USA
PRADER-WILLI SYNDROME ASSOCIATION
Still hungry for a cure.

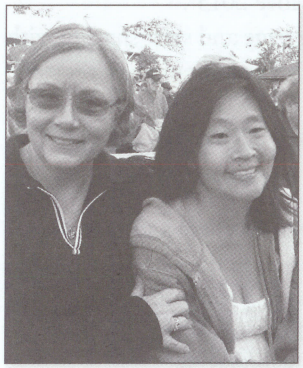
The
Gathered View
National Newsletter of the Prader-Willi Syndrome Association (USA)

Adoption – Prader-Willi Style

By Denise Servais

Bringing home a new child into the family is a life-changing experience. We all have a special story to tell about the joys and challenges of bringing up children, whether typical or special needs. The families highlighted in this article all have something in common. They all have adopted children with Prader-Willi syndrome!

Choosing to adopt a child is not always an easy decision, but for some families it just seemed like the right decision to make. Kate Beaver and her husband, from Madison, Wisconsin, have two biological boys aged 28 and 31. Kate and her husband had always thought about adoption as they felt there were many kids that needed homes. One day a friend who had just adopted two children from Korea brought Kate and her husband a catalog of special-needs Korean children available for adoption.



Kate, with daughter Hana, age 26

This led to Kate and her husband adopting Hana from Korea at 18 months in 1988. Hana was not diagnosed with PWS until she was six. Hana is now 26 years old and living in a PWS group home in Oconomowoc, Wisconsin. Kate talked about her experience raising Hana, "We have learned a lot about ourselves and how to give and how fortunate we are…Hana is sweet and funny. There are challenges, but they bring out the best in you."

Sometimes adoption comes about from an unexpected conversation. Mary Lynn Larson and her husband Mike ended up adopting a boy with PWS after her husband was contacted by a mother hoping to find someone to adopt her baby with PWS. The Larsons are from Appleton, Wisconsin. Their biological son Alex, who has PWS, was seven years old at the time. Mary Lynn was hesitant to have any more kids after Alex; she described her pregnancy with Alex as "tumultuous." Alex was born prematurely and was in the NICU for six weeks. They adopted Matthew at five months. Just a couple of weeks earlier Mary Lynn had a garage sale and sold all her little boy clothes! Alex is now 20 years old, and Matthew is 12.



Left: Alex Larson, age 20 with brother Matthew, age 12

Mary Pringle, of Cape Coral, Florida, has 15 children, 12 of whom have been adopted (ages 3-34). Two of her children have PWS, Tressa, 11, and Zoe, 4. Mary also was contacted by someone who made her aware of a young child with PWS (Zoe), who was to be given up for adoption. Mary gave this advice on adoption, "It is important that you continue to make time for all kids. I did an hour up to one night a week for each child….Build supports around you and be sure you are taking care of yourself."

The ability to cope in some way is always essential in childrearing. Parents like Stephanie Tanner reported that finding humor helps her. Stephanie lives in Russellville, Arkansas with her husband Robert and their children. Stephanie has seven adopted children and one biological child, who is also the youngest. Three of her adopted children have PWS.

Stephanie related that when she had just given birth to her son, her adopted children asked all kinds of questions: who were the birth parents, did she go to court yet, did they get the (adoption) papers,…etc. Stephanie offers this advice,

continued on page 3



Kaelin Tanner, age 16

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Volume 38, Number 2 ~ March-April 2013 ~ Our 38th Year of Publication

Get On The Move in MAY!

Spring is just around the corner and most of you know what that means…Prader-Willi Syndrome Awareness Month! May is also the month we engage in our ***On The Move*** fundraisers around the country…

What?

On The Move is so important to PWSA (USA) because Awareness is a vital component of the long-term mission at PWSA (USA). The more Awareness we can bring to the general public means the easier life will be for our loved ones living with the syndrome. The more Awareness we bring to the world means the more chances we have of finding a cure. The list goes on and on…. And that is why we are so passionate about getting **YOU *On The Move* (OTM)** this year. In order to spread Awareness, we need your help.

Why?

Your involvement in **OTM** as an event organizer, fundraiser, and/or participant empowers you and educates others. With the money you raise from your event we are able to continue enabling life-saving research, increase behavioral and medical support services to all families, enhance medical resources, develop State Chapters, fund PWSA (USA) National Conference and so much more….

How?

As we developed this campaign, we wanted to make sure it was easy for everyone to get involved! Now with **Firstgiving.com** having ***On The Move*** events, spreading awareness and raising money for PWSA (USA) is easy.

Through Firstgiving.com/PWSAUSA, events can be set up, participants can ask for donations online through emails and social media, and registration is automated through the process.

Here's how it works:

If you are having an ***On The Move*** Event:

1. Submit your PWSA fundraising packet.
2. We will create a **FirstGiving** event at **www.firstgiving.com/PWSAUSA** and send you a log-in & password.
3. Log-in and add event information and pictures to customize your event page.
4. Send emails or post to your social network using the easy to use tools for registration and donations.

Not Hosting an Event but Still Want To Fundraise? – We Have a Simple Solution

Firstgiving.com makes it easy to spread awareness and fundraise whether you are having an ***On The Move*** event or not.

If you want to set up your own fundraiser/awareness page online:

1. Go to FirstGiving.com/PWSAUSA.
2. Click "Start Fundraising" Button.
3. Select the "PWSA On The Move 2013".
4. Set up your own fundraising page and start sharing with friends and family through the simple email and social media tools.

For more information, email **bkarp@pwsausa.org.**

Now, it is your turn to get out there and help the ones you love. Our challenge for you is to raise $1,000 during the month of May! Those of you who can reach this prestigious goal will receive a special ***On The Move*** thank-you gift from PWSA (USA) and everyone here at National. ■



*Is your community **On The Move?***

The PWS Advisory Board met in January; read more on page 4.

