recently, my dad forgot my brother at the DVD shop... Every now and then, my farther would drop him off at the DVD shop and then whilst my dad ran his errands, my brother could take his time deciding on a DVD. My father got so engrossed in what he was doing that when he finished his errands, he drove straight home. My parents were sitting on the veranda, watching the sun go down when my mom

You will save yourself a lot of pain and frustration if you can learn to embrace life exactly in the way it has been given to you. I think it was Roosevelt that said that you should do what you can, with what you have, where you are.

asked where brother was. They both flew up, my father looking for the car keys and my mother of to check my brother's bedroom and there he was, in his chair, watching his soapie, obviously not too happy. Turns out, he simply asked the shop assistant for a lift and knew exactly how to explain the way home.

My brother has the knack of saying exactly what is on his mind. Once I brought a new boyfriend home to meet my family and he bought my brother a present. My brother shook his hand whole heartedly and told the guy that he was his unmarried brother in-law. My parents found this extremely funny but I was slightly embarrassed not to mention the poor boyfriend. On another occasion, watching TV, he was quite baffled by the way the male ballet dancers were dressed. After pondering the situation for a bit, he promptly voiced his concerns by saying, "Well, I am just saying, you can't go into town dressed like that."

My brother is quite a good natured fellow; he is very religious and likes copying the bible. He has comic and CD collections that he loves to read and listen to. He smokes a pipe, which can be quite comical as he hardly smokes it but spends more time cleaning it out and then very carefully, putting the tobacco in the pipe. Then he still needs to find a good angle to try and light the darn thing. Then he would sit there with his arms slightly crossed, half holding the pipe, half picking at a scab, with a seriously pensive look on his face. I always wonder what he is thinking about.

So how did having a brother with PWS affect me as a sibling? Sure there was funny parts, where you couldn't help but laugh for want of crying, but then there were darker days as well. I could also, from a young age, see the immense strain it was putting on my parents. I think what made it even more difficult, was the uncertainty of the situation. When he was around 7 years old, a doctor even went as far as to accuse my mother of over feeding my brother.

My brother was only diagnosed with PWS when he was 12 years old and even then the doctors were not familiar with the diagnoses. In fact, my brother was treated more like an oddity, his hospital bed crowded by interns and doctors, yet no one could or would advise my parents on how to deal with the immense pressure that they were under.

I guess I always knew that he was different but sometimes children can quite easily accept something that is perceived as different purely because it has always been there. I am very close to my brother, he is my friend and I care for him deeply. I worry about him a great deal, about his future, his health and if he is happy, whether I am doing right by him and so much more. I have learnt a few things in my life and one thing that resonate with me, is that there is no point resisting life because it will just go on and happen anyway. You will save yourself a lot of pain and frustration if you can learn to embrace life exactly in the way it has been given to you. I think it was Roosevelt that said that you should do what you can, with what you have, where you are.

In the same breath I want to acknowledge that looking after a child with PWS is by no means an easy task, it takes more than it gives and I want to thank my parents for doing the best job they could, with what they had, where they were.

Every time I hear the song “He aint heavy, he’s my brother” by the Hollies, every single time, without a doubt, I will think of my brother. I will think of him and it would feel like my heart was walking a tight rope between melancholy and immense love. I wish I could improve his life so that he could be happier; I wish that South Africa was more equipped to deal with PWS, that there was a respite option for the parents and a care facility geared specifically toward PWS. He is my big brother, he has shaped my life in every remarkable way and I wouldn’t exchange him for anything in the world. So many of the most important life lessons I have learnt, I have learnt through my brother, he can take most of the credit for that which is good in me. I don’t think I would have been half the person I am today, if he had not been a part of my life.

I love him dearly.

We invite all siblings to share their stories and experiences with the rest of us. Writing about our experiences is like therapy, it helps to relieve our feelings of stress that come from the sometimes painful events and lets us relive again those moments of joy.

FAMILIES . . . PARENTS . . . SIBLINGS . . .

A mobile is one way of describing the family system; everyone different and unique, but nevertheless bound together with delicate threads like in a cobweb. When one touches a mobile or cobweb, it is inevitable that the disturbance affects the whole system or structure. All members of a family which has a member with special needs are affected. ***“Children are not immune from experiencing the anxieties and stress which their parents are experiencing”.***

Receiving the diagnosis of Prader-Willi syndrome creates massive stress and usually triggers feelings of loss, depression, and grief. As the child grows, new stressors replace or compound previous ones. Each of us reacts to stress depending upon our individual character makeup, temperament, family-of-origin and life experiences, and learned coping strategies. Our reactions to stressors reflect the way we choose to protect ourselves from becoming overwhelmed, which for couples who have a child with Prader-Willi syndrome represent some of the *highest* levels of stress. Like other couples who have a child with a disability, the stress created by PWS will impact the couple; they will respond by beginning or continuing to work together as a united team to respond to the new challenges they face, or they will turn away from each other and begin the process of disengaging from their marriage. *This is a critical dynamic in the marriage of a couple who has a child with PWS and will impact the entire family dynamic throughout the years ahead.*

Extract from: Laughter After Tears: Building a Strong Family Creating a strong, supportive and healthy marriage and family, Janalee Heinemann and Lisa Graziano

Families of people with PWS are subject to more stress than those of people with intellectual disabilities of mixed etiologies [Hodapp et al.,1997] and 70% of mothers have high levels of stress needing psychological counselling [Sarimski, 1995]. Parents are divided on which particular phenotypic characteristic is most stressful for them, but most cite either the eating behaviour or the obsessiveness, depending on which of these is predominant in their offspring's behaviour. Closely related to these two characteristics is the problem of temper outbursts, which most often occur when expectations are not met, such as expectations about food and routine, and also of concern is the extreme hoarding behaviour. Worries about their offspring's health and wellbeing also cause stress, and in the cases of severe skin picking and psychiatric illness, may also be exacerbated by social stigma.

