



People With Strength

Newsletter for parents by parents

Volume 15 Issue 1 **FOOD SECURITY** March 2012

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



Celebrations with family and friends can be a time of stress for our PWS families.
With good planning, it is possible to make it a happy time for all. *Page 13*

CONTENTS

From the chairperson	2
Van die voorsitter	4
Dale's story	5
Food Security - basic concepts	9
Food Security - check lists	10
Eating our way through the holidays	13
Psychotropic Medication Tip Sheet	15
Journaling your way through stress	17
Making sense of genetics	19
IPWSO News	21
Photo Gallery	23
About PWSA (SA)	25
Advice to new parents	25

WHAT IS PRADER-WILLI SYNDROME?

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

Chairperson:	Rika du Plooy	rikadup@mweb.co.za 012 344 0241
Vice-chairperson:	Janet Legemaate	legemaate@absamail.co.za 031 767 4493
Secretary:	Brian Legemaate	legemaate@absamail.co.za
Medical Advisor:	Dr Engela Honey	engela.honey@up.ac.za 012 319 2269

FROM THE CHAIRPERSON

Dear Readers

We commence 2012 by cherishing the hope that all the information in this newsletter will be to the advantage of all persons with PWS and that it will give parents and persons concerned new insights and motivation and raises their hopes. Following the guidelines and constantly doing the right thing, is not easy. The information about food may be new or well-known. The fact remains that the uncontrolled availability of food can cause uncertainty and stress for parents and persons with PWS. A parent gives us on IPWSO's blog her experience of the reality together with a bit of humour. Do read it. Give this newsletter to friends, family members and everybody concerned. I am sure that it will help to alleviate the burden of parents.



Andy and Mark Richards are members of this association since 2010. They recount the story of their son, Dale, and the struggle they had in obtaining a clear diagnosis of PWS. They express the desire that the FISH analysis test and the DNA methylation test should be done simultaneously in South Africa in order to reach a rapid diagnosis, thereby saving the parents unnecessary costs as well as all the uncertainty. We thank Dr Engela Honey for her explanation on the use of these two tests.

A revised article by Janice Forster and Linda Gourash of the *Pittsburgh Partnership* in Pennsylvania, about the most necessary control over food and food security appears once more in this issue. The planning and availability of meals must be discussed with the person with PWS in order to diminish any uncertainty and stress. Do the same when you are planning a change in the daily routine. The sooner a child with PWS is introduced to 'n structured and healthy meal plan, the better. The basic concepts they use to ensure success are ***no doubt, no hope*** and ***no disappointment***. Follow the check list and it will guide you in the correct procedure of FOOD SECURITY.

Does the prospect of visiting friends or family members or attending a party always cause tension in families with a person with PWS? Janalee Heinemann gives clear advice on how to handle this problem. Once again a team effort is of the outmost importance and includes everybody concerned. Janalee advised that her TIPS are printed out and are handed well in advance to all members of the family, visitors and friends. Ask for this newsletter in electronic format in order to distribute it via e-mail.

In the November 2011 issue of *People With Strength*, and also in this letter, the fact is mentioned that a parent who cares for a child with PWS experiences much stress. Read how

keeping a diary, or journaling, can be an extremely effective tool to discover your innermost thoughts and releasing tensions. It might be worth trying.

For professionals and even parents, an interesting article on the use of psychotropic medication by persons with PWS as well as relating hints are included. Apart from the use of this type of medication, interesting hints on the management of difficult behaviour are also given. Give this article to your family doctor.

Please take note of the following:

- A friendly request: What about an article about your family for our June edition? The writer can be a parent, brother or sister or even a grandmother or grandfather.
- Notices which appear under IPWSO News
- Assistance with the distribution of the *IPWSO Medical Alert Booklets*
- DVD: *FOOD, BEHAVIOUR AND BEYOND* which is still available free of charge
- More news on Huis Henri
- A website bringing genetic counselling closer to the community
- This newsletter is also available in electronic format (A4)

Once again a friendly invitation to all our readers to share your needs and joys. If you want to get involved in some way or another (like sending birthday cards to English speaking persons) or putting your skills to our advantage, let us know about it.

Best wishes
Rika du Plooy.

Using the analogy of the mobile being touched, the only outcome does not need to be constant turmoil. The motion of the mobile can also create a rhythm that brings about a sense of calm. Just as an outsider controls the movement of a mobile, so support networks around a family with a person with PWS can help adjust the rhythm, creating a sense of ability and coping.

From: **Making Sense of Genetics**, page 19
By Noelene Kinsley and Suretha Erasmus – genetic counsellors

Liewe Lesers

Ons skop 2012 af met die verwagting dat al die inligting in hierdie nuusbrieff tot voordeel van die persoon met PWS sal wees en dat dit vir ouers en alle ander betrokkenes nuwe insigte, motivering en hoop sal bring. Om al die riglyne en inligting te volg en altyd die regte ding te doen is nie maklik nie. Van die inligting is nuut, ander bekend maar die feit bly staan dat die kwessie van die ongekontroleerde beskikbaarheid van kos, vir die ouer en veral vir die persoon met PWS onsekerheid en stres kan veroorsaak. 'n Ouer skryf op die blog van IPWSO en gee vir ons die realiteit met 'n tikkie humor – lees dit gerus. Versprei hierdie nuusbrieff aan vriende, familie en almal betrokke en ek is van mening dat dit sal help om die las van ouers so 'n bietjie minder te maak.

Andy and Mark Richards is sedert 2010 lede van die Vereniging en vertel die storie van hulle seuntjie, Dale en die stryd wat hulle gevoer het om tot 'n duidelike diagnose van PWS te kom. Hulle spreek die wens uit dat die FISH analiese toets en die DNA metileringsstoets gelyktydig in Suid-Afrika gedoen moet word, om vinniger tot 'n diagnose te kom en so die ouers onnodige onkoste en onsekerheid te spaar. Waardering aan Dr. Engela Honey vir die verduideliking van die gebruik van hierdie twee toetse.

