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

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

Rob Nicholls Ride for Research

Join Rob Nicholls as he rides for PWSA (USA) and the fight against childhood obesity!

One man, one bike, one ride across the country for a cure –

Rob Nicholls, Ph.D., a researcher at The Children's Hospital of Pittsburgh who is Director of the Birth Defects Laboratories, has decided to take on Prader-Willi syndrome and childhood obesity in a unique and interesting fashion. In the name of research, Rob Nicholls will be putting both his life and physical endurance to the test.

Starting in San Diego, California and finishing in Orlando, Florida at the **Prader-Willi Syndrome Association (USA)'s National Conference** (www.pwsausa.conference.com), Rob will bicycle over 3,000 miles through desert, mountains, forest, and tropics in less than one month, enduring all the challenges along the way.

Why?

Rob's goal is to raise funds and awareness for PWS. As a leading researcher who has focused on PWS since 1987, Rob will use the funds raised from the ride to administer cutting-edge research for PWS.

The bike route will be along the southern part of the United States, but we encourage everyone across the country to join us as we increase awareness of Prader-Willi syndrome.

You can follow Rob's journey at www.robsrideforresearch.com. We will continually update the website with more information on Rob, his research, the Ride, sponsorship opportunities, and our progress as we meet our fundraising goals!

COME TO THE NATIONAL CONFERENCE IN ORLANDO TO HELP WELCOME ROB AT HIS RIDE'S END!

PWSA USA ALL-STARS 2013

How to get involved

Needs include:

- Volunteers For Event Committees
- Help Fundraising Online at (https://www.firstgiving.com/pwsausa/robs-ride-for-research)
- Make a donation for Rob's Ride and leave him a personal message of encouragement (Donations can be mailed to PWSA (USA) or submitted online at https://www.firstgiving.com/Page/2700855/Donation.)
- Raise awareness of Rob's Ride, spread the word!
- Financial Sponsors
- Event Organizers
- In-Kind Contributors

For more info on how to get involved contact Beth Bush at 941-312-0400 or bbush@pwsausa.org. ■

Did you Know?

... that if your child was diagnosed with the maternal uniparental disomy (UPD) type of PWS, it is thanks to Dr. Rob Nicholls?

Did you Know?

... that this discovery by Dr. Nicholls and his fellow researchers was a major breakthrough in the field of genetics by showing for the first time that there was genetic imprinting in humans (meaning that some of our genes have to come from a particular parent to work normally)?



Vick

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Volume 38, Number 5 ~ September-October 2013 ~ Our 38th Year of Publication

Report on the International Conference in Cambridge July 2013

By Janalee Heinemann, M.S.W.
PWSA (USA) Director Of Research & Medical Affairs

IPWSO's Eighth International Prader-Willi Syndrome Organisation Conference was hosted by the PWSA-UK in Cambridge. There were 33 countries represented, attending the scientific conference, the provider conference (with 23 countries represented), the general conference, and a program for people with PWS. The PWSA – UK did an outstanding job of hosting this very complex group of events, including a wonderful celebration supper with Ceilidh Scottish dancing.

PWSA (USA) was well represented, with 10 professionals presenting at the conference. There were 37 scientific presenters and workshops on genetics, endocrine, and mental health issues. There were also an amazing 80 scientific poster presentations! We do not have the space here to give you anywhere near the outcome of all of these presentations and posters, so I will just touch on a few interesting facts and/or outcomes. The 8th International Conference Abstract/Programme book, along with some of the presentations, is now available on the following website: *http://www.pwsa.co.uk/index.php/list-all-categories/79-slider/310-international-conference-2013-abstracts-and-presentations.*

- In the 1980s the **average age of diagnosis** in the USA for PWS was 8-12 years of age. Now it is less than two months. (Dan Driscoll, USA). In the recent Victoria Registry, the mean age at diagnosis in 1993 was 14 years of age, and in 2012 it was 3.5 weeks of age. They report that the estimated birth prevalence was 1:14,000. (Tess Lionti, Australia)
- The trial of **oxytocin spray** use for PWS in a study from the University of Sydney did not shown improvement in the food drive, behavior, or picking. (Ellie Smith, Australia) These results are in conflict with the positive results of the France study by Dr. Maite Tauber
- An eight year study on **growth hormone treatment** (GHT) demonstrated that GHT is a potent force for counteracting the clinical course of obesity in children with PWS. (Nienke Bakker, The Netherlands)
- The results of a study on **anesthesia** were similar to what we have reported regarding potential complications which include a narrow oropharyngeal airway, prolonged/exaggerated response to anesthesia, difficult IV access, dental issues, behavior issues, and an abnormal physiological response to hypopnea. (Graziano Grugni, Italy)
- **Spinal deformities** are probably underreported with PWS. The PWSA (USA) medical database statistics were given on various scoliosis issues. Every delay of a month starting growth hormone increases the risks of future surgery by .7%. (Harold van Bosse, USA)
- In a Texas Children's Hospital study of 145 children, **80% of the births were C-section**. There was no difference in the rate of cesarean deliveries between deletion and uniparental disomy (UPD). There was a trend toward lower BMI in PWS with breast milk exposure during the neonatal period. (Ann Scheimann, USA)
- Regarding **pregnancy and PWS**, there was a report on four documented pregnancies of women who have PWS. Looking for common features, other than significant weight loss prior to the pregnancy in three of the four women, there were no predictive factors that were evident. It is possible that fertility in a few women just reflects variability in hypogonadism and absence of opportunity in others who are potentially fertile. (Suzanne Cassidy, USA)
- The conclusion of an Italian study further confirms that **long-term growth hormone treatment in adults** with PWS significantly improves body composition, muscle size and quality, and increases muscle strength and exercise tolerance. (Graziano Grugni, Italy)
- The findings in this study in Japan were consistent with previous research that was done on mainly Caucasian patients indicating that in adolescence m-UPD patients were more prone to **ADHD and autistic symptomatology** than deletion patients, but there was no difference in younger children. (Hiroshi Ihara, Japan)
- In assessing **behavioral changes with age in PWS,** it was found that skin picking was more common in adolescence than in children, but less common in older adults compared to younger adults. Preference for routine, restricted interests /obsessions, repetitive language, impulsivity, physical activity level and positive mood were reduced as individuals got older. In general, many problem behaviors decreased in older adults with PWS. (Leah Bull, UK)
- In another study on **clinical neuropsychiatric diagnosis** among adults with PWS living in residential homes in Oconomowoc, WI, it was reported that there were similar findings in that the younger age group of individuals with PWS were more severely affected regarding neuropsychiatric diagnoses, but depression and anxiety were more prevalent in the older group. (Nicolette Weisensel, USA)
- **Prenatal PWS diagnosis**, a diagnosis before birth, is known in only nine cases worldwide. Due to this study, they recommend considering prenatal genetic screening by methylation test for PWS when any combination of

