People With Strength

Newsletter for parents by parents

Volume 16 Issue 1 **EDUCATION** March 2013

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

Circumstances differ, but it is so important that parents negotiate the best possible form of education for their child with Prader-Willi syndrome – it will require perseverance and a lot of hard work.

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WHAT IS PRADER-WILLI SYNDROME?

- Genetic disorder
- Floppy baby (low muscle tone)
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VAN DIE VOORSITTER

Liewe Lesers

Saam met die draai van die seisoen en die eerste tekens van herfs, die eerste nuusbrief vir 2013. Aan al die lesers……..laat van julle hoor en stuur gerus voorstelle, julle ervarings en stories.

Hierdie nuusbrief is ietwat anders in die sin dat drie verskillende gesinne se ervarings gedeel word en ek is seker dat daar vir elke leser iets sal wees om by baat te vind. Ons hoor van twee ma's se soeke na die regte onderriggeleentheid vir hulle onderskeie kinders en aan die anderkant die storie van 'n jong dame met PWS wat die grootmenswêreld betree. Ons het waardering vir die drie lede wat waardevolle en leersame ervarings met ons deel.

'n Groot deel van die inhoud van hierdie nuusbrief word aan onderwyssake gewy. Van ons ouers wat alreeds daar deur is, weet dat dit nie maklik is om die regte skool vir jou kind met Prader-Willi-sindroom te kry nie. In die meeste gevalle het ouers nie veel van 'n keuse nie. Die kind met PWS het vele eie soortige behoeftes wat inaggeneem moet word. Ouers se taak eindig nie net by 'n soeke na 'n skool nie. Dit is ook belangrik dat die persone wat by die kind met PWS se onderrig betrokke is, die probleem in al sy fasette verstaan. Lees gerus wat Kate Beaver sê oor denke en prosesseringsprosesse by die kind met PWS en dat die rol van angtigheid nooit uit die oog verloor moet word nie. 'n Volgehoue en noue wisselwerking tussen ouer en leerkrag is baie belangrik wat aan beide partye unieke uitdagings bied.

Karin Clarke neem haar dogtertjie se behoeftes inag en lees gerus haar weergawe van die voor-en nadele van hoofstroomonderwys en 'n skool vir kinders met spesiale onderwysbehoeftes.

Janet Legemaate deel met die lesers haar vereistes vir die onderrigsituasie wat by Luke sal pas. Neem kennis van die opmerking van die sielkundige oor toetsing in Luke se geval en dit is my mening dat dit wel van toepassing op die meeste kinders met PWS is.

Li Deegan het die skoollewe verlaat en Margie dink met dankbaarheid terug aan twee spesifieke personeellede. Ons wens Li geluk met die 12 kg gewig wat sy verloor het en Margie vertel hoe dit reggekry is.

Aanvullend tot die unieke eienskappe van die kind met PWS word twee artikels geplaas. Die eerste lig gedragsaspekte aan die leerkrag uit en gee aanbevelings hoe die leerkrag daarop kan reageer. Hierdie inligting kan ook vir vriende en familie insiggewend wees. Soos ons almal weet, verskil kinders met PWS en is daar nie 'n vaste patroon wat gevolg kan word nie. Die nodige aanpassings moet gemaak word om by die kind se behoeftes te pas. Huiswerk is 'n ander kwessie en Barb Dorn gee raad uit eie ondervinding. Sy benadruk dat 'huiswerk' ook gesien moet word as verskillende leer-ervarings in die huis. Sy maak ook 'n interessante opmerking oor die eise wat aan ouers gestel word.

In die November 2012 nuusbrief is berig oor die FamCare komitee onderleiding van Georgina Loughnan van Sydney, Australië, 'n initiatief van IPWSO. Die doel van die komitee is om aan ouers van volwassenes met PWS wat in die huis woon, ondersteuning te gee. Die eerste artikel uit die pen van hierdie komitee handel oor velkrappery (skin picking) en dit is

volgens ‘n vraelys die aspek wat vir ouers die moeilikste is om te hanteer. Lees gerus die artikel elders in hierdie nuusbrief.

Kyk gerus na die potpourri van inligting. Bronne word gegee - vir daardie lesers wat nie toegang tot internet het nie, sal die PWSV (SA) graag help om die inligting beskikbaar te stel.

Lees ook meer oor die volgende elders:

- 8TH INTERNATIONAL PRADER-WILLI SYNDROME ORGANISATION CONFERENCE
- *IPWSO Medical Alert Booklets* is steeds beskikbaar
- Besoek gerus die blog van IPWSO – interessante terugvoer oor “skin picking”
- Baie welkom aan Colleen Norwood en die van Wyk gesin
- Wie is Nakita Verkijk?
- Ledegeld vir 2013 nou betaalbaar
- Hierdie nuusbrief is ook elektronies in A4-formaat beskikbaar – epos dit gerus aan almal wat mag belangstel

Dit is dan ook met hartseer dat ons gehoor het van die afsterwe van JJ Rademan. Ons innige meegevoel aan die Rademan gesin.

Tot ons weer gesels wanneer die volgende nuusbrief einde Junie 2013 verskyn.

Vriendelike groete
Rika du Plooy

FROM THE CHAIRPERSON

Dear Readers

Our first newsletter appears parallel to the first signs of autumn. Keep this newsletter going by sending us your proposals, experiences and stories.

The format of this newsletter differs somewhat from previous editions. We have placed the stories of three different families and from their experiences everybody should find something which will be to his or her benefit. Two mothers are seeking suitable educational institutions for their children. Then there is also the story of a young lady with PWS on the threshold of adulthood. We thank these members, for giving us an insight into their particular world.

A large part of this newsletter deals with educational matters. Parents who have been through this process would know that it is not easy to find a suitable school for your child with PWS. In most cases they don’t have much of a choice either. A child with PWS has special needs which must be taken into account. Looking for a school is just one aspect of the problem. A parent with a child with PWS must know him or her through and through and should help the educator to understand the child. Please read Kate Beaver’s article on thought and the way the child with PWS is processing information. Anxiety plays an important role and should not be disregarded. A sustained interaction between parent and educator is of utmost importance. This of course will set new challenges to both parent and educator.

Karin Clarke talks about her daughter's needs. Read her version of the pros and cons of mainstream education as well as the pros and cons of a school for children with special educational needs.

Janet Legemaate sets her requirements for a teaching situation that will satisfy the needs of her son, Luke. Take note what the psychologist says regarding the use of standardized tests for Luke. It may also apply to most children with PWS.

Li Deegan has completed her school career. Margie remembers two teachers specifically for whom she will always be thankful for. Congratulations Li, for losing 12 kg. Margie reports on how she has achieved this.

