

# The Gathered View

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

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

## Growing Up Well

By Lota Mitchell

Most parents *wonder* how their children will turn out when they are adults. Parents of children with PWS *worry!* So news of successes of young people with PWS, even within the limitations of the syndrome, is welcome!

**Dan Calabrese**, from Allandale, NJ, is 17 and in his senior year of high school with a 3.7 GPA. What's exciting about Dan is that he has been accepted at three different colleges, with one awarding him a scholarship of \$6500 a year for all four years!



Dan Calabrese

However, his mother, Brenda Calabrese, says that "this good news is bitter-sweet. Dan will probably attend one of these schools on a part-time basis and never use his scholarship money. Although academically

prepared, the functional, life skill side of life" needs much work for him to be able to become a full-time student, a requirement of the scholarship.

She also observes that it's been difficult "trying to get the school system to address the functional, life skill independence part of the disability when there are good academic capabilities."

Another Dan, **Dan Goble**, age 26, lives in Buffalo, NY. This amazing young man captained the high school football and wrestling teams, where his mother, Louise Biela, says he starred. He went through school without need of special education and graduated with a 3.0 from Hobart & William

Smith College. Dan will be going to Thomas Cooley Law school in Lansing, VA. In addition, in the spring of 2007 he married Rene, a social worker and "very special young woman," according to Louise.



Rene and Dan Goble

A preemie weighing 2.2 pounds at birth, he was documented with PWS when he was 7 and weighed 100 pounds. Today he is 5'10" without benefit of growth hormone, weighing circa 250 pounds. Sports injuries, high blood pressure, and weight have all contributed to medical problems, and he has the typical behavioral and emotional characteristics of PWS, including anger issues.

His mother remarks, "My high functioning son became a leader though his quirky behaviors remain misunderstood by peers, authority figures and family. Dan is an anomaly. He is a productive, successful adult with PWS. (But) because he appears normal, life remains very hard."

*Growing Up Well continued on page 8*

### In this Issue

- 3 The Growing Strength of the PWS Network
- 4 Study of Psychotropic Medications in PWS
- 6 2008 Conference Update
- 9 Recent Research Grants
- 10 Board Nominees and Ballot

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

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

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Note: If you have difficulty logging in, please contact [info@pwsausa.org](mailto:info@pwsausa.org).

E-mail Support Groups:

We sponsor nine groups to share information.

Go to: [www.pwsausa.org/support](http://www.pwsausa.org/support)

### The Gathered View (ISSN 1077-9965)

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

## Executive Director's View

Photo by Eric Hilton



Craig Polhemus

## The Growing Strength of the PWS Network

Every parent of a child with PWS can look back proudly at how strong their child has grown – amazingly strong considering how weak they were at birth.

The PWS network of families, friends, and professionals has gained great strength as well. When PWSA (USA) was organized in 1975, just a handful of people were involved. By 1976 that number was 240. And today we are thousands, all committed to working together to promote and fund research, provide education, and offer support to enhance the quality of life of those affected by PWS.

One tool for reaching all 3 goals – research funding, education, and family support – is advocacy. Working together with our state Chapters, the Foundation for Prader-Willi Research (FPWR), National Organization for Rare Diseases (NORD), Genetic Alliance, and others, PWSA (USA) has scored some major public policy victories over the past several months.

In the January-February issue, I wrote of the 200 people who contacted the Social Security Administration on behalf of those with PWS regarding the process for determining disability – well over 10% of the comments received by SSA from those concerned with all disabilities combined. This stunning achievement by a rare disease community led to changes in the information we recommend parents include with their teenage child's application for SSI and Medicaid, and may soon lead to inclusion of PWS on a list of impairments for which disability is automatically presumed.

More recently, the PWS network turned back threatened U.S. Senate passage of a bill to further restrict access to human growth hormone. Before we got involved, Senator Charles Schumer of New York was quoted in USA Today as saying, "There's very little opposition to this bill." Once parents in the PWS network learned of the horrible possibility that access to HGH for their children could have been further complicated, the "opposition" was so clear that Senator Schumer withdrew his bill for redrafting.

In early March, Cathryn, John, and Tommy Maczko appeared on WBNG-TV in Binghamton discussing the PWS network's advocacy effort regarding growth hormone. The WBNG story said:

Children with PWS often take growth hormone to develop muscle mass.

But on Wednesday, Tommy's parents found out that the U.S. Senate was voting on a law that would restrict access to Tommy's medication.

"Keep laws for the ones that don't need it that are using it illegally but let's have some type of protocol for ... people who need it," says John.

They had less than 24 hours to act.

Along with parents across the nation they emailed 300 of their friends asking them to call their legislators to postpone the vote.

It worked.

"Yeahhhh. Oh my gosh, I can't believe it. We actually did it! Just a bunch of nutty parents," says Tommy's mom Cathryn Maczko.

The U.S. Senate told the PWS Association they will work with them to revise the language of the law.

Senator Schumer's staff has been consulting with us, FPWR, and NORD, among others, and we are optimistic that the revised bill will be better than current law. This is another case where the PWS network – small but committed – has had an impact far beyond its size. Inspired by our desire to improve the lives of those with PWS, we can achieve our dreams by working together. ■

See pages 10 and 11 for brief bios of this year's nominees for the Board of Directors, along with a proxy ballot. At its April meeting, the Board amended PWSA (USA)'s bylaws so that the Board may have from 12 to 15 members, rather than the previous 12. The six nominees listed will expand the Board to 14 following the National Conference in Milwaukee, July 2-4 (see page 6).

We are also looking for new participants in PWSA (USA) leadership. Email [cpolhemus@pwsausa.org](mailto:cpolhemus@pwsausa.org) if you are interested in serving on a committee or task force.

To continue to grow as a vibrant, effective organization, PWSA (USA) needs volunteers for fundraising, advocacy, and family and research support, among other areas. If you are able to free up some time to help, please fill in our volunteer form at [www.pwsausa.org/help/volunteer.asp](http://www.pwsausa.org/help/volunteer.asp).

## Medical View

# A Pilot Study of Psychotropic Medications in PWS

By Elisabeth M. Dykens, Elizabeth Roof, Vanderbilt Kennedy Center

People with PWS generally respond well to appropriate and coordinated interventions that help reduce their problem behaviors. Even so, some individuals benefit from psychotropic medications that help them focus, settle, and take better advantage of these behavioral or educational interventions.

We are very grateful to the PWSA (USA) Capraro Grant for supporting a pilot study on psychotropic medications in PWS. This pilot study identified medication use, target symptoms, and perceived effectiveness of medications. We also identified changes in single genes or alleles that belong to a family of genes (CYP450) involved in the first wave of drug metabolism in the liver. Two of these alleles (2D6 and 2C19) produce enzymes that are involved in the metabolism of many psychotropic medications. Changes or poly-morphisms in these alleles may explain some of the variable responses to medications that we see in PWS. There is no reason to believe that alterations in the PWS 15q11-q13 region are associated with altered 2D6 or 2C19 status. Much like the general population, however, changes in these alleles may help explain why different people with PWS may react favorably, adversely, or not at all to the same type or dose of psychotropic medication.

For the study, 86 parents completed medication surveys, and we obtained buccal cells (saliva with a swish of Scope mouthwash) for genetic analyses from offspring with PWS aged 8 to 51 years (average = 24 years).

