



The Gathered View

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

Andy Works Hard to Make His Dream Come True

By Bronnie Maurer

In the spring of 2001, my son Andy Maurer, age 43, told readers of *The Gathered View*: "My dream is to go to the 2002 International Special Olympics in Ireland. I hope I make it..."

He has!

Andy has been selected as a member of the USA Equestrian Team, and he will be traveling to Dublin, Ireland in June 2003. Andy and Melissa Thames, both residents of Prader-Willi Syndrome group homes in Batesburg, South Carolina operated by Babcock Center Inc., are two of three nominees selected from South Carolina for the USA Equestrian Team. Andy will be competing in three events at his skill level: equitation, dressage and English trail.

During the year leading up to the Olympic games, Andy and his team mates will take part in many events, including personal appearances and fund-raising, in order to raise the approximately \$15,000 needed to get to Ireland. This amount covers training, uniforms, travel, meals, lodging and personal equestrian equipment necessary to compete in the Games.

Andy and Melissa will continue their weekly training lessons and will also attend training camps — two in South Carolina, and a southeastern team building session in Georgia. At the camps they will train in team sportsmanship, socialization with the southeastern region athletes and families and train in equestrian sport, said Lewis Dyer, South Carolina Special Olympics Equestrian Sport Head.

"These athletes have a once-in-a-lifetime chance to show the world the talents and skills they have developed in the equestrian sport. But more importantly, they will show the world how people with special needs from all walks of life can live and compete together in a peaceful atmosphere, helping each other along the way," Dyer said.

Andy and his 29 South Carolina Special Olympics team mates representing several sports were honored this summer. Each was presented with a Certificate of Achievement for becoming a member of the team by South Carolina Governor Jim Hodges.

When Andy first began riding, he needed a leader and a

side walker, but now he rides independently. "At first I walked the horse around the ring and did exercises on the horse," he said. "Then when I got a little better, I

started to learn to trot and control the speed of the trot," he added. Later, Andy practiced leading his horse around various obstacles and making 360 degree turns and going through mazes.

Andy has ridden in horse shows and won several ribbons. He has also learned how to groom and care for his horse. "I love horseback riding a lot," he said.

Andy and Melissa already have a lot of supporters who are cheering for them. This summer, more than 150 staff and clients of the Babcock Center hosted a cookout in honor of their accomplishments.

Andy's dad and I are of course very proud of him, and we're looking forward to the trip to Ireland. We've already been in contact with a Prader-Willi family in Dublin, who told us that a young lady in Ireland who has PWS will also be competing in the equestrian arena at the World Games.

Bronnie, Andy and Stewart Maurer are from Lexington, South Carolina.



Andy Maurer with South Carolina Gov. Jim Hodges

In this issue

Research Study Participants Wanted	3	Estate Planning & PWSA	11
New PWS Advisory Board Forming	5	Holiday Diet Survival Tips	12
New Valentine Research Fund	7	View From The Home Front	13
Does Your Child Need Orthotics?	8-9	Learn the Heimlich Maneuver	15

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\$40 Agencies/Professionals

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Check out the PWSA (USA) web site
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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.

First Call for Papers

PWSA (USA) National Scientific and Provider Conference

**July 2, 2003
Orlando, Florida**

For an application to present at the Scientific Conference on July 2, go to:
www.pwsausa.org/conf_25/sciform.htm
Deadline: April 1, 2003

For an application to present at the Providers' Conference on July 2, go to:
www.pwsausa.org/conf25/proform.htm
Deadline: April 1, 2003

Scientific and Provider Conference
Attendees are also invited to participate in the General Conference July 3-5, 2003



PWS featured on 60 Minutes II

Matt Heineman (center) stands with camera and sound technicians during the taping of a segment about PWS that should air in the coming months. Asked whether he had anything important he would want to say on 60 Minutes II, Matt responded, "Yeah. I want to give my address and phone number and say that if anyone wants a boyfriend to call me."

Nominations wanted for PWSA (USA) Board of Directors

Who can be a Board member?

Any member of PWSA (USA), which includes parents, caregivers, adult relatives, grandparents and professionals, may submit his or her name for consideration.

Who is qualified to be on the Board of Directors?

Anyone willing to volunteer time, talents and expertise to support the mission of PWSA (USA).

What are the expectations of a Board member?

Board members are required to attend two board meetings a year, one at the annual PWSA (USA) conference and one in January at the PWSA (USA) national office in Sarasota, Florida.

Are there any other responsibilities?

Conference calls and mail votes are required throughout the year. Each Board member is expected to be on at least one committee. Current committees are: Leadership Development, Publications, National Conference, Crisis/ Intervention and Training, Finance, Funding and Grant Development, Board Advisory, and Executive.

What is the term of office?

The Board member serves a 3-year term and can run for three terms consecutively.