'n Hersiene weergawe deur Janice Forster en Linda Gourash van Pittsburgh Partnership in Pennsylvania, oor die baie noodsaaklike kontrole oor voedsel en ook oor voedselsekureit word weer eens gegee. Beplanning en beskikbaarheid van maaltye moet met die persoon met PWS bespreek word om onsekerheid en gevolglike stres te verminder. So ook wanneer daar 'n verandering in die roetine gaan wees. Hoe gouer die kind met PWS aan 'n gestruktureerde en gesonde eetplan bloodgestel word, hoe beter. Hierdie kwessie word deur geen onsekerheid, geen verwagting en geen teleurstelling aangespreek. Hulle gee ook 'n sinvolle vraelys om ouers tot die korrekte optrede te lei.

Vir gesinne waar daar 'n persoon met PWS is, bring die gedagte aan 'n partytytjie of die samesyn met familie en vriende altyd 'n vorm van spanning. Janalee Heinemann gee duidelike wenke oor hoe om hierdie probleem aan te spreek. Weer eens kom dit neer op beplanning waar almal betrek word en 'n spanpoging is beslis 'n vereiste. Sy stel voor dat haar wenke betyds beskikbaar gestel word aan familie, vriende en besoekers. Vra gerus hierdie nuusbrieff in elektroniese vorm aan as dit makliker is om dit met epos te versprei.

In die November uitgawe van die nuusbrieff en telkens in hierdie stuk kom die feit na vore dat ouers wat na 'n kind met PWS omsien, onder baie druk verkeer. Lees hoe die hou van 'n dagboek of bloot deur te skryf 'n terapeutiese uitwerking op innerlike gevoelens kan hê. Dit mag die moeite werd wees om te probeer!

Vir professionele persone en selfs vir ouers word 'n baie insiggewende artikel met wenke oor die gebruik van psigotropiese medikasie by persone met PWS geplaas. Naas die gebruik van hierdie tipe medikasie word ook ander praktiese wenke vir die bestuur van moeilike gedrag gegee. 'n Goeie artikel om ook aan die huisarts te gee.

Neem ook asseblief kennis van die volgende:

- 'n Vriendelike uitnodiging.....wie gaan vir die Junie uitgawe van die nuusbrief 'n stukkie oor hulle gesin skryf? Dit kan 'n ouer wees, broer of suster of dalk 'n oupa of oma?
- Kennisgewings wat onder IPWSO Nuus verskyn
- Hulp met die verspreiding van IPWSO Medical Alert Booklets
- DVD: FOOD, BEHAVIOUR AND BEYOND wat steeds gratis beskikbaar is
- Meer nuus oor Huis Henri
- 'n Webwerf wat genetiese berading nader aan die gemeenskap gaan bring
- Hierdie nuusbrief is ook elektronies in A4-formaat beskikbaar.

Weer eens 'n vriendelike uitnodiging aan ons lesers om insette te lewer – deel julle behoeftes en vreugdes. As daar 'n behoefte is om betrokke te raak, soos om die verjaardagkaartjies aan die Engeslsprekende persone te hanteer, of as jy sekere vaardighede het wat jy wil aanbied, kontak ons gerus.

Beste wense
Rika du Plooy.

DALE'S STORY

By Andy and Mark Richards



Dale is 4 years old and will be turning 5 on the 25th July. After a long labour, he was born by emergency Caesar at 37 weeks. The doctors and nurses were concerned immediately after his birth that he was very floppy and had a weak cry. He was rushed into neo-natal ICU and was there for 2 days before being transferred to the neo-natal ward. We visited him every day twice a day for a month as he was too weak to suck or cry, and had to be tube fed through his nose. We were told that he might have spina bifida as he had a sacral dimple with a small patch of hair at the bottom of his spine, and that he could have muscular dystrophy, and we wondered if he would ever walk. He had tests done on him in hospital, but nothing came up.

With the help of some very good nurses, we taught him to suck from the bottle. He was fed four hourly as he was too weak to cry. Dale was discharged one month later.

We had more tests done and one of them was for spinal muscular atrophy – the test took three weeks to come back and the waiting was very stressful. The tests however, came back negative. We took Dale to a paediatrician in PE when he was 5 months old, and she did further testing. The paediatrician asked us what tests we would like her to do as we had done so much research on the internet trying to get a diagnosis. One of the tests we asked her to do was the Prader-Willi test, as it came up a few times when we typed in the word “floppy” under symptoms. The Fish test (common deletion type) was done and it came back negative. We were not aware at that time of another PWS test called the Methylation test which detects the rarer type of PWS. A CT scan was done on him, and we were told that he had generalised cerebral atrophy, and that he could have periventricular leukomalacia. We were very upset with this news as we read up on the internet that it had something to do with brain damage.

We took Dale to physiotherapy, and did the therapy at home every day. Our physiotherapist was positive throughout, and she always encouraged us. Even though Dale’s milestones were delayed, he was going from strength to strength, and walked at 20 months. We were happy as he was eating better, but realised he needed intervention at 18 months as he was getting very big. (He was called “Big boy” for a bit) We took him to a nutritionist, and she drew up a meal plan for us, and we cut down on his food intake. Dale also saw an occupational therapist and a speech therapist as he has articulation problems. He wears glasses to help his strabismus, and he wears inserts in his shoes to help his feet walk straight. One of the most common questions asked of me, “was there a lot of movement when you were pregnant?” It was my first pregnancy and didn’t know what to expect.

We were told that Dale needed a muscle biopsy to rule out any muscular dystrophies and atrophies. We decided to have this operation done at the same time as he needed an operation for descending his testes. He was 2 years and 7 months when it was done, and it all came back negative much to our relief.

Our paediatrician phoned us and told us that a geneticist from Johannesburg is coming to East London, and asked us if we would like to see her. I told the geneticist that he had the symptoms of PWS, and had chatted to my uncle who is a paediatrician in New Zealand who was baffled because he said Dale had all the symptoms of PWS, but the test had come back negative. The geneticist said she would like to do the methylation test as they had only performed the fish test, and explained the process to us. The test came back positive and Dale was diagnosed with PWS at 2 years 10 months. The news came as a great shock when she phoned to tell us, even though I always had a suspicion. Nothing prepares you for that kind of news. On the one hand we were very upset about him having this, and on the other

hand we thought at least we know what we are dealing with. We were very upset about the first test indicating negative for PWS as this put us on the wrong track and did so many unnecessary tests.



