



# The *Gathered View*

September-October 2003  
Volume 28, Number 5

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

## New Advisory Board Meets at 2003 Conference

*By Mary K. Ziccardi*

On July 4, 2003, the first-ever PWSA (USA) Advisory Board comprised entirely of adults with Prader-Willi Syndrome met in Orlando.

As anticipated, the meeting was lively and interactive! The members introduced themselves to their Advisory Board colleagues and presented insightfully.

Each participant shared his or her past and current residential and vocational experiences, and successes and disappointments were openly and enthusiastically debated within the group.

Interestingly, members said they do not wish to live or work completely independently, agreeing that they feel happier and healthier when supervision and support are consistently provided.

The new Advisory Board members discussed goals for the coming year, and ways they can communicate throughout the year. They also decided to actively address ways to raise funds so that an "in-person" meeting could be held in 2004 separate from conference. They will be raising money to sponsor their meeting, and welcome donations.

Highlight of the meeting was the Advisory Board's participation in the general membership meeting and luncheon. Members shared a table of honor near the front of the room, and were thrilled to be introduced to and applauded by the general membership. More memories were captured by the extensive photo session (thanks to professional photographer Eric Michael Hilton, husband of Gilda, triage advocate in the National office) that followed the meeting.

Stay tuned for more enlightened insights and discussions as this Advisory Board works together to help us all remember our organization's mission.



*Photo by Eric Michael Hilton*

**Members of the new Advisory Board for adults with PWS hold their first meeting at the 2003 Conference in Orlando, Florida**

### Board members for 2003 – 2005

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Brooke Fuller – Michigan  
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Andy Maurer – South Carolina  
Margaret Miller – Pennsylvania  
Mike Nacht – Ohio  
Abbott Philson – Maine



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## NEWSLETTER

Jane Phelan, Editor  
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Opinions expressed in *The Gathered View* are those of the authors or editors and do not necessarily reflect the views of the officers and board of directors of PWSA (USA) unless so stated. Medical information published in *The Gathered View* should not be considered a substitute for individualized care by a licensed medical professional.

*The Gathered View* welcomes articles, letters, personal stories and photographs and news of interest to those concerned with Prader-Willi syndrome. Communications regarding *The Gathered View* or PWSA membership and services should be directed to the national office of PWSA (USA) in Sarasota, Florida.



**Our Mission:** Through the teamwork of families and professionals, PWSA (USA) will improve and enhance the lives of everyone impacted with Prader-Willi syndrome (PWS) and related conditions.

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Check our PWSA (USA) web site  
**Members Only** section for Special Opportunities  
Limited to Members: [www.pwsausa.org](http://www.pwsausa.org)  
User Name: members  
Password this issue is FALL



# Highlights from Scientific Day 2003 Conference, Orlando, Fla

Chairperson: Dan J. Driscoll, Ph.D., M.D.

*This day was dedicated to the memory of  
Camilynn Brannon, Ph.D. 1963-2002 and Rob Wharton, M.D. 1944-2002*

**Editor's Note:** The following is Part 1 of 2 parts, excerpted from abstracts presented at the Scientific Day. A full copy of the Scientific Conference Abstract booklet can be ordered through PWSA (USA) at a cost of \$20.

## **Effects of Growth Hormone Therapy on Body Composition and Motor Development in Young Children with Prader-Willi Syndrome**

**Susan Myers<sup>1</sup>, Barbara Whitman,** Aaron Carrel, Tracy Bekx, David Allen. Pediatrics, <sup>1</sup>Saint Louis University, Saint Louis, Missouri and Pediatrics, University of Wisconsin, Madison, Wisconsin.

**Discussion:** After 12 months of GH therapy, PWS infants and toddlers show normalization of length, decreased body fat, and increased lean body mass with improvement in hypotonia. Medical and nutritional management in this age group can be challenging. A 4-year study is in progress to assess the impact of early GH treatment on motor abilities, cognition, and development of obesity.

## **Polycystic Ovary Syndrome (PCOS) and Prader-Willi Syndrome (PWS)**

**Moris Angulo,** Mariano Castro-Magana, Yaw Appiaye-Danka, Michele Lamerson, and Jose Atilio Canas. Genetics-Pediatric Endocrinology, Winthrop University Hospital, New York

**Discussion:** The clinical and biochemical manifestations of functional ovarian hyperandrogenism (FOH), also known as PCOS, was relatively common (26.3%) in our PWS population. Hypogonadotropic hypogonadism, characteristic of PWS individuals, brings further evidence compatible with the possibility that insulin excess may stimulate gonadotroph LH release directly by enhancing sensitivity to GnRH. Direct effect of LH on the ovaries and insulin on the ovaries and adrenal glands may explain the hyperandrogenism,

characteristic of PCOS. Adolescents with PCOS are at risk for diabetes mellitus and cardiovascular disease, therefore PWS individuals with signs of hyperandrogenism and extreme difficulties in weight control should be evaluated for PCOS and treated accordingly.

## **Microarray Analysis of Gene/Transcript Expression in Prader-Willi Syndrome: Deletion vs UPD**

**Douglas Bittel,** Nataliya Kibiryeva, Zohreh Talebizadeh, and Merlin G. Butler. Section of Medical Genetics and Molecular Medicine, Children's Mercy Hospitals and Clinics and University of Missouri-Kansas City School of Medicine, Kansas City, Missouri.

**Discussion:** Our data suggest that the expression of genes and transcripts in and around the PWSCR is possibly influenced by chromatin structure and content as well as the imprinting center. The dynamic interactions suggested by the microarray data reinforce the observations of the complex nature of expression in the 15q11-q13 region. Finally, we recognize that the targets applied to our microarray were isolated from lymphoblastoid cell cultures, and gene expression in cell culture may not be in complete concordance with gene expression in brain tissue. Our results suggest candidate genes which may contribute to the differences observed between PWS subjects with deletions and UPD and warrants further investigation.

## **Imprinting in Prader-Willi Syndrome**

**Karin Buiting<sup>1</sup>,** Maren Runte<sup>1</sup>, Hülya Nazlican<sup>1</sup>, Alexander Hüttenhofer<sup>2</sup>, Stephanie Groß<sup>1</sup>, Christina Lich<sup>1</sup>, and Bernhard Horsthemke.<sup>1</sup>

<sup>1</sup>Institut für Humangenetik, Universitätsklinikum Essen, Hufelandstrasse 55, 45122 Essen, Germany.

**Results and Discussion:** Sequence analysis in 32 PWS non-IC deletion patients did not reveal any point mutation in the critical IC element, the *SNURF/SNRPN* exon 1/intron 1 region. We conclude that the vast majority of imprinting defects are epimutations that occur spontaneously in the absence of DNA sequence changes. In all informative PWS non-IC deletion patients the imprinting defect always occurred on the chromosome inherited from the paternal grandmother. These data suggest that the (grand) maternal imprint was not erased in the paternal germline.

