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The Gathered View

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

Rising Above the Clouds

by Janalee Heinemann, Executive Director, PWSA (USA)

On my return trip from visiting the Iowa PWSA chapter, I had a stormy flight, with dark thunderclouds all around and threatening lightning strikes illuminating the sky. There was no sign of relief in sight until finally the pilot flew up into the clouds, and when he broke through the other side, I was struck by the beauty and serenity waiting for us. It was there all the time — we just couldn't see it. Our PWS parents are like the pilot — trying to find their way above the threatening clouds to a calmer place in life.

As with other state associations I have visited (Georgia, California, Minnesota), I enjoyed the camaraderie of sharing stories with other parents and admired their strength and fortitude. Besides handling the day-to-day task of a raising a child with special needs, caring for siblings, and often working a full-time job, they must struggle to become experts on IEPs, IHPs, SSI, Medicaid waivers, PT, OT, speech, psychology, growth hormone, ADA, advocacy, genetics, respite, ACCH, TASH, CAPP, NICHCY, COBRA, SSA, HIPP, EPSDT, HCBS, ADC, Title 19, FIP, DHS, COMPASS, and their county, state, and federal systems. Then, after they figure out what the system is supposed to do for them and their child, they have to figure out how to contact the right people in the system, how to wade through the paperwork of the system, and what to do if it doesn't work for them. These are parents who had no intention of becoming experts in the human services and

legislative fields … yet experts they become. They thought their destiny was to quietly raise their family and become a beautician, engineer, accountant, farmer, or … but PWS steers them in a new direction. It certainly is not in the direction they planned to take, yet with time, education, and support, they find the fortitude and knowledge to brave the storm and find their way above the clouds.

I often get that "first call" from a heartbroken new parent who looks at their beautiful, fragile baby and is devastated by what they have heard and read about PWS. Yet, somehow, like the rest of us, they find an inner strength they did not know they possessed, and acquire the knowledge and skill to take on each "thunderstorm" that threatens their family. Then, above the clouds, they find a world that has its own special beauty. It is a beauty that cannot be seen by all — only those who worked hard to find it. I have been fortunate enough to have visited it many times:

- In the voice of a veteran parent who says something remarkably profound or wonderfully witty about living with the syndrome.
- In the faces of a hundred young people with PWS that illuminate the room with their smiles at the national conference dance.
- In the words of parents who write us from Egypt, Japan, Israel, Australia, etc.—dealing with PWS in all corners of the world.

and

- In the arms of my 25-year-old son, Matt, when he hugs me and says, "I love you, Mom."

inside

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President's Message

Someone You Should Know

by Jerry Park, PWSA (USA) President

In preparing my last article as president I would like to take a few liberties in this open forum to expound on PWSA (USA) and the volunteers that make up this organization.

We as parents and professionals are constantly seeking ways to properly fund and provide a better way of life for our individuals with Prader-Willi syndrome. We are the custodians, and the organization prides itself in hopefully enhancing that role. There are circumstances when all of us ask much more from PWSA than we are willing to give. In the final analysis this takes its toll on the organization. I challenge each of you to evaluate what you can contribute to PWSA in time, talent, and/or donation. We take for granted that the organization is large enough to handle the demands placed upon it. Most nonprofit organizations are run by a volunteer core group. Acquaint yourself with the needs of the organization and question that core group through phone calls, during the conference, or through the home office: *How can you help?*

This organization would not be successful without the large volunteer base that helps meet the daily requirements. My hat is off to Jim Kane, board chair, Don Goranson, vice-president, and Jim Gardner, treasurer, who in the last year have spent an enormous amount of time and resources to facilitate the organization in all areas, and to the entire board, who give tirelessly and can always be counted on for responsive and professional decision making. The organization has made some very critical and decisive moves this year that in the long term will be beneficial for PWSA (USA). Our executive director, Janalee Heinemann, will be the catalyst in the future of the organization. The combination of parent-professional provides an empathetic ear and organized structure that will benefit all of us. Linda Keder, as our editor of *The Gathered View*, has provided that communication link between the individual and the organization. The publication has become so professional and informative that I cannot wait to read it when it hits the mailbox. The most unsung group are the conference committees and the states that support them. The annual conference is a two-year effort, and we cannot take for granted the work that it takes to put on a conference for 1,000 people. This year Jim Boyle and Pat Shiley have done a great job in preparing for our conference in Columbus, July 23-25.

Get to know the organization—it is here for you. You will give far more than you will ever ask for if you give yourself the opportunity.

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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). *The Gathered View* welcomes articles, letters, personal stories and photographs, and news of interest to those concerned with Prader-Willi syndrome.

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Communications regarding *The Gathered View* or PWSA membership and services should be directed to the national office of PWSA (USA), 5700 Midnight Pass Rd., Suite 6, Sarasota,

Oklahoma Kicks Off Awareness Week with State Conference

The Oklahoma chapter kicked off this year's PWS Awareness Week with its 3rd Annual State Conference, Saturday, April 18, in Oklahoma City.

The attendance was an all-time high—over 100, including 24 people with Prader-Willi syndrome ranging in age from 10 months to 41 years. Others attending were parents, care givers and local professionals. Also, one family from Texas and one from Kansas were in attendance.