This year will be the Advisory Board's 10th Anniversary. We hope to recognize them at our National Conference in November. This board is a constant reminder of the title of the book of writings by people with the syndrome, ***Prader-Willi Is What I Have – Not Who I Am!***



Dale and Dottie Cooper
Interim Co-Executive Directors

"The only certain means of success is to render more and better service than is expected of you, no matter what your task may be."

Og Mandino, author of
The Greatest Salesman
In The World

Contributed by
Clint Hurdle

Getting to Know you, Getting to Know all about you!

We are proud to announce that effective 1/01/2013…

Beth Bush as **Director of Operations** joined our national office team to oversee the operations of the PWSA (USA) national organization based in Sarasota. Beth brings with her 20 years experience with the American Red Cross (both locally and nationally) in a variety of positions with responsibilities that included board development, financial development, recruitment and management of both paid and volunteer staff, strategic planning, process and financial analysis, and much more. Her strengths include team building, public speaking, program management and staff development.

Beth reports directly to the Executive Director(s) and is responsible for the management of operations which includes finance, budgeting, communications, IT, family support, research and medical affairs, conference, and business office operations. In addition, this position is responsible for coordinating and guiding a strong volunteer network across all states.

Since joining PWSA (USA), Beth has been actively engaged in orienting herself to our organization and truing up job descriptions, in addition to meeting key stakeholders and volunteer chairs of various committees (**getting to know you**). We look forward to reaping the benefits of her strong organizational, chapter and volunteer support experience she brings to the organization as we fast forward in building and supporting stronger state chapters.

Beth, her husband Jay, and their two lovely daughters, Jordan and Jacqui, are originally from Columbus, Ohio, but currently live in Bradenton, Florida. Welcome aboard, Beth!

Ben Karp as **Communications Specialist** has degrees in both Marketing & International Business and possesses a keen knowledge of social media communications. Ben worked with our ***On The Move*** campaign last year, then spent some time in Peru teaching English in disadvantaged areas.

Ben is responsible for supporting the organization's fundraising, marketing, and PR activities. In addition, this position is responsible for coordinating, guiding, and supporting the financial development activities of PWSA (USA)'s state chapters.

Since joining PWSA (USA), Ben has been busy diving into our Facebook, blogs, and other social media channels (**getting to know all about you**). He will be actively engaged in working with state leaders and families across the country regarding their communications and fundraising activities, at both a national and state level.

Ben lives in Sarasota. We are so glad he elected to join PWSA (USA) on a full time basis. Welcome, Ben!

You will have plenty of opportunities to interact with Beth and Ben as we work closely with the PWSA (USA) state leaders and chapters, standing shoulder to shoulder with you in 2013 to push your priorities forward. **We are On The Move!** ■

Adoption, *continued from page 1*

"I try to keep it simple. It doesn't mean I don't get stressed. Sometimes I put a diaper on someone and then I can't remember who…it's knowing when to take a break…all the kids know that the Ben and Jerry's ice cream in the freezer is mine!"

Whether we have chosen to be a part of the Prader-Willi Community or it was chosen for us, we all share this journey together. May we find strength, support, and humor as we take this journey with our very special children. Thank you to these amazing families for sharing their stories. ■



Abbott Philson, creator of the awareness video.

Learning from the Experts – Those who have Prader-Willi Syndrome

By: Janalee Heinemann, Mary K Ziccardi, & Ken Smith

One of our favorite meetings is each year when we spend two days with the PWS Advisory Board. They are fun, insightful, and able to give us a glimpse into the thoughts of someone with PWS. We spend so much time dealing with the medical and support issues that we sometimes need to be reminded that the "syndrome" is not just a set of symptoms, but a thinking, feeling person.



Shawn Cooper, Kate Kane writing letters

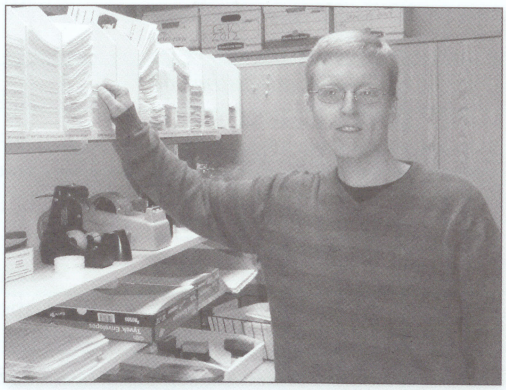
Abbott Philson shared a wonderful awareness video he created, starred in and did all of the art work. Go to our home page at **www.pwsausa.org** to view this amazing video. Abbott also wrote a song in support of all with disabilities and sang it for us.

Besides working on thank you cards and letters for donors, plus helping us create a picture gallery, we discussed many topics at our January 2013 meeting. (See article on grief in this issue on page 12). Some of the other topics were:

How to protect people with PWS from being bullied

a. What is bullying?

i. Name Calling (All had to tolerate name calling).
ii. Not being accepted (All felt left out at some point)
iii. People Taking Lunch Money
iv. Putting People in Locker
v. Locker Room Issues (the biggest issue for the males with PWS)
vi. Spreading Rumors



Conor Heybach helping staff in the mail work room.

b. Advice for people being bullied – things they tried

i. Tell someone (an adult)
ii. Stand up for yourself (admittedly hard)
iii. Try to be friends with the bully because they may need help (even harder)
iv. Put the bully in your shoes – "What if you were me?"