The Eating Behaviour in PWS

This phenotypic characteristic deserves special mention for several reasons. It is the distinguishing feature of PWS, giving rise to the most difficulties for the family and leading to social isolation for both the person with PWS and for the family. It is also one of the aspects of the syndrome most researched.

From: Neurobehavioral Phenotype in Prader–Willi Syndrome

Whittington J, Holland A. 2010. Neurobehavioral phenotype in Prader–Willi syndrome. *Am J Med Genet Part C Semin Med Genet* 154C:438–447.

SIBLINGS

Barbara Y Whitman

Perhaps no area of research is more neglected than the impact on, and adjustment of, siblings living in a family coping with PWS. When parents are obliged to constantly focus on the needs of the affected child, the risk for siblings having adjustment difficulties, although not inevitable, is clearly increased. Anecdotal evidence suggests that siblings of a child with Prader-Willi syndrome often have conflicting and confusing feelings about their brother or sister. They may be embarrassed by their abnormal eating behaviours and resent the need for controlling access to food. The constant risk of behaviour problems in public, particularly around these issues, are a chronic source of stress and anxiety, frequently leading to a “Does he/she have to go?” query. Siblings often express reluctance to invite friends to their home, while at the same time indicating a lot of guilt associated with this reluctance. Jealousy at the attention given the affected child is often noted, along with a conflicting feeling of being glad they can “hide” and get away with doing what they want while the family is preoccupied with the affected sibling. Often siblings are pressured into parenting roles (e.g. “I have to run to the store; make sure he/she doesn’t get into the pantry while I am gone”), given additional responsibilities, or forced to “grow up” too quickly. Even feelings of guilt that the sibling does not have food restrictions often emerge.

It is important to give siblings the permission to express all feelings regarding their brother or sister and the syndrome. Parents may need to be taught how to encourage this expression, and how to hear them in a nonjudgmental way. Parents can model for their children by inviting them to medical or counselling appointments where the parents identify and talk about their own feelings. Attending siblings should be encouraged to ask questions; the tone of their questions can serve as a conduit for asking: "That makes me wonder if you are feeling....," and pave the way for the siblings to air concerns and feelings.

Younger siblings may wonder if they can "catch" Prader-Willi syndrome, while older siblings may worry about having a child of their own with PWS. Most geneticists encourage genetic counselling for the maturing adolescent so that all questions can be honestly and sensitively answered.

Many adult siblings retrospectively report that they knew that their family was different and had to be more careful about food, but they didn't see it as "abnormal". Research documents that many adult siblings feel that they have developed a greater understanding and acceptance of differences and a sense of empathy for those who are disenfranchised.

From: Management of Prader-Willi Syndrome (Third Edition)

Extract from chapter 18: page 435. *Social Work Interventions: Advocacy and Support for Families*, by Barbara Y Whitman.

PWSA (SA) has a scanned version of the entire chapter 18 from *Management of Prader-Willi Syndrome (Third Edition)*. Please email or phone the chairperson.

BIRTHDAY CARDS

To parents . . . please acknowledge receipt of birthday cards, either by SMS or email!!

Afrikaanssprekendes na Magdaleen Kloppers

Selnommer: 083 663 7234

English speaking folks to Janet Drysdale

Tel: 011 465 6201 or e-mail: dad@mweb.co.za

A WARM WELCOME TO THE CLARKE AND STEENKAMP FAMILIES!

David and Karin Clarke joined in September 2011 and they are from Cape Town
Hendrik en Ingrid Steenkamp van Pretoria het in November 2011 aangesluit

MEMBERSHIP FEES ARE DUE: 1 APRIL 2011

(MORE) SIBLING ISSUES

Extract from: *Laughter After Tears: Building a Strong Family*

Creating a strong, supportive and healthy marriage and family

Janalee Heinemann and Lisa Graziano (The article is available from PWSA (SA))

Managing the needs of multiple children poses great challenge. Having insight into some common sibling experiences provides parents the opportunity to proactively help their children understand and manage them. Common feelings siblings feel include:

- resentment, guilt, love, jealousy, anger
- a desire to protect
- feeling left out from being told what is going on
- a fear of the disability being contagious or inherited
- embarrassment, compassion, loneliness
- feeling parents love the disabled sibling more
- seeing the siblings disability as a stigma on themselves
- a desire to be "sick" themselves to get attention

Younger Children may be at risk because:

- They have a limited understanding of what is wrong.
- They are egocentric thinkers and wonder "*Will I catch it?*" "*What will happen to me?*"
- They have magical thinking, i.e. "*It is all my fault because I said...*" "*Did I cause it?*" "*Will God make it happen to me if I'm bad?*"
- Their parents are the most important people in their world, and their parent's attention is often diverted to the disabled child.
- In their great desire to please their parents, they may willingly take on too much responsibility.

Pre-Teens and Early Teens are more focused on the following:

They are much more aware of their sibling's differences and much less willing to be different themselves, thus they are more likely to be embarrassed or ashamed of how their disabled sibling looks or acts.

- They feel guilty for various reasons, e.g. because they are healthy and their sibling isn't; because they resent their sibling; because sometimes they wish their sibling was dead.
- They feel isolated, i.e., "*My parents don't understand me.*" "*My friends don't understand what I have to go through.*"
- They are acutely aware of their parent's double standard for their sibling on discipline, chores, achievements, and tolerated behaviour.
- They now may resent having to "take care" of their disabled sibling.

- They are the least sympathetic and understanding of their disabled sibling at this age - but that's true in "normal" family situations also.

Older Teens often begin to feel more comfortable with themselves and their situation but parents need to be aware that:

- If the disabled sibling's problems cause too much home disruption and alienation from parents, this is the age when the sibling will "escape" by being away from home a lot.
- Sometimes a parent sees a way to "escape" and expect the teen to become overly responsible.
- They feel a need to "make up" for their disabled sibling by being an overachiever.
- They may question more the justice of why God let this happen.
- They feel a need to protect their sibling from the world.
- They begin to become concerned about who will take care of their disabled sibling if something happens to their parents.

