People With Strength
Newsletter for parents by parents
Volume 18 Issue 1 CELEBRATING 25 YEARS March 2015

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

On this our 25th anniversary, PWS (SA) would like to honour all those, nationally and internationally who spend time and energy on improving the quality of life for all people with Prader-Willi syndrome and their families. We salute all the volunteers involved in bringing awareness to PWS in whatever way. Lastly and with much humility, we want to honour each and every parent or carer worldwide, who selflessly gave all they have to secure the wellbeing of their love one with Prader-Willi syndrome. You are all amazing individuals.

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WHAT IS PRADER-WILLI SYNDROME?

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

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PWSA (SA) IS CELEBRATING 25 YEARS!

IT ALL BEGINS WITH THE PRADER-WILLI SYNDROME

In 1956 Professors Andrea Prader, Alexis Labhart and Heinrich Willi described nine children (five males and four females between the ages of 5 and 23 years) with increased weight, short stature, small hands and a low level of intelligence in a scientific publication. This abnormality was thereafter named as the Prader-Willi syndrome.

Anli Engelbrecht with Dr Andrea Prader (1919-2001) at the 2nd International PWS Conference in Oslo, Norway, June 1995. Dr Prader gave the opening address. Anli is an honorary member of PWSA (SA).

Birgit Shröder-Hadsbjerg was the founder of the Prader-Willi Syndrome Association in South Africa in 1990 and led the association as chairperson until 1996. She was also the parent delegate to IPWSO until her decease in 1998.

CONGRATULATIONS FROM IPWSO

The International Prader-Willi Syndrome Organisation (IPWSO) sends very enthusiastic congratulations to PWSA (SA) on reaching the admirable milestone of 25 years of serving the PWS population in South Africa!! What an accomplishment! This is definitely an achievement that few PWS organisations can claim. Not only have your helped many affected individuals and their families during that time, but you have done it extremely well, producing wonderful materials as well as directly serving those who reach out. Your Association is admired by people around the world.

On behalf of the board of directors, staff and 103 member countries of IPWSO, please accept my heart-felt congratulations on this very special occasion!

Suzanne B Cassidy, MD
IPWSO President

PREVIOUS CHAIRPERSONS AND PROFESSIONAL DELEGATES TO IPWSO

Jeff Donenberg served as chairperson from November 1996 – 1998. Jeff and Hilary joined the association in 1995.

Terry Gordon and family joined the association in 1995 and Terry served as chairperson from 1998 – 1999. They immigrated to Australia in 2005 and currently live in St Ives, Sydney, Australia.

Prof Arnold Christianson served as professional delegate to IPWSO and medical advisor to PWSA (SA) from 1989 and resigned in 2003. He is currently at the Division of Human Genetics at the University of the Witwatersrand, Johannesburg.

After Dr A Christianson resigned, Dr Engela Honey was elected as the professional delegate of PWSA (SA) to IPWSO. Dr Honey is a paediatrician and a senior lecturer in the Department of Human Genetics at the University of Pretoria. She is also the medical advisor to PWSA (SA) and the clinic for persons with PWS is under her care.

FROM THE CHAIRPERSON

Dear Members and Friends

On 12 March 1990 a group of parents gathered in Bryanston, Johannesburg and founded the Prader-Willi Syndrome Association of South Africa. This initiative was undertaken by Birgit Shröder-Hadsbjerg who remained the chairperson for the following six years. In this issue we commemorate this very special event 25 years ago.

I invite members to join me in reviewing the highlights of events over the past 25 years. The founding of IPWSO and all the international conferences organised by this body are included in

Rika was elected as chairperson in September 1999 and is since 2001 also parent delegate to IPWSO.

this review. PWSA (SA) is inextricably associated with the international body. Birgit represented South Africa at the foundation of IPWSO in the Netherlands during 1991 and since then, PWSA (SA) has been a member of the international body.

Please feel free to read the congratulatory message from the President of IPWSO, Dr Suzanne Cassidy, done on behalf of IPWSO and the 103 member countries. We extend our gratitude not only to Dr Cassidy for the good wishes, but also to IPWSO for so much worthy support over the years.

The wonderful donation of R20 000 made by the ladies of the Pretoria Country Club was a pleasant and most welcome surprise in this our 25th anniversary year. We offer our heartfelt gratitude and appreciation to these ladies for their loyalty and care which they have once again extended to the PWSA (SA). See photo elsewhere in newsletter.

PWSA (SA) has now reached the stage where, after 25 years, members will be asked to make an input into deciding the future of PWSA (SA) in a changing world and members will shortly receive a questionnaire in this regard. The association needs people to assume leadership in the years ahead.

Four widely different articles have been reproduced in this issue which should be of benefit to every parent and caregiver. Some of the articles cover areas where parents and caregivers experience difficulties.

It is usual at the onset of a new school year for parents and educators to make enquiries with regard to the handling of children with PWS in the school environment. It is so important that people involved with the education of children with PWS understand all aspects of the problem. In the March 1997 newsletter, Janet Legemaate described the process which they went through in order to find the correct school for their son. Please read the recommendations that Janet has made in the current newsletter. At the beginning of each year Janet requests permission to address educators. This takes dedication but this interaction with the school is so important for the wellbeing of your child. Janet invites all parents to communicate with her via email.

A parent who attended lectures by Dr Janice Forster in the Cape during October 2014 requested help in obtaining information regarding sensory processing and the use of sensory stimulation. Patrice Carroll of Latham Center, USA, complied and wrote an article in this regard. The guidelines contained in the article may also be applied to adults with Prader-Willi syndrome.

A team of experts discuss theft connected with some people living with PWS. Theft may be manifested to a lesser or higher degree. This phenomenon is explained by means of various scenarios and worthwhile advice is given.

The FAMCARE committee has been once again very active. Kindly read about the highly sensitive issue which they tackled. Various professional people have contributed towards this effort. Many thanks to Georgina Loughnan, who still acts as the team leader of this committee.

Tantrums by children or adults living with PWS are often unavoidable. What can we as parents and caregivers do? Patrice Carroll makes four invaluable suggestions – please read this, the implementation thereof will greatly assist you and your child.

Please take note of the following:

- A friendly invitation. Who will contribute an article about their family experiences for the June issue? It could be a parent, sibling or even a grandparent!
- Regarding IPWSO news, see valuable educational and supportive material
- Other supportive material for parents and educators is available via email.
- Membership fees for 2015 are now due.
- This newsletter is also electronically available in A4 format.

