

The Gathered View

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

Obesity Still Kills

By Janalee Heinemann, MSW, PWSA (USA) Director of Research & Medical Affairs

As I write this, I am working on getting money to pay toward the funeral of a nine-year-old girl with PWS, reminding me once again that PWS is still the deadly appetite. Although currently many of our children and adults who have Prader-Willi syndrome (PWS) are slim due to early diagnosis, education of parents and other care providers, plus growth hormone, I do not want us to get too complacent.

While the holiday season usually requires extra vigilance, careful monitoring day in and day out all year is essential.

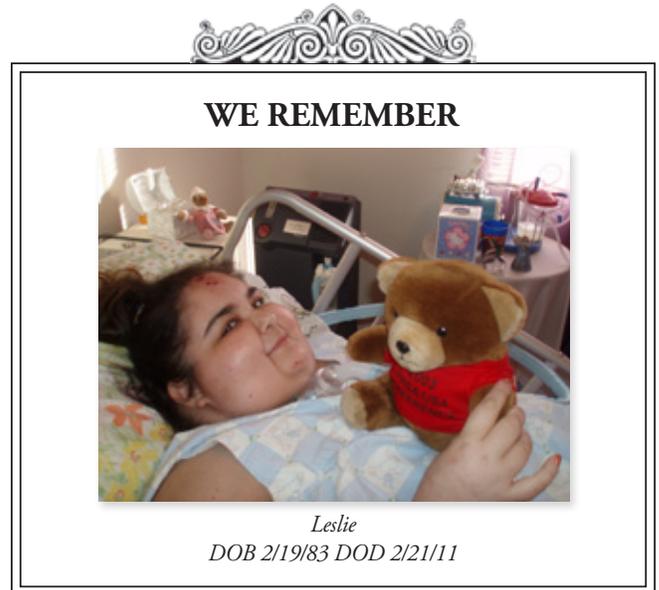
Recent calls for help that I have received in our crisis program include: girl, age 4, 120 pounds; girl, age 5, 117 pounds; boy, age 9, 126 pounds; girl, age 13, 254 pounds; boy, age 11, 220 pounds; teen, 326 pounds; male, age 24, 550 pounds—and the list goes on.

In studying the 163 PWS deaths that are in our PWSA (USA) Study of Death database, Dr. Stevenson wrote: “Regarding the obesity-related deaths, in removing all pediatric cases and cases where cause of death was unknown or clearly not obesity related (accidents, choking, etc. – although some of them may have some obesity component), the average weight at death for these individuals was 257 pounds.” Besides people with PWS being at greater risk of obesity, this obesity puts them at risk to die of obesity-related complications. In separate international reports of deaths in PWS, a large proportion (half or more) were related to respiratory or cardio-respiratory disease.

Dr. Linda Gourash (Pittsburgh Partnership) reports in her poster presentation, **Clinical Presentation of Obesity Hypoventilation and Right Heart Failure in Prader-Willi Syndrome**, “The all-too-familiar clinical picture of shortness of breath, decreasing physical activity, and leg swelling seen in morbidly obese persons with Prader-Willi syndrome is due to hypoventilation during sleep, leading eventually to respiratory failure with or without right heart failure. The onset may be rapid or slow but is always insidious, that is, initially unrecognized.”

In **Mortality in Prader-Willi Syndrome** from New South Wales (published in Am J Ment Retard, 2006 May), the authors of the study state: “Prader-Willi syndrome is a substantial risk factor for death, above the risk related to intellectual disability alone. Those with Prader-Willi syndrome have higher mortality rates than those with intellectual disability in general. They have a much higher estimated mortality ratio than a comparison group with mild or borderline intellectual disability. The pattern of death in those with Prader-Willi syndrome suggests that obesity-related disease is a likely major risk factor. Management of caloric intake is truly a life-and-death issue for people with this syndrome.” ■

Please remember, and remind your relatives and schools, when you are showing your child love during this holiday season, with Prader-Willi syndrome, you can love your child to death.



Alden

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Acute Gastrointestinal Episodes can be Life-Threatening

By Janalee Heinemann, MSW, PWSA (USA) Director of Research & Medical Affairs

(Note: I wrote this article a few years back, but have been asked to have it reprinted due to the holidays coming – a time of risk for our older children and adults. Remember, when in a group holiday setting with food very available, someone should be designated to watch over your child/adult with PWS. If “everyone” is watching, then no one may be watching. For holiday tips, type in “holiday survival tips” in the search section on our web site, or call the office for a copy of the holiday tips. Also on our web site, go to the “Medical” tab on top of the home page which leads to the medical alert article, “Risk of Stomach Necrosis and Rupture”.)

I recently received a call from a physician who related that one of our mothers brought our Medical Alert booklet with her to the emergency room. He said, “If she had not brought the articles and insisted I go to your web site, this child would have died. This information saved her life.” His patient, a slim 15-year-old, had an episode of binge eating. She came in with vomiting and belly pain. The physician said that normally he would have treated it like the flu for a couple of days. Due to our alerts, they pursued this further and found the girl with PWS had such a bad hernia that her spleen, stomach, and duodenum were in her chest. She is now recovering from surgery.

Unfortunately, not all parents carry the articles with

them and not all physicians heed our warnings. In another situation, a slim young man had an episode of binge eating; the ER and hospital did not take his symptoms seriously enough, soon enough. Even though we had one of our physicians called as a consultant and emphasized the urgent need for exploratory surgery, there was a 14-16 hour delay in surgery before the local hospital physician believed how life threatening his condition was. This young man had been doing very well prior to this incident and a few hours after the eating episode initially only exhibited signs of stomach pain and vomiting.