## **Clinical Differences Between Subjects with Prader-Willi Syndrome Type I and Type II Deletions**

**Merlin G. Butler<sup>1</sup>,** Douglas Bittel<sup>1</sup>, Nataliya Kibiryeva<sup>1</sup>, Zohreh Talebizadeh<sup>1</sup>, Travis Thompson.<sup>2</sup> <sup>1</sup>Section of Medical Genetics and Molecular Medicine Children's Mercy Hospitals and Clinics and University of Missouri-Kansas City School of Medicine, Kansas City, Missouri.

**Results and Discussion:** Recent studies have shown that the proximal breakpoint in PWS subjects with deletions occur at one of two sites within either of two large duplicons. The Type I ((TI) (larger) deletion results in the loss of approximately 500 kb of genetic material in addition to what is missing in the Type II (TII) (smaller) deletion.

Significant differences in maladaptive and adaptive behavior assessments and difficulties relating to living skills were found among the three groups analyzed (TI, TII and UPD). These differences manifested as poorer scores in psychological, behavioral and academic achievement for TI deletions compared to either TII or UPD. Several measurements relating

*Highlights continued on page 14*





## President's View

**Lota Mitchell**

# Our Chapters Build Strength for PWSA (USA)

One of the big blazing highlights of the Orlando conference for me was the Chapter Presidents Meeting. Of course, this could be because I was responsible and had spent months of planning in anticipation! Nevertheless, it was exciting to have 24 of our 30 chapters sign up a president or a representative.

We were honored by a visit from Carlos Molinet, president of the Chile Association, and his wife Marta. We were deeply touched when Giorgio Fornasier, our international president (IPWSO) and professional opera singer who translated for them, sang the PWS song "Fly High" ("Join hands across the world..."). This created an emotional moment of connection so powerful that everyone's hands instinctively reached out to those of the people beside them to form a huge linked circle while the music poured into our hearts.

Eight short hours is never enough time into which to cram all the information, discussion and sharing. Topics ranged from the Parent Mentoring Program to chapter organization to the problem of getting people to attend meetings — and then getting them to help with the work of the chapter. The latter is a problem identified by many of our chapters.

A particularly important area had to do with a new organizational structure, which a committee of the Board of Directors has been working on for many months, with legal and financial consultations and numerous conference calls and e-mails. The assumption has been all along that all of the chapters are incorporated within their states and have a federal 501c3 entitling them to be tax exempt. Wrong! Some are, but not all. From a legal point of view, this situation had to be addressed, as well as the secondary question of having more than one chapter within a state.

The Board approved the committee's recommendation of the following four possible relationships that groups could have with national, as well as allowing more than one chapter within a state. This new policy should be of interest, not only to current chapter members, but also to those who are contemplating either doing a fund-raiser or starting a new chapter. If anyone has questions, please e-mail me at [ljecholsm@juno.com](mailto:ljecholsm@juno.com).

Over the next few months, we'll be working to sort out our present chapters, determining which will be Full Chapters or Affiliates or even support groups. Regardless of which relationship, our chapter system is a vital and active part of the PWSA (USA) family. Just take a look at the Chapter View column for some of what has been going on.

Peace, Lota

## Relationship Options

- A Full Chapter is incorporated (state) and has its own 501c3 (federal). Any funds raised are tax exempt, and donations to the chapter are tax deductible.
- An Affiliate is incorporated (state), but does not have its own 501c3 (federal). It can use the 501c3 of the national association under firm guidelines for tax-exempt fund raising or tax-deductible donations. The Affiliate is entitled to all the benefits of a full chapter from national, but does not have the paperwork involved with obtaining and maintaining a 501c3.
- A group (or an individual) that wishes to do a fund-raising event can use the 501c3 of the national association under firm guidelines, so that money raised will be tax exempt.
- An informal support group is not incorporated and has no 501c3. The national office wants to be informed of the group's meeting status and contact person so that referrals can be made if there is no chapter in the geographic area.

**Mark Your Calendar NOW for these upcoming Conferences**

**Sept. 19- 20, 2003 - PW Florida Association, Miami**

**June 30-July 1, 2004 - PWSA (USA) National Conference, Huron, Ohio**



## Active Chapters Build PWS Awareness Around the World

Here's a sampling of what some of our chapters are up to, both fun and project-oriented. If you're not a member of one, consider joining. Chapters need you, and you'll be glad you did!

Walks are popular!

**PWSA of Connecticut** held a Walk-A-Thon May 31 and a parent dinner along with their annual meeting May 17. **PW Northwest**

**Association** held an Awareness/Fund Raising Walk June 8.

Golf outings are major fund raisers, too. **PWSA-New Jersey** has one planned for July 28. **PWSA of Pennsylvania**



Photo by Eric Michael Hilton

**PWSA (USA) officers and Chapter leaders gather to share information at the 2003 Conference in Orlando, Florida**

### The Chuckle Corner

#### No Thanks for the Favor

For the special July 4<sup>th</sup> event at the 2003 conference in Orlando, we emphasized the reasons for food restrictions with PWS. Sea World accommodated with a calorie-restricted meal and fruit bars for dessert, and promised to do something special for us.

We were envisioning a visit from Shamu the Whale, so imagine my surprise when my son Matt came to our table with the largest red, white and blue cupcake I have ever seen!

Both Linda Ryan and I rushed up to tell the Sea World catering staff they had to get rid of the cupcakes.

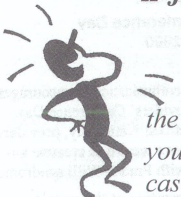
I went back to my conversation, and shortly after, I saw a young man with PWS walking by with another cupcake.

I again said not to hand out the cupcakes.

"It's OK, the caterer replied, "we are only giving them to the adults."

As is often the case in trying to explain PWS, these folks just didn't get it!

-- Janalee Heinemann, Executive Director



Please send your joke or funny story to the PWSA (USA) office. Be sure to include your name, phone number and address in case we have any questions.

held their annual golf outing in May. Money raised is dedicated for grants for Pennsylvania families to attend the national conference. On Aug. 23 Keystone Pocono Residences outside Scranton will host the chapter's fourth annual family picnic.

The organizing chapter of **Kansas-Western Missouri** held their second horse trail ride, a fundraiser, in May at the estate of Delfin Beltran, M.D, a previous president of PWSA.

**PW Alliance of New York** had a highly successful 13th annual conference in April. Goals for this year include, among others, working on a stronger relationship with the state's Office of MR/DD, and acquiring grant monies to develop a database identifying people with PWS in New York, along with present and future needs.

**PW Colorado Association** bowled instead of walking, holding their eighth Bowl-a-Thon in conjunction with Awareness Week the end of April.

**PWSA of Oklahoma** enjoyed a big success in being able to assist its legislators in the law that designates the state's DDSD to fund assisted-living homes for individuals with PWS. They currently have six assisted-living homes in Oklahoma, serving a total of 14 people.

No sooner was the national conference in Orlando over than **PW Florida Association** got busy planning for its Fall Conference on Sept. 19 and 20 in Miami.

-- Lota Mitchell, Associate Editor





## Executive Director's View

### "...Cause to Dream I'll Dare"

Janalee Heinemann

At our 2003 conference in Orlando, Florida, the little children were precious, the sessions were outstanding and the scientific collaboration was invaluable for future research. Parents bonded, supportive care providers learned from each other and chapter presidents shared successes and concerns.