Dale's cousins have been instrumental in helping his development and stimulation. From left to right Dale, Cassie, Amber, Tayla and Jade

My Aunt who is a doctor in Microbiology in Australia works with geneticists in the labs, and she said they do both the methylation test and fish test together. We wish that this same procedure for all PWS tests could be done in South Africa as this could rule PWS out entirely, and would save people time, expense, and a great deal of stress. If we had waited just three months, we wouldn't have had to do the muscle biopsy, and regretted doing it as it has left a huge scar on his arm, as it did not heal properly after the operation.

Dale had growth hormone stimulation tests in Johannesburg in 2010, and he scored 6 out of 10 which is a failure. We were very apprehensive to start on growth hormone therapy as we were concerned about his sleep apnea. We wanted sleep studies done prior to starting growth hormone, and tried three tests, all of which failed as Dale would pull the wires out of his nose. We went to Cape Town end of last year and saw a paediatric endocrinologist who is now managing Dale. Dale started on growth hormone therapy, and has currently been taking it for one week. We are very grateful for the support of our family GP who has been wonderful in helping us.

Dale attends a pre-school with his carer Linda. He is very happy there, and has improved and grown in confidence. He struggles with fine motor skills, and gets frustrated when he can't do something. His teacher – Aunty Sally has been very supportive, understanding and accommodating.

Dale brings joy to our lives every day. He loves to be outside, and he enjoys running, swimming, gardening, bicycles, motor bikes (real ones!) and his pets. He is a very determined little boy, and always concerned about others. His favourite toy's, are his vacuum-cleaner, lawn mower, Teddy and weed-eater.



Dale and the mower, his favourite in the garden.

We are grateful to have good support from the family. My Mom has been a rock for always listening, words of advice, encouragement and being positive. We appreciate that Paula, my sister showed her support for PWS and had T- shirts made for her and the kids with “I love somebody with PWS” and encouraged us to do same, and make people aware of PWS. Jane, my sister-in-law in Australia has been great with her advice and words of encouragement via e-mail and phone calls.

Dale has always thrived when he has been around his cousins in the way they teach him things, and stimulate him. It always amazes us how much he learns from them when he has been with them. We are also thankful to them for always helping and protecting him, and we know it is very difficult, but appreciate that everybody tries so hard not to snack in front of him.

Dale has taught us so much, and we have learned to appreciate the little things in life. We have also learnt to take one day at a time.

Dr Engela Honey explained the value of the two genetic tests used to diagnose Prader-Willi syndrome. Dr Honey is the medical adviser of the PWSA (SA)

There are two different tests available to diagnose PWS and each has its own indications. The FISH test will pick up a deletion, but not if the PWS is due to any other mechanism such as uniparental disomy or an imprinting mutation. The METHYLATION analysis will confirm or rule out PWS as diagnoses, but won't be able to distinguish between all the different types. The major reason why doctors won't ask for both of the tests is the cost involved. The fact that you will be able to diagnose PWS or exclude it with the methylation test should prompt doctors to rather decide to do this test first and then the decision could be made if it is necessary to continue with other tests. These tests should maybe also include a chromosomal analysis if a translocation is expected.

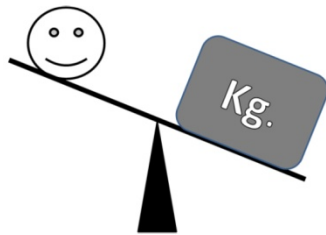
A WARM WELCOME TO MR AND MRS BURGER

’n Hartlike welkom aan Mnr. en mev. Burger van Oudtshoorn wat Februarie 2012 aangesluit het. Hulle is die oupa en ouma van Ruan Burger.

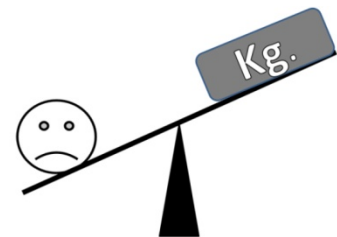
FOOD SECURITY - BASIC CONCEPTS

Prader-Willi Syndrome - Food Security - Basic Concepts

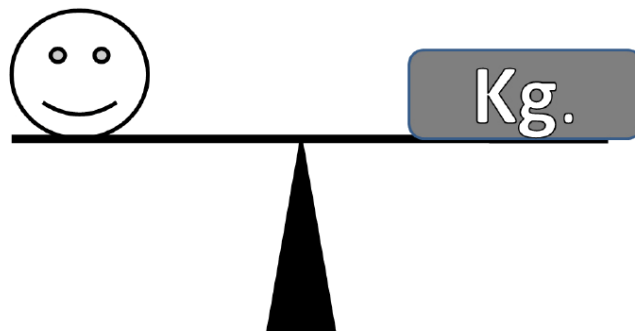
By: Linda M. Gourash, MD & Janice L. Forster, MD of the Pittsburgh Partnership
Specialists in Prader-Willi Syndrome From: www.pittsburghpartnership.com



Families and professionals often mistakenly believe that the patient cannot be happy unless he has as much food as he demands. Because efforts to limit food, if attempted without establishing food security cause increased stress and behaviour problems.

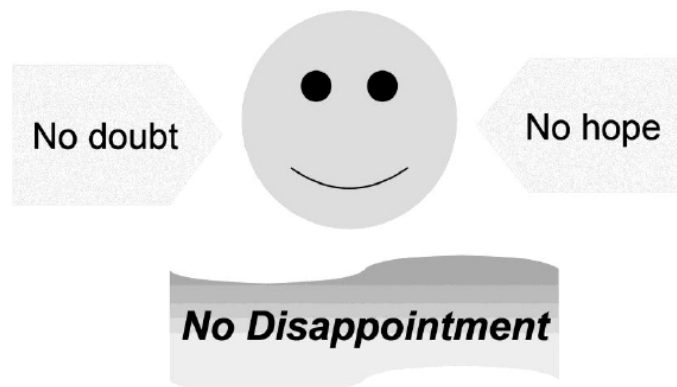


When *Food Security* is fully implemented, weight and behaviour are both managed successfully and simultaneously.