How to Apply

We ask that names of members interested in or recommended for a seat on the PWSA (USA) Board of Directors be submitted to the committee by January 14, 2003 to provide an opportunity for board discussion at the January meeting.

Recommendations should include a brief description of the member's qualifications to serve on the Board.

Please send recommendations by mail, fax or email to:

PWSA(USA)

Attention: Ken Smith, Chair, Board of Directors

5700 Midnight Pass Rd., Suite 6

Sarasota, Fl 34242

Email: pwsausa@aol.com

Fax: (941) 312-0142

PWSA (USA) Now Approved for the Combined Federal Campaign

PWSA(USA) is now in the Combined Federal Campaign (CFC) brochure for charitable organizations. This is the federal government's version of the United Way, and all employees of the federal government are encouraged to give through the CFC. This includes postal employees, veterans hospital employees, the FBI, the Secret Service, etc.

Our PWSA (USA) identification number for CFC is 9858.

Employees will use either payroll deductions for ongoing bi-weekly payments, or give via cash or check.



In Search of A Signature

By Lota Mitchell, PWSA (USA) President

Since the last *Gathered View* came out, we have all lived through the anniversary of 9/11, with its painful stories of loss (often invoking memories of our own losses) and shattering images we'd rather forget. In the sorrow and smoke everyone experienced once more a bitter tragedy caused by the human drive for power and control, fueled by hatred.

Coping with all this seems to me to be triple-decker. The big thick layer in the middle is everyday life with all its demands, despairs and delights, day-to-day busyness that is so absorbing that the other two layers are almost forgotten. Almost.

The thin layer on the top is the anxiety about the many events beyond our control. Will the U.S. attack Iraq? Will the terrorists strike again — and where? And the sum of it all: what does the future hold?

The bottom layer is the hope for peace. Everybody wants it. Does anyone believe it will ever happen? Even the Bible says there will always be “wars and rumors of wars.”

It seems the hopes we have for our children with PWS are more realistic than any hope for peace. With the drives for power and control always at work, not only cultures and countries can't get along, conflict exists right down to the personal level.

During my 20 years as an Employee Assistance Program counselor listening to the wide array of problems that came through my door, I heard couples heading for divorce, parents and teenagers locked in battle, co-workers who couldn't get along with each other, subordinates with bullying bosses, stories of family members who hadn't spoken to each other for years, antagonism between neighbors, and a host of other hostilities.

During my past year as PWSA(USA) president, I've seen a few of our chapters in conflict over differing interests of parents of young children versus those of parents with older children and adults, or over issues of how the chapter should be run (Hello again, power and control!), often seasoned with interpersonal animosities.

We worry about our children with PWS often not being able to get along with their peers and not having friends as we would like. But what kind of example do the adults set? Is more expected from our children than from the grownups?

Discouraging, isn't it? But wait — there was a lovely song with words that went like this: “Let there be peace on earth and let it begin with me.” We can't change the course of world history, but we do have the power to change the negative patterns of our personal relationships, beginning with ourselves and our own attitudes.

...there was a lovely song with words that went like this: “Let there be peace on earth and let it begin with me.”

Our previous PWSA(USA) president Barb Dorn signed all her e-mails with “Take care.” Even though I knew it was standard for all, not just me, somehow it said that she really was concerned with my well being. And Carolyn Loker, our current vice president and Parent Mentoring Program coordinator, uses “Hugs” to sign off, which I find warm and caring.

For the past year I've been looking unsuccessfully for my own signature word or phrase, and now I've found it: Peace. I wish peace for each and every one of you — from global peace, to peace between the factions in our own country, to peace within PWSA(USA) and its chapters so that the focus can remain on serving our children, to peace within our families, to that treasured inner peace which allows us to go about our daily business with a smile whatever the circumstances.

Peace.

Participants Sought for California Research Study

Dr. Suzanne Cassidy, pediatrician and medical geneticist, is seeking individuals with PWS to participate in an ongoing research study sponsored by the March of Dimes.

This study seeks differences between the clinical, cognitive and behavioral findings of PWS due to the two major genetic causes, deletion and uniparental disomy (UPD).

The study involves 2½ days in beautiful, warm, activity-filled southern California. Travel and housing expenses are reimbursed.

The studies include physical findings, blood tests (primarily hormones), bone density, X-rays, cognitive, behavioral and speech assessments, with the results made available to the families.

Though people with PWS due to both genetic causes are encouraged to participate, those with UPD are especially needed.

Please contact Ellen Simpson, study coordinator, at (714) 456-6881.



New PWS Advisory Board Forming

Prader-Willi Syndrome Advisory Board For people with PWS ~ by people with PWS

PWSA (USA) is establishing a Prader-Willi Syndrome Advisory Board. The new advisory board will consist of six people with Prader-Willi syndrome who are age 18 and older.