I trust that 2015 will be a year of great possibilities for all. Please support PWSA (SA) by letting us hear from you.

Sincere greetings
Rika du Plooy

VAN DIE VOORSITTER

Liewe Lede en Vriende

Op 12 Maart 1990 het 'n klompie ouers in Bryanstan, Johannesburg bymekaar gekom en die Prader-Willi-Sindroomvereniging van Suid-Afrika gestig. Die inisiatief is geneem deur Birgit Shröder-Hadsbjerg wat vir die daaropvolgende ses jaar die voorsitter was. In hierdie uitgawe herdenk ons daardie gebeurtenis, 25 jaar gelede.

Ek het 'n terugskou geneem en volg saam met my die hoogtepunte. Van ons lede sal die begin jare onthou – ek nooi almal om die pad oor 25 jaar saam te stap. Die stigting van IPWSO en al die internasionale konferensies wat deur hierdie organisasie gereël is, is by die hoogtepunte ingesluit. PWSV (SA) is onlosmaaklik verbonde aan IPWSO. Birgit het Suid-Afrika by die stigting van IPWSO in 1991 in Nederland verteenwoordig en sedertdien is PWSV (SA) lid van die internasionale organisasie.

Lees gerus die gelukwense van die president van IPWSO, dr. Suzanne Cassidy. Sy doen dit namens IPWSO en die 103 lande wat lid is van IPWSO. Ons dank nie net aan haar vir die goeie wense nie, maar ook aan IPWSO vir waardevolle ondersteuning oor baie jare.

'n Groot verrassing was die donasie van R20 000 wat van die dames van die Pretoria Country Club ontvang is. Wat 'n wonderlike gebaar aan die Vereniging juis nou tydens hierdie 25-jarige herdenking. Aan hierdie dames ons dank en waardering vir die lojaliteit en sorg wat hulle weer aan PWSV (SA) bewys het. 'n Foto elders in nuusbrief.

Nou is dit 25 jaar later en PWSV (SA) het by 'n punt gekom waar die lede hul insette gevra gaan word om te help besluit oor die toekoms van die PWSV (SA) in 'n veranderde wêreld. Lede sal binnekort 'n vraelys in hierdie verband ontvang. Ons het mense nodig om in die jare vorentoe die leiding te neem.

In hierdie uitgawe word vier wyduiteenlopende artikels geplaas. Elke ouer en versorger behoort iets waardevols daaruit te kry. Van die artikels raak ook aspekte aan wat vir ouers moeilik is om te hanteer.

So in die begin van 'n nuwe skooljaar is daar gewoonlik navra vanaf ouers en leerkragte oor die hantering van die kind met PWS in die skool. Dit is so belangrik dat die persone wat by die kind met PWS se onderrig betrokke is, die probleem in al sy fasette verstaan. Janet Legemaate het in die Maart 2013 nuusbrief oor die proses waardeur hulle is om die regte skool vir hulle seun te kry, geskryf. Lees gerus die aanbevelings wat Janet hierdie keer in die nuusbrief gee. Aan die begin van elke jaar vra sy vir 'n geleentheid om die leerkragte toe te spreek. Dit vra toewyding, maar hierdie interaksie met die skool speel so 'n belangrike rol in die geluk van jou kind. Janet nooi ouers om met haar deur epos te gesels.

'n Ouer wat die lesings van dr. Janice Forster gedurende Oktober 2014 in die Kaap bygewoon het, het 'n versoek gerig om inligting oor sensoriese verwerking en die gebruik van sensoriese stimulasie. Patrice Carroll van Latham Center, USA het ingestem en 'n artikel geskryf. Die riglyne kan ook op volwassenes met PWS toegepas word.

'n Span deskundiges verduidelik diefstal wat by sommige persone met PWS voorkom. Diefstal kan in 'n mindere en meerdere mate voorkom. Hulle verduidelik die voorkoms aan die hand van verskillende voorbeelde en gee waardevolle wenke.

Die FAMCARE komitee was weer bedrywig en lees gerus die uiters sensitiewe onderwerp wat hulle aangepak het. Verskeie professionele persone het ook hiertoe bydraes gelewer. Baie dankie aan Georgina Loughnan wat steeds die spanleier is.

'n Uitbarsting by die kind of volwassene met PWS is dikwels onvermydelik. Wat kan ons as ouers doen? Patrice Caroll gee vier wenke. Lees dit gerus en die toepassing daarvan gaan jou en jou kind help.

Neem ook asseblief kennis van die volgende:
- 'n Vriendelike uitnodiging……wie gaan vir die Junie uitgawe 'n stukkie oor hulle gesin skryf? Dit kan 'n ouer wees, broer of suster of dalk 'n oupa of ouma.
- Onder IPWSO News – sien waardevolle ondersteuningsmateriaal
- Ander ondersteunende materiaal vir onderwysers en ouers wat per epos beskikbaar is.
- Ledegeld vir 2015 is dan ook nou weer betaalbaar
- Hierdie nuusbrief is ook elektronies in A4-formaat beskikbaar.

Mag 2015 vir almal 'n jaar van nuwe moontlikhede wees. Ondersteun PWSV (SA) en raak asseblief betrokke deur jou stem te laat hoor.

Opregte groete
Rika du Plooy.

THE 65th SMYTH CUP GOLF DAY

Rika du Plooy, chairperson of the PWSA (SA) received a donation of R20 000 from the Pretoria Country Club Golf Ladies. The presentation was held at the PCC on Wednesday 25 February 2015. With Rika (middle) is Rona Erasmus (left) and Myrle Irons (right). Rona and Mylre were responsible for the organisation of the traditional Smyth Cup Charity Golf Day.

PWSA (SA) highly values the support and generosity of the golf ladies of PCC.