Dr. Louise Greenswag was the guest speaker and panel facilitator. The morning panel focused on medical issues with a medical doctor, psychologist, and nutritionist. The afternoon panel covered social services, advocacy for school age children and legal issues.

The Oklahoma chapter continues to focus its efforts on educating the state's medical profession, educators, and the general public to better diagnose and serve its individuals with Prader-Willi syndrome. Chapter officers are: Daphne Mosley, president; Mike Hill, vice president, Marion Shacklett, treasurer; Gretchen Hannefield, secretary; and Curt Shacklett, chairman of the board.

—Daphne Mosley

Oklahoma chapter officers, board members, and conference committee: (standing, left to right) Gretchen Hannefield, Bill Walker, Penny Park, Curt Shacklett, Mike Hill, Mary Hill, Kevin Kramer, and Sherri Kramer; (seated, left to right) Russell Mosley, Marion Shacklett, Daphne Mosley, Katy Walker, Derrick Kraemer, and guest speaker Dr. Louise Greenswag.

Other Awareness Week Goings-On

The **Michigan** chapter, under the new leadership of Jim and Carolyn Loker, sponsored its fourth annual PWS Awareness Walk-Along on April 25 in Grand Rapids.

Arizona, which now boasts a Self-Advocates Club, held an awards ceremony on April 26 for the winners of its First Annual [miniature] Golf Tournament in March, and held its annual walk-along on May 2 at sites in Tucson and Scottsdale.

The **Wisconsin** chapter held its spring dance on April 25 at the Oconomowoc Developmental Training Center, a residential service provider in Oconomowoc.

Florida, under new President Dan Krauer, held its annual spring meeting in Gainesville on April 24-25, featuring bowling and a zoo trip for the kids, a tour of Dr. Dan Driscoll's research lab, and a group home open house.

The **New York Alliance** chapter held its annual PWS conference May 1-2 in Al-

Announcements

Infant Girl With PWS Needs a Home

Adoption Services Associates (ASA), a licensed child-placing agency in San Antonio, Texas, is seeking help in placing a baby girl of Hispanic descent. The child was born on 2/16/98 at 34 weeks gestation and has been diagnosed with Prader-Willi syndrome. She is currently in foster care with ASA.

For information, please contact Nickie Lopez at ASA: 1-800-648-1807.

(For more information on ASA, Internet users can visit the organization's Web site: http://asasatx.org)

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Jewish PWS Group Home In the Planning

Melvin Handwerger, a grandparent from Maryland, is seeking other families interested in a Jewish group home. He writes:

"It is my intent to work toward establishing a Jewish PWS Group Home. The structured life of Judaism would greatly benefit the individuals with PWS. Since this is such a rare disorder, I need help in locating Jewish families that have Prader-Willi children or adults. Those interested, please contact Melvin Handwerger at 410-484-6508 or 410-828-4446."

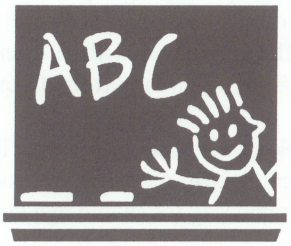
❖

New Awareness Tools

"Questions & Answers on Prader-Willi Syndrome," PWSA's introductory brochure about PWS, has been updated and reorganized. It is available on our Web page (www.pwsausa.org) and from the national office in Sarasota.

An information packet for law enforcement officers has been developed by the PWSA office to support families whose children's behavior has led to police

Something Special for Preschoolers At the Ohio Conference ...



"Child Care" takes on a whole new meaning this year for the children age 3 to 5 whose families are attending the PWSA National Conference in July. The Ohio conference committee has decided to break the mold and take this support service well beyond babysitting for the first time. Dottie Lee, a preschool teacher with 20 years of experience, is designing a special conference-long program for our blossoming preschoolers. Each day will feature a theme, expressed throughout the day in songs, art, activities, and even snack! One day will have a zoo theme to complement the program that the Columbus Zoo is bringing to the hotel. Gross motor activities will also be built into each day—no couch potatoes in the preschool room this year!

Animal Encounters, Movie Night, and Rap Sessions for Adults and Sibs

Rather than take our whole youth program to the Chicago Zoo on a hot July day, the zoo is coming to the cool Adam's Mark Hotel during conference week. Our entire Child Care and Youth/Adult Activity Program group will have an opportunity to meet—and pet—some zoo animals during carefully controlled one-hour sessions scheduled on Thursday and Friday.

Thursday night will be family movie night at the conference, sponsored by Blockbuster Video—a great time for families to be together and unwind after a busy first day at the conference.

Thursday features a rap session for adults with PWS to share with each other the successes and struggles of the syndrome. Siblings will have a combined lunch and rap session to talk about issues they deal with in being the brother or sister of a person with PWS.

Reservations & Registrations

Hotel —Call 1-800-444-2326 (national Adam's Mark information and reservation line) or 1-614-228-2525 (Adam's Mark conference hotel in Columbus).

