

The **Gathered View**

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

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

BREAKING NEWS AT PLANET PWSA (USA)!

PWSA (USA) is pleased to announce the appointment of Evan Farrar as our permanent Executive Director by unanimous vote of the Board of Directors on August 26, 2010 effective immediately.

Since being hired as a Crisis Intervention Counselor in the summer of 2007 Evan has served in a variety of management capacities for PWSA (USA) including Acting Executive Director and more recently as a member of the Executive Management Team that has guided our agency for the past several months. These experiences in management of day-to-day operations at PWSA – along with his extensive experience working with families through our Crisis Program – uniquely qualify Evan to lead our organization into the future.

In applying for the position, Evan identified these strengths he brings to this position: continuity, PWSA experience, an understanding of PWS, knowledge of staff and providers, experience with the international PWS community, professional and personal strengths matching PWSA's current needs for an Executive Director, and an ability to hit the ground still running.

Most important, he wrote: "I have a vision for this organization that builds on our past rather than replaces it – a pivotal distinction. We have a proud history. An amazing history, really, as an organization that started small and now has a global outreach which was unimaginable when PWSA was first formed by a few parents desperate for community and support. It is that original vision of effectively serving people and families living with PWS that inspires me to want to step into the role of Executive Director. Through working in our Crisis Program, I've learned firsthand the pain and struggle some of our families experience. But I also know the joy our families experience as well. I will carry this knowledge into every



conversation I have, and decision I make, as the Executive Director of PWSA (USA). I believe I am uniquely qualified – at this time – to provide the executive leadership PWSA needs in collaboration with you and others who care so deeply about our mission."

A little personal background includes a B.A. from Baldwin-Wallace College in Ohio, and an M.Div. from Union Theological Seminary in New York City. He is currently close to earning a Master's in Mental Health Counseling from Argosy University in Sarasota, where he lives with wife Laurie and dog Grace. Not a Florida native, he has lived in Chicago, New York City and Cleveland. He enjoys reading, sports (loves all Cleveland sports teams), and travel--he's been to many countries in Europe and Asia.

Evan comments, "I have always worked to help people whether through the church, working with the homeless, serving people battling addictions, or people with disabilities. And I love being part of the PWS community, which is one of the warmest and most vibrant I've ever known."

Board of Directors Co-Chairs John Heybach and Ken Smith say, "Celebrate with us the advancement of one of our own staff into this important position. With Evan's appointment as Executive Director we also look forward to hiring quickly a new Crisis Intervention Counselor so PWSA (USA) will continue to provide high-quality responsive services to meet the needs of our families."



Julie

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Skin Picking and Prader-Willi Syndrome

By "The Pittsburgh Partnership"

Linda Gourash, M.D., Janice Forster, M.D.

[Note: This article was originally printed in the GV in early 2008. Updates by the authors and the importance of the topic have made it appropriate to print it again.]

The "skin picking" behavior of PWS has a wide range of severity from patient to patient and sometimes in the same patient over time. A stability over time is more typical, however, as Wigren reported in 1999. Some patients have occasional minor skin picking while others maintain large open wounds. In the "PWS Personality" presented in 2006 we separated *skin picking as a habit behavior* and *self mutilation* associated with extreme emotional distress, which is far less common. Here we will only address the former and leave the latter and rectal picking for another day.

Why do they pick? Some speculation.

Much of PWS behavior makes more sense when we view it as a failure to inhibit. The eating behavior is largely due to defective "brakes" called satiety. The drive to skin pick may be a normal drive (who has not picked a scab or other bodily irregularity?) designed to free us of unwanted parasites. But in PWS the limiting signals are weakened. We speculate that these signals are pain and disgust, both neurologically based (not just cultural) phenomena and apparently reduced in PWS.

Skin picking as a habit behavior

Here, skin picking is defined as an activity that goes on when the patient is calm and does not appear to be expressing emotional distress by the behavior. It has been related to boredom and anxiety, but objective evidence for this is difficult to establish. Features include:

- Opportunistic topography (i.e. location is convenient to reach)
- Arms, face, scalp
- Nose, nasal septum
- Picking cuticles
- Pulling out toenails, teeth
- Peeling skin from soles of feet

Points on management

No specific intervention has been uniformly effective. The behavior often extinguishes if healing of the wound is achieved. There has been limited success using protective dressings and an intense program of alternative activity until wound healing occurs. Behavioral interventions have been effective in some cases (see box).

Because skin-picking behavior occurs intermittently and secretively, behavioral interventions targeted at the activity itself are difficult to implement. A basic principle is that no attention, positive or negative, should be paid to the behavior itself other than to require the patient to observe social conventions and good hygiene.

Obsessional, but not OCD

The behavior appears to be "obsessional;" however, this is not an obsessive-compulsive behavior and medications targeting OCD (Obsessive-Compulsive Disorder) or anxiety have not been specifically helpful. If the behavior is clearly related to other signs of anxiety, then the anxiety should be addressed first with environmental changes. Remember that anti-anxiety medications all carry the risk of increasing irritability or of triggering abnormal mood elevation.

Use of Topiramate

Topiramate (Topamax) in low doses has been effective for some patients and should definitely be considered in persons with severe picking. In 2004 Shapira¹ and others used 25-50 mg daily and reported that some patients responded and some did not. Clinical experience with higher doses of topiramate as a treatment for mood disorder or appetite suppressant have been disappointing, but impressive improvement in picking behavior was also noted.