What moved me the most about this, our 25th conference, and what made it stand out as unique was the emphasis on the emotional well-being and empowerment of our older children and adults with Prader-Willi syndrome.

That message started on Wednesday, the pre-YAP day, with the session "Fishing for a Date" and ended with the rap song "My Name's Not Willy!" created

by Tad Tomaseski (my son) and his youth group, the Xcel Team. It continued through ventriloquist Cindy Nelson and her Taylor Rabbit skit with the message "Yes you can!" The culmination was the meeting of the first PWS Advisory Board and their introduction at the General Membership Meeting. As the rap song says, "You know my appetite is always testin' me, but I ain't gonna let it get the best of me, 'cause I know my life has a destiny."

Although I was moment-to-moment busy behind the scenes organizing the conference, and was not able to spend much time with the families or attend sessions, some of the personal highlights for me were:

- Carlos and Marta from Chile treating us to their native dance in full costume at the Thursday evening dance, and presenting me with a large flag from Chile.

- IPWSO President Giorgio Fornasier singing "Fly High" at the banquet and closing, and the entire banquet room encircled with hundreds of parents and professionals holding hands and singing to the chorus, "Across the world's oceans, across the world's skies, we join hands together and love makes us fly."

- Meeting with the PWS Advisory Board (our page 1 article), I was most touched by their response when I asked

if they wanted free access to food. All responded emphatically, "No!" They all made it clear they knew that in order to live, food must be restricted. What they did want were well-trained, compassionate caregivers from well-staffed agencies.

- The dance — I am always amazed at the untapped energy level our young people find when it comes to dancing! It touched my heart to see parents, siblings, staff and those of all ages with PWS dance with each other. One

young man made my day when he ran up to me hollering, "You are my hero!" He saw Matt and me on the *60 Minutes II* television program, and wanted my autograph.

- How the children clung to our volunteer

clowns and laughed with glee when Tad got pied in the face — over and over again.

What inspired me the most was the way so many people worked so hard to make this conference happen. The volunteers who chaired the different program sections, the volunteer speakers; the YIP and YAP volunteers (some stayed up until 3 a.m. each day setting up for the next day and were back up again at 6 a.m.); our office staff, who worked uncompensated weekends and nights and brought their families to volunteer; Wauneta and Bob Lehman who took care of all of the food; Steve and Matt Lundh and Henry Lee, who did such a tremendous job with the technology needs; Barb McManus on registration; the Leightmans and Lutzes on fund development; our office and parent volunteers on publications and logos... the list goes on and on.

I do not know of a more beautiful example of what makes this organization work than how everyone from around the nation — and even around the world — cheerfully pitched in to help make this conference such a success. The sea of hands connected around the ballroom as each person reached out to others was symbolic of how we are all like angels with one wing — knowing we can only "Fly High" by embracing each other.



Photo by Eric Michael Hilton



## The Sibling View

### "Siblings 'R' Us"

By Sarah Tenaglia

What a wonderful experience this year's national conference turned out to be! For those of you who don't recognize the new last name "Tenaglia," I was formerly known as Sarah Heinemann, the eternal 7-year-old in *Sometimes I'm Mad, Sometimes I'm Glad*. The book was written for siblings by my mom, Janalee Tomaseski-Heinemann, the executive director of PWSA (USA), and I did the artwork.

My husband Chris, my dad Al Heinemann and I had the awesome experience of spending our conference time with all of the brothers and sisters in attendance. Looking back, I still smile at the experience.

By the second day, strong friendships were made among the teenagers. Separating them from their brothers and sisters with PW really gave them a chance to share. I had the pleasure of leading our impromptu discussion group and was so impressed with their maturity.



Sara Tenaglia with 19-year-old Whit Park, who has PWS, from Oklahoma City, Oklahoma

Photos by Eric Michael Hilton

The need for an explanation about people with PWS behavior was on everyone's mind. After we experienced the group settings and the field trip, the youngest kids had a lot of concern about what their PW siblings would be like in a few years. We talked about how our parents are working together

to help control the behavior issues and how as siblings we can help. We talked about why kids with PW look different and how it makes us feel.

It truly touched my heart to see all of these children with their questions and it prompted my husband and me to commit to volunteering again for the national conference 2 years from now. Next time we plan to lead more formalized discussion groups with all the brothers and sisters, separated by age.

Some final thoughts about my experience both with the siblings and also about the adult sibling panel I was on. It is so magnificent to see this organization grow. Kudos to each and every parent out there! You are all doing a terrific job with your children!

Personally, it's a blessing to have my brother Matt, who has PWS, in my life. He helped make me who I am today. He taught me kindness to those less fortunate, patience to those physically slower than I am and how to appreciate life for its simplest pleasures. To quote my husband Chris after his first national conference: "You just don't know what joy is until you see a 10-year-old boy with PWS excited about raspberries in his salad."

As always, we were both overwhelmingly moved by the experience. Thank you for sharing your wonderful children with us! Keep talking with them, they *are* listening!



Sharing thoughts about siblings

sisters.

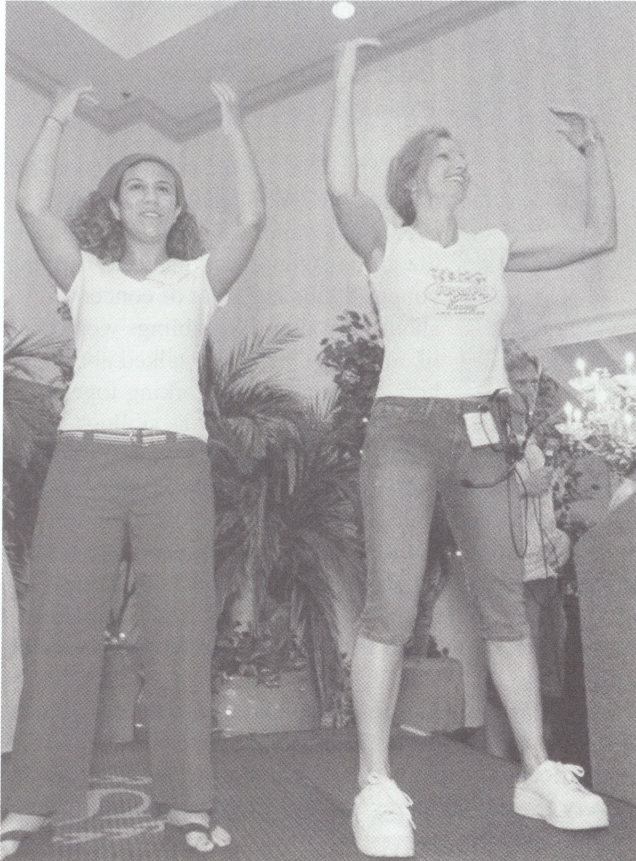
I am equally impressed with the amount of knowledge these teenagers had about the syndrome. Discussions about growth hormone, food control and behavior modifications led to some great insight among the teenagers.