Why do we need PWSA (USA)?

c. Support, Support and More Support

i. Tell someone (an adult)
i. For parents (new & old)
ii. Medical Help
iii. Advisory Boards
iv. Gives people with PWS an identity
v. Awareness / Advocacy
vi. Education
vii. Research to find help for the hunger

Abbott, Andy Maurer writing thank yous and Ken Smith



Being a Self-Advocate

By Brooke Fuller, PWSA (USA) Adults with PWS Advisory Board, and Evan Farrar, PWSA (USA) Crisis Counselor

What is self-advocacy? Self-advocacy, on its most basic level, involves telling people what you need to be happy, successful and healthy in life. For a person with Prader-Willi syndrome (PWS), practicing self-advocacy might mean:

- ☐ Asking a parent or a professional for help with food security
- ☐ Asking a friend for help in solving a problem
- ☐ Asking someone at school for assistance in getting involved in a new activity you like
- ☐ Telling a case worker what your hopes and dreams are for your life
- ☐ Sharing your story of what it is like to live with PWS
- ☐ Saying what you believe about an important issue in society

So self-advocacy can take many forms, and the good news is that it is a skill you can learn and develop throughout your lifetime.

The PWS community is fortunate to have many self-advocates including Brooke Fuller, who was born with PWS. Being on the PWS Advisory Board is part of her role as an advocate. But her self-advocacy work doesn't stop there. In her own community, she has created an advocacy business called Brookside Advocacy to help other people with disabilities to become better self-advocates. Through her advocacy business Brooke has been invited to speak to other people and organizations about what it means to be a self-advocate.



Brooke Fuller laughing with David Wyatt at the Advisory meeting in January.

Brooke is passionate about the need for people with disabilities to advocate for themselves. She explains, "I think it is important to be a self-advocate because you help yourself and others to get what you need and to live the life you want instead of always having people tell you how to live. It means doing more on your own." Brooke believes, "It is important to make your needs known to staff and others so you can make your life as normal as possible."



Photo from PWS Advisory Board meeting- front row l to r: Janalee Heinenman, Abbott Philson, Conor Heybach. Back row, l to r: Brooke Fuller, Andy Maurer, Kate Kane, Ken Smith, Mary K Ziccardi, Shawn Cooper

In her role as a self-advocate Brooke is helping people with PWS and other disabilities to live more self-determined lives. And she believes anyone can learn to be a self-advocate. For those wanting to improve their self-advocacy skills, she recommends:

- ☐ Speaking up for yourself about rights and responsibilities in your life.
- ☐ Learning about person-centered planning which means having a life built more around what you want as a person with a disability.
- ☐ Deciding what it is important to you and communicating those priorities to people you work with (doctors, residential providers, etc.) so they can help you accomplish your goals.
- ☐ Learning how the mental health and developmental disability systems work on the local, state, and national level. A great way to do this is by volunteering to be on local disability-related advisory boards and committees. These opportunities are available in most communities.
- ☐ Meeting other self-advocates in your community and learning from them.

Brooke says it takes a lot of hard work to become a good self-advocate but it is worth it. And also fun. Brooke believes learning to be a self-advocate has made her feel better about herself, given her more confidence, helped her to meet and help others, and improved her life. If you would like to learn more about being a self-advocate, send your questions to Brooke at **cic3@pwsausa.org**

We regret to inform you that after 27 years of dedicated service to Prader-Willi syndrome and as an employee of The Children's Institute (formerly named The Rehabilitation Institute), Ken Smith's position at The Children's Institute has been eliminated. Ken remains a much valued asset to our association, and he is committed to working with PWSA(USA) and our families. He began his board service in 1995 and other than stepping off for two one-year terms (as required by the bylaws after board service of three 3-year terms) he has continuously served on the Board of Directors for 18 years. He has served as either board chair or board co-chair since before 2001. He has been a member of the crisis team during his board tenure and also works with the PWSA Advisory Board.

If you want to contact Ken, you can do so by emailing him at ksmith@pwsausa.org.

Grief and Prader-Willi Syndrome

By Janalee Heinemann, MSW
Director of Research & Medical Affairs & PWS Advisory Board, Prader-Willi Syndrome Association (USA)

As our children are living longer, we need to address new issues. At the national office, due to our family support work and bereavement program, we get calls on a variety of deaths – often where the issue is supporting the child/adult with Prader-Willi syndrome who is dealing with a loss of a parent, grandparent, sibling, or roommate. Also, adults with PWS are dealing with other types of loss such as losing a job or beloved staff at their supportive living placement, feeling the stress of a parent losing a job, losing a long-time friend of the family, the death of a beloved pet, etc.

We discussed the issues at our PWS Advisory Board (which consists of adults who have PWS) meeting and I have been doing bereavement groups for over 20 years. The following are suggestions that may help in understanding the grief process of a person with the syndrome and how to provide support.

POSSIBLE GRIEF REACTIONS FROM A CHILD OR ADULT WITH PWS

- ☐ A lot of questions that may be hard to answer!
- ☐ Anger – lashing out
- ☐ Refusal to talk about it – isolation
- ☐ May not openly show grief with tears
- ☐ Self abuse accentuating
- ☐ Fear of losing others
- ☐ Guilt – logical and illogical
- ☐ Fear of own death -- health phobias
- ☐ A surprising external lack of response/emotion
- ☐ Setbacks in behavior after a home visit
- ☐ Occasional setbacks for unknown reasons
- ☐ Fear of financial insecurity or loss of home stability

REMEMBER – PEOPLE WITH PWS OFTEN

- ☐ Lead more protected lives – have less exposure to dealing with "real world" issues.
- ☐ Think more concretely rather than abstractly; thus, if younger, may have a harder time with the dimensions of death – E.g. that it is irreversible and that everyone dies.
- ☐ See the world from an egocentric viewpoint – how it affects them. They also may blame themselves for the death or family stress.
- ☐ Have a hard time dealing with sudden change.
- ☐ Sometimes have a limited ability to communicate feelings.
- ☐ Often have a lot of loss and grief issues to deal with – loss of staff or roommates through moves; dealing with rejection from others; grieving over all of the restrictions on their life; not being able to have children, drive, marry, etc – yet bright enough to know what they are missing.