Two articles reveal more about the unique characteristics of a child with PWS. The first article would help the teacher to learn more about specific behaviour aspects and how he or she can respond to it. Friends and family will also find this article illuminating. Everybody knows that no two children with PWS are the same. No pattern can be followed. Some adjustments have to be made to satisfy the child's needs. In the second article Barb Dorn writes about homework and gives advice from own experience. Homework must also be regarded as yet another different learning experience at home. She also makes interesting remarks about the demands homework sets to the parent.

The November 2012 issue mentioned the FamCare committee under the leadership of Georgina Loughnan of Sydney, Australia. It is an initiative of IPWSO. The purpose of this committee is to support the parents of adults with PWS living with them. The first article of this committee deals with skin picking. According to a questionnaire skin picking is the most difficult aspect for parents to handle.

Do read our potpourri of information. Sources are given where obtainable. To those readers who don't have access to the internet, the PWSA (SA) will gladly supply the necessary information.

Don't forget to take note of the following as well:

- 8TH INTERNATIONAL PRADER-WILLI SYNDROME ORGANISATION CONFERENCE
- *IPWSO Medical Alert Booklets* are still available
- Visit IPWSO's blog – interesting feedback on skin picking
- Welcome to Colleen Norwood and the Van Wyk family
- Membership fees for 2013 are now payable
- This newsletter is electronically available in A4 format. Do e-mail it to everybody who may be interested

We have learned with sadness of the death of JJ Rademan. All our sympathies accompany the Rademan family.

Until our next newsletter by the end of June 2013!

Greetings
Rika du Plooy.

My appreciation to Francis Morrison who did the translation.

Innige meegevoel

Innige meegevoel word namens die lede van PWSV (SA) aan Frikkie en Anje Rademan en familie oorgedra met die afsterwe van JJ.
JJ is 21 Februarie 2013 op die ouderdom van 20 jaar oorlede.

Condolences

It is with great sadness that we announce the passing of JJ Rademan. He passed away at the age of 20 years on 21 February 2013.
Our deepest condolences go to Frikkie and Anje Rademan and family.

Please help ……who made this deposit?

A cheque deposit was made on 3 August 2012 in Eastgate, Gauteng for the amount of R200.00 - no reference. It might be for membership or a donation?
The treasurer would like to issue a receipt.

BIANCA'S STORY

Written by Karin Clarke

Bianca is about five years and nine months now. She will be turning six on 29th June. She has an older brother Byron who is eight. When we first heard about Prader-Willi syndrome and that Bianca might have it, we were filled with a sense of doom after reading up about it. But so far Bianca has been an absolute joy to us. Obviously we do worry about her future but I try to live in the moment and take it day by day as I find life is far more enjoyable that way. She has a lovely nature, she is pretty easy going and generally co-operative. She is very caring towards other people and has a good sense of humour. She thrives in a routine environment and can sometimes get upset if the routine changes but so far her tantrums have been mild compared to her older brother. We know this may all change but so far so good.

The Diagnosis:

She was born in Cape Town. We noticed two weeks before she was born that she had suddenly stopped growing. Up to this point the pregnancy had been normal. I had a caesar as she was breached and she came out silent, unlike her brother who came out screaming. I was immediately concerned. She remained silent for about two days and couldn't feed. She was in hospital for 10 days until she could drink a bottle on her own. She had to wear a hip brace due to shallow hip joints. We were referred to a neuropeadiatric specialist who called for loads of tests which all came back negative, including two MRI's. We found it all very stressful. At 18 months she recommended we do the test for Prader-Willi syndrome. The geneticist we saw told us the test could only pick up 70% of the cases but that the other test was not available in South Africa. We had read up about Prader-Willi and asked if growth hormone treatment was available in South Africa and she said no. I don't know if we misunderstood her but this was the impression that both my husband and I got. As it turned

out that test came back negative and we thought we would never know if she fell into that other 30% and that there was nothing we could do about it anyway.

A short while after she turned two, my parents were killed in a terrible car accident. It was a huge shock and very hard for me to deal with. I was so grateful for my two sweet innocent children who brought so much light to my days. After losing two perfectly healthy individuals so suddenly like that, made further testing on Bianca seem irrelevant. I was just so glad that she was healthy, happy and alive. We dealt with the symptoms by going to physiotherapy, we went to a dietician when she was about two years old and started speech therapy as early as possible.

Although she would "pig-out" at parties or playdates where sweet food was on offer, her eating did not seem that bad - she was even fussy about what she would eat.

When she was about 3½ her orthopaedic surgeon recommended I see Dr Karen Fieggen, a geneticist at Red Cross War Memorial Children's hospital, as he said he needed a future prognosis in order to decide what to do about her hips. This was the kind of push we needed to do further testing. However, it was a lengthy process due to Red Cross being a government hospital. Just after she turned four we had the Prader-Willi diagnosis confirmed. Even though we suspected it, it was still hard to hear. We were really hoping she would come up with something else…..I guess I sort of knew in the back of my mind the chances that she had it were good, but my husband only dealt with the reality of it when he had the diagnosis confirmed.

Benefits of having the diagnosis:
Despite our reluctance in doing the testing it was beneficial to know, mainly for two reasons. Firstly, we were referred to an excellent dietician who put her onto a semi high protein diet. As a result of this I don't have to count calories as much. The biggest help was putting her on the routine eating schedule. She knows when to expect food and rarely looks for food outside of those time slots. Make no mistake, she does love food. When her brother asked her what she wanted Father Christmas to bring her she said: "A chocolate cake!"

Secondly, we decided to start with growth hormone treatment. As she was 4½ when we started and we have been doing it for a year now, I can see how incredibly it has helped with her physique. She is stronger and leaner and her metabolism has definitely increased. She wasn't hugely over weight before we discovered she had Prader-Willi syndrome but she is definitely thinner, stronger and taller now.

Most importantly Bianca is still Bianca and the diagnosis hasn't changed her, it has made us more aware of the troubles heading our way but has also hopefully equipped us with some skills to handle them.

Developmental challenges and schooling:
The biggest challenge for us so far has been the developmental delays and where to send her to school. We found very vague information on milestones for Prader-Willi as there seems to be so much variance across the group. It felt like we waited forever for speech. At age two she was saying single words so it didn't look too bad at that point but she only really started stringing sentences together from the time she turned five. It was a huge relief, she still doesn't talk much to other children or people, but I am sure with more confidence in her talking ability she will.

We are lucky to live right opposite a small playschool and before Bianca even turned two she started gate-crashing (she couldn't even walk unassisted yet, but she did at two). She stayed there for 2½ very happy years after which I felt I had to move her along. She joined a smallish normal pre-primary. She found this school harder. She tended to drift around quite a bit during freeplay. She likes structure and was a bit lost at break times despite the fact that she had a lovely friend who was a real support to her. They met at playschool and went to the pre-primary together. While at the pre-primary she attended a "special school" called the Centre for Play and Learning once a week. Here she worked one-on-one with a tutor. She also went to a speech therapist and occupational therapist at this centre. She loved going to the "Play Centre", as we called it.

