



The *Gathered View*

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

Our Journey to Acceptance

By Terry Bender

He's small? Low tone? Poor suck? What are you trying to tell me about my precious bundle of joy? No one plans for it, no one expects it, no one is prepared to hear "there may be a problem with your child."

Most of us who have taken the journey of getting a PWS diagnosis have heard these similar words. Now what? Where do I go....who do I talk to...where do I run....where do I hide?

In recent years families have been given their PWS diagnosis very early in infancy, unlike our families of older children and adults. Our genetics personnel have a keener eye and more sophisticated testing.

Unfortunately, many of our medical professionals do not have updated information and overload our heads and hearts with information we don't want to hear and probably don't need to hear. Much of what we are told is horrific at best and some things just are not true anymore.

I remember sitting in a cold chair in a conference room at the Children's Hospital of Philadelphia with a whole team of "experts". Then it started. "Your son has Prader-Willi Syndrome.... It's UPD; this means he received two maternal chromosome #15's from his mother...." The room suddenly closes in on me... the words run together and there is lots of medical jargon. I'm thinking "So what? Tell me what this means for my son!" Then, without time to absorb, we seem to be slammed with the signs and symptoms to expect and what our future holds.

Most is too hard to sit and listen to. I remember feeling physically ill, excusing myself from the meeting and sitting on

the restroom floor with my head in my hands wondering, "What can I do?"

I began talking to myself... "OK, he's your son! GET UP! Go figure out what to do." But my legs couldn't lift me... I was crushed, my heart aching.

I finally find the strength to go back in front of all these people to listen to more of what's in store for our family. One thing that stood out was how definite they were that *all these things* would happen. The blessing in the meeting was the genetic counselor. She had the name and web site information



In New Jersey, PWS families gathered recently at the home of Sybil Cohen

for PWSA(USA) and encouraged us to "get in touch, get informed, and talk to other families." So that's what we did!

We called National, received our packet, called our local chapter, and got busy making ourselves informed.

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We never deny parents membership for any reason.

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

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

Communications regarding *The Gathered View* or PWSA membership and services should be directed to the national office of PWSA (USA) in Sarasota, Florida.



PWSA 2003 Annual Conference

July 2-5, Sheraton World Resort, Orlando Florida

Fulfilling The Dream: Joining Together to Secure Brighter Horizons

Let's Rap About YAAP

The following is some of the programming we are planning for our *Dream Weavers* youth and adult program for those with Prader-Willi syndrome (ages 6 to 16 and 17 up) and their siblings (ages 6 to 15). Siblings 16 and older are encouraged to volunteer. Note to parents: We have a nurse coordinator on site and physicians available.

About our YAAP Co-Directors — Tad and Gina Tomaseski (The Dream Team)

Tad has been running children's and youth programs for 20 years. He has a sibling who has PWS. Tad models and is a motivational speaker in public schools across America. Tad and Gina currently pastor student ministries (ages 13-19) in Frisco, Texas. Gina is also a licensed physical therapist, professional fitness competitor and spokesmodel for MET-RX Sports Nutrition.

Tad and Gina write, "We are looking forward to making this year's YAAP program full of great memories as well as entertainingly educational, challenging our children and adults with PWS to bring greater purpose to their lives by becoming an MVP (Most Valuable Player) for the Dream Team."

About our Special Entertainer — Cindy Nelson

Through the use of ventriloquism in a fun-filled, interactive program, Cindy motivates, educates and inspires audiences to think outside the box, to begin to realize the potential that lies within them, and to become aware of their own intrinsic value. For more info visit www.insideoutproductions.org.

THURSDAY

It's getting-to-know-you time: Siblings will have their own group. Both those with PWS and siblings will have a fun morning of videos, motivational/ inspirational talks and ventriloquist events that deal with self esteem and peer issues.

Wonder Works: Thursday afternoon, buses will take all to Wonder Works, which has more than 100 hands-on interactive exhibits. (see www.wonderworksonline.com)

YAAP Banquet & Dance: All three groups — Children and adults with PWS and siblings will all have their own special banquet in the evening as will parents — then all will come together for a gala dance.

FRIDAY

Indoor carnival, movie, and the "wild and wacky room" — the three groups will rotate between all three rooms

throughout the day. Carnival games will be supplied by Absolute Amusements. More to be announced. Sea World and fireworks for the 4th of July — evening event.

SATURDAY

Crafts, entertainment — and preparation for the closing ceremony at 11:30 a.m.

...And For the Little YIPs (0-5)

About M&M — our YIP Co-Directors —

Michelle Holbrook — of Lehi, Utah did the outstanding job of chairing the Youth & Infant Program for national conference last year in Utah. Michelle has an 8 year old with PWS. She is currently teaching special education at Lehi Junior High.

Michelle Torbert — lives in Homestead, Florida and has a 5 year old with PWS. Michelle has attended five national conferences, is a board member of the Florida Chapter and on

the Board of Directors for the Little Angels Foundation.

Check Our Web Site for the latest Conference Information

www.pwsausa.org.

For the Youth and Infant program 0-5, there will be Cindy, our ventriloquist, and clowns. M&M are planning on having movie time, crafts, coloring, games and singing, some outdoor playtime in the little gazebo area, a nap room and more.

General Conference Topics

For parents and support people of children with PWS 0-5

Medical Overview for the Young Child ages 0-5 • Update on Growth Hormone Research for Our Very Young Children • The Early Years - Developmental Overview of Our Children's Sensory/Gross Motor Development and Types of Intervention • A Parents' Guide to Verbal Dyspraxia • Feeding: Strategies for Our Very Young • Sensory Integration: What You Really Need to Know for Our 0-5 Population • Fine Motor Development for Your Young Child

For Parents and Support Staff of School-Aged Children

Educating Educators About Students With PWS • Growth Hormone Therapy And Related Endocrine Issues • Behavior Management Strategies And Sleep Disorders • How Does Your Engine Run? (Sensory Integration Strategies For Self-Regulation) • Adolescent Dating And Sexuality • Speech Dyspraxia • How To Handle Food Situations At School, Work And Home

2003 Conference continued on page 14



A Special Conference During Extraordinary Times

By Lota Mitchell, PWSA (USA) President

When my daughter Julie, who has PWS, was here on a visit from her group home a few months ago, I took her as a treat to see the stage production of "The Producers." It's about the hilarious happenings when a couple guys come up with a scheme to get rich quick, illegally of course, by producing the worst possible musical show. After reading mountains of prospective manuscripts, they think they have found a real winner (i.e., loser) in "Springtime for Hitler."