The board will meet in person annually and correspond by e-mail and mail throughout the year.

The board's objective is to represent the interests and needs

people with Prader-Willi syndrome to the PWSA (USA) Board of Directors and the general membership, said Mary K. Ziccardi, the volunteer board's coordinator.

The first meeting will be at the Orlando Conference July 2-5. The application deadline for those wishing to be considered for a board position is February 15, 2003.

PRADER-WILLI SYNDROME ADVISORY BOARD APPLICATION FORM

Name: _____

Address _____

Email address: _____

Phone #: _____

Age: _____ Occupation/School: _____

I live with: (circle one and explain)

- My parents (name) _____
- In a supportive living home (name of agency) _____
- Other (explain) _____

I would be a good board member of the PWS Advisory Board because:

(In 50 words or less. You can write this on a separate paper with your name on it.)

I think the most important issues for PWSA (USA) to address regarding the needs of the person with the syndrome are:

(In 50 words or less. You can also write this on a separate paper with your name on it.)

Please also attach a letter of recommendation from someone who knows you well. Applications should be

mailed to: Mary K. Ziccardi Reg. Dir.
REM Consulting of Ohio, Inc
299 Alpha Drive
Cleveland, OH 44143

Behaviors and Disorders Associated With PWS

By *Janice L. Forster, M.D. and Linda M. Gourash, M.D.*

Editor's Note: The following are excerpts from an article prepared to provide guidance to parents and other providers of care in seeking out psychiatric services. Clinical information for the consulting psychiatrist is included. The article will appear in its entirety in the Members Only section of our web site at www.pwsausa.org. Members who do not have Internet access can call the PWSA (USA) national office and request a printed copy of the article.

We caution that some parents may find details in the article to be disturbing. This is not recommended reading for parents of young children.

It is not necessary for the treating psychiatrist to have experience with Prader-Willi syndrome. Because this is a rare disorder, there are few clinicians who have had the opportunity to see large numbers of patients with PWS.

Rather, parents should seek a credentialed psychiatrist (ABPN certified in either Child and Adolescent Psychiatry or General Psychiatry) who has an interest and experience in caring for people with developmental disabilities and who is willing to listen, read and learn about the syndrome.

Above all, parents should seek a psychiatrist who is expecting to follow the patient over time and who requests office visits and follow-up phone calls whenever prescribing a new medication or when changing a medication dose.

Behavior Clusters

There are a large number of features to the Prader-Willi personality; we consider it helpful to categorize them into four clusters: food related behaviors, oppositional defiant behaviors, cognitive rigidity and inflexibility, and behaviors indicating anxiety/insecurity. (Personality and psychological traits that are typical with PWS are detailed in the article.)

Psychiatric Disorders

The following psychiatric disorders appear to occur with increased frequency in people with PWS: sleep disorder, ADD and ADHD, oppositional defiant disorder and conduct disorder, obsessive compulsive disorder (OCD), anxiety and mood disorders, psychosis, developmental learning disorders, impulse control, factitious disorder.

Management

The choice of psychotropic medication is much the same as in non-PWS patients. As in the general population, some patients respond well to one medication and others do not.

Neuroleptics, atypical neuroleptics and valproic acid have all been used effectively without a discernible change in food-seeking behavior.

Psychiatric evaluation can:

- Delineate symptoms
- Identify stressors
- Recognize strengths/weaknesses in coping strategies
- Indicate an underlying psychiatric disorder

Recommendations for intervention may include:

- Prescriptions for environmental change
- Alterations through behavioral modification
- Education to teach new coping strategies
- Medication to alter response to stress
- Medication to treat underlying psychiatric disorder

For more information, members may request the complete text of the printed article or view it on the Members Only section of the PWSA (USA) web site.

Drs. Forster and Gourash are affiliated with The Children's Institute of Pittsburgh, Pennsylvania. The Children's Institute is an inpatient rehabilitation program for persons with PWS is a licensed psychiatric and rehabilitation unit for children and adults with PWS. The program receives referrals from around the USA and Canada for medical and psychiatric crisis intervention and has managed more than 800 inpatient admissions.

**All persons with Prader-Willi syndrome qualify for an Axis 1
Diagnosis of Personality Change Due to a Medical Condition (310.1)**

PWSA (USA) Storage Site Damaged

An arsonist has been arrested for setting fire to the storage units in Sarasota, Florida that house the PWSA (USA) publications and logo items.

One third of the units were burned to the ground, one third had fire and water damage, and the other third had smoke damage – which is the area of the PWSA (USA) units.

Because of structural damage at the facility, PWSA staff had not been allowed into the site and the amount of loss could not be evaluated at the time of *The Gathered View* publication deadline.