Parents, a note to you: help your teens remain in touch with each other and keep the lines of communication about the pressures of the syndrome open. The teens feel such a responsibility to their siblings and were unanimously proud of their brothers and sisters. It was great to help them discover new friends that truly understand the quirks of Prader-Willi.

I also had the opportunity to discuss some topics with the younger siblings aged 5-11 years. The 7-, 8- and 9-year-olds had a lot of questions: Why? Why did my sister get PW? Why can't they eat like we do? Why do they act so "weird" some of the time?

**We welcome writings from siblings** for *The Sibling View*: good experiences, bad experiences, we want to hear what you think. They can be signed or anonymous, whichever you prefer. Send them to the attention of Lota Mitchell at the PWSA (USA) national office, or e-mail to her at [ljecholsm@juno.com](mailto:ljecholsm@juno.com).



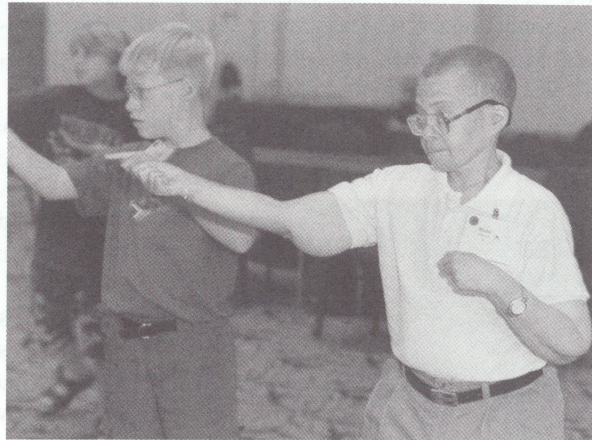


The conference was very inspiring and very encouraging. Every year is finding new and better things to help our kids live more. There was much information and it was all presented in ways that even a child can understand.

I sincerely thank all those involved in the conference, and I encourage you to attend next year if you can.

There was a rap song written for the conference called "I've Got a Name's Not Willy." It is the cutest song, and presents this syndrome in a very understandable, interesting and funny way. It is a great tool in explaining PW to other family members and friends. It is a great song and my family loves it.

Take care, and God bless you, Jennifer Lindsey, Smithdale, Miss.



We enjoyed help at the conference. We had a great time meeting a few new Florida families. The best of course was the Willy Rap song. Thank you, Deborah Peaton, Tampa, Fla.

Thank you all for all the hard work that went into making this year's conference an incredible one that will be remembered forever! You are very special to us, we love you very much! XOXOXO  
The Weavers: William, Faith, Steven, Donnie, Little Will and Ericka, Sarasota, Fla.



Tad (Tomaseski) is really remarkable.... if anyone has any fears about their other (siblings) growing up with PWS, then they should look at Tad. I know Janalee must be so proud of him!  
Cheryl Couch, Meridianville, Ala.





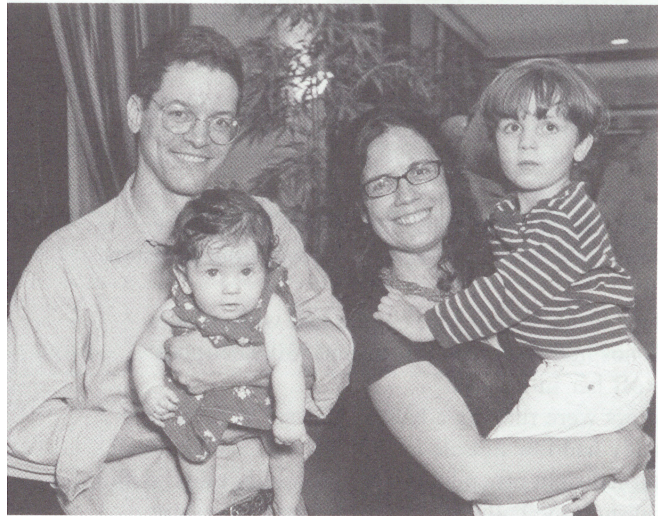
# Orlando, Florida

Photos by Eric Michael Hilton

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I think the conference made a world of difference for my 14-year-old.... She's already asking if we can come back in 2 years if the conference is held in Orlando again. She wants to be a counselor or volunteer for the YAP.  
Lori A. Reddinger, Harrisburg, Pa.



see more photos,  
go to  
[www.pwsausa.org](http://www.pwsausa.org),  
k on Members Only  
assword is FALL



I enjoyed the conference,  
GREAT JOB.  
Moris Angulo, M.D. Mineola, N.Y.





## A father's gift

By Paula Parrish, Rocky Mountain News  
June 14, 2003

*I know what you are thinking. You need a sign. What better one could I give than to make this little one whole and new? I could do it; but I will not. I am the Lord and not a conjuror. I gave this mite a gift I denied to all of you — eternal innocence. To you, she looks imperfect — but to me, she is flawless, like the bud that dies unopened or the fledgling that falls from the nest to be devoured by the ants.*

Clint Hurdle [manager of the Colorado Rockies baseball team] read these words, and he cried.

Usually, the mail is pretty predictable for the Rockies' second-year manager: compliments, complaints, suggestions, autograph requests.

But this letter was different. It had no return address, no telephone number, no signature. It was, in fact, only a single page, a photocopy of some lines, apparently from a book, with a simple note attached: "This will help you understand."

And it did.

*She will never offend me, as all of you have done. She will never pervert or destroy the work of my Father's hands. She is necessary to you. She will evoke the kindness that will keep you human.*

The timing of the letter was, at the very least, extraordinary — and maybe indicative of something else, though that probably depends on individual faith, and Hurdle's is strong.

The letter was in the stack of mail waiting for him at Coors Field when the Rockies returned from a three-game series in September at Houston. During that series, America observed the Sept. 11 anniversary, Hurdle served a one-game suspension for an earlier brouhaha involving the New York Mets and the Rockies lost two of those three games.

Privately, the pain of dealing with his newborn daughter's diagnosis was cresting during that trip. Madison Reilly was born prematurely Aug. 7. She spent her first 18 days in the hospital, where a genetic test confirmed she had Prader-Willi syndrome.

"It was a period where I was probably struggling harder with it than (wife) Karla — Karla had had a little more grieving earlier, I think — but it just overwhelmed me at that point," Hurdle, 45, said. "For a period of about three days, when I was in Houston, it got to the point where Karla was really just keeping me getting through it, talking to me on the phone.

"It almost got to the point where I wasn't complaining or whining, but I was also asking (here, Hurdle extended his forearms, palms up, and looked heavenward), 'Hey, you know, hey, would you give me a little something here, give me a little insight? What's going on? We're good with it, but you know, tell me something.'"