Air travel—Call Travel By Design at 1-330-896-0776 (Johanna Costello) or 896-7601 (Rene Speight) for information on discount flight rates. E-mail: south266@aol.com

Conference registrations—Registrations are being handled by the office of Jim Kane in Baltimore, Md. This office can be reached at 410-321-8526.

See you in Ohio!

Medical News of Note

Growth hormone has been the subject of a number of articles in the past year. A November supplement to the international pediatrics journal, *Acta Pediatrica*, covered the 23rd International Symposium on Growth Hormone and Growth Factors in Endocrinology and Metabolism, held in France in April 1997. Articles by Eiholzer et al., Hauffa, and Lindgren et al., included in this supplement, reported studies of GH use in children with PWS (See list on p. 5 for full article cites.) The studies by Hauffa and Lindgren et al. were "controlled" studies, meaning some children got the growth hormone and others did not. The Hauffa study reported only improvements in height velocity in the treated group, whereas the Lindgren study reported improvements in body composition and behavior as well. A later article by Lindgren et al. (*Acta Paediatrica*, January 1998) concludes that "treatment with growth hormone is beneficial for the majority of PWS children." Dr. Martin Ritzén of Sweden, who is one of the authors of the Lindren reports, was a featured speaker at the International PWS Conference in Italy and will speak at our national PWSA conference in Ohio.

Hormone insufficiencies in PWS are discussed in an article by J. Müller of Denmark, also in the November issue of *Acta Paediatrica*, which concludes that "more aggressive endocrine treatment strategies in children and adults with Prader-Willi syndrome are certainly warranted."

An overview of PWS by Scientific Advisory Board Chair Dr. Suzanne Cassidy appeared in the November issue of the *British Journal of Medical Genetics* as the "Syndrome of the month." This seven-page article with photos, references, and the latest in genetic testing for PWS would be an excellent introduction to the syn-

Research

Recent Journal Articles on Prader-Willi Syndrome

These articles concerning PWS appeared in MEDLINE or other journal indexes since our last listing in the November 1997 issue of *The Gathered View*. The more technical or narrow articles on the genetics of PWS are not included here; however, a comprehensive list of articles on PWS published from 1995 to the present is available on PWSA's Web page (http://www.pwsausa.org). Abstracts of many of these articles can be found on the National Library of Medicine's PubMed and Internet Grateful Med Web sites (http://www.nlm.nih.gov/databases/freemedlhtml).

Copies of the full articles can be obtained from a regional medical library. Call the National Network of Libraries of Medicine at 1-800-338-7657 to locate the library nearest you.

MEDICAL

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PSYCHOLOGY & BEHAVIOR

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Osteoporosis, Calcium, and PWS

by Gail M. Thune, M.S., L.N.

Gail Thune, a licensed nutritionist, is training coordinator with the Prader-Willi Syndrome Project for the State of New Mexico. She is also a current member of the PWSA (USA) board of directors.

We at the Prader-Willi Syndrome Project for the State of New Mexico have joined doctors at the University of New Mexico Hospital to study osteoporosis in all persons over the age of 10 years who have the diagnosis of Prader-Willi syndrome.

Osteoporosis is a condition in which the bones become brittle. It can be a very serious disease with the potential to cause many problems through the lifetime. Bones can break easily or spontaneously. Complications can lead to being confined to a wheelchair or even to death.

Osteopenia is the beginning stages of osteoporosis.

Bone is active, living tissue. Every day, until about age 35, bones go through a remodeling process: being built up and being torn down. After this age, we begin to slowly lose the minerals in our bones. "Thinning of the bones" to the danger point usually happens to elderly people, but we have seen it happen to young people with PWS. Differences in bone content can be determined by several factors: how much exercise we do, how well-balanced our diet is, and by the amount of hormones we produce. There are several reasons why we believe both males and females with PWS develop this condition: 1) lack of hormones, 2) lack of weight-bearing exercise, and 3) lack of diets high in bone-building nutrients.

The lab results for those who have had bone density studies done show a decrease in the amount of calcium and other bone minerals, leading to concern that all persons with PWS may be at risk for developing this disease. As a result, we have developed treatment measures to reduce the risk of developing it, as well as what to do if osteoporosis already exists. If the proper actions are taken, the progression of this disease can be stopped or even reversed. The recommendations offered are also the best ways to prevent osteoporosis.

Detection and Monitoring

We strongly suggest that all persons diagnosed with PWS have bone density studies done, beginning at age 10, and continue with regular follow-up testing.

To assess the mineral status of the bones, a special X-ray device called DEXA is used. (See box below.). The three areas tested are the lumbar spine, hip/pelvic bone, and the wrist. It is essential that regular bone density studies be done on the individual and that follow-up studies be done on the same machine. Machines differ, and results from one machine compared with those from another will not give reliable results. If osteoporosis is diagnosed, bone density studies need to be performed yearly. If osteopenia is diagnosed, studies should be done every other year. Finally, if there is no decrease in the mineral content of the bones, studies should be done every three years.

About Bone Density Tests

By the time osteoporosis shows up on a regular X-ray, significant bone loss has already occurred. It is necessary instead to use one of the specialized "bone mineral density" (BMD) tests to evaluate bone mass and detect thinning of the bones at an early stage.