continued on page 3

Conference, *continued from page 2*



Mary K. Ziccardi, Suzanne Cassidy, Janalee Heinemann, and Hubert Soyer from Germany as Mary K. and Hubert received recognition plaques for their work in co-chairing the international professional provider conference.

intra-uterine growth retardation (a smaller fetus than expected) or asymmetric intra-uterine growth, polyhydramnios (an excess of amniotic fluid) and diminished fetal movement is present -- particularly when asymmetrical intrauterine growth and polyhydramnios coexist. (Noa Gross, Israel)

- In investigating the **brain functional status** using whole-brain fMRI in PWS comparing to healthy controls, it was found that patients with PWS exhibited higher connectivity in different parts of the brain involving not only hunger and satiety, but also in sensory processing, movement generation and behavioral response control. (Assumpta Caixas, Spain)
- In a Scandinavian study looking at **growth hormone treatment (GHT) in adults** with PWS to see if there was an increased risk of **sleep apnea** due to GHT, they compared those treated with GHT or a placebo for 12 months. They did a baseline and a follow-up sleep study. It was found that GHT in adults with PWS is not associated with an increased risk of sleep apnea.(S. Farholt, Sweden)
- A study further confirmed that **psychotic illness** is more prevalent among those with PWS who have genetic subtypes of mUPD compared to those with the deletion. (CG Waltman, The Netherlands)
- **Serial body cast** application is a useful treatment option in young patients with PWS with moderate to severe scoliosis. Smaller curves can be fully corrected; larger, more rigid curves can be controlled to delay the need for surgery. (Harold van Bosse, USA)
- In a study on **Vagus Nerve Stimulation** in PWS and the effects on eating and behavior, they surgically implanted a vegas nerve stimulator (VNS) in three people with PWS. The effects were that one person put on weight and the other two showed some improvement in their eating behavior. Unexpectedly, two of the three participants reported marked improvements in their behavior. (Katherine Manning, UK) ■

International General Assembly Meeting

- Dr. Suzanne Cassidy, (PWSA (USA) Scientific Advisory Board member) was voted in for a term of three more years as IPWSO president
- Janalee Heinemann (PWSA (USA) Director of Research & Medical Affairs) was voted in for a term of three more years as IPWSO vice-president
- Three new board members were voted in:
  - Marguerite Hughes – Ireland (PWS parent)
  - Mariona Nadal Farre – Spain (PWS sibling)
  - Dr. June-Anne Gold – California, USA, citizen of the UK
  - Don Tallon – Ireland (PWS parent)
- The next international conference in three years was awarded to Foundation for Prader-Willi Research of Canada

Did you Know?

...that IPWSO now has 101 countries who are members and associate members?

PWS Deaths – the Fears – the Facts

By Janalee Heinemann, M.S.W.
PWSA (USA) Director of Research & Medical Affairs

When word spreads throughout the PWS community about the death of a child or adult with PWS, I often get calls or reports of concern from parents wanting to know the cause of death. I appreciate that not knowing is worse than knowing. Sometimes we can give out more information than others, but no matter what we as an organization say or do, word goes out quickly on the Internet through Facebook and email support groups, etc. So I thought it might be helpful to give a broad perspective.

The reality is that most PWS deaths are still obesity-related. Due to the weak muscle tone, our children/adults who have PWS may even be more at risk from obesity-related complications at a lesser weight than the general population. (The average weight at death for individuals with PWS who appeared to die from obesity-related complications is 257 pounds.) Right-sided heart failure, respiratory problems and diabetes all can happen due to the obesity which makes other illnesses or surgeries more of a risk.

As for the non-obesity related deaths, in the little ones the deaths are typically due to respiratory complications. For an older child or adult, there are a variety of reasons – from choking and GI perforation to accidents. At PWSA (USA) we do have a committee of doctors that studies the cause of the deaths, and we put out an alert if we see a reasonable risk for which we can warn parents and caregivers. Of course, as a parent you need to keep yourself armed with the Medical Alert booklet at all times and articles from our medical section of the PWSA (USA) Web site as needed. Every day we are emailing or faxing articles to hospitals, physicians, and psychiatrists at the request of parents.

Our support goes beyond death through bereavement support calls and booklets.

God didn't promise days without pain, laughter without sorrow, sun without rain, but He did promise strength for the day, comfort for the tears, and light for the way. ■



PWSA BULLETIN BOARD

PWSA ★ USA
ALL-STARS
2013

PWSA (USA) NATIONAL CONFERENCE

November 7-9, 2013
Walt Disney World
Buena Vista Palace Hotel and Spa
Orlando, Florida

Register by September 30 for the best price. On October 1, the cost increases by $25 to $275.00 per person. Registration is open until October 15, 2013.