If the publications cannot be cleaned appropriately from the smoke damage, please accept our apology for any delays in your future publication orders. It may take some time to get all publications reprinted. We are hopeful that insurance will cover most of the cost of restoring our products. Many unit renters had no insurance coverage.

Be My Valentine

Support the Valentine Research Fund Campaign

By Carolyn Loker

How can we promote support for research and treatment of PWS? How can we give PWS families hope that some day there will be better treatment options?

The Valentine Letter is not only a warm greeting to family and friends, it's also a way to educate them about Prader-Willi syndrome and ask for their support through a donation to the Valentine Research Fund.

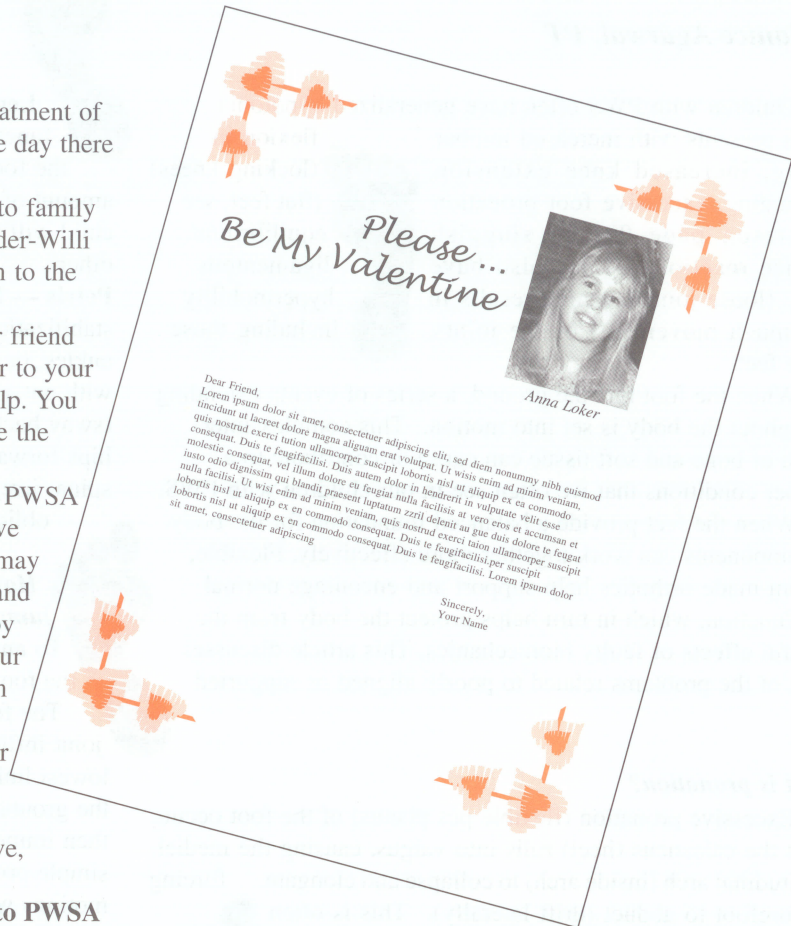
The letter is written so that any family member or friend may send it. You may wish to send the Valentine letter to your family, friends, neighbors and anyone you feel may help. You might even ask friends or family members to distribute the letter to their circle of friends as well.

This letter will be available to download from our PWSA (USA) web site: www.pwsausa.org. The letter will have space to insert a child/adult's picture and name. You may do this yourself if you are comfortable with scanning and pasting. If you're not computer savvy, you may send by regular mail to the PWSA (USA) office a picture of your child/adult with PWS, along with your completed form (shown below). You may chose to have PWSA (USA) make a floppy disk that you can take to a print shop, or tell PWSA (USA) the number of copies of the letter you'd like sent to you.

PWSA (USA) will assign a staff member to receive, prepare and send the appropriate materials requested.

Deadline to have your picture and information to PWSA (USA) will be January 2, 2003. It's important to meet this deadline so that your letters can be mailed by the first week of February in time for Valentine's Day.

The Valentine Research Fund is a special fund-raising appeal, separate from our annual Angel Fund Drive, which supports essential PWSA (USA) operations and programs.



It is our hope that this Valentine Research Fund Campaign will become an annual event. All proceeds will be designated to the PWSA (USA) Research Fund, minus a nominal amount to cover project operating costs.

If we all join together, we can create better treatment options as a result of research.

Please detach and send information and photo to
PWSA (USA), 5700 Midnight Pass Rd. Suite 6, Sarasota, FL 34242

First & Last Name of person with PWS _____

Your Name _____

Address _____

Chose only one: Copies of letter _____ or Floppy Disc _____

Your signature: _____ Date _____

What to Consider When

How can I tell if my

By Janice Agarwal, PT

Children with PWS often have generalized hypotonia which presents with increased lumbar flexion in sitting, increased knee extension in standing, excessive foot pronation (locking knees) (flat feet, see pictures on page 9) and sluggish equilibrium/ligamentous balance reactions. They also have laxity (loose joints), which results in hypermobility (too much movement) of the joints, including those in the feet.