Higher doses (1000-200 mg/day) are associated with more side effects (irritability and renal tubular acidosis), but these are dose dependent, and reversible. These issues should not deter a trial of the medication, only guide the physician in what to monitor. Presumably if lesions heal, a trial off the medication makes sense. Allow 2-3 months on the medication to evaluate. Anecdotally, sensory stimulation has been quite effective for some severe picking behaviors. Sensory modalities have included vibration or massage administered on a schedule multiple times per day. The sensory stimulation should not be linked verbally or temporally with the picking behavior, as this could result in rewarding the behavior. More information on using sensory integration techniques has been assembled by Janice Agarwal, P.T. and is available on www.pwsausa.org.

¹ Shapira, N.A., Lessig, M.A., Lewis, M.H., Goodman, W.K. and Driscoll, D.J.: "Effects of Topiramate in Adults with Prader-Willi Syndrome." *Am. J. Mental Retardation*, 109:301-9, 2004.

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Skin Picking, continued from page 2

A Program to Address Typical Skin Picking

By “The Pittsburgh Partnership”

Linda Gourash, M.D., Janice Forster, M.D.

1. Tell the child that you want to help her sore to heal. Do not talk about the “picking”.

2. Tell him that when the sore heals you will celebrate with a special reward.

■ *This reward should be motivating, but not too motivating; rewards that are too motivating can create anxiety. Also there is the risk that an older, more clever individual will deliberately create wounds to heal to earn the reward!*

■ *Be prepared to offer the same reward on multiple occasions.*

■ *Try to anticipate the situations when picking tends to occur, and before he starts to pick, remind him that he is working to gain this reward.*

■ *Once the reward is earned, offer it weekly (for very young or low functioning children or for severe pickers) or monthly for “no new sores.”*

■ *If a reward must be withheld because of a continued open sore, express your disappointment that the reward was not earned and your optimism that he can achieve it very soon. Most superficial sores show considerable healing in a matter of 2-3 days if there is no picking going on.*

3. Tell her that you have medicine to help the sore to heal.

■ *Plastic surgeons use Polysporin [Bacitracin/Polymyxin] ointment on healing wounds to minimize scarring. Also, it has the effect of keeping the area soft, slippery, and less tempting or less easy to pick.*

■ *Use Polysporin ointment on the sore as frequently as possible (every ½ - 1 hour while awake) and apply thoroughly at bedtime.*

4. Use a dressing or some other barrier where anatomically possible. Your purpose is to make the picking less convenient.

■ *The ideal dressing is NOT airtight but is difficult to remove. On arms and legs this can be gauze wrap covered with cling wrap.*

■ *If there is no evidence of picking during sleep, leave the area open to the air. Socks or mittens taped at the wrist have been used for nighttime picking.*

■ *Other covers have been effective barriers: “Onesies”; tight fitting clothes e.g. Scuba suit or leotard for trunk; panty hose for legs; can be cut and redesigned for arms or scalp. ■*

Guidelines on Scoliosis Monitoring and Treatment for Children with Prader-Willi Syndrome

By Harold J. P. van Bosse, M.D.

Shriners Hospital for Children - Philadelphia

Contributors: Janice Agarwal, P.T.; Jamie Bassel, M.D.; Janalee Heinemann, M.S.W. & Jennifer Miller, M.D.

BACKGROUND

Children with Prader-Willi syndrome have an incidence of developing scoliosis at rates between 40-90%. Approximately 15% of children with Prader-Willi syndrome will develop severe or significant curves, requiring bracing or surgery. The earlier the curve is detected, the better the possibilities for treating the curve with casting or bracing.

There are two peak ages for scoliosis presentation in children with PWS. Under the age of 4 years, most of the curves are C-shaped and are most likely related to the hypotonia. The second peak, centered around 10 years of age, typically is the more common idiopathic S-shaped curve. Fifteen percent of curves diagnosed before 4 years of age subsequently required surgical treatment; 41% of curves diagnosed after 4 years of age required surgical correction, as per a PWSA (USA) survey of membership. Spinal deformities in children with PWS are often diagnosed late. This delay appears to be due to unique characteristics of spinal deformities in children with PWS, rather than the presence of obesity. Fewer children with PWS now develop obesity, and often the curves are diagnosed prior to the onset of obesity. What seems to be the more important factor is that spinal deformities in children with PWS have less vertebral rotation than seen in other children with scoliosis curves of a similar size. Vertebral rotation causes the asymmetry of the chest wall seen during forward bending, usually the first sign of scoliosis. Therefore, the child with PWS may have a moderate curve radiographically, but only mild findings clinically. For that reason, there should be a much lower threshold for working up clinical findings in children with PWS, compared to otherwise unaffected children.

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Scoliosis, continued from page 3

CONDITIONING

Children with PWS should be encouraged to be as active as possible, particularly those activities that build core musculature, strengthen the abdominals and the back muscles. In addition to sports and recreational activities, focused physical therapy and hippotherapy, emphasizing core muscle strengthening, may help improve a hypotonic curve in a young patient with a flexible deformity. If kyphosis is noted to develop, a physical therapy regimen should be included with specific exercises to strengthen the back extension muscles. A number of parents have also found Pilates to be beneficial.

MONITORING

Scoliosis in infants with PWS is unlikely to develop prior to the influence of gravity across the spine. Therefore, monitoring of spine should begin when the child first sits independently, usually around the first birthday. Yearly screening radiographs of the seated or standing spine should be used in addition to a clinic examination. If a deviation greater than 10° from straight is noted, radiographs should be obtained more frequently, depending on the age of the child, size of the curve, and apparent risk towards progression.