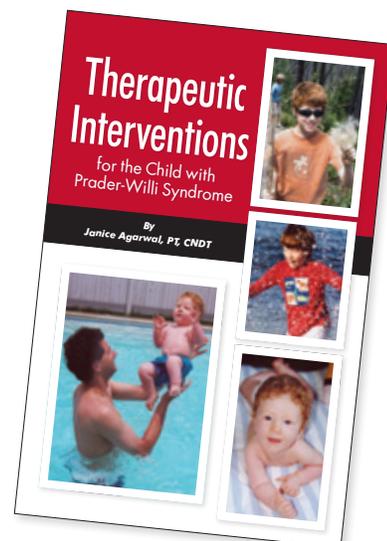
See our web site for Dr. Rob Wharton’s article, initially printed in *The Gathered View* in 1999, which described “acute idiopathic gastric dilation.” This is where part of the stomach tissue dies, similar to a heart attack where part of the heart tissue dies. It comes on suddenly, is very life threatening and needs immediate surgery. I have spoken to several people, including our GI specialist Dr. Ann Scheimann and the pathologist who did this report with Dr. Wharton (now deceased), about the cause. Our conjecture is that if a person with PWS greatly distends their stomach with food (slimmer people may be more at risk) and does not get the normal message of full or pain, they may distend it to the point that it cuts off the blood supply, thus causing necrosis (the stomach becomes blackened and dead) which then can quickly lead to a gastrointestinal (GI) perforation. There also may be a prior unknown weak site in the abdomen.

In addition, when there is severe stomach pain, a physician should consider an ultrasound due to the possibility of gallstones and pancreatitis. The pancreatitis can be differentiated by chemical analysis of the blood and a CT of the abdomen. Gallstones are more common in PWS. ■

A New Book!

Published by Prader-Willi Syndrome Association (USA)

The eagerly anticipated Physical Therapy Plus book is soon to be released. If you are interested in ordering a copy and wish to be notified, please contact us to order.



History of the Need for Advocacy for Growth Hormone Treatment for PWS *and* GHT research... *the rest of the story*

By Janalee Heinemann, MSW, PWSA (USA) Director of Research & Medical Affairs

A member commented that we need to be looking for the next big breakthrough like growth hormone treatment (GHT). He is right, but the history of GHT helps explain that it takes more than funding research. It is a partnership between research, advocacy and support. The following will provide insight into how our support services played into the success of GHT:

- The pioneer researchers Dr. Phillip Lee and Dr. Moris Angulo are very involved with PWSA (USA), and their clinical experience is what led them to believe GHT would work for PWS.
- I was working with physician/researcher Dr. Barb Lippe, who got GHT for PWS approved under the Orphan Drug Act, and we as an organization did a significant amount of advocacy on behalf of approval and education on GHT for PWS.
- We created and distributed to thousands of endocrinologists and parents the first GHT booklet for PWS. We have just completed the 2nd edition of this booklet, which is now available. Please see the outside page.
- When they discovered the handful of deaths worldwide of those on GHT, there was a great risk of the FDA pulling its approval. I worked with Dr. Lippe and some of our advisory board members to try to sort out what might be causing these deaths and to stem the wave of panic and come up with appropriate guidelines. I also worked with Barb McManus to gather statistics from our member database that were helpful.
- We did many education and awareness booths at major medical conferences over the last ten years to educate the key physicians on GHT.
- Since 2000, I have had calls almost DAILY from parents and physicians with questions, concerns and information needed on GHT.
- We have helped several other countries with information they needed to advocate for approval of GHT in their country.

Although growth hormone treatment is a good example of what research can accomplish, I believe that it is also a good example of how research is done best in the fertile soil of advocacy and support services. ■

Crisis Counselor

We are pleased to let you know that Evan Farrar will be serving PWSA on a temporary basis for a while as a crisis counselor.

PWS RESEARCH
HAPPENS
BECAUSE YOU
HELP MAKE IT
HAPPEN

*A Special
Thank You*

The Transcranial Direct Current Stimulation (tDCS) grant detailed in the last *Gathered View* was funded thanks to a partnership between PWSA (USA) and the Capraro Family Foundation a 401(3), and also designated funding in honor of Nicholas Joncas.

This year at the national conference in Orlando, the state leaders met to discuss resources and support in each state. To learn more about your state, visit <http://pwsausa.org/links/chapter.htm> and sign up for email list for your state.

Executive Director View

*By guest author John Heybach, Ph.D.,
Chair, Board of Directors, Prader-Willi Syndrome
Association (USA)*

As you read this, the PWSA (USA) Annual Conference will probably be over, though as I write we are still in advance of the conference, and our staff, board and volunteers are all working diligently toward a successful event. However, following the conference is a good time to take a step back to remember the reason that we are all involved in this endeavor. That is, to try to the best of our abilities to improve the quality of life for individuals with Prader-Willi syndrome and to support their families and caregivers. If we keep our eyes on that prize, the inevitable stresses and strains and daily problems we all encounter can be kept in perspective, part of the price we happily pay to further our mission.

We hope that everyone who attended conference took full advantage of this unique opportunity to understand in better detail the breadth and depth of the work that is ongoing in a wide variety of areas from scientific and medical research projects, to support and education programs, to advocacy work at the local, state and national level. And we hope that you are as energized as we are with the rapidly developing cooperation with our fellow travelers in the Foundation for Prader-Willi Research (FPWR).