HOW TO PROVIDE SUPPORT

- ☐ Do acknowledge the death and ongoing loss issues.
- ☐ Do ask questions and listen to the answer.
- ☐ Find a person he/she feels comfortable talking to and nurture their time together.
- ☐ Do look at developmental not chronological age. For example, a child before the age of eight may think a person is only dead for a period of time and will come back.
- ☐ Do understand that acting out may be due to grief issues.
- ☐ Do acknowledge special occasions and help the person with PWS find a way to keep the memory of their loved one alive. (i.e.: view pictures or videos together, light a special candle on the deceased person's birthday, buy an angel for the tree in memory of their loved one.)
- ☐ Do expect the person with PWS to become somewhat phobic and have concerns that may seem illogical to you but are very real to him/her.
- ☐ Do use simple and direct language about death.
- ☐ Do all you can to help the family with getting the person with PWS to the funeral. If in placement, staff support for that person at the funeral would be optimum.
- ☐ Do be alert to the potential of depression and psychosis.
- ☐ Do be careful if you are using religion as a support, to keep it within the person and their family's own belief system. Ask the person with PWS what they think happens after death.

Don't get caught up in "stages of grief". They are only windows to look into the human experience rather than an exact prescription of how a person should grieve. Grief is a roller coaster rather than a ladder. There is no "right" or "wrong' way to grieve. ■

Production, printing, and mailing of this newsletter was underwritten by a generous grant from Eastside High School student-sponsored "Spirit Week" Fundraiser in Greenville, South Carolina.



Battle Fatigue I

By Lisa Peters

Special Needs Battle Fatigue

As a parent of a child diagnosed with Prader-Willi syndrome, there are times in my life when the medical complexity of this diagnosis begins to take its toll on me.

This month has been one of them.

After being diagnosed and treated for strep throat, my son Nicholas developed a severely swollen left lymph node. Our pediatrician, an ER doctor and our Ear/Nose and Throat specialist, all suggested that Nicholas may have a branchial cyst or malformation of the lymph node. With so many astute physicians in agreement, it seemed like a medical certainty

We scheduled an MRI. Nick's anxiety issues required that he be sedated during the procedure. We were asked to come into Boston early for our appointment, only to discover that the MRI staff was many hours behind schedule. It was a long and torturous experience for our entire family. When it was over, we waited for almost a week before hearing back from the ENT.

Results of the exam showed that Nicholas did not have a cyst or malformation.

While we were very thankful to hear the happy news, the emotional and physical stress of the event made us feel overwhelmingly vulnerable and fatigued.

These feelings are a healthy response to a stressful situation. But when you are the parent of a child who is medically complex, these difficult medical scenarios can begin to accumulate one after another, and pretty soon it becomes difficult to transition the soul back to that quiet, peaceful, and healthy emotional state.

Last week, I had trouble relaxing. I wondered why this was happening since I should be happy that there was nothing wrong with Nicholas. I thought back to all the events of this past year and rewound in my mind the enormity of my load

Nicholas and I have met with specialists in endocrinology; neurology; psychiatry; gastroenterology; nutrition; ENT; ophthalmology; orthodontists; two neuropsychologists; an orthopedist; PT, OT and ST evaluations often requiring two days in Boston; not to mention his regular visits with his dentist and pediatrician. He has been fitted for a back brace, foot orthotics, braces and glasses. He has had x-rays, EEGs and an MRI plus several visits to the ER and an overnight stay in the hospital. There were several IEPs, a hearing and negotiations to transfer Nicholas to a new school.

While all of this running around took a physical toll on my body, there was a much more debilitating consequence. I experienced a type of emotional bleeding that occurs when a parent truly understands and accepts their child's medical fragility and vulnerability. It is a sobering awareness, an in-your-face understanding of a harsh and unthinkable reality.

In response, a booming voice of doubt inside my head hollers into my soul, questioning whether I have the strength to survive this grueling pace and emotional trauma that accompanies such a life. It is a silent and paralyzing fear that secretly gnaws at my subconscious.

I am not complaining or seeking sympathy. I am painfully aware that our situation could be much worse. I realize there are families who suffer from far greater challenges. I am thankful every day for our good fortune. I am also however, only human, and unable at times, to overcome this feeling of helplessness.

I believe I am suffering from Special Needs Battle Fatigue.

Much like a soldier who is no longer able to withstand the sight and sounds of continuous battle, I, too, am experiencing a type of involuntary paralysis of sorts, a shutting down of the nervous system in response to the constant demand of the "fight or flight" response.

I am experiencing things like headaches, fatigue, edginess, difficulty concentrating, a lack of tolerance for noise and confusion, emotional numbness, bad dreams, strong feelings of guilt, depression and worry, angry outbursts, difficulty sleeping, and a loss of interest in things that were once enjoyable.

I realize that by exposing myself to this constant heightened level of stress, my physical body may begin to rebel and become vulnerable to a variety of sicknesses or disease, which only serves to perpetuate the greatest of all my fears.... that of leaving my son too soon.

But it is difficult to incorporate rest and relaxation into a lifestyle that is accustomed to caregiver chaos. Even when life settles down for me, still there is a secret soldier that lives just beneath the surface of my cheerful persona. A warrior, ever-ready and alert, instinctively programmed to pounce into action at the slightest hint of an emergency situation, an inevitable consequence of my child's many medical issues.

I have discovered there is a critical aspect of special needs parenting that I am neglecting.

My mental health.

I need to develop a plan that seeks to address this issue. I need to help myself.