CASTING

If scoliosis is detected in the infant, spinal casting has been shown to be effective before 3 years of age. Curves over 20° should undergo casting with the Mehta technique, with a goal of decreasing the curves to as close to 0° as possible. Even curves over 90° can obtain some correction with casting and should be attempted in this age range. In general, a child's third birthday is often seen as the upper limit to starting casting, but in practice casting has been initiated even up to the fourth birthday. The casts are changed every 2 months in children under 2 years of age, and every 3 months in children over 2 years of age. Casts are continued until the curve has been successfully reduced, or if correction plateaus over successive cast. The child is then braced to maintain the size of the curve.

BRACING

Brace treatment should be considered for curves over 20° in children under 10 years of age, and for curves over 25° in children 10 years or older. The brace, a thoracic-lumbar-sacral orthosis or TLSO, should be worn 22 hours per day, allowing an extra hour or two out-of-brace for physical activities. When the brace is prescribed, initial ra-

diographs in brace should be obtained to verify moderate correction, as compared to the out-of-brace radiograph. Smaller spine curves in children with Prader-Willi syndrome are often flexible, although it will not be possible to obtain a 50% correction of all curves. Follow-up out-of-brace radiographs are obtained every 4 to 6 months, having the child remain out of brace overnight, up until the time of the radiograph.

SURGICAL INTERVENTION IN THE GROWING CHILD

In growing children (usually up to 10 years of age) with progressive scoliosis that cannot be maintained under 50°, a surgical intervention is needed. Performing a definitive spinal fusion at this age may improve the child's deformity, but will restrict spine and chest growth. At maturity, the patient will be adult sized, but with a child-sized chest. Therefore, implantation of an expandable device is likely required. (In practice, once I have identified a curve that will require surgery, I try to postpone intervention until the curve cannot be maintained below 50° in an *in-brace* radiograph.) The goal of this type of surgery is to decrease the curve's size initially, then prevent it from progressing while allowing for spinal growth. There are two kinds of expandable implant: one is the "growth rods" or "nonfusion spinal instrumentation" (NFSI), the other being the "vertical expandable prosthetic titanium rib" (VEPTR) device. The VEPTR device has proven to be problematic in children with PWS, primarily due to the low bone mineral density leading to frequent failure from rib fractures. For that reason, we recommend the use of a NFSI. For PWS, the construct that has worked well is a two segment fusion cranially, and a two segment fusion caudally, each with bilateral pedicle screws, for four pedicle screws anchor above and below. The segments are spanned with dual rods. A typical construct would be from T3 to L4, fusing T3 and T4 to act as the upper anchor, and L3 and L4 as the lower anchor (see figure). A characteristic of PWS is a cervical-thoracic junction kyphosis. Therefore the proximal extent of the fixation should be as low as possible (T3 or T4), and a moderate amount of existing thoracic kyphosis can be accepted. Over-correction of thoracic kyphosis appears to drive the cervical-thoracic junction kyphosis towards progression. The construct is lengthened every 6 months, to keep up with spinal growth. Near skeletal maturity (as determined by bone age), the construct will need to be converted to a definitive fusion.

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Due to length, the complete version of this article can be downloaded from the web, or PWSA (USA) members can call 800-926-4797 to get a copy mailed or emailed to them. The following is an outline of the rest of the sections of this article.

DEFINITIVE SPINAL FUSION SURGICAL AND ANESTHETIC CONSIDERATIONS IN PWS

- Respiratory
- Bone Mineral Density
- Pain Tolerance
- Food Seeking and Gastrointestinal Issues
- Skin Picking

If the above points are carefully observed, surgery can be performed safely in children with PWS. ■

[note: The following is a report on research funded by a grant from PWSA (USA).]

The Expression and Regulation of Necdin in the Mouse CNS

By Teresa M. Reyes, Ph.D., University of Pennsylvania, School of Medicine

The goal for this project involved an examination of necdin expression within hypothalamic neuronal populations, in an effort to relate necdin loss with hyperphagia. Our original hypothesis was that necdin expression would be concentrated within neurons that function to inhibit food intake (loss of necdin would affect the survival of these neurons and without proper signals to inhibit food intake, overeating occurs). We were successful in localizing necdin and alpha-MSH, a potent neuropeptide that inhibits food intake, in a subset of neurons. However, the majority of the alpha-MSH neurons did not express necdin and the majority of the necdin neurons did not colocalize with alpha-MSH. The distribution of necdin suggests that it may be expressed with NPY containing neurons, which can strongly drive food intake. Our initial hypothesis was not supported.

Additional experiments examined necdin expression more broadly in the CNS in two animal models in our laboratory that both have a hyperphagic phenotype (diet-

induced obese animals (DIO) and intrauterine growth restricted animals (IUGR)). Reduced necdin expression was observed in aspects of the arcuate nucleus of IUGR animals; however, the overall impression was of increased expression throughout the entirety of the hypothalamus in both IUGR and DIO animals. Interestingly, we also observed an increase in the expression of necdin within a select set of neurons within the striatum. While we did not phenotype these neurons, their location within the striatum suggests that they participate in the encoding of the rewarding properties of food. Overall, there is a suggestion that necdin expression may be increased in the CNS in parallel with hyperphagia in the adult animal.

At least two primary conclusions can be drawn from our data. (1) The expression of necdin within the hypothalamus is not restricted to neuronal populations that inhibit food intake, and (2) in our adult animal models of hyperphagia, necdin expression was increased. These studies are correlative and not causative, so we can only state the observed correlation. It is interesting to note, however, that our two models of hyperphagia were very different in origin, with one being the result of chronic intake of high fat diet and the other the result of a developmental insult (reduced intrauterine growth).