Julie loved the show's marvelous dancing and singing, but I had a feeling there was something she didn't "get." When I asked her if she knew who Hitler was, the answer was no. I got out the encyclopedia, showed her Hitler's picture and then read aloud the account of the beginning of World War II. I found tears running down my face, feelings evoked from the past, because I had been a very small child at that time, living in England with my parents. The parallels between Adolf Hitler then and Saddam Hussein now were just too close. Reading that and then about the triumphant return from Germany of Neville Chamberlain proclaiming "Peace in our time!" took away all the ambivalence I had felt about the position of the U.S. toward Iraq. How many others are as unaware as Julie of history and its lessons?

Chapter View

Here's a round-up of what some of our busy chapters have been doing the past six months. If you're not in a chapter, please consider joining one in your state—or starting a new one. PWSA(USA) will help you through the process.

PWSA of Ohio is lucky to have a gourmet cook in its membership — **Sandy Guisti** — and in January a gourmet dinner was held as a fund raiser. They plan a "Skip-A-Meal" fund raiser in April, and on May 3 a Family and Friends Festival at Lake Choctaw. Contact #1-440-926-1357.

PWSA of Wisconsin again hosted its annual Hobby - Social and Training day on April 5 at Oconomowoc Developmental Training Center School and Gym, from 9 to 3. The day consisted of a morning filled with various hobbies (e.g., Sports Card Collecting, Woodworking Projects, Clothespin Figurine Creations, Bead Activities) for participants to choose from and an afternoon of dancing while parents and caregivers attended a speaker on Nutrition. Contact # is toll-free 1-866-797-2947 or E-mail to: wisconsin@pwsausa.org

PWSA of Arizona, after having a successful Walkalong in 2002, has another Walkalong/Training day on May 3 in Tuscon. These events raise both money and awareness.

My hope today is that by the time this newsletter reaches your mailboxes the U.S. will be engaged, not in war, but in the humanitarian task of rebuilding the Iraqi nation into one without the savage brutality — and threat — of Saddam's regime.

My hope, too, is that this conflict will not in any way affect people's decisions to attend the national conference. As the aftermath of September 11 so clearly showed, we Americans have always been a courageous people, determined to live our lives in freedom despite extraordinary circumstances. If we change our way of life because of fear, then the terrorists will have won. This conference is shaping up to be one of the very best, and those of you who have attended conference in the past know how terrific they all are.

There will be world-class speakers and home-grown ones with information, opportunities to share and bond with other parents and siblings, great activities and care for the YIP and the YAAP, and a marvelous gathering of the PWS family for the Fourth of July. Don't miss it! This will be special, and perhaps even more special because of the times through which we are living. See you in Orlando!

Peace.

PWSA California Foundation's Fran Moss, who has done such a wonderful and dedicated job for so many years, has retired as Executive Director of the California Foundation. Stepping very ably into the position is **Lisa Graziano**, mother of Cameron, aged 4, and by profession a family therapist. Thank you, Fran, and congratulations, Lisa! Lisa reports that California's third annual Walk Along fundraiser is scheduled May 3 in Northern California and April 27 in Southern California. Contact #s are 1-800-400-9994 (CA) and 310-316-3339.

PWSA of Michigan plans its ninth Walk-a-long for May 3. They raised \$7,000 last year and contributed it all to PWSA(USA)! Thank you, Michigan, and good luck this year.

Prader-Willi Florida Association scheduled its Spring Conference in Gainesville with dinner and socializing at the home of **Bill and Kathy Noffsinger** the evening of April 11 and speakers and YAAP activities on April 12.

— **Lota Mitchell**

WHAT'S HAPPENING with PWSA (USA) & Research?

By Janalee Heinemann, Executive Director

CoQ 10 — PWSA (USA) and the United Mitochondrial Disease Foundation are working toward a collaborative CoQ 10 research project. Teams of physicians from both organizations are trying to put a proposal together that would benefit both groups. Some of the complex issues they are attempting to resolve are:

- 1) Since most of our children with PWS are on growth hormone, how do researchers ensure they are looking at the results of CoQ 10 and not growth hormone?
- 2) Should this be a single-center study or should it be a multiple-site study? A multiple-site study would be more complex to set up, but may give us larger numbers and more comprehensive results.
- 3) Should researchers measure only functional changes or also attempt to measure chemical changes?



Executive Director
Janalee Heinemann (center)
with Correspondent Vicki Mabrey
and Producer Raylena Fields
from CBS-TV's "60 minutes II"

PSYCHOTROPIC MEDICATIONS —

Thanks to the Capraro fund-raising event, PWSA (USA) has \$15,000 designated for studying psychotropic medications. The board has voted to add another \$5,000 from the Valentine Research Fund to this amount. At this time, an RFP (request for proposal) is being drafted on studying the types or combinations of psychotropic medications that have been the most beneficial for children and adults with PWS. Our members, and the professionals they are working with, have a great need for good advice on medications that might be helpful in dealing with psychiatric, emotional and behavior issues. When do you use them? What dosage? What combination of drugs? We hope to have some better-defined guidelines through this research.

GHRELIN — At least three major pharmaceutical companies are investing extensively in ghrelin research. If you missed the CBS-TV "60 Minutes II" segment about the current research related to Prader-Willi syndrome on this hunger hormone, go to the web site www.cbsnews.com/stories/2003/03/11. Pharmacia (By the time you read this, all of Pharmacia will be under the name of Pfizer — the company that bought them out.) and Eli Lilly are involved with ghrelin research, as is another company I am not at liberty to disclose. I have signed a confidentiality statement with this company in order that we may have a collaborative relationship. Be assured, PWSA (USA) will be on the forefront of ghrelin research!

NATIONAL PWS REGISTRY —

Many physicians and researchers could benefit from a comprehensive national registry on Prader-Willi syndrome. We are looking at ways to build on our existing database to: 1) make it more reliable; 2) add essential medical information. A team will be meeting at conference to move this project forward.

RESPIRATORY CONCERNS —

Although it is too premature to give specifics here, I want to assure members that we are taking a serious look at the respiratory issues/concerns published in the March/April 2003 edition of *The Gathered View*. There has been a meeting and many e-mails to discuss how to address this issue, and we should have more to report by the next issue of our newsletter.