Some sessions have limited space available (YIP, YAP, and Sibling programs). So register now!
www.pwsausaconference.com

For room reservations at the Buena Vista Palace Hotel & Spa, Lake Buena Vista, Florida, starting at $129 a night, plus tax and resort fee, the direct link for our discounted rate at the hotel is **https://reservations.ihotelier.com/crs/g_reservation.cfm?groupID=759035&hotelID=6579**

Or call 1-866-397-6516 and mention **PWSA (USA) National Conference** or use the block code 1104577PW to receive the discounted conference rate. ■

WEBINARS

PWSA (USA) is presenting a series of monthly webinars on topics of general interest. The last two were on G.I. and school issues. Usually held on the last Tuesday of each month, the best place for people to find out about upcoming webinars is to follow our Facebook page or email Ben Karp, **BKarp@pwsausa.org** to request being added to the Webinar mailing list. ■

Coming Soon!

PWSA (USA)'s New Website
What: newly designed and improved

A Balloon Launch for the Love Of Noah



Six-year-old Noah Carrington, who had PWS, went to heaven on July 13, 2013. Many of our families from around the world knew Noah and his mother, Kendra, from Facebook and followed his valiant battle since he had a major medical crisis in 2008.

Kendra says, "The whole balloon launch started with Dianne Guerie Bryden. She told me she wanted to do a balloon launch in his memory on the day of his memorial, and with that I decided to put a post on Facebook and ask everyone to do so, not only in memory of Noah but to raise awareness. Immediately it caught on and went worldwide. So it is thanks to her and her compassion and wanting to show her support to us that got the whole thing started."

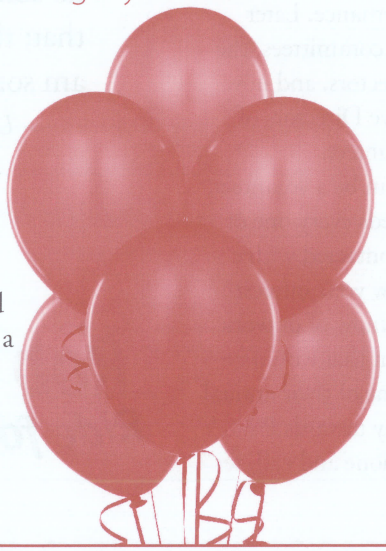
PWS families from 17 states and nine countries launched balloons in his memory on that day. Also, four PWS families traveled to come to his memorial service in Georgetown, Ohio, including Lon Seidlitz and his 19-year-old son Max, who has PWS. They drove 500 miles to attend. The love our families have for each other knows no borders, and when one of our children dies, the tears rain down from around the world.

Described by his mom as a very happy little boy who made everyone smile, Noah's life touched people around the world, and his memory will stay forever in their hearts. The following was on his memorial card:

Memories and little prayers
We are all mourning you
But we'll celebrate the short life you led
We will never forget you Noah

PWSA (USA) BALLOONS

Noah and this balloon launch inspired us to have PWSA (USA) balloons made that say, *"forever in our hearts"* that we can send to families who want to do a balloon launch in memory of a loved one. ■



Be There for Me

by Patrice Carroll, Manager of PWS Services, Latham Centers, Brewster, Massachusetts



We don't always know what's behind a meltdown or behavioral crisis, but we do know that their feelings are real. Their reactions to certain circumstances can seem over the top or unnecessarily dramatic, but underneath are real feelings of frustration, sensory overload, rage, and plenty more.

To effectively de-escalate a meltdown, you don't necessarily need to know why the behavior is occurring, only that whatever happened is causing this child or adult to feel out of control, and validate that. Compassion and empathy, validation and a calming presence can go a long way in helping someone who is feeling out of control to calm down and come back to their baseline.

"I don't know what's made you upset but I care about you and I want to hear about it."

"I know how much you love your sister and you must have been really mad to say those things to her. Tell me what got you so mad."

"You're my friend and it hurts my feelings to see you this upset. Will you tell me what I can do to make you feel better?"

(Make sure you have the time to listen after this question!)

Commands, threats, or bribes don't work and often make the situation much worse. Being present and caring goes a long way and is a more respectful way of allowing a person to come back from an outburst. Afterwards, let them rest and allow them time to talk about what happened and what led up to it, talk about other ways of handling strong feelings--and over time these alternative approaches to feelings of hurt or anger may sink in.

I have seen amazing transformations happen simply by letting a child know that you are on their side and allowing them to have at least one person who really believes that they can do this, that they can be in control of their feelings. It takes time, but it does happen. And doesn't everyone need someone in their lives who keeps coming back even when we show them our worst? ■

YAY Volunteers!

With the lazy, hazy days of summer now behind us, we have transitioned to the hustle, bustle days of fall. So much to do and so little time! We are all busy, busy, busy!

That is also true at PWSA (USA). The redesign of the national website is well underway and your new site will be launched soon. Monthly informational webinars are in full swing. Numerous fundraising efforts are occurring nationally – Party for a Purpose, Bowl-a-thons, Golf tournaments, Gala extravaganzas, On-The-Move walks, and the Rob Nicholls ***Ride for Research*** beginning in October from San Diego and ending in November at our national conference. Phone calls have increased related to medical and school advocacy issues. We can't forget planning for the November 2013 PWSA (USA) National Conference in Orlando! That's just a few examples of what's being addressed daily at PWSA (USA). We are working hard for you!

It takes a dedicated staff to pull it off and you have that. Yet, as we offer more and more services and support, we are relying more and more on volunteers to supplement the many activities that propel our forward momentum. That's where our new **Coordinator of Volunteers, Ruby Plummer**, excels. Ruby has experience implementing volunteer programs for agencies such as the Red Cross, First Call for Help, the Volunteer Center, and United Way.

Ruby's success at enlisting volunteers for PWSA (USA) with the skills we need has been astounding.

Currently, 14 volunteers work alongside the paid staff to provide services such as bereavement follow-up, mailing of informational packets, phone triage, preparing materials for conference, assisting with the study of death, supporting needs related to graphics and communications, and aiding with fundraising activities. Ruby finds out what our needs are and then goes about finding volunteers with the skill sets required. And we are not just utilizing people who have a loved one with PWS. She has been amazingly successful at getting volunteers from organizations such as Volunteer Match and AARP and in implementing a new intern program with local universities.