This year the "Play Centre" decided to offer a special needs class as they had quite a few kids like Bianca with learning difficulties who just weren't fitting into traditional schools but wanted to be socialised and not just learning one-on-one with a tutor. I then decided to move Bianca to this school from the Pre-primary school. It was a difficult decision and for us, there have been pros and cons to both which I have summarised below.

Pros for mainstream

- Kids providing appropriate role models, especially in terms of speech
- Ability to make friends with kids without special needs
- Mainstream kids have the opportunity also be desensitised to "different" children (her class mates all loved her even though they didn't interact with her much)
- Loved doing group activities such as counting together, singing, movement to music

Hello Kitty

Cons for mainstream

- Too much unfacilitated free time, free time would have been fine if someone was there encouraging her to "join in" (some children are happy to play on their own but I could see Bianca tended to stick to the sidelines and watch and was very sensitive to the way other children treated her)
- She could lose concentration if there was too much speech e.g: descriptions of themes by the teacher, as the teaching might not be visual enough
- As children get older they work more in groups and get less one-on-one attention from the teacher for the activities they are doing
- Difficulty in interacting with the other children who are talking a lot more

Loving "Bling-bling"

Pros for a school or class for learners with special educational needs

- She is 100% happy in this environment
- Ability to achieve targets and feel accomplishment for doing so
- Morning ring and talking about themes is pitched at an appropriate level
- She still feels a sense of belonging to a group but the group is only six
- More one-on-one attention in teaching new skills
- More visual learning

Cons for a school or class for learners with special educational needs

Lack of peer role models. They are not part of a normal school and I feel they are a bit isolated from other kids as Bianca is a watcher and copier. This was her method of survival at school before she could talk and understand much speech. She just watched her peers and copied them. Now she doesn't have that opportunity so much anymore and there is the potential to copy incorrect behaviours/speech.

Other hobbies and interests:

Bianca also started horse riding this year with the South African Riding for the Disabled Association (SARDA) and she loves it. SARDA is a wonderful organisation and aims to provide the opportunity of therapeutic and recreational horse riding for people with disabilities. She also enjoys swimming which she is relatively better at than most other sports and has just learn to swim safely this summer. She is very enthusiastic to get out and do things. One of her favourite activities is going for "Gold Doubloon" hunts (treasure hunts for 5c coins). We can actually get her to walk a really long way doing this. She has little fear and loves things like the Super tube and even did some tree-top foeffie sliding on a recent holiday. We didn't pay for her as we didn't think she would do it but she climbed up on the obstacles and joined in with the other kids. Her go-getter attitude and enthusiasm has in many ways made up for her "inabilities" which has always been so encouraging for us to see.

A request from Karin Clarke: I would love to hear what other families have found best with older primary school aged children; maybe we could share this information on face book? www.facebook.com/pwsasa Or, you are also welcome to respond to Karin's request by email: karin@discoverymail.co.za

WHAT IS SARDA?

In riding a horse, freedom and independence become a reality.....

South African Riding for the Disabled Association (SARDA) was established in Cape Town in 1973 by Belinda Sampson and Joy Finlay. Today there are branches in Durban, Port Elizabeth, Pietermaritzburg and Gauteng. SARDA is affiliated to the RDA in the United Kingdom and the Federation for Disabled Riding International.

SARDA's aim is to provide the opportunity of therapeutic and recreational horse riding for disabled people so that they might benefit in all aspects of their mental, physical and social lives. All instructors and helpers volunteer their time and knowledge. Background information on the person with the disability is very important in order to provide the safest, most effective care possible.

Please visit www.sarda.co.za for more information

RE-REGISTRATION OF BENEFICIARIES RECEIVING SOCIAL GRANTS

SASSA requested all beneficiaries of Social Grants, including persons with disabilities, to re-register. Upon successful re-registration you will be issued with a permanent SASSA biometric smart payment card that has a chip that contains your biometric information. Your social grant will be transferred on a monthly basis into the SASSA card. Please call SASSA for the nearest venue for your re-registration. **Re-registration date is extended till 30 April 2013**

SASSA Toll free number: 0800 60 10 11

FINDING THAT SPECIAL SCHOOL

Written by Janet Legemaate

At the beginning of 2012 I began the arduous quest to find an acceptable junior school for Luke, our six year old son with Prader-Willi syndrome. 2013 was going to be his first year at “Big School”. By acceptable I mean one where I truly felt that his best interests and needs would be served. It is an understatement to say that I was worried about Luke’s future schooling. This is despite the fact that he had had a really good experience at preschool. This is now “BIG SCHOOL” and all the stresses this entails.

South Africa unfortunately is not geared up for our children like so many other countries are, e.g. Germany, the United Kingdom and United States. At least in these countries the children are given tutors and Individual Evaluation programs etc. But I digress.

Luke's first year at "Big School"

I was also looking for a school where Luke would be in a structured environment, where he would be encouraged to try, try, try, where discipline was good and where they were open to listen, learn and implement ideas to help a child with Prader-Willi syndrome. I began my search in January and quickly identified a few schools in our area which could possibly meet some of my criteria.

I met with an educational psychologist and discussed PWS with him. He then did his own research and called me back for another meeting prior to doing Luke’s assessment over three days. He was very concerned that the standardized tests used world wide would not show Luke’s potential. He was particularly concerned that Luke would be “Written Off” because he was slower in processing. I was really encouraged by his attitude and willingness to assess Luke differently. After assessing Luke he made a point of meeting with Luke’s occupational therapist and speech therapist (Luke has been doing both therapies for 6 and a half years twice a week) and discussing Luke and his progress with them too. Then as a team they approached the schools we had applied to and met with the principle and teachers. The psychologist was determined that Luke was to be given a chance and that the school would accommodate his “differences”.

After much discussion and frustration we narrowed it down to two schools. These were a remedial school in Hillcrest, with speech and occupational therapy on site and the other Charlton Scholars Remedial School in Kloof. The Hillcrest school was larger with 25 children per class whereas Charlton Scholars had a maximum of 10 children per class. We finally chose Charlton Scholars. I then got an opportunity to have a meeting with all the staff to explain what Prader-Willi syndrome was, how it affects Luke and what needs to happen to keep him safe. What a privilege it was to be able to do this. I know that Luke will be cared for and accepted here.