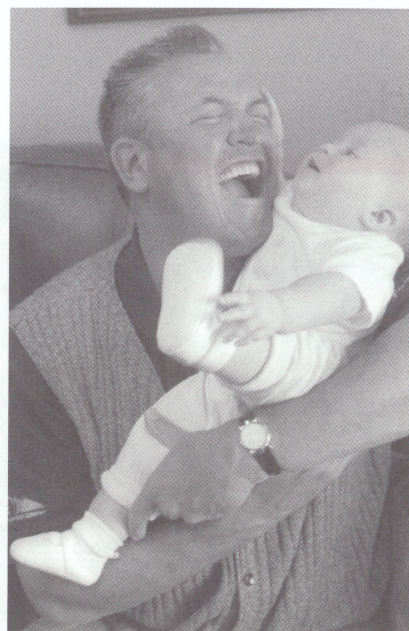


Photo by Steve Nickerson  
© Rocky Mountain News

Clint Hurdle plays with 10-month-old daughter Madison, who has PWS.

*Her infirmity will prompt you to gratitude for your own good fortune... More! She will remind you every day that I am who I am, that my ways are not yours, and that the smallest dust mote whirled in darkest space does not fall out of my hand...*

Hurdle read the letter at 2 a.m. Sept 12, when the Rockies returned to a darkened Coors Field from Houston. \*\*\*

Before that Houston trip, Hurdle had walked into Maddy's hospital room one day to find "30 electrodes hanging off her little head."

Doctors were running a battery of tests to determine why Maddy had low muscle tone and wasn't feeding well.

"I turned right around and I left; I couldn't deal with it, I went out into the hallway and hid somewhere where nobody was," he said.

He went right back later that night. There were several nights after Maddy's birth when he drove directly from Coors Field to the hospital.

During the day, both parents sat with Maddy until Clint had to go to the ballpark, then Karla would take over. At night, after games, Clint went back to the hospital and sat beside Maddy's incubator, talking to her about the game and other things for at least a couple of hours, until about 1 a.m.

In the incubator right beside Maddy was Hayden Lepsis, son of Denver Broncos offensive lineman Matt Lepsis, who was born three months prematurely.

"I'd talk to Maddy, then I'd talk to him and tell him what a big man he was going to be. I'd say, 'Everybody's looking at you right now, you look like a little chicken in there, but you're going to surprise 'em all, because you're going to grow up to be 6-foot-5, 280 pounds and we'll all have a laugh,'" Hurdle recalled, smiling. "I put a little Dinger doll on his incubator. I'd say a little prayer for her and then a little prayer for him before I left."

And he never doubted someone was listening, which led to his pleas during that Houston trip. He was not angry — only confused....

Hurdle investigated the origin of the words contained in the letter and found they had come from *The Clowns of God*,

*continued on next page*



## View From The Home Front

a 1981 novel by Morris West about the second coming of Christ. At the end of the book, priests demand proof that Christ is who he says he is. At the time, a little girl with Down syndrome sits in his lap.

*I have chosen you. You have not chosen me. This little one is my sign to you. Treasure her!*

It is unavoidable.

Maddy looks just like her daddy.

"I didn't want to agree, the fact you have a baby girl, you want her to look like her mother," Hurdle said. "But I think she does look like me — and everybody else has brought it to my attention. (Pause.) She'll grow out of it, hopefully."

Today, Maddy is fascinated with Daddy's head — particularly that spiky hair, which gets reinforced with Bed Head hair gel every morning and looks as if it could hold up The Baseball Encyclopedia all by itself.

When he puts Maddy on his chest, she immediately reaches for the hair spikes and bends them around her chubby fists.

He growls into her tummy and she giggles. He laughs, she giggles, he laughs as her exploration continues.

\*\*\*

Put down on the couch in the family room of the Hurdles' home in Highlands Ranch, Maddy demonstrates her skills by rolling to her right side and subsequently kicking the dog Jackie, a mild-mannered Jack Russell terrier, with her left foot. Jackie doesn't even lift her head from her paws while Maddy gurgles, coos and kicks, then suddenly becomes entranced examining her own foot....

Hurdle loves to be the one who gets Maddy up in the morning — and, yes, change the diaper....

For Hurdle, every day is Father's Day. At breakfast, he slurps coffee while feeding Maddy bananas and oatmeal, or cereal and pears. While feeding her last week, he turned his back — and she promptly stuck her hand in the baby food jar.

"She loves pears, just like her daddy," he said....

It's hard to imagine, with so many signs of normalcy, what might lie ahead for Maddy — including a life never lived independently.

\*\*\*

### Learning of Prader-Willi

Even though there is no cure, early diagnosis and education is the key for the parents and the children, as the Hurdles have found out. Both have spoken with (Janalee) Heinemann (executive director of PWSA (USA).

"In the first couple of weeks, a million things go through your head — will she go to the prom? Will she get married? Am I going to be able to roller skate or play catch with her?" Karla Hurdle said. "There are a lot of unknowns you have to come to terms with, it's part of the education process...."

Madison was fortunate that one of her doctors suspected that her symptoms at birth were caused by Prader-Willi, and a genetic test confirmed that diagnosis. An early diagnosis allows time for parents to become educated about the

syndrome and to start taking steps that can help their children.

Maddy undergoes physical therapy once a week and occupational therapy every other week to help develop her muscle tone, which will, in turn, help develop motor skills.

After day games, Clint spends up to 2 hours on the floor playing with Maddy — and unbeknownst to her, play time doubles as stretch time, as he works her muscles and tests her tracking skills with noises and toys that provide aural and visual stimulation.

In May, she began receiving a shot — once a day, six days a week — of growth hormone to help her grow to normal height. Karla, 36, administers the shots, but Clint is learning.

\*\*\*

The Hurdles received a big boost to their spirits when they met Lynette Hosler, president of the Colorado chapter of PWSA, and her daughter Jennifer, 10, who has Prader-Willi. Jennifer, a typical fourth-grader, plays piano and soccer. This past school year, she attended regular classes, except for an hour a day when she was in a special education class. She sometimes wears a back brace to correct scoliosis....

"But I'm not even sure any of her friends think anything is wrong, except she has a restricted diet," Lynette Hosler said. "Yes, she's hungry all the time, but she doesn't rummage for food. We can set food out on the counter and she doesn't eat it unless she asks. She makes breakfast for herself and her 4-year-old sister, usually cereal and toast."

\*\*\*

### Doting dad

Hurdle revels in being a dad, for Maddy and Ashley, his 17-year-old daughter who is graduating from high school this month. She lives in California with Hurdle's first wife, but when she was a little girl, Dad changed her diapers, too, and washed and fixed her hair.

Maddy, too, gets all that attention and more because Prader-Willi parents must keep themselves informed on everything, from an increased risk of choking because of poor muscle development to telling an emergency room doctor that there really is something wrong....

\*\*\*

For now, though, education and attitude are the best medicines. Hurdle's humorous, even-keeled approach to life has been tempered by hardships that were self-inflicted at times....

"It's just like I was telling the ball club earlier — adversity is not something you try to avoid, it's something you learn to deal with and overcome, and I've had my share," Hurdle said.

"We were chosen, he said. This was no accident."

Karla framed the letter, and it now hangs in Madison's room.