PWSA (USA) has many volunteers from all walks of life who give freely of their time. Fifteen officers and members on the national Board of Directors meet quarterly regarding the strategy and direction of PWSA (USA) – all volunteers. Volunteers all over the country provide input, guidance, and proofing for the many PWSA (USA) publications and webinars. Our chapters and committees across the USA are composed of volunteers who have had amazing accomplishments. Did you know you and your talents, energy, skills, and knowledge are wanted and needed to help push the momentum forward?

How do you start? When Dale and I first heard the words Prader-Willi syndrome, we went from being stunned, to heart broken. Over time, we became motivated. We wanted to fight – to "do something" about PWS. We started participating in chapter events such as hosting local and national conferences, legislative advocacy, fundraising, opening supported living homes, and board and chapter president governance. Later we served on national committees, the national Board of Directors, and now as co-Interim Executive Directors of PWSA(USA) - all volunteer.

Every one of us can be a volunteer, and PWSA (USA) needs every one of us. Don't wait to be contacted with a specific request - follow your interest/ passion. Perhaps you know of or work for a major corporation that would be willing to forward some of their annual corporate philanthropy towards PWSA (USA). Pick up the phone and call, set up a meeting, and talk to them from your heart. It's amazing how much weight that carries. Perhaps you would like to work with your local chapter and host a meeting of families with PWS to learn and share with each other. Maybe you would like to host a fundraiser or help with one that is already underway. For example, Rob Nicholls **Ride for Research** needs volunteers (see page 1). Perhaps you want to strengthen your local chapter, help build awareness, or serve on a local committee. Volunteer to be a volunteer coordinator for your chapter.



Dale and Dottie Cooper
Interim Co-Executive Directors

It's fun, it feels good to work with such a strong support group, and it feels especially great to be able to "do something" about PWS.

Yay VOLUNTEERS!!! ■

Contributed by Clint Hurdle:

"I always wondered why somebody didn't do something about that; then I realized I am somebody."

~ Unknown

Rob Nicholls
Ride for Research

The Coveted Commencement of The Magic Season

By Lisa Peters

It's September and back-to-school time here in New England. For most of us, this usually means a trip to Kmart for some running shoes and school supplies.

But for my son, Nicholas, this fall month is far more significant than just a time for buying some notebooks and colored pencils. To him, September is the official kick-off to... The Magic Season.

What is The Magic Season, you ask?

It is that time of year when you can officially begin to decorate the home with all things cozy and warm. It means that you can light candles and plug in things that glow. It is the official start to months and months of twinkling lights and holiday decor.

To Nicholas, however, it means just one thing: happiness.

Yesterday we drove by our local farm stand when suddenly I heard a scream from the back seat,

"MOM, LOOK.....PUMPKINS!"

Sure enough, as we passed Paisley's Farm, rows and rows of bright orange pumpkins lined a long, wooden table.

"CAN WE GET ONE? CAN WE GET ONE?"

Typically buying a pumpkin in the middle of September doesn't pose a particular problem. The colder evening temperatures here in New England help to preserve the freshness of the gourd-like giant squash. Unfortunately for Mom, however, Nicholas insists on carving it right away. He delights in quickly gutting the poor unsuspecting vegetable so he can place a lit candle directly in its belly. He will watch his cheery little friend for hours and will carry him wherever he goes.

But as you all know, the shelf-life of a carved pumpkin is two, maybe three days, tops, and then the once-grinning gourd now becomes a rotting, smelling, moldy piece of pulp more suitable for the compost pile than the bedroom nightstand.



The ever-tolerant Nicholas, however, accepts his faithful friend as he is and disregards the decaying nature and God-awful smell that accompanies him.

Usually I try to avoid passing Paisley's or visiting shopping malls until at least midOctober, giving us only a few weeks to collect our gobs and gobs of grinning ghouls and goblins. But this time I blew it. I failed to redirect my route and unknowingly tipped off my son too soon to the coveted commencement of The Magic Season.

"CAN WE, CAN WE MOM, CAN WE GET A PUMPKIN?" Nicholas asked excitedly.

"I'll tell you what," I said, "You have a good day at school tomorrow and we will get one."

"OK!" he said, absolutely positive that he would be triumphant in earning the iconic reward.

Sure enough, the next day Nicholas behaved beautifully in school. So, it was off to Paisley's we went in search of the perfect pumpkin pal. He chose a small somewhat oval little friend.

At home he carefully drew a smiling face on the front of the pumpkin and had Daddy perform the delicate seed removal operation. Nicholas placed one of his thousands of candles inside the hollowed orange squash and voila...

The Magic Season has officially begun!

I wonder if anyone has invented a pumpkin embalming kit yet for parents of children with PWS? ■



A quilting club in the Villages, Florida, where Barb McManus (grandmother of Jessika, who has PWS) lives has made quilts for conference so that the little ones who nap can be comfortable.

In the planning stages as we go to press

Mediterranean Nights

Hors d'oeuvres and Cocktail reception
First class dinner
Entertainment
Many valuable auction items including a villa for four in Tuscany, Italy

Enjoy an evening of fun and enchantment as we say goodbye to summer in style

Sunday, September 29
5:30-9:00 p.m.

at the

TPC Prestancia Clubhouse

4409 Prestancia Drive
Sarasota, FL 34238

Proceeds benefit the Prader-Willi Syndrome Association (USA), headquartered in Sarasota, FL

Thanks to

Grapevine Communications
The Charmer Sunbelt Group
Pittsburgh Pirates Baseball and 18 additional sponsors for their generous support of this event.

To purchase tickets, visit:

www.mediterraneanights.eventbrite.com

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.