Luke started school in January 2013 and has never been happier. He is up and ready for school by 5:30 in the morning. He has four lunch boxes for school. His breakfast snack as many children have breakfast at school, morning snack, lunch and afternoon snack for the

two days he stays for aftercare. He does his homework immediately on arriving home and is incredibly persistent at school. When I collect him from school, his teacher has at least one anecdote to tell me as he is quite a character. She said to me one day that she told him to stop shouting out, and that he should rather put up his hand. He then put up his hand, looked at her, looked at his hand and promptly said "But Mrs. Jones, my hand can't talk!" A person can not help but laugh. Many such situations have arisen since the first day of school and on occasion we have laughed till we cried.

It took two weeks at school for Luke to begin reading! He is just going from strength to strength and although I know there will most probably be hiccups along the way, I am thrilled at his progress so far.

Our little ones with PWS are so incredibly special and given the opportunity can show the world this too. I am so thankful that I know that God has a plan and a purpose for each of us, Luke included, and that He will work out situations for the good.

HOW DOES A PERSON WITH PWS THINK?

Kate Beaver, Crisis Intervention Counsellor, PWSA (USA)
The Gathered View ~ Prader-Willi Syndrome Association (USA), January-February 2013

Persons with PWS are generally concrete thinkers. Terms like, "Hop to it!" may not be understood to mean "Begin the task immediately" and may cause confusion, anxiety, and result in an unwanted behaviour.

Persons with PWS have a delay in processing the information you give them. Most children will take between 3-5 seconds to understand what you say. If too many instructions are given or the instructions are generalized, they can miss the middle part of what you said and misunderstandings occur. Instead of saying "Go get ready for bed", try breaking the process down into steps. For example, "It's time to brush your teeth", then wait 3-5 seconds before repeating the request. If after the second request they do not comply, do the task with them before asking that they do the next step.

Problem-solving skills are often impaired. This is in part due to the processing problem and not being able to put things in order of how they should be done, which also creates anxiety. Children become frustrated and anxious trying to do what you want them to without being able to know what to do first and what all it entails.
Short-term memory is often poor.

Long-term memory is usually excellent (thanks to ghrelin) so that once something is learned, it's remembered forever.

PWS is about Anxiety
Persons with PWS typically feel high levels of anxiety – all the time.
Maladaptive, unwanted behaviours are often attempts to reduce the level of anxiety the individual with PWS is feeling: skin picking (also done when feeling bored); repeated questions; excessive talking; controlling, oppositional or argumentative behaviour; sleeping.
If you can reduce or eliminate the cause of the anxiety, you'll reduce or eliminate the behaviour problem! The best start is to remember they have a processing delay and they want to please you.

INFORMATION FOR SCHOOL STAFF: SUPPORTING THE STUDENT WHO HAS PRADER-WILLI SYNDROME

Compiled by Barb Dorn, Crisis Counsellor PWSA (USA) www.pwsausa.org

All students with PWS are individuals. Each has varying strengths and needs.
This chart does **not** reflect the behavioural needs of all children and young adults.

COMMON BEHAVIOURS OFTEN SEEN IN STUDENTS WITH PWS	POSSIBLE MANAGEMENT STRATEGIES
Rigid Thought Process It is common for people with PWS to receive and store information in a very orderly manner. There is a strong need for routine, sameness, and consistency in the learning environment.	• Foreshadow changes and allow for discussion. Do this in a safe area where they can share feelings. (The student needs to time to adapt to this change) • If there is a change - use visuals; put things in writing – lists, schedules • If able, communicate changes in personnel ahead of time – but not too far ahead. • Don't make promises you can't keep • Break down procedures into concise, orderly steps. • To resolve "stubborn issues" try using "compromise". Both the student and the educator have to come up with a totally new solution. Not only is this a successful problem-solving strategy – it can also be a form of diversion • Provide praise when being flexible
Perseverative or Obsessive Thinking This is the tendency to get "caught" on one issue or thought to the point where it overshadows the main theme of the learning or social event. This behaviour can contribute to difficulty in transitioning from one topic/activity to another. Students often have an great need to complete tasks. It can lead to loss of emotional control.	• Use reflection – have student restate what you said • Put in writing; use visuals. Carry a small notebook if needed. • Less is best – give less amount of work at one time rather than more. Add to the work as time allows. • Avoid power struggles and ultimatums • Ignore (if possible) • Don't give more information than is necessary especially too far in advance. • Use "strategic timing" – time the activity that the student has difficulty ending right before snack or lunch. • Set limits. "I'll tell you 2 more time, then we move on to next topic. This is #1."
Tenuous Emotional Control Any combination of life stressors can lead to emotional "discontrol".	• Be aware of "hallway over stimulation" – especially before the school day begins. Have student enter the building at a less popular

The result may be exhibited as challenging behaviours such as tantrums – yelling, swearing, aggression, destruction, self-injury. During these episodes, reasoning is lost. Recovery of control takes time and is often followed by sadness, remorse, and guilt. Because of a problem in sequence processing, students are not always able to turn what not to do into what to do.	entrance. If possible, have arrival time be 5-10 minutes after school starts. Dismiss early. • Start the day off on the right foot by allowing time to go over the schedule for the day and work through any changes there may be. Putting the new schedule in writing often helps to decrease anxiety. • At the start of the day – set daily goals with the student. Limit to no more than 3. • Communicate behaviours you wish to see. Make it a cooperative task that provides concrete behaviour expectations. Put goals in writing. Avoid the word "DON'T"… focus on the word "WILL". (Ex. "Please talk in a quiet voice …instead of "Don't yell". When I feel frustrated, I **will** tell Mr. Smith or another adult.") • Provide positive attention and praise when student is maintaining control, especially in difficult situations. Celebrate success! • Encourage communication and acknowledging feelings. Words are important – LISTEN carefully! • Include the student in behaviour plans. Having their input elicits cooperation and a sense of support. • Be a role model. "I always say "darn" when I am angry. Let's try that for you …darn, darn, darn". Practice when the student is **not** agitated or angry. • Depending on the student and the situation – use humour. It is often effective. • Anticipate build up of frustrations and help him/her to remove self to "safe area" • Create a key word or phrase that will alert the student that it is time to go. • Practice using these words/phrases when the student is calm. • Develop a plan and **teach the student what to do** if he/she feels angry or frustrated. Many students substitute a means of releasing this pent up anger – long walks/exercise, ripping paper, tearing rags, popping packaging bubbles… • **Don't try reasoning during times when out of control. Limit discussion.** • Have a plan in place if student becomes more violent. Safety for all is a priority. • Consistency in approach is imperative • Provide positive closure. Don't hold a grudge.