We welcome writings from siblings for *The Sibling View*. They can be signed or anonymous, whichever you prefer. Send them to the attention of Lota Mitchell at the PWSA (USA) national office, or e-mail to her at ljecholsm@juno.com.

Making a Commitment to Fulfill The Dream

We have good news to share with all of you!

In July 2002, the PWSA (USA) Endowment Fund was formally created by the faith and vision of the Board of Directors and the financial generosity of Dr. Paul Paolini. As you may remember, Dr. Paolini, the former president of the Prader-Willi California Foundation, generously donated \$40,000 to fund the endowment.

In February 2003, PWSA (USA) Board member and Endowment Committee Chair Rob Lutz wrote the following in a letter to PWSA Chapter leaders:

"I am the proud parent of Isabel, a 3 year old with Prader-Willi syndrome. Although realistic, I am hopeful that her future will include many options and choices that we can only imagine today. To play an active role in furthering her future, I am serving on the PWSA (USA) Board of Directors so that I can be involved in the primary national organization to support families and help build bright horizons for all those with Prader Willi syndrome.

"I am excited to tell you about a project I have been working on: the PWSA (USA) Endowment Fund. The purpose of the Endowment Fund is to create a long-lasting financial base for PWSA (USA) just like the endowments that colleges and other charities build. PWSA (USA) will benefit from the income and security that comes from having a permanent endowment fund.

"Currently, PWSA (USA) depends on contributions from individuals, chapters and corporations to fund all its activities, including running the conference, creating awareness of Prader Willi, resolving crises, supporting the chapters and promoting research. As the activities and financial needs of the national office have expanded and matured, the PWSA (USA) Board concluded that complete dependence on annual giving was risky and inappropriate. And I personally believe that PWSA (USA) needs to increase its financial footprint in order to continue to provide outstanding services to families in need of information and support while expanding its role in funding promising research. An endowment fund can help make that possible.

"An endowment fund is a base of permanent capital that is invested rather than being used to fund operations. As that invested capital generates returns, those returns (but not the principal itself) can be used to support an organization's goals and mission. The Board's intention is for the PWSA (USA) to develop a permanent endowment fund that creates annual income for PWSA (USA) and helps to offset a portion of the annual expenses.

"In addition, many donors prefer giving to an endowment because the gift is permanent and will contribute to PWSA (USA) forever rather than being used in one year. The Board is pleased to provide expanded options for potential donors.

The PWSA (USA) Endowment Fund

- The Orlando Conference will be the official kick-off of the PWSA (USA) Endowment Fund
- State chapters and loyal supporters will develop events and fundraisers specifically to provide for the PWSA (USA) Endowment Fund
- We will encourage honorary gifts and bequests which are well suited for the PWSA (USA) Endowment Fund due to the permanence of the gift
- We will have special events and targeted campaigns to fund the PWSA (USA) Endowment Fund

Our next step is to raise capital for the endowment fund. We intend to have a multi-pronged approach.

"We hope you will join us in our enthusiasm about the PWSA (USA) Endowment Fund and work with us to make it a success and to leave a legacy for all Prader-Willi families now and in the future."

Rob's letter begins to lay the groundwork for a very special challenge that stands before us as we fulfill the dream of securing brighter horizons for all of those impacted by PWS. The challenge for all of us is in building the PWSA (USA) Endowment to provide for the security of our programs and to guarantee our expanding role in promising research.

We have more than \$50,000 in the PWSA (USA) Endowment Fund. By the end of this year, with your help and the help of new friends and donors to PWSA, we hope to double that amount. After the official kick-off at our July conference, you will be receiving more information about the PWSA (USA) Endowment Fund and the role that you can play in working with us in building it. This is an exciting time for PWSA (USA) and its entire membership!

CIBC WORLD MARKETS

Miracle Day Fund-Raising Campaign

With a special thank you to the INVESCO
co-workers of Mark Greenberg
who gave in honor of his son, Zachary

Would you like to raise funds for PWSA (USA)?

Call Diane at 1-800-926-4797 and ask for a free fund-raising packet.

For the Love of A Brother

By Glenna Kanish

At a get-together of the [then] Western Pennsylvania Prader-Willi Syndrome Support Group at the Children's Institute in Pittsburgh some time ago, the topic came up concerning sibling relationships.

In our family, Zach, age 17, is the older brother of Luke, age 15, who has PWS. I was pleased to share with the group that Zach is proud of his brother and tries to include him in whatever activities he can.

Zach, as a coach of the junior girls in Powder Puff football, appointed Luke the water boy. In our hometown of Ford City, Zach and Luke are on the same bowling team on Saturday afternoon. When Zach has his peers over to our home, Luke is right in the midst of the festivities. Zach also takes Luke to basketball games at the high school and then to the dances that follow, after helping Luke pick out his attire and the best-smelling cologne.

Now that Zach's senior year is quickly winding down, he is looking toward leaving home and heading off to college. We were not surprised when Zach announced that he wanted to be a Special Education teacher. He has been a buddy for Special Olympics; a summer counselor at Camp Sunshine, a local summer camp for the physically and mentally challenged; and has an independent study course with one of the Life Skills classes at our high school where he observes, aids, teaches and researches exceptionalities.

I'm pleased to share Zach's senior essay with our national Prader-Willi family.



Zach Kanish and his brother Luke, who has PWS

One Day in My Shoes

By Zach Kanish

Sometimes when I lie awake in bed thinking about my problems, I hear my younger brother's voice or his bed creak as he rolls over, and my outlook on life takes a total 180-degree turn.

Luke was born with a birth defect called Prader-Willi syndrome. The piece missing off the 15th chromosome causes Luke to feel that he is always hungry. He could eat a five-course meal and be ready for the next meal five minutes later. Luke has difficulty learning. He reads at a third grade level and struggles with basic math problems, even with the help of a calculator. He was delayed in the milestones of a baby's life like crawling, walking and talking. My mom tells me that his muscles were so weak that he could not suck on a bottle. Many hours were spent forcing Luke's tiny facial muscles to take a bottle.

Luke inspires me. In spite of his struggles, Luke is always happy. The experiences that I take for granted day in and day out are the highlights of his life. Everyone is Luke's friend. In the morning at school before the bell rings, Luke doesn't go to the first floor to talk to his peers; he is found on the third floor talking with my friends. He only sees the positives in the people that he comes in contact with.