Going forward, future experiments that alter necdin in a developmental manner (more in line with Prader-Willi patients) would likely shed more light on the developmental effect of necdin loss on hypothalamic development. Additional regions outside the hypothalamus (including the brainstem (NTS) and forebrain reward circuitry) should be included in analyses as well. The role of necdin on neuronal function is likely to be different in the developing versus adult nervous system, and this critical variable must be considered in the interpretation of the present experiments. ■

WEBINAR The Ten Elements of a Successful School Year

Wednesday, October 13, 2010, 8:00 p.m., EST

Co-presenters Mary K. Ziccardi and Kerry Headley will address topics such as managing transitions, transportation issues, and having a schedule, suitable for both parents and educators. Ms. Ziccardi has worked extensively with people with PWS and providers over the past decade. Ms. Headley is the mother of a son, 12, with PWS. She will share her personal experience in working with her son's teachers and schools. Check PWSA (USA) website for details. ■

“One must be poor to know
the luxury of giving.”

~George Eliot

Christie Bevacqua, mom to **Jack**, 8, who has PWS, and family held a Dine-in at **T.G.I. Friday's** in May in New Jersey. Along with a great night out, the event raised \$135 for PWSA (USA). Others who are interested in this type of event can contact their local T.G.I Friday's restaurant for details.

Sabrina Lakey of Texas, mom to 1-year-old **Abby** with PWS, sent in a \$430 donation for research after family and friends gathered at their local high school for a **walk-a-thon** in Abby's honor. She wrote, “We plan to return next year to do the same. It is our hope that each year we will become even more successful.” She ended with, “Thank you all at PWSA for all your hard work!”

Deahl Wilson set up a Firstgiving page to celebrate the **birthday** of **Matthew David**, with PWS who turned 1 in May. His page has so far collected \$225 and more may be coming.

In June **Maria and Marty Sinclair**, New Jersey, organized **Cuts for a Cause in honor of Mikhel Sinclair**, 8, who has PWS, at **Sapphire Salon and Spa**, founded and owned by **Josephene and Danielle Farahmand**, Mikhel's aunt and cousin. Hairdressers and beauticians donated their time, and 100% of proceeds, \$5,014, went to PWSA (USA) for research. Other entertainment included face painting, crafts, games, and donated food. Wrote Marty, “We hope to do a benefit every year. Whether we do this same theme remains a decision for the future.” With the media exposure, they were also able to make hundreds aware of PWS.

Also in June, **Veronica E. Conner Middle School**, Grand Island, New York, sent a \$100 donation to PWSA (USA) after faculty and staff held **Casual Dress Days**. Kristine Taylor, representing the school's charity fund, wrote, “Please accept the...check...in appreciation for... trying to find therapies and cures for Prader-Willi syndrome.”

On July 10 **Bill Fleming**, grandfather to **Kayleigh Steck**, 5, with PWS, and friends held the **5th Annual Golf Outing Benefiting PWSA (USA) and Light of Life Foundation** in New York. The event so far has raised \$1,790 for hyperphagia research. Bill wrote, “...despite the threat of thunderstorms all day we were able to complete the day's event... We anticipate continuing this event and hopefully thru the years to come.”

In Washington in July **Beth and Dave McLean**, parents to **Abigail**, 4, held their **PWS Night at the Mariners**, raising \$4,000 for PWSA (USA). This annual event has been a success from the first time at bat. The McLeans wrote, “... we just wanted to send a big THANK YOU to everyone who came out and supported Abby and the PWSA (USA) organization...In our 3 years of running this event, we have made over \$13,000 for this wonderful organization thanks to your generosity of time and money!”

Crystal Mertz, Missouri, organized a **Trivia Night in Honor of Colten Shields**, who has PWS. The July event netted \$1,366 for research. That's some brain power. ■



Set your heart on it! The **PWSA (USA) Annual Valentine's Day Research Fund Campaign** will again begin January 1. It could not be simpler to raise funds for research. Please join us. More details will follow in future communications. ■



Monkeys Made of Sockies

Monkeys Made of Sockies (MMOS) is an adorable character available as a golf club headcover to help with PWS awareness and fundraising from Daphne's Headcovers. With each MMOS headcover purchased, a portion of sales is donated to PWSA (USA). MMOS is carried in the golf bag of LPGA player, Leta Lindley, who was inspired to help those with PWS after meeting a child, Josilyn Levine, with the syndrome. Lindley was invited to participate in First Lady Michelle Obama's initiative, “Let's Move,” to help fight obesity as a result of her work with PWS. Daphne's Headcovers and MMOS, designed by Shannon Grissom who is proud to support PWS this way, too, continue to receive recognition. Read a recent write-up about it at <http://thehackersparadise.com/home/?p=9280>. MMOS makes a great gift for the holidays or for any golfer any time. Consider alternative uses as a puppet or just decoration. To purchase MMOS and support PWSA (USA), go to Daphne's Headcovers at <http://www.headcovershop.com/praderwillisynndrome.php>. ■



The Make-A-Wish Foundation granted Reagan's wish to meet Rascal Flatts!

By Diane Seely, Plain City, Ohio

The folks at MAW sent our entire family to Orange Beach, Alabama, to meet them backstage and go to an outdoor concert! The concert was amazing, the entire experience outstanding, every detail taken care of for us. For the first time in six years, it felt like a real vacation...no worries...just fun and relaxation. Reagan Seely, age 7, who has PWS, was so excited to ride in the limo but fell asleep shortly on the way to the airport.

