People With Strength

Newsletter for parents by parents

Volume 15 Issue 2 **UNDERSTANDING** June 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

Members of the Professional Providers and Caregivers' Advisory Board (IPWSO)

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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

VAN DIE VOORSITTER

Liewe Lesers

Dit is winter!

Hierdie tyd van die jaar word die tweede nuusbrief uitgegee en moet voorbereidings vir die Algemene Jaarvergadering getref word. Ek moet erken dat dit vir my moeilik was om hierdie nuusbrief saam te stel. Die hoeveelheid inligting en navorsing wat rondom die Prader-Willi-sindroom plaasvind, is oorweldigend. Ek het soveel waardering vir elke Prader-Willi-Sindroomvereniging, navorsingsprojek, kundige, ouerpaar, donateur en ander wat saamwerk om nuwe en beter maniere te kry om die persoon met PWS te ondersteun. Ek plaas 'n kennisgewing oor die 2nd International Conference on Hyperphagia, in Los Angeles. Dit gee 'n idée van die navorsing wat rondom die onversadigbare eetlus of hiperfagie, gedoen word.

Ontmoet vir Tshiamo en haar ouers. Dede en Patricia is sedert 2009 lede van die Vereniging en vertel die storie van hulle dogtertjie, Tshiamo. Tshiamo is in die Chris Hani Baragwanath-hospitaal gebore en die korrekte diagnose is baie gou gemaak. Die dokter het die ouers ook ingelig oor die PWSV (SA) as ondersteuningsgroep. Hulle praat Suid-Sotho met Tshiamo en bly in Vosloorus, aan die Oosrand. Waardering aan Dede en Patricia vir hulle deelname!

'n Gesin word uitgenooi om vir die volgende nuusbrief hulle storie te vertel. Dit kan 'n ouer wees, broer of suster of dalk 'n oupa of ouma?

Na aanleiding van die derde jaarlikse Caregivers Conference wat gedurende Meimaand in Bavaria, Duitsland gehou is, het ek besluit om inligting te plaas wat oor twee jaar heen, deur hierdie kundiges opgestel is. Onderleiding van Hubert Soyer en Norbert Hödebeck-Stuntebeck van Duitsland lewer hierdie span uitstekende werk. Meer as 100 kundiges uit 18 lande het nou weer in Duisland saamgekom. Hulle deel kennis, ervaring en besluit dan wat die beste riglyne is om toe te pas in die opleiding van versorgers en die hantering van die persoon met PWS, soos in 'n residensiële opset. Elke jaar word nuwe inligting bygewerk. Inligting waarna ek uitsien is die resultaat van 'n werkwinkel wat gelei is deur Patrice Carroll (VSA) met Dr. Janice Foster en Dr. Hubert Soyer teenwoordig. Dit het gehandel oor sensoriese intergrasie met die fokus op die beste riglyne en hoe dit by die program van die persoon met PWS ingesluit kan word.

In Suid-Afrika is die omstandighede van so 'n aard, dat elke ouer as 'n kundige moet optree en daarom is kennis en insig so belangrik. Die gunstige omstandighede vir die persoon met PWS in van die oorsese lande, in vergelyking met SA, maak 'n mens dikwels moedeloos. Vir die ouers voel dit dikwels asof hulle alleen is in die stryd om vir hulle kind 'n beter plek en omstandighede te beding. Daar is egter soveel inligting beskikbaar en dit is belangrik dat ons as ouers daaruit haal wat op ons omstandighede van toepassing is en dit ook oordra aan diegene wat by ons kinders betrokke is.

Die PWSA (UK) is hard besig met die reëlings vir die IPWSO 8th INTERNATIONAL CONFERENCE wat volgende jaar in Cambridge gehou word. Langs hierdie weg ook baie geluk aan die bestuur en lede met die 30ste verjaarsdagvieringe van die PWS Vereniging van Brittanje.

In hierdie nuusbrief is daar ook ‘n potpourri van boeke, artikels en webwerwe – ek vertrou dat daar iets vir elkeen se behoeftes en omstandighede sal wees. Bronne word gegee waar die inligting beskikbaar is - vir daardie lesers wat nie toegang tot internet het nie, sal die PWSV (SA) graag help om die inligting beskikbaar te stel.