CYP450 status was assessed at Vanderbilt, and PWS genetic subtypes were clarified as needed by Dr. Merlin Butler's lab. As noted in Table 1, a full 76% of participants were taking SSRIs, or agents that selectively block the re-uptake of serotonin in the synapse (or how neurons communicate), thereby increasing the amount of serotonin available in the brain. Most participants were taking an SSRI plus another agent(s). Although multiple medications make it hard to tease apart which agent is the most helpful for a specific symptom, parents reported that SSRIs or atypical anti-psychotic medications helped the most with tantrums, irritability and repetitive behaviors. As shown in Tables 2 and 3, neither agent was rated as particularly helpful in reducing skin picking, food preoccupations or food seeking.

Regarding CYP450, the Vanderbilt DNA Core used a handful of probes to identify changes in 2D6 and 2C19. These were research-based probes only and pale in comparison to the numbers of probes now readily available for clinical and commercial use in the recently marketed, FDA-approved Roche Amplichip CYP450 Test®. Although preliminary, we found that most participants were so-called normal "extensive metabolizers", meaning that they had one or two functional copies of the 2D6 and 2C19 alleles. Some participants with PWS, however, were "poor metabolizers",

at rates consistent with the general population (See Table 4). These participants had two non-functional alleles and would not be considered good candidates for medications that are metabolized using 2D6 or 2C19.

Interestingly, 37% of the PWS sample were identified as "intermediate metabolizers" of 2D6, meaning they had one non-functional allele and one allele that had low enzyme activity. It is tempting to conclude that this intermediate category explains why people with PWS often respond better to very low dosages of medication, but researchers in pharmacogenetics do not yet agree on the clinical relevance of this intermediate category.

While CYP450 status may assist clinicians in making appropriate medication choices, how people with or without PWS metabolize psychotropic medication also depends on a host of other factors. These factors include gender, age, diet, ethnicity, diseases and health, and interactions with other medications that may inhibit or promote drug metabolism. All of these variables need to be carefully considered by psychiatrists or physicians as they make decisions about medication trials.

In the weeks ahead we will be submitting this study for

**Table 1. Rates of medication use in PWS sample**

SSRIs alone	33%
SSRI + anti-psychotic	17%
SSRI + anti-psychotic + anti-convulsive	17%
SSRI + anti-anxiety or anti-depressive	9%
Atypical anti-psychotics	11%
Anti-psychotic + other	12%

**Table 2. Parental or care provider responses regarding the helpfulness of SSRI's**

	<b>No</b>	<b>Yes</b>
Tantrums	14%	86%
Skinpicking	60%	40%
Compulsions	29%	71%
Irritability	14%	86%
Food issues	61%	39%

**Table 3. Parental or care provider responses regarding the helpfulness of anti-psychotics**

	<b>No</b>	<b>Yes</b>
Tantrums	4%	96%
Skinpicking	47%	53%
Compulsions	37%	63%
Irritability	7%	93%
Food issues	72%	28%

**Table 4. 2C19 and 2D6 status for poor or intermediate metabolizers**

	<b>Poor Metabolizers</b>		<b>Intermediate Metabolizers</b>
	<b>2C19</b>	<b>2D6</b>	<b>2D6</b>
Caucasian population	2-4%	5-10%	unknown
PWS pilot study	3.2%	2.5%	37%

publication, and working with our psychiatric colleagues to create a tip sheet for psychiatrists and other prescribing physicians who treat people with PWS. In the meantime, we end with some general rules of thumb, and some excellent resources regarding CYP450 testing and people who have “dual diagnoses”, or co-occurring intellectual disabilities and psychiatric or behavioral disorders. We again thank the PWSA (USA) for their support, the many families who participated in this project, Merlin Butler for genotyping participants, and Cara Sutcliffe in the Vanderbilt DNA Core.

### General Tips

When possible, judge the effectiveness of one medication before adding others to a trial. This approach will help later when you want to taper medications that don't seem to be effective.

the medication affects their thoughts, mood, or behavior.

Medications are most effective when used in conjunction with behavioral or other therapies. A good response to medications is not a reason to discontinue or reduce behavioral, educational, recreational, speech, or other interventions. Medications may help people take better advantage of more intense intervention or instruction.

Document what you observe during the trial, including any changes in mood, behavior, sleep, etc. Ask your physician for a checklist to help guide your observations.

Communicate with your prescribing psychiatrist or physician. Communication often wanes after the trial is under way. Have a plan for how often you will stay in touch even when the trial is going well and target symptoms are stable. This is

Begin with small doses, and increase doses very slowly. In general, decrease doses when there are signs of adverse reactions or loss of beneficial effects. Stop the trial if symptoms worsen considerably, or if they stay worse and do not improve.

Individuals with PWS are partners and stakeholder in their medication trials. Expect them to share how they think

important as the same medication may not continue to work as well over an extended period of time.

Ensure that all members of the intervention team are aware of the medication trial, and of the symptoms being targeted.

New medications are continually being developed, with fewer or different side effects. Even if a previous medication trial did not work well, check in with your physician or psychiatrist from time to time to see if newer agents may be of help.

Consider working with your physician to obtain the CYP450 allele status of your child or client, (see resources below). Allele status is just one of several factors to consider in planning a medication trial and may be especially helpful for individuals with previous unsuccessful trials.

### Key Resources:

- Roche Amplichip CYP450 Test; [www.amplichip.us](http://www.amplichip.us)
- De Leon, J., Armstrong, S., & Cozza, K., (2006). Clinical guidelines for psychiatrists for the use of pharmacogenetic testing for CYP450 2D6 and CYP450 2C19. *Psychosomatics*, 47, 75-85.
- [www.theNADD.org](http://www.theNADD.org)
- Fletcher, R., Loschen, E., Stavrakaki, C., & First, M. (Eds). (2007). *Diagnostic manual—intellectual disability: A textbook of diagnosis of mental disorders in persons with intellectual disability*. Kingston, NY: NADD Press.
- Szymanski, L., & King, B.H. (1999). Summary of the practice parameters for the assessment and treatment of children, adolescents and adults with mental retardation and co-morbid mental disorders. *Journal of the American Academy of Child and Adolescent Psychiatry*, 38, 1606-1610. ■

## Medical View Byetta and Hunger

By Tony Goldstone, M.D.

Department of Endocrinology,  
St. Bartholomew's Hospital, London

Byetta is an analogue of the gut hormone GLP-1, that is normally released after a meal.

It is used as a novel daily injectable treatment for diabetes as it increases insulin secretion by directly acting on the pancreas. GLP-1 is what is called an "incretin", i.e., increases insulin.

It seems to have an advantage over some other diabetes medicines in that (like metformin) it does not cause weight gain and may even cause mild weight loss of under 5%.

It is unclear if this weight loss

is just due to delaying stomach emptying (and so increased sense of "fullness"), or also by its actions on nerve cells in the brainstem directly or indirectly via the vagus nerve to reduce appetite. Nausea can also be a side effect of Byetta (perhaps related to the above two effects).

My studies have shown that blood levels of GLP-1 are normal in PWS (either fasting, area under curve or peak level after a breakfast meal).