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## Bringing Home an Olympic Medal from Ireland

By Andy Maurer

*Editor's Note: In 2001, Andy told The Gathered View readers of his dream to compete in the International Olympics in Ireland. Earlier this year he was selected as a member of the USA Equestrian Team for the Special Olympics World Games 2003. Here are excerpts from his Journal of the event, with some editing help from his mom.*

**June 14:** Team members in all sports from South Carolina met at the Sheraton Hotel in Columbia for a "send-off" dinner attended by athletes, coaches, South Carolina Special Olympics officials, parents and friends.

**June 15:** We left for the airport at 4 a.m. We flew from Columbia to Atlanta, changed planes and flew on to Orlando, Florida. We went to Disney World where

Andy Maurer, who has PWS, earned a bronze medal at the International Special Olympics



we participated in the Disney parade, then back to Epcot where there was a rally for us with several speakers and a laser show. We boarded a 747 at midnight for our flight to Ireland.

**June 16:** We received a big welcome in Belfast — the host city for Team USA. We were to spend some "fun time" there to get over jet lag before moving to Dublin for the competitions. While waiting for our passports to be stamped, we were entertained by a band playing Irish music. Welcome signs were everywhere. We stayed at Queen's Elms, Halls of Residence.

**June 17:** We went for our first horse training at Millbridge Riding Club, but did not ride for safety reasons. We watched other riders who were really good. Back at our residence, we went for a walk and changed our dollars to the money used in Northern Ireland. That evening we went to the Belfast Waterfront Hall, a conference and concert center. We saw many important people such as the Lord Mayor of Belfast. There was a spectacular show — including U-2.

**June 19:** We went back to the Millbridge Riding Club and were able to ride. Katie Miller, a coach from Texas, helped me a lot. That evening there was a really great disco at the Belfast Indoor Tennis Arena. Belfast was fun!

**June 20.** We loaded on buses for our 3 hour move to Dublin. We stayed at the City West Golf Resort for the rest of our time in Ireland — a great hotel!

**June 21:** We rested during the day and got ready for the Opening Ceremonies held in Croke Park that evening. The 80,000 seat stadium was full. There were 7,000 athletes from 160 countries and 30,000 Irish volunteers, coaches, families, friends and many local citizens. We marched in just like the regular Olympics. People along the route into the stadium waved and shook our hands. There were speakers at the Ceremonies, including the President of Ireland Mary McAleese, Nelson Mandela, Arnold Schwarzenegger, Maria Shriver, Eunice Shriver, Mohammed Ali, Pierce Brosnan and many others. The entertainment was out of this world and included Bon Jovi, U-2, River Dance (100 dancers), a 500 voice choir, a song written especially for the Special Olympics 2003 by an award-winning composer, lots of bands and much, much more. It is hard to describe — it was so fantastic!

**June 23:** Our equestrian team went to the Kill Equestrian Center in Kildare where all our events were to be held. This day was for preliminary rounds held to make up the Divisions. The judges told me I had done very well. Riders and horses were matched up. My horse's name was Paddywack. I would be riding him all week. There were 138 equestrians from 27 countries. Back at the hotel that night we had a dance.

**June 24:** Back to Kill Equestrian Center for the first real day of competition. My event today was Working Trail. I won a Bronze Medal and cried with joy because I never expected to win any medals in anything.

**June 25:** Another day of competition — today was English Equitation. It was really fun to compete with people from other countries in front of a large crowd. Another dance at the hotel that night.

**June 27:** Competition today — Dressage — my last event. I had never competed in Dressage before, but I love it and I was excited. I didn't win a medal, but I loved being in the competition. I really never expected to win any medals — I was so happy to be in Ireland and to be a part of everything going on. That evening we had a dance and a carnival at our hotel.

**June 29:** Spent the day relaxing and packing. That evening we went to Closing Ceremonies in Croke Park — another fantastic event. While we were there we traded some clothes (we had been trading pins all week). I now have a jacket from Pakistan, a hat from Venezuela and a shirt from Great Britain.

This is a shortened version of my journal. I had the best time of my life, the horses were beautiful and the people of Ireland were wonderful. Meeting people from so many other countries was an unbelievable experience. I really do thank everyone who helped make it possible for me to participate in the World Games in Ireland. It was the largest sporting event to be held in the world this year and I still can't believe that I was part of it.

*Andy Maurer, 43, is from Lexington, South Carolina.*



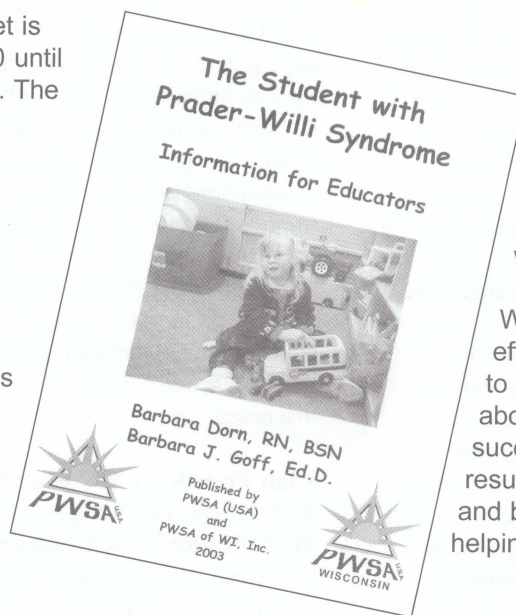
*Get Ready for the 2003-2004 School Year*

## PWSA Educator's Resource Packet Is Now Available

The long-awaited Educator's Resource packet is now available. The entire packet sells for \$14.00 until October 1, 2003 and then the price will increase. The Teacher's Resource Manual, which is part of the packet, sells for \$10.00 and can be purchased separately.

You can make this packet part of your IEP requirements. The authors are outstanding authorities on Prader-Willi syndrome.

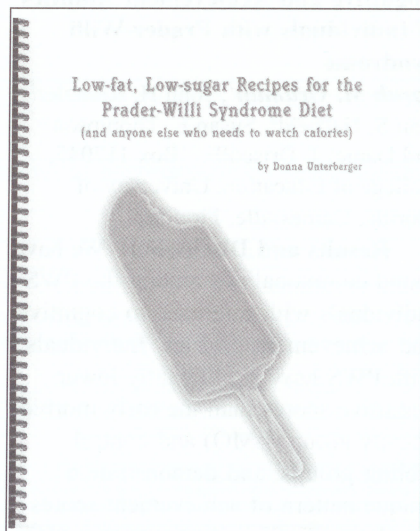
Barbara Dorn, RN, BSN is the Outreach Program Director PWSA of WI, Inc. She has served as an educator and consultant for persons with PWS in the State of Wisconsin for the past 10 years. Barbara J. "BJ" Goff, Ed.D. is a disabilities consultant, specializing in Prader-Willi syndrome. Her work includes the development of residential, vocational and crisis intervention programs; advocacy, program evaluations and training.



This marvelous team has produced a book that spans the entire school experience and on into the transition to work.

We are proud of this effort and look forward to hearing from parents about the student success stories that will result from providing new and better approaches to helping our children learn.

## Your PWSA Cookbook Is Here!



Creating a comprehensive Prader-Willi syndrome cookbook has been a goal of PWSA (USA) for years – and as we have witnessed many times in the past, it took a wise and dedicated parent to accomplish this goal!