I would give anything to let Luke live in my shoes for one day. He would love to play football, drive a car, go out to eat with friends, or even something simple like read a book all by himself. Luke taught me to never quit when things aren't going my way and to do everything to the best of my ability. When Luke is doing his homework and he can't seem to get the math problem right or find the answer in the book, he keeps on trying until he finds the solution.

Sometimes people ask me who my hero is and I reply, "my little brother." Luke might look up to me, but he doesn't know that I look up to him also.

The Chuckle Corner

"Erin quotes" are our major source of entertainment around here. She's just about to turn 7, and as she says, "Mom, I'm growing up and there's nothing you can do about it!"

Somewhere in the discussion of her birthday over the last several weeks, Erin, in her unique, dramatic form, suddenly said, "Mom, You've been in this old world a long, long time, haven't you?"

Insert pause in which Mom purses lips, raises eyebrows, sighs deeply and says nothing, but then just laughs.

Rachel Tugon, Louisville, Kentucky



Do you have a joke or funny story to share with us? Please send it to the PWSA (USA) office. Be sure to include your name, phone number and address in case we have any questions.

Horseback Riding



By Janice M. Agarwal, P.T.

Horseback riding has long been considered an enjoyable activity for people of all ages and abilities. The benefits of therapeutic riding, both physical and emotional, have been recognized for individuals with disabilities for centuries. Horseback riding for rehabilitation has been used formally in Europe for more than 30 years and continues to grow in popularity as the therapeutic value of the horse is recognized throughout the medical community.

What is therapeutic riding?

During a therapeutic riding session, a riding instructor teaches riding skills. Therapeutic riding is for adults and children (usually older than 5) who have the physical ability to control a horse. Although many programs use therapists as consultants, therapeutic riding is not a treatment; it is a recreation program.

In addition to the recreational pleasures of horseback riding, therapeutic riding promotes social, emotional and physical benefits. Horseback riding has a calming effect and often helps a child/adult relax. For some, taking time to enjoy a ride and getting away from traditional exercises and machines may be what keeps them going. Horseback riding is also a very normalizing and equalizing activity, giving people with disabilities the opportunity to participate and succeed at something that others may hesitate to try. It gives them the opportunity to socialize and be with others who not only have similar problems but similar interests, such as riding.

Horseback riding also encourages the rider to interact with the horse. Individuals with delayed language or other language problems are encouraged to give the horse the necessary commands, such as "go" or "walk." Riders learn the benefits of meaningful speech; when they speak to the horse, they get results. This, in turn, stimulates additional interaction and speech.

The motion and heat of the horse during riding improves the rider's blood circulation and muscles. The horse's three-dimensional movement provides a natural rhythmic and progressive combination of sensory and neurological input that can be used to address a variety of disabilities. These movements cannot be duplicated by traditional exercise or by machines that typically work on only one muscle group at a time. If you've ever ridden a horse, you can attest to the fact that riding exercises a wide variety of muscles, including muscles you don't even realize you have!

Horseback riding can exercise portions of the body that often remain unused or are not working normally. Therefore, riding can serve as an alternative to muscular therapy or exercise equipment, especially for those who are tired of performing the same exercises in the same room with the same equipment, day after day. Horseback riding provides a rich, motivating, therapeutic environment by combining the fresh air of the outdoors with the emotional contact and movements of a horse.

Riding a horse involves moving a rider's trunk, arms, shoulders and head, thereby improving posture, and toning the muscles of the abdomen and arms. All of these movements result in increased strength, flexibility, and mobility, as well as improved balance and coordination (staying atop a moving horse is a high motivator for maintaining one's balance and posture).

What is hippotherapy?

The term "hippotherapy," from the Greek *hippos* for horse, means treatment with the help of the horse. A specially trained physical, occupational or speech therapist, in conjunction with an experienced horse handler, uses a horse as a mobile therapeutic tool to treat patients as young as a child unable to support himself in a sitting position. The action of the horse, coupled with traditional therapy, stimulates muscle tone, mobilizes joints, activates muscle action, increases sensorimotor integration and develops balance and equilibrium reactions. Improvements in cardiopulmonary function may lead to improved speech production and cognition. The movement of the horse is the tool the therapist uses to improve a client's overall neuromotor function. Whereas in therapeutic riding, a rider influences the horse, in hippotherapy, the horse influences a patient.

The primary focus is development of a rider's posture (pelvis/trunk/neck/head) and movement responses. The child may be positioned on the horse facing forward or backward while seated, or in quadruped, tall-kneel, half-kneel, squat, stand, prone, prone on elbows or supine. The child interacts with, and actively responds to, the horse's movement. The therapist constantly analyzes the child's responses and adjusts accordingly the manner in which the horse is moving. For this reason the therapist must have sufficient understanding of the movement of the horse to direct the experienced horse handler to alter the tempo and direction of the horse as indicated by the child's responses.

Hippotherapy takes place in a unique environment in which sensory input can be manipulated and graded to elicit appropriate adaptive responses from the child. While riding, the patient will be exposed to varied gait patterns, may be given objects to grasp, or may be asked to perform a task. Hippotherapy does not teach specific skills associated with controlling a horse. It provides a foundation for improved neuromotor function and sensory processing that can be generalized to a wide variety of activities outside treatment.

Although hippotherapy is frequently used to achieve purely physical goals, it also affects psychological, cognitive, social, behavioral and communication development. As an example, while the horse is moving around the arena, a child may be asked to change from facing forward to facing

for All Ages

backward and then to quadruped (kneeling on their hands and knees), all while working on petting the horse or grabbing rings. In addition to working on automatic postural responses and stimulating the trunk and arm muscles, the therapist has also challenged the sensory system, the vestibular system, and proprioceptive system (heavy tactile pressure through the knees, hips, wrists elbows and shoulders while in quadruped). This is a very meaningful activity for children who exhibit trunk weakness, poor pelvic control, decreased gross motor skills, poor motor planning and a diminished ability to process sensory information.



Agarwal enjoys hippotherapy

Occupational, or Speech Therapy, it will cover hippotherapy. The horse is merely a tool, just as a ball or bolster used for strengthening the trunk. Insurance is not paying for a hippotherapist, it's paying for PT/OT/SPT that happens to use a horse as a therapy tool. This is similar to an OT working on sensory integration. Insurance pays for OT, not SI. For physical therapy services provided under the diagnosis code for Prader-Willi, Hypotonia (759.81 for Prader-Willi syndrome), a treatment code of 97110 (Therapeutic Exercise, 15 minutes x 2) would cover a 30-minute treatment. You need to check what diagnosis code (ICD) and therapy services code (CPT) you would be using, and if insurance covers PT, OT or SPT under that diagnosis.