When the foot hits the ground, a series of events extending throughout the body is set into motion. This complex interaction of bone and soft tissue can cause or contribute to a number of conditions that we often see in our children with PWS.

When the feet provide a balanced foundation for the body, its components can work together more effectively. Flexible, custom-made orthotics help support and encourage normal foot function, which in turn helps protect the body from the harmful effects of faulty biomechanics. This article discusses some of the problems related to poorly aligned or supported feet.

What is pronation?

Excessive pronation (flexible pes planus) of the foot occurs when the calcaneus (heel) rolls into valgus, causing the medial longitudinal arch (inside arch) to collapse and elongate, forcing the forefoot to abduct (drift laterally). This is often referred to as flat-footed. A child with abnormally pronated feet likely has:

- Poor ankle/foot positions
 - a. Feet are flat and collapse/rolled medially (inward)
 - b. Feet show a wide base of support (are kept far apart)
- Genu valgus (knock-knee)
- Hip adduction – legs held together
- Arms in high guard (hands held up at shoulder level to keep balance and protect during falls)
- Poor balance/coordination

What problems does this pose for my child?

The foot functions as the base of a biomechanical chain. If foot alignment is compromised or not supported correctly, the rest of the body, which is balancing over the feet, has to work even harder. This can cause significant increases in fatigue and reductions in endurance. Joints most often affected by this condition are:

Knee — Foot pronation forces use of muscles that are not normally used to support and stabilize the foot and ankle, placing excessive strain on the medial ligaments of the knee. When the medial (inner) side of the knee weakens, children develop genu recurvatum (hyperextension) or genu valgum (knock knees) of the knees in standing.



Leg length — Excessive pronation can create a functional leg length discrepancy that forces muscles from the foot to the pelvis to work harder and changes the amount of weight supported by the joints. To compensate, a child will favor one side, making one leg seem shorter than the other.

Pelvis — Because of weak abdominal muscles, the pelvis lacks stabilization to compensate for irregularities of the feet and ankles, or of the spine. Children with PWS typically present with anterior pelvic tilt (hips tilted forward) and hyperextension (sway back) of the lumbar spine when standing, pushing the hips forward. Compensation for leg length discrepancies (or spinal irregularities) causes side-to-side pelvic tilting (pelvic obliquity).

How will this affect my child's ability to walk, run, and jump?

To answer this question, it is necessary to understand how the foot works.

The foot functions as one link in a chain. Movement of one joint influences movement and position of other joints. As the lowest link of this chain, the foot is subjected to the forces of the ground with every step, cushioning the body on landing, then immediately launching the body forward. This seemingly simple process requires a series of complex biomechanical motions within the foot. This series of movements are “stance phase” of the gait cycle.

Three distinct things happen in the stance phase:

1. **Heel Strike** (Contact) — When the foot makes contact with the ground, it should do so on the lateral (outside) aspect of the heel. The knee is generally fully extended at this time and weight is transferred from the opposing leg. As the foot comes down, there is a gradual distribution of weight across the foot.
2. **Midstance** — As the weight of the body propels over the foot and the leg becomes vertical, the full weight of the body comes down directly on the foot, and is distributed evenly across the foot (50 percent on the heel and 50 percent at the forefoot). At this moment, the foot should be in a neutral alignment. It is when alignment is most crucial, as the body is most influenced by misalignment of the knee and hip joints.
3. **Propulsion** — With weight shifted forward, the midfoot unlocks and the foot pushes down into the ground. The foot at this point needs to be able to pronate slightly to lead into a push off on the first metatarsal head (ball of foot). The foot leaves the ground and the body launches into the “swing phase” of the gait cycle, during which no weight is borne by the foot until contact again occurs.

The Foot Hits the Ground Does it need orthotics?

One of the most common causes of a walking difficulty is due to excessive pronation during the stance phase. In normal walking the foot needs to be flexible to hit the ground and react appropriately. The foot has to absorb the shock, support the body while moving, then become rigid enough to push off for the next.

Such balance cannot exist when the foot is maintained in pronation. The pronated foot remains loose and adaptable throughout walking. Because the forefoot does not become rigid, the foot cannot effectively transition from midstance to push off.

When weight shifts forward, the medial aspect of the foot (instead of the ball of the foot) pushes into the ground, and muscles that are not normally used to support and stabilize the arches of the foot and the ankle during toe-off are forced to work harder, become strained and weaken, thereby limiting strength and endurance.

Until excessive pronation is corrected, simple activities such as walking, running and jumping are performed inefficiently, causing prolonged abnormal stresses on all the links of the chain. A child with uncorrected pronation will strain and grip with toes and sides of feet to maintain balance.