REMEMBER: "FOOD IS STRESS"

Food Security includes:



NO DOUBT

The person with PWS is able to relax and think less about food when he knows the plan for his food each day. This is achieved by a predictable routine for the day in which meals are scheduled reliably among his other activities. Focus on the sequence of events and not the time of each meal. Advanced planning assures the individual of what activities will precede the meal and which will follow. Advanced menu planning provides him with expectations which will be reliably fulfilled.

NO HOPE (NO CHANCE)

As children get older, opportunities for food acquisition increase and they require more measures to assure that they are not hopefully scouting for food all day. Chances to obtain food are stressful and therefore, as much as possible, should be eliminated. The measures taken will depend on the individual's history and capability of food acquisition.

Successful Behavior Management of PWS means that uncertainty about food must be eliminated as much as possible. Advance planning of meals, a schedule of all the day's events with the place of meals clearly identified, reminders of these plans and a behavior program which requires completion of one task before the next activity (including meals) is begun, all contribute to successful behavior management.

FOOD SECURITY CHECKLIST FOR THE FAMILY

NO DOUBT

- | | |
|--|---|
| <input type="checkbox"/> My child has a menu posted. He/she always knows what he/she is eating for the next meal. | <input type="checkbox"/> My child rarely asks about what he/she will be eating. He/she already knows. ☺ |
| <input type="checkbox"/> My child takes his/her lunch to school/work. | <input type="checkbox"/> My child knows when his/her meals are scheduled during the day. ☺ |
| <input type="checkbox"/> My child is rarely disappointed about food. He always gets exactly what he is expecting. ☺ | <input type="checkbox"/> I never threaten my child that a meal will be delayed or changed in any way. |
| <input type="checkbox"/> My child sometimes corrects others about his/her diet. ☺ | <input type="checkbox"/> My child has scheduled zero calorie treats built into his /her daily schedule. |
| <input type="checkbox"/> My child knows when he/she is going to get a treat well in advance. There are no surprises. | <input type="checkbox"/> My child knows that if his usual menu is disrupted for any reason he can always count on the same "alternate". |
| <input type="checkbox"/> My child never receives unplanned treats | |

NO HOPE

- | | |
|--|--|
| <input type="checkbox"/> My child does not have free access to calorie free foods or beverages other than water. | <input type="checkbox"/> [As far as I know] My child has not successfully stolen extra food in the last 2 weeks. ☺ |
| <input type="checkbox"/> During meal preparation another member of the family is assigned responsibility for watching my child with PWS. | <input type="checkbox"/> We have a plan for every special occasion and my child knows what the plan will be well in advance. |
| <input type="checkbox"/> My child rarely argues/tantrums about food. ☺ | <input type="checkbox"/> Even though my child knows and expects his/her diet, I know that he cannot be trusted to maintain it him/herself. ☺ |
| <input type="checkbox"/> When we go to a buffet at a restaurant or party my child knows that I will be preparing his/her plate. | <input type="checkbox"/> My child never prepares his/her own plate. |
| <input type="checkbox"/> My child has someone assigned to be with him/her during lunch at school/work. | <input type="checkbox"/> When we “dine out” or “order out”, we get the menu in advance so that my child knows exactly what he/she may order. |
| <input type="checkbox"/> My child does not keep his/her own money. | <input type="checkbox"/> My relatives/neighbours never offer my child food. I have successfully explained |
| <input type="checkbox"/> At this moment there is no unlocked food anywhere in my home. | |

☺ = signs of success. If you have all of these signs of success your food security is complete!



FOOD MANAGEMENT: "It's sort of a relief knowing the locks are on the cupboards and I don't have to keep looking".

Caption from: Prader-Willi Syndrome and the Older Person, by Linda Thornton.

Available to members of PWSA (SA)

FOOD SECURITY CHECKLIST FOR THE SCHOOL/WORKPLACE

NO DOUBT

- ☐ This student/worker has a menu posted. He/she always knows what he/she is eating for the next meal.

OR

- ☐ This student/worker brings his/her lunch to school/work.
- ☐ During any food preparation another member of the team is assigned responsibility for watching this student/worker with PWS.
- ☐ This student/worker is rarely disappointed about food; he/she always gets exactly what he/she is expecting. 😊
- ☐ This student/worker sometimes corrects others about his/her diet. 😊
- ☐ This student/worker knows when he/she is going to get a treat well in advance. There are no surprises.
- ☐ This student/worker knows that if his usual menu is disrupted for any reason he/she can always count on the same “alternate”.
- ☐ This student/worker rarely asks about what he/she will be eating. He/she already knows. 😊
- ☐ This student/worker knows his/her schedule every day.
- ☐ This student/worker knows when his/her meals are scheduled during the day.

NO HOPE

- ☐ This student/worker is never offered food that is not planned in advance and cleared with his/her family or residence.
- ☐ I never threaten this student/worker that a meal will be delayed or changed in any way.
- ☐ This student/worker has scheduled zero calorie treats built into his /her daily schedule.
- ☐ This student/worker has no access to calorie free foods or beverages other than water.
- ☐ This student/worker rarely argues about food. 😊
- ☐ This student/worker has someone assigned to be with him during lunch at school/work.
- ☐ This student/worker has no opportunity to get food during transitions or transportation. He/she is continuously supervised or the food is stored out of reach.
- ☐ At this moment there is no unlocked food anywhere in the areas where this student/worker is permitted.
- ☐ This student/worker does not have access to money or to vending machines.

- ☐ We have a plan for every special occasion such as birthdays or holiday celebrations and this student/worker knows what the plan will be well in advance.
- ☐ Even though this student/worker knows and expects his diet, the entire team understands that he/she cannot be trusted to maintain it him/herself. ☺
- ☐ This student/worker has not successfully stolen extra food in the last 2 weeks. ☺
- ☐ The other students/workers never offer this student/worker food. Our team has successfully explained to them why they must never do this. ☺
- ☐ Our team never uses treats as unplanned rewards

☺ = signs of success. If you have all of these signs of success your food security is complete!

EATING OUR WAY THROUGH THE HOLIDAYS.....

By Janalee Heinemann from the blog of IPWSO, 4 December 2011
<http://ipwso.blogspot.com>

So... we are coming up to Christmas, Hanukkah, Lunar New Year or just holiday time, and our kids are either off school for weeks, or coming home for the holidays and we experience that panicky feeling of "how can I make this go right!"

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.