I have not heard anything or seen data about Byetta helping appetite or weight loss in PWS. A concern would be that people with PWS already have delayed stomach emptying, and so there is a theoretical risk of this getting worse with Byetta treatment in

PWS which might increase the risk of gastric necrosis associated with severe over-eating.

*Ed. Note: Tony's area of expertise is research on the appetite in PWS. ■*

**Chuckle Corner**

Dorica Dan of Romania and her daughter, who has PWS, were walking by a street beggar who had a sign that said, "Hungry – need food." Her daughter told Dorica, "I am hungry too, but you don't see me complaining!"

## 2008 PWSA (USA) National Conference

**July 2 – 4, 2008, The Wyndham Milwaukee Airport and Convention Center — Milwaukee, Wisconsin**

Please join us for the 30th Annual PWSA (USA) Conference "Moo-ving Forward" General Conference includes sessions of interest to all, as well as specifically geared breakout session tracts.

Here are a few of the presentations slated for this year.

**Keynote Speaker – Richard Pimentel "The Music Within"**

An expert on Disability Management, Job Recruitment, Job Retention, and Attitude Change, he is also an authority on the Americans with Disabilities Act (ADA).

**Health Update – What Everyone Needs to Know** (medical professional panel)

**Prader-Willi Syndrome: From the Orthopaedist's Viewpoint** – Harold van Bosse M.D.

**Parenting a Child with Challenging Behaviors** – Janice Forster M.D., Linda Gourash M.D.

**Behavior Management for the Teen and Adult with PWS** – Forster and Gourash

**Sensory Integration for the Person with PWS** – Janice Agarwal, P.T.

**Strategies to Minimize and Treat Skin Picking** – Greg Cherpes M.D., Gus Ludwig O.T.R., Denise Buenzili R.N.

**An Overview of Prader-Willi Syndrome** – Dan Driscoll M.D., Ph.D.

**Making a House a Home, Residential Models** – Jackie Mallow, Mary K Ziccardi, Jan Bradely, Steve Drago and Jeff Covington

Go to [www.pwsausa.org/conf/Agenda.htm](http://www.pwsausa.org/conf/Agenda.htm) for a complete overview.

Registration is open and available online on the PWSA (USA) website.

**PLEASE** make your hotel reservations through Globetrotter Travel by phone at 800-322-7032 (press 2) or online at [www.globetrottermgmt.com/pwsa-usa](http://www.globetrottermgmt.com/pwsa-usa).

A fun, structured childcare/YIP program is offered for children ages 0 – 5 (limit — 50 participants).



## View From the Home Front Racing for The Finish Line

By Diane Schaaf

It was 6 a.m. Saturday morning, in-line skate race day. Joey, 7 with PWS, and his sister Kate, 9, woke very excited to head to St. Paul for the 7:30 a.m. start of the race. Joey skated with his dad Paul, a strap pinned to the back of his shirt as a safety handle for down hills. Kate skated with her grandfather.



The morning was cool (a big plus for Joey, who can overheat) with a light drizzle. Joey went out at his deliberate pace, a big smile on his face as he made his way through the 11-mile course through the streets of St. Paul. He was greeted by the many, many people who passed by with enthusiastic calls for him to keep going! Joey always responded with a cheery, "Have a good race."

Two hours later, Joey crossed the finish line. He got his St. Paul Inline Marathon T-shirt for finishing the race and a trip through the after-race food tent. A very tired, very proud kid had finished the race. A party followed at grandma and grandpa's house to finish the special day.

Six years before, grandpa had been diagnosed with prostate cancer. After surgery (a success) grandpa, then 63, mentioned that getting old was

not very fun. My husband Paul, who had skated previous marathons, didn't ask, but signed up grandpa and me to join him skating an in-line marathon that fall. "You aren't ready to get old yet," Paul said to his father.

This was the beginning of our participation in multiple in-line skate marathons. Since then, Grandpa has finished as high as third in his age class.

Last summer, Joey announced he wanted to be in a race like other family members. Paul told Joey that he would need to train a couple of times a week all summer long. He promised Joey he would sign him up for the race once he could go 8 miles.

Joey started with 2 miles without a complaint. We were impressed, but we were not sure that Joey could complete the 11-mile race. Seven is the minimum age required to enter.

Paul started to lengthen the training runs, thinking that Joey might reach the conclusion that the race might have to wait a year or two. Five miles, 6 miles — Joey was still going without a complaint! The day Joey finished 8 miles, Paul kept his promise and signed him up for the race.

Joey lengthened his training runs up to 10 miles a week. He also spent quite a bit of time learning how to stop in our driveway—another requirement his dad had made. Joey slimmed down, his strength increased, and most impressive of all, his determination did not waver. Wow, were we proud.

Two weeks later Joey started second grade. His teachers noticed a big change in Joey from the previous spring — he was thinner, more self confident and interacting with his peers more. Had Joey had a good summer, they asked.

Had he ever!

*The Schaaf family lives in Scandia, MN ■*

## How To Tell If your Child is Sick

By Catt Maczko

Trust your gut. Our kids are so crazy with presenting us with symptoms. And they *change* what they show you as they grow! Whenever my gut tells me I need more insight, I call PWSA National. They are wonderful! They answer all the (in hindsight) silly little Q's I have — which don't seem so silly at the time. I'm always glad I took the time to bother them and call.

I told Janalee [Heinemann] I wanted her to tell me that *IF*

Thomas was really sick, he would have a purple eyeball. That way I could know. No such luck!

Remember, if you do end up in an ER, put them in touch with PWSA (USA). National will put the docs on the phone with serious bigwigs (who the ER docs will respect and listen to), and you will have the best possible care for your baby. I keep National's 800 number on my cell, just in case I

ever need it, and that little "PWS Medical Alert" pamphlet with us in the diaper bag. Better safe than sorry. Makes me feel like we can cover the bases if we need to.

Go with your gut. It's why God gave it to us, I believe.

*Catt and John Maczko from Binghamton, NY, are parents to Julia, Jack and Thomas, age 3, "PWS by UPD and the cutest little blessing that ever ran into you!" ■*

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## Growing Up Well – continued from page 1

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Families define success differently, some seeing success as related to money or academic achievement. But all want their child to be happy and realize their dreams. **Lauren Ledgerwood**, age 28, from LaPorte, IN, used to start lots of sentences with “My dream is to...” and then end it with things like “live in my own apartment;” “have a pet of my own;” “make decisions on my own;” “live by my family;” “choose my own friends and my own social activities.”



Lauren Ledgerwood

All came true. She has her own apartment, assisted with 24-hour-staff; goes to a sheltered workshop 3 days a week; and has her own small business called “Lauren’s

Dream”, making hats, scarves and unique purses. Five feet tall, she weighs 111 pounds and exercises over an hour a day. She loves being thin and wearing stylish clothes.

Her mother Melanie reports that the younger Lauren struggled with all the classic PWS issues: overweight, tantrums, self-abuse. At 19, they placed her in an out-of-state group home—and for 7 years they drove from Indiana to Wisconsin every single month. Her behavior improved dramatically with environmental changes and proper medication.

Two years ago they moved her back to their hometown. Melanie describes her as very polite, never rude or unkind, cooperative, and taking great pride in her job and the care of her apartment. Melanie emphasizes that the decision to have a child live in a group home for PWS does not have to be permanent.