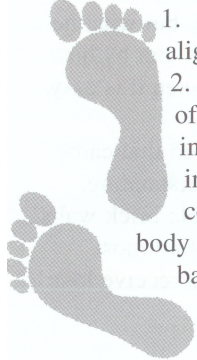
One of the most common causes of a walking difficulty is due to excessive pronation during the stance phase. In normal walking the foot needs to be flexible to hit the ground and react appropriately.

Reducing pronation lessens the biomechanical forces that strain the medial ligaments of the foot and the surrounding muscles. Hypotonia, underdeveloped ligamentous structures, and poor postural control prevent spontaneous correction of pronation. The next step is an orthosis.

What type of orthosis is most effective for a child with PWS?

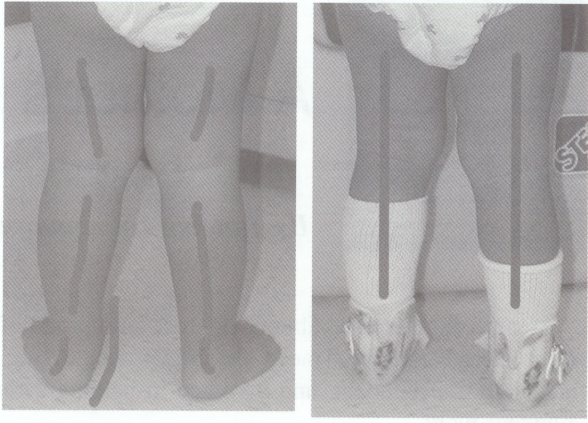
Dynamic supra-malleolar orthoses (SMOs) are lightweight, very thin and extremely flexible, distinguishing them from conventional orthoses. They have contoured foot plates to support and stabilize the arches of the foot. SMOs can be designed to prevent excessive pronation.

This has four positive effects:



1. The foot bed maintains the foot in neutral alignment, which improves foot stability.
2. When fit snugly around a foot, the flexibility of the lightweight plastic gives to the foot information regarding where it is in space. This information is then sent up to the brain to help coordinate other balance reactions throughout the body that are necessary to stay upright or maintain balance. The rigidity of the plastic also prevents extreme movements that cause abnormal compensations for poor alignment.

3. SMOs are tolerated more easily than conventional bracing systems. Because



Pronated feet before and after orthosis

the SMO is measured to match the contours of each foot, pressure is distributed more evenly, reducing skin breakdown. 4. The lightweight, thin and flexible plastic allows for regular shoes and socks. Most orthoses require shoes that are two to three sizes larger than the child requires, inhibiting the natural development of proprioceptive awareness and balance reactions.

When should my child start using orthoses? How long will orthoses be needed?

From the time a child with pronation begins to stand, to the point of epiphyseal (growth plate) closure, orthoses should be used to maintain alignment and function of the

foot and ankle. This usually means that children with PWS will need orthoses until the end of puberty. Some children will need shoe inserts (a different type of orthosis) throughout adulthood.

References

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



A Mother's Pride....A Son's Love

By Janalee Heinemann

I am fortunate to be able to say that I am proud of all five of my children. Tina, 39; Tracy, 38; Tad, 36; and Sarah, 28, are all financially independent, and involved in helping careers and/or volunteer work.

In spite of our other four children's accomplishments though, while taking my morning walk on the beach today, I thought about the fact that the child I am the most proud of is Matt, our 29-year-old son who has Prader-Willi syndrome. Still feeling a warm glow from an early morning call from Matt, I was able to take the time before my day got too busy to appreciate his call. He wanted to thank his Dad for helping him figure out how to fix his X Box video system, and to tell me he loved me.

Although Matt's accomplishments are not as visible to the rest of the world, they are outstanding in my book. He has achieved what was considered impossible for a person with Prader-Willi syndrome just 20 years ago. Matt is tall, slim and happy. He has also managed to find joy in this life in spite of his limitations, and love in his heart for all of us who have had to put so many restrictions on his freedom.

Although during Matt's more difficult teen years, I sometimes wondered how often I could forgive him after he would "blow up" — I now realize that Matt has had to forgive us almost every day of his life — for not feeding him when he was hungry, for not allowing him to do many things he thought he should be able to do because they were normal freedoms of others his age, and for knowing his siblings had a lot more privileges than he was allowed. Yet, forgive us he has... and love us unconditionally he has.

Many adult children turn their backs on parents they feel have injured their psyche, and dread calls from their parents, but Matt is always happy to get our calls, and usually when he sees me, he gives me a big hug and thanks me for "saving his life."

While many young adults would be mortified to have their parents write anything about them for the world to see, Matt has given me permission to do so to "help all children with PWS." For the same reason, he always wants to participate in research — not only to help himself, but also to help the next generation. Matt knows that he and others like him with PWS may someday help solve the complex puzzle of obesity for all people suffering from weight-related problems.