When Nicholas was first diagnosed with PWS, the initial stress of this devastating diagnosis and the accompanying lengthy list of specialist appointments caused me to experience a similar period of darkness. I named this depressive period..... the Prader-Willi Blues or PWB. It was, I believe, a form of Post Traumatic Stress.

In order to preserve my soul and continue to care for my suffering child, I developed a list of helpful strategies to help combat the PWB. Now, 10 years later, I am finding the need to revisit some of these same therapies and perhaps employ them on a more regular basis. ■

(In the next Gathered View, *watch for Battle Fatigue II, Lisa's Sanity Saving List, which she says is "an ever-changing record of helpful tools that help to preserve my emotional strength.")*

PWS Seizures Explanation & Medications

By Douglas Rose, M.D.

Usually, 'absence' seizures last 10-30 seconds, and 'complex partial seizures' may last 1-2 minutes (ictal) during which a person is unresponsive to others (won't respond to name, will not answer questions) and then may be confused for 4-5 minutes afterwards (postictal confusion). If, in fact, the time duration is longer in terms of minutes, this would be a bit long for a seizure involving staring and 'spacing out' but could still be a complex partial seizure with a somewhat longer postictal confusion.

For seizures, the history is the most important part for diagnosis. The routine 20-40 minute EEG can often be normal, since the recording is not during the event. However, if the EEG does show epileptiform discharges (spikes and sharp waves that last a 10th to a 15th of a second but do not cause behavioral changes), then the EEG can be helpful with the diagnosis. For the history, we often spend time talking with whoever saw the person during the first 1-2 minutes of the event to learn what the person was doing during that time.

If the events occur very frequently, every day or at least several times per week, we can sometimes capture an event on combined EEG with simultaneous video ('video/EEG') recording 24 hours a day for several days (this is a very common test we use). This test can help us decide whether the events are really seizures or something else that would not benefit from increasing antiepileptic medications. If the events do not occur that frequently, video/EEG will not be able to capture an event, and we are back to relying on the history of those who have observed the events. Sometimes if the parents can capture video of the event at home, especially the first 2 minutes, this can be helpful to the neurologist.

Topamax can be a very good antiseizure medication, and we use it frequently. The side effects are that at higher doses it causes 'word-finding' difficulties even in very verbal adults, so in general at the higher doses it can interfere some with language. Also I have noticed some slowed responding to questions (slowed thinking?). Also at higher doses there is decreased sweating, which can be a problem in the summer, and a person needs to stay in the shade. Others need to know to look for reddened skin color, indicating overheating. Also at higher doses Topamax can cause kidney stones, so a person on Topamax needs to be well-hydrated.

Keppra also is a very good antiseizure medication and is good for complex partial seizures. Whereas Topamax tends to make a person quiet, Keppra tends to make a person more alert and active. Although this can be great first thing in the morning, being very alert can be a problem. So when I prescribe Keppra for the morning and bedtime, I tend to prescribe the larger dose in the morning, the smaller dose at bedtime and suggest giving the bedtime dose 1-2 hours before bedtime. Parents have told me giving Keppra near bedtime means it takes about one hour longer for the person to fall asleep, so I have suggested moving the start time for the bedtime routine an hour earlier.

Topamax, depending on the dose, is often very good to control both 'absence' and 'complex partial seizures' -- the two kinds of 'spaced out' seizures that we see most frequently.

There have been about 20 peer-reviewed published articles on seizures in PWS since 2003. Although one seizure type is termed 'atypical absence', this is, in fact, a very common typical seizure pattern that we see and should be very recognizable to a neurologist. And, as you know, about 25% of persons with PWS will have at least one seizure in their lifetime, about 5 times more frequent than the general population. ■

Douglas F. Rose, M.D., Professor of Pediatrics and Neurology, is Medical Director at Cincinnati Children's Hospital Medical Center, Cincinnati, Ohio, and a member of the PWSA (USA) Clinical Advisory Board.

¡HOLA!

By Nina Roberto, E.D. of the New York Association and on the State Chapter Leaders Team as representative to Spanish-speaking families with PWS.

¡Hola! Me llamo Nina Roberto y soy la especialista para familias hispana. Estoy disponible para ayuda, apoyo y informacion sobre el Syndrome de Prader-Willi. Yo tengo tres ninos. 20, 10 y 9. Mi hijo que tiene 10 anos tiene SPW. Yo vivo en NY pero ayudo familias en los estados unidos que nececitan informacion y ayuda. Les quiero directar a www.pwsausa.org donde vas a encontrar informacion en espanol. Si tienes algunas preguntas me pueden llamar a (718) 846-6606 o email, ninaroberto@verizon.net. ¡Hablamos pronto! ■

Thank you

to our Angel Fund contributors.

Our cherished donors and their honorees are listed on pages 14, 15 and 16.

Aging in Prader-Willi Syndrome: Twelve Persons Over the Age of 50 Years

Summary of research article

By Sinnema M, Schrander-Stumpfel CTrm, Maaskant MA, Boer H, Curfs LMG. 2012. Am J Med Genet Part A 158A:1326-1336

Introduction: *We have to remember that this study, which was done on PWS and aging by a group in the Netherlands, is looking at a population that did not have the benefits of our current generation. As they state: "No one in this group had received sex or growth hormone therapy" and presumably did not have other early intervention benefits. But for those pioneers working with our first large population of older adults who have the syndrome, this gives a glimpse into the potential issues. ~ Janalee Heinemann*

Physical health problems	Total prevalence (N)
Hypertension	3/12
Stroke	3/12
Diabetes	6/12
Pneumonia	3/12
Excessive daytime sleepiness	8/12
Constipation	5/12
Reflux	2/12
Anaemia of unknown origin	2/12
Kidney problems (congenital)	1/12
Osteoporosis	2/12
History of any fracture	6/12
Primary amenorrhea (no menstruation at any time in life)	1/7
Scoliosis	5/12
Foot problems	10/12
Hip problems	2/12
Oedema/Edema	9/12
Erysipelas (skin infection)	6/12
Varices (varicose veins)	3/12

This study looked at 12 individuals with PWS aged 50 and older. Individuals with PWS aged 18 – 49 years were used as a control group.