FOLLOW PWSA (SA) OVER 25 YEARS

1990	March	PWSA (SA) was founded on 12 March 1990 by a small group of concerned and dedicated parents whose children had been diagnosed with Prader-Willi syndrome. The Association owes its existence to the initiative of the late Birgit Schröder-Hadsbjerg and the five families who were present at that first meeting: Hadsbjerg, Kosir, Lake, Basson and du Plooy.
1991	May	The First International PWS Conference was held in Noordwijkerhout, Nederlands. Dr Andrea Prader was invited to this Conference and gave the opening talk.
1991	May	IPWSO was founded on 5 May 1991 at the First International PWS Conference held in the Netherlands. PWSA (SA) was represented by Birgit Schröder-Hadsbjerg and she was then elected on the first Board of IPWSO.
1993	January	Dr Arnold Christianson, then at the University of Pretoria started with research to establish a DNA diagnostic service for patients with PWS. His research was completed in 1998.
1995	June	2nd International PWS Conference was held in Oslo, Norway. Dr Andrea Prader gave the opening address. Birgit Schröder-Hadsbjerg also attended this conference.
1998	April	Birgit Schröder-Hadsbjerg passed away April 1989. Her leadership was recognised, not only in South Africa but also internationally where she represented the PWSA (SA).
1998	May	3rd International PWS Conference was held in Lido Di Jesolo, Italy. Five South African families attended as well as Dr Arnold Christianson who was then elected as professional delegate to IPWSO. David Gordon was elected as parent delegate.
1999	September	First South African Prader-Willi Conference was held at the University of Pretoria. Prof Martin Ritzen (Sweden) and Prof Louise Greenswag (USA) and others were the speakers.
1999	September	The Medical Multi Disciplinary Clinic for persons with PWS at UP was founded under the leadership of Dr Arnold Christianson.
2000	August	Seminar to celebrate the 10th anniversary of PWSA (SA). The Seminar was in honour of the late Birgit Schröder-Hadsbjerg founder of PWSA (SA).
2001	June	The 4th International PWS Conference, Saint Paul, Minnesota, USA. Attended by Dr Engela Honey, professional delegate to IPWSO and Rika du Plooy, who took the place of David Gordon as parent delegate.
2002	April	All parent and professional delegates were invited to an IPWSO meeting in Vicenza, Italy. Rika du Plooy attended this meeting.
2002	August	Workshop presented by Tammy Greyling on *Life Skills for Children*

		and Young Adults with special Educational and Training Needs.
2003	August	After Dr A Christianson resigned, Dr Engela Honey was elected as the professional delegate of PWSA (SA) to IPWSO. Dr Honey is a paediatrician and a senior lecturer in the Department of Human Genetics at the University of Pretoria.
2004	April	5th International PWS Conference was held in Christchurch, NZ. Attended by Rika du Plooy, parent delegate to IPWSO.
2004	October	PWSA (SA) was registered as a Non-Profit Organisation.
2006	January	PWSA (SA) registered as a Public Benefit Organisation.
2007	June	6th International PWS Conference was held in Cluj-Napoca, Romania. Attended by Rika du Plooy, parent delegate and Dr Engela Honey, professional delegate to IPWSO.
2009	June	www.praderwilli.org.za A new website for PWSA (SA)!
2010	May	7th International Prader-Willi Syndrome Organisation Conference was held in Taipei, Taiwan. Attended by Rika du Plooy, parent delegate to IPWSO.
2010	August	Celebrating 20 years. Workshops presented by Linda Thornton in the Strand, Bloemfontein, Durban and Pretoria. *"Understanding the person – understanding the syndrome"*
2010	November	Willowton Oil celebrated their 40th Anniversary and PWSA (SA) was one of 40 charities that received R100 000
2013	July	8th International Prader-Willi Syndrome Organisation Conference was held in Cambridge, United Kingdom. Attended by Rika du Plooy, parent delegate to IPWSO.
2014	October	Dr Janice Forster addressed professionals as well as parents at the Red Cross Children's Hospital, Cape Town.
2015	March	PWSA (SA) was founded 25 years ago!

PLEASE RENEW YOUR MEMBERSHIP

Please consider renewing your membership to the Prader-Willi Syndrome Association (SA). Your financial support enables PWSA (SA) to continue to support parents and to promote knowledge and awareness of the syndrome.
Thank you for your loyalty and support.

A FRIENDLY REQUEST

The next newsletter will appear in June 2015. We invite you to share your story and tell us about your loved one with PWS. Parents, brothers, sisters or even a grandma or granddad are welcome to contribute to our newsletter.

ACKNOWLEDGEMENTS 2015

On this our 25th anniversary, PWS (SA) would like to acknowledge with gratitude the goodwill and support of:

All previous committee members for their dedication
All those who contributed to *People With Strength*
Previous and current members for your loyalty and financial support
IPWSO for continuously forward information regarding important PWS issues
All other international PWS Associations for assistance and sharing of knowledge
All previous donors for your support to our Association
afrihost.com for hosting the Association's website

Elsa Volschenk for her involvement in assisting with the newsletter
Wilna Basson for taking care of the Library and educational material
Karin Clarke and Magdaleen Kloppers for the birthday cards
Johan and Elmaré Mostert for the annually preparation of the financial statements
Dawid Basson, the webmaster of the website and also responsible for Facebook
Jan Els, chartered accountant for auditing the income and expense accounts
Dr Engela Honey, the medical advisor of the Association, who is always available

MY CHILD – FOR TEACHERS

Written by Janet Legemaate

Luke, who is now 9 years old, has Prader-Willi Syndrome (UPD). I was understandably concerned about how things would work out when he went to school. I geared myself up for a huge fight from the beginning but I have been pleasantly surprised. Pre-school was hard from a physical point of view, but Luke is a very determined soul and so wants to do well and please us. He is also very competitive which has its own issues at times. What amazed me was that Luke flourished at pre-school and was well accepted amongst his peers.

I have written previously of the process of getting Luke into a Remedial School from Grade 1. This has been the best decision that we could ever have made. Luke loves school, achieves really well and because everyone there has "issues" of some sort he is a very normal little boy.

Each year, at the beginning of the first term, I have made it my duty to address the whole staff compliment and specifically his class teacher on what Prader-Willi Syndrome is and how it affects Luke personally, and what accommodations need to be taken in class to ensure that he is able to learn properly. This has proved to be of immense value.

My presentation covered basically the following:
A short overview of PWS including the medical issues related to PWS. I focused on those that affect Luke specifically.

I told the staff what we have done and what we are still doing to give Luke the chance to become the best Luke that he can be. For example: Speech Therapy, Occupational Therapy, Bio-kinetics and swimming lessons.