Although there are at least three types of BMD tests currently available, the one most commonly used is called DEXA, for "dual-energy X-ray absorptiometry." DEXA machines use a very small amount of radiation to assess bone density at the critical sites most vulnerable to osteoporosis. The amount of radiation used is so small and so focused that the technician is able to sit next to the scanning table.

Like most bone X-rays, DEXA scans require no special preparation, and the patient remains fully clothed. In a DEXA test, however, the patient must lie still on the machine table while the scanner passes over the body, which takes a few minutes.

DEXA tests can cost around $300 but are usually covered by insurance for patients at risk of osteoporosis. Less expensive BMD tests may be on the horizon,

Medications and Supplements

The current therapies available to physicians to treat and prevent bone loss include drugs and supplementation with vitamins and minerals. The drugs physicians might prescribe include hormone replacement (estrogen and progesterone for females) and Fosamax (binds calcium into the bone). These may be necessary but must be combined with nutrient supplements and exercise.

It is difficult to recommend a brand-name supplement you can purchase or have your doctor prescribe because pharmacies carry different products. The cost of products also varies. This is important depending on whether you pay out of pocket or have Medicaid.

You will not find a "formula" which is exactly like my recommendations. However, a good prenatal vitamin [the kind women take during pregnancy] with added supplements will work, and so will Centrum Silver. If either of these products is used, you will need to supplement further with extra magnesium (in an amount equal to the calcium in the multivitamin) and with vitamin B6 to reach the levels of intake suggested. You may have to do some detective work with your doctor and pharmacy to find the right supplement.

Diet

Current research and reports in the

Recommended Vitamins, Minerals and Trace Elements

Nutrient	Daily Dose	Food Source
Calcium	1000 mg	Milk, yogurt, cheese, dark green leafy vegetables, broccoli, citrus fruits, canned salmon and fish with edible bones, and whole grains
Magnesium	750-1000 mg	Whole grains, nuts, seeds, green vegetables, and animal products
Vitamin D	400 IU	Vitamin D-fortified dairy products, eggs, fish, and liver Other source: ultraviolet rays from the sun
Vitamin C	500 mg	Citrus fruits, green and red peppers, collard greens, broccoli, spinach, tomatoes, potatoes
Vitamin K	150-500 mcg (1.5-5 mg)	Dark-green leafy vegetables
Vitamin B6	50-100 mg	Whole grains, watermelon, bananas, fish, chicken, beef, tomatoes, and some nuts
Folic Acid	400-800 mcg (0.4-0.8 mg)	Fresh vegetables, wheat germ, and brewer's yeast
Manganese	5-25 mg	Whole grains, particularly brown rice and rice bran, nuts, seeds, leafy vegetables, and meat
Zinc	15-30 mg	Whole grain products and brown sugar
Copper	1.5-3 mg	Whole grains, nuts, organ meats, eggs, poultry, legumes, and green leafy vegetables
Silicon	1-5 mg	Rice bran, rice polish, brown rice
Boron	1-3 mg	Fruits, vegetables, and nuts
Strontium	0.5-3 mg	Tap water, plant foods grown in strontium-rich soil

ent vitamins, minerals, and trace elements are needed if bones are to remain healthy and strong. The easiest way of getting the nutrients we need is to eat a balanced meal that is high in the calcium, vitamin D, minerals, and trace elements which promote growth of bone tissue. Eating foods high in specific vitamins/minerals and taking supplements will help provide the essential nutrients. (See box, above.)

Other Food Considerations

There are other issues to be aware of, also. Eating and drinking some types of foods can "leach" the calcium and other minerals out of the bones. I strongly advise avoidance of the following: refined flours and grains, sugar, caffeine, and excess protein and phosphorus.

- Refined flours and grains are highly processed. The bran and kernel have been removed by milling, making
- Sugars come in many forms in many products. Avoid white sugar products like bakery goods, soda pop, and "fun" cereals.
- Caffeine is found in coffee, tea, cocoa, chocolate, and even some medications. Use the decaffeinated varieties.
- Phosphorus is found in red meat and cola-type beverages. Avoid excess protein due to the phosphorus content, and use clear-colored soda beverages. Buy decaffeinated, diet Sprite, 7-Up, Diet-Rite and other sodas to use in place of the cola type.

A problem with all food produced nowadays is that the amount of nutrients is lower than it was 20 to 50 years ago. The amount of minerals in the soil crops are grown in has decreased. Vegetables, fruits, and grains are deficient; animals that graze on pasture do not get adequate

bles and fruits. It is hard to get the level of nutrients we need from the food we eat because of this. The only way we can obtain the level of nutrients we need and maintain a reasonable calorie intake is to take a daily supplement. I recommend this for all people, not just persons with PWS.

Exercise

We know that the amount and type of exercise one does is important to maintaining sturdy bones—not just any type of exercise, but weight-bearing exercise.