Neem ook asseblief kennis van die volgende:

- Die Algemene Jaarvergadering word op Sondag 19 Augustus 2012 in Pretoria gehou. Meer inligting aan lede gedurende Julie 2012
- Kennisgewings wat onder IPWSO Nuus verskyn
- IPWSO Medical Alert Booklets is steeds beskikbaar
- Twee DVD’s wat gratis beskikbaar is
- Terugvoer oor Huis Henri
- Baie welkom aan die Theron-gesin wat aangesluit het
- Hierdie nuusbrief is ook elektronies in A4-formaat beskikbaar.

Dit is my verwagting dat die inligting in hierdie nuusbrief 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. Lesers is welkom om insette te lewer – deel asseblief julle behoeftes en kwellings.

Wintergroete

Rika du Plooy

FROM THE CHAIRPERSON

Dear Readers

It’s winter!

It’s time again for the second newsletter. It’s also time to prepare for the annual general meeting. It was quite a task to compile this newsletter. The volume of information and research regarding Prader-Willi syndrome in overseas countries are overwhelming. I speak with appreciation of IPWSO, every Prader-Willi syndrome association, research project, specialist, parent, donor and others who all work together to find new and better ways to support the person with PWS.

You'll find a notice in this newsletter of the 2nd International Conference on Hyperphagia in Los Angeles. It gives you an idea of the research being done on the insatiable appetite or hyperphagia.

Meet Tshiamo and her parents. Dede and Patricia are members of our association since 2009. They relate the story of their daughter, Tshiamo, who was born in the Chris Hani Baragwanath hospital. The correct diagnosis was soon made. The doctors also told Dede and Patricia about PWSA (SA) as a support group. They stay in Vosloorus, at the East Rand and speak Southern Sotho with Tshiamo. Thank you, Dede and Patricia, for your informative article.

We cordially invite any family to tell us your story. We are pretty sure that there must be a parent, brother, sister or even a grandmother or grandfather who would like to write their story.

Referring to the annual Caregivers Conference which took place in May in Bavaria, Germany, I decided to publish some of the information compiled by these specialists over a period of two years. Under supervision of Hubert Soyer and Norbert Hödebeck-Stuntebeck of Germany this team does wonderful work. More than 100 specialists from 18 countries gathered again in Germany. They share their knowledge en experience and decide on the best guidelines to use in the training of caregivers and in the treatment of persons with PWS especially in a residential environment. The information is annually updated. I would like to see the results of a workshop led by Patrice Carroll (USA). Dr Janice Foster and Dr Hubert Soyer were part of this workshop. They discussed sensory integration and how to include and apply it in the programme designed for persons with PWS.

In South Africa, the circumstances are of such a nature, that every parent has to virtually be a specialist, and therefore knowledge and insight is important. The favourable conditions in overseas countries that people with PWS seem to enjoy, in comparison with South Africa, can often make us demoralised. Parents often feel that they are alone in the battle to ensure their child is in a good situation. There is in fact a lot of information available and it is important that we as parents keep on seeking information that is relevant to our children and our circumstances and pass it on to those people who play and important role in the lives of our children.

The PWSA (UK) is already busy with the arrangements for the 8th INTERNATIONAL CONFERENCE which will be held in Cambridge in 2013. See the notice on the Conference in Cambridge under IPWSO News. We want to congratulate the committee and members with the 30th birthday celebration of the PWS Association in Britain.

You will find a potpourri of books, articles and websites in this issue and where to look for them. You will definitely find some interesting information. If you do not have access to the internet, we will gladly supply the information.
Please take note of the following:

- The annual general meeting on Sunday, 19 Augustus 2012, in Pretoria. More information to members will be forwarded in July 2012.
- Notices under IPWSO News.
- IPWSO Medical Alert Booklets are still available.
- Two DVDs free of charge.
- Feedback on Huis Henri.
- Welcome to the Theron family who joined our association.
- This newsletter is also available electronically in A4 format.

I hope that this newsletter will supply the information you need. Your input is most welcome. Let us share your joys and worries, and please remember to forward the newsletter to those who are involved with your child.

Winter greetings

Rika du Plooy.

My appreciation to Francis Morrison for his assistance with the translation

While it is important to have good research, it is just as important to recognise the person under the syndrome.

From: A Case Study by Linda Thornton

From: the **Pam Eisen Memorial Talk** by Linda Thornton at the **3rd International PWS Caregivers' Conference.** (The audience was a group of specialised caregivers of people with PWS).

The reason I am telling you all of this is because your information is infinitely more important to caregivers and parents than a medical description.

Because understanding the syndrome means understanding the person.