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PARENTING, BROTHER, SISTER AND PWS

Lota Mitchell

FROM: SEE ME, HEAR ME, I'M HERE, TOO.
Editors Lota Mitchell and Nina Roberto
PWSA (USA)

In every family with more than one child, sibling relationships are a highly important and sometimes problematic part of growing up. For better or worse, brothers and sisters learn from each other in this, their first social network, such interactions as competition, sharing, resolving conflict, who will dominate and who will be submissive, who will take care of and who will be taken care of, and a host of other patterns and behaviours absorbed through time and proximity. Indeed, birth order (whether one is oldest, youngest or in the middle) is a contributing factor in the development of personality.

Tips that help

Here are some general guidelines for parents dealing with siblings. These are appropriate for any family and certainly applicable for the family of a child with PWS.

SEE ME, HEAR ME, I'M HERE, TOO

Perhaps reading this booklet will help some siblings to understand that they are not alone in struggling with the problems created by the syndrome, that lots of others have the same feelings, and that they don't have to feel guilty over the times of anger.

Available to members of
PWSA (SA)

DON'T COMPARE

Instead focus on what is good and positive about the individual. Comments like “Why can’t you behave like Susie?” is definitely not motivating.

SET ASIDE A SPECIAL TIME FOR EACH CHILD

This isn’t always easy in today’s busy world, but even 15 minutes a day solely devoted to that child can make him or her feel important and secure. The time may be spent playing a game or going someplace together or just talking, but no other child should be allowed to intrude. This may be especially important to the sibling of a child with PWS, who often feels that all the time and attention goes to the one with the disability.

PROVIDE A SAFE PLACE FOR BELONGINGS

Separate rooms are best, if possible. In addition, have a cabinet for each child with a lock on it (and several spare keys or combination lock) where he/she can keep treasured possessions. Sometimes children are expected to share too soon; a child must feel he truly owns something before he can share it. Younger brothers or sisters may break the more fragile things of the older sib, and when the brother or sister has PWS, the need for a secure spot is likely to continue indefinitely.

SET LIMITS

The two basic rules always are: 1) no hurting and 2) no destruction of property. The rules (these and others) should be the same for the nondisabled children and the child with PWS. It takes parental energy, but the rules must be every time enforced.

WHEN IT IS POSSIBLE, AVOID TAKING SIDES WITH EITHER CHILD

It is not always possible, and certainly not when one of the above rules is being broken, but if the parent is constantly drawn into sibling conflicts, children learn that superior force decides everything. The weaker one also learns to use his weakness to manipulate Mom or Dad. Nondisabled siblings may be expected to give in to keep (or to get back) the peace. Or, less commonly the child with PWS may become the scapegoat for everything.

WHEN NECESSARY USE GRADUATED DISCIPLINE

Keep in mind that the word “discipline” does not mean “to punish” but to “teach and train”. The first level of discipline is to express disapproval plus understanding. If that does not bring the desired effect, isolate the offender or combatants in a time out or an area in the house where the child can cool down. Next in the hierarchy is deprivation of privileges. Physical punishment, i.e. a swat on the well-padded bottom, might be used in the early years, but only as a last resort and very sparingly (many experts advised against spanking).

When the smoke has cleared, a discussion of the feelings behind the misbehaviour is important. Humiliation damages self esteem and should never, ever be used as a means of discipline.

ACCEPT THAT YOU CAN'T ALWAYS BE FAIR

Most parents try very hard to be consistently "fair." This is very rarely possible. Then, too, "It's not fair!" can often be a manipulative phrase on the part of one or more siblings. A good phrase to use is the following:

"Everyone has rules, but not everyone has the same rules. Each person is an individual."

It is essential that each be allowed to develop his or her own abilities and talents and at his or her own pace. And it is also important that each be given his or her share of recognition, praise, and attention for accomplishments – even if the normal one has achieved much more.

Research has shown that the more children there are in a family with a disabled child, the more normal the family environment will be. There are some special issues when there are only two children in the family, and awareness of these may help to prevent emotional problems later on in the "normal" sibling.

When the child with PWS is the older one, problems can arise when the younger starts to pass up the older in social, intellectual, and/or physical areas. As young children, they play on an equal basis. But as they grow older, the normal sibling begins to, and ultimately does, surpass the other. This can lead to feelings of guilt and even deliberate dropping behind on part of the normal sibling. Some parents, too, in their desire to protect the disabled one and because of their own struggle with denial and guilt, may contribute to the problem by repressing or not encouraging the abilities of the younger so he or she won't outdo the older.

TAX BENEFITS FOR "DISABILITIES"?

Do you need assistance?

Contact Eugene Bendel at Bendels Consulting
Tel: 021 526 0444 ebendel@bendelsconsulting.co.za

'N OPE BRIEF. . . . HUIS HENRI

Liezl Vlok

My naam is Liezl Vlok en ek het 'n seun, Ruan wat met Prader-Willi-sindroom gediagnoseer is. Ruan is 15 jaar oud. Ek hoef vir geen ouer van 'n kind met PWS, al die vreugdes, uitdagings, hoogtepunte en laagtepunte van ons daaglikse bestaan te verduidelik nie. Vir my is die grootse leemte in al die ondersteuning en kennis tot ons beskikking, die gebrek aan 'n huis wat ingerig is om net kinders met PWS te help en te akkommodeer op 'n sinvolle en stimulerende manier. Dit is dus met groot opgewondenheid dat ek die volgende inligting met julle deel.



My familie, wat bestaan uit my ouers, twee broers en ek en my man, beplan om so 'n huis vir persone met PWS te skep. As 'n familie kan ons dit nie alleen doen nie, so ons is oop vir enige voorstelle, raad en ondersteuning van enige iemand wat wil betrokke raak by hierdie droom van ons. Hierdie is nuwe grond vir ons almal, maar die riglyne wat vir ons belangrik is, wil ons met julle deel:

- Dit moet 'n huis net vir individue met Prader-Willi-sindroom, wees
- Die huis moet selfonderhoudend kan funksioneer.
- Dit moet deur professionele mense wat die sindroom ken en verstaan, bestuur word
- Dit moet 'n veilige plek wees met 'n vriendelike, huislike atmosfeer waar ons kinders 'n sinvolle bestaan kan voer.