Print these tips out and hand it well in advance to all members of the family, visitors and friends.

- 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?”*
- 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 on how to contain the accessibility of food. See to it that where your child is sitting there will not be a lot of bowls of food, rolls, or condiments nearby (many people do not consider how many calories/kilojoules our children can consume with the extras – sugar, butter, catsup, etc.)
- After eating, when people are just visiting, see to it that if the food cannot all be put away, 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. I know you get tired of hearing it, but 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 yet similar to others in variety. 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 clever at doing so.

HOLIDAY WARNING

The holidays have an extra risk factor for our older children and adults with PWS. In the USA, four individuals with PWS were reported to have died of gastric rupture and necrosis. Furthermore, 4 additional individuals were suspected to have gastric dilatation and perforation, but without autopsy evidence. Some of these were over the holidays or special events and due to a food bingeing 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 one also has many opportunities for food ingestion, the lack of feeling full, the high pain threshold, and a weak vomiting reflex – then one has the potential of filling the stomach dangerously full. Because there are many food bingeing 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 that 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.

PSYCHOTROPIC MEDICATION TIP SHEET FOR PATIENTS WITH PRADER-WILLI SYNDROME FOR HEALTH CARE PROVIDERS PWSA (USA)

By: Elisabeth M. Dykens, Ph.D., and Elizabeth Roof, M.A., L.P.E., Vanderbilt University, Nashville, Tennessee, USA
From the website of the PWSA (USA) www.pwsausa.org

Prader-Willi syndrome (PWS) is caused by the absence of expression of paternally derived genetic material to chromosome 15q11-q13 and it occurs in about 1 in 15,000 births. There are three main subtypes of PWS: 70% of cases are due to a deletion of the PWS region on the paternal chromosome 15, and 25% to maternal uniparental disomy (UPD), or when the child inherits both 15 chromosomes from the mother and none from the father. Approximately 2-3% of cases are caused by imprinting mutations (IM) which silence the expression of the critical PWS 15q11-q13 region.

Knowing the genetic subtype is increasingly important, as certain behavioural and psychiatric characteristics are more common in one subtype versus another. Those with UPD, for example, are more apt to show autistic tendencies or autism spectrum disorder, and as they get older, to manifest psychosis or affective disorders. Severe psychiatric illness in cases with UPD likely relates to the over expression of maternal genes in the 15q region, while psychiatric problems in those with deletions seem related to family history. Across subtypes, behavioural or psychiatric flare-ups also relate to stress, environmental changes, and having fewer problem-solving or coping skills than those without intellectual disabilities.

The characteristic physical features of PWS include hyperphagia, food seeking, risks of obesity, and increased pain threshold. Behavioural characteristics include intellectual disabilities, cognitive inflexibility, rigid repetitive behaviours, tantrums, oppositionality and skin-picking. Much focus has been on hyperphagia and food seeking in PWS, which do not typically respond to pharmacological treatments. Yet most parents and caregivers express more concern with the behavioural features of PWS, as these often impede optimal daily living and can pose significant management challenges for families. Many families caring for children and adults with PWS will seek psychiatric treatment for problems such as mood lability, tantrums, skin picking and repetitive behaviours.

Most psychiatrists will not have treated more than one or two cases with PWS. More important than previous experience is a willingness to learn about the management of the clinical features of PWS. Patients with PWS will require more time for the initial evaluation and will need to be carefully monitored and seen with their parents or caregivers, as these informants provide data regarding presenting problems, environmental stressors, concurrent medical problems timelines, etc. Patients with PWS often have limited insight or social judgment, and while they can share their thoughts and feelings, they need help identifying more abstract information related to treatment goals.

Many guidelines used to treat people with intellectual disabilities in general also apply to those with PWS. In this population, for examples, behavioural or psychiatric episodes may relate to untreated pain or medical conditions (e.g. constipation, UTI, dental caries), change

in daily routines (e.g. a teacher is ill, activities are not as planned), or emotional upsets related to loss or change (e.g. pet dies, staff member moves, exaggerated grief reactions). Additional tips that optimize psychiatric work in those with intellectual disabilities involve basic communication. It is often best, for example, to take the lead from parents as to how to best communicate with the patient, to use simple words, speak slowly without shouting, use visuals as needed, and talk directly to patients instead of referring to them in the 3rd person while in ear shot of their parents or staff. The personality strengths and hobbies of those with PWS can also be used in the service of their treatment.

Behavioural interventions are a critical feature of treatment in PWS; they should be tried before psychotropic medications are used, and in combination with all medication trials. Functional behavioural assessments or input from an applied behaviour analyst are highly recommended. The goal of behavioural assessments may be to change the environmental conditions rather than expecting the person with PWS to change. In addition to an individualized behavioural plan, more general supports that work well in people with PWS include daily routines, visual schedules, and positive rewards instead of punishments. Psychiatrists are critically important to the success of the individual's treatment team, which often includes behavioural, educational, residential, and occupational specialists who are less familiar with medications or side-effects.

Psychotic symptoms often emerge in young adulthood and may be missed due to unusual pre-morbid social functioning and reduced abilities to articulate changes in mood or thoughts. Precursors can be subtle, including a worsening in self-care or grooming, changes in sleep and eating patterns, increased withdrawal or sadness, and the onset or worsening of intense or odd preoccupations. Often the insatiable drive to eat may disappear as psychotic symptoms emerge. It is unknown if persons with PWS are prone to reoccurring episodes throughout adulthood, but early identification and treatment of symptoms is a critically important step in optimizing outcomes. Symptoms can be exacerbated by stress and looking to the environment for clues (loss, grief) is often helpful. Psychotic episodes may require brief hospitalization to treat effectively. If so, it is critically important to ensure food supervision during hospitalization.

In a pilot study of 86 individuals with PWS who were currently prescribed medications, Dykens and Roof found that 76% were taking an SSRI and most were taking an SSRI along with other medications such as an atypical antipsychotic. Parents reported that SSRI's or atypical antipsychotic medications helped the most with tantrums, irritability and repetitive behaviours. Neither of these agents was rated as particularly helpful in reducing skin picking, food preoccupations or food seeking.