- Age range 50 – 66 years
- 5 males, 7 females
- 4 with deletion, 8 with mUPD (maternal disomy)
- 11 in community or residential facilities, one living at home with elderly mother
- Mean age at moving to residential facility – 19.4 years
- Mean BMI in persons with deletion was significantly higher than persons with mUPD – three of the latter had a BMI under 25.
- Mean maximum BMI was 36.5, with a range of 23.6 – 44.4.
- 3 people smoked (cigarettes, pipe, cigars).

Health Issues

- One woman died, aged 65, shortly after data collection, due to lung problems.
- Half had diabetes mellitus, mean age of diagnosis 41.6 years.
- No one in this group had received sex or growth hormone therapy.
- No one had epilepsy or cancer.

Comparison with younger people with PWS

Functioning, behaviour and care dependency revealed worse functioning in the older than the younger groups.

- Scores in the older group were significantly lower on the following items: personal hygiene, dressing, eating, being ambulant, mobility, grooming, memory, orientation, sleeping difficulties, physical complaints, hearing, vision, dependency on medical care and care dependency (*note that deterioration in some of these areas would also be evident in the over 50-population without PWS).*
- Older individuals scored higher on bizarre speech, gorging food, masturbating or exposing oneself in public, and hallucinating.
- Scores on lack of self-confidence or poor self-esteem were, however, statistically significantly lower than those for people under 50.
- No significant difference in eating behaviour between over and under 50s.
- No reduction in behaviour problems as people got older, as opposed to findings in some previous studies. More behaviour problems were noted in those with mUPD, which may overlap with the psychiatric disturbances that this sub-group displays.

Psychiatric illness

- No one with deletion (4 people)had a psychiatric illness.

continued on page 10

Aging, *continued from page 9*

- 7 out of 8 mUPD had a history of psychiatric illness:
  - Bipolar disorder with psychotic symptoms – 3
  - Psychotic illness – 2
  - Depressive illness without psychotic symptoms – 1
  - Bipolar disorder – 1
- All with mUPD used psychotropic medication.
- One woman presented with symptoms highly suggestive of dementia.

Health checks

- The study underlines the need for regular health checks for adults with PWS, in particular, re:
  - Cardiovascular disease
  - Diabetes
  - Dermatological problems
  - Orthopaedic problems
  - Sleep problems
  - Osteoporosis
  - All usual age-appropriate screenings should be carried out (e.g., hearing, eyes, cancer, etc., with possible exception of cervical smear tests for women with no history of sexual activity.

Sleep problems and osteoporosis are likely to be under-reported and deserve special attention.

- Diagnosis of pneumonia is frequently delayed in older adults with PWS because of absence of fever.
- No indication that sensory impairment or cancer is more prevalent in PWS than in the general population (bearing in mind that this was a very small study).

Functional decline

- From 40 years onwards, individuals showed decreased energy levels and lessening of mobility (*as is evident in most of the general population*).
- Special medical surveillance should be available to those aged 40 and older to ensure significant medical, behavioural and social issues are not overlooked.

Other points

- There were relatively more individuals in this study in the moderate-severe learning disability range. These individuals may have required earlier intervention by being placed in structured residential settings at an earlier age, which in turn could have contributed to their longevity because of better weight management and prevention of serious medical complications.
- The researchers remarked on the predominance of those with mUPD type of PWS in this age group (*Across all age groups, mUPD is estimated to account for about 25% of the entire PWS population).* They comment that this may have implications for the survival rates of different genetic sub-types, but stress that more studies are needed to check these findings.
- The researchers commented, "Undiagnosed psychopathology or physical morbidity can have an atypical presentation in people with PWS …" and emphasise that support in residential settings should be adjusted to fit the higher levels of care dependency, the different needs in the day care programme, and diminishing mobility.
- Greater likelihood of bereavement for these people, as parents die. Recognition that this may cause behavioural disturbances and emotional distress.
- The researchers hypothesize that there may be premature aging in PWS, especially where no sex or growth hormone is given. They state that aging in PWS starts at 50 or younger.
- With better management, the number of people with PWS aged over 50 is likely to increase. ■

In the PWSA UK

- We are currently aware of 30 individuals aged 50 or older: 27 in England, 2 in Scotland, 1 in Eire.
- The oldest is aged 65 (66 next month).
- Of these 30, three people are aged 60 or older.

We hope you find this publication and our materials helpful and that you consider a donation to PWSA (USA) to assist in developing more good work(s) like this. Please see our Web site, www.pwsausa.org

CHUCKLE CORNER

Kristi Cole Rickenbach, from Blaine, Minnesota, shares her new favorite Justice (age 9) quote:

"Mom, no one is perfect. Look at me, I am a princess and I am not even perfect."

Prevalence of Poisoning in People with Prader-Willi syndrome

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This pilot study assessed the prevalence of poisoning in people with Prader-Willi syndrome (PWS). Hyperphagia and unusual food-seeking behaviors are key features of PWS and may lead to ingestion of unappetizing and unappealing foods such as garbage or pet food. The main goal of this study was to examine whether this unusual food related behavior would lead to an increased prevalence of ingesting a poisonous substance.

The subjects in this study included individuals with PWS, of ages four years old and older. Participants who completed the anonymous online survey were either the parents or the primary caretaker of individuals with PWS. The participants also provided information about the non-PWS siblings, who served as controls.