**Josh Gilbert’s** success story is about change and dramatic improvement in him and the life of his family. His mother, Kathleen Critchley, related,

“Everyone we consulted said Josh had the most extreme behaviors they had ever seen. My message for struggling parents is, if you think there is no hope for your child, there is.”

The worst years in middle school deteriorated into even worse in the teenage years, so he ended up living at the State Hospital from ages 16 to 18. Kathleen

says, “He had violent behaviors over food and other fixations, he would run off and steal frequently, once breaking into a gas station for food. Due to the hospital’s interventions, medication, consistency, our devotion and love, Josh did finally begin to grow up and mature.”

He is 23 now, in a group home in Wichita, KS, 5’7” and 148 pounds, accepting of his diet and other restrictions, and developing into a compassionate and kind-hearted man. Each year he becomes more stable. His great passion is the Kansas City Chiefs. Last year he had his picture taken with a cheerleader and got her autograph. He got so excited he forgot to finish his popcorn!



Josh and a Kansas City Chief’s cheerleader.



Conor Heybach

On May 3, 2008 **Conor Heybach** (age 27) received the degree Bachelor of Arts from Northeastern Illinois University in Chicago. Conor graduated with a major in Criminal Justice and a minor in Political Science. Conor made the

*continued on page 9*



## Research View

### PWSA (USA) Recent Research Grant Awards

By Janalee Heinemann, Director of Research & Medical Affairs

We are happy to announce that PWSA (USA) has recently awarded four more grants (two in December 2007 and one in March 2008 and one in April 2008) totaling \$344,211. Adding these awards to grants approved earlier in 2007 makes **total awards \$540,721**. I have listed the grants awarded below and in the next edition will give more details on the significance of each grant.

Dates for PWSA (USA) 2008 research grant application can be found in the research section of our web site ([www.pwsausa.org](http://www.pwsausa.org)). We want to thank all of our members who have donated or hosted fundraisers to make this important research possible.

#### RECENT GRANTS AWARDED:

**Development of a Microsphere Suspension Assay for the High Throughput Screening of Prader-Willi Subjects** – Principal investigator is Heather Newkirk, Ph.D.

**Genetic Underpinnings of Restricted Repetitive Behavior** – Principal investigator is Soo-Jeong Kim, M.D.

**Autistic Symptomatology in PWS** – Principal investigator is Anastasia Dimitropoulos

**Expression of Four Genes Between Chromosome 15 Breakpoints BPI and BP2 in Subjects with Prader-Willi Syndrome and Impact on Cognitive and Behavior Measures** – Investigators: Douglas C. Bittel, Jennifer Zarcone and Merlin G. Butler ■

## Research View

### Vanderbilt Online Parent Survey

Tell me about the good stuff: Positive Growth in Parents

Principal Investigator: Teresa Ulman, M.S., supervised by Dr. Elisabeth Dykens, Ph.D.

This study looks at factors that relate to improved outcomes in parents of a child with a developmental disability. Parenting a child with a disability is hard! But many find that the experience has led to personal growth in unexpected ways.

Surprisingly, there are almost no studies on how the parenting experience can strengthen people. We hope this study will provide for a more balanced understanding of how having a child with a disability can change a person's life.

The survey will take about 60-90 minutes to complete. There are many questions about you and your child. At the end of the survey, you will have the opportunity to tell us anything else you would like us to know.

You can complete the survey in more than one session. The survey will be online until July 1, 2008. You start by going to the PWSA (USA) web site, [pwsausa.org](http://pwsausa.org).

Participants needed: Parents, 18 years or older, who have a child between the ages of 8 and 25 with a diagnosis of one (and *only one*) of the following: Angelman syndrome, autism, Down syndrome, Prader-Willi syndrome, or Williams syndrome.

Compensation: An opportunity to reflect upon your own positive growth from parenting your child with a disability.

Contact for more information: email [Teresa.Ulman@vanderbilt.edu](mailto:Teresa.Ulman@vanderbilt.edu) or by phone at 615.414.9665 or 1.888.322.5339 (toll-free). ■

PWSA (USA) gratefully acknowledges the production, printing and mailing of our newsletter is made possible by a generous grant from CIBC World Markets Corp./Miracle Day USA.

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#### Growing Up Well – continued from page 8

deans list his first semester as a senior. As part of the degree requirements, Conor completed his senior internship as an intern with the non-profit Glenkirk Full Life Program, a program that provides services to adults with disabilities, including a large number of adults in the Chicago area with PWS. Conor was involved in teaching computer and reading classes

and in a number of administrative tasks as an intern. He will continue to be involved with Glenkirk's Full Life Program. Conor will also work with his father at the Midtown Education Center for Boys in Chicago, a non-profit organization that provides educational assistance, sports and character-building training and activities to inner-city boys. ■

## 2008 Board Nominees

### Janice Agarwal

from Zionsville, IN, has 18

years Pediatric Physical Therapy experience, with emphasis on infants, children and adults with Prader-Willi syndrome. She combines Sensory Integration (SI) techniques with Neurodevelopmental Training (NDT certified by the Bobath Centre in London, England in 1995). She was part of the Neurodevelopmental Evaluation team at Boston City Hospital from 1992-1996 and the Early Intervention team at St. Marys Hospital for Children in New York from 1996-2000. Janice has lectured extensively at both National PWSA (USA) and International (IPSWO) conferences on infant development and therapeutic intervention to treat the challenges facing therapists and parents of children with PWS. Janice is a member of the PWSA (USA) Board of Directors, is the mother of 8-year-old Alex with PWS and 7-year-old Sam, and is married to David Agarwal, an Interventional Radiologist and a member of PWSA (USA) Research Committee.



**Michael Alterman** from Atlanta, GA, is brother and co-guardian to Andrew Alterman, 37, who has PWS.

"I come from a family that has been very involved with PWS causes for a long time. Along with my sister Katie, I was an Assistant Director with Josh's Friends, the organization that ran the Youth and Adults Programs (YAP) for over 5 years in the late '90s and



early 2000s, including the international conference in Minneapolis. My sister and I were permanent fixtures for the kids every year. I began coming to PWSA (USA) Conferences when I was 7 years old and have attended about 15 of them."

After graduating from Clemson in 2002, Michael began his career in Commercial Real Estate with The Shopping Center Group, LLC, in Atlanta, Georgia. He is a trustee of both the Sam P. Alterman Family Foundation and the Chippie Alterman Trust, which have supported PWSA (USA) and the Alterman Crisis Counselor generously for years.

"I am very passionate about issues surrounding PWS and would very much like to rekindle my family's relationship with PWSA (USA). I am extremely interested in the work of the organization, and I am excited by the prospect of joining the Board."

### Daniel J. Driscoll

is a Professor of Pediatrics and Genetics at the University of Florida College of Medicine, in Gainesville, FL, where he is the John T. and Winifred M. Hayward Professor of Genetics Research. He received his M.D. at Albany Medical College and his Ph.D. in Medical Genetics at Indiana University School of Medicine. His Pediatric residency and Medical Genetics fellowship were done at the Johns Hopkins Hospital where he also received his training in molecular biology and epigenetics.

He has had a long-standing interest in the Prader-Willi syndrome and the phenomenon of genomic imprinting. His laboratory has made several important contributions including being the first (in collaboration



with Dr. Rob Nicholls' laboratory) to propose and use DNA methylation analysis to diagnose the Prader-Willi and Angelman syndromes. His clinic closely follows over 200 individuals with Prader-Willi syndrome.