Because understanding the person means understanding the family, their culture, their economic background, their beliefs and values, and what their child/adult means to them and the place they have in their family and it is their heartfelt desire that you will understand their child as they do, and will give their son or daughter the kind of life that they want for them. And quite often, that they as parents are unable to give.

NOTICE AND INVITATION

THE PRADER-WILLI SYNDROME ASSOCIATION
TAKES PLEASURE TO INVITE YOU TO THE ANNUAL GENERAL MEETING ON
SUNDAY, 19 AUGUST 2012
Vriendekring Bowls Club Grounds, Groenkloof, Pretoria
More info to members to follow

KENNISGEWING EN UITNODIGING

DIE PRADER-WILLI-SINDROOMVERENIGING
NOOI U VRIENDELIK UIT NA DIE ALGEMENE JAARVERGADERING OP
SONDAG 19 AUGUSTUS 2012
Vriendekring Rolbalgronde, Groenkloof, Pretoria
Inligting aan lede volg

PWSA (SA) acknowledge those members for prompt payment of 2012 membership fees

TSHIAMO'S STORY

By Dede and Patricia

Tshiamo 8 months old

Our daughter Tshiamo, turned 9 on the 13th June this year. She was born in the Chris Hani Baragwaneth Hospital by Caesarean section at 37 weeks. It was my first pregnancy, so I did not have the experience to ask common questions like "Is there enough movement in my tummy?" when there were some movements. When she was born the doctors were immediately concerned about her floppiness. They placed her in an incubator for a week while they ran many tests on my baby. I visited her everyday but as she was not able to suckle by herself, I had to feed her with a cup. Sometimes I tried to get her to breastfeed, but she was always sleepy. She just lay there, not crying much.

With the help of the nurses we taught her how to suckle from a bottle. After a week or so, Tshiamo was finally discharged from the hospital, but we were still waiting for the test results. We took her for check ups and after two months Dr Ramdin had the test results. He told us that our baby had Prader-Willi syndrome. We had not even heard of this syndrome, so Dr Ramdin gave us information about it (not many doctors know much about it) and gave us the knowledge we needed about the future challenges in our daughter's development. Because of this, we can now be the best parents we can for Tshiamo.

We were very scared, because despite the information, we really did not know what we were dealing with. Sometimes you think that God is punishing you with this situation, because it has never happened in our family before and we were not prepared for this kind of circumstance. We desperately needed encouragement and support, and we thank our families for understanding that our child is not like other normal children her age.

Tshiamo with her parents on her second birthday

Dr Ramdin suggested that we see a paediatrician called Dr Parbhoo, at the same time in hospital. When we took her there, the paediatrician confirmed it, that really it was PWS. We were told that as our child develops, we would need to take her to a psychologist, a dietician, physiotherapist and a speech therapist, as she would have very slow development compared to other normal children. After taking her to these therapists, we saw that there were some small improvements. She started walking on her own at about 20 months, making baby noises - she was a very lovely baby!

At around about 36 months we noticed that Tshiamo was beginning to gain weight. This raised Dr Parbhoo concerns and he referred us to a dietician. She helped us to draw up a meal plan for Tshiamo, telling us we should cut down on her food intake. Dr Parbhoo also suggested that Tshiamo should take growth hormonal injections, but we were reluctant at first because we did not know the side effects of it. He told us about the sleep test that she had to undergo to check for the risk of sleep apnoea, as well the effects that PWS might have on her spine.

Dr Parbhoo was still doing research on the potential side effects of the Growth Hormone treatment. We had doubts and were concerned that the disadvantages were greater than the advantages. The treatment would have to be taken everyday. Finally, we agreed to have the Growth Hormonal treatment, as we were convinced that it would help Tshiamo's development. We started the treatment when Tshiamo was 6 years old, and we have seen good progress in her development since then.

The difficult aspect of PWS is when we visit other family members in their homes. They don't understand that this child has to be under constant surveillance when it comes to food. They forget that we can not allow her the goodies that normal kids have, and on the other hand she too can't understand why she cannot have these goodies. She is stubborn by nature, but we have managed to teach her that she can't have everything that other kids eat. At least we can be grateful that she hasn't started waking up at night for something to eat. We are also pleased that Tshiamo is very active and she plays with other children. She likes to dance, play with her dolls, playing outside and walking. She even exercises with her mother and they attend a gym every day.