The 2013-2014 Angel Drive

(http://www.pwsausa.org/angel/)

Your contributions help us offer:

Extensive Support/Advocacy/Awareness • Parent mentoring
• Crisis support with trained staff
• Information and referral services
• Advocacy: special education, SSI, therapies, public policies and more
• Assistance with TV, radio & print media

Medical and Research Programs

• Scientific & Clinical Advisory Boards
• Consultations with medical board members available to all physicians
• Scientific conference at annual national PWSA (USA) conference
• Research grants awarded annually
• Booths/presentations at medical conferences nationally and internationally
• Research advocacy & more

Outreach & Networking

• Bi-annual conference for families and professionals
• Moderated online support groups
• Bi-weekly e-news, timely medical alerts, social media interaction
• PWS Awareness Month, national awareness campaign & grassroots events

More details coming soon!

Contact Ben Karp at 941-312-0400 or email bkarp@pwsausa.org for more information.

Rob Nicholls Ride for Research

Consider a donation to support Rob's Ride across the United States to raise funds and awareness for Prader-Willi syndrome.

Or get involved in other ways – see Page 1 article for suggestions.

Help keep his wheels whirling!

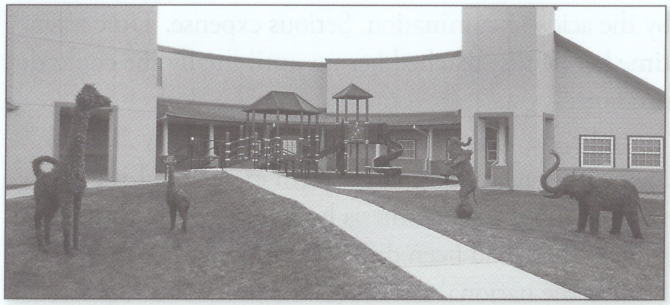
For more information, contact Beth Bush at 941-312-0400 or bbush@pwsausa.org



Texas Hospital Initiates PWS Inpatient Program

By Ken Smith

For the past five months I've had the pleasure of working with the dedicated staff from HealthBridge Children's Hospital in Houston, Texas, in the capacity of Consultant and Administrative Program Manager for the newly developed Prader-Willi syndrome program.



This Pediatric Specialty Acute Care hospital serves as a bridge between the hospital and home for families that face complex medical issues. Its long-standing obesity program has included a number of individuals with PWS. The ultimate goal at HealthBridge Children's is to send its patients and families home with the tools and knowledge needed to confidently handle at-home care—and for every family to be successful.

HealthBridge Children's Hospital PWS program is an inpatient interdisciplinary treatment program that addresses the complex medical, physical, emotional and social needs of children and adolescents with PWS. Our program incorporates physician-led plans, which include meal plans developed by Registered Dieticians, set daily schedules, individualized physical training programs, and mental health support for both patient and family. I can report that the entire organization has embraced the challenges and pleasures of working with our children and their caregivers. From senior management to direct care staff including clinicians, all have shown a sincere and devoted interest in serving the unique needs of children and young adults with PWS, currently up to the age of 21.

Additional Information:

1) I've been working closely with our admissions team to enhance and develop relationships with regional and national healthcare insurers as well as Medicaid programs.

2) Caregiver advocacy and education will be vital components of the program.

3) We are available to work closely with primary care physicians, support agencies, schools and caregivers during the pre-admission, admission and discharge planning processes.

4) Multidisciplinary caregiver education will be a vital component of this program.

5) The program includes Dr. Rose Ann King, a Ph.D. level psychologist with extensive behavioral management and family training experience.

6) Out-of-state patients will be accepted.

7) Initially, the program will serve six to nine clients in a dedicated inpatient treatment environment.

At this point I can proudly announce that the program is officially up and running and accepting new referrals. Contact person for intake at HealthBridge Children's is Sherrie Daniels, R.N., 713-351-6611, sdaniels@nhsltd.com. Or you can email me, ksmith@nhsltd.com, and I promise a return phone call. ■

PWSA USA ALL-STARS 2013

Ken Smith has been working with and for people with Prader-Willi syndrome for over 25 years. Formerly with The Children's Institute of Pittsburgh, he became involved with PWSA (USA), was elected to the Board of Directors and attended his first board meeting at the Seattle national conference in 1995. Many meetings later, he has chalked up 18 years of service on the board. He has served as board chair or co-chair, been a member of the crisis team, and is active with the PWS Advisory Board. Today he is traveling a lot, doing consulting with the goal of setting up treatment programs for PWS in other parts of the country.

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John W. Cassidy, M.D., President/CEO, and Chief Medical Officer, says, "Our organization has a very simple mission and that is 'the patients always come first.' This mission and the value system derived from it have been and continue to be the only way to sort my priorities." ■

How Our Organization Helped

Dental Double Trouble

by Lota Mitchell

The earliest of our daughter Julie's dental woes started in second grade when she tripped, fell on her face and loosened a permanent front tooth. Mindful of the tooth fairy's rewards for her baby teeth, she pulled the tooth on the way to the dentist. Lesson learned too late: **teach early the difference between baby teeth and permanent teeth**. It had not occurred to us to do that. Thus began ongoing problems with bridges to fill in the gap.

Her permanent teeth came in straight—but the uppers were rather buck, not a characteristic of PWS, but instead inherited from her paternal grandmother who had a lesser version. In high school braces were tried unsuccessfully, so next came surgery to remove two teeth and move her upper jaw back. Her jaw was wired shut for a couple months, during which her nutrition came through a straw. Julie felt the pain was worth it because she had hated being called "Beaver" by the other kids.

When Julie was perhaps twenty, she and I were sharing a bed at a PWSA (USA) national conference when I realized that she had bruxism, i.e., grinding her teeth. I heard it. The grinding usually happens at night when the person is asleep, so listening then is about the only way to be sure. We got her a mouth guard to protect her teeth at night, but she'd forget to wear it or lose it. I gave up after a while; big mistake.