What should you look for in a horse?

(Adapted from Elizabeth M. Cannon, Therapy Equine Coordinator, Intercollegiate Riding Coach, Equine Massage and Energy Therapist.)

It takes a special horse to fulfill the therapy needs of human riders and patients. Once therapy horses settle into their jobs, they are usually very trustworthy and reliable. Horses often enjoy the influence they have on their riders. Riders should be paired with complimentary horses, and proper equipment should be used.

- **Temperament and Personality** - Therapy horses should be patient, willing, gentle, tolerant and non-aggressive toward humans and other horses while working. They should have good ground manners, be able to be easily handled by many different types of individuals, be able to stand for long periods of time, and be tolerant of the many people and toys/tools that are involved in therapy.

- **Conformation** - Appropriate physical attributes of the horse (good conformation) include straight legs, correctly angled pasterns and hooves, a neck proportionate to the body, and a back length that is neither too long nor too short. The head should not be much longer than the length of the neck. Muscles should be well toned and top-line straight. A well-conformed horse moves smoothly.

- **Age** - Middle-aged horses (10-20 years) are usually ideal. Extremely old horses (over 25) wear considerably due to job stress and are more susceptible to ill health and lameness. Young horses (under 7) can be spooky, high strung, and are often inattentive.

- **Size** - Ideal therapy horses are not big but not too small. They should not be much taller than shoulder height to keep riders accessible to side-walkers. Pony-sized equines are too small, both for side-walkers and riders (and ponies move differently than horses).

- **Sex** - Stallions are not suitable for therapy programs. Although mares can be hormonal, they can work well in the therapy setting.

What are the requirements?

The recommended minimum age for hippotherapy is 2 years. Younger children require horses with well-integrated movements and smaller displacement. The effects of repetitive movement on the developing spine of a young child are unknown. Sitting balance is not required. Horse movement can be an effective tool to help develop sitting balance. As a general rule, the horse should not carry more than 20 percent of its body weight (see NARHA Guidelines). Although larger horses can support larger riders, heavier persons may not be candidates due to increased risk for falls during mounting and while mounted and to increased stress on the therapy horse. Medical contraindications include fixed scoliosis, unstable spine and unstable internal spinal hardware.

Is this covered by insurance?

Therapeutic riding is considered a riding lesson and is not covered by insurance. If your insurance pays for Physical,

Riding continued on page 14

Does a Child With Disabilities = A Disabled Marriage?

By Janalee Heinemann, Executive Director

"Don't let one tragedy multiply into other!" warned Dr. Michael Kaback of Torrance, California in a speech at the 1985 Missouri Genetic Conference.

It helps to cope with the disabilities of our children if we can minimize the other stressors in our life and have a good support system. Often though, the "domino effect" begins gradually after the birth (or diagnosis) of a child, and over the years, we find that our relationship and our house comes tumbling down.

Does the tragedy of the disability x the personal trauma to each parent x the stress between a husband and wife automatically = a disabled family system?

When our son Matt, who has Prader-Willi syndrome, was 7 and I was considering marrying his father Al (who had custody of Matt), I had to seriously contemplate the answer to that question. Fortunately, I have found the answer is no — as long as you put the same effort into yourself, your relationship and your other children as you do your child with a disability.

Although Matt is now 29, the need for a good relationship and a life of meaning and joy is still the same today as it was when he was 7. So I have been asked to reprint the following survival strategy that I wrote many years ago, which we tried to live by during the "best of and worst of" years.

Absolve Yourself Of Guilt

Parents are people too and have a right to their own lives, even if they have a child with a disability — especially if they have a child with a disability. As a person who has to deal with more daily stress than the average parent, you need to make time to replenish yourself. Notice, I said, "make time," not "find time."

With five children, two grandchildren, both working full time, and doing volunteer work, Al and I have found that we have to continually be conscientious about prioritizing our time. This may mean the car never gets waxed, the oven seldom gets cleaned and the TV never gets watched. It also means that sometimes our children get "neglected" for the sake of our personal time together.

But we feel that if we don't nurture ourselves as individuals and as a couple, we cannot joyfully give to our children.

Take A Good Look At Your Stress Factors

It helps to know where the enemy lies rather than have a vague feeling of being bombarded from all sides. We periodically take count of what our stress factors are.

Last year, we had many unforeseen and unavoidable crises. We were able to take count and say, "No wonder we are feeling stressed — we should be!"

Then it was a matter of deciding on survival tactics and reminding ourselves that this too shall pass. This year, life is going much smoother. Now, when we are feeling stressed, we take count and usually find we are getting uptight over minor things that just aren't worth getting upset over.

Share The Parenting Role

One of the things I love about Al is how good he is with his children. Raising Matt and Sarah alone before I came into his life, he had to learn to play a strong parenting role. But I have seen fathers who are fearful of their children with PWS. It is important that mothers allow the dads the opportunity to play and bond with their children. I've seen fathers get turned off to their children because of their wives. Every time the dad picks up his child, feeds him/her, etc., the mother is constantly right there, telling him how to do it.

When a child who has a disability, there is even more potential for this to happen. One mother said it well when she wrote, "Personally, I found it very difficult (and still do) to not tell my husband what needs to be done, how rough he is, how he is really messing up 'the schedule,' etc. I have to bite my lips and turn away. I've had to leave a room when my son was crying, knowing that I could stop him in a second but it wouldn't help his Dad learn. I've watched while he threw him in the air, fearful of my son falling and yet knowing that he was giggling and having a great time and so was dad, it was my fear. When dad has the kids for a day the schedule is off but truthfully, he has learned so much and the kids have had a great time. None of this would have been possible if I had been nagging him about how to do things *properly*."

Savor The Good Times

It is easy to get caught up in "ain't life awful" and not really appreciate the good times (or what could be good times). We often worry about what will happen next week, next month or next year — and don't really appreciate today.

To get the most out of each day, you must be willing to be flexible. If it's a beautiful day outside, will you drop your project of cleaning out the garage to take a long walk together with the kids? Are you willing to give up your nightly TV program for an hour together in the bedroom where you can talk about the day over a glass of wine?

Sometimes Al and I remind ourselves and recite to each other what we are thankful for. (Of course, this is easier to do when we are out alone for dinner, and the kids, the house and the bills are at least 10 miles away!)