He has received board certification in Pediatrics, Clinical Genetics, Molecular Genetics, and Cytogenetics. He was recently elected to the prestigious Society of Scholars at the Johns Hopkins University. He is currently Chair of the Clinical Advisory Board for PWSA (USA) and is a past member of the Board of Directors. In addition, he is a member of the Medical and Scientific Advisory Board of the International Prader-Willi Syndrome Organization (IPWSO).

### Kerry Headley

from Columbus, OH, is the mother of a 9-year-old little boy, J.R. J.R. was diagnosed very shortly after birth with the Uniparental Disomy (UPD) diagnosis of PWSA.

Her goal since finding out J.R.'s diagnosis has been to get involved and stay involved and dedicate whatever free time she has to the Prader-Willi Syndrome Association. She's a past board member of the PWSA Ohio Chapter, the past Vice President of PWSA (USA) and a current officer in the Prader-Willi Family Association of Ohio. She has also served as the PWSA (USA) National Conference Coordinator for the past five years.

"Being involved in the National Conference for the past five years has been such an incredible privilege for me. The conference group that I've worked with now for the past five years is the most talented group that I've worked with in my career. The way this group gets things done while



considering the human beings that make up the organization is what attracted me to want to further my involvement as a Board Member."

Kerry works full-time as the Director of Learning Solutions with a consulting firm based out of Covington, Kentucky. In her professional position she is responsible for the design and delivery of educational solutions, such as e-learning courses and leadership seminars, for large corporations, not-for-profit, and government entities.

**Carol Hearn** practices law in Minneapolis, MN. She and husband Tim have two daughters in college and a son, age 15, who has PWS.



Of her son, David, she writes, "It's hard to describe how delightful this kid is and how

much pleasure he brings to us. He loves everyone he has ever met and often remarks on what a great day this is, even if it seems to everyone else that it's a really lousy one. He does have his bad days, of course, but he usually manages to find the joy in life better than anyone else I know."

A board member and past president of PWSA of Minnesota, Carol currently co-chairs the PWSA (USA) board. She writes, "PWSA (USA) has seen such remarkable growth and development in the past three years. Through research, crisis inter-vention, mentoring, conferences, advocacy and the like, we are raising awareness, serving more families and addressing more needs than ever before. At the same time, through volunteering and grassroots fundraising, more and more families are becoming involved in PWSA (USA)'s mission. It's really invigorating to work with so many wonderful folks for such a great cause."

**Ken Smith** has been employed at the Children's Institute in Pittsburgh, PA, since 1985. During this time, he has worked in several different capacities within the organization.



The Children's Institute established its program for children and adults with Prader-Willi syndrome and related disorders in 1981. Since then, they have served over 1100 individuals in their in-patient and outpatient programs.

Ken's first exposure to PWS was in a direct care capacity in The Institute's nursing department. For the past 15 years he has worked in various administrative roles including managing the treatment team. Ken has served on the board of directors for the PWSA (USA) for 13 years, where he is currently serving as Co-Chair of the board.

## Prader-Willi Syndrome Association (USA) 2008 Official Proxy

**Must be received at PWSA (USA) office by June 19, 2008**

I hereby appoint \_\_\_\_\_ of \_\_\_\_\_ to vote as my proxy  
(print name of your designated proxy voter) (state of residence)  
 at the PWSA (USA) Annual Meeting in Milwaukee, Wisconsin, in July 2008.

### Instructions to proxy voter: vote for up to six candidates.

Please cast my vote as you see fit. OR

Please cast my vote for the Board of Directors candidates I have marked below:

I am a member in good standing of PWSA (USA).

Janice Agarwald\*     Kerry Headley\*

Name: \_\_\_\_\_

Michael Alterman\*\*     Carol Hearn\*

Signature: \_\_\_\_\_  
(please print)

Dan Driscoll\*     Ken Smith\*

Date: \_\_\_\_\_

\*three-year term

\*\*two-year term

ALL VOTERS must check one of the following:

We have a Family Membership, which has two votes, and are both voting for the same candidates.

We have a Family Membership, but are voting for different candidates and so will submit two proxies.

I have an Individual Membership.

## Fundraising From the Home Front Ride for PWS goes the Distance

**By contributing writers Rachel Elder,  
Jodi O'Sullivan and Lota Mitchell**

On March 27, 2008 Steven Tomasini and Robert Hughes of New York travelled all the way to PWSA (USA)'s headquarters in Sarasota, Florida to cycle 370 miles – that's right, 370 miles – from Sarasota to Key West. With their focus to raise awareness for Prader-Willi syndrome ahead of them, they literally went the distance for PWSA (USA), arriving at their destination three days later on March 30th. A support vehicle followed them the entire trip to ensure their safety during the trek that took them halfway across Florida.

Inspiration for the ride came from Steven's friend Denise Steck, whose three-year-old daughter, Kayleigh, has PWS. Steven and Denise are both physical therapists and worked together at the Nassau University Medical Center. Denise was the first therapist Steven hired when he opened his company. "Denise and her husband James are both very strong individuals," Tomasini said. "Their strength inspires people and it inspired me. Every time I see them together as a family I see such great hope for what it is we should all be doing in life: living, loving and growing together and learning that when life gets challenging we live and learn from it. Denise has always said that the world will learn something from Kayleigh and I know that is true too. I have learned from the Steck family already."

Although Steven and Robert said they probably would not touch their bikes for a week after they finished the ride, the ride went smoothly. They reached Key West tired, but with uplifted and

energized spirits. Along the way they saw lots of wildlife and got to see beautiful parts of Florida. Plans to do Ride for PWS again next year are already in discussion since both the road and route were good.

Together as an organization or as an individual rider, you can help next year by spreading the word about Ride for PWS. Create PWS awareness, too, and even raise funds to support PWSA (USA). With the help of volunteers to cheer the cyclists along their route, meeting up with them along the way or hopping on a bike and joining them for the whole or part of the ride, you can make this a great event for PWSA (USA). So, if you're up for supporting the cyclists or training for any part of the 370-mile ride to raise awareness and spread the news far and wide about PWS, keep a look out in *The Gathered View* and email support groups and on the PWSA (USA) web site for more information. You, too, can go the distance!

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### Nothing But Net!

It was an NBA game like no other. February 22nd at Oracle Arena in Oakland, CA, was the date and place of the Prader-Willi Awareness Night: Golden State Warriors vs. the Atlanta Hawks which raised an outstanding amount of knowledge about PWS thanks to **Ashley and Clint Hurdle**, sister and father respectively to 5-year-old **Madison Hurdle** who has PWS. Contributing to these efforts was **Michael Moore** of Comcast. Ashley said, "Each one of my colleagues, directors, managers, and friends was so touched by our families. You could really see it in all

of their faces throughout the night. You all touched my heart in a way that I can't really find words to explain, and the whole experience made me want to put my entire heart into everything that [we] all can do for our children."

For four weeks prior to the event, ten different Comcast Networks in the Bay Area ran a Public Service Announcement about the event, featuring Clint, manager of the Colorado Rockies, more than 350 times. Clint also graciously spent time meeting and speaking with everyone who attended. In addition, more than 300 PWS brochures and wristbands were given away to attendees at a booth on the first floor and funds were raised to support PWSA (USA) and the California Prader-Willi Foundation. "I don't think Oracle Arena has ever been so full of hope, love and support," said Ashley.