One hundred forty-one responses were submitted using the online survey. Of these responses, **19.8% (N=26) of subjects reported at least one instance of poisoning, compared to 3% (N=4) in their non-PWS siblings. There were a total of 43 episodes of ingestions in the 26 individuals, with a range of 1 to 5 different potential toxins per ingestion episode.**

The food-related behavior of 'looking or searching for food' was found to be related to poisoning. An individual with PWS who looked or searched for food was 2.5 times more likely to be poisoned than if they did not look or search for food.

A second relationship was found between poisoning and the cognitive level of the PWS individual. None of the PWS individuals reported as having 'no retardation' (N=7) had an instance of poisoning, whereas all of the PWS individuals reported as having 'severe retardation' (N=3) had at least one instance of poisoning. 10.7% (N=6) of the PWS individuals reported as having 'developmental delay' reported at least one instance of poisoning, 27.9% (N=12) of the PWS individuals reported as having 'mild mental retardation' reported at least one instance of poisoning, and 25% (N=5) of the PWS individuals reported as having 'moderate mental retardation' reported at least one instance of poisoning.

A history of eating unusual objects in a PWS individual also showed a relationship to poisoning. PWS individuals with a history of eating unusual objects were found to have a 5.7 fold increased risk of poisoning over the PWS individuals reported to not have such a history. A history of extreme behaviors was also seen to have a relationship to poisoning. PWS individuals reported as having histories of extreme behaviors were found to have a 2.2 fold greater risk of being poisoned than PWS individuals reported as not having histories of extreme behaviors.

This study found an increased prevalence of poisoning in people with PWS compared to their non-PWS siblings. **Several features of PWS, including the food-related behaviors (specifically 'looking and searching for food'), decreased cognitive ability, eating unusual objects, and a history of extreme behaviors appear to correlate with this increased prevalence.** Awareness should be raised by alerting parents and caregivers of the increased prevalence of poisoning in people with PWS. Primary care providers and poison control centers also need to be aware of this association, as well as the implications of PWS for diagnosing and treating ingestions. ■

Prescription and non-prescription drugs should be locked up. Spoiled foods should be disposed of carefully, and if the child or adult with PWS is an extreme food seeker, other items may need to be locked up. See list of substances ingested.

Toxic Substances Ingested by Subjects with Prader– Willi Syndrome

Toxic substance	Number of reports*	% Reports
Over-the-counter medicine	12	21
Prescription medicine	9	16
Vitamins	1	2
Spoiled food	11	19
Plant or wild mushroom	5	9
Personal care product	7	12
Cosmetic	4	7
Alcohol	4	7
Cleaning product	2	7
"Other" not specified	3	5

*Some ingestions involved multiple substances, so the total is greater that the 42 reported instances of ingestion.



Valerie, age 11 with her brother Pablo, age 6.

My brother has blue-green eyes like the deep sea, golden brown wonderful hair that smells like rasberry and cherry, Pale tanned skin that smells like strawberi he sings in the morning like an angel after a good night dream.
He hugs you sweetly when you cry or will cry with you until you smile.
Everyone that meets my brother immediately falls in love with him.

He may have constant melt-down He may have Prader-Willi syndrome, but that doesn't stop him from being my favorite boy, best friend or my brother. He is Pablo, and I love him just the way he is.

I don't know anyone who has a Sibling with special needs, but I think teachers should try harder to help all kids.

Valerie H.



Rose, age 17, touches many hearts at the mission she serves: the Camden Rescue Mission.

All Heart

For the past five years Rose Cohen (PWS, age 17) has saved her holiday and birthday money to buy toys that are then donated to the Camden Rescue Mission. Camden is one of the poorest cities in the U.S. and only 20 minutes from Rose's family home. Hundreds of children wait in line to receive their one toy and a Build-a-Bear. This year, Rose donated over $400 worth of toys, spent an afternoon setting up the toy display inside the warehouse, and then helped the children on the day that the toys were distributed. Rose collects toys at school but really enjoys picking out all the toys at stores throughout the year with her mother, Sybil.

Rose's mother remembers taking Rose to the mission for the first time five years ago just before the holidays. They shopped together for toys to donate. When Rose saw the line of children waiting for gifts, she realized how important it was to help others. She will tell you that it makes her feel good to know that she has brightened the life of a child who may not have received any gifts were it not for the Mission.

Rose spends a great deal of time shopping and picking out gifts for different age groups. She is now enrolled in a course at her high school that requires community service and the Mission is her chosen charity. She hopes to do more for the Mission throughout the year.

According to her mother, Rose has a heart of gold. Over the years, Rose has grown her hair and donated it to Locks for Love, rescued and fostered cats, helped take care of an elderly aunt, and reached out to other children with special needs. ■



Daniele with Chef.

Daniele ~ The Village Boy Becomes a Man

By Janalee Heinemann, MSW, Director of Research & Medical Affairs & PWS Advisory Board

New parents of a baby with Prader-Willi syndrome (PWS) typically are devastated because they get on the Internet and read about children with PWS – low IQ, lack of social skills, behavior problems. They envision their beautiful baby someday becoming this person who grabs food from others, digs in garbage cans, and cannot be taken out in public. The people who wrote those articles and did the studies obviously never met 36-year-old Daniele, who lives in Italy. He is the son of our International Prader-Willi Syndrome Organisation (IPWSO) Executive Director, Giorgio Fornasier.