I also included how we regulate what Luke eats, how important it is for *Food Security* and how food in the classroom and food type rewards are an absolute no. I also told them to let me know if ever he has something to eat at school that has not been prepared by me so that I can adjust what he gets at home. Amazingly Luke tells the teacher every time there is cake that he can only have half the size other children have and no icing because he knows mom always has something special for him for snack or dinner later. I make a HUGE effort to make small interesting snacks for Luke and he sees this is a reward.

From an educational point I tell the teachers that their word is law according to Luke so please be VERY careful what you say in class or to Luke. Promises as perceived by him will need to be carried out (otherwise behaviour may change) that is, unless they have offered an alternative during the initial discussion. (This is actually a good thing to do from a parenting and teaching perspective anyway.)

I always make the point of saying at the end of the presentation that what they have learnt today is not just of value to Luke but to all the children in their classes. Food or the knowledge that sweets are available will always be a temptation. Making sure that you explain yourself properly and clearly and offering alternatives for when unexpected things happen to stop you doing something, will always make your life as a teacher easier. For example: we will do art outside tomorrow but if it rains we will watch a short national geographic video.

Luke arrives home from school, does his homework, goes to the therapies scheduled for that day, then comes home to swim or play and do his chores. He is a very contented young boy who is achieving far better than we ever thought he could when he was born. There will always be issues to work on but so far it has definitely not been what I envisaged when he was a little baby.

If you would like to chat and find out more on what we do each year to try and ensure that Luke has a safe and happy year at school, please feel free to email me on legemaate@absamail.co.za What works for one child will not necessarily work for all as parenting styles, expectations and family life differs. However there are a number of really good articles that will give you more insight into what you can do best for your child with PWS.

SUPPORTIVE MATERIAL FOR TEACHERS AND PARENTS

NEW: EDUCATIONAL PACK FOR TEACHERS

PWSA (UK)

A very comprehensive summary of the different aspects the teacher will come across when confronted with a child with PWS in his/her class. Useful tips are given to teachers. Parents with young children are advised to provide this info to their child's teacher as soon as they start nursery or primary school.

Contact Erin Deegan at EDeegan@pwsa.co.uk

DVD: UNDERSTANDING THE STUDENT WITH PRADER-WILLI SYNDROME

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

PRADER-WILLI SYNDROME TEACHER TIPS ON YOUTUBE

http://www.youtube.com/watch?v=Y5LhSePDvqk
A PWSA (USA) video with Elizabeth Roof presenting Tips for Teachers is available on YouTube. Elizabeth Roof is a M.A. - Senior Research Specialist at the Vanderbilt Kennedy Center, USA. This fantastic resource provides very helpful information and practical strategies for teachers who have students with PWS in their classroom. It has two parts:
The Video and 2) A related Tool Box for Teachers
We encourage you to send the video link and the attached Tool Box to your child's teacher and please let other families you know in the PWS community about this amazing new resource. We want as many teachers as possible to use the video and tool box to better understand how to effectively support students with PWS.

The following articles are available from the chairperson of PWSA (SA)

STUDENTS WITH PRADER-WILLI SYNDROME – AN OVERVIEW

PWSA (USA)

FOOD SECURITY AND SNACKS AT SCHOOL

by Evan Farrar, Director of Crisis Intervention Program, PWSA (USA).

HEALTH CONCERNS AND THE STUDENT WITH PRADER-WILLI SYNDROME

Information for School Staff, PWSA (USA)

PRESCHOOL YEARS: YOUNG STUDENTS WITH PRADER-WILLI SYNDROME

Information for Educators, PWSA (USA)

SUPPORTING THE STUDENT WHO HAS PRADER-WILLI SYNDROME

Information for school staff: Behaviour management strategies
Compiled by Barb Dorn, Crisis Counsellor, PWSA (USA)

KEY COMPONENT FOR SUCCESS WITH A CHILD WITH PRADER-WILLI SYNDROME IN A SCHOOL SETTING

These notes on working with children with Prader-Willi Syndrome in a school setting are taken from the presentation "Behaviour Challenges in a School Setting," written by Mary K. Ziccardi. She serves as a behavioural and educational consultant for the PWSA (USA).

SCHOOL RECOMMENDATIONS FOR DANTE JOHNSON

A personal letter to a school which was posted on the Prader-Willi Open Forum Facebook page. This was done by someone in the USA. Parents can use this example and adapt it to suit their circumstances and school system.

IDEAS FOR NON-FOOD CLASSROOM REWARDS

PROMOTING A HEALTHY SCHOOL ENVIRONMENT

Champions for Change, Network for a Healthy California

PLEASE CONTRIBUTE TO *PEOPLE WITH STRENGTH.*
Whether you are a parent, medical practitioner, therapist or relation, please send your contribution, questions or suggestions to: PWSA (SA), PO Box 2399, Brooklyn, 0075
or email: chairperson@praderwilli.org.za

SENSORY PROCESSING

By Patrice Carroll, Manager of PWS Services, Latham Centres, USA.

Sensory processing is how we respond to the information that comes to our brains through our senses. A sensory processing disorder is the brain's difficulty receiving that information coming to it through the senses. Each of us struggles with sensory processing difficulties in some way to varying degrees. For example: some people struggle with crowds, some struggle with noise or tight clothing but the person with sensory processing disorder reacts negatively or avoids those situations altogether.

Schools place children in classrooms with loud noises or lights which are far too bright. We then look to the child to correct their behaviour when it is unwanted or otherwise negative. The truth is that some children simply feel itchy in some types of clothing. A child's fidgeting is not always a result of ADHD, non-compliance or attention seeking as we often label them. In this example the child has a sensory processing difficulty and we should look to reduce their discomfort rather than using medication or using behavioural interventions to reduce what we see as disruptive behaviour. Of course in some cases children or adults do require medications or other interventions to reduce unwanted behaviours, but we first need to look to the basics:

- Are they comfortable?
- Can they see?
- Can they hear over the background noises?
- Are they too cold or too hot?
- Do they feel physically grounded to the floor or are they dizzy or off balance?

Because people with PWS are so good at compensating for that which they struggle they often go on for a long time before anyone picks up on the true issues. A registered occupational therapist can tell you if your child has needs in this area.