Die beplanning is in die begin stadium, maar die volgende is reeds gedoen:

Die dokumentasie vir die registrasie van die maatskappy, is afgehandel en weggestuur. Die maatskappy se naam is die **Henri Warnich Stigting/Henri Warnich Foundation**. Ons het die Stigting vernoem ter na gedagtenis aan my oudste broer se oorlede seuntjie, wat soveel lewens deur sy bitter kort lewetjie aangeraak en verander het. Die Stigting sal ons die vermoë gee om fondse in te samel en hou ook 'n belastingvoordeel vir donateurs in. Ons wag nog vir die finale registrasiedokumente, maar op hierdie stadium is dit bloot 'n formaliteit.

Die naam van die huis sal wees "Huis Henri".

My broer is besig om 'n webtuiste te skep vir die Stigting, waarop die misie en visie sal wees en om ook so blootstelling op Facebook en *twitter* te kry.

'n Tussentydse bankrekening is geopen, totdat 'n rekening vir die Stigting geopen kan word. Die rekening is geopen by die firma Von Lieres Cooper & Barlow wat ook onderneem om die

wetlike aspekte rondom die finansies te hanteer. Enige iemand wat solank 'n finansiële bydrae wil maak, kan die volgende rekening gebruik:

Von Lieres Cooper en Barlow

Bank: **Eerste Nasionale Bank**

Rekeningnr: **620 4521 9492**

Takkode vir elektroniese betalings: **250 655**

Verwysing: **L3722 en besonderhede van deposant**

Faks asseblief die bewys van inbetaling na faksnommer: 021 413 0911 of epos na henniew@silversky.co.za. Van Lieres Cooper en Barlow is in Kaapstad en kan gekontak word by 021 411 1870.

Ek dink dit is realisties om te sê dat hierdie nie 'n projek is wat oornag staan gemaak gaan word nie. Ons grootste uitdaging is om fondse te genereer en dit sal ook vir die eerste jaar ons prioriteit wees. Die eerste fondsinsameling geskied op 19 November 2011. My oudste broer, Hennie Warnich, is die eienaar van sy eie IT maatskappy, maar is ook baie lief vir skryf. Hy het sy eerste eenmanvertoning geskryf en gaan dit ook self opvoer. Ons het die Dorpstraat Teater in Stellenbosh bespreek en al die kaartjies is amper uitverkoop. Alle fondse wat daardie aand gegenereer word, gaan direk in die Henri Warnich Stigting se fondsrekening betaal word. Die reaksie van vriende en vreemdelinge was oorweldigend en daar is baie mense wat nie die aand kan bywoon nie, maar wat graag fondse wil skenk!

Soos ek vroeër genoem het, is hierdie 'n droom wat op hierdie stadium nog net in ons harte leef. Ons nooi almal wat wil betrokke raak, om ons hande te neem en saam kan ons dit laat werk! Ek weet daar is baie vrae wat ons nog nie voor antwoorde het nie soos:

- Waar gaan die huis wees?
- Hoeveel kinders/volwassenes sal die huis kan akkomodeer?
- Wat gaan die kostes wees, ens?

Hierdie vrae sal antwoorde kry, soos ons die pad vorentoe stap. Ek het eendag die volgende stelling gelees en ek dink dit moet die leuse van hierdie projek raak: "Do not tell me the sky is the limit when there is footprints on the moon!"

Ek sal dit waardeur as daar ouers of ander is wat belangstel om hul kinders in so 'n huis te sit my net sal kontak. Ons wil net so min of meer 'n idee kry van watter getalle ons praat.

Vrede!

Liezl Vlok

072 243 5251

info@karoospirit.co.za

Liezl Vlok

My name is Liezl Vlok and I have a son, Ruan who has been diagnosed with Prader-Willi syndrome. Ruan is 15 years old. I do not have to explain to parents of a child with PWS the joys, worries, high and low points of our daily lives. For me the biggest “shortfall” within all the support and knowledge available to us, is the lack of a house which is designed to accommodate just children with PWS in a meaningful and stimulating manner. I would like to share the following information with you all:

My family, which includes my parents, two brothers, my husband and I, plan to develop a house for individuals with PWS. As a family we cannot do it alone. We are open to any suggestions, help and support from anyone who wishes to be involved with this dream of ours. This is new ground for us all; however we do wish to share with you the criteria which are important to us.

- It must be a house for individuals with Prader-Willi syndrome only
- The house must function in a self sustaining manner
- It must be administered and run by professional individuals who understand the syndrome.
- It must be a safe place with a friendly, homely atmosphere where our children can enjoy a meaningful life.

The planning is in the beginning stages; however the following has already been done:

The documentation for the registration of the company is completed and submitted. The company’s name is the **Henri Warnich Stigting/Henri Warnich Foundation**. The Foundation is named after my eldest brother’s deceased son, who touched and changed so many lives in his short life. The Foundation will give us the opportunity to fund raise as well as allow for the tax benefits for those who donate to the foundation. We are waiting for the final registration documents; however it is just a formality now.

The name of the house will be “Huis Henri”.

My brother is busy developing a website for the Foundation on which the mission and vision will be posted. We aim to do the same on Facebook and twitter.

A temporary bank account has been opened until a bank account for the Foundation can be opened. The account has been opened at the firm of Von Lieres Cooper and Barlow who will also be ensuring all lawful compliance of the account. Anyone who wishes to make a donation may do so to the account below.

Von Lieres Cooper en Barlow

Bank: **First National Bank**

Account number: **620 4521 9492**

Branch code: **250 655**

Reference: **L3722 and details of depositor**

Please fax the payment advice to 021 413 0911 or e-mail it to henniew@silversky.co.za.