	• If using consequences – they should be immediate and help the student learn from the outburst – saying "I'm sorry", sending a note to say they are sorry ...
Food Craving and Diet Restrictions For people with PWS, the message of fullness never reaches the brain – they are always hungry. In addition to this craving for food, food is metabolized at a rate that causes extraordinary weight gain. Food must be monitored and the individual supervised in all environments.	• Make sure lunch is placed with a bus driver and /or an assistant on the ride to school. • Educate and inform all people working with this student – including bus drivers, custodians, secretaries and volunteers. • If the student states he/she has not had breakfast – call parents or caregiver before giving more food. (Often times they say this to get more food.) • Supervise in lunchroom and in all food related areas – including vending machine areas. In some cases, student may need to eat in classroom (with peer/friend) • Many require supervision in hallways or near unlocked lockers at all times. • Avoid allowing the student to have money. Lock up all sources of money – including purses. Money buys food! • Address any stealing or trading of food in private. • Follow guidelines for treats or eating of extra food. Communication with home is very important. • Follow calorie-controlled diet. If a special calorie diet is needed and served by the school, a prescription must be obtained from a health care provider and should be a part of the student's educational plan. • Don't delay snack or lunch; if this is necessary discuss ahead • Limit availability and visibility of food. Be aware of candy dishes. • Avoid using food as a reward or incentive. • Be aware of smells – there is nothing like the smell of popcorn to make a student with PWS agitated. • When going on a field trip or other outing, discuss all food-related issues ahead of time. Will you bring snack along or will it be purchased? If purchased – what will it be? Will the outing interfere with the time of a meal or snack? • Obtain weekly weight by school nurse if indicated. • Daily exercise should be a part of student's

	schedule. **If a student with PWS is caught with food in his/her possession that is stolen – DO NOT ATTEMPT TO PHYSICALLY TAKE IT AWAY. Try to compromise, trade or other forms of negotiation. Do not threaten. Evaluate what happened. Institute measures to prevent reoccurrence.** • If it is discovered that student has had a binge episode and eaten a large quantity of food – contact parent immediately. This could result in a health emergency. • Encourage to eat slowly – student may choke from eating too fast.
Poor Stamina People with PWS tire more easily and may fall asleep during the day. Morning is typically their optimal learning time, when energy level is highest	• Get person up and moving. Send on errand. Take a walk. • Schedule high energy, mobilizing activity after lunch • Offer items /activities which stimulate large muscles and deep breathing - balloon blowing, party blowers • Provide scheduled rest time or a quieter activity if needed
Scratching and Skin Picking These two behaviours are often seen in individuals with PWS and may be worse during times of stress. Combined with a higher pain threshold, these behaviours can result in tissue damage if not controlled.	• Use diversion - provide activities to keep hands busy (colouring, computer time, play dough, hand-held games, magazines, book…) • Keep nails short. Apply lotion liberally – it keeps skin slippery and soft making it more difficult to pick. Applying lotion can also be an effective diversion. • In extreme cases, provide constant supervision – even in the bathroom. Limit time in the bathroom. • Cover area with band aide or similar covering • Don't just tell him/her to stop picking – it won't work. • Apply mosquito repellent before any walks or outside activity.
Difficulty with Peer Interactions While children want and need other children and value friends, they often lack age-appropriate social skills. They often face challenges in issues of fairness and comparing themselves to others, often	• Many do better in small groups. Benefit from verbal cues and guidance. • Pre-plan outings. Keep time short • "Supported recess or social outings" – planned activities with a friend • Include child in planning activities that are of interest to him/her (board games, puzzles,

resulting in frustration and anger.	computer games…) • Provide social skill classes that emphasize sharing, taking turns… • Role play and practice appropriate social situations. • Clearly state and write do's and don'ts for social interactions w/ friends of opposite sex

Students with Prader-Willi syndrome are very caring, sensitive and conscientious. They want very much to be successful, have friends and be a part of their school community. Although they face some unique challenges, with proper support and understanding … they are playing, learning, working and living successfully in our communities.

Nuwe lede – baie welkom

'n Hartlike welkom aan Loekie en Adriana van Wyk van Durbanville in die Wes-Kaap, wat Februarie 2013 by PWSV (SA) aangesluit het. Hulle seun Chris is 12 jaar oud.

A warm welcome to Colleen Norwood who joined the association early 2013. Colleen is a family member of Nicolas Hall and resides in Bryanston, Gauteng.

HOMEWORK… A LESSON IN FRUSTRATION

by Barb Dorn, Consultant and Training Coordinator, PWSA of Wisconsin, USA.
The Gathered View ~ Prader-Willi Syndrome Association (USA) January-February 2013

I recall the days when homework was a nightmare for our family. As my son Tony, with PWS, grew older; the challenges of homework grew more intense. For many (but not all) homework can destroy family time. There may be students who have PWS and families who do not face this challenge. But for those of you who do…this article is for you, a view on this common educational practice.

Homework is a task that all of us experienced as students. A teacher taught us the material; we performed in-class exercises; then we practiced what we learned in out-of-class "home" work. Homework can teach many students responsibility and accountability. It can help students transfer the learning process from school into the home environment. But…there are a variety of reasons that homework can cause tremendous stress in the home life of students with PWS.

Difficulty in transferring learning to different environments causes frustration in many students with PWS as well as those with other cognitive or learning differences. Most have difficulty transferring or generalizing what is taught in school to the home or other environment. A child may seem to have a clear understanding of a concept or task at school, but when he or she is asked to perform that task outside of the area in which they learned it, they are often unable to do so.

Changes and new ways of teaching have taken place since the times when parents learned many concepts. In addition, many students with PWS require special modifications and approaches that parents have never learned. Well-meaning parents try to reinforce or re-teach a concept during homework time. The child with PWS becomes confused and/or anxious because the parent is explaining things in a different way. Battles often begin when this student then wants to complete the assignment, but the parent hasn't the ability to teach the material in a consistent manner. This results in at-home chaos and emotional upheaval for the entire family.

Role confusion also contributes to frustration. Many students with PWS do not see parents as teachers (even though that can be one of their undercover responsibilities). Many children and adults with this disability rely on the "expert" for the final decision. Unfortunately, the parent is not always viewed as this expert. Siblings often try to help out as well. There are situations where this is successful. There are other times when the whole household gets pulled into the emotions of frustration and misunderstandings that accompany this role confusion.

Poor auditory and short-term memory is often seen in many students with PWS. If exact instructions or assignments are not clearly written down, the student is often unable to remember how to complete the work. The parent is often placed in a "no win" situation--the parent's word against the child's word. Emotions can escalate; logic and learning is lost.

Home can and should be a safe-haven where students with PWS can unwind, relax, and work on home-related and social activities. Many students with PWS work very hard all day long in order to stay focused and in control of their emotions and behaviour. The school environment can present them with many challenges academically, behaviourally, and socially. Lowering stress levels for all who support these students should be a priority. A "no homework" expectation asks for sanity and peace in their homes. Parents face so many challenges; out-of-school work should not be one of them.