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### Raising Funds in Minutes with Firstgiving

Fundraising can be an easy 20 minutes. Go to [www.firstgiving.com/pwsausa](http://www.firstgiving.com/pwsausa) and create your own personalized web page by following the very simple instructions. Then send the link to everyone you know, asking them to support PWSA (USA), a cause that's near and dear to you.

Just recently at the PWSA (USA) Board meetings in April, a demonstration of just how easy it is was given, and five people set up their page right then and there alongside the demonstration ... in just 20 minutes. It couldn't be easier!

You can check out upcoming events in your area on the PWSA (USA) events page at: [www.pwsausa.org/fundraising/events/](http://www.pwsausa.org/fundraising/events/) ■

## Chapter View

A dozen families from PWSA of **Pennsylvania** enjoyed a "Woodlands weekend" at the Woodlands Foundation in January. Bonfire, movies, visitors from the Pittsburgh Zoo, and swimming were only a few of the activities designed to provide fun and respite. Chapter members were also fortunate to have as speaker at their November meeting Dr. Laura Marshak, author of *Married With Special Needs Children*. Next after a sharing meeting in April comes the annual Golf Outing Scramble in May.

The theme of the spring workshop in April of Prader-Willi Alliance of **New York** was "Sensory Strategies to Improve Children's Learning and Behavior." Featured were speakers Carol Stock Kranowitz, author of *The Out of Sync Child*, and Florida physician Dr. Rex Birkmire discussing medications in the treatment of sensory processing disorders. In addition, Nina Roberto has been appointed Executive Director. The annual Alliance Conference occurred May 1-3 in Albany.

PWSA of **Wisconsin** has been busy planning for the 2008 national conference in Milwaukee July 2-4. Nevertheless, they found time late fall to have a Health Update on PWS training for parents and caregivers.

Also in late fall was the annual Prader-Willi **California Foundation** General Education Meeting, targeting medical and behavioral interventions. Featured speakers were Dan Driscoll, M.D. (medical), Mary K Ziccardi (behavioral), Janalee Heinemann (research), and Craig Polhemus, PWSA (USA). April (southern) and

May (northern) will find members Walking for Prader-Willi Syndrome to raise both awareness and funds.

## Colorado Opening First-Ever Group Home

The Colorado PWS chapter has teamed with an experienced group home provider, Triangle Cross Ranch, to create a unique and safe group home exclusively for those with PWS. Working with the chapter, Triangle Cross Ranch management is currently renovating one of the existing homes to fit the needs of people with PWS. Plans are to open in late spring 2008, with applications now being accepted from across the country.

Triangle Cross Ranch is excited to be able to offer a private pay group home living environment for people with PWS and is hoping to fill the home with five residents by the end of 2008. The Ranch does not receive any state or federal funds; it is a private, non-profit organization. Triangle Cross Ranch, located 45 minutes north of Denver on 20 beautiful acres of ranch land, has been a group home for more than 25 years, with individual houses serving adult ranchers with developmental disabilities.

Triangle Cross Ranchers participate in numerous activities such as Special Olympics, job placement, and community activities. But the best thing about the ranch is its two in-house cottage industries—gardening and wool production. The gardening program grows herbs that are then dried and packaged for sale. In the other program people care for the ranch's wool-producing herd of angora goats and alpacas. They shear the animals, process the fiber, and then use the felt to make finished products such as hats, purses, ornaments and other art. The ranch is also

designing an equestrian therapy program; the vision is to have an indoor arena where community members may come for riding lessons and therapy.

For more information go to [www.trianglecrossranch.net](http://www.trianglecrossranch.net) or telephone Executive Director Lorelei Faglier at 970.454.2219. All inquiries are welcome.

*By Amy Wissmann, mother of Amanda, 17, from Cherry Hills Village, Colorado.*

## Tales from the Colorado Rockies

When Clint Hurdle led his Colorado Rockies baseball team to a miraculous run to the National League pennant in 2007, he and his team became instant role models. But he always kept things in perspective, often saying, "Baseball's just a game." He learned five years earlier with the birth of his daughter, Madison, who was diagnosed with Prader-Willi syndrome (PWS), that real heroes are individuals who fight to live a normal, healthy life despite the obstacles presented by a serious health condition. As the national spokesperson for the Prader-Willi Syndrome Association (USA), Clint is to be commended for all he has done to improve the lives of those with PWS. He is the real hero in our book – and in the new book coming out titled, *Tales from the Colorado Rockies*, by Tony DeMarco, which takes a historical look at the history of the franchise. Clint Hurdle authored the foreword in exchange for publicizing PWSA (USA) within the book and also making a \$1,000 donation to our organization. The book will be available in May for purchase at all bookstore chains (and online) in the Colorado region. The publisher is Sports Publishing at: [www.sportspublishingllc.com](http://www.sportspublishingllc.com). ■