Tshiamo in her school uniform

She started nursery school when she was four years old up until the age of six. She coped very well at the school, and she is currently doing Grade 2 Special at the Sparrow Foundation School. She still has challenges in some areas at school but over all I think she is coping well. Tshiamo brings joy to our lives everyday; she is very talkative but always concerned about the well being of others. However, if she does not want to do something, she won't! She is a very sociable child and loves to visit other family members - she is a very lovely and adorable child. Even when there are sport days at her school and she will try and participate. But best of all, she loves to colour in - I think that one day she will become an artist.

We are grateful to have a very support and understanding family.

GUIDELINES FOR BEST PRACTISE CARE FOR THOSE WITH PRADER-WILLI SYNDROME

Professional Providers and Caregivers' Advisory Board

Above mentioned document has been developed from the International PWS Organisation (IPWSO) Caregivers' and Providers Advisory Board, an international group of specialised caregivers of people with PWS, over a period of three year from 2008. At two international conferences specifically for caregivers, but also including psychologists, behavioural specialists, medical, health, fitness, and dietary specialists, the basics for *Best Practice Guidelines* were forged in order to provide a clear, concise dictum for the overall care of people with PWS. A third conference in Germany was held in May 2012 and the guidelines and recommendations will be revised to include recommended outcomes as they are developed over the next few years.

The document developed for New Zealand by Linda Thornton is available by email from the chairperson PWSA (SA). The document has 158 pages and the file is 3MB. This document not only provides a high level of skilled management, but also assists to recognise the individual needs of each person with PWS.

Excerpts here are taken from *Best Practice Recommendations Guidelines for Residential and Environmental Structure in New Zealand.* Developed from the IPWSO Best Practised Guidelines by Linda Thornton, National Director, PWSA, New Zealand, July 2010.

Members of the Professional Providers and Caregivers' Advisory Board (IPWSO)

See picture on front page – Courtesy of IPWSO

Fanny Cortes (Chile), Larry Genstil (Israel), Mary Ziccardi (Ohio, USA), Norbert Hödebeck-Stuntebeck (Chair, Germany,) Hubert Soyer (Germany), Janice Foster (Pittsburgh Partnership, USA), John Ford (New Zealand), Jackie Mallow (Oconomowoc, USA), Susanne Blichfeldt (absent, Denmark).

Appendix 8

CRISIS MANAGEMENT IN SUPPORT OF PEOPLE WITH PRADER-WILLI SYNDROME: UNDERSTANDING, ACTING, REFLECTING AND PREVENTING CRISIS

Norbert Hödebeck-Stuntebeck (Germany)

Every person who is involved with the care and management of a person with Prader-Willi syndrome will eventually experience a crisis situation. And each crisis experience offers an opportunity to learn how to better manage a crisis in the future. Crisis management is best understood as a circular rather than linear process as demonstrated by the diagram below. Note that the caregiver is at the centre of what is called a circle of support.

This model suggests that successful management and prevention of crisis situations depends on the completion of several steps.

First, caregivers must understand the crisis. Some strategies for understanding include:

- Asking searching questions to gather information about what the person in crisis is thinking and experience.
- Observing the person's physical reactions, expressions, and gestures.
- Making eye contact with the person so that communication remains open throughout.

- Examining any environmental factors that contributed to the crisis.
- Noting who is present and involved in the crisis.
- Establishing what happened before the crisis erupted.
- Determining if this is new behaviour.
- Exploring what the client hoped to gain from this behaviour.
- Recording any consequences (negative or positive) that were applied and to what effect.

Caregivers can then explore what meaning can be derived from information gathered, while completing additional steps in the process.

Second, caregivers must know what to do when a crisis occurs. It is important that caregivers understand their own goal in a crisis situation, and how they will act as a leader in the situation to restore control to the situation. This foreknowledge will allow caregivers to present a clear and stable personal plan for the person with PWS to follow out of the crisis. Specific strategies can be invoked such as:

- Allowing space to the person in crisis
- Use clear and calm speech
- Delay consequences
- Stay out of power struggles
- Help client to get “unstuck” from behaviour or thought contributing to crisis
- Know limits

Third, after the crisis is resolved caregivers should take time to reflect with the client involved. Some issues for client reflection include:

- What did the client do well during the crisis or in resolving it?
- Encourage the client, as able, to explore the perspectives of others involved in the crisis.
- Develop, if possible together, a new behavioural plan to encourage improved behaviour.
- Build bridges with the client through the reflection process. Even if the client is resistant to reflecting allow their participation.