At twenty five she moved to a group home for PWS. Her brother Doug's wife Shannon teaches graduate and undergraduate dental hygiene students at the University of North Carolina. Shannon tried very hard to impress on Julie the **importance of prevention** and the proper ways to do it—**thorough cleaning, flossing, wearing the mouth guard**. Julie agreed but really didn't do it. She didn't realize how important it was—until too late.



The condition in her mouth continued to deteriorate. She had ground her teeth almost level with her gums. Her dentist fixed bridge after bridge, got her a sonic toothbrush. More mouth guards.

Abcesses. Root canals. Tooth extractions. Weak enamel to start with, eroded by the acids of rumination. Serious expense. Time after time her dentist patched her up until finally she could do no more.

Julie, now 43, was then scheduled in May 2013 to have all her remaining upper teeth extracted. I was very worried about the anesthesia because after her earlier oral surgery there had been difficulty bringing her around. I called the national PWSA (USA) office and requested that all the information about PWS and anesthesia be sent to the anesthesiologist.

The day of her surgery, I was able to speak with the anesthesiologist, who had received the information. This time there was no anesthesia problem. **Thank you, PWSA (USA)!**

The current chapter of Julie's dental story is that she is now waiting for the gums to heal so she can get an upper plate. Sometime in the future she will have to have all the lower teeth extracted, too, but the effort will be to save them as long as possible for the sake of maintaining the bone structure. ■

CHUCKLE CORNER

Mom to Mikey, age 14 with PWS: "I've told you ten times not to do that!"

Mikey to Mom: "No, it was only six times!"

~ Nikki Henshaw, Pittsburgh, Pennsylvania

¡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! ■

Enamel Erosion and Severe Tooth Wear in Children and Adults with Prader-Willi Syndrome

By Barbara Dorn R.N. and Dr. Kimberly Wachter, D.D.S.



For years, it has been noted that individuals with Prader-Willi syndrome (PWS) have problems with saliva production resulting in dental caries/cavities, loss of enamel and severe tooth wear. Recent studies on "Salivary Flow and Oral Abnormalities in Prader-Willi Syndrome" as well as the study on "Severe Tooth Wear in Prader-Willi Syndrome: A Case-control Study" done by Saeves, Nordgarden, Espelid and Storhaug (2010 and 2012) from Oslo, Norway continue to support and validate these findings. The challenge now facing those with PWS is what to do to prevent and/or manage these problems. The following resource provides an overview of these dental problems along with some possible approaches.

ENAMEL EROSION is the wearing down of the protective coating (enamel) of the teeth.

When enamel wears down, microscopic channels in the tooth open up and become exposed. Most people with this problem complain of discomfort and pain. However, since persons with PWS have an altered pain response, they may not experience this sensation.

Common Causes:

- Abnormal salivation
- Diet high in sugars and acid

EXAMPLES OF FOODS AND BEVERAGES WITH HIGH ACIDITY:

Soft drinks, sport drinks, fruit juices, lemonade, coffee, tomatoes, strawberries. (Citric acid, phosphoric acid, ascorbic acid are a few ingredients to watch for in foods.)

- Grinding of the surfaces of teeth
- Health conditions including gastric reflux
- Medications (aspirin, antihistamines and some vitamins)

Signs:

- Translucency of the enamel
- Darkening or discoloration of the teeth
- Pain or cold sensitivity (may not always be reported in persons with PWS)

Prevention:

- Drink water. Limit soft drinks, sport drinks, juices and coffee in moderation. Dilute juices with water.
- Swish your mouth out with water or brush your teeth after drinking or eating items high in acid
- Don't sip on beverages for extended periods of time.
- Do not drink or eat high acid beverages/food in the evening after supper.
- Use a straw to keep acids away from teeth.
- Brush with fluoride toothpaste. Minimize swallowing. (Too much fluoride can cause problems like enamel fluorosis. This condition can occur in children and causes defects in the enamel of the teeth. Ingesting large amounts of fluoride can be toxic and cause nausea, stomach pain and/or vomiting. It may not be quickly detected in persons with PWS).
- Get regular dental checkups and cleanings – at least every 6 months.
- Talk to your dentist about daily fluoride mouthwash if there is a history of cavities (Use as a rinse; do not swallow). If needed – apply with Q-tip.
- Ask the dentist if sealants may be helpful in preventing enamel erosion and tooth decay.

Treatment:

- Once lost, enamel cannot be replaced. Treatment of tooth enamel loss depends on the underlying problem.
- If a person with PWS is found to have a sudden loss of tooth enamel, testing should be done to determine if a medical condition is present. (May require special diet and medication intervention).

SEVERE TOOTH WEAR / GRINDING

(also called bruxism) occurs most commonly at night. When teeth grinding occurs on a regular basis, teeth can be damaged and other oral complications can arise. Often seen in both children and adults with PWS.

Causes:

- Exact cause is unknown.
- Often contributed to stress and/or abnormal bite
  Treatment:
- Mouth bite guard – best if individually fitted by a dentist. Used most commonly while the person sleeps. May require incentive program for compliance.
- Avoid or cut back on foods and drinks that contain caffeine, such as colas, chocolate, and coffee.
- Avoid alcohol. Grinding tends to intensify after alcohol consumption.
- Discourage chewing on pencils or pens or anything that is not food. Minimize chewing gum. It allows jaw muscles to get used to clenching and makes it more likely to grind teeth.
- Work with person with PWS to learn not to clench or grind his/her teeth. Have him/her practice relaxing jaw muscles.
- Try holding a warm washcloth against the cheek in front of the earlobe.
- Include plenty of water. Dehydration may be linked to teeth grinding.

Prader-Willi Syndrome Association of Wisconsin, Inc.

Message from Yosuke, Self Advocate

My name is Yosuke. I am 21 years old and I study social welfare at the College of Health and Welfare in a University in Japan. I have PWS and am fighting against the devil in PWS.