"Home work" should focus on different learning experiences. Parents can become experts at teaching the student with PWS life skills, home-related responsibilities, exercise and social skill activities. Parents should be teaching and reinforcing grooming and household tasks. The "parent-teacher" is responsible for teaching bathing and other hygiene tasks, instructing on bed making, laundry, and other cleaning responsibilities. Parents also orchestrate appropriate recreational and social opportunities. Arranging community experiences, providing structured time with friends, expanding social skills, practicing phone skills…and making sure food security is in place are all examples of many valuable life lessons and "home work" that parents provide.

Homework should be eliminated or modified. Students with PWS have some degree of cognitive (learning) and/or behaviour limitations. As the child-and-family advocate, parents need to feel confident in requesting that home time be a time of positive social and leisure opportunities. Educators need to support the separation of school work and home work. Parents are not giving up; instead they are focusing on different yet very important areas of the student's learning needs.

LI DEEGAN – A NEW CHAPTER BEGINS …

By Margie Deegan

Li will be 19 in March and left the Pioneer School in Worcester after 5 memorable years – including two failed attempts at hostel-living, tears of joy and sorrow, up days, down days – in other words, the normal day-to-day story of a teenager living with PWS! All praise and thanks go to her teachers – Mary Ungerer and Hildegard Rabe – whose love, understanding, help, encouragement and, above all – patience, were the major contributing factors in Li's progress plus, of course her own determination!

For six months leading up to the end of last year, Li trained at Pioneer Printing two mornings a week, in the department where they put the finishing touches on CD's they record for sight-challenged people in South Africa, then distribute nationally.

Her function is to make sure that all the incoming (old) CD's are clean and unscratched – if not, she has to clean them then use a special machine to remove the scratches. Once the new CD's have been recorded, it is her responsibility to ensure that they are placed in the correct bags for posting. She loves going to work from 8-1 every day and takes her job very seriously, is conscientious and helpful and gets along with everyone. Pioneer Printing is ideal for Li as everyone is aware of her situation and really supports her. There is no food that she can get her hands on and no money lying around to tempt her!

2012 was a big year for Li regarding weight loss – from the end of January 2012 to December 2012 she lost 12kg and managed to keep it off over the holidays! I am so proud of her achievement and determination. Obviously, the more weight she lost the more incentive she had to continue losing and the "carrot being dangled" of cute new clothes was something she just could not resist!!Initially, our attempt at a weight loss programme was trial and error but we finally succeeded in finding the right balance for Li. We began by giving her main meal at lunch time during the week. Grilled fish, steamed veggies and brown rice (for example) 2x a week; grilled skinless chicken, steamed veggies and brown rice (for example) 2x a week and red meat only once during the week (wors or ostrich mince pasta, etc.).Breakfast is either a measured quantity of corn flakes or maize meal porridge, sprinkled with oat bran and digestive bran with 250ml fat free milk and 1 fruit. Mid-morning snack is a small fat free yoghurt and either a brown rice cake or Ryvita with perhaps peanut butter (no margarine or butter) or Oxo/Bovril with a very thin layer of margarine or fat free cottage cheese. Afternoon snack is a small fat free yoghurt and 1 fruit and supper either a fresh mixed salad with a small quantity of tuna, or smoked chicken breast, 1 scrambled egg or baked beans or boiled egg with sliced tomato and cucumber on the side, a bowl of veggie soup in winter, etc. Li unfortunately does not like to drink water but prefers very watered-down Oros instead! Over weekends I try to stick to the programme as much as possible perhaps only deviating with a late afternoon braai or cooking a curry for dinner. We have stopped ALL bread intake and only go for brown rice, brown pasta and, now and then a small baked potato with plain fat free yoghurt or cottage cheese. We are fortunate to have a lockable pantry at home where we keep our fridge and all foodstuffs – the pantry *is always locked* – which mean no access to the fridge or to other food.

Another big contributing factor in her weight loss has been attending Pilates classes once a week. There has been a huge improvement in her fine and gross motor skills, co-ordination, balance, stamina and toning of all muscles. From March she will do Pilates twice a week. Li also walks home from work every day, with her carer Eunice, a distance of about 2km.

For the past two years Li has been seeing Dr Elizabeth Peter – a Specialist Psychiatrist working out of Groote Schuur Hospital - once every two months initially, now twice a year. Dr Peter prescribed Topamax and Lamotrigine for mood management as well as Vitamin D^3, B Co, Folic Acid, Pro-Biotics, Omega 3, N-Acetyl Cysteine (NAC) for Li-specific reasons. Initially, it was trial and error but we now have the ideal mix and dosages and the results have been very encouraging and there has been a major improvement, especially as far as mood management and general well-being is concerned. Li very rarely gets colds and flu – in fact she is very healthy, thank goodness.

Li, Eunice and Mom

The highlight of 2012 was definitely Li's Matric Dance – you can just imagine the anticipation leading up to it!! The dress was chosen two months before and I held thumbs that she would lose the 1kg necessary to close the zip! She was so determined and it worked! Her dad, who lives in Sweden, arrived a week before the dance and he and I were both invited to attend. The day of the dance was a blur of hair being done, manicures, pedicures and spray-tanning – can you believe?! I insisted on a rest in the afternoon – even at the risk of a little hair damage!! Eventually, the excitement level was at such a peak that I realised Li needed the help of Rescue Remedy – 5 drops under the tongue every half-an-hour – worked like a charm, she was as calm as can be.

Looking back, it has not always been an easy road – however, we both take each day as it comes and face the challenges as they arise. Being a young, newly-independent teenager has brought on a new set of challenges for Li – she misses her school friends and the "comfort zone" of a school environment but we try and organise visits with friends over weekends.

Li certainly would not be where she is today if not for the love and support of family, friends, teachers, colleagues at work and – most importantly, her carer Eunice Menze. We've been blessed to have her in our lives for almost 9 years. Eunice has always been the one constant in Li's life who fully understands the challenges of PWS – both for the person with PWS and the people involved in their lives. She's an absolute *Star*.

Li too, deserves so much credit – she's a feisty young lady who always tries to give her best, no matter what. Her main project this year is to attend a 12-week training course with her beloved dog, Boris. Good luck to the trainer, I say!!!

WHO IS NAKITA VERKIJK

by Rika du Plooy, Chairperson PWSA (SA)

Nakita's motto: "Be kinder than necessary, for everyone you meet is fighting some kind of battle."

I met Nakita Verkijk at the Workshop on PWS held in the Strand, August 2010. She was then a student at the University of Cape Town doing her honours in Human Genetics. She has an interest in PWS and since then she informed parents who visited their clinic about the PWSA (SA) and on a regular basis forwarded their details to be put on the association's address list. She also provided the parents with appropriate educational information on the syndrome.