Exercises which involve an action of supporting the weight of the body are considered to be weight-bearing. Resistance training is also a form of weight bearing. The easiest weight-bearing exercise for the lower body is walking. This may be done on flat, even surfaces like sidewalks, tracks *or even in the swimming pool*. It is also necessary to work the upper body. Many gyms have free

weights that can be lifted, pushed, or pulled to work all areas of the arms, back, and shoulders. The amount of weight need only be one to two pounds. If you do not belong to a gym, you can use books, bricks, or cans of food, etc., to make your own weights. [*Editor's note:* Weights that strap onto the wrist are relatively inexpensive and would be safer for an individual with a weak grasp.]

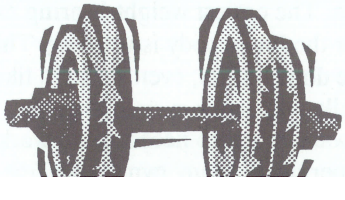
Each exercise for a particular body area should be done as a "repetition." A repetition is a series of the same movement performed over and over. Repetitions with minimal weights firm and tone but do not "bulk up" the muscle.

If an individual is diagnosed with osteopenia or osteoporosis, it is important that participation in activities be appropriate. A person with weak bones would not do well playing football, skiing, wrestling, or track and field events. However, swimming, bowling, and riding a stationary bicycle are good forms of exercise which will not stress the joints or bones.

Any form of exercise needs to be done at least three times a week for a minimum of 30 minutes. To begin, do 10 minutes three times a week and gradually increase the time for each session until the workout is 30 minutes in length. The secret to gaining good results from exercise is the time spent doing it, the frequency of times a week, and the intensity of the workout. Using exercise as a method to build stronger bones must be a lifetime commitment.

Conclusion

We encourage you to take this information very seriously. Failure to act positively now may cause unfortunate problems in the future—which could have been avoided with a little effort and consistency. You know what they say about an "ounce of prevention" …



Calcium Made Simple

We know that most Americans don't get the amount of calcium they should, but sorting through the recommendations on calcium—daily requirements, best dietary sources, and most effective supplementation—can be mind-boggling.

The April 1998 issue of *Nutrition Action Healthletter*, published by the nonprofit Center for Science in the Public Interest (www.cspinet.org), offers the latest wisdom on calcium, based on interviews with calcium experts who served on the National Academy of Sciences Panel on Calcium and Related Nutrients. Last year this panel released new, higher recommendations on calcium intake, ranging from 1,000 to 1,300 milligrams per day, based on age. It's important to note that the daily recommendation for calcium is the combination of *all* calcium you take in, both from the diet and from supplements. The article simplifies the latest recommendations as follows:

- ✓ **Eat three low-fat dairy products a day**—their calcium values plus the 200-some milligrams you get from miscellaneous foods will total 1,000 to 1,200 mg of calcium per day. (For example, one cup of plain nonfat yogurt has 452 mg, a cup of skim milk has 316 mg, and one ounce of swiss cheese has 270 mg.)
- ✓ **"For each calcium-rich food you *don't* eat, get 300 mg of calcium** from a supplement or a *healthy* fortified food like calcium-fortified orange juice."
- ✓ **Choose either calcium carbonate or calcium citrate malate** as your supplement. All calcium supplements are absorbed well, but calcium citrate malate (used in juices) is the most easily absorbed, and calcium carbonate (such as Tums) is the most concentrated, making it the best value for the money.
- ✓ **Take calcium supplements with meals** for best absorption, ideally in quantities of 500 mg or less.
- ✓ **Get enough vitamin D from milk, the sun, or a supplement** (200-400 IU for most people) to boost calcium absorption. (Note: Each glass of milk has 100 IU. Be aware that you can't get vitamin D from the sun in the winter if you live north of the line running from Atlanta to Los Angeles or if you are wearing sunscreen.)

In a March 1997 "Consumer Alert" on calcium supplements, *Prevention* magazine offered advice on reading supplement labels, which, because they're not standardized, can be very confusing. To locate the amount of *usable* calcium in a specific product, look for a quantity in milligrams (mg) labeled either "elemental calcium" or plain "calcium." The total weight of a tablet is typically more than the usable calcium content. The article also warns consumers to pay attention to dose amounts or serving sizes; don't assume that it's one tablet for the advertised calcium amount on the label—read the fine print. Some additional cautions: Avoid the so-called "natural" calcium supplements that are derived from oyster shells, dolomite, or bonemeal; they may contain dangerous levels of lead. Be aware that oyster-shell calcium is sometimes identified as "natural" calcium carbonate—this is one case where "natural" is not necessarily good.

Resources on the World Wide Web:

- ♦ The complete 1997 National Academy of Sciences report on calcium, phosphorus, magnesium, vitamin D, and fluoride — http://www.nas.edu/newsrpt
- ♦ The 1994 National Institutes of Health consensus guidelines on optimal

Letting Go

Liz Clark of Washington state shares with us her feelings about the transition of her daughter with PWS to a group home.

My 18-year-old daughter, Melissa, was placed in a children's group home for about six months. She was close to home, so I was very involved and did not have to "let go." However, she has now moved to the Prader-Willi group home for adults, which is about a two-hour drive. I would like to share my feelings with you.