This step should also included reflection of the caregivers to identify what they learned and experienced. A significant portion of time should be allowed for this step and no restrictions should be placed on what is said or shared. The goal is to see the crisis honestly and accurately and with some distance and perspective.

Fourth, caregivers should use information and insight gathered in the three previous steps to inform prevention. Prevention can include making changes to:

- The daily schedule
- Opportunities for people with PWS to expend energy through the day
- The number of available caregivers
- Qualification of caregivers (i.e. would additional crisis response training help?)

- Crisis response protocol
- Level of support the institution provides for crisis intervention
- Utilization of external support (clinics, psychologists, etc.) to help in crisis situations or prevention planning.

Fifth, caregivers must feel empowered. This model is demanding of caregivers and requires strength to complete. However, if implemented properly and continuously, these steps allow caregivers to draw strength from their own experience and the support of those around them. Only empowered caregivers can create a process of crisis management and prevention that is reliable.

During Disruptive or Shutdown Behaviour NEVER:

- Give IN
- Bribe
- Apologise
- Try to Reason
- Make Threats
- Talk about the past or the future
- Tell him/her how desperate you are
- Talk about how he/she is inconveniencing others
- Appear angry or shocked

An excerpt from: Chapter 5 Communicating with persons with Prader-Willi Syndrome

Presented by Linda Gourash, MD, USA

C. BEST PRACTICES

- Caregivers should be trained in active and diagnostic listening. This means they must discern the person’s ability to communicate and to assess their emotional state. They should be aware that there can be a large discrepancy between a PWS client’s apparent understanding and their actual grasp of the big picture, or long term goals.
- They should show concern without being emotionally reactive. Caregivers much be on guard against not making the client feel scolded or shamed; it is important to allow them to save face and to preserve their dignity.
- Care givers should learn to listen without agreeing or disagreeing. Many comments do not require a response. Do not need to directly contradict false statement, fantasies, claims, and dreams.
- Caregivers may need to allow extended periods of time to gradually redirect false beliefs and look for opportunities to provide for the emotional needs with other positive but realizable experiences. Individual counselling can be used very effectively with persons with PWS if the counsellor is patient and understands their need to cling to ideas as long as they need them.
- There is agreement on the value of proactive communication. It is necessary to choose the timing and the opportunity to communicate important information. Weekly meetings and designated communicators are used.
- Proactive communication includes teaching coping skills and scripts to help the person learn in advance ways to be disappointed and angry and to ask for help or to take action to calm themselves down. This learning takes place through discussions when the

person is calm, role playing how to cope when angry, practicing written scripts which may be a part of a contract for how to behave when stressed or angry.

- Schedules can establish expectations and avoid disappointments.
- Persons with PWS benefit from many verbal reminders and frequent praise.
- Caregivers should learn how important their choice of words can be. In particular the person with PWS may overreact to negative statements or the word "no". It is a skill to learn to turn a "No" statement into a positive statement, e.g., rather than say "No, we are not going out today." You might say (with enthusiasm) "Yes! We are going to go next week!"
- Caregivers must be trained on how to communicate during emotional outbursts: Giving physical space, knowing when to remain silent, waiting for the person to calm, intervening only as needed to keep everyone safe. It is effective to limit verbal comment to making suggestions for alternative and safe behaviour.
- Proactively, clients can learn from rehearsing how to cope when they are angry by practicing words and actions that will be acceptable.
- Counselling can help clients to distinguish their own emotions. For instance the difference between mad and sad and the need to take time away when very angry in order to calm down
- Caregivers must be trained on the importance of their tone of voice. Persons with PWS are very sensitive to scolding or blaming tone. Enthusiasm or upbeat tone when appropriate. Redirect in a matter of fact or even supportive tone. If you find someone is trying to provoke, shock or upset you the best response is to look and sound "bored."
- Using humour is a valuable strategy to defuse a tense situation. Sarcasm is never appropriate.
- Caregivers must work in a supportive team model with frequent communications among the team members to prevent misunderstanding and manipulation leading to inconsistency. Inconsistency, even when caused by the client, creates anxiety in the client.