How do we measure a person's worth? Who is to say that the brightest and the richest are the best? What I have always wanted most for my children is that they have compassionate hearts, and are happy.



Matt gives his mom a hug

Matt has achieved what was considered impossible for a person with Prader-Willi syndrome just 20 years ago.... He has also managed to find joy in this life in spite of his limitations, and love in his heart for all of us who have had to put so many restrictions on his freedom.

Sometimes in the grieving of the early years, parents of children with PWS are not able to appreciate that although their dreams may have to be modified, their child with Prader-Willi syndrome may one day be their greatest source of pride — and their greatest source of undying love.

How do you measure a person's worth?

Not so much by what the person has done, but by what he or she has overcome. Not by what the person has, but what he or she gives. Not by how thin the person's body is, but by how big the heart is. Not by the love someone gives when it is easy, but by the love given when it is difficult.

Matt, you are a special blessing I have received that came in disguise. Thanks to you, I have grown in understanding, knowledge and compassion. I have learned to scale brick walls, not only for you, but for all children with PWS. And most important, I have felt what it means to give and to receive love unconditionally.

Leaving A Legacy to PWSA (USA) Through Your Will or Estate Plan

By Maureen Wheat, Director of Development

As members and supporters of the Prader-Willi Syndrome Association (USA) lend financial support to a future that provides new answers for people impacted by the syndrome, we want to offer many pathways for your generosity.

There are many ways to leave a legacy to PWSA (USA) to ensure that its mission of "improving and enhancing the lives of everyone impacted by Prader-Willi Syndrome and related conditions" will continue for future generations.

Using Estate Gifts

One easy and vital way is by making a lasting and significant contribution to PWSA (USA) via your estate plan. Besides the simplicity of making such a gift, it is also important to remember that bequests of cash, securities and other assets to PWSA (USA) entitle your estate to a charitable deduction that can reduce or eliminate estate tax liability.

Your bequest will help support research on PWS and related conditions that will significantly impact the understanding of obesity and appetite regulation in the general population.

Finally, your bequest will support instilling compassion and understanding for those with the syndrome through our dedication to providing awareness and knowledge to the public.

Types of Bequests

Unrestricted Bequest: used for general purposes, such as the programs and services that PWSA (USA) offers.

Restricted Bequest: used to support a specific program that PWSA (USA) offers, such as research, education and awareness, bereavement or the Parent Mentoring Program. We welcome restricted gifts, if that is your preference, and would happy to assist you in choosing a program that best matches your intentions.

Making a Bequest

Specific Bequest: used through assets such as cash, securities, retirement plan benefits and IRAs. You may designate a specific amount or percentage of the property as the gift.

Residuary Bequest: a bequest honored after all other bequests have been satisfied and all debts, expenses and taxes have been paid.

Contingent Bequest: a bequest is fulfilled if certain conditions are met. For instance, if your primary beneficiary does not survive you, you can indicate your next choice through a contingent designation.

Naming PWS (USA) in Your Estate Plan

The language for making a bequest in your will can be as simple as the following:

"I give, devise, and bequeath to the Prader-Willi Syndrome Association (USA), a charitable corporation located at 5700 Midnight Pass Rd., Suite 6 in Sarasota, Florida, (___ percent of my estate) or (the sum of \$___) or (the following described property___) or (all the rest, residue, and remainder of my estate) for (the general use of the Prader-Willi Association (USA) or (for the following use or purposes___).

Consult With Your Attorney

As with all charitable bequest intentions, PWSA (USA) reminds all donors and potential donors who consider a charitable bequest that the information provided in this article is not intended to be tax or legal advice. Please share the suggested bequest language with your attorney when drafting a will or codicil that will achieve your charitable estate plans.

PWSA (USA) is IRS 501(c)(3) Non-profit

The Prader-Willi Syndrome Association is an IRS-qualified 501(c)(3) non-profit organization. Copies of our tax-exempt letter are available upon request. The PWSA (USA) federal identification number is 41-1306908.

A copy of the official registration and financial information for PWSA (USA) may be obtained from the Florida Division of Consumer Services by calling toll free within the state of Florida 1-800-435-7352. Registration does not imply endorsement, approval or recommendation by the state.

If you would like further information on making a bequest, contact me at 1-800-926-4797 or by e-mail at devpws@aol.com.

Consider Giving a Gift of Stock

If you are thinking about donating to PWSA (USA), consider giving shares of stock or other appreciated assets in lieu of cash. Why?

When you give an appreciated asset, such as stock, neither you nor PWSA (USA) has to pay capital gains taxes.

In addition to the capital gains tax savings, you receive a full tax deduction for your donation.

By contributing to the Angel Fund, you can feel good about helping us continue giving to those who need our help.