Nakita started off at the University of Stellenbosch in 2006 doing a BSc course in Human life sciences with biological subjects. The fact that psychology was also included made it the perfect fit for Nakita. She was always fascinated by biology and how the mind works. After her honours she enrolled for the 2 year Masters degree in genetic counselling in 2009, also at UCT and graduated in 2011. She completed her internship over 15 months in order to be allowed to practise as a genetic counsellor.

Unfortunately, Nakita can't continue at UCT as there is no full-time post for her in genetic counselling for this year. However, a wonderful opportunity came her way and she was offered to work part-time with the cardiology department at Groote Schuur with some of their research projects involving inherited cardiac conditions. She is excited because she would still be able to work with the genetics team.

Nakita summarises the work of a genetic counsellor as follows: A genetic counsellor is someone who speaks with families affected by or at risk of having a genetic condition. We discuss the condition itself, how it's inherited, the chances of it happening again in the family, testing options, management, resources, together with seeing how people are coping with the condition in the family.

The genetic counsellor speaks with the parents of children affected by genetic conditions, including other family members who are concerned about their risk to have a child with the same genetic condition, as well as adults who themselves have a genetic condition. They also see couples and women who are pregnant and may have a risk for a genetic condition based on ultrasound scans, other screening tests or their family history. Under discussion is then their risk together with options for testing during a pregnancy if this is something that they would want to pursue.

I want to thank Nakita for her involvement in the lives of parents and their children with PWS. She has such a carrying and friendly personality and on behalf of the PWSA (SA) and all the parents who were supported by her, we wish her a very success career and a blessed personal life.

For more on genetic counselling: www.geneticcounselling.co.za

MEMBERSHIP FEES ARE NOW DUE
1 APRIL 2013

A POTPOURRI OF INTERESTING INFORMATION

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

TWO BOOKLETS FROM THE UNIVERSITY OF QUEENSLAND, AUSTRALIA.

Exercise and Physical Activity for children with PWS by Kristy Reid & Peter Davies
A guide for parents and carers
This guide is intended to give you a better understanding of the importance of managing your child's energy balance, exercise and/or activity levels. We hope the information will help you to ensure they are limiting their calorie intake and expending enough energy to prevent excessive weight gain over time. Other members of the community are important in supporting you and your child. We encourage you to share this guide with your extended families, other carers, educators, and people in your community.
Available via email from the chairperson PWSA (SA): chairperson@praderwilli.org.za

Need to know Nutrition for children with PWS by Prof Peter Davies
A guide for parents and carers
This booklet will provide parents and carers with many hints about how to manage the diet of a child with PWS. This is no easy task in a society where we are bombarded with food, snacks and drinks. The authors will guide you from the infant years to the teens highlighting important aspects of managing their diet at each stage and a food exchange system is explained with practical examples. Throughout the booklet, it is stressed that good habits, once established, will be of great benefit in the long term.
Available via email from the chairperson PWSA (SA): chairperson@praderwilli.org.za

NEW BOOK FOR PARENTS OF BABIES AND CHILDREN WITH PWS

Miracle In Potential, by Australian author Joanne Griggs, is an inspirational story and early intervention resource. This sensitively-written 267-page soft cover book outlines how Joanne and husband Adam created the Multiple Initiative Approach (MIA) to overcome their daughter Mia's global development delay which was due to Prader-Willi syndrome. With a foreword by Associate Professor Dinah Reddihough, Director of Developmental Medicine, The Royal Children's Hospital Victoria, Australia, this "intervention lifestyle" program is based on the idea that everyday life and resources can be used as intervention, when targeted to bring out your child's potential.

From the time Mia was four months old, the family creatively constructed an approach to combat the difficulties related to low muscle tone, global developmental delay, vision impairment, obsessive compulsive behaviours and other behavioural problems associated with food. The strategies and processes they developed are individualized to your family/child's needs and are easy to follow.
www.miaresearchfoundation.com or to order info@pwsusa.org

NEW! ELEMENTARY SCHOOL POWER POINT - DALE AND DOTTIE COOPER

Creating understanding is one of the keys to developing a more welcoming and successful classroom environment for students with PWS. Rob and Debra Lutz, parents of Isabella, created this PowerPoint to promote understanding and awareness in Isabella's elementary school classroom. In a fun and effective way this PowerPoint presentation helps classmates learn about the syndrome and what to expect when sharing a classroom with a student with PWS. This presentation helps to encourage stronger peer relationships and support for a student with PWS, and it enriches the world and understanding of all students as they learn the important lesson that every person is unique, has challenges, and needs support. We invite you to adapt and use this PowerPoint presentation for your child's classroom.
You can download this from the website of PWSA (USA) and revise it to fit your child. www.pwsausa.org. It can be found under Educational Awareness Tools.

THE RED YELLOW GREEN SYSTEM FOR WEIGHT MANAGEMENT (RYG)

The Children's Institute, Pittsburgh, USA

Six colourful pages illustrating the concept of the RED YELLOW GREEN system for weight control. Foods are divided into different groups based on their nutrient content and calorie levels and it provides a generous amount of food that is pleasing to the eye. The illustration is catching and it is easy to understand and even a very young child can participate and make choices, increasing the chance of good dietary compliance.
PWSA (USA) website: www.pwsausa.org and search for RYGBook or go to Products.

HELP OUR CHILDREN AND HELP OTHERS TO UNDERSTAND PWS BETTER!

DVD: FOOD, BEHAVIOUR AND BEYOND PWSA (USA)
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.
Please contact Wilna Basson at 012 991 3399 or e-mail: bassons@iafrica.com

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

A SECOND EDITION OF "GROWTH HORMONE IN PRADER-WILLI SYNDROME"

A reference for families and care providers has now been printed and is available in pdf format from IPWSO's website: www.ipwso.org.
Also available from the chairperson PWSA (SA): chairperson@praderwilli.org.za

MEDICAL CONSIDERATIONS IN PRADER-WILLI SYNDROME

Medical Considerations in Prader-Willi Syndrome Chapter 5, from *The Management of Prader-Wili Syndrome* (3rd Edition) Urs Eiholzer and Phillip D.K. Lee
Available from the chairperson PWSA (SA): chairperson@praderwilli.org.za

AUTISTIC-LIKE BEHAVIOURS IN PWS

It has often been commented upon that behaviours in PWS seem autistic-like. For many years parents have seen this in their son or daughter with PWS, but it wasn't until recently that behavioural specialists and medical researchers started to look more seriously at what this could mean. Read the article on www.ipwso.org under *support*

IPWSO NEWS

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

Read the different stories as well as the news and views of IPWSO around the world. Currently on the blog interesting information on skin picking, from the point of view of those who do the picking. If you've any comments to add, it would be great to hear from you on this topic. http://ipwso.blogspot.com