Don't Take Your Relationship For Granted

A good relationship won't stay good without a lot of time and effort put into it. When you have a child with disabilities, your entire life can easily become wrapped up in that child, with everyone else taking second place. It takes a lot of effort to keep a marriage nurtured, but most of us were willing to put that effort in when we were dating. Without nurturing the relationship, it is easy to forget why you got married in the first place. Besides prioritizing our time, we made a pact to never go to bed angry. This may mean a long, late night "discussion," but little hurts build into major problems if they are not dealt with. Besides, what is your alternative? A bad marriage can be the loneliest place in the world.

Marriage continued on page 11

Look What Our Kids ARE Accomplishing!

By Vickie Fetsko

After talking with so many doctors, therapists and agencies, I found that it was very easy for me to get emotionally “stuck.” I kept thinking of all the things my son Jason, now 2 ½ years old, couldn’t do.

At times I even wondered whether my “perseveration” (a behavioral problem where the child/adult gets stuck and repeats an idea, thought, emotion, or movement — a behavior common in PWS) could be genetic, and whether I have passed this onto my son regardless of the Prader-Willi syndrome diagnosis.

Fortunately, the more I read and the more I listened to other parents, I was able to focus on the excitement in their voices telling me of various accomplishments. Then for me, those times of getting stuck became few and far between.

I’m not kidding myself, though; at times I will still compare my children, special needs or not, in varying degrees with other children and their development. But the next time you are watching your child play and start thinking “he/she should be doing...,” shut your eyes, open, take another look and smile. See what your child *has* accomplished. Here is a comical example of taking another look at a situation.

During dinner one night as I was in the kitchen fixing my plate and hoping to have at least a luke-warm dinner, I heard, “Mom, Jason ate all his food and he’s trying to get more off my plate.”

I turned the corner just in time to see Jason with his toddler spoon trying to scoop food from his 6-year-old brother Jonathan’s plate. Jon had his right hand and arm up in a defensive move to keep Jason from getting to his target. As I got closer, Jason proceeded to hit Jon on the top of his head with his spoon. Jon’s hand went straight to his head while



Jon and his brother Jason, who has PWS

simultaneously announcing his complaint to me.

At this time, Jason made his move, scooped up some food, and in a split second it was in his mouth.

I shut my eyes, opened them, took another look and smiled. Because Jason had mastered:

- Problem Solving - I want his food, how can I get it?
- Cause and Effect - What do I need to do to get Jon to move his arm before Mom gets here?
- Fine Motor and Gross Motor Development - He had to hold his spoon tight enough to hit with and get his arm high enough to hit the top of his brother’s head.

Result? Goal accomplished!

Of course Jason got into trouble for two unacceptable behaviors: taking food from someone’s plate and hitting his brother. But with my second look that day, I was so tickled by all that he had accomplished that my cold dinner tasted a little better, even enjoyable.

Vicki Fetsko and her family live in Grafton, Ohio. Husband Steve is president of the Ohio Chapter of PWSA (USA).

Marriage - continued from page 10

Get Physical

We’ve all read of how important it is to relieve stress by getting regular exercise. Al works out, and I swim at a local health club. We always feel better when we exercise regularly 2-3 times a week, but I have to admit that sometimes we have more difficulty prioritizing this time. (Once it was so long between visits that I forgot my locker combination.)

Physical fitness is certainly good for our health. But when I see other swimmers trying to beat the clock, instructors shaming members for their body fat and racquetball players collapsing on the floor, I wonder just how stress reducing this is when it becomes just one more area in which we have to compete or feel like failures. Personally, I have never let one of those instructors touch my body fat, and I use swimming as a way to relax and meditate. For Al, swimming isn’t relaxing — just a means to keep from drowning. As for me, in this era of jogging, I am proud to say I have never run a block in my life. It’s all in what turns you on and your tension off.

Speaking of what turns you on, how hard do you work at turning each other on? “Getting physical” also means

touching each other a lot, holding hands, kissing and making love even if it’s not Saturday night. It’s amazing how many couples feel it’s okay to fight in front of the kids, but not okay to snuggle and hold hands in front of them!

Couples often are at different places sexually when they are in the early stages of grieving. Typically, the husband finds comfort in making love, where the wife may have diminished sexual desire. It is important to address your different sexual needs openly and come to an open agreement on what you can do to meet each other’s needs.

Cry A Little, Laugh A Lot, Be A Little Crazy

Living with any child with special disabilities, there are going to be times when life seems overwhelming and you’re hurting — for yourself and your child. It’s okay to cry. It’s even more okay to cry together.

But even in the worst of situations, you can often find things to laugh about. What’s funny about Prader-Willi

Marriage continued on page 13

SECURITY ALERT, PWS Style — An Alarming Situation

By Teresa Kellerman

Security is an issue in many families raising children with Prader-Willi syndrome (PWS). Most children with PWS need close supervision at all times. Many will require very close supervision that is beyond what a human being can reasonably provide in a family setting.

Security is an issue for the obvious reason that individuals with PWS cannot control their appetite. It is as if the hypothalamus is in starvation mode, and the person will do anything and everything to get food.

This can be life-threatening, as individuals have been known to suffer early death due to heart failure from obesity, complications due to diabetes, ruptured stomach, or choking on unauthorized food. There are also issues where people with PWS have run away, which places them at risk if they are unsupervised in the community. They lack control over their impulses, have very poor judgment, and are naively vulnerable to the suggestions of others.

Some children get up at night and engage in risky behavior. For whatever reason, there are many families who want to know how they can possibly provide 24/7 supervision without giving up sleep and trips to the bathroom.

I'll never forget my horror at discovering my daughter's repeated attempts to go shopping in the middle of the night by climbing out of her bedroom window. She would manage somehow to get \$10 or \$20 and would hide it in the inner sole of her shoe. Then she would wait until 2 in the morning to walk to the 24-hr. supermarket over a mile away to get all the sweets and goodies her money could buy.

The weight gain would be serious enough. But I was truly concerned for her safety, as she was a trim 110-lb. teenager with long blonde hair. I still shudder to think about it.

The easiest way to monitor children's behavior is with alarms. There are several types, and many are not expensive at all. Here are some links to products available online:

Radio Shack: <http://www.radioshack.com/> Click on "Security and Home Automation" on the left, and click on "Personal Security." There are 17 products in the Personal Wireless section. Some families may also want to check out the section on Surveillance for monitoring products as well. I use the wireless motion sensor alarm in the refrigerator and in the hallway by the bedrooms.