Van Lieres Cooper and Barlow are in Cape Town and can be contacted on 021 411 1870.

It is realistic to say that this is a project that will not be completed overnight. Our biggest challenge is to raise funds and this will be our priority during the first year. The first fund raiser is on the 19 November 2011. My oldest brother, Hennie Warnich, is the owner of an IT business, but also loves to write. He has written his first one act play and is going to present this. We have booked the Dorpstraat Theater in Stellenbosch and have almost a sold out of tickets. All the funds generated by this event will go directly to the account of the Henri Warnich Foundation. The reaction of friends and the public has been overwhelming and many people who are not attending have expressed a desire to donate to the Foundation.

As I mentioned earlier this is a dream which is still in the beginning stages. We invite anyone who would like to be involved to join with us to ensure that it can work. I know there are many questions that still need answering like:

- Where is the house going to be?
- How many children/adults will the house accommodate?
- What will the costs be, etc.?

These questions will be answered over time. I read the following quote one day and think it should be the aim of this project. "Do not tell me the sky is the limit, when there are footprints on the moon!"

I would appreciate it if parents who are interested in placing their children in a house like "Huis Henri" will contact us. We would just like to get an idea of what numbers we are looking at.

Kind Regards

Liezl Vlok

071 243 5251

info@karoospirit.co.za

DENTAL TIPS AND TRICKS

Provided by Barbara Dorn

Start teaching tooth care at a young age. Cleaning teeth should be done twice daily, beginning as soon as the first teeth appear.

- Start cleaning teeth in infants and toddlers with a very soft toothbrush, a washcloth or finger toothbrush pads. Not only will this help establish good dental habits and prevent tooth decay – this may help with oral motor stimulation and strengthening.
- Wide brush handles often make brushing easier. There are many brands and styles. One trick is to insert a bicycle handle grip, rubber pencil grip or other special grip device (available from an Occupational Therapist) on to the toothbrush handle.
- Ask your dental hygienist to help teach and motivate the person receiving dental care. (Many often do more to please others than they do to please parents.)
- Use a SOFT brush to prevent or minimize trauma to gums.
- Typically the parent should assist in brushing teeth up until early middle school. Encourage and teach the child to do it ... but the parent should finish it up with a “once (or twice) over” to make sure all areas have been reached.
- Make tooth-brushing fun. Don’t be afraid to vary things to keep it fun as well as novel. There are many fun toothbrushes. Ones with:
 - Movie and cartoon characters. Let the child choose!
 - Music (so the child/person learns to stop brushing when the music stops).
 - Batteries – “Electric” toothbrushes.
- Use good tasting toothpaste with fluoride. Always provide supervision with toothpaste use to prevent the child from overeating it. Toothpaste in small amounts will not hurt you.
- 1-2 times a week, use tablets or a stain to check for plaque build up. Your dental care provider may be able to assist you with obtaining tablets or a small amount of food coloring on a Q-tip works well too.
- Make the tooth care a game. Establish a routine. “Count 20 brushes on the top right; 20 on the top left; 20 on the bottom right; 20 on the bottom left; and don’t forget the areas behind the upper and lower front teeth and tongue”. Post the sequence on a small index card and post it to the mirror or other nearby spot so everyone who may be assisting uses the same approach.
- Make a chart ... use incentives for good habits and cooperation. (Possibly reward with a new toothbrush, sugar-free gum...)
- Use a tooth-brushing timer so that adequate time is spent doing the brushing. (See Product Sharing)
- Teach and encourage flossing. There are flossing instruments available at most pharmacies and other stores to help make this easier.

- Limit sugar and/or use sugar-free products. (Sugar + Bacteria = Acid Production Acid + teeth = Cavities)
- Visit a dental professional every 6 months for cleaning and monitoring.

Product sharing

- “TOOTH TIMER” is a fun device that helps patients brush their teeth for 2 minutes, the proper time for brushing. NO batteries needed. COST: \$9.99 + \$4.95 for standard shipping. Available at Open Wide catalogue at 1-800-232- 4244 or on line at www.OpenPlease.com Just write “timer” in the search box (item # CM940)
- BIOTENE (toothpaste, mouthwash & gum) are products that help decrease bacteria and found to be very effective in decreasing the white ring and/or crusting often seen around the mouths of persons with PWS. It is expensive and not available at all stores. (Walgreen’s carries it) ... and it is worth it.

Finding a Dentist for the Person with PWS

- Select a dentist who is not only a good professional but one that also makes your child and the experience a positive one.
- Don’t be afraid to shop around. Talk to other parents in your community. Get a referral. Choose a dental team that works well with children/adults who have cognitive limitations. Finding dental professionals that take Medical Assistance is very challenging.

Since the reimbursement rate is very low, dental practices often choose not to take this type of insurance. If your child/ young adult has been receiving dental care from a dentist for many years and then begins to be covered under MA, talk to him/her to see if they would be willing to continue to care for your child. A dental practice can dictate how many patients they serve with MA and if you have a long-term relationship with this professional, he/she may consider doing this. Some dental care providers have opted to donate their services in lieu of filing with MA. In planning for your child’s future, you may want to budget funds so that your son/daughter can receive adequate dental care. Even with dental insurance, there are many services that are either only partially covered or not covered at all.

DENTAL PROBLEMS AND PWS

By Dr. Tom Hughes, DDS, Treasurer PWSA of WI, Inc and Parent of Sara with PWS

Most dental problems with PWS are related to decrease salivary flow and mouth breathing. These two concerns combined promote tooth decay, periodontal disease and crowded arches. What can be done? First, make sure the child or adult has either a fluoridated water supply or fluoride tablets (1 mg /day to help fight tooth decay.) Have them brush with a fluoride toothpaste after each meal and then before bedtime. Parents will need to check their teeth after brushing, especially at night so that they don’t leave food along their gum lines. This leads to decay and periodontal disease. Persons with PWS also have a tendency

towards dry mouth because of their mouth breathing which leads to thicker saliva, which promotes both decay and periodontal disease. Normal saliva is thin and washes the teeth clean, while thick saliva sticks to the teeth and harbors bacteria that cause tooth decay and periodontal disease. Finally, as a result of mouth breathing during their early years, individuals with PWS have a greater chance of developing narrow arches which causes crowded teeth. Getting orthodontic care early (age 6-9) to help develop the arches to a more normal shape can make it easier to keep the teeth clean, which helps prevent tooth decay and periodontal disease. It can also help reduce their tendency to mouth breathe, which would decrease tooth decay and periodontal disease. Professional dental cleanings every 3 to 6 months is also a big help in keeping the teeth and gums clean and healthy.