I have been a widow for the past seven years. It is almost impossible to do this job alone. I love my daughter very much, but I had reached burnout. The constant vigilance around food, police involvement, and not being able to have a life of my own left its toll on me. I wanted to be a mother, not a policeman in my own home.

It was hard to place Melissa in a children's group home. I knew it was necessary, but I hurt for her and for me. This was the group home where she spent her respite care weekends, so the transition was fairly simple. I felt immediate relief. What a change to go to the grocery store and buy anything. I was still nervous leaving the pantry and refrigerator unlocked. I would jump when I heard a noise in the kitchen. I liked having the home close to me because I could still be very involved with Melissa. What I enjoyed the most was the changed relationship of being a mother and enjoying more normal times with her.

At times I felt guilty. This was my baby. Was I letting her down? Was this right? She had a right to be with her family. I felt the unfairness of the syndrome for her and for me. I had met her needs all her life and left mine out in the process.

Now Melissa is an adult and has moved to the adult group home. The State of Washington has only one PWS group home, and it is almost impossible to get into it. I know this would be the best place for her. I am counting my blessings, and we are both very very excited and happy. However, I am going through a grieving process, and I am having a hard time "letting go." I have been preparing myself for this for the past 18 years, and now that it is here, I am feeling sad and I cry easily.

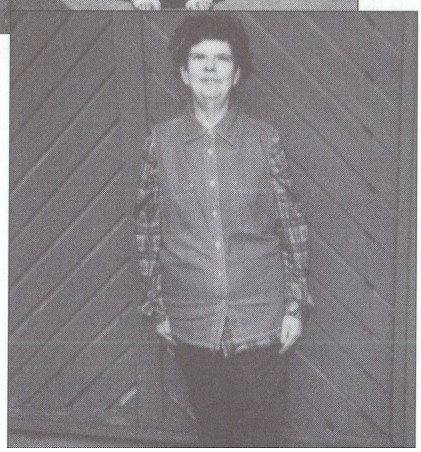
I also knew I would become her legal guardian when she turned 18. I have asked myself many times the moral ramifications of this. I continue to feel it must be done for her own safety. It was not easy for me to do this and to see the legal papers. It all sounds so foreboding.

Melissa wanted to move, wanted to move into this group home, and likes being treated as an adult. At this time she has no problems with me being her legal guardian. She enjoys her time with me. She wants to be with other people with PWS.

Among my other feelings I am scared. I know and understand my daughter so well. What if she is violent and they don't understand? What if she can't settle in and must move, what then? They have not had 18 years to bond with her and to know her. They have not had 18 years to love her and to see her tremendous amount of growth. They have not seen the obstacles that she continues to wrestle with because of the syndrome. They have not seen her uniqueness and the loving person that she truly has become. Can they look beyond the syndrome to see the person sometimes hidden there?

We are forced to be so protective of our children because of the syndrome. You would think that I would be ecstatic to have her placed and to be able to live a more normal life. My emotions are mixed. I feel joy, and I feel sadness. I also feel a tug at my heart. I look forward to a life of my own. I have paid the price, and I am still around to tell the story. Sometimes I wonder if she will still need me, and yet I know I will always be a part of her life. Parenthood is a mixed blessing. We can't wait for our own independence, and when it comes, we panic.

And so, my dear Melissa, I let you go, and I pray that God will ever be at your side to protect you and to keep you safe. I entrust to the group home my most precious child that you may grow to know her specialness and treat her with kindness.



Beth's Success Story

Hi, Gathered View!

I weighed 277 lbs. at my family camp, 1995. I weighed 263 lbs. when I first weighed in [at the group home she entered in August 1996]. I weigh 145 pounds in 1998. I celebrated my nephew's 16th birthday today. I had salad, one piece of pizza, a tiny piece of cake, and super low-fat ice cream. I stuffed Easter bags for the kids. I have one nephew 16 years and one niece 11 years. I have a great home and a great family.

—Beth Carlyon

Beth "before" in 1995 and "after" her weight loss in 1998. Beth's mom, Eva Carlyon of Auburn, Calif., tells us Beth is 46 and "has read *The Gathered View* most of her life—also watched the pictures of those 'before and after' and now has some

Being a Dad

Going Crazy ... for Sanity's Sake

Editor's note: The following thoughts on craziness are offered by Mike Larson, who is the father of 5-year-old Alex, president of the Wisconsin PWSA chapter, and webmaster for PWSA-USA's World Wide Web page. His remarks appeared in the January issue of The Wisconsin Connection, his chapter's newsletter.

Does admitting that you are crazy make you saner? Recently, caring friends were asking about how we were doing. They commented that from their point of view we have a lot to deal with, and they were worried how we were handling things. In our house we live with PWS, diabetes, and multiple sclerosis, along with the daily stresses of raising a family in the '90s, both parents working, day care, school, taking care of a house, rental property, personal finances, family commitments, working with the state and national PWSA organizations, and trying to have a regular social life with friends.

I'm not really sure what they expected, but the standard response of "Oh, we're just fine" was given. I don't know how this person would have reacted if I had told him the truth: that most days we are absolutely, undeniably, and certifiably CRAZY!! Who wouldn't be with all this? I don't know about most parents of children with PWS, but most days I feel like I am walking a fine line between being a responsible, civic-minded adult and losing control or "going on a rampage." There always seems to be a struggle to "keep the balance."