We hope also that having a better understanding of the scope of what we as a community have accomplished and what we still need to accomplish can energize you and your local communities to participate in the full range of fundraising programs that will be conducted in the coming

year to generate the critical financial resources that are needed to continue and expand our efforts in all of the areas mentioned above. It is imperative that we all do our best as individuals, families and chapters to fully support all of the fundraising efforts undertaken by our broader community. This includes:

- PWSA (USA) support and awareness functions through the *On the Move* campaign,
- the full range of PWSA (USA) programs through the Angel Fund Drive,
- PWSA (USA) research;
- the joint research program undertaken in cooperation with FPWR, funded by the One Small Step program; and the additional research undertaken by the FPWR.

All of these efforts benefit the broader PWS community in critically important ways and need the support of all of us.

We also hope that you had the opportunity to meet others who are daily struggling with the challenges presented by PWS and develop a deeper appreciation and sense of the broader community of people of which we are members and how closely connected we are to each other.

And lastly, I hope that you enjoyed as much as we did seeing our relatives and friends with PWS enjoying themselves and each other in the YIP, YAP and Siblings programs and the Gala.

I would encourage you, if you currently are not, to get more involved in your national organization either as individuals and families or through your chapters.

A heartfelt thanks to everyone who worked so hard to prepare and participate in the conference and to all those whose attendance made it successful. ■

Success of PWSA (USA) & FPWR Collaborative Effort!

Thanks to working together for designated research funding, the *One Small Step* fundraiser raised \$700,000 to support research on the following:

Question 1:

What underlies the shift from failure to thrive to excessive hunger in PWS?

Question 2:

Can the maternally silent genes in the PWS chromosome region be selectively reactivated?

Question 3:

What are the cellular phenotype(s)

in PWS?

These key areas of research were the outcome of the *Prader-Willi Syndrome Research Strategy Workshop*. Please note that both PWSA (USA) and Foundation for Prader-Willi Research (FPWR) also have other areas of research that we are interested in funding, but we made a mutual commitment to fund the areas deemed most needed by the group of experts attending the workshop. This is just one way we are working together to make life better for those affected by Prader-Willi syndrome. ■

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and mailing of
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Eastside High School
student-sponsored
"Spirit Week"
Fundraiser in
Greenville, South Carolina.

Musings of a proud father...

By Rob Lutz, Pennsylvania

My thoughts drift back to THAT DAY. That day was almost exactly 11 years ago when we found out. That day has defined so much of what we have grown to become. That day was horrible—no one should have a day like that. That day impacts every day that follows—sometimes imperceptively and other times obviously. Yet that day sowed the seed for today's triumph.

I knew my mother and mother-in-law would cry TODAY. I thought my wife would cry, too, but I am surprised when she breaks down and starts visibly sobbing. She feels it, too. No one else can understand what we're celebrating today. We deserve to cry with joy and love and sadness combined.

We cried on THAT DAY, too. Our dreams were shattered—our fears realized. But we didn't know then how proud we would be 11 years hence. We didn't know how lucky we were that Isabel was so determined. We could not have predicted the experiences and the people and the life lessons.

Today is the 5th grade promotion ceremony at Gladwyn Elementary School. The other parents can't suspect what is going through our minds. Isabel is exactly fiftieth percentile in height and weight. She is not wearing her scoliosis brace today. She looks great. She looks typical. So no one can SEE what we know. They call her name, and she simply walks out of the center of the auditorium. She is going to 6th grade on schedule with her class. That seems like nothing, but, in fact, it is UNBELIEVABLE.

THAT DAY 11 years ago, I didn't think today was possible. We were informed that Isabel—our first-born



Isabel, age 11

daughter—had Prader-Willi syndrome. We learned she would likely be short and obese; temperamental and difficult; weak and learning delayed. How many of the other parents in the crowded auditorium heard that when their child was 6 months old?

Isabel deserves the credit. She has endured 3,650 shots of growth hormone starting when she was one year old—now she does them herself. She puts aside the overwhelming food craving of PWS to control herself and learn of other things. She wears a brace to straighten her back all but one or two days a week. She develops close bonds with the teachers and people who work with her. She is lovable.

She has to FIGHT so hard to get what comes naturally to other children. Walking, talking, reading, multiplying, swimming, socializing, controlling her temper—all required her to work harder. The world does not slow down for her—so she STRUGGLES valiantly to keep up. Where did that determination come from? A few months ago I watched her at a swimming practice. She was swimming laps in a lane with kids two or three years younger. She was still the slowest in the lane. But she didn't give up. PWS causes her muscles to be weaker. She has to work much harder than the others. But she finishes each lap in her own slower, unique way. If only I had worked as hard as she growing up...

So, because of THAT DAY and because of Isabel, today I feel AMAZING. The other parents are proud when their children graduate to 6th grade. But they have no idea that their pride is pitiful in comparison to what I feel. All it took was for Isabel to walk down the center aisle of an elementary school auditorium. But that walk reminded me of the 11 years since THAT DAY and all Isabel has accomplished. And I am SO PROUD!!! ■

PWS Shines at Special Olympics

Martha McDonald, mom of **Alexandra Pope**, reports that "Zanders" received a gold medal for working trails, a silver for equitation and a 7th for Dressage in the A division of the Special

Olympics equestrian sport in the World Games in Athens, Greece.