# Contributions

## Thank you for Contributions through March 2008

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

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<b>Jace Coltrane</b>	Kurt & April Langford	George & Catherine Mulry	Lisa Smith	Ronnie & Ira Levine
James Van Becelaere Company Inc	Jason Lounsbury	<b>David Hearn</b>	<b>The Kane Family</b>	<b>Rachel Levy</b>
<b>John Ross Comes</b>	Marta Peraza	Arnold Hearn	Rick & Mary Ellen Huether	Diane & Lawrence Hoefler
John & Susan Comes	Angela Sangiovanni	Mark Schubin & Karen McLaughlin	<b>Kate Kane</b>	Joshua & Kristin Levy
<b>Harry Connerty</b>	<b>Wilma Fiske</b>	Rand & Bonnie Sortland	Robert & Rebecca Baummer	<b>David Lopatin's 15th Birthday</b>
Jeff Fender	Kenneth & Mich Fiske	Tim & Carol Hearn	Tom Kane	Helen Tricarico
Judith Ratner	<b>The Fiske family</b>	<b>Abby Heathman</b>	Cindy & Hal Marshall	<b>Natalia Lopez</b>
<b>Chrissy Cornell</b>	Anne St. Onge	Beta Kappa Chapter 13690	<b>James Kane &amp; family</b>	Andrea Hidalgo
Susan & Richard Cornell	Suzanne St. Onge	Heath & Kae Hogan	Allan Zalesky	<b>Jackson Lowe</b>
<b>Emily Costa</b>	<b>Brennen Riley Fletcher</b>	Cody Krenka	<b>Haley Kavrell</b>	Jean & Douglas Lowe
Erika Good	Cindy & Sandy Guerrero	<b>Janalee's tenure as</b>	Catherine Masi	<b>Peder Lundh</b>
Elizabeth Prochazka	<b>Ryan Fochs</b>	<b>Executive Director</b>	<b>Julia Kenney</b>	Steve & Susan Lundh
<b>Brayden Crosson</b>	Harlan & Melba Hamlin	Nancy Snow & Dan Glazier	Elizabeth Kenney	<b>Lucy Page Luttrell</b>
Hutch Crosson	<b>Jacob Ford</b>	<b>Sara &amp; Sara Everett Henry</b>	David & Tammy Kenney	Amy & Thomas Luttrell
<b>Emily Rose Curran</b>	JoAnne Riley Barron	David & Elizabeth Ward	<b>Grace Kercheville</b>	<b>Isabel Lutz</b>
Jacqueline Reid-Piscitelli	<b>Rachel Forster</b>	Hanna Herne	Charles & Nancy Hartwigsen	Andrew & Laurie Braun
<b>Stephen Dam</b>	Carla Roehner	John Burke	Philip Schmidt	<b>Evan Macks</b>
Ole & Kristin Dam	Robert & Patty Dion	Peyton & Jady J Joiner	Jeanette & Francis Wortham	Lee & Rhonda Linville
<b>Olivia Danese</b>	<b>Peter Frazin</b>	<b>Conor Heybach</b>	<b>Jaycie Kinn</b>	Lisa Zeiter
John & Mary Ann Danese	David & Phyllis Jeffery	Sara Conley	Connie Karcher	<b>Ramon Madrid, Jr.</b>
<b>Ray &amp; Sherry Davis</b>	<b>Jack Gardiner</b>	<b>Lexi Higgins</b>	<b>Jake Klauber</b>	Kelly & Patrick Gibbs
Angela Spradlin	Ed & Rose Maloy	Ed & Kay Griffith	William & Cynthia O'Haire	<b>Allison Mahan</b>
<b>Dorothy Davis</b>	<b>Talyn Garofalo</b>	<b>Oscar Hill</b>	<b>Janna Rae Knaak</b>	Robert & Elizabeth Fuller
Bill & Mollie Stinson	Sharon Pohn	Jennifer Hill	James & Marcia Joseph	<b>Christian David Maierhofer</b>
<b>Tanner Dean</b>	Kathleen & Alan Critchley	<b>Mr. &amp; Mrs. Steve Hill</b>	<b>Vicki Knopf &amp; family</b>	Janet & Keith Schuman
Cathi Pena	<b>Gavin Gill</b>	Richard & Ellen Fletcher	Marianne & Joseph Mione	<b>Michael Mancheno</b>
<b>Richard de Lone</b>	Edward & Janine Gill	<b>Mackenzie Claire Holley</b>	<b>Glen Koch &amp; Laural Solana</b>	Jessica & George Kruse
Anthony Hawksworth	<b>Sienna Grace Godfrey</b>	Rebecca Nicholson	Erik Giles	<b>Matthew Mansourian</b>
<b>Brooke Detiege</b>	Lois Bascom	<b>Joey Holmes</b>	<b>Marco Kolcheff</b>	Michael Pappagallo
Wayne & Darline Gurney	<b>Rochelle Goetz</b>	Hazel Hodgson	Bruno & Sylvia Caruso	<b>Dom Marci, Jr.</b>
<b>Jessika Dickinson</b>	Ken Evanoski	<b>David Homer</b>	<b>Shaun Kopietz</b>	Pat & Dick Hamel
John & Mary Ann Bellanti	<b>Oliver Maxx Golub</b>	John Homer	Richard & Shelly Kopietz	<b>Eli Markle</b>
Kristen & Lionel Lepine	Joe & Mary Ann Golub	<b>Thomas Riden Howard</b>	<b>Lia Kreacic</b>	Jeanne Markle
Barbara & Michael McManus	Ivy Lantry	Carole & Doy Lively	Florence & Tony Kreacic	<b>Zoe Marks</b>
Matt & Becky Reardon	Priscilla & David MacInnis	<b>Jakayla Howard</b>	<b>Nathaniel Kufus</b>	Bill & Terri Marks
James Tomkins	Michael Parker & Megan Rhynne	Mary Lou Waller	Martin & Kim Kufus	<b>Evan Matesevac's 1st Birthday</b>
<b>Danielle DiCola</b>	<b>Alexandria Gotoh</b>	<b>Mr. &amp; Mrs. John Hruska &amp; Sam</b>	<b>Jack Kuna</b>	Jeff Eichelberger
Paul & Patricia DiCola	Rev. Dawn Gotoh	Paul & Betty Kramer	Brady & Katie Bernhoft	Rita Stonefoot
<b>Kaitlyn Disney</b>	<b>Cameron Graziano</b>	William Ronald Hughes II	Mike & Lori Kuna	<b>Andy Maurer</b>
Jeff & Sheila Erhardt	Lisa & TJ Graziano	Abel & Barbara Parsons	<b>Vince Connelly &amp; Florence</b>	Robert & Mary Gulick
<b>Angela Ditta</b>	Chuck & Melinda Morrow	<b>Clint Hurdle &amp; the</b>	<b>Larson</b>	Stewart & Bronnie Maurer
Sandy & Frank Ditta	<b>80th Birthday of Dr. Louise</b>	<b>Colorado Rockies</b>	Alice & Herb Zarov	<b>Norma McAlister</b>
<b>Ben &amp; Li Drotar &amp; Jaeda</b>	<b>Greenswag</b>	Selina Garces & James Fein	<b>Jackson Latimer</b>	Barbara Mitchell
Graham Phalen	Hy & Ruth Chausow	<b>Clint Hurdle &amp; his family</b>	Lois Carson	<b>Aaron McCleary</b>
<b>Aidan Dunn</b>	<b>Alexandra Grussing</b>	Holly Hoxeng	Cleo Latimer	Patrice McCleary
Long Island Super Sport Team	Chester & Roberta Lonnquist	Drew Jacobs	<b>Noah Joseph Lauer</b>	<b>Quinn McCauley</b>
<b>Stephen Fabio</b>	<b>Megan Gurney</b>	<b>Madison Hurdle</b>	Dolores Ferrier	Esther Hedrick
David & Judith Fabio	Mark Angel	2008 Colorado Rockies	Erin & Joseph Lauer	<b>Ellen McDonald</b>
<b>Erin Favret</b>	<b>Brody Haggard</b>	Fantasy Camp	<b>Ivan &amp; Fern Lefkowitz</b>	Barrett Heywood, III
Gerald Favret	Norine & Cecil Haggard	Scott Aurand	Peter & Gayle Girard	
Brian & Terri Hall				