One thing that keeps threatening to disrupt my balance, pushing me over the emotional edge, is playing the "What's going to happen in the future?" game. (Somehow, no matter how much I play, I still lose every time. You would think that I would get better the more I play, but I keep finding ways of beating myself.)

This is a very difficult game because we don't know the future, and we always play out the worse possible scenarios over and over in our mind. I don't know who doesn't worry about how the "hand they have been dealt" in life will play out, but this is not a good game to play and is designed to surely push you over this emotional edge. If I start play this game, I feel lucky when, rather than going over the edge, I just feel like I'm going crazy! And, traditionally, when you're crazy, you've lost the game ... or have you?

They say that if you think you are crazy, you're really not. I have the greatest concerns about people who say they have everything under control. Either they are lying or they are the real nut cases. I can't say I know of any other parents of kids with PWS that aren't, in their own way, crazy — to some degree. Most parents of "normal" kids generally venture in and out of this state of emotional instability, but manage to hold on to some semblance of normalcy by today's standard.

My personal way of dealing with life the past few years has been to tip the scales and admit to myself that: I really AM crazy! I would be crazy NOT to think I am crazy! And that this is alright. I have a crazy life. I am going to live in a house with other crazy people, and a lot of strange and crazy things are going to happen there. Many of the things are so strange that an outsider would call "the nice young men in their clean white coats" to come and take me away (ho-ho!) if they knew they were happening! I **will** struggle living with PWS, and there **will** be times when I just want to cry. And there **will** be times I can't stand it any more and burst out laughing at something an outsider would not find in the least bit funny. I **will** do just what I have to do not to "lose" my balance and maintain my sometimes tenuous hold on my sanity. So what I'm trying to say is, if you feel like you are going crazy, maybe you are doing all right handling your own situation. Maybe it's okay to allow myself to be "crazy" and to keep a "balance" in life, rather than going over the edge.

So, all you friends and relatives who might read this ... Yes, we are crazy! This helps us to hold onto our sanity.

Tech Resources

A Medical Equipment Exchange program has been launched by the National Organization for Rare Disorders (NORD). The purpose is to match families who want to sell or exchange equipment they no longer need with those who need such items—e.g., wheelchairs, hospital beds, walkers and crutches, toileting equipment, communications equipment, and so forth. For information, write: NORD, P.O. Box 8923, New Fairfield, CT 06812; e-mail: orphan@nord-rdb.com; or visit NORD's Web page: www.nord-rdb.com/~orphan

✦

Closing the Gap, a Minnesota organization that provides information on computer-related technology for individuals with disabilities, publishes an annual directory of commercially available hardware and software for all types of needs. A 200-page tabloid-size publication, the directory is the annual Feb/Mar issue of the organization's newsletter and can be purchased separately for $14.95 plus $3.00 shipping and handling in the U.S. (and 6.5% sales tax in MN). Quantity discounts and foreign shipping are also available. This directory is an excellent resource for finding the best software to help a child develop particular skills. For more information, contact: Closing the Gap, P.O. Box 68, 526 Main St., Henderson, MN 56044; e-mail: info@closingthegap.com; or visit their Web page: www.closingthegap.com

Medical Definitions from the Home for the Bewildered

Clinical depression: The print your behind makes on the doctor's examination table.

Derange: Kitchen appliance. Usually sits right next to de fridge.

Bonding: What chewing gum does between your shoe and the pavement.

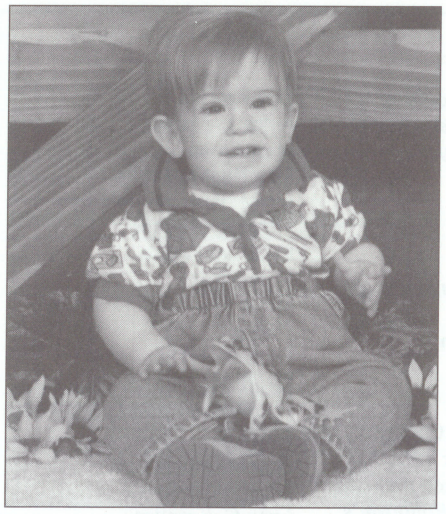
Repressing: What you'll be doing to your pants after a 13-hour car trip.

Healing: Teaching your dog to walk beside you.

(Reprinted from The Wisconsin Connection)

Not So Bad

It's been a whole year now since Jacob was diagnosed with Prader-Willi. We've had the usual roller-coaster ride of emotions, and I think we're coming down around the final corner of acceptance. He is such a wonderful boy … we couldn't love him more. I have spent endless time on the phone with other parents, called the national organization, searched the Web, gone to stay/visit with parents who have children with PWS, and I have got people I can e-mail when I'm down or have a question. My husband, on the other hand, doesn't feel drawn to overindulge on information; he accepts and loves Jacob for the child he is today (must be nice!).



Jacob Soncarty at 13 months.