She did really well with her riding, and we all are so very proud of her.

She is settling back down to reality now. The Special Olympics coaches were just amazing as was the whole event.

The organization is just wonderful.

You can check articles out on Facebook.com under Alexandra Pope -

Special Olympics. ■

Another proud mom, Teresa Pierson, reports that daughter **Molly**, age 8 with PWS, participated in her first bowling tournament for Special Olympics, took 1st place and will be going to the State Tournament in Indianapolis. Best of luck, Molly! ■

Communication Breakdown

By Linda Thornton

The thing about PWS is being able to understand *why* your child may have temper tantrums, or explosive behaviours, melt-downs, call them what you will. What may seem like an out-and-out extreme behaviour may well be your child's method of communicating when all else fails.

In other words, the child without PWS who has temper tantrums at age 2, 3, and on at varying stages, even through to the teen years, is trying to make you see how frustrated they are. We can accept that from the two-year-old who wants a packet of sweets temptingly put out on the supermarket counter and wants it NOW and can't see why that is not going to happen.

We can even understand the seven-year-old who wants to have a new dress for a party because all her friends have one and she doesn't want to be the odd one out.

We can even attempt to understand the non-communicative teenager whose love-life has gone bad and the end of the world is just around the corner.

But hardest to understand is the teen or adult with PWS whose behaviour is still remarkably like the two-year-old, or the seven-year-old, particularly when that person is 19, 20, or older and 'should know better'. The thing is, they don't.

It's as though they are unable to process the information given to them, something in their brain short-circuits, and presto, out comes the explosive behaviour.

Witness a young adult at work. She works at the SPCA and does her work well. She has a job coach who is there to help only when needed. Then, one day out of the blue, she is told that she needs to change her routine, that the cats are not responding to a certain food and the dogs aren't getting enough exercise.

What she hears is this: "You are not doing your job. You made the cats sick. The dogs aren't being looked after."

The information going into her brain was short-circuited, and the outcome is an argument followed by explosive behaviour.

When asked what went wrong, after things had calmed down and the job coach had been able to intervene successfully, the girl replied, "I didn't hear what was said. My brain got scrambled." It was interesting in this case to hear the girl give a very clear message back to those in charge. What she was saying was, "Don't *tell* me a great heap of negative information because I can't take it in and I think you are accusing me of something. It is better if you *ask* me one thing at a time and I can answer you in my own way."

A long time ago it was common to describe behaviours of those with PWS as being in the 6-10-year range. Then

that became discarded in favour of looking at the person as a whole. Personally, I have always kept in mind that when the behaviour becomes challenging, it pays to remember that the teen or adult often reverts to typical 6-10-year-old behaviour.

What may seem like an out-and-out extreme behaviour may well be your child's method of communicating when all else fails.

To back this up, I found Ross W. Greene, Ph.D., has the following to say in his book "The Explosive Child", (*a new approach for understanding and parenting easily frustrated, 'chronically inflexible' children*). Although not specifically designed for people with PWS, the pattern fits remarkably well, no matter what the chronological age of the person might be:

Common Characteristics of Explosive Behaviour

1. A remarkably limited capacity for flexibility and adaptability and coherence in the midst of severe frustration. *The child often seems unable to shift gears in response to parents' commands or a change in plans and becomes quickly overwhelmed when a situation calls for flexibility and adaptability. As the child becomes frustrated, his or her ability to "think through" ways of resolving frustrating situations in a manner that is mutually satisfactory becomes greatly diminished; the child has difficulty remembering previous learning about how to handle frustration and recalling the consequences of previous inflexible-explosive episodes, has trouble thinking rationally, may not be responsive to reasoned attempts to restore coherence, and may deteriorate even further in response to punishment.*

If that doesn't relate to PWS in a nutshell, I'll be most surprised! In his second point, he goes on:

2. An extremely low frustration threshold. *The child becomes frustrated far more easily and by far more seemingly trivial events than other children of his or her age. Therefore the child experiences the world as one filled with frustration and uncomprehending adults.*

In the PWS world, this does not relate just to children.

3. An extremely low tolerance for frustration. *The child is not only more easily frustrated, but experiences the emotions associated with frustration more intensely and tolerates them far less adaptively than do other children of the same age.*

continued on page 7

In response to frustration, the child becomes extremely agitated, disorganised, and verbally or physically aggressive.

Took the words right out of my mouth...

4. The tendency to think in a concrete, rigid, black-and-white manner. *The child does not recognise the grey in many solutions ("Mrs. Robinson is **always** mean! I hate her!" Rather than "Mrs. Robinson is usually nice, but she was in a really bad mood today."); may apply oversimplified, rigid, inflexible rules to complex situations; and may impulsively revert to such rules even when they are obviously inappropriate ("We **always** go out for recess at 10:30. I don't care if there is an assembly today, I'm going out for recess!").*

Sound familiar?

5. The persistence of inflexibility and poor response to frustration despite a high level of intrinsic or extrinsic motivation. *The child continues to exhibit frequent, intense, and lengthy meltdowns even in the face of salient, potent consequences.*

We all know about that one!

6. Inflexible episodes may have an out-of-the-blue quality. *The child may seem to be in a good mood, then fall apart unexpectedly in the face of frustrating circumstances, no matter how trivial.*

7. The child may have one or several issues about which he or she is especially inflexible—for example, the way clothing looks or feels, the way food tastes or smells, and the order or manner in which things may be done.