8TH INTERNATIONAL PRADER-WILLI SYNDROME ORGANISATION CONFERENCE

The Prader-Willi Syndrome Association UK, in partnership with the University Of Cambridge Intellectual & Developmental Disabilities Research Group and the International Prader-Willi Syndrome Organisation (IPWSO) is proud to be hosting the 8th International Prader-Willi Syndrome Organisation Conference to be held at Fitzwilliam College, Cambridge from 18 to 21 July 2013.
A very warm invitation is extended to you to join the PWS community, leading scientists, researchers and practitioners from across the globe. We very much look forward to welcome you at this prestigious event.
For all the relevant information and registration online please contact www.pws2013.co.uk

FAMCARE - A NEW INITIATIVE FROM IPWSO FOR THOSE CARING FOR AN ADULT WITH PWS AT HOME

Famcare is an international committee that has been formed for the purpose of supporting families who have their adult son/daughter/relative with PWS living in the home with them. Georgina Loughnan, an IPWSO Board member, is heading the project. She is supported by a committee consists of parents of adults with PWS and experienced professionals. The committee is also most fortunate to have a highly skilled team of advisors. For more information please contact Georgina at: Famcare@ipwso.org

SKIN PICKING IN PEOPLE WITH PRADER-WILLI SYNDROME

By the Famcare committee, a project of IPWSO

Skin picking or scratching is a common behaviour seen in people with Prader-Willi syndrome (PWS). The intensity and duration of this behaviour varies from person to person and episode to episode. It may occur in the form of scratching an insect bite until it bleeds and becomes an infected sore or it may manifest in the form of nose picking or anal picking. When this behaviour continues for a prolonged period it can cause unsightly and distressing open wounds. 75% of the people surveyed by FamCare reported skin picking in their relative with PWS. A USA study reported anal picking in 9.5 % of people who skin picked.

Why do people with PWS skin pick?

The behaviour is thought to start in response to boredom, stress and anxiety or as a form of self-stimulation. It is also known that people with PWS have a high pain threshold and do not feel pain so intensely. Once commenced it is difficult for the person with PWS to cease the behaviour without some form of external intervention, as they become "stuck" in the behaviour.

If the underlying cause of the skin picking can be identified, especially where stress or anxiety is thought to be a contributing factor, the ideal would be to investigate and discuss what is causing the stress for the person with PWS. If the stress can be removed or decreased, the skin picking should also reduce. Remember, however, that the picking may continue as it may have built up to a repetitive behaviour which will take longer to stop.

What works to avoid skin picking

There are simple and practical strategies that help to minimise the severity and frequency of skin picking, despite the fact that it may still occur spasmodically.

These include:

- routine cutting of finger nails e.g. weekly
- daily use of moisturiser for fingers, hands and arms
  - it is best if the moisturiser is applied by the person with PWS
- positive reinforcement for "healthy, good-looking skin"
- keeping hands occupied – using a "word-find" or puzzle book, computerised game use, object kneading – e.g. soft ball, worry beads, hand craft – such as knitting, crocheting, beading, unravelling woven blankets
- daily sensory stimulation of the hands and arms – e.g. massage
- maintaining a PWS appropriate and calm environment
- brushing hair daily for a number of strokes, counted – e.g. 50, encourages the growth of "beautiful, shiny hair" when the habit of pulling hair out, is a problem.

What works to limit skin picking while it is occurring?

Skin picking often occurs in waves. These can be hard to work through but it is possible to lengthen the time between episodes and shorten the actual periods of skin picking.

Below is a list of strategies that parents and carers have found successful to reduce this behaviour

- tell the person how wonderful their "unpicked" skin is
- tell the person you want to help their *sore* to heal
- give verbal praise for periods of time spent not picking

- offer the person a reward (not food) for time spent not picking – this can be for a few hours or lengthened to days or at the end of a week for 7 days of no picking. Drawing up a *contract* involving "periods of non picking" often works well.
- keep hands occupied at vulnerable times (see above)
  If anal picking is a problem rolling balls of toilet paper while sitting on the toilet may keep hands occupied
- try *not* to focus on or talk about the skin picking
- using distracting calming strategies and verbal re-directive strategies e.g. asking the person to tell you about something that interests them
- dress any picked sores with antiseptic cream if necessary
- cover the picked area with a gauze dressing and bandage to prevent access to the area
- maintain supervision of the person if they are only picking in secret – but nighttimes are difficult
- try using a strong solution of salt and warm water to bathe picked areas
- an Aloe Vera based cream works very well on the sores
- using Calamine lotion to cover the area and make less attention attracting
- in severe cases medication (*only* prescribed by a doctor) may be beneficial –
  e.g. Topiramate, topical Bactroban, ReVia (naltrexone hydrochloride)

All medications must be monitored by a doctor to prevent any reactions within the person with PWS

Skin picking does not occur all the time. Prevention is always the better option, however, techniques used to avoid skin picking need to practised regularly – as with all PWS management

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

WHAT IS PRADER-WILLI SYNDROME?

Prader-Willi syndrome is a complex genetic disorder that typically causes low muscle tone, short stature, incomplete sexual development, cognitive disabilities, problem behaviours, and a chronic feeling of hunger that can lead to excessive eating and life threatening obesity. It is estimated that one in 12,000 to 15,000 people is born with PWS. Although considered a "rare" disorder, PWS is one of the most common conditions seen in genetics clinics and is the most common genetic cause of obesity that has been identified. PWS is found in people of both sexes and all races.

WOULD YOU LIKE TO JOIN THE PWSA (SA)?

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

COST OF MEMBERSHIP

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

BANK DETAILS OF SAVINGS ACCOUNT

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

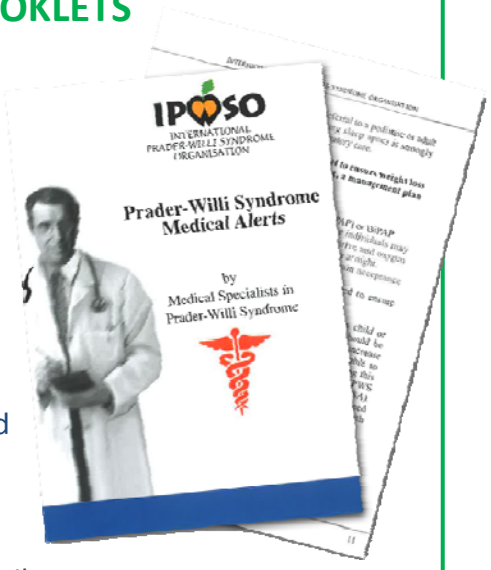
MAAK 'N VERSKIL MET 'N SKENKING!

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.

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.

PLEASE HELP: IPWSO MEDICAL ALERT BOOKLETS



Readers 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 responded to a previous request!
Please contact Janet Legemaate at:
Tel: 031 767 4493 or 082 737 6144 legemaate@absamail.co.za

You are invited to contribute to People with Strength

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

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