The Alzheimer's Store: <http://www.alzstore.com/> Click on "Safety" for a listing of 22 products, including a car battery disconnecter and faucet adapters to prevent bathroom flooding. They also have an 800 number you can call to discuss what type of alarm might best suit your needs. One parent's favorite alarm is the Motion Detector and Remote Alarm (Product #0025), where both the alarm and the receiver can be moved, and they operate on battery power.

If you are feeling guilty about this, know that you are not alone, you are not a terrible parent. You just want to keep your child safe.

Baby Universe: <http://www.babyuniverse.com/> Click on "Safety" on the left to find products for homes with younger children, like a toilet lock for \$5.99, or a Listen N Talk Monitor for \$59. Actually, the baby monitors can be used for older children too. I have one from Fisher-Price that I still use from time to time.

Clean Sweep: <http://www.cleansweepsupply.com/pages/subsection1132.html> Get a 160-degree mirror to keep an eye on what is going on behind you. If you want to have eyes in the back of your head while you are on the computer, get the portable clip-on mirror — very inexpensive.

AV Tech: <http://www.avtechsolutions.com> Find hi-tech equipment here, like a wireless night-vision camera system that can monitor several rooms. It's on sale right now, 50 percent off. Click on the "Baby Monitor" link.

Safety and Security Center: <http://www.safetyandsecuritycenter.com/> They have a tracker watch that can help to locate a runaway child.

Micro Tech: <http://www.surveillance-equip.com/surveillance2.html> You can purchase a tracker device to track a runaway child. The transmitter is small and could be attached to a shoe or cap or backpack. Very expensive, but I know families who have resorted to a wrist device that the child cannot remove, used by court order as part of probation, to help parents keep the child safe from his own lack of control and poor judgment.

Maybe you won't ever need a tracker, but a \$20 motion detector can be a life saver for the child who climbs out of the window in the middle of the night.

If you are feeling guilty about this, know that you are not alone, you are not a terrible parent. You just want to keep your child safe. The discomfort of installing alarms is minor compared to the discomfort of hiring a lawyer or spending the night in the ER, or going to a funeral. The bottom line is, Keep Your Child Safe.

Teresa Kellerman of Tucson, Arizona is the mother of Karie, 28, who has PWS.

syndrome? Come to a PWS support meeting or conference and you will find out. The day your child got caught with his pockets full in the Brach's mixed candy section of the grocery store may not have been funny at the time, but can bring shared humor at a group meeting.

I have worked with people whose children have cancer. There is laughter at their meetings also. A sense of humor is essential to one's mental health. It helps to be able to laugh at yourself and with others. (I do want to note here that this usually only becomes possible with time. Young parents are often shocked at what parents of older children with PWS can laugh about.)

Take Control Of Your Life Again

When you have a child with Prader-Willi syndrome who is sometimes out of control, and whose destiny you can't control, it is easy to lose a sense of control yourself.

Acceptance - continued from page 1

Our first contact was with the V.P. of PWSA(USA) and Parent Mentor Coordinator, Carolyn Loker. *What a breath of fresh air!* Words can never do her justice. Her heart is the biggest I've ever encountered. She helped us to see through all the symptoms and to see our son Austin more clearly. First and foremost, he is our little boy who needs love and attention, and he happens to have PWS. Truly a SPECIAL WOMAN. Her constant reminder — we are not alone and we will never be alone. She never wavered in her belief that we, as a family, could "handle" this.

She assigned me to a parent in New Jersey, Sybil Cohen, who has a 6-year-old daughter with PWS. And suddenly it started... our journey of acceptance. Opening our hearts and home to people who are taking the same journey. We involved ourselves in the e-group from PWSA(USA) and met many families. All of us telling our stories, giving our best advice and encouragements. Many making special contacts and bonds that will now last a lifetime. I've met my best friend ever through PWSA(USA)... a friendship never to be broken.

Each day you wake to PWS... everything is PWS. It's all you can think of. As time passes, the tables turn... each day is just a little less PWS and a little more Austin... till somehow it happens. "OK, Austin has PWS — we can do it." Our days are still filled with PWS... therapies, specialists, appointments, etc., but it's become part of our life and routine. This is what we do so our son can be the best he can be.

PWSA(USA) opened our minds and hearts, which lead us to our wonderful state of well-being. It's what we had to do. Now, as a parent mentor for the state of New Jersey, I get a great deal of satisfaction in helping new families prepare for their journey.

It happens in different ways and at different times for everyone. All of our children each have their own special concerns and needs, each as different as any other "typical" child.

No, life has not been fair and there are some things that wallow in how unfair life has been to you and your child, or you can pick yourself up and decide how to make the best of your situation. What can you do differently? How can you find some happiness in each day? How can you give some happiness each day? Do you forgive yourself when you have not handled your child as well as you would like? Do you forgive your spouse when he/she does not handle your child as well as you would like? Do you take your anger over the situation out on those you love? What can you control — and what is beyond your control?

Our personal strength and the strength of our relationship can grow out of difficult situations.

Remember, the best thing you can do for your child is to have a good relationship with your spouse and to show your children how to enjoy life. God has not put you on the earth to suffer with your child, but has given you a challenge to find your way above the suffering.

We recently had a small gathering in New Jersey at the home of my parent mentor, Sybil, and nine families attended. Our children ranged in ages from 2 months to 8 years. It was refreshing to sit in a room with people who take the same journey and it feels safe. We can ask any question. It gave many of us hope for a future full of joys. Our plans are to do this on a regular basis and form a bond of hope, love and understanding.

I would encourage many to try to get your local chapters active, inform the general public, and become pro-active in getting our medical professionals to get up-to-date on what is going on with our children who have PWS.

I can't thank National, Carolyn, Sybil, and all my new friends enough for holding us up along our journey to acceptance. Finding people in our area, meeting with each other and seeing we are all just regular people who now take the same journey is uplifting. If we all can walk with each other, united, we can do miraculous things for ourselves, each other, our families and most importantly our children.

I will never forget my first phone call to National and how blessed I was to have Carolyn Loker to give us direction and send us on our way, empowered to handle anything. Sybil, my parent mentor, allowed me to open my heart to her about all my worries. And my best buddy ever, Tina, who listens to my every gripe and whim! My message here is to please allow yourself to receive the gift of acceptance through other families and mentors.