Medications commonly used in people with PWS include SSRI's to target irritability, perseverative behaviours, tantrums and depressed mood. Mood stabilizers (lithium, depakote, carbamazepine) can target mood lability and outbursts. Atypical antipsychotics (respiridone) have proven effective in aggression, impulsivity and anger outbursts in PWS. A typical side effect from these medications, weight gain, is less common in PWS, perhaps due to high levels of food supervision in PWS. Some side effects (extra pyramidal) are more difficult to assess due to hypotonia, poor temperature regulation and sleep abnormalities in PWS. Long acting stimulants can help settle and focus some patients with PWS, allowing them to take better advantage of educational opportunities or therapies. Most individuals

with PWS do not present with classic hyperactivity (and are instead prone to under activity and daytime sleepiness), but may be distractible and inattentive in the classroom or in social settings. Small doses of long acting stimulants may prevent irritability and increase focus during school hours. Careful attention should be paid to an increase in repetitive behaviour or skin picking, or the emergence of tics. Though many typically-developing children may lose weight or appetite with stimulants, weight and appetite in those with PWS is not usually affected.

Some classes of medication (SSRI's and neuroleptics) are more likely to have side effects at standard doses, possibly as a function of individual drug metabolism differences in PWS. As a general rule, start with small doses and increase slowly watching for possible mood activation or other side effects like agitation or increased irritability. In general, decrease doses when there are signs of adverse reactions or loss of beneficial effects. Clinical lore suggests that patients with PWS respond to unusually low doses of medication. When possible, judge the effectiveness of one medication before adding others to the trial. This approach will help later when you want to taper medications that don't seem effective. Some patients with PWS require more than one medication to control different symptoms. Parents and caregivers need to be informed about possible adverse reactions or drug interactions as they monitor effectiveness. CYP450 testing to assess individual drug metabolism can be very helpful, especially in patients who have not responded well to previous medication trials.

In addition to appointments or calls, a good way of staying in touch with families and patients during treatment is through checklists or diaries that track information about mood, sleep, behaviour and thoughts. Families who seek psychiatric care should keep a diary of every medication visit including the medication prescribed, dosage used, symptoms targeted and reason why discontinued. It is important to let parents know that some medications may lose effectiveness over time, or that sometimes several medications will be tried before finding just the right combination. Expect patients with PWS to give feedback on how medications or dose changes may affect their sleep, moods and behaviour and to be a stakeholder in this process. Listening carefully to their feedback can help ensure better patient compliance and success.

Key Resources for this article are available on the website: www.pwsausa.org

JOURNALING YOUR WAY THROUGH STRESS: FINDING ANSWERS WITHIN YOURSELF

By Robert Naseef, Ph.D.

From: Disorder Zone Archives - www.specialchild.com

Support groups don't seem to work for me. I do get something out of them when I'm there, but day in and day out, sometimes it feels like more than I can bear. Is there anything else that I can try? This is a question I commonly hear from parents of children with special needs. Often we are told to take one day at a time, and that is a helpful concept when we are trying not to be overwhelmed about the future. But what can you do when one day is

just too long and too hard? Try reaching for a pen and paper. Keeping a diary, or "journaling," can be an extremely effective tool for discovering our innermost thoughts and releasing tensions. Setting aside 10-15 minutes to put your thoughts into words may just help to reduce your stress or get its physical symptoms under control.

Many people believe that it is easier to hold in their feelings, but nothing could be further from the truth. In ancient Greece, Hippocrates, the father of medicine, stressed that emotional factors could be a contributing cause in disease as well as a factor in recovery. In more recent times, research psychologist James Pennebaker and others have found a mountain of evidence that demonstrates that disclosing our pain when we're suffering through a major upheaval can greatly improve our physical and mental health. Conversely, holding it in can lead to recurrent health problems as serious as colds, flu, high blood pressure, ulcers, and even cancer.

Having a child with a disability certainly qualifies as a "major upheaval." The inhibition of our upsetting thoughts and feelings is physical work, the burden of which can lead to long-term health problems. People who can open up in a group generally report that they enjoy it and learn from it. In addition, their health notably improves - which incidentally provides the scientific basis for the rapid increase of self-help groups for all sorts of problems. But one size does not fit all. Not everyone can open up in a group, and even for those who get great benefit, the group isn't always there at the time you may need comfort and support.

According to Pennebaker in *Opening Up: The Healing Power of Confiding in Others* (New York: Avon, 1990), writing about our inner turmoil can also be therapeutic. Writing helps us to organize and understand our thoughts and feelings. Keeping a journal that we write in with some regularity can thus be extremely helpful for our physical and emotional well-being. By translating the feelings about the events into words, we can gain perspective and understanding about ourselves and what has happened. When we confront upsetting circumstances by talking or in writing, we are often relieved to discover or rediscover that we are not alone, and this helps us gain insight. We can see ourselves as just ordinary people who happen to be going through a difficult ordeal, and this may be a great consolation.

On a practical note, don't let journaling become a stressor in itself. Writing as a method of emotional release should be done when you feel the urge. It can be daily, weekly, monthly, or just when you feel like it. One technique is to try writing in response to a question. Here's a few to get you started:

1. What's been really hard about being a mother or a father today?
2. What have I learned from this?
3. What moment gave me pleasure or satisfaction?
4. What contributions have I made to my child and my family today?
5. How do I feel about my life in general?
1. Another way to approach this is to complete a sentence stem. Here are a few that I use in the workshops I present:
 1. The best thing about my child is...
 2. The worst thing about my child is...
 3. A feeling or thought that I am embarrassed about is...
 4. Something that made me proud lately happened when...

5. The worst thing about my spouse is...
6. The best thing about my spouse is...
7. The nicest thing someone said to me lately was...
8. I hope that...
9. I grieve about my dream that will never be...
10. I dream a new dream that...
11. My child has taught me that...
12. I am becoming a better person because...

Just as you would consult a specialist for your child if necessary, do likewise for yourself. It is intelligent and wise to acknowledge your own needs as well as your child's. You deserve it.

Try to just let it flow. What comes out may surprise or enlighten you. Often in a conversation, the flow of the interaction will unleash thoughts we never knew we had.

Writing expressively can do the same thing. Thoughts and feelings will emerge from your inner self. The important thing is to look for meaning and growth. Merely writing about the same painful things over and over will not bring healing. Focus on thought as well as emotion in order to tap into your inner healing power. Keep track of your growth or change as you write about your experiences. Searching for new realizations and understandings will keep you on a path of healing.