8. The child's inflexibility and difficulty responding to frustration in an adaptive manner may be fueled by behaviours—moodiness/irritability, hyperactivity/impulsivity, anxiety, obsessiveness, social impairment—**commonly associated with other disorders.**

9. While other children are apt to become more irritable when tired or hungry, inflexible-explosive children may completely fall apart under such conditions.

So, while we may think that PW behaviours are 'unique' (and often they are), there are many that fall into a category common to children without the syndrome. The difference is that although the behaviours described above are pretty much exactly the same as we have experienced with PWS, they are actually describing the behaviour of young children. I don't advocate treating those with PWS as constantly being in the 6-10-year age bracket—they're definitely not!—but it pays to remember that when issues become too complex for the teen or adult with PWS to deal with, their behaviour may well revert to this level.

... when the behaviour becomes challenging, it pays to remember that the teen or adult often reverts to typical 6-10-year-old behaviour.

Knowing this gives us an opportunity to more clearly understand the nature of the syndrome and give us clearer insights into how to communicate. ■

- Linda Thornton, from New Zealand, is the mother of an adult daughter with PWS and the Secretary of the International Prader-Willi Syndrome Organization.

e-Bulletin...

Reminder – stay informed and stay current with PWSA (USA)'s free weekly e-Bulletin.

Sign up today at www.pwsausa.org!



Zach:

"Tis the season to be jolly,
fa la la la la, la la la la.

Tis the season to be jolly,
fa la la la la, la la la la.

Tis the season to be jolly,
fa la la la la, la la la la."

Greg: "Okay, Zach, we're done with that song now."

Zach, after a short pause: "Well, I'M not done with it...Tis the season....."

Gotta love him!!!!

- Tammy Reals

Mom to Greg (14), Zach (12,PWS),
Emily (7), and Dorothy (5)

Our Family and The Great Ohio Bicycle Adventure

By John Boughton, Indiana

The Great Ohio Bicycle Adventure (GOBA) is an annual event. Each year the organizers set up a circular route in a different part of Ohio which involves cycling 50-60 miles a day for seven days, for a total of over 350 miles. You park your car at the starting town and set up your tent in a school field or large park. Next morning you load your tent and gear into one of several semis that drive it to the next town while you bike.

In 1989, the first year, 1200 people participated, including me and my three oldest children.

That year our sixth child, April, was born. Although she spent two weeks in hospitals because of her low muscle tone and difficulty feeding, she was sent home without a diagnosis. "Just love her and see what happens," we were told.

The following summer, 1990, our whole family signed up for GOBA. April wasn't able to hold her head up well enough to ride in a child seat. She mostly stayed in her car seat and enjoyed her meals.

At five April went on her next GOBA and rode in a child seat on the back of my bike for the next five years. She often fell asleep, and passersby sometimes worried about how far over she was tipping. She thoroughly enjoyed every playground along the route and later looked forward to opportunities to go swimming.

When April was 10, I had a conflict that week, so she was shepherded by her oldest brother, Eric, 23. Riding a trail-a-bike attached to his bike, she still tended to fall asleep. We finally got her PWS diagnosis around this time.

It seemed like her low muscle tone and difficulty balancing would make it impossible for April to ever learn to ride her own bike, but she was one determined young lady.

She kept at it and sought prayer at every opportunity. Finally she mastered that skill! But she couldn't make her small bike travel fast enough to do the GOBA route on it.

April did her next GOBA when she was 14, on a tandem bike with me. "This is too slow, Dad," April complained. "Why are we walking up this hill? I'm never going to ride on your bike again!"

The following year April rode her own cheap department-store bike for the first time. Because the route that year was hilly, we had to be "sagged" (picked up by a vehicle that patrols the route) into camp too many days and left the ride to drive home mid-week. This made April extremely angry. In future years, she took training ahead of time much more seriously.

The OCD that accompanies PWS shaped this training. April starts training in March, as soon as the Indiana weather permits. The first day, she cycles one mile. The next day, it's two miles...with a goal of 65 miles on the last day she can ride before GOBA starts. Fortunately, my employer lets me take flex time to accompany her, and other family members or staff sometimes help out.

In 2008, April bought a new bike, a Townie whose design made it easier for her to get on and off and use the gears to handle hills. She has taken it on every GOBA since then and rarely had to be "sagged," although she did suffer heat exhaustion/dehydration that required medical attention once. Low muscle tone and poor balance have led to many falls through the years.

In 2010, the route was in hilly southeastern Ohio. April was very proud that her rigorous training meant she didn't have to be "sagged" into camp a single time that year, and she got up every hill without walking her bike. Keeping track of April's diet and whereabouts can be challenging, but we figure she's getting enough exercise to burn off a few extra calories.

2011 was April's 15th GOBA. She and I came up with the fund-raising idea, realizing that PWSA could also stand for "Pedal With Special Athlete." ■

[This novel idea for fundraising raised over \$2,000!]

In Grateful Appreciation to our 2011 Conference Sponsors



SURVIVOR ORLANDO 2011

“Over 900 people attended, from 44 states and 10 different countries! Many parents as well as some of the providers, researchers and other guests shared with me how much they were enjoying conference – the programs, the workshops, the hotel and access to Disney, the YAP and YIP programs for their children, items at the store – pretty much everything! And it was clear that this was a great event for the children and adults with PWS as well. You could see it in their smiles and the pride and glow on their faces when they presented their program at the closing ceremonies.”