People with PWS do not always develop their senses in a typical way. This is a result of poor muscle tone and dysfunction of the endocrine system. Often it is not until they reach school age, that we see the struggles that they are having. Early work with a registered OT can save a lot of time in meetings later on with teachers and administrators telling you that your child can’t seem to sit still or can’t focus, won’t follow directions or is disrupting the group. Before you let anyone tell you that your child needs medication or a special plan needs to be put in place, especially if that plan involves restrictions, ask yourself: is he comfortable? Is she grounded in space (not dizzy or feeling like she’s tipping)? Does he feel constricted or not constricted enough? Does he always seem to bump into things; is he “clumsy” or tripping more than he should? Does he cover his ears even at the slightest noise? Is he only happy when he’s moving or is he fearful of any movements other than walking? These are all signs of sensory processing disorder and the great news is that there is a lot that you can do about it.

TYPES OF SENSORY ISSUES/DISORDERS

Tactile - people who need further development of their tactile sense often seek out or avoid contrasting textures. These will be kids who constantly rub the fabric of their clothes or furniture. The avoider will refuse to wear any clothing with tags or stiff fabric. Tactile kids and adults will benefit from stress balls, sand or water tables, bubble wrap, small stones or rocks (careful for those that ingest objects), play dough, finger paints, etc.
Auditory - people who react strongly to loud noises. Earphones that block out background noise can be extremely helpful in allowing the person to remain focused without becoming agitated by extraneous noise.
Proprioception - this is the ability to sense muscle strength and position in space. People who need further development with this sense often appear clumsy or heavy footed. People will report that they often break objects by walking into them or use too much or not enough strength in picking up or moving objects. Using items such as weighted lap blankets or vests, small weights or bean bags will help to improve this sense.
Vestibular - this sense controls balance. I have personally seen marked improvement in some of the most problematic behaviours when I have focused on increasing vestibular enhancing activities. When our children feel more balanced, less "off center" they appear to be calmer in different environments. People who struggle with the vestibular sense often refuse to walk on any surface that isn't perfectly flat, they often refuse to bend over which is sometimes mistaken for laziness but in reality they fear falling over. Any activity that promotes balance will enhance this sense, e.g. horseback riding, walking on a balance beam close to the ground (this will require someone holding their hand initially), yoga, learning to juggle and participation in most sports will be effective.
Oral - any activity that involves chewing or intense flavours improves this sense. Gum chewing (sugar free) has proven to be effective for lessening teeth grinding, excess drooling and also improves digestion.
Interoception - this is the sensitivity to stimuli inside the body such as body temperature and heart rate. Deep breathing and mindfulness activities are effective.
Olfactory - this is your sense of smell. Scents can be both calming and alerting depending on the need.
Visual - people with PWS are often visual learners and can also become overwhelmed by too much visual stimulus. Using visual schedules as well as written schedules can be helpful. If the person becomes easily distracted or shuts down often try allowing them to wear a hat or visor that they can pull down over their eyes when they want to “get away”.

WHAT SPECIFIC SENSORY ACTIVITIES ARE USEFUL?

There is no easy answer. It is specific to each individual's preference. It also is dependent upon which behaviour one is trying to decrease. That being said, here are some ideas for sensory tools and activities that have had great results for different needs:

For the person who picks - all tactile tools including stress balls, sand and water tables, silly putty, bubble wrap, chewlery (these are bracelets and necklaces that are designed to be chewed on), strips of material to shred and therabands. All of these also work well for decreasing agitation and increasing focus.

For daytime fatigue - therabands used under feet so the individuals can bounce; scents that are strong such as citrus or patchouli; and all activities that involve bouncing, jumping or climbing.

Reducing agitation - all activities that require using muscles in a positive way such as lifting objects (not too heavy), sucking thick liquid through a straw, stretching, blowing bubbles or jumping.

Preparing for transitions – we know that many children and adults diagnosed with PWS struggle with transitional times (before and after school or work, before bed, any time one activity changes to another) counting, colouring, tapping or clapping to a rhythm or rocking can be effective decreasing anxiety during these times.

Winding down - calming scents such as lavender or sandalwood, deep breathing, a warm bath or hand soaks. Due to poor muscle tone it is often difficult for the person with PWS to take an effective deep breath. Blowing bubbles or making a game of blowing a ping pong ball across a table can ensure that they are taking a deep breath.

It is always recommended to consult an occupational therapist before starting a sensory program. After a consult, you can experiment on what works best for your child. A rich array of sensory techniques can ease many of the typical behaviours seen in PWS as you and your child master long-term coping skills.

Your child does not have to live their life being uncomfortable or feeling out of control. Sensory integration as a part of daily life will make an enormous improvement to your child's quality of life. Always consult a registered occupational therapist before incorporating sensory integration but do it early and do it often. I have seen firsthand the transformation that takes place once we target and treat the problematic areas.

Remain calm. Your adrenaline is high, you are upset and if the incident was in public you are embarrassed and angry. Don't let those emotions get in the way of the final goal of keeping your child calm and teaching the appropriate tools for preventing this in the future.
From Tip of the week by Patrice Caroll

THEFT AND PWS

By Katherine Crawford, PWCF Family Support Coordinator and Lisa Graziano, PWCF Executive Director with input from Elizabeth Roof, Ph.D.; Senior Research Specialist, PWS Research Project, Vanderbilt University; Janice Forster, Child & Adolescent Psychiatrist, The Pittsburgh Partnership Specialists in PWS; Evan Farrar, Crisis Counsellor, PWSA (USA).

From: The Gathered View ~ Prader-Willi Syndrome Association (USA) September-October 2014

- Megan stole a bag of chips from another student's lunch.
- Kirk took money out of his father's wallet to buy candy from a vending machine.
- Walter went into his brother's backpack and took one of his comic books to trade for food on the bus.
- Eloise went into her mother's room and took some jewellery to sell at school to get money for a candy bar.
- Isabelle was given recess detention after she took a star eraser from her teacher's desk.

There are many reasons for theft amongst children and adults with PWS. Like all things in the spectrum-world of PWS, not everyone with the syndrome has the same degree of symptoms, including the theft of food and non-food items. For those who are impacted by this challenge, this article is for you.

Food-Related Theft

Food-related theft is a well documented challenge with Prader-Willi syndrome. Parents and care providers who live with a high food drive individual know that theft can be a recurring concern. Within food-related thefts, there are differing levels of complexity.

One-Step: Megan

Acquire Food

The simplest form of food-related theft is one-step food acquisition. Such individuals are at risk of stealing food - from other's lunches, from the school or work cafeteria, or even shoplifting from the gas station down the street. Megan's story is a good example of simple, one-step food acquisition to gain access to food: just taking it.