The morning of the concert the first thing that Reagan said was "Today I get to meet Rascal Flatts! I almost forgot, my wish came true"...silence for a while and then..."Joe Don used to wear his hair like this" and pushed his hair off his forehead to make it stick straight up and spiky.

For one weekend we were able to totally put Prader-Willi syndrome in our back pocket and not think about it--no doctor appointments, no therapies, no behavior modification. We didn't count his calories or journal his food intake (within reason, of course, and completely supervised by mom and dad). For the first time ever at the restaurant we allowed Reagan to have dessert after dinner. Just a few bites of rich chocolate cake. He also wanted vanilla ice cream (just a small scoop). He took one bite of cake, and the look on his face said: "Mom...Dad...you been holding out on me"...

Meeting Gary, Joe Don and Jay will be a memory that will last Reagan's entire lifetime. When they came out, they looked like they were ready for a photo shoot for one of their album covers. It seemed like they were almost as excited to meet Reagan as he was to meet them. Reagan talked to them like he had known them forever and asked Joe Don if he could see one of his guitars. The manager brought out a beautiful electric guitar, and Joe Don helped him put it over his shoulder. Something astonishing happened; when he was talking to them, he did not stutter once nor did he bounce or lunge (we endearingly refer to it as his little 'jig'). This was a miracle in itself. He was just in the moment and aware of what was going on, so opposite of what I expected him to do.

When we took the group photo, I stood next to Gary. I'm thinking to myself...should I put my arm around him?



Rascal Flatts with Reagan

Of course you know I did!! Geezze and I say out loud to him..."Oh, my goodness you smell good." He answers in his sweet southern voice, "Well, thank you, darlin'"...I am giddy like a school girl!

The stage manager let us go onto the set and check out the rest of the guitars. Reagan had a chance to 'play' some of them. The guys played the chords to "Life is a Highway" as he sang into Gary's personal microphone. The manager gave Reagan a set of drumsticks from the drummer and several guitar picks from Jay and Joe Don.

*Gary held Reagan
as he sang their song
"My Wish" to him.*

For the concert, the kids made a poster that read "We Love Rascal Flatts. Thank you Make-A-Wish." Gary reached down to take Reagan by the hand, picked him up and held him as he sang their song "My Wish" to him. "More than anything, yeah more than anything, this is my wish: I hope you know that somebody loves you. May all your dreams stay big."

It was so unexpected and unbelievable!! Tears of happiness and love... After the concert, women came up to hug me, and the guys were giving Reagan high-five's on the way out. Wow! I just can't stop smiling... ■

Welcome to PWSA (USA) Development Coordinator



David Crump

We are happy to announce the addition of a new staff member, David Crump, Development Coordinator. David, who has a master's

degree from the University of South Florida and a doctorate from the Catholic Theological Union, plans to raise the level of awareness and funding of PWSA (USA). He has a strong background in fundraising, program expansion, management and community awareness.

Although born near Chicago, David spent most of his childhood in Brazil where his parents were missionaries. He is multilingual, speaking Spanish and Portuguese beside English. Initially he was in the ministry working with Native Americans in a reservation setting, then went on to become Executive Director of San Jose Obrero Mission in Chicago, Illinois, for ten years. From there David moved to the Sarasota area to be closer to his aging parents and started a consulting business, working with non-profit organizations.

David comes to us with the highest of recommendations. We trust he has the compassion for our cause and the knowledge needed to help us in many ways to continue to fulfill our mission. He will be full time and will also be working on our grassroots fundraisers while Jodi goes on maternity leave. Welcome, bienvenido, David! ■

PWSA (USA) Conference 2011

A contract has been signed with the hotel for our upcoming conference to be held November 11-13, 2011, in Orlando, Florida! The Buena Vista Palace Hotel is located on Walt Disney World property across the street from the Downtown Disney Marketplace. The hotel sits on 27 beautifully landscaped acres just 20 minutes from the Orlando International Airport. For a photo tour of the hotel, please visit:

www.buenvistapalace.com.

The Scientific and Providers Conferences will be held on November 11, followed by two days of stimulating speakers and informative sessions for our families that includes exciting, fun-filled YIP and YAP Programs. Save the date and mark your calendars now!

Details for making reservations under the PWSA (USA) conference group rate will be provided soon. Please make your reservations under the group after this information is given. ■

If you are a Federal Employee, you can help!



PWSA (USA) CFC ID Number is 10088

PWSA (USA) qualified for membership and is part of the Combined Federal Campaign (CFC). If you work for the federal government and its agencies, you can make a donation via the CFC to PWSA (USA)! Funds derived from the CFC offer essential support for programs and research supported by PWSA (USA) and, with the help of those who can participate, will continue to do so. The CFC holds activities during their campaign in different local areas around the nation. You can participate by selecting PWSA (USA) to receive donations, and spreading awareness of PWSA (USA) so others can learn about PWSA (USA) and make donations, too! The PWSA (USA) CFC identification number is 10088. Thank you to all those who support PWSA (USA) this way! Your contributions are greatly appreciated and help ensure our loved ones with PWS have the best futures possible! Questions? Please call PWSA (USA) at (800) 926-4797 and ask for Debi Applebee. ■

Michigan Clinic Opens!