F. FURTHER RECOMMENDATIONS

- It is recommended that all communication with people with PWS be a combination of verbal and visual communication. For those who read, writing a summary of what was said is helpful. A simple drawing can also improve what was understood.
- Using sign language or other hand gestures are ideal as an adjunct to verbal communication for people with PWS.
- It is recommended to check with the person with PWS exactly what he understood. This is easily done by asking him what he heard. He should be able to repeat back what was said.
- When it is desired to communicate instructions, it is best done by clearly stating what is wanted in short, concrete sentences, accompanied by the appropriate visual prompts for that individual When a person with PWS begins verbalizing or arguing in a way which

indicates increasing rigidity, staff continuing making demands of the person only increases rigidity While there may be incidents which cannot be ignored (i.e., self-injurious behaviours), in general, calming, supportive communication is best at reducing the rigidity and preventing a possible tantrum

- The method most recommended is similar to assertiveness training, in which a behaviour which has been problematic is role played as previously occurred, and then role-played again as it could occur with better judgment. The entire session is video-taped.
- Then the participants in the group view the video and the person critiques his/her behaviours. The Staff asks which role-play made the person look better, which person he/she would prefer to be, which person he/she would like to show to the world.
- The person is then given a homework assignment until the next group meeting for behaviour rehearsal. The homework is to "practice" the behaviour that was found by the person himself to be the best one for him. The combined visual and verbal way he learned of the need for change together with the multi-sensory way of changing it for a more pro-social behaviour by seeing himself/herself on TV, hearing himself/herself, and from the experience of acting it out and rehearsing the new behaviour all create the conditions necessary for improved behaviours.
- Use simple, concrete language.
- Keep communication short.
- Always use visual cuing in addition to verbal language.
- Develop a communication plan for every person, which defines the verbal and visual communication appropriate for each person.
- When giving instructions, use recommendations above, plus demonstration of the instruction and having the person demonstrate back, thus showing he "got it."
- When teaching new behaviours or improving old ones, using a method similar to assertiveness training with video feedback is quite effective. The new behaviour is role-played or the problematic old behaviour is role-played and then an improved version is also role-played At the end of the session, the person is asked which behaviour he/she preferred, which person he/she would prefer to be, etc. Then each person in the group is asked to "practise" the new behaviours until next group.

2ND INTERNATIONAL CONFERENCE ON HYPERPHAGIA

Pennington Biomedical Research Center
Louisiana State University - Baton Rouge, LA
October 17 - 20, 2012

Hyperphagia: Excessive and insatiable appetite which may lead to life-threatening weight gain.

Join the top international scientists in the fields of appetite control and obesity for an opportunity to hear the latest in research and strategy. Parents are encouraged to attend and learn more about this vital aspect of PWS and expand their knowledge for more effective advocacy. The new ideas will be flowing freely, so don't miss out on this unique opportunity!

Top Ten Reasons to Attend the 2nd International Conference on Hyperphagia

- Learn the latest progress in the fight to solve the mystery of hyperphagia from twenty-five world-renowned scientists.
- Tour the largest most sophisticated facility in the world dedicated to appetite, nutrition and obesity research and meet their world-renowned collection of scientists, the Pennington Biomedical Research Center.
- Add to your understanding of the new role stem cell research will play in developing treatments for different aspects of human disease, including the neurology of appetite control.
- Understand the real meaning of hyperphagia and its implications in the public health menace of obesity.
- Observe a debate about the Pros and Cons of bariatric surgery, behavioural therapy and pharmacotherapy in treating hyperphagia, particularly in Prader-Willi syndrome.
- Hear about the connection between the hypothalamus, the brain stem and the various neurological signalling chemicals.
- Answer the question is *Prader-Willi syndrome really the "Window of Opportunity" to help solve the hyperphagia and obesity problems.*
- Build your understanding of the many ways genetics, including epigenetics, the SIM1 gene and gene sequencing are at the forefront of medical research especially appetite control and obesity.
- Enhance your understanding of addiction as a possible central force in runaway appetite.
- Hear about the 2009 Best Idea Grants and meet the grantees and their progress.

For registration details see www.hyperphagia.org

A POTPOURRI OF INTERESTING BOOKS, ARTICLES AND WEBSITES

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

IPWSO'S BLOG

www.ipwso.blogspot.com

The latest IPWSO blog entitled "What Comes Next?" (Saturday, 9 June 2012) is based on a paper written by a senior medical student in Australia who has followed the first year of life of a young child with PWS. The author was amazed at the huge amount of forward planning that is needed for this young child to be successful in competing with the non-disabled world. It points out exactly what can be done for a child where help is available, and without saying anything else; it leaves us wondering what can be done for those where help is not forthcoming.
The full paper written by the medical student is available from the chairperson PWSA (SA).
chairperson@praderwilli.org

BEST PRACTICE RECOMMENDATIONS - GUIDELINES FOR RESIDENTIAL AND ENVIRONMENTAL STRUCTURE IN NEW ZEALAND

By Linda Thornton, National Director, PWSA New Zealand, July 2010.