Two-Step: Kirk

Acquire Money, Buy Food

Two-step food acquisition – stealing money to purchase food – can occur as well. Kirk's story (where he took money out of his father's wallet in order to buy food) is a classic example. When an individual is known to steal money to acquire food, it becomes necessary to lock away purses, wallets, and bedrooms to keep the individual safe.
But money isn't the only thing that gets food.

Two-step: Walter

Barter Possessions for Food

Another form of two-step food acquisition is bartering – trading an object for food. Walter knew that the boys on the school bus were interested in comics, so he took one out of his brother's collection to barter for food. There can be a delay in the discovery of this kind of behaviour, and restitution is difficult because it involves both the brother and another child.

Three-Step: Eloise

Acquire Object, Exchange Object for Money, Buy Food

Next we move on to three-step food acquisition: stealing an item which can be exchanged for cash which then is used to buy food. Eloise's story highlights the potential emotional repercussions that such thefts can cause; her mother could be deeply hurt by theft of her jewellery. Unfortunately, potential emotional repercussions may not enter into Eloise's thinking. She doesn't intend to hurt her mother; she simply intends to obtain food.
Each of these examples is food-related theft, no matter how many steps we add. Each also involves a breach of boundaries to acquire food.

Managing Food-Related Theft

When managing food-related theft it is important to remember that the underlying drive of the theft is outside the control of the person with PWS. The individual with PWS wants to be "good" in your eyes and do the "right" thing, but the drive to obtain food is too strong. It is up to the family, care providers, and the community around them to provide the compassionate supports they need.

Restrict one-step food theft by preventing access to all food sources with a lock (i.e., refrigerator, food pantry, etc). Human supervision alone is inherently fallible. Lock down sources of money to prevent "two-step theft." Reinforce personal boundaries by locking bedrooms, especially older siblings. For "three-step" acquirers, lock jewellery boxes or keep valuables behind locked doors. In addition to locking access to food wherever possible, provide continuous supervision. When the hope or chance to acquire food is not possible, the person's mind is free to think about other important things.

Sometimes people, especially extended family members, are resistant to the idea of locking up food or keeping food in a restricted area. In this case, it may be helpful to describe PWS's hyperphagia food drive like this: think of having a good friend who was just diagnosed with diabetes. Would you have rich desserts or candy bars out on your counter tops or on the table, even though you know they are trying not to eat such foods? Of course not, it wouldn't be the compassionate thing to do. It would just increase your friend's anxiety, suffering, and daily struggle. More than most of us, when someone with PWS sees food, he wants it, and he can't get the thought of it out of his mind.

When working through food-related theft (whether one-, two-, or three-step) it is best to respond by matter-of-factly acknowledging the taking of the food and quietly reducing calories from the remainder of the day or week to compensate. Take responsibility for your lack of providing adequate food security and secure the food source so that it is no longer accessible. Never punish or shame the individual for stealing food; this is simply a symptom of PWS.

Some may suggest punishment (such as taking away a preferred activity) in response to a food-related theft. Such a person might say, "Megan knows that she can't go out to recess because she stole chips from another student's lunch. How could we reward her with recess after she stole food from another student?" They may even be proud of the individual with PWS for verbalizing their understanding that they have lost recess because they stole food. But the question is not "does the person understand why they are being punished" but rather "will the experience of punishment or threat of punishment prevent the individual with PWS from stealing food in the future?" In almost all cases the answer is "No, neither punishment nor threat of punishment prevents food stealing behaviour." The critical piece to understand is that even if the individual with PWS understands and accepts such punishment it will not shape future behaviour, which is the intended goal of punishment.

The most effective way to manage food-related theft is to eliminate all opportunities for the individual with PWS to do it!

Non-Food Related Theft

There is a different kind of theft that occurs in some people with PWS, that of stealing non-food items. This behaviour can range from the "innocent" taking of items to compulsive stealing. Underlying all non-food stealing are likely higher degrees of egocentricity ("It's all about me") and impulsivity ("I want what I want and I want it right now").

Not understanding social boundaries ("what's yours is yours and what's mine is mine") may make stealing non-food items more likely. In the case of Isabelle, this would be the case if she took the star eraser from her teacher's desk without understanding that she should ask before taking something that is in or on someone else's property.

Having low impulse control may increase the potential for non-food stealing behaviour. An example of this might be the individual who walks through a store, sees an item they really like, and impulsively pockets it. In our case of Isabelle, the fact that she knows the eraser does not belong to her or that to take it constitutes theft, or even that she's already been in trouble for stealing something in the past does not enter into her impulsively-made decision-making process.

There are also people with PWS who appear to have extremely “sticky fingers” and indiscriminately steal objects. These individuals may experience more of a compulsive “need” to steal or “collect.”

Managing Non-Food Related Theft

The management of non-food theft is similar to that of food-related theft. First, teach and reinforce the understanding of boundaries. Make sure that stolen objects are returned to their owners with a written letter of apology whenever possible. Writing the owner’s name on all objects to the extent possible is helpful. Mutually and cooperatively creating rules regarding non-theft behaviour is helpful. Writing down or using pictures to symbolize the rules helps make it easier to enforce them. Here’s an example scenario of how to create those rules together.

Aide: “Isabelle, I heard that you love erasers! Which eraser is your favourite?”

Isabelle: “I don’t have a favourite. I like all of them.”

Aide: “Me too! Hey, I was thinking of our class rules the other day. Do you think it would be a good rule to say that other students shouldn’t take your erasers, even if they like them?”

Isabelle: “Yeah!”

Aide: “What should a student do if they take an eraser?”

Isabelle: “Give it back and say sorry.”

Aide: “Brilliant idea! I’ll write that down on the bottom of our Class Rules List! Students should not take erasers from other students. If they break that rule, they should give the eraser back and say sorry.”

You’ll notice that throughout this dialogue the aide is phrasing things in the positive and turning the discussion towards how Isabelle would feel if someone took her erasers. This is done to get Isabelle’s buy-in to increase her compliance, not necessarily to reduce her degree of egocentricity or to teach empathy, although these are excellent skills to teach.