I have magic words for fighting. I learned them from my best friends grandfather. *Makete oboeru sumou kana.* It means "Failure teaches success." *Katte kabutono o wo shimeyo.* It means, "Don't let your guard down even after you've won." And this, *Naseba naru nasaneba naranu nanigotomo naranu wa hitono nasanu narikeri.* It means, "You can do anything if you try." This one is special to me.

These words help me to stop my overeating. Whenever I get "I want to eat!! I want to eeaaatt!!!" I remember these magic words which I have written on a card and I am carrying it with me in my bag.

And when I walk, I am always conscious of the way I walk. It improves metabolism, and increases perspiration. I have actually lost weight using such a walking method. I showed my father the walking method, and he was glad that it worked on him, too. Therefore, I believe that the other children with PWS who are having the same trouble can get better. I am walking with consciousness on my way to and from school, at school, and anywhere.This is how I walk. I follow the rules which I learned from a walking lesson called " 10 Important Points to Remember for Beautiful and Healthy Walking."

Not lower your eyes. (Keep them horizontal.)

Lightly pull up your belly. (Enhances breasts, raises hips, and tightens waist.)

Raise toes and land on the heels. (Prevents falling.)

Rub your knees together lightly. (Prevents bow-legs)

Stand and walk with vertical balance. (For a shapely figure)

Basically walk with shoulder-width strides. (For a smart walk).

Use your sole evenly (prevents cold feet and swelling legs)

The three points--the shoulder, the waist, and a knee, should be on a straight line. (Improves stiff shoulders, back pain, and knee pain.)

Feel the bases of your legs and arms in around your stomach. (Makes your legs look long.)

My happiest experience in my life was when my teacher said, "Come to my room and consult me whenever you are being bullied" when I was being bullied about my body shape at a high school.

The most painful thing that happened in my life was when I was teased, and was looking down crying and teacher said, "Don't sleep in class."

The hardest thing when on a diet is that there are always worries about when my "devil" might come out. For example, I worry that even though I know I will gain weight, I might not be able to stop myself from buying food.

Although it is not easy, I always think about food calories and how I can cut them down. Whenever I am hungry and want to buy food at a supermarket, I have to check labels and make it less than 300 calories. I am always thinking about it. This is the hardest thing.

When you see a person like me, with same syndrome, and they are about to buy extra food, I would like you to say, "You should stop. If you stop now, you will have a better future."

Although controlling myself is not easy, it is easier when I have aims and when I am enjoying it, so I would like to think of the ways which I can relax and enjoy myself.

For example, in a Subway Sandwich, there is a service which you can ask for more vegetables with a low calorie sandwich. I enjoy buying it, together with a zero calorie drink. Moreover, I enjoy having bony parts of fish (which are called "ara" in Japanese) for dinner so that I can take time in eating them clean with my chopsticks. ■



Yosuke, center, at the IPWSO conference.

Giorgio and the Pope

Dear friends of the [IPSWO] Board,

I came back from Rome yesterday where I drove with my van together with my family and a friend of mine who is a famous poet. We performed three successful concerts in cooperation with Vatican Radio and Caritas to raise funds for a PWS project in Cuba.

[An] official communication [was] sent to the secretary of the Pope to inform him about our Mission, our initiative to help families with children affected by PWS in Cuba and our presence at Saint Peter's Square last Wednesday for the General Audience with him. We can proudly say that even the Pope knows about Prader-Willi syndrome and that he was informed about IPWSO and what we're doing.

Last Saturday I made a long interview in Spanish at Vatican Radio explaining what we are doing and especially the Cuba project. My friend, the journalist, asked me to repeat at the end the characteristics and main symptoms of the syndrome…The interview has been broadcast via satellite and webpage throughout Latin America. Vatican Radio is the most [wide]spread and organised radio in the world, reaching

continued on page 13

Giorgio, *continued from page 12*

every corner in the globe. I made various interviews on behalf of IPWSO in the past in English, French and Spanish, because many missionaries in poor countries, especially in Africa, are also running hospitals and could meet cases of PWS. I am close friend of the journalist Patricia Ynestoza at Vatican Radio…and she is helping IPWSO a lot.

Furthermore, while in Rome, Patricia introduced me to a famous singer from Honduras (Central America) who was performing concerts there. As we are not organised in this country, he proposed to plan a concert together in Honduras soon after my visit to Cuba in cooperation with the National Pediatric Society, to give me the possibility to talk to doctors about PWS in Spanish.

Love,
Giorgio Fornasier

[Note: Caritas International is a confederation of 164 Roman Catholic relief, development and social service organizations operating in over 200 countries and territories worldwide. Collectively and individually, their mission is to work to build a better world, especially for the poor and oppressed.] ■

Article on PWS in Top 100

A review in the journal *Pediatrics, Official Journal of the American Academy of Pediatrics,* identified and analyzed the top 100 most frequently cited articles published in journals dedicated to pediatrics between 1945 and 2010. An article about Prader-Willi syndrome was 53rd on that list!

Although PWS was first described by Swiss doctors Prader, Willi and Labhart in 1956, there was no criteria for a diagnosis until 1993. That year a gathering of professionals particularly involved with PWS gathered for a consensus conference at the Western Look resort in Tucson, Arizona. PWSA provided a grant to support this effort.

From the conference came the article: Prader-Willi syndrome—consensus diagnostic-criteria. *Pediatrics.* 1993;91(2):398–402.

Participating in that conference and authoring the article were Dr. Vanja Holm, Dr. Suzanne Cassidy, Dr. Merlin Butler, Dr. Jeanne Hanchett, Louise Greenswag, Ph.D., and Barbara Whitman, Ph.D. All of the authors are—or were—members of our Advisory Boards.

This is a tremendous honor, given that this article made the top 100 out of over 450,000 articles published in 191 pediatric journals between 1945 and 2010. ■

WE REMEMBER

Marge Wett, Our First Executive Director

We are very sad to report that Marge Krueger Wett, age 81, the first Executive Director of PWSA, passed away on Aug. 22, 2013.