This document is developed from the IPWSO Best Practised Guidelines.
The document has 158 pages and the file is 3MB. This document not only provides a high level of skilled management, but also assists to recognise the individual needs of each person with PWS. This document is only available via email from PWSA (SA).

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. A hard copy can be ordered from the PWSA (USA). Contact info@pwsausa.org

CHARACTERIZING AND MANAGING BEHAVIOUR IN PRADER-WILLI SYNDROME

Kevin Jackson. Ph.D., CBA. ARC of Alachua County, Gainesville, Florida

Kevin Jackson wrote: "This series of articles is based on my training as behaviour analyst and on my thirteen years of experience in working with children and adults with PWS in family settings, schools, and as director of behavioural services for a large residential treatment program specialising in PWS. The concept and interventions discussed here have been extremely effective in addressing the behaviour of individuals with Prader-Willi syndrome.
Website: www.pwsausa.org

AUTISTIC SPECTRUM 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*

THE FOUNDATION FOR PRADER-WILLI RESEARCH (FPWR) LOS ANGELES, USA

www.fpwr.org

The Foundation for Prader-Willi Research was established in 2003 by a small group of parents who saw the need to foster research that would help their children with Prader-Willi syndrome lead healthier and fulfilling lives. Today, FPWR is composed of hundreds of parents, family members, researchers, and others who are interested in addressing the many issues related to PWS, including childhood obesity, developmental delay, psychiatric disorders and autism spectrum disorders.

The mission of FPWR is to eliminate the challenges of Prader-Willi syndrome through the advancement of research.

INFORMATION SHEET: SELF-INJURIOUS BEHAVIOUR

Self-injurious behaviour was defined by Murphy and Wilson (1985, p. 15) as:

'Any behaviour, initiated by the individual, which directly results in physical harm to that individual. Physical harm includes bruising, lacerations, bleeding, bone fractures and breakages, and other tissue damage.'

From: The Challenging Behaviour Foundation – making a difference to the lives of people with severe learning disabilities. www.challengingbehaviour.org.uk

PWS LOOK-LIKE DISORDERS

In April 2001, Celanie K. Christensen, MS, and Bryan E. Hainline, MD, PhD from the Dept of Medical and Molecular Genetics and Pediatrics of Indiana University School of Medicine, wrote a comparative article on syndromes that have some similar characteristics as Prader-Willi Syndrome, namely other genetic syndromes which presented with obesity and intellectual disability.

Read the article on www.ipwso.org under *support*

FATHERS WITH DISABLED CHILDREN FEEL MARGINALISED

The poll of 500 fathers of disabled children in the United Kingdom by online support community *Netbuddy* and the disability charity *Scope* shows dads are doing all they can to be involved in their child's life but face hurdles every step of the way.

New study of Carer Dads reveals shock findings:
2/3 has relationship problems
15% keep their child a secret from their employers
www.netbuddy.org.uk

FORWARDED BY PWSA (USA)

Have trouble getting your kids to brush their teeth? Try out this great chart! It makes brushing fun and helps them create a great habit! http://www.loveyourteeth.net

TAX MATTERS

"An article which was in the Personal Finance section of your local weekend newspaper".

Disabled not using all their tax breaks
June 10, 2012 at 12:20
By Laura du Preez

Taxpayers with disabilities or who have disabled family members are probably not making full use of the tax deductions to which they are entitled, a tax consultant who specialises in assisting families affected by disabilities says.
www.iol.co.za/business/personal-finance/tax/disabled-not-using-all-their-tax

BIRTHDAY CARDS…

A friendly request…Janet Drysdale would like to stand back and requested for a volunteer to do the English cards from after the AJM in August 2012. Any one is welcome to do the cards and the volunteer can claim expenses. Please inform the management committee if you are interested.

IPWSO NEWS

PWSA (SA) joined the **Candle Lighters** and donated $1000 to IPWSO. You are invited to support this **Light-a-candle-for-IPWSO** project. IPWSO provides valuable resources in all languages which go to desperate parents, many of whom do not have the good fortune to live in countries where there is already information and help. Please take a look at this project – 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 - 18 - 21 JULY, 2013.