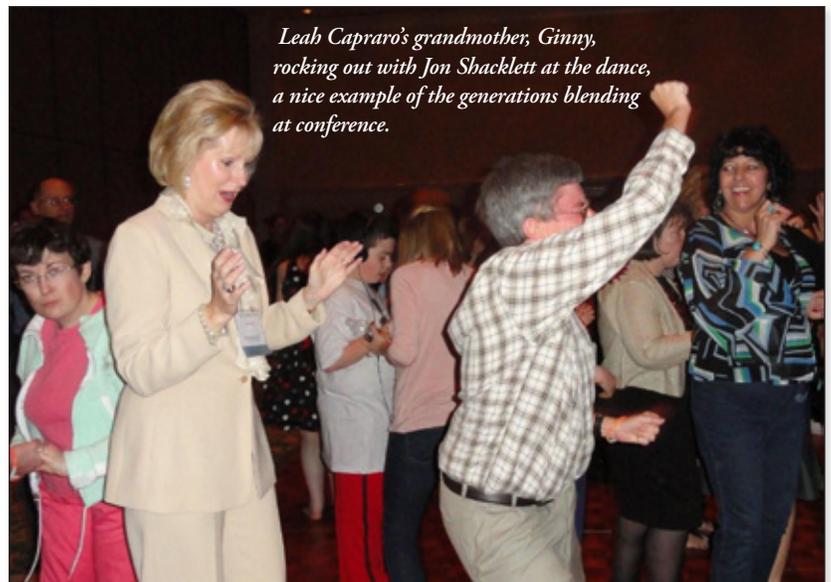
- David Crump



Clint Hurdle, keynote speaker, manager of the Pittsburgh Pirates and parent of Madison, age 9, with PWS, paused to have his picture taken with oldest and youngest attendees with PWS: Suzanne Books, age 64 and Leah Bender, age seven months.



Shawn Cooper and Conor Heybach



Leah Capraro's grandmother, Ginny, rocking out with Jon Shacklett at the dance, a nice example of the generations blending at conference.

*With warmest wishes to you and yours
for a joyous and peaceful
Holiday season*

PWSA (USA) at Work at Home and Abroad

Serving our PWS families wherever they are

SCOTLAND -

Janalee Heinemann, PWSA's Director of Research & Medical Affairs, reported from Glasgow in September:

I want to give you an update on our International Prader-Willi Syndrome Organization (IPWSO) awareness booth at the European Society for Pediatric Endocrinology (ESPE) conference. (Research report will appear in the January issue of *The Gathered View*.)

There are 2,500-3,000 participants from all over the world – and I mean **all over the world**. Giorgio Fornasier, Executive Director of IPWSO, and I are both invigorated and exhausted with so many people stopping by our booth for information on PWS. Sometimes, even with two of us, we could not talk to everyone--but they all got one of the packets Giorgio put together. We have

extensive packets for those who have no information, packets for those that got information from us before but were looking for new information, and crisis packets for those dealing with weight and behavior issues.

I also brought a suitcase full (75) of our brand new growth hormone books that we created and printed at PWSA (USA). Between Giorgio's nine cartons and my suitcase full, we gave out everything we had—educational materials to doctors from 62 different countries! Giorgio has been able to recruit physicians from four countries where we are not represented to be the IPWSO professional delegate--Georgia, Malta, Belarus and Indonesia. We have also made contact with the key people at the two pharmaceutical companies that have the indication on GHT and PWS. Having the new GHT booklet helped to peak their interest.

I handle the medical questions, but Giorgio is really the impressive one. He can greet people in almost any language and have conversations in 6-7 languages. He also knows the delegates in all of the countries.

I am sharing this to point out the

significance of this important education service IPWSO offers with the support of PWSA (USA). Giorgio gets the funding from Pfizer International (which we cannot do in the USA) and prints the materials I recommend. We donated the GH booklets. This is another example of our important collaborative efforts, serving our worldwide family of PWS families.

And here is more from some of our worldwide families:

FRANCE - How can I thank you enough! The letters are both very powerful, we are so grateful for your quick attention to this. When our son Pablo was born we felt so very alone, we don't feel that way anymore.

CUBA - In 2009 we received your DVD, Food, behavior and beyond, it was the most important present to us and Gabriela, because the life of my daughter began to change. Gabriela do not use GH yet. The big change just was with diet and exercise, thanks to Your DVD, IPWSO informations and Taiwan conference, maybe when Gabriela begin to use GH will be better.

HUNGARY - We have read all the documents you wrote and sent us couple of months ago and I have to tell you, the way you write and the things and thoughts you write down help us enormously and help to other hungarian families either. We are continuously translating them and put the hungarian text to our website in reach to others. *[Note: in July the Hungarian Prader-Willi Association was proudly established.]*

USA - I just got a call...that Julie's Provigil has been approved! Thank you! That research article [you sent] may have turned the tide – and it arrived at precisely the right moment.

USA - I enjoy reading *The Gathered View* for its uplifting stories, research updates and general information. It is a good publication. I know each of you work hard on it and as a parent I appreciate it.



Janalee with professional delegate from Iran and Giorgio Fornasier, Executive Director of IPWSO

continued on page 11

USA - We would like to thank PWSA (USA) and let you know why we chose to have 100% of the profits from our walk go to support the organization. From the very day Aedan was diagnosed, PWSA (USA) was there to help [and] make difficult times on Aedan's journey easier. Even during our scariest moments, when Aedan has had medical emergencies, they were only a phone call away.