Ask the Dentist

The following are common questions regarding dental issues for persons with PWS. Dr. Hughes has provided us with some answers.

QUESTION 1:

Sealants are often used in protecting a child's teeth from the formation of cavities. Is this something an adult with PWS could have done? *Yes, an adult can have this done, but this only protects the biting surfaces from decay. Along the gum lines is where most decay due to dry mouth and thick saliva occurs. In these cases, only proper brushing with fluoride toothpaste and topical fluoride rinses or varnish is effective.*

QUESTION 2:

Is there anything a dentist can do to help this be covered by the person's insurance? *The Wisconsin Medical Assistance program covers sealants on permanent posterior teeth (which are the only ones that need sealants) the problem with the program is that it is underfunded and difficult to work with. That is why many dentists don't accept it in their practices. (Please contact your state assembly and senate person and ask them to fund this program better.) Other insurances may cover this if a preauthorization is completed however, each insurance may be different.*

QUESTION 3:

Is there anything to help address the thick sticky saliva that is often seen in persons with PWS? Would scheduling "water snacks" at certain intervals help? *The reason for thick saliva is mouth breathing for the most part and less fluid intake secondly. "Water snacks" (a glass of water 4-6 oz.) might help but too much water is bad also. (Water intoxication can occur if a person drinks a very large amount of fluids in a short period of time. The large amount of fluid washes away the sodium in their system and can result in a serious health emergency.) However, if this was done twice a day mid morning and mid afternoon it could help. (Many parents also report the use of Biotene toothpaste has been helpful.)*

QUESTION 4:

Is it true that chewing gum after meals helps to prevent tooth decay? If so, is there any special gum that helps more than others? *Chewing gum could help clean the teeth, but here again you have to be careful. Use sugar free gum and only let them chew 1 (one) piece. This can last from breakfast to lunch or lunch to dinner or dinner to bedtime. But as we know, many people with PWS will try to eat many pieces either at a time or one after another as the flavour goes away. If they eat many pieces of gum containing sugar, it can have the opposite effect and cause cavities and weight gain.*

QUESTION 5:

Is it true that there are certain foods (like apples or carrots) that can actually assist in removing the buildup of plaque? *Foods with hard textures do help clean the teeth of plaque. But again you have to use them in moderation because they still have calories and eating all day long produces plaque build-up.*

QUESTION 6:

Are there foods that should be avoided that may be contributing to the development of cavities? *Any food that is soft, sticky and sugary (raisins, "gummy anything", candy ...) should be avoided.*

QUESTION 7:

It is often common to see white crusting on the sides of the mouth in persons with PWS - what causes this and can anything be done to prevent this? *This is dried saliva from mouth breathing. If your child has crowded teeth and narrow arches (need a dentist to assess this), having orthodontic treatment to widen the arches might help with their ability to breathe through their nose instead of their mouth. Also have their tonsils and adenoids checked because if they are enlarged this causes mouth breathing also.*

QUESTION 8:

Are there any special considerations that parents and dentists need to be mindful of when considering orthodontia for a person w/PWS? *The biggest problem is keeping the teeth cleaned. Parents will have to help their children keep their teeth cleaned during orthodontic therapy.*

Did You Know??? Water with fluoride is available in plastic disposable bottles. If your water source does not contain fluoride, feel free to use it not only to drink but also with your recipes, juices, and/or Kool-Aid. In addition to cavities, gum disease and periodontal disease,

poor oral care can lead to other health problems. Bacteria can break away from the teeth and gums and travel to other parts of the body causing infections.

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PWSA (USA), 8588 Potter Park Drive, Suite 500, Sarasota, Florida 34238

info@pwsausa.org & www.pwsausa.org

IPWSO NEWS

From: The IPWSO blog Wednesday, September 28, 2011

IPWSO at ESPE: "Why wait for obesity to diagnose PWS?"

Dear IPWSO members,

I just wanted to give you an update on our IPWSO awareness booth at the ESPE conference. Although it is the "European Society for Paediatric Endocrinology" there are 2,500 - 3,000 participants from all over the world – and I mean all over the world. Giorgio and I are both invigorated and exhausted! We were just crazy busy today with people stopping by our booth for information on PWS. There were times when even with the two of us, we could not talk to everyone or get them all scanned because there were too many at a time, but they all got one of the packets Giorgio put together.



We have extensive packets for those who have no information, packets for those that received information from us before, but were looking for new information, and crisis packets for those dealing with weight and behaviour issues. I also brought a suitcase full (75) of our brand new growth hormone books that we created and printed at PWSA (USA). Between Giorgio's 9 cartons and my suitcase full, we only have 3 cartons left and have 2 ½ days to go! We are looking at ways to stretch the information.

Giorgio has been able to recruit physicians from three countries where we are not represented to be the IPWSO professional delegate. We have also made contact with the key people at the two pharmaceutical companies that have the indication on GHT and PWS. Having the new GHT booklet helped to peak their interest. One physician from the country of Georgia even personally brought Giorgio blood samples to the conference in order to get the free diagnosis services we provide in collaboration with BIRD. Another physician from Vietnam stopped to personally thank IPWSO for the free diagnosis services. They are now getting children with PWS diagnosed in their country.