On July 16, 2010, five children with PWS attended the inaugural Multidisciplinary Prader-Willi Syndrome Clinic (Pediatrics) at the University of Michigan. Children and their families met with the Endocrinologist and Pediatric Endocrinology Nurse Practitioner; the Sleep Team, with both neurology and pulmonary physicians; Behavioral Health; Social Work; Psychology; and the Registered Dietician. Beginning in December, an orthopedic surgeon will join the team. For information, contact Kathy Clark (PNP) at 734-764-5175. Website coming soon. ■

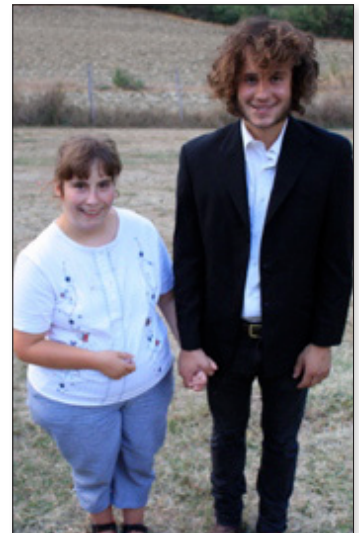
Sibling View

Ashleigh Lininger, Cucamonga, California, died at age 20 on May 16, 2010. Christopher Lininger, just 11 months older than his sister Ashleigh, who had Prader-Willi syndrome, wrote this poem for her after her death. It was printed on the card distributed at her memorial/funeral service. ■

Last Thoughts of Ashleigh

By Christopher Lininger

It is time. Time for time.
Time gone for mother's breast and mother's hand and father's teaching.
The ice cream shops are closing, the toy stores have the lights off,
and it is too late to go for a walk
around the park.
But for you, little sister everything is open.
Open.
For much seemed closed to you in your life, but all you
saw was the opening you created.
Time is open for you now.
The plum blossoms are falling. Each blossom honored life.
You have honored life, little sister.
You have honored us all.
From every question to every smile.
You gave us much. You gave us everything.
And now you take the journey, so take it well.
Know that you are loved.
Take your journey well.
"Death is the remedy that all great singers
sing of."
Take the new dream, leave your mind in the grass of your choice, it's all the same.
Take your remedy,
"no more suffering for you.
I know where you've gone. It is good."



Welcome to our PWSA (USA) Board Members



Michael Alterman



Jamie Bassel



John Heybach



Stephen Leightman



Mary K. Ziccardi

As a result of our recent election, Michael Alterman, Jamie Bassel, John Heybach and Stephen Leightman were

re-elected to serve a three-year term. We also welcome Mary K. Ziccardi as a newly-elected board member. ■

International View

The following is a letter to Giorgio Fornasier, Executive Director of International Prader-Willi Syndrome Organisation, from Loisel Bello, physician from Cuba whom Giorgio helped to be able to attend the Taiwan conference. The letter is printed as Giorgio translated it.

Best regards to you.

I hope you are enjoying your family with happiness.

I wish to share with you the happiness I have thanks to your help and what I learned in Taiwan Yesterday it was a memorable and wonderful day to me, I wish to report to you:

Yesterday I had an appointment with the Vice Minister of Health and made him a long report of my experience with all details together with the benefit families with children affected by PWS in Cuba could have as part of an International network. I told him also about BIRD and the cooperation for rare diseases they intend to establish with Cuba, mentioning the free diagnosis service they offer together with IPWSO and the importance that an early diagnosis has to manage such a complicated disease together with the importance of GHT.

He put several questions to me and then gave me the following suggestions to follow:

1- Contact with the director of National Genetic Centre to inform her about the tests BIRD can offer for some rare diseases, including PWS.

2- The possibility to introduce myself to the director of the Institute of Endocrinology of Cuba. When I had this meeting, I told them about the Conference in Taiwan and what is done in the world for this disease. They were very sincere to me and showed a great interest as they admitted they know nothing about managing patients with PWS and asked my cooperation to get literature and information about this rare disease. I told them about GH and promised a detailed scientific infor-



Loisel Bello, M.D.; Giorgio Fornasier

mation for the benefits patients with PWS can have. I spoke about Pfizer and they said they buy already their products. They need to discuss about this issue and promised to go back to me next week.

I also made the proposal to organise a Conference in Cuba with presenters like Dr. Moris Angulo who can speak in Spanish.

I felt really very happy because they listened to me and it seems there is great interest to cover this lack of attention towards patients with PWS and their families. I feel **useful** and **free** because I have the opportunity to return some way what you all gave me, as information and love.

When you invited me to join Taiwan Conference covering all costs involved, I promised you this was not done in vain. I will fight together with my wife until the present reality of PWS in Cuba will change and improve. It is only 10 days that I returned home from Taiwan, but I am dedicating all my time for this.

3- I wish to inform you officially that our reference name from now on will be FCSPW (familia cubana syndrome de prader willi), that will never become an association or organisa-

tion which are not allowed here, but we may have a support group for families. You must be very proud because we fixed already the date of our first meeting which will take place on 23 and 24 September, with the participation of 15 families only to start with, which I invited already.

I am practicing all your advice and wisdom.

Hugs to all, Maurizia, Daniele and remaining members of your family.

Eternally grateful, Loisel ■

¿Habla español?

WANT AD / NECESITADO

Needed: mentors and interpreters for Spanish families. Can you help? If so, please contact Barb McManus, at 800-926-4797.

Necesitado: Los mentores y los intérpretes para familias españolas. ¿Puede ayudar? Si eso es el caso, contacta por favor Barb McManus, en 800-926-4797. ■



Our five-year-old Kate loves to go to our church "primary," a Sunday meeting for children ages 3-11. The kids all love to sing a song called "Follow the Prophet." However, in true Prader-Willi syndrome fashion, Kate sings, "Follow the Chocolate!"