We cannot thank Donna

Unterberger enough for creating this wonderful cookbook with unique and creative low-fat, low-sugar and low-calorie recipes. What is special for our children with PWS, who have to live their lifetime on a diet, are the many fun recipes included here so that their meals are not all bland and boring.

It's a great holiday gift, so order your glossy 160-page, 8x10, large-print cookbook today. The cost is just \$19.95 plus shipping, or get a box price of 18 books for only \$16.95 each plus shipping.

Your family will thank you and PWSA (USA) will thank you too!

### Adult PWS Study of Genotropin®

New York Medical College is directing a multi-center study of adults with Prader Willi syndrome, in collaboration with Pediatric Endocrinology Services at St Louis University, Ohio State, and UCLA. The purpose of the study is to evaluate the safety and efficacy of Genotropin® treatment in adult Prader-Willi syndrome patients with documented growth hormone deficiency, based on an L-dopa stimulation test.

The study was designed to determine if Genotropin® can improve body composition in adults with Prader-Willi syndrome. The one-year study is funded by Pfizer and will cover the costs of growth hormone treatment for one year, and many laboratory tests, including bone density, body composition, and cardiac ultrasound studies.

Eligible individuals must be at least 18 years of age, with a molecular diagnosis of Prader-Willi syndrome and not currently using growth hormone replacement therapy. The New York Medical College site, located 10 minutes from the Tappan Zee Bridge in Westchester County, is recruiting a few additional patients from the northeast to complete our enrollment.

Please contact Study Coordinator  
[Lucille\\_Dagnillo@NYMC.edu](mailto:Lucille_Dagnillo@NYMC.edu) or at (914) 594-3359 to learn more about participating in the study.

-- Harriette R. Mogul MD, M.P.H., Principal Investigator



to control or resistance to compulsive behavior indicated that the TI group had greater difficulty in controlling compulsions.

Academic achievement scores represented a convergent set of intellectual assessments, suggesting a reduction in scholastic aptitude in TI subjects compared with the other genetic subtypes. Surprisingly, the TII subjects also appeared to do better than TI or UPD subjects in certain maladaptive and adaptive behaviors and for some obsessive-compulsive behaviors. These measurements suggest that TII subjects had better daily-living skills than subjects with TI deletions or UPD. Intelligence as assessed by a number of subtests indicate that TI and TII subjects did not differ from each other and were each lower than UPD for verbal IQ, which agrees with previous reports comparing UPD to deletion. Four candidate genes recently identified between proximal breakpoints 1 and 2 (NIPA1, NIPA2, GCP5 CYFIP1) may contribute to the differences observed between PWS subjects with TI and TII deletions. Interestingly, NIPA1 has been shown to be expressed in mouse brain tissue and may be an important gene for brain development and/or function. These or other unidentified genes in the region may be implicated in the compulsive behavior and lower intellectual ability that were seen in Type I deletions.

### Gender Differences in Compulsive and Related Behavior Problems in Prader-Willi Syndrome

**Mary Caruso**, Travis Thompson, Jennifer Zarcone, Jamie Young, Laura Holsen, and Merlin Butler. Institute for Child Development, University of Kansas Medical Center.

**Results:** Though there were few significant differences on most cognitive measures, sex differences emerged in psychopathology. Although there are differences in types of obsessions and compulsions in typically developing males and females with OCD, these differences were not noted for males and females with obsessive-compulsive behavior and

PWS. Like typically developing males with OCD, males with PWS appear to have greater symptom severity. Verbal IQ was higher in people with UPD; however sample sizes of each sex within this group limited statistical comparisons on this dimension. Implications for the contribution of basic brain developmental and neuroendocrine factors in gender differences in expression of psychological characteristics of people with PWS and related disabilities were discussed.

### High Prevalence Of Altered Glucose Metabolism In Young Adults With Prader-Willi Syndrome

**A. Crinò<sup>1</sup>**, P. Ciampalini<sup>1</sup>, R. Schiaffini<sup>1</sup>, A. Sartorio<sup>2</sup>, G. Grugni<sup>2</sup>  
<sup>1</sup>Unit of Autoimmune Endocrine Diseases, Bambino Gesù Hospital, Piazza S. Onofrio 4 – 00165 Rome, Italy.

**Results and Conclusions:** Nine patients (12.7%) (4 males, 5 females, aged  $23.9 \pm 0.7$  yrs) were affected by diabetes mellitus, while 5 subjects (9.1%) (3 males, 2 females, aged  $25.0 \pm 0.4$  yrs) had an impaired glucose tolerance. Finally, three patients had only elevated fasting insulin levels ( $>25$  mcU/ml). Our data show an abnormal glucose tolerance in 14 out of 54 (25.9%) adult subjects with PWS. Nevertheless, the high prevalence of impaired glucose metabolism may be secondary to the large proportion of PWS patients with gross obesity rather than a feature of the syndrome itself. Further investigations are needed to better define the pathophysiology of altered carbohydrate metabolism in adult PWS.

### Behavior and Emotional Problems in Prader-Willi Syndrome: Comparisons to Autism and Williams Syndrome

**Anastasia Dimitropoulos**, Cheryl Klaiman, Joel Bregman, Barbara Pober, and Robert Schultz. Yale Child Study Center, Yale University School of Medicine.

**Results and Discussion:** Preliminary analysis of DBC

(developmental behavior checklist) items indicates that individuals with PWS exhibit emotional and behavior problems more similar to people with autism spectrum disorders than to individuals with Williams syndrome. Both the PWS and autism groups exhibited means above the critical value for significant behavior problems. In addition, individuals with PWS had higher scores on the antisocial behavior subscale than both participants with autism and Williams syndrome. Similarities found between PWS and autism during individual item analyses were discussed. In addition, findings from the DBC were discussed in relation to repetitive behaviors and sensory sensitivities that were assessed using a comprehensive inventory of behaviors including compulsions, restricted activities, impulsivity, and sensory sensitivities.

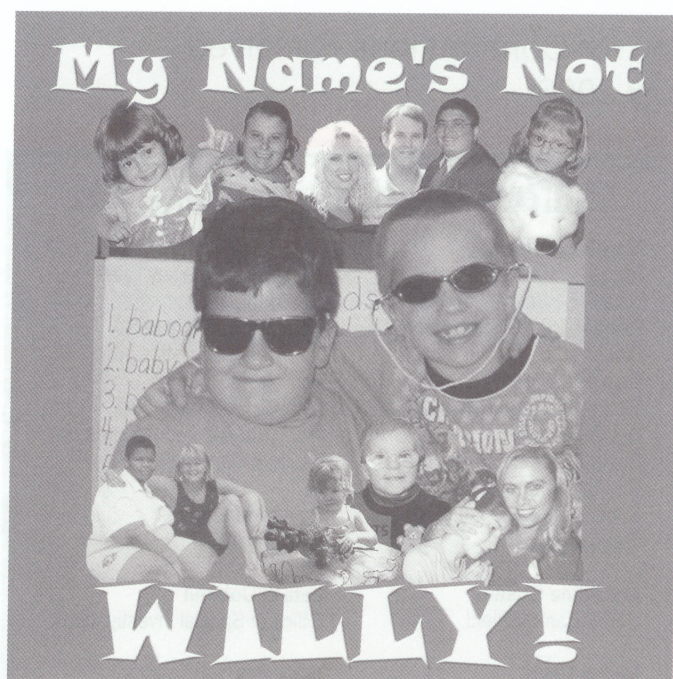
### Cognitive and Achievement Abilities of Individuals with Prader-Willi Syndrome

**Sarah M. Graman<sup>1</sup>**, John H. Kranzler<sup>1</sup>, Ann S. Hatfield<sup>2</sup>, Susan E. Thompson<sup>2</sup> and Daniel J. Driscoll<sup>2</sup>. <sup>1</sup>Box 117047, College of Education, University of Florida, Gainesville, Florida.