Websites about journaling can help you get started. Journaling Your Life, for example, offers writing techniques and tips. Check this out at <http://h.arce.tripod.com/journalingyourlife/>. If you don't take to journaling, or if you tend to get more upset instead of less, then try another approach: go to a support group, talk to a fellow parent or close friend, read a good book on the subject, or seek assistance. Sometimes a mental health professional (a social worker, psychologist, or psychiatrist) or a member of the clergy can be helpful to you in understanding your needs. Some people are reluctant to take this step, but when it becomes hard to function from day to day, this kind of help may be in order. Just as you would consult a specialist for your child if necessary, do likewise for yourself. It is intelligent and wise to acknowledge your own needs as well as your child's. You deserve it.

MAKING SENSE OF GENETICS

By Noelene Kinsley and Suretha Erasmus – genetic counsellors

An average meeting of two strangers usually starts off with the traditional ice-breaker, "What work do you do?" To which the answer is, "Genetic counselling", and this is usually met with a "What's that?" These responses do not only come from friends, family and acquaintances, but also medical professionals. This prompted us to develop the website, www.geneticcounselling.co.za.

We are two genetic counsellors in private practice whom realised that many people, including health professionals, are not aware of the clinical genetic services offered in South Africa or of their value. Our website is an online resource where South Africans can get

information about the relationship between genetics and health and how to access appropriate support.

As members of PWSA (SA) you have seen and experienced how the diagnosis of a genetic condition, Prader-Willi syndrome (PWS), can change lives and affect families. This was emphasised in quotes from articles in the last *People With Strength* newsletter, such as “funny parts...could not help for crying...darker days too”, and the analogy of a family as a mobile, that if it is touched the whole structure is disturbed. Both of these stories are reminders of the ongoing effect that a diagnosis of a genetic condition can have on a family and the world around them.

Using the analogy of the mobile being touched the only outcome does not need to be constant turmoil. The motion of the mobile can also create a rhythm that brings about a sense of calm. Just as an outsider controls the movement of a mobile, so support networks around a family with a person with PWS can help adjust the rhythm, creating a sense of ability and coping.

One such service is a support group such as PWSA (SA) where ongoing access to support, help with caregiving and contact with other parents in the same situation provides a sense of community and stability.

Another is genetic counselling, where you are given information to help you understand the complex nature of the genetic condition and its impact on your life, helping you cope and come to terms with the diagnosis. This hopefully enables you to make informed personal and medical decisions.

Many people who could benefit from genetic counselling have not accessed this service. We believe that it is because they are not aware of this resource and its benefit, they were not referred by their medical practitioner or there was no information available that helped them access this healthcare option.

Our goal for www.geneticcounselling.co.za is to build a genetic counselling community website for all South Africans by facilitating interactions between the public, people affected by a genetic conditions, healthcare providers, support groups and genetic services. We hope to achieve this by:

- Promoting an awareness of genetic counselling in South Africa
- Providing a comprehensive web-based genetics resource
- Creating a platform for the public, patients, healthcare providers, support groups and genetic counselling services to connect.

On geneticcounselling.co.za you will find information on genetic counselling – what it is, who should access it; contact information for genetic counsellors, clinical genetic services and support groups. We have also included links to other websites and news articles relating to genetics and health.

The establishment and ongoing development of this website is a step-by-step process based on feedback from you, our community, of your needs, wants and likes. We thank PWSA (SA) for agreeing to be part of this community and look forward to working together with you,

helping people make sense of how genetics impacts health and forming a supportive network between everyone involved.

IPWSO NEWS

It's always about the food...

From: The IPWSO blog Friday, 5 February, 2012

<http://ipwso.blogspot.com>



Here it is, Sunday early afternoon, and I hear, "Is someone coming down for lunch, or are we just not eating today?" It's my daughter, the one with PWS. I know I won't be able to finish this blog until she's had lunch... so...

Later: This week has been a little tiring insomuch as food has been even higher on the list of priorities. We've had a wedding and a baptism to attend and, of course, this is always around food in one way or another. I remember when she was very little, before she was diagnosed, we went to Church one Sunday, and I took her up to Communion whereupon she thrust out her hand to the Vicar and demanded to be fed, "I want bread! I want bread! Unfortunately, at the same time, she upset the chalice of red wine all down his white cassock. I didn't know quite where to put myself and quickly carried her down the aisle to our seat, with her demanding very loudly all the way back, "I want bread! I want bread!" I don't think it went down all that well with either the Vicar or the congregation.

Trying to avoid food issues is a huge struggle for most of us: parents, caregivers, family or friends - whoever the person with PWS is with, and it is quite possibly the most tyrannical issue to deal with. Society demands that food is a natural part of socialising. As our sons/daughters get older, they know this and adapt their tactics accordingly... they know that in a crowd of people, parents are less likely to refuse them food as the thought of a socially embarrassing outburst is not what they want...my daughter, particularly. What's more, she's extremely adept at manoeuvring her way out of sight, and picking her times when I'm deep in conversation. I find social events a huge trial and would rather stay home than face the test!

Last week as we were struggling to reach 35 lengths (walking) up and down the pool, the chief topic of conversation was, yes, food. It's all about what she wants me to buy, whether I have this, or that on the grocery list, when I'm going to get it, what looks as though it's about to run out etc. Whenever she comes shopping with me, and this is something I do try to avoid if at all possible, I notice that she always puts two of whatever into the shopping trolley. Two packets of this, two packets of that. I always take one out, saying we won't starve and the car won't break down, so we can always come back. But she seems to harbour this innate fear of running out of food and won't stop her habit of storing. She also

has a cat which is here with us at the moment - that cat has such a backup of food that I swear we could feed all feral cats within several miles.

I asked her the other day whether she felt full after her meal. She said she did. She knows the difference between feeling hungry and feeling full, or even just feeling ok. She can even hold off and wait for a meal if she's busy doing something else. Once all the food has been cleared away and cupboards locked, she doesn't food-seek or ask for food until she judges it is time for her meals. But she is a fully-fledged opportunist and should any opportunity for accessing food arise, she will take it. So, it's always a situation of being 'on guard', locks secured, guests warned, and situations scanned for any weak spots.