To meet Daniele is to be charmed by him. My latest example was a recent trip to Italy after driving with the Fornasier family to Germany to provide PWS education at the ESPE conference. Daniele insisted (as he does with all their international guests) to pay for one nice dinner for all of us. His dad drove him to the bank after his work day ended, but the bank had just closed. Daniele knocked on the door and told the bank teller that he needed to get some of his money to pay for a special dinner that night. His dad said he would loan Daniele the money, but Daniele said no, it must be his money. Daniele asked to speak to the bank president. The bank president came to the door and after Daniele explained the importance of his withdrawal, the president agreed to let him come in and make the withdrawal!

Over the years I have observed that in any restaurant in his area in Italy, Daniele is allowed to go back into the kitchen and greet the staff. He also gets big hugs from restaurant owners, and everyone on the streets of his village knows and greets Daniele. He always has a smile on his face and a swagger of confidence. Daniele is the altar boy at mass every week and also prepares the altar for service. He has "adopted" two children in Peru and pays for their care out of the money he earns.

As far as the male Italian charm, I will never forget the time we were driving and Daniele was between Pam Eisen and me, with arms around us and giving us kisses on our cheeks. His dad told him to cut it out. After Daniele responded in Italian, I asked Giorgio what he said. He told his dad, "*You are just jealous because you are married and I am not!*"

Compared to anyone with or without PWS, Daniele is exceptional – but so are many of our children and adults with PWS. Their charm, their generosity, their capabilities are not what studies are made of – but are the qualities I wish we could share with all of the new parents before they sink into despair. I wish they could meet Daniele in the hallways of the hospital right after they get the diagnosis. With a big smile, he would shake their hand, give them a big hug, and tell them they have a beautiful child of God. ■



Al and Janalee Heinemann, along with Daniele's parents, are guests of Daniele's at a dinner out on the town.



Daniele paying for the meal.

(Parents reading this may wonder where Daniele gets his money. Giorgio reports that Daniele worked over 10 years in mechanical factories. Now he works in sheltered workshops in their town instead, where he goes daily making artistic ceramics, assembling parts for factories and writing articles for a local disabled-people newsletter in a computer workshop. He also receives two Government pensions: one is related to the 10 years of factory work, the other is a disability pension which allows them to care for him at home.)



Daniele in the kitchen with friends.

WE REMEMBER

Doris Jane (DJ) Miller



On January 8, 2013, DJ Miller passed away at the age of 87 years. She served on the PWSA Board of Directors from 1983 to 1995, chaired the 1992 PWSA national conference in Philadelphia, co-sponsored and directed the five-state Mid-Atlantic organization (which gave birth to several chapters) and was a founding member of the PWSA Pennsylvania chapter. For 22 years she attended every single national conference until the format changed. Here are tributes to one of the early "pioneers" for people with PWS from two other early "pioneers".

Bronnie Maurer, Lexington, South Carolina, writes:

It was 36 years ago at a small restaurant in Minneapolis when Stewart and I shared a table for lunch with DJ and Bobby Miller. We discovered that we were in Minneapolis for the same reason--the first Prader-Willi syndrome conference. That meeting was the beginning of a friendship that never wavered. It was as if we evolved from being strangers to being "family" in just a moment. Our list of PWS experiences could go on and on, but in those early years being able to share those experiences was priceless. So little was known about the syndrome and we were functioning on instinct alone. We met Lota Mitchell at the second conference. Over the years, our son Andy, who has PWS, labeled us the three M's -- Miller, Mitchell and Maurer -- and he called DJ and Lota his other mothers. I truly thought of DJ as my "sister", and I will miss her more than I can say.

Isa Breneisen, Lancaster County, Pennsylvania, writes:

DJ was the ultimate mother and caregiver, first of her four daughters, one of whom is Margaret Miller who has PWS, and later in life, of her husband Bobby, who passed away six years ago. I first met DJ and Bobby in Minneapolis at the first national PWSA conference in 1979. My daughter was four then, and Margaret was about 14. DJ and Bobby lived in Doylestown, Pennsylvania, a mere two hours from my home in Lancaster.

I was overjoyed and thrilled to meet her and her family and to discover that I could contact someone close to home. We became close friends and began a lifelong friendship and collaboration to improve the lives of our children with PWS.

Together we established the five-state Mid-Atlantic organization. For over ten years we lobbied legislators, community leaders, mental and physical health organizations and the general public to establish the first all-PWS group home in PA. In August 1989 this group home opened in Lancaster County for six adults with PWS. Without DJ's influence, input and personal experiences, this would never have happened. Today this home and another one continue to serve seven adults with PWS, giving them a safe environment to live their lives to their fullest potential.

DJ was a tireless worker for her family, for PWSA as well as for her local community where she served on the Board of Directors of Doylestown Hospital and the Village Improvement Association. PWSA (USA) has lost a valuable and dedicated member. I will miss her forever and her endless energy. She will join other angels gone on before her who worked hard to alert everyone about PWS. ■

The following names are those who donated to the 2012-2013 Angel Drive (October-January). either In Honor of (IHO) someone very special to them or In Memory of (IMO) a person whose memory is deeply treasured.

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Johanna Balkie
Tommy Neems & Peter's Wedding Auction
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Declan Edward Shelton
Edward and Gail Frey
James Randall Shelton
Randall Shelton
Carter Shingleton
Mary Shingleton
Kenneth Shoemaker's 33rd Birthday
David and Jane Shoemaker
Brayden Smith
Kim and Lonnie Meredith
Bobby and Norva Smith
Madison Smith
Carolyn Cheeseman
Nate and Barbara Olson
Edwin Sojka
Irene Jones
Theodora Sojka and Phyllis Uzendowski
Jacob Soncarty
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Tyler Stoeck
Robert and Anny Stoeck
Naomi Storr's 10th Birthday
Marlene Pratto
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Check **http://www.pwsausa.org/events**

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8TH IPWSO CONFERENCE

Where: Fitzwilliam College, Cambridge, UK
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What: "From Research through to Practice"

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