I can't say it's been a great experience, but I can say that I wouldn't go back to the person I was before I had Jacob. I am so grateful to all of the people and organizations that are willing to help. So many of you have told me heartwarming stories about your children! At the beginning I felt so helpless and hopeless. Now I can see a wonderful future … different than the perfect one I had planned, yes, but still wonderful.

I would love to hear from other parents of young children with PWS. I think it would be neat to start a support group specifically aimed to fit the emotional and physical needs of parents and children who have been newly diagnosed. If you are interested you can e-mail me at: Soncarty@colfax.com OR "snail mail" me at: 2901 Glenwood Road, Garfield, WA 99111.

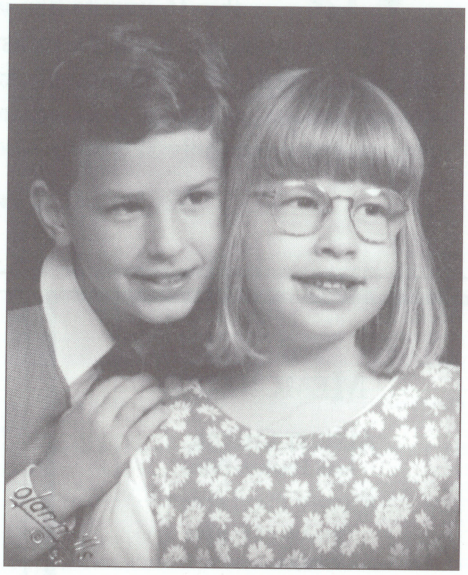
I feel fortunate to be a part of such a super group of people!!

God Bless,

—Amy Soncarty

My Journey Through PWS With Colleen

When Colleen was born "floppy" on September 21, 1991, we definitely knew something was wrong. I asked well-wishers not to visit except for supportive family members. Three months after Colleen's birth, I returned to work. I would cry when asked about my bundle of joy. I felt robbed of the joy one receives at the birth of their child.



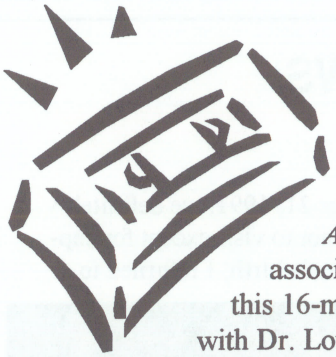
Colleen, age 6, with her brother, Geoffrey, 8.

Now, six years later, I realize I have been celebrating the joy of her birth for quite a while. I want to tell everyone how "lucky" I am. I could never ask God to trade Colleen in for a daughter without PWS. Ironically enough, it is PWS that makes her so special. For example, on Valentine's Day she gave the candy she received at school to her teacher because she "knew Mom wouldn't want her to have it." One Saturday at her ballet class, she was the only child without a snack. I couldn't understand why Colleen was not offered a snack. Colleen said, "I knew I shouldn't eat it so I said no." Saying no to chocolate and snacks can be difficult for any of us, but especially for a child with PWS.

Colleen has an endearing way about her that makes everyone who enters her life feel special. She tries hard at everything she does. My husband, son, and I are very shy and introverted at times. This is impossible if Colleen is with you. She speaks up at science fairs, introduces herself to glass makers and conductors, calls her friends on the phone, and I am told she is one of the most popular students in her school. Needless to say, I have met a lot of interesting people through Colleen's introductions, and I, too, have become somewhat more talkative.

I thank God so much for the joy Colleen brings to our lives. My outlook on life has changed because of Colleen. It's no longer so important what I have accomplished or where I am going, but what joy will Colleen bring to me today. My journey through PWS had started out to be lonely and painful, until I discovered I'm not alone, especially with Colleen at my side. She brings to my life laughter, happiness, and love.

—Joanne McMaster
New York



New PWSA Video Will Debut in Ohio!

At last! The video we've all been waiting for has been completed and will be unveiled to association members at our national conference in July. Entitled "Searching for Solutions," this 16-minute film was created by award-winning producers and graphic artists in cooperation with Dr. Louise Greenswag and PWSA Vice President Don Goranson, drawing from hours of footage shot at the 1997 PWSA conference in Orlando. It features nine of our families, as well as interviews with renowned experts on Prader-Willi syndrome. This professional-quality film will introduce the world to PWS … for a very modest price (only $20 each—look for ordering information in the next issue of *The Gathered View*).

No parent, service provider, or chapter will want to be without it!

Memorials

August Caponi
Joan Hughes-Peifer

Kathy Carlson
The Arc of Warren County

Lee Echols
Lota Mitchell

Michael Gallagher
Lynn C. Krautter
Tom and Paula Wood
D. Canale Beverages
April & Michael Petros
Berclair Insurance Center
R. Lee Whipple
LandEquities

Mary Kilgallen
Andrea Danaher
Jeanette McKenna

Carl J. Kludt
Audrey & Robert Fon

Forrest W. Lovell
Buddy & Kit Welch

Stella Saacks
Roz & Mick Borger

Emily Silverman
Dr. & Mrs. Jack T. Gordon

Lynn Till
His mother, Jean Till

Janet Wolf-Mahar

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LandEquities

1998 Conference Donations
Donna Weisner

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