Although miles separate many of us, PWS can bring us together as a "family" — always there to lend an ear or helping hand. I wish everyone a blessed transition into this new world we now live in.

Terri Bender of Woodbury, New Jersey is mother to sons Adam James, age 5½, and Austin Jacob, 16 months, who has PWS, and wife to Jim.

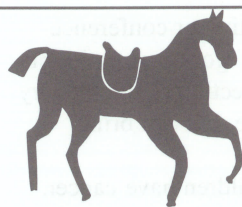
- Health - Horses should be free of major health problems and have regular vaccination/examination/de-worming schedules. They should have their feet trimmed regularly and be on a proper diet and feeding regimen. For the psychological well-being of the horses, they should have regular turnout periods (time outside of therapy work).
- Previous jobs/uses - A horse's former job or particular training may affect behavior, attitude and physical condition. For these reasons, it is helpful to obtain the horse's full background.

What should you look for in therapists and instructors?

For hippotherapy, PTs, OTs and SPTs should have a license to practice, maintain professional and general liability insurance and be trained in the principles of hippotherapy, equine movement and equine psychology. Therapists should have a thorough understanding of the effects of neuromuscular, musculoskeletal and cardiopulmonary dysfunction on growth, motor development and function.

For therapeutic riding, instructors should be certified and well educated in special needs and equine issues. They should practice proper safety standards and be able to defuse a situation that is becoming unsafe. They should maintain a positive, easy-going attitude, respectful of animals and riders.

All therapists and instructors should make riding fun while challenging each rider's individual capabilities. Evaluate several facilities and instructors before choosing the team that will work for you. Talk with instructors to learn about their experience and teaching philosophy. Ask about specific therapist-recommended needs for the patient or rider. Take a tour of the facility, paying close attention to the condition of equipment and the condition of the horses. Make your final decision only when all of your questions have been



answered and you feel completely comfortable with the instructor, staff, facility and horses.

Much of the background information for this article is taken from North American Riding for the

Handicapped Association (NARHA) training manuals.

Horseback riding is for everyone — take the time to enjoy it.

A special thanks to Lesley Lautenschlager, MS, OTR, who has worked with my Alex since he turned 2 and taught me so much about hippotherapy and therapeutic riding. Lesley is the founder of TheraAplay Therapy Services in Carmel, Indiana. She is a NARHA Advanced Certified Instructor, on the Board of Directors for the American Hippotherapy Association and is active with the Indiana Therapeutic Riding Committee.

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Janice Agarwal is a physical therapist specializing in the needs of young children. Her son Alexander, age 3, has PWS. Janice serves on the PWSA (USA) Board of Directors and volunteers in the Parent Mentoring Program.

Praise For Our PWSA National Office Team

What a beautiful remembrance of Tim. Thank you so much for giving to our family the crystal plaque in Tim's honor. I cried! It makes me so proud to know you remembered what Tim did (behind the scenes) to help so much with PWS. Your thoughtfulness and caring is appreciated more than you know.

Tina - continued from page 15

Tina had a good life, but it is still was hard to let my little sister go. I love her so dearly and I always will.

Some people do not understand those with disabilities. They run or hide in fear of talking or seeing a person with a handicap, whether it is a mental, physical or an emotional disability. The people who judge them or run from them are the ones who are missing out in learning from these wonderful people. Tina had a wondrous giving ability. I have learned so much from her. How to love all people, how not to judge those who need help, how to love the animals of the world that God has given to us, and most of all how to love yourself no matter what.

*Barbie Riggs Kelly
Georgetown, Kentucky*

2003 Conference - continued from page 3



For Parents and Carers of Adults who have PWS

Social Aspects Of Teaching Kids To Be Cool • Residential Options And Models • Staffing Group Homes: Training And Parent Involvement • Community Involvement • Behavior: Temper,

Obsessive And Self-Absorption • Law Enforcement And Legal Episodes • Models And Jobs That Work Barriers In The Workplace • Social Support And Guardianship Issues For Adult Siblings • Impact On Siblings And Families In Transition • Adult Growth Hormone • Aging Of Older Adults Who Have PWS: Aging 35-50 Years • Behavioral Medications • Respiratory Concerns And Sleep Apnea

**We look forward to seeing you
at the 2003 Conference!**

We Remember

Tina Riggs

Let me tell you about my sister Tina. Tina was born 1 month premature and was a very tiny baby, weighing only 4lbs 7oz. As a baby she would eat very slowly would need to be fed every 2-3 hours. Tina grew very slowly and did not have much motor development. She was 18 months old before she walked. Tina was also born with a diseased kidney that was removed when she was 3. By the time Tina was 4 she began to gain weight and always wanted to eat. We noticed that she developed an attitude also, but we thought that was normal for a 4 year old.

But the attitude was even more noticeable when she



was a teenager. Tina never lost an argument. She was ready and willing to argue with anyone at any time.

She was also a very loving child with greatness in her heart. She would cry for no reason only to release what she couldn't express. She loved babies and animals.

She loved our mother very much. She always wanted to know that mom was OK. If Tina had any problems or difficulties, she would call me to help resolve them.

Our family saw Tina as a blessing, not a problem or something that we wanted to hide. Tina worked in centers for handicapped citizens and was proud of the money that she earned. She would buy all of the nieces, nephews, great nieces and great nephews Christmas gifts every year with her own money. Tina loved to go Christmas shopping.

Tina never complained about hurting or feeling bad. She would always say, "I'm fine." Tina's one kidney began to fail and her body filled with fluid. She developed pneumonia and went into the hospital.

By the second day in the hospital she developed

another disease called ARDS (Adult Respiratory Distress Syndrome). Within three weeks of staying at the hospital Tina passed away. She died on February 8, 2003 at the age of 37.

Tina continued on page 14

Angel Fund Contributions

February to March 2003

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Arch Angel (\$250-\$499)

Lovelinda & Domingo Cheng

Angel (\$100-\$249)

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Prader-Willi syndrome (PWS) is a birth defect first identified in 1956 by Swiss doctors A. Prader, H. Willi, and A. Labhart. There are no known reasons for the genetic accident that causes this lifelong condition, which affects appetite, growth, metabolism, cognitive functioning and behavior. The Prader-Willi Syndrome Association (USA) was organized in 1975 to provide a resource for education and information about PWS and support for families and caregivers. PWSA (USA) is supported solely by memberships and tax-deductible contributions.