BELGIUM - My daughter's endocrinologist was refusing to give her GH when she was 6 months old (she used to be against GH for children before 3) so I wrote her a letter and included information I found on the PWSA website, etc... It worked and she changed her mind. Now she even prescribes it to other babies with PWS.

KAZAKHSTAN - We received the booklet. [Ed. note: a bereavement booklet like we send to our U.S. families] Thank you very much...you have provided

a wonderful and sincere comfort and support for us. We have become more aware of children like Sultan and also of support required for parents/people looking after such children. Please know that if you ever hear of such children with special needs somewhere in Central Asia or anywhere in Former Soviet Union Republics we would want to know about them and try to help them with sharing our experiences and with possibly visiting them. This would be a privilege for us to do.

INDIA - Thank you Mr. Janalee, and Mrs. shikha harlalka. I am a bit relax by knowing the updates and guidance from both of you. I have also contacted Dr. Arya and soon meet her.

USA - I think it is so important that as parents we stay refreshed. We live this life daily and it can wear us all down. I am so thankful for these email lists, my local chapter of PWSA (USA), and the annual conferences that occur for our benefit.

USA - I am a high school senior



who recently completed a project on Prader-Willi Syndrome. My biology class is in the midst of a unit on genetic disorders, and I randomly picked PWS. I had never heard of it before... your website was a prime source [of information]. Simply by presenting an organized FAQ list you managed to encompass more than many other sites that presented information in a very different way. Thank you for the time and dedication you have clearly put into this website. ■

Meet the 2011-2014 PWSA (USA) Board

A very special "Thank You" to outgoing PWSA (USA) board members Carol Hearn, Kerry Headley and Janice Agarwal. Your out-going board worked on several issues and opportunities, including the forming of a collaborative relationship with the Foundation for Prader-Willi Research Canada (FPWR), the hiring of a full time development director, planning for the upcoming national conference, and assistance with day-to-day operations.

Welcome to new board members **David Agarwal** and **Michelle Holbrook**, and welcome back to **Ken Smith** and **Dan Driscoll** who were elected to stay on for another term.

David has been Director of the Vascular and Interventional Radiology Fellowship Program at Indiana University School of Medicine in Indianapolis, Indiana, since 2001. David has previously served on the PWSA (USA) Research Advisory Team and remains on the Clinical Advisory Board. He is married to outgoing board member Janice Agarwal and has two sons, including Alex, 11 with PWS.

Michelle, who lives in Lehi, Utah, is a special education teacher at Lehi High School, working with students with severe disabilities. She served on the Utah PWSA board and was president for four years. She has directed the YIP program for national PWSA (USA) for three conferences. She and her husband Scott have been married for 32 years and have a son, Curtis, 17, with PWS.

Ken has been employed at The Children's Institute in Pittsburgh since 1985. For the past 23 years he has worked in various administrative roles including the treatment team's manager. He has served on the board of directors for PWSA (USA) for 15 years, and one term as Vice-President and one as co-Board Chair.

Dan is a Professor of Pediatrics and Genetics at the University of Florida College of Medicine where he is the John T. and Winifred M. Hayward Professor of Genetics Research. He has been conducting clinical and laboratory research on PWS since the late 1980s. A member of the Board of Directors and Chair of the Clinical Advisory Board PWSA (USA), he is also a member of the Medical and Scientific Advisory Board of the International Prader-Willi Syndrome Organization (IPWSO). ■

[Ed. Note: This one appeared in a 1993 issue--before we knew to worry about the serious risks of overeating binges and before we knew much about psychotropic medications that can help normalize behavior.]

The World According to Matt

~By Janalee Tomasecki-Heinemann

Al and I have discovered that having a son with Prader-Willi syndrome who is in a supportive living program doesn't totally eliminate the problems of PWS from your life. It just means that the syndrome is no longer all consuming. Dealing with it intermittently gives us a new appreciation of how frustrating and puzzling PWS can be at times. Most of our visits with Matt are positive, and he is often sweet on the phone--but there are times he can still cause turmoil in our lives.

An example was the trip we took for Al's brother's wedding. Our traveling companions were Matt and our two grandsons. The first issue we had to deal with was Matt's attire. Although we think the world of Matt's staff, in his "home" Matt is given more freedom than we are comfortable with to decide what he wants to wear. We personally feel that if he wants to be treated "normal," he must look "normal." For this trip, we made a special effort to alert the staff that Matt would need to have appropriate clothing. So we cringed when Matt walked out wearing white shorts, red and blue socks with Christmas trees on them, a wrinkled green tee-shirt and carrying his winter jacket over his shoulder. To add that extra GQ flair, he had shaved the sides of his head with his electric shaver. Al leaned over to me and whispered, "Cool misses Matt by a mile." His suitcase and bag had what seemed like a year's worth of clothing stuffed into them. My first delicate challenge was to get him to change his outfit and leave three-fourths of his clothing behind. Fortunately, he was eager enough to go that it went better than it might have under other circumstances.

The rest of the trip went fine until the wedding reception, where food was an issue, as expected. The main problem came from our attempt to allow Matt some independence. We let him roam on his own at the reception hall after the food was cleared from the tables. What we didn't know was that all the food was still accessible and that Matt was making many clandestine trips to the kitchen and slinking out the back door. What embarrassed and amazed us later was that we let our guard down. The other part that bothered us was that none of the relatives who saw Matt sneak the food bothered to alert us to the problem.