It should be remembered that Isabelle’s egocentric desire to have that eraser may still overpower her affection or empathy for her teacher. There is, however, an appropriate recourse built into the rule-making process: Isabelle told the aide what a student should do if they take an eraser and it’s written down in black and white. Isabelle may initially deny and/or perseverate, but if the aide is patient and calmly brings Isabelle’s attention to their written agreement, this will help Isabelle return the eraser. As soon as Isabelle returns the eraser the aide will **praise, praise, and praise** her.

What if our hypothetical Isabelle brings home an object from school that does not belong to her and when questioned she says a friend gave it to her? The circumstances of this scenario should be investigated for accuracy. Or what if another parent calls Isabelle’s parents because they believe Isabelle took their child’s CD? While Isabelle is adamant that the CD is hers, a search of her collection reveals an identical CD. It could be that Isabelle didn’t intend to steal anything but actually believed her friend’s CD was indeed her own. This example underscores the importance of labelling all of the individual’s items to allow parents and care providers the ability to quickly resolve such situations.

What we’re looking for isn’t exactly a “cure” for impulsive theft but rather management of the environment to eliminate the expression of the symptom. It is possible that the individual with PWS may struggle with impulsive theft throughout their lifetime, so the knowledge and understanding of this symptom by those around them will make a big difference.

Continuous supervision is highly advisable when someone is known to have a history of stealing and especially in situations where theft could have serious repercussions. It is also advisable to introduce your individual with PWS to your local police department, and provide officers with written information about the syndrome. Please visit the website of Prader-Willi California Foundation: www.fpwr.org for more information.

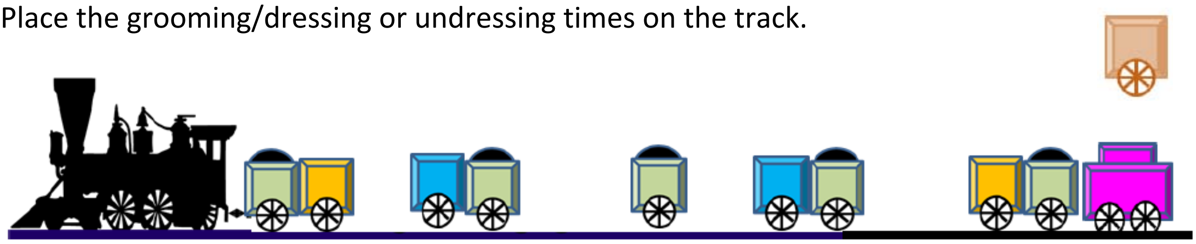
Theft can be tricky to manage in persons with PWS. The fundamental keys to reducing both food and non-food theft are environmental management, supervision, and continuous caring support of the individual with PWS.

CORRECTION - *People With Strength,* November 2014.

Please note: Article, THE TRAIN, page 10, step 5.
Step 5 should read: Place the grooming/dressing or undressing times on the track.

STEP 5

Place the grooming/dressing or undressing times on the track.



PWSA (SA) wants to apologize for any confusion caused by this slip up.
Rika du Plooy, chairperson

I WANT THE SAME

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

How do you answer your person with PWS, who asks why they can't have the same or do "the same" as other people?
The "same" includes many more things than just food. People with PWS want to travel independently as do other adolescents and adults. Once someone with PWS learns how to reach a destination they can usually repeat the journey alone, without getting lost and are, consequently, considered to be good at "travel training" - so what's the problem? They want to have their own money to buy the things they like. They want to go out with friends, to the movies or to restaurants and of course, they want to eat the food they see advertised as being fun, good for you or healthy, just as other people do. Some people with PWS want to learn to drive, get married and have babies, just like other adults.
Achieving the highest of potentials is important for everyone, including people with PWS, so how do family members encourage and support their adult child to reach for "appropriate" goals? Parents and carers may think 'Who are we to determine what an "appropriate" achievement for another person is?' "It all comes down to recognising the interests and abilities of the person with PWS and then considering what is possible for that person, while taking into account the characteristics of PWS. Remembering that people with PWS have cognitive limitations reinforces the need for boundaries in everything they do. Just as

boundaries keep children safe, they also provide protective freedom, for both physical and mental health, in people with PWS of all ages. A person with PWS with only a mild intellectual disability still only has the emotional level of a young child, which may be part of why temper tantrums occur readily in children and adults alike. On the other hand, families may believe their adult child is perfectly capable of accomplishing goals such as independent travel, shopping, going to the movies, visiting friends and more, and in practise this may be true. However, it would be failing that person with PWS if the family did not recognise the areas of potential failure and "stranger danger" - the late arrival of a bus or train; a conversation started with a stranger that could lead to danger; the temptation of asking for food, money or cigarettes; or just becoming a "nuisance" to other members of the public which can lead to escalated stress and consequent antisocial behaviour.

A person with PWS, whether living with their family as the only child, or as a sister or brother to others, or who has left home to live in a supported residential care, will likely think that he or she does not have the same choices in life or opportunities as most other people. This can be a source of grief and despair for the person with PWS. It is most likely a source of grief for parents and other family members also! Little choice or little opportunity is a sadness for any person in such a position, yet we as caregivers, need to protect our people with PWS from serious obesity and related health problems, mental illness, exploitation and even the possibility of them causing injury to others. The problem for people with PWS is that limiting their choice and opportunities not only includes very basic needs and desires, it is made worse by the overwhelming desire to eat, when we know they must eat less than others to maintain a healthy weight and good health.

I want the same may be expressed in relation to:

1) the type and quantity of food given. It may be loudly stated and/or acted upon with a temper tantrum or oppositional behaviour whenever a person with PWS sees other people eating what has been denied to them, or they have been given a smaller quantity, especially compared to that of a younger person.

2) going out – with others and to places where other people go. It may be loudly stated and/or acted upon with a temper tantrum or oppositional behaviour which can cause slowness in organisation and embarrassment for others.

3) having access to money. This is probably the second greatest cause of stress, after food, for the adult with PWS and his or her family. Not managing or accessing money independently can cause constant anxiety for the person with PWS. The value of hindsight tells us it's best if people with PWS are never given money to manage themselves, other than for purchases that are planned for and supervised. Otherwise, money is constantly demanded and the boundaries around the amount of money requested are continually challenged.

There is no quick and easy solution, but if the following strategies are constantly practised, the quality of life for people with PWS is much improved.