Married to the late anesthesiologist Richard Wett, she and Dick had seven children, one of whom was Lisa, born with Prader-Willi syndrome. When the newly incorporated Prader-Willi Syndrome Association held its first national conference in 1979, she was appointed Executive Director of the fledgling organization, and Dick became president.

Soft-spoken and efficient, she did it all—sent out the newsletter, collected the dues, organized national conferences, kept all the records, helped families in crisis—and most of this happened at her kitchen table, equipped with a phone and a typewriter. She often came up with her own unique ways to describe some of the foibles of PWS, such as "unauthorized acquisitions" when someone took something that didn't belong to them.

Dottie Cooper recalls, "Families across the country benefited from her efforts when she ran the organization from her kitchen table for over a decade. Marge was the first person we talked to when we heard the words 'Prader-Willi syndrome', and she patiently, gently, and straightforwardly talked us through understanding the challenges that lay before us."

As the organization grew, she had to be convinced to take a small salary. For 12 years she remained on the job, until 1991.

It is probably safe to say that today's PWSA (USA) might not be in existence now were it not for the energy, dedication and business knowledge that Marge brought to the job. She will be remembered fondly by the many she worked with and with gratitude for what she accomplished.

The family has asked that memorial donations be made to PWSA (USA). ■

Rob Nicholls
Ride for Research

Tips for Teachers is available on YouTube.

A PWSA (USA) video with Elizabeth Roof presenting **Tips for Teachers** is available on YouTube. This fantastic resource provides very helpful information and practical strategies for teachers who have students with PWS in their classroom. It has two parts:

1)The Video

2) A related Tool Box for Teachers

We encourage you to send the video link and the attached Tool Box to your child's teacher and please let other families you know in the PWS community know about this amazing new resource. We want as many teachers as possible to use the video and tool box to better understand how to effectively support students with PWS.

Prader-Willi Syndrome Teacher Tips www.youtube.com
http://www.youtube.com/watch?v=Y5LhSePDvqk



Here are some comments about the video:

"I can't thank you enough. I forwarded the video to my son's new teacher. I think it will really help her understand PWS and how to avoid behavior issues."

"Amazingly helpful."

"This is great! I will be working with a student with PWS and this video offers great strategies."

Note: Elizabeth Roof will be one of the speakers at PWSA (USA)'s National Conference in November! ■

Due to the increased activities within our organization and important information regarding research and support that we want to share with all of our readers, we struggle with limited space in *The Gathered View*. Therefore, we have discontinued publishing a list of our donors -- for whom we are eternally grateful and with whom we will continue to acknowledge and communicate on a personal level--and without whom our association might not survive. We thank you for your support and dedication to PWSA (USA) and the individuals, families and all those involved with PWS that we serve.

Counselors Corner

A **New** PWSA (USA) E-Letter – all about PWS School Issues!

At PWSA (USA), we are dedicated to helping parents enhance their special education advocacy skills. We also strive to encourage productive and healthy collaboration between parents and schools to benefit students with PWS. To help in this effort we've created a brand new bi-monthly e-letter called ***School Times*** which will focus solely on school issues for the PWS community. Features include:

- Hot Topics like Independent Evaluations and Discipline
- Special Education Law Corner
- Guest expert columns on behavior management and more
- News about upcoming trainings and webinars
- Reviews of resources you can use
- Tips to help parents enhance their advocacy skills
- Reports and Insights from ***Wyatt Special Education Advocates***
- And more!

This is the ***first*** publication to focus solely on school issues for the PWS community. It is a great resource for parents and school professionals. So don't miss out! Sign up today by e-mailing Evan Farrar, PWSA (USA) Family Support Counselor, at ***cic3@pwsausa.org***

We are getting lots of good responses to the first issue of ***School Times.*** Here is a nice example: "**A brilliant publication!** Thank you all **so** much, keep up the great work, you make a huuuuuge difference to our lives and we are very grateful for all your efforts!"

~ Evan Farrar
Crisis Intervention and Family Support Counselor

PWSA USA ALL-STARS 2013

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

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Access our website, www.pwsausa.org, for downloadable publications, current news, research, and more. The Members Only section is now available to everyone and the password is "pws."

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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If you work for the Federal government, the Combined Federal Campaign (CFC) is a program through which you can give to the charity of your choice. The campaign's mission is to provide "all federal employees the opportunity to improve the quality of life for all."

PWSA (USA) CFC ID # is 10088

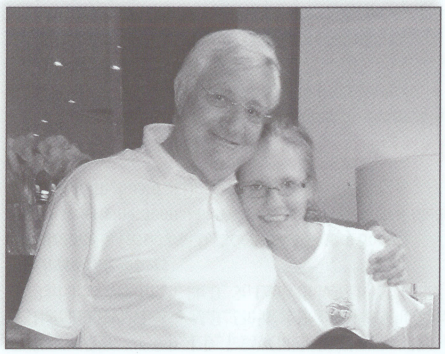
For more information about the CFC program and how it works, go to their Web site at http://www.opm.gov/cfc/index.asp, or contact the PWSA (USA) office at (800) 926-4797 and ask for Debi Applebee. ■

Come to the National Conference in Orlando to help welcome Rob at his Ride's end!

See Page 1 for details.



www.pwsausaconference.com



David Gordon of Dunwoody, Georgia (but originally South Africa), IPWSO's legal advisor, and his daughter, Katie, age 16 with PWS.



Scenes from the IPWSO's Eighth International Prader-Willi Syndrome Organization Conference. Photo above shows Linda Thornton (on the right) from New Zealand (PWS parent who is now IPWSO director of communications), enjoying the evening with Susan Blichtfeldt, a doctor and PWS parent from Denmark, and Tina Siilvest, IPWSO retiring board member from Finland and PWS parent.

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

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