So, being oblivious to any problems, we had a good evening dancing and visiting, our grandsons had fun running away from the girls who were trying to get them to dance, and Matt had a great evening stuffing himself. Matt did take time out from his food fest now and then to dance. In his suave demeanor, while dancing with his cousin Jodie, he casually told her, "Jodie, did you know that my sister doesn't like you?"



The next morning, Matt started his day being irritable and pushed for more food at breakfast. One thing we have found is that if he is given too much latitude with his eating, it only makes him push for more. I'll never forget the pool party at

Al's boss's home years ago. Matt was very slim at that point and was doing exceptionally well on his diet. We decided that just this once we would give him a lot of free reign at eating. The only restriction we set was that he drink the diet soda we had brought. Keep in mind that Matt had never been allowed regular soda pop. Getting more food than he ever had was not enough for Matt. He insisted that he was not going to drink the diet soda and got himself upset enough that he ended up hollering and taking off down the street. So we left the party embarrassed and learned a lesson. Small, limited, pre-arranged diet exceptions work out as a special treat, but too much freedom seems to have the reverse effect.

Due to Matt's testy mood, and the severe gas he had from eating all the food the night before at the wedding reception, the eight-and a half-hour drive home was a real "treat." We used an old ploy and had him sit in the back seat of the van where we could pretend not to hear him, but we couldn't avoid smelling him. About every 15 miles our grandsons would yell, "Matt!! Roll the windows down, everybody!!" And so we continued the long drive home passing cars, passing gas, and passing time by singing "Ninety-nine Bottles of Beer on the Wall."

Matt continued to be pushy about food all day and was argumentative, but on the whole he held his composure in front of his nephews. It is interesting to note that he has the ability to control himself enough not to "lose it" in front of them. Toward the end of the trip, Matt got on the car phone and tried to talk the staff into having a second supper ready for him when he got there. Al called the home back and explained that Matt had already eaten. When Matt had got into his house and the boys were back in the van, he immediately unleashed his verbal abuse on the staff and at Al and myself as we walked out the door. That is the difference; we now can shut the door behind us on the torrent of ranting and raving that guaranteed to consume the evening. God bless the staff for being there in our place. We pray every day for their health, understanding, and fortitude. ■

Contributions

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Prader-Willi Syndrome: Growing Older

By Terrance James, Ph.D.,

A Review by Barb Dorn, R.N.

Prader-Willi Syndrome: Growing Older begins to explore a topic that is becoming very pertinent—our aging population of adults with PWS. James interviewed parents, caregivers and 14 adults with PWS ages 40+ years who reside in western Canada. He covers a variety of topics that impact them, including services, genetics, health, residential supports, and employment as well as their aging parents and/or caregivers. He also focuses on quality-of-life issues and shares the personal views and experiences of these adults.

The first few chapters help readers gain a historical perspective on the changes and advances in the field of developmental disabilities and PWS. “Younger” readers will learn to appreciate the advances in genetics and

diagnosis of PWS. (Most adults over 40 did not, and many still do not, have genetic confirmation of the diagnosis). James briefly touches upon the many areas impacted by the aging process, such as cognition, behavior, physical health, mental health. He shares research resources from all over the world that support his findings.

James devotes one chapter to aging parents – an emotional topic near and dear to all parents of adults with PWS. He touches on several concerns about the future including family, residential and funding concerns of government programs. Even though most references are for Canadian programs, it was interesting to learn that we share many of the same challenges and worries.

My favorite part is the chapters

about the personal life experiences of 14 older adults. They share their accomplishments and what has helped to improve their quality of life. It is enlightening to read about the various models of residential support and great to see how many are taking advantage of volunteer opportunities in their communities to keep them connected to social and cognitive stimulation when employment was no longer a full time option.

Although the book focuses on aging adults with PWS in Canada, the topics, issues and concerns cross national boundaries. It is an initiative toward the research, discussion and attention that are needed to address this important topic. ■

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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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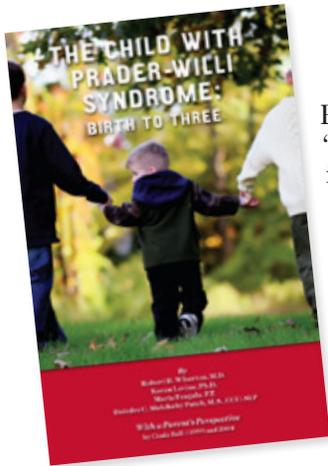
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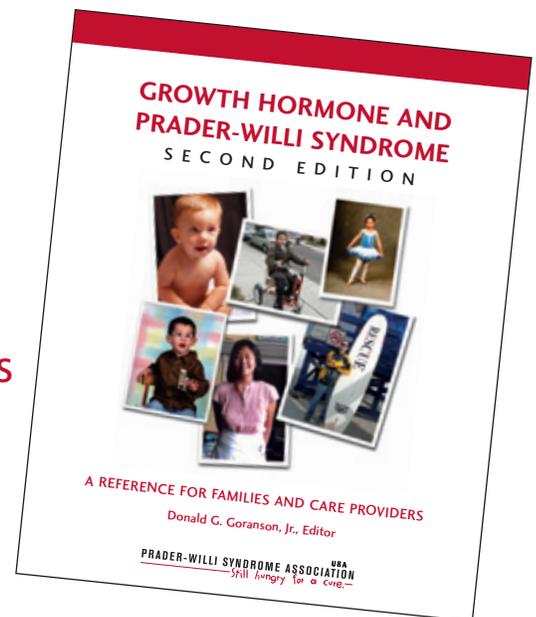
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