Strategies that work

- Listen and empathise – look for less risky alternatives wherever possible
- Provide choice - but limit it to 2 options only. Make sure the choices offered are appropriate and realistic
- Link cause and effect (e.g. "because you have been cleaning your teeth daily, you didn't need any dental work today!")

- Encourage positive thinking to consider what they have *rather than* what they are missing out on
- Encourage a busy routine where there is less time to ponder on what others are doing differently
- Try to predict the occasions when the person with PWS is likely to feel they are missing out and arrange events or activities that don't involve food or money, for those times.
- Discard junk mail advertising inappropriate food, items or events
- Make sure family and friends are aware of the topics of conversations that particularly upset the person with PWS
- Sometimes, eat the same as your person with PWS – go without a treat they shouldn't have, and let them know it's "for your health" as well
- When going on an outing try to predict what others will be eating and negotiate healthier alternatives in advance, for example, take homemade popcorn and a diet drink to a movie
- Do not hope the person with PWS will cope at a special occasion when you know they can't at similar regular occasions. This just sets them and you up for failure and embarrassment. For example: pre-plan for the event and say NO instead of maybe, when necessary.
- Speak to places of work or day programmes places or event organisers to see if "rules" can be put in place for everyone attending, for example, no sharing of food, set portions of food provided, no second helpings
- Give the person with PWS responsibility for something within the family
- Insist all family members support your strategies

A parent writes:
In practice, the word "diet" should refer to everyone's attempt to eat healthy types and amounts of food. Use trusted family and friends to talk informally on different occasions, while the person with PWS is present, about what they do and don't eat to be healthy. (There is a lot of information about healthy eating, but use scientifically accepted information!)
It can be useful to highlight similarities to other people that your person with PWS knows in support of what they need or can't/don't have. For example, "John is not married and doesn't have children"; "Jane is walking a lot now instead of driving, to get fit." Pointing out similar needs/situations of people without PWS enables them to see that they are not the "only ones".

Work on Positive Thinking!

Commend the association made by the person with PWS, between cause and effect. For example, a very positive experience is when a person with PWS says he is walking faster and more easily because he has been eating less and lost weight.

Always give praise when the opportunity arises!

TIP OF THE WEEK

Website of Latham Centres - www.lathamcenters.org look for *Tip of the Week*

It is crucial that we keep our cool during an incident- remain calm, keep distractions down, use a calming tone of voice. It is equally as important, however, to remember these tips after an incident has occurred:

1. **Don't judge**. Even if the trigger seems trivial to you, something caused your child to become extremely upset. Whether or not you think it warranted a strong reaction is not important.
2. **Remain calm**. Your adrenaline is high, you are upset and if the incident was in public you are embarrassed and angry. Don't let those emotions get in the way of the final goal of keeping your child calm and teaching the appropriate tools for preventing this in the future.
3. **Teach.** After the incident and recovery time, talk about what happened gently and calmly. What was he or she upset by? What can be done differently in the future?
4. **Take time for yourself**. You need some recovery time as much as your child does. Take it.

No one wants to see their child melt down but this will inevitably happen. Do what you can to prevent it but know that sometimes even the best plans are not going to prevent a loss of control caused by any number of possible triggers. Allow yourself the time that both you and your child need post incident to regroup and learn from the experience.

Patrice Carroll
Manager of PWS Services

PLEASE CONTRIBUTE AND HELP TO MAKE A DIFFERENCE!

PWSA (SA) is registered as a non-profit organisation (No. 035-837 NPO)
Public Benefit Organisation (PBO Exemption no.930 016 853).

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

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.

IPWSO NEWS

WELCOME TO THE REVOLUTION.

"JOIN THE FIRST APP OF ITS KIND!"

Thanks to our international organization IPWSO, you can now put Prader-Willi World in your pocket and never be without help or information about the syndrome. You can use this app to find facts, show others, and to keep up with the world of Prader-Willi syndrome. The first app of its kind, Prader-Willi World links you to websites around the world. It also shows you where else in the world other families live. This app will be especially helpful for PWS families living in countries with little or no support. It is in English and Spanish - and is FREE! Designed primarily for the android market and soon to be released for the Apple market.

Join IPWSO's huge family around the world, make new friends and get the very best information for your child and your family. Prader-Willi World will give you information from diagnosis to support, from birth to old age. Check out the Prader-Willi-World web page: http://www.prader-willi-world.com/ **and sign up.**

CARING FOR YOUR ADULT DAUGHTER OR SON AT HOME? NEED SOME HELP?

Please share these FAMCARE articles with others!

The following articles are available from the FAMCARE page on IPWSO'S website:
- SKIN PICKING IN PEOPLE WITH PRADER-WILLI SYNDROME – MARCH 2013
- COPING WITH CHANGE IN PEOPLE WITH PRADER-WILLI SYNDROME – June 2013
- THE BASICS OF A HEALTHY ADULT LIFE – Nov 2013
- "GOOD HEALTH" CHECKLIST – March 2014
- STORY-TELLING – June 2014
- "I WANT THE SAME" – March 2015

Articles are also available from the chairperson PWSA (SA): chairperson@praderwilli.org.za

NEW RELEASE OF PWS FILMS

Earlier this year IPWSO and the Prader-Willi Syndrome Association of Ireland joined forces to make four educational films. Please share these and use them for educational purposes.

The following are available on YouTube:
A New Diagnosis of Prader-Willi Syndrome: by Dr Susanne Cassidy
Growth Hormone Therapy in Prader-Willi Syndrome: by Dr Charlotte Höybye
Dietary Management in Prader-Willi Syndrome: Introduced by families
Behaviour and Mental Health in Prader-Willi Syndrome: by Professor Tony Holland

SAVE THE DATE: 9TH IPWSO CONFERENCE:

The International Prader-Willi Syndrome Organization (IPWSO) and Foundation for Prader-Willi Reseach, Canada are proud to announce that the 9th IPWSO Conference will take place in Toronto, Ontario Canada, July 20 – 24, 2016.

Mark the dates on your calendar and start making plans to attend.
Our online registration form and additional Conference details will be released in 2015.

THE PRADER-WILLI SYNDROME ASSOCIATION OF SOUTH AFRICA

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

ACTIVITIES OF THE ASSOCIATION:

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

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

WOULD YOU LIKE TO JOIN THE PWSA (SA)?

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

COST OF MEMBERSHIP

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

BANK DETAILS OF SAVINGS ACCOUNT

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