Giorgio and I make a good team for these conferences. I handle the medical questions, but Giorgio is really the impressive one to watch in action. He can greet people in almost any

language and have conversations in 6 -7 languages. He also knows the delegates in all of the countries, so can discuss that with them. He also works very hard to get all of the materials together (I send him the new articles we need to add) and knows the details on how to ship internationally – and of course, is renowned for being frugal! He knows the conference organizers and they treat us well. We have a great corner location for our booth. As always, we are not in the fancy hotels with the doctors, but in a cheap one and Giorgio drove 4 hours to fly out of an airport where the flight was much cheaper.

I am sharing this information so you can appreciate the significance of this important education service we offer, and the collaborative efforts between IPWSO, BIRD, and PWSA (USA).

Warm regards,
Janalee Heinemann, MSW
Vice President, IPWSO and
Director of Research & Medical Affairs PWSA (USA)

PLEASE VISIT IPWSO's blog and become a FRIEND of IPWSO

Read the different stories as well as the story of Luke and Matthew, two brothers in South Africa.

<http://ipwso.blogspot.com/2011/10/come-and-meet-luke.html>

If you want to respond with a comment - on the right-hand side of the blog is a place where you can become a friend. Click, join, and then comment.

IPWSO 8th INTERNATIONAL CONFERENCE 2013

The PWSA (UK), in partnership with the University of Cambridge Intellectual and Developmental Disabilities Research Group, (headed by the President of PWSA (UK), Prof Tony Holland) warmly invite you to the 8th International PWS Conference.

The conference will be held at the Fitzwilliam College, Cambridge, UK, from 18 - 21 July, 2013. Please visit www.pwsa.co.uk

PHOTO GALLERY



Mr Eugene Bendel was the guest speaker at the AGM in August 2011.
The topic he addressed was:
PWS - How parents can obtain tax benefits.



Brian Legemaate was elected as secretary.
We would like to welcome Brian on the management committee and wish him all of the best.



Our best wishes to **Wilna Basson**.
Wilna served as secretary for many years and has now resigned. She is willing to continue being responsible for the LIBRARY. Members can contact Wilna for educational material, etc.
Tel: 012 991 3399 bassons@iafrica.com



We want to thank **Elsa Volschenk** from Octoplus Information Solutions, for the design and layout of the newsletter. Elsa's support and guidance are much appreciated.

CHILDREN WHO ATTENDED AGM WITH THEIR PARENTS



Chaim Segal



Diane Drysdale



Marise Basson



Zack Nel

PARTY IDEAS FOR CHILDREN!

Gabi Steenkamp & Tanzia Merlin & Jeske Wellmann

How can we ensure that our children enjoy parties but do not overload their bodies with second-rate eats? It is therefore ideal to serve only foods, snacks and drinks that are nutritionally beneficial. Children will eat what is served at a party – if healthier options are offered, that's what they will eat. The aim is to include slower release carbohydrates and to control sugar and fat content. Here are a few ideas from above-mentioned book!

Example for a party pack: 2 jelly-babies or jelly sweets, 1 small low-fat/fat-free fruit yoghurt with a plastic spoon and 250 ml (1 cup) home-made popcorn. Include one or two (non food) delights; like hair accessories for girls, mini note pads, funky pens, water pistols and cars for boys.

Drinks: Ice tea, but also give children the option of water, still or sparkling. Fruit juices are very concentrated sources of carbohydrate and should always be drunk in small quantities, preferably diluted with water or tea. Diluted fruit juices can also be frozen to slush. Fizzy drinks should be restricted to no more than 100 ml at a time, and then only as a special treat.

Vegetables: Try a vegetable finger platter or vegetable kebabs, raw or roasted. Arrange vegetables in patterns on individual paper plates so that it is catching for the eye!

Fruit: Use any fruit in season, but remember to vary the colours, shapes, texture and flavours as much as possible. The children would like the fruit on sticks/skewers. Dried fruit pieces can also be used.

Lean protein snacks: Try the following - chicken strips or pieces, cheese cubes or wedges (lower fat), biltong strips, Ostrich Vienna bites.

For more interesting and motivating ideas please consult the above mentioned book. Start at an early age if you want to establish healthy eating habits in your children

ICE TEA: RECIPE FROM *SUSTAINED ENERGY FOR KIDS*. (P. 139)

Dietician's notes

A healthy substitute for fizzy cold drinks at parties

No more than 250 ml (1 cup) of this tea (or any other diluted fruit juice mixture) should be consumed at one time. Serves 16 (125 ml {½ cup} per serving)

1 litre hot rooibos tea (made with 2 rooibos tea bags)

3 mint leaves (optional)

1 litre fruit juice: orange, apple, apricot, or cranberry and kiwi – use a low GI juice.

15 ml lemon juice

1 Pour the hot rooibos tea onto the mint leaves in a 1-litre jug.

2 Pour the fruit juice into a 2-litre jug.

3 Add the hot rooibos tea to the fruit juice, pouring through a sieve (to catch the mint leaves). Mix lightly.

4 Stir in the lemon juice.

5 Chill and serve ice cold in frosted glasses.

125-ml serving	Nutrients	GI low 51	Carbohydrates 8 g	Protein -	Fat -	Fibre -	kJ 138	GL 4
	Equivalent to	½ fruit						

For information on the SA GI and GL Guide available from GIFSA see

www.gifoundation.com or www.wellmann.co.za or www.gabisteenkamp.co.za

Our appreciation to Jeske Wellmann for permission to use information from

Sustained energy for kids, written by Gabi Steenkamp & Tanzia Merlin & Jeske Wellmann

(Registered Dieticians SA) First published in 2006 by Tafelberg Publishers.

2ND ASIA PACIFIC PRADER-WILLI SYNDROME CONFERENCE

The Prader-Willi Syndrome Associations of Australia and New Zealand are proud to host the 2nd Asia Pacific Prader-Willi Syndrome Conference on

10 and 11 March 2012 in Sydney, Australia

Building bridges - Possibilities not disabilities Email: conference@pws.org.au

Help our children and help others to understand PWS better!