I know it will never go away and I know I will never hear the truth about what happened to the packet of biscuits left out on the bench, and I know there will still be slip-ups with who's got the key, and I realise I will never get the better of the social situations either, but it's amazing how quickly you learn to use those eyes in the back of your head, practice your own sleight of hand, and to lie, yes, outright bare face lie, about things to do with food.

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

Read the different stories as well as all about the activities of IPWSO around the world. <http://ipwso.blogspot.com>. 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.

Our **Light-a-candle-for-IPWSO** fundraiser is going very well and, thanks to the generosity of our donors, we have nearly reached our target of USD60 000. Please take a look at our project – you will see that we have single donors, but we also have group donors. If you feel you are able to contribute, this would be wonderful for IPWSO! The name of the donor or honoured individual will appear with the lighting of the candle. Please visit www.ipwso.org.

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

Diana Drysdale celebrated her 40th birthday on 3 March 2012. We wish Diana good health and lots of happiness for the future. Diana and her parents are members of the association since 1991.

Who is Diana?

Diana loves doing all sorts of crafts with her craft group once a month and the social afterwards. They sell their crafts at a Christmas Market every year and make quite a bit of money for themselves.

Diana enjoys pottering round and dead heading the flowering plants in the garden. She is also fond of bird watching. Diana writes the shopping lists and is a great help getting the shopping

done in quick time. She also likes arranging flowers. Her favourite thing at the moment is going for a massage. Swimming in the sea, looking in rock pools and walking on the beach when the family are at the coast is something she usually looks forward to.



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).

BIRTHDAY CARDS

A friendly request..... Janet Drysdale would like to stand back and requested for a volunteer to do the English cards from next year. Any one is welcome to do the cards and the volunteer can claim expenses. Please inform the management committee if you are interested.

MEMBERSHIP FEES ARE NOW DUE: 1 APRIL 2012

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

HUIS HENRI

Feedback by Botha Warnich, chairman of the Henri Warnich Foundation

We are very excited to announce that the Henri Warnich Foundation is now officially registered as a Section 21 company and we are now geared to get our hands dirty and start raising the much needed funds in order to achieve our goals! The Henri Warnich Foundation was the initiative of Liezl Vlok's family, whose eldest son Ruan, has PWS. Liezl's brother, Hennie, stepped up to the plate and kicked off our fundraising events with his very own stand-up comedy show "Hond se gedagtes" at the Dorpstreet theatre in Stellenbosch. The positive feedback on this sold out show was of such magnitude that a further two shows are to be held in the near future, one of which is already sold out! For bookings, please visit http://website.dorpstraat.co.za/Info_Site/program.aspx?content=1

We are also in the process of brainstorming future fundraising events for 2012 and your feedback and ideas would be much appreciated. We know that there are numerous obstacles and crossroads that await us, but as a very close friend of mine once said: "A miracle we can do the impossible will just take a little bit longer!"

For more about the foundation, our mission and upcoming events, or if you would like "Hond se gedagtes" to come to your town, or if you would like to get involved in any other way, whether in a personal or financial capacity, please go and visit our website at www.henriwarnichfoundation.co.za or contact Botha Warnich on 079 509 2407

or Liezl Vlok on info@mpafa.com

Together we CAN make a difference!

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 assisting with the newsletter
- **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**

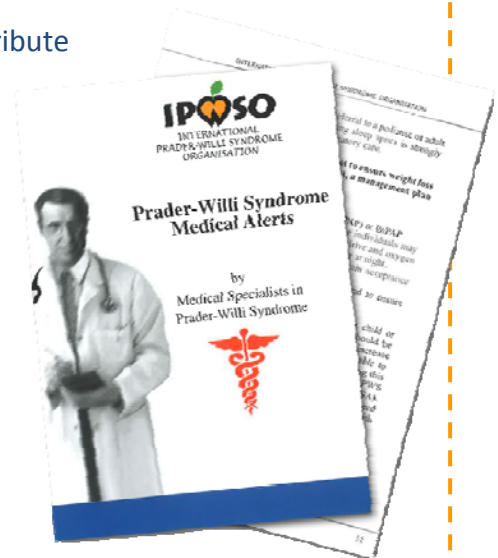
PLEASE HELP: IPWSO MEDICAL ALERT BOOKLETS

Members are requested to assist the committee to distribute the IPWSO MEDICAL ALERT booklets to professionals who you come into contact with. 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. 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



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

THE PRADER-WILLI SYNDROME ASSOCIATION OF SOUTH AFRICA

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

ADVICE TO NEW PARENTS

YOUR CHILD HAS PRADER-WILLI SYNDROME – WHAT HAPPENS NOW?

From the website of the PWSA (SA) www.praderwilli.org.za

It comes as a great shock when you heard that your child is been diagnosed with a syndrome you haven't heard of before. It is natural to be upset and you may experience emotions of

grief, depression, anger, bewilderment, guilt, disbelieve, denial, rejection or perhaps relief. However, how hard it seems to be, it is now the time to consider the well-being of your child and what your child needs most is your love and devotion.

Get as many information on the syndrome, but always remember that behind the syndrome, behind the mass of information, there is a human being who needs love and acceptance.

Some of the information on PWS might be very disturbing and depressing, but it is important to remember that not all people with PWS experience all of the symptoms and certainly not all at the same time in their lives. Never underestimate your child's abilities.

Share the information with family and friends. It will help them to understand your child's problem and their support can play an important role in the management of behaviour and controlling the food environment.

Establish family habits and routines from the very start that will support your child's diet and behaviour needs.

Seek professional help and please do not try to handle this complex syndrome on your own. Families have to deal with very strenuous circumstances and therefore parents and other family members might need counselling to understand and manage the complexities associated with the syndrome.

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

Remember: you can experience a great deal of joy and happiness from your child with PWS.

Take life one day at a time!

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 proof of payment to the treasurer.

Fax: 012 344 0241

BANK DETAILS OF SAVINGS ACCOUNT

PRADER-WILLI SYNDROME ASSOCIATION (SA)

ABSA BROOKLYN, PRETORIA

Branch number **632005**

Acc. no. **11 364 1800**

Reference: Your **SURNAME**

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

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?

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.