## In Honor Of (Honoree in bold)

<b>Virginia Anne McMahon</b> Joe & Joanna McMahon	<b>John "Jake" Pawulak</b> David Dempsey	<b>Lyndsey Schultes</b> Agnes Schultes	<b>Maddilyn (Maddi) James Smith</b> Matthew & Susan Davis	<b>Pauline Utley's Birthday</b> Janet Arnold
<b>Christopher Mesropian</b> Claudine Roman	<b>Rita &amp; James Hobday</b> Jones & Sons Inc	<b>Laura Schutz</b> Mary Anne Diehl	<b>Madison Smith</b> Carolyn Cheeseman	<b>Maria Christine Vucci</b> Mark & Karen Reid
<b>Jessica Rose Miller</b> Rosa Brigner	<b>Art &amp; Beth Kane</b> Thomas Mudd	<b>Debra Shavitz</b> <b>Preston Schwartz</b>	<b>Barbara Sponder's Special Birthday</b> Harriet & Alan Cohen	<b>Thor Wagstrom</b> Rolf Wagstrom
Tina Miller	<b>Sabine Tourville</b> <b>Ed &amp; Patricia Pelszynski</b>	<b>Kathleen Schwartz</b> <b>Cameron Scott</b>	Ron & Gloria Schwartz	<b>Avery Waldrop</b> Emily Allan
<b>Pamela Minos</b> Patricia Minos	<b>Christine Persanis</b> Harry & Muriel Persanis	<b>Rosemary Asmus</b> Sarah Cook	Rita Scott	Sarah Cassidy
<b>Giorgio Mirabile</b> Elsa Filosa	<b>Roxanne Frances Peterson</b> Craig & Frances Peterson	<b>Colleen Engstrom</b> William Hilton	<b>Paulette Sherman</b> <b>Christina Spradlin</b>	Sarah & Tom Young
<b>Maggie Mitlo</b> Mary Porter	<b>Brooke Evelyn Pfeiffer</b> Patricia Pfeiffer	Linda Jarvis	Alice Bell	<b>Katy Walker</b> Sherrod Braxton
<b>Ryan Montgomery</b> Kelly & Brian Hartley	<b>Lauren Pfeiffer</b> Randolph & Rebecca Morgan	Scott & Dana Mol	<b>Bella Stakely</b> Cheri & Tracy Stakely	Cecile Richards
<b>Crosby Mook</b> Hope & Nelson Leonard	Patrick & Shawna O'Brien	Donna Munoz	<b>Kayleigh Steck</b> Denise & Bill Fleming	<b>Cameron Wallace</b> Christopher & Catherine Barras
John & Jean Mook	James & Mary Risch	Janet Schally	Robert & Lisa Steck	<b>Brenna Walsh</b> Paul & Debbie Dobson
<b>Faith Morse</b> Frank & Rita Warren	<b>Ashlee Grace Piercy</b> Donna & Willie Piercy	Geoff Scheuber	<b>Alexis Stephens</b> Betty Bitting	Jill Rotondaro & Ed O'Brien
<b>Julia Morrison</b> Douglas Howie	<b>Addison Pogradt</b> Laurina Breit	Missy Schmitz	<b>Naomi Storr's 5th Birthday</b> Marlene Pratto	Noreen O'Neill
<b>Cabot School &amp; Julia Morrison</b> Cathleen & Scott Morrison	<b>Lorrie Prettyman</b> Kenneth & Ruth Prettyman	Missy Schmitz	Carol & Hans Storr	Heather & Kenneth Sessa
<b>Faith Morse</b> Bob & Brenda Sattelberger	Thomas Prettyman	Barbara & Walter Scott	<b>Jacob Summerlin</b> Grace Nelson	<b>Dr. &amp; Mrs. D. E. Ward</b> Sara O. Henry
<b>Diane Morse</b> Laura Stephens	<b>Kiley Quinn</b> Heather Muckenhirn	Diane Sentinella	<b>Julien Isaac Swiger</b> Barbara Bell	<b>Taylor Warren</b> Jess & Marjorie Blount
<b>Kira Marley Nadler</b> Cynthia Abel	<b>Luke Ranieri</b> William & Barbara Ranieri	Debby Weitzberg	Maurice & Irene Jernigan	James & Valerie Campbell
Carrie Bellware	<b>Ashlyn Ricardo</b> Elizabeth & Wayne Morse	Barry Williams	<b>Daschel Szapacs</b> Kathryn Stazzone	James & Bronda Curtis
Jeanney & Steve Kutner	Nancy & Channing Morse	<b>Reagan Seely</b> Robert Seely	Gerard Thorell	<b>Bailey Morgan Watson</b> Carol & Jim Goodridge
Beryl Sara	Tracey Ricardo	Jenny & Andre Swinerton	<b>Teresa Tabor</b> Donna Sparre & Robert Dahlin	<b>Brian Weakly</b> Gary & Carolyn Weakly
<b>Miriam Nadler's 3rd Birthday</b> Leslie Moradi	<b>Andrew Richardson</b> Anthea Richardson	<b>Zachary Selden</b> LaVerne Rajala	<b>Troy Toby</b> Kentuckiana Yacht Employees	<b>Kevin Westphalen</b> Michael & Susan Evans
Sheila Namanworth	<b>Severino (Sonny) Roberto</b> Severino & Catherine Roberto	<b>Hudson Self</b> Wanda Keefer	<b>Leslie Torbert</b> Bill & Marilyn Baggett	<b>Katie White</b> Brian & Lara White
<b>Callasandra O'Connor</b> Colleen DiColella	<b>Jorden Roulette</b> David & Elizabeth Phillips	Carrie Orahood	Millie & Jim Keener	<b>Ashley Willis</b> Laura Lilac-Tate
Martha Hansen	<b>William Francis Sammons</b> Bill & Maria Lisa Sammons	Perkins & Lund, PLLC	Karen Pendleton	Andrew Willis
Michelle Hansen	<b>Alaina Satterly</b> James & Raymah Satterly	Jennifer Orahood	Torbert Produce, Inc.	<b>Truman Willoughby</b> Jean & Chuck Willoughby
Paul & Barbara LaPointe	<b>Joseph Schaaaf</b> Diane & Paul Schaaaf	<b>Maya Servais</b> Rick & Darii Wohlers	Sandra & Sam Wood	<b>Amanda, Nicole &amp; Alex</b> Wissmann
Ann Walsh	<b>Lily Clare Schactman</b> Ellen Jaeger	<b>Isla Shaw</b> Virginia & Raymond Podmenik	<b>Tommy Torbert's Birthday</b> Julie & Jeff Doherty	Robert & Karen Wissmann
<b>Dr. Judith Odenheimer</b> Jeff & Amy Willinsky	Ben & Raina Nadler	Tony & Donna Franco	<b>The Travis Family, Salt Lake City</b> Leah & Scott Brockway	<b>Trevor Wolfer</b> Bev Stutzman
<b>Lily O'Leary</b> Rene & Irene Mailloux	Minette & Gerald Nadler	<b>Kenneth Shoemaker</b> David & Jane Shoemaker	<b>Jessica Travis</b> Tri-Mont Engineering Company	<b>Mika Kay Woo-Nelson</b> Yeanna Woo
<b>David Olivacz</b> Bob & Doris Hendrickson	<b>Christopher M Schankin</b> Barbara & Paul Aiello	<b>Brenna Siegfried</b> Norbert & Grace Mandeville	<b>Kolbe Troxel</b> Barbara Cheney	<b>George &amp; Pat Wright</b> Denise Bujalski
Digital Innovation, Inc.	Carole Monroe	Cheryl Ross	<b>Brendon Tsai</b> Hong Der Tsai	<b>Sheridan York</b> Tibbels Marina, Ltd.
<b>Jeanette Orahood</b> Rick & JoNeil Caldwell	<b>Aubrey Scheer</b> George & Sara Karpach	Mark & Maria Siegfried	<b>Ridley Grace Underwood</b> Jessica Murray	<b>Oliver Young</b> Richard & Jennifer Gemberling
<b>Katherine Pate</b> James & Dolly Brien		<b>Adalee Sims</b> Stephanie & Richard Adlin	<b>Marisa Underwood</b> Powell & Joane Underwood	<b>Tyra Young</b> Claude & Nancy Lockhart
Michelle & Jay Brien, Jr.		<b>Eliot Slifcak</b> Joseph & Mary Ellen Matts		
Clara Triche		Anna Russell		

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 Syndrom 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](http://www.pwsausa.org/donate)

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*Still hungry for a cure.*