**Results and Discussion:** We have found commonalities among the PWS individuals with reference to cognitive and achievement profiles. Individuals with PWS have significantly lower cognitive scores than the early morbid obesity group (EMO) and control sibling groups, and demonstrate a unique pattern of achievement scores in relation to their intelligence scores. Behavior problems were noted in both the PWS and EMO groups. The characteristics of PWS and EMO individuals when considering their intelligence, academic achievement and behavioral profiles may have significant effects on their schooling and vocational futures when considered in conjunction with other important individual factors.

*Part 2 of the Scientific Day Highlights will appear in the November/December issue of The Gathered View.*





Yeah sometimes I'm mad, but sometimes I'm glad  
Emotions and hunger, I wish control I had  
The point of this song is not to make you sad  
But for opening minds and the awareness it will add

My syndrome brothers and sisters, are hopin' for a cure  
Prader-Willi should be stopped, that's for sure  
Annihilate it, like the Terminator  
We'll all be set free, so let me hear ya' holler!

Now here's my final statement, excuse me m'am  
Prader-Willi's what I've got, not who I am  
If you think you know me, take a second look  
Just lookin' at the cover, you can't judge a book

There's a lot more to me, than meets the eye  
I have dreams for my life, my only limit's the sky  
So if you really want to know me, come close and take a peek  
One promise I can make you, I am truly unique

© Xcel

(Big Tiny, Trey Smith, Lauren Fleming, Tad Tomaseski  
and The Grand Master of Mix Scott Garrison)

The Day I was born, my parents got the news  
My fifteenth chromosome had blown a fuse  
I was born with Prader-Willi, so weight's tough to lose,  
But you ain't gonna hear me singin' the blues

There is no cure, no help from the doc's  
All my parents can do is buy some new locks  
'Cause I always be thinkin' about that ice box  
So they lock it all down, as tight as Fort Knox

#### CHORUS:

I've got Prader-Willi, but my name's not Willy  
My name's not Willy! My names not Willy!  
I've got Prader-Willi, but my name's not Willy  
My name's not Willy! My names not Willy!

You know my appetite is always testin' me  
But I ain't gonna let it get the best of me  
'Cause I know my life has got a destiny  
So you gotta take the time to know the rest of me

Some kids make fun of me, 'cause I'm not the same  
Like I had a choice Dawg, I'm not to blame  
See havin' Prader-Willi is not the true shame  
It's you bustin' on me, and don't even know my name

This songs about a syndrome I can't ignore  
'Cause my appetite and me, is always at war  
Sometimes I get so mad, that I slam the door  
It makes my emotions, so hard to store

Havin' Prader-Willi is my cross to bear  
But I'm not cryin' about it, 'cause this I swear  
It ain't stoppin' me, 'cause to dream I'll dare  
My life is like a diamond, so precious and rare

## The Origin of 'My Name's Not Willy!'

As the sibling of Matt Heinemann, an adult brother with Prader-Willi syndrome, Tad Tomaseski is intimately aware of the self-esteem issues with which a person with PWS struggles.

Understanding that any positive message would have to be delivered through a fun and "cool" medium, Tad, his youth leaders and the Xcel teen group from Celebration Covenant Church in Frisco, Texas decided to create a rap CD about PWS. The above CD is the result, and it has been donated to PWSA (USA).

### How To Get the CD

Call 1-800-926-4797 to place an order and it will be mailed to you. Or, you can go to [www.pwsausa.org](http://www.pwsausa.org) to download the CD. We ask that you help with a suggested contribution of **\$6.00 or more** per download. Send your contributions to PWSA(USA), 5700 Midnight Pass Road, Suite 6, Sarasota, FL 34242

## Angel Fund Contributions

### Gabriel (\$1,000 or more)

Clinton & Karla Hurdle (in honor of Madison Riley)

### Heavenly Angel (\$500 - \$999)

James & Dolly O'Brien, Sr. (in honor of Katherine Pate)

### Angel (\$100-\$249)

Teri & Barry Douglas  
Raymond & Mary Luther, Jr. (for Research in memory of Ruth K. Paret)

### Angel (\$100-\$249)

Katherine D. Radaz (in honor of Ashley Fender)  
Jean Till (in loving memory of my son Lynn)

### Cherub (Up to \$99)

Amy & Christopher Evans  
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Gary & Lynette Hosler  
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Alley's "Smiles Across the Miles"  
Photographer Eric Hilton  
Prizes — Friends of Leslie Torbert  
Rap CD for YAP - Michael Moore  
(Big Tiny) & Tad Tomaseski  
Ventriloquist - Cindy Nelson  
Dream Bed by Signe Ruddy

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First Congregational Church

*Because of space limitations,  
additional donations will be listed in  
the next issue of The Gathered View*

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Rosemarie & Dewey Clark  
Elsa Hahn  
Richard & Patricia Hill  
Jeremiah & Lucretia Lyons  
Doris & Neil Maggio  
Diane & I. Edward Price  
Kathryn & Richard Rabinow  
Sandy & Dennis Smith

**Ray Lambert**  
Mary Ingalls

**Leta O'Connell**  
Office of Special Investigations

**Mark Ray**  
Cyrus & David Ray

**Harry Saacks**  
Cohen Family  
Richard & Eleanor Friedman  
Mark & Neysa Maisel  
Beatrice R. Osterer

**Robert & Peggy Sabella**  
Julie & Jeffrey Doherty

**Louis Setaro**  
The Baptist Foundation of  
Oklahoma  
Mayme Duecker  
Paul & Roda Guenther  
Dr. J. Richard Hall  
E Jerry Kucera  
Saundra & Fred Levan  
New Life Ranch  
Samuel & Barbara Rader  
Inez Shacklett  
Virginia M. Shacklett  
R.L. Teel  
Kent & Sue Ann Thieman  
E.C. & Barbara Wiesenmayer

**Robert Wharton**  
Erica Jen & George Zweig

## Valentine's Day/Research ~ Total to date \$38,747

Diana Amos  
William & Dana Bieber  
Mickey Case

Chris Grivakis  
Guy & Lori Hurley  
Meredith Nilsson

Prader-Willi syndrome (PWS) is a birth defect first 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. The 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.