PWSA UK
125a London Road, Derby DE1 2QQ
T: 01332 365676 www.pwsa.co.uk
Registered charity 284583

The conference will be held at the Fitzwilliam College, Cambridge, United Kingdom.

From the organisers: We are delighted to announce that the conference will be event-managed by The Conference People who will be handling an online registration system. They will develop a website with all the necessary information about the conference. Registration is planned to be open by January 2013. Contact Patricia Dziunka at pdziunka@pwsa.co.uk in order to receive further details about registration and the website.

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

HUIS HENRI

Feedback by Botha Warnich, chairman of the Henri Warnich Foundation

We are very excited to announce that for the past four months the Henri Warnich Foundation has already been making a difference in the lives of individuals with PWS. The foundation is currently funding two children with PWS to attend Pilates and swimming classes on a weekly basis. The aim is to strengthen their core muscles and hand/eye/feet-coordination and the feedback from their instructors have been extremely positive!

As you all probably know by now, the long term aim/mission of the foundation is to establish a home for individuals with PWS. "Huis Henri" as it is called, must be a safe place with a friendly, homely atmosphere where our children can enjoy a meaningful life. We have had the privilege to meet with Jay and Susan from the USA who has a 24 year old daughter in one of these homes in Wisconsin, USA and they have shared a lot of their knowledge in order to get us closer to our dream. I think if I had to take one positive out of our meeting(s), it will be the fact that there are already numerous such houses in the States and that we might be a lot closer to realising our dream than we think. We knew from the start that the biggest obstacle that we will have to cross will be a financial one.

We have subsequently launched an initiative whereby individuals can get involved by buying a symbolic brick by means of a monthly donation.

Please visit http://www.henriwarnichfoundation.co.za/Page/Details/19 for further information on how to get involved with this initiative, or should you wish to contact us personally, you could call me on 079 509 2407. We would like to thank each and every one who has helped us thus far, whether by financial, spiritual or physical contribution, you are all making a huge difference in the lives of these children.

Together we CAN make a difference!

PHOTO GALLERY

VISITORS FROM THE USA

Susan Henoch and her husband Jay Coggeshall live near New York City, USA. Their 24 year old daughter Sophie lives in one of the Prader-Willi Homes of Oconomowoc, in Wisconsin. They visit Sophie every two months and talk to her every day. During March 2012 they visited Botswana and on their way back spent a few days in the Western Cape. They expressed the wish to meet families or providers involved with PWS in South Africa. Susan and Jay spent time with Karin and David Clarke. Margie Deegan and members of the Warnich family had the opportunity to discuss residential matters with Susan and Jay.

Susan Henoch (left) together with Karin and David Clarke.

From left to right: Hennie Warnich, Susan Coggeshall, Botha Warnich, Margie Deegan, Henri Warnich and Jay Coggeshall.

‘n Hartlike welkom aan Kobus en Rina Theron en hulle twee dogtertjies van Pretoria, wat April 2012 aangesluit het.

You are invited to contribute to People with Strength

Whether you are a parent, medical practitioner, therapist or relation, please send your contributions, questions or suggestions to:

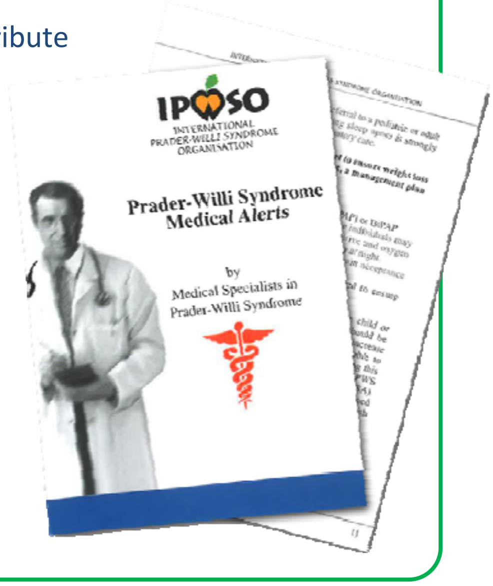
PWSA (SA), PO Box 2399, Brooklyn, 0075 or email: chairperson@praderwilli.org.za

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



IPWSO
INTERNATIONAL PRADER-WILLI SYNDROME ORGANISATION

Prader-Willi Syndrome Medical Alerts

by
Medical Specialists in Prader-Willi Syndrome

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: Strategies for Success PWSA (USA)

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

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).

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.

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.