~ Lisa Thornton
Salt Lake City, Utah

Chapter View

By Barb McManus, Director of Family Support

Michigan held its annual walk in May to promote awareness of PWS—a huge success this year. Before the walk Jessica Belanger was shopping in WalMart and noticed an adult woman being pushed in a wheelchair who looked like her son. She decided to approach the woman pushing the chair and asked about what the woman in the chair had. The reply: “You’ve never heard of it.” Jessica started to walk away and then turned back and said, “Try me.” The reply: “Prader-Willi syndrome.” Jessica explained her 9-year-old son has PWS and the next day they were holding an awareness walk. The woman pushing the chair and her adult daughter in the chair attended. They were thrilled and want to become more involved. Jessica has an 11-year-old, and the woman has a 12-year-old daughter who was looking for someone to connect with who understood. ■

Speaking of becoming involved, would YOU like to become more involved? There are many opportunities waiting just for you and your talents, abilities and compassion. PWSA (USA) and its chapters are always looking for individuals that are willing to help on the local and national level.

Consider our New Parent Mentoring Program, where a parent that has a small child with PWS is connected with and talks with the parent of a newly diagnosed child.

Are you in an area where you would like to meet others with children having PWS? Well, how about helping PWSA (USA) get a meeting or group together in your area? You can work with your state chapter or help us create a chapter where there is none.

Contact Barb McManus at the national office, 1-800-926-4797. ■

Registration opens for **PWSA of Ohio** Fall Weekend Camp at Recreation Unlimited in Ashley, Ohio

Grants available for Ohio campers who are members

Camp begins at 7:00 p.m. on **Friday, October 15 and ends at 1:30 p.m. on Sunday, October 17, 2010.**

Camp cost is \$160** for chapter members/residents of Ohio and \$215 for nonmembers/nonresidents of Ohio.

Children and adults ages 8 and over with Prader-Willi syndrome may attend.

Meals and activities will be totally adapted for those with PWS.

A nurse will be on site for the entire weekend.

If the camper requires one-on-one assistance, a support person must accompany him/her to camp. The fee for food and lodging for the support person is \$110.

For more information, contact Sandy Giusti at 614-876-1732 or by email at juicete@aol.com ■

**Florida announces:
Fall Conference -
October 15-16, 2010**

**Regal Sun Resort
Orlando, Florida**

**Guest Speaker:
Dr. Greg Cherpes
Children's Institute
in Pittsburgh**

**Other speakers
to be announced.**

**Check our website for
updates: www.pwfa.org**



The Editor requests your input...

Two “Ask the Parents” articles have appeared in *The Gathered View*, using responses from our e-mail groups. Now I’d like to open it up to the membership and ask for your input in any of these three areas:

1. Carrying the PWS ball is hard enough when there are two people, but it has to be lots harder when there is only one. **What are your experiences as a single parent?**
2. We are very focused on caring for our children and their needs. But remember what you are told on an airplane: put the oxygen mask on the parent first, so that the parent can take care of the child. **What are you as parents doing for yourselves to stay healthy, mentally and physically?**
3. Having an adult child with PWS does not take away all the responsibility even when that child lives in a residential setting. **What’s it like, now that your child is over, say, 30?**

Please send responses to me, Lota Mitchell, Editor, at ljecholsm@juno.com, or if you don’t use a computer, to the national office marked to my attention. THANKS! ■

Introducing a new section under From the Home Front:

Parent-to-Parent!



Appearing occasionally, it will contain information that parents want to share with other parents, but does not imply a recommenda-

tion from PWSA (USA). "The Face-book Bus" is the first article to appear in P2P. The site is not endorsed by PWSA or coordinated in any way by us but is an example of a parent-created support group on Facebook.

THE FACEBOOK BUS

By Misty Adams



Facebook can be an amazing vehicle. This big bus we're riding is picking up passengers and team members very quickly. It's as if we are all in a big hurry to get to our destination. That would be "teaching us all to be great parents" to our beloved children with Prader-Willi syndrome.

I am Misty Adams, proud parent of a 19-year-old beautiful, wonderful daughter named Holly Rose, who happens to have PWS.

Our journey has been interesting and challenging, not unlike many others on the bus...

I was majoring in Special Education at CSUChico when our first son, Corey, was born with serious birth injuries. He didn't actually survive the trauma, but the medical team resuscitated him without our knowledge. In fact, we didn't know this until 7 years later.

Four years later, our beautiful Holly Rose was born. It took us four years to have her diagnosed, with earlier tests all negative. But once the technology caught up, she finally received a positive test result: PWS by

deletion.

Initially, I was very active in advocating for our children--anything from speaking to the American Board of Pediatrics to getting an Assembly Bill and a separate Senate Bill passed into law. I sat on the Board of Directors for a California Regional Center for a few years. As time went by, I was totally needed at home to care and advocate for our own children. Thus I was off the radar for several years.

Then six years ago, a friend from our church gained custody of her niece Amy, then 8. She called one day and asked for help. I said sure, then asked what. Amy lived with us for the following several years. We were attempting to adopt her. Then, a little over 1 year ago, we adopted our son, Ricky, now 15.

Needless to say, I have been seriously pre-occupied. Corey was on life support for the past 8 years--bringing with it a whole new set of complicated issues with staffing, medical services, quality of life issues with outsiders, etc... Corey's courageous journey came to a sudden end January 26, 2010. Amy left our home unexpectedly. And in August 2009, Holly moved into a group home for PWS. Talk about "empty nesting"--from 4 children in the home last August to 1 currently.

In dealing with my grief and trying to do something positive and constructive, I started researching PWS again. I noticed that there wasn't much available on a daily basis for parents and caregivers to quickly access "Inside" information.