DVD: FOOD, BEHAVIOUR AND BEYOND

Members, parents and other interested people are welcome to order above mentioned DVD (free of charge) from the PWSA (SA). It is a valuable tool in teaching caregivers, teachers and other professionals to have a better understanding of the person with PWS. If you are interested and want to make use of this opportunity, please contact Wilna Basson at 012 991 3399 or e-mail: bassons@iafrica.com

PLEASE HELP: IPWSO MEDICAL ALERT BOOKLETS

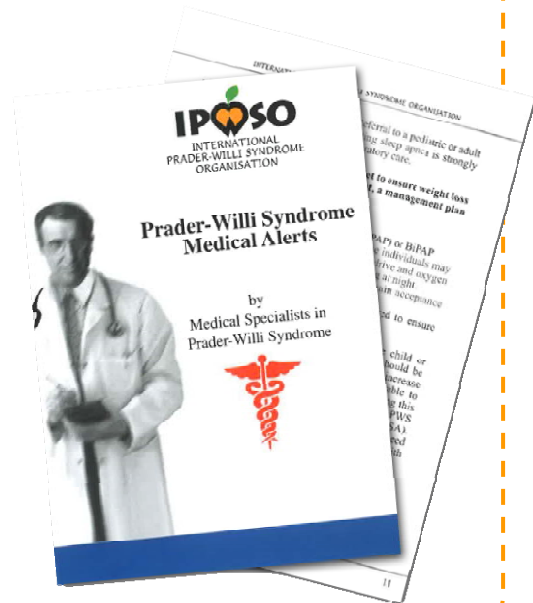
In order to further awareness of the Prader-Willi syndrome the decision was taken to provide all final year medical students, at six universities in South Africa, with an **IPWSO Medical Alert Booklet**. The aim is to make it a priority to get information about PWS out to the medical professionals. The booklets are specifically printed in A5 format and the contact details of the PWSA (SA) are included as well as the diagnostic testing procedures for PWS in South Africa.

Members can help to assist the committee to **distribute these booklets** to medical professionals who you come into contact with. Please inform **Janet Legemaate** (Vice-chairperson) if you are willing to assist and how many copies you would need. Thank you to those members who already respond to a previous request!

Please contact Janet Legemaate at:

Tel: 031 767 4493 or 082 737 6144

legemaate@absamail.co.za



A NEW WEBSITE

Providing specialist dietary advice for infants, toddlers and children

Message from Natasha Martins:

"On the website, I have set up an interactive blog page for parents as I commonly receive reports saying that they receive so much conflicting dietary advice, often leaving them very confused as what to follow. My aim for the blog is to provide regular updates on nutritional topics and to keep everyone up to date with advances in child nutrition, new information or dietary guidelines, product updates or launches, talks and workshops."

Please visit: www.paediatric-dietician.co.za

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

ACKNOWLEDGEMENTS

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

- **afrihost.com** for hosting the Association's website
- **Dawid Basson** the webmaster of the website. His advice on other matters is sincerely appreciated.
- **Elsa Volschenk** for her involvement in redesigning People With Strength
- **Mike Dovey** of McCarthy Ford and Mazda-Silver Lakes for the generous donation towards PWSA (SA)
- **IPWSO** for continuously forward information regarding important PWS issues
 - Also available on www.ipwso.org
- **Janet Drysdale** and **Magdaleen Kloppers** for the birthday cards
- **Dr Engela Honey**, the medical advisor of the Association, who is always available
- **Members** for prompt payment of membership fees
- **THE CO-WORKERS AND ALL THOSE WHO CONTRIBUTE TO PEOPLE WITH STRENGTH**

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).

WHAT IS THE PRADER-WILLI SYNDROME ASSOCIATION OF SOUTH AFRICA?

The Prader-Willi Syndrome Association of South Africa is a support group and was established by a small group of concerned parents in March 1990.

Activities of the Association:

- Provides support to parents and caregivers of individuals with Prader-Willi syndrome.
- Promotes knowledge and awareness of the syndrome among the public and the medical and paramedical professions.
- Improves the care given to individuals with Prader-Willi syndrome.
- 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 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 individuals 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 PWSA (SA)

Registration fee R 50.00 (once-off payment)

Annual membership fee R 200.

R 220 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 the deposit slip 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**

WE ARE MEMBERS OF

- The International Prader-Willi Syndrome Organisation (IPWSO) www.ipwso.org
- The South African Inherited Disorders Association (SAIDA) www.saida.org.za
- WESTERN CAPE FORUM for Intellectual Disability (WCFID) www.wcfid.co.za
- The South African Association for the Scientific Study of Mental Handicap (SAASSMH)
email: saassmh@telkomsa.net

PWSA (SA) SUPPORT SERVICES

Various support structures and mechanisms are available to our members and interested persons. Educational material such as newsletters is made available to members on a regular basis.

Upon request, other interested persons such as family, friends, professionals, health care workers, teachers, residential care workers, etc. are provided with information regarding the syndrome. Upon request, parents of newly diagnosed children are assisted in making contact with members of the Association with a view to sharing in their experiences and knowledge.

A clinic for persons with PWS functions under the guidance of Dr Engela Honey, of the Department of Genetics, Division Human Genetics at the University of Pretoria. Dr Honey is available for consultations by appointment. She is also the medical advisor to the Association.

Contact details: Tel. +27 (0)12 319 2269 or email: medic@praderwilli.org.za

MAAK 'N VERSKIL MET 'N SKENKING!

Die PWSV (SA) is geregistreer as 'n nie-winsgewende organisasie (Nr. 035-837 NPO) ook as 'n openbare weldaadsorganisaie (PBO Exemption no.930 016 853).

Hierdie registrasie hou voordele in vir die donateur en donasies wat aan PWSV (SA) gemaak word is aftrekbaar van die donateur se belasbare inkomste. 'n Amptelike sertifikaat sal vir bedrae groter as R100.00 uitgereik word.

Maak gerus 'n direkte inbetaling. Sluit asseblief jou van en selnommer as verwysing in.

WOULD YOU LIKE TO MAKE A DONATION?

With your help we can 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.