Thus filling up the bus began!!! The Facebook site, started April 16, 2010, is called "Prader-Willi problem solving & solutions exchange" for parents and caregivers. The other two "drivers" are Janis Tull Williams, mom to Audrianna (9), and Ali Foley Schenk, mom to Dean (1). Our goal

is simple: to grow, become powerful and have a very strong prominent voice for our beloved children.

We currently have 455 passengers. A few passengers have fraternal and identical twins, and a fair number of adults with PWS are on board as well. In the past month and a half, we have had passengers from 17 different countries and this past week alone, we have had 1200 visits to our site.

Discussions have included NG feeding tubes, skin picking with potential treatments, HGH, IEP's, Behavior Plans, Dentin, fantasy vs. reality issues, locks for food, and many, many other topics. Input with respect for all others on the site is always welcome.

My personal belief is that WE the parents and caregivers are the REAL experts in what is working and what is not. Without us, it would be even more difficult to get from point A to point Z. So next time you're site seeing on Facebook, be sure to come take a ride on our very colorful bus. Hope to see you there. ■

Dylan Krambeer at his First Communion - Crystal Lake, Illinois





WE REMEMBER

Columbia, South Carolina – **William Rhett Eleazer, Jr.** “Billy” went to be with the Lord on July 23, 2010, and claim his new body—free from the chains of Prader-Willi syndrome that had

bound him for 42 years. No more pain when he walks, no more struggling for breath. Free at last in the arms of angels.

Born on March 18, 1968, he was the son of Rhett and Jeanne Eleazer of Chapin, South Carolina. Billy attended public schools and graduated from Spring Valley High in 1988. Soon after graduation he moved into a new group home with seven other people who suffered from the same disability. This home was built through the efforts of his parents and the Babcock Center and was a model for people with this unique disability which was used by many other states. At the time of his death he was living in his own apartment with support staff provided by the Babcock Center.

Billy enjoyed people and never met anyone who would forget him. He loved animals, music, movies, fishing and acting. Prior to his death, he was involved in numerous productions mainly through Carolina Actors with Special Talents (CAST). ■

Written by his mother, Jeanne Eleazer

Note: His father, Rhett Eleazer, was a member of the Board of Directors of PWSA (USA).



Did you Know?

Although there are nearly 7,000 rare diseases, there are only about 1,200-1,400 patient support and advocacy groups for these rare diseases.

~Office of Rare Disease Research (ORDR)

Counselors Corner

School and Holiday Planning

As school resumes and another holiday season approaches, this month in the Counselors Corner we want to point you to some important planning and prevention resources.

For school related questions, make sure to visit <http://www.wrightslaw.com> which is a comprehensive special education website. And, for PWS specific educational information, the PWSA Educator’s Page is the place to go <http://www.pwsausa.org/Educator/index.htm> for useful information, links, and resources.

Because the holiday season presents unique challenges for a person with PWS – especially around the issue of food security – we encourage you to visit our website to review the following helpful holiday planning resources.

<http://www.pwsausa.org/resources/Trickortreat.pdf>

<http://www.pwsausa.org/Intervnt/christmas.htm>

<http://www.pwsausa.org/Providers/Holiday.pdf>

And remember, if you have a specific school or holiday related question, please call and speak to a Crisis Counselor for more information and assistance. We wish you all a happy and safe school year and holiday season!

See you next time in the Counselors Corner! ■

~Evan Farrar

Crisis Counselor

AN IMPORTANT MEETING

Dateline August 12 -- We are very pleased to announce that the Prader-Willi Syndrome Association (USA) and the Foundation for Prader-Willi Research will hold a joint board meeting on September 11, 2010 in Washington, DC. The purpose of the meeting is to strategize about the future needs of individuals with PWS, their families, and their care providers, and to identify potential solutions in the areas of both care giving and research. We will also focus on how the two organizations can work together to meet these future challenges. We, as the leadership of PWSA and FPWR, are excited about the meeting and the opportunities it will create for us to work together to accelerate progress in serving the Prader-Willi syndrome community. We will keep you informed. ■

Contributions

Thank you for Contributions in June and July 2010 We try to be accurate in recognizing contributions, and apologize for any errors or omissions. If you notice an error, please tell us.

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Bob Wojciechowski's 80th Birthday

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SAVE THE DATE!

November 11-13, 2011

Orlando, Florida

PWSA (USA)'s National Conference with YIP and YAP programming.

Keep an eye on our website for more information.

Prader-Willi syndrome (PWS) is a birth defect identified in 1956 by Swiss doctors A. Prader, H. Willi, and A. Labhart. There are no known reasons for the genetic accident that causes this lifelong condition, which affects appetite, growth, metabolism, cognitive functioning and behavior. Prader-Willi Syndrome Association (USA) was organized in 1975 to provide a resource for education and information about PWS and support for families and caregivers. PWSA (USA) is supported solely by memberships and tax-deductible contributions. To make a donation, go to www.pwsausa.org/donate

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Our Mission: PWSA (USA) is an organization of families and professionals working together to promote and fund research, provide education, and offer support to enhance the quality of life of those affected by Prader-Willi syndrome.

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Note: If you have difficulty logging in, please contact info@pwsausa.org.

E-mail Support Groups:
We sponsor nine groups to share information.
Go to: www.pwsausa.org/egroups

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Medical information published in *The Gathered View* is not a substitute for individual care by a licensed medical professional.

**Deadlines to submit items
to *The Gathered View* are:
Dec. 1; Feb. 1; Apr. 1;
June 1; Aug. 1; Oct. 1**

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