If you are interested in making a gift by stock or other appreciated assets, please call, or have your broker call our Representative from Edward Jones Investments, Richard Graveley, at 877-346-0560 (toll-free business phone) or 941-539-3979 (mobile phone).

He will be more than happy to make this a painless process for you and answer any questions you may have.



*We Wish You Happy Holidays
and Peace in the New Year*

Diet Tips for Surviving the Holidays



Don't let the holiday party hearty syndrome get you off track. Celebrate with friends and family and control your child's weight by keeping the emphasis off food.

Here are some ideas to help keep the New Year healthy and happy.

- Use all low-cal products. Fat-free margarine, cream cheese, sour cream, and cooking spray in place of traditional ingredients can decrease calories in some recipes. Use sugar substitute in place of sugar or honey.
- Wrap and freeze baked goods in individual portions so you can defrost just what you need when guests arrive, eliminating leftovers and temptations.
- Give any leftovers to friends at the end of the party.

Tips for party-goers

- Serve sugar-free hot chocolate and low-calorie veggie snacks.
- Exercise before and after dinner or holiday party.
- Do a holiday jigsaw puzzle with family.
- Bring fresh out-of-season fruit (a ripe pineapple, perhaps) to gatherings – a welcome contribution and something to eat besides heavy holiday fare.
- Discuss food choices before attending the party.
- Allow second servings of vegetables and no-calorie drinks only. Try calorie-free soda, sugar-free punch, or ice cold water with lemon or lime before or after meals as a "cocktail."
- For holiday dinner allow 1-2 tablespoons of all the foods on the table to prevent the feeling of being deprived of a favorite food.
- Chew a piece of sugar-free gum after the meal is over.

Tips for the Hostess

- Keep calories down, flavor up, by experimenting with herbs and spices as seasonings for vegetables. Try cinnamon with carrots or oregano with green beans.

Try these suggestions to reduce calories in holiday baking

- Reduce the amount of fat in muffin or quick-bread recipes by one-third to one-half.
- Use fat-free, sugar-free ice cream or frozen yogurt instead of ice cream.
 - Chew a piece of sugar-free gum after the meal is over. Substitute cocoa powder for chocolate in cookies or cake to reduce fat. (3 Tbsp. unsweetened cocoa powder = 1 ounce unsweetened chocolate.)
- Replace heavy cream with evaporated skim milk.
- Use non-fat yogurt or low-fat cottage cheese with 1 tsp. lemon juice per ½ cup cheese to substitute for sour cream, or use fat-free sour cream.
- Substitute two egg whites for each whole egg.
- Top cake with fresh fruit, fruit sauce, or a sprinkle of powdered sugar instead of frosting. Eliminate nuts.

From Beverly Ekaitis, DTR, The Children's Institute Prader-Willi Syndrome Program, Pittsburgh, Pennsylvania



Find Last-Minute Holiday Gifts and Benefit PWSA(USA)

Shop the PWSA(USA) Web Mall

Shop from 140 Internet merchants who pay commissions up to 14 percent to PWSA(USA) on every sale.

Participating merchants include Amazon, Borders.com, Disney, ESPN, L.L. Bean, Lands End, Hallmark, CDNOW and FTD.

Find the mall at www.pwsausa.org. All shopping is fully secured, and the mall offers full privacy protection.

Shop CyberGadgets Online

Find the coolest gadgets in cyberspace, including Oregon Scientific fitness electronics: pedometers, heart rate monitors, body fat percentage scales and lots of other electronic items which make great gifts.

Go to www.cybergadgets.com and place your order. As you check out, find the box that asks where you heard of the site, type in PWSA(USA) and 25 percent of your order total will be donated to PWSA(USA)!

Colin Has Taught Us Patience, Understanding and Love

By Anne Moran

I will never forget the drive home from the Westchester Medical Center six days after my son Colin's birth. My husband and I stared blankly out the window, tears streaming down our faces, unable to say a word.

Colin Moran was born on April 29, 1999. I kept insisting throughout the whole pregnancy that something was wrong because I never felt any movement. I had 20 ultrasounds throughout the pregnancy, but each time the baby moved a little and the doctors would say, "The baby's fine, don't worry."

Colin was born three weeks premature by a scheduled cesarean. My first indication that something might be wrong was when the doctors announced Colin's weight. He was 6 lbs 2 ounces. My daughter, who had been born 20 months earlier, was 9 lbs. 3 ounces. I thought that was strange.

The next day my husband came in to my room, sat in the chair and said, "They think something's wrong with the baby, they called a geneticist."

This isn't happening, I thought. As the days went on, I was very aware of the differences with Colin. He was unresponsive, floppy and never opened his eyes. He was, however, able to suck, so feeding was never a problem. We took him home and waited for the results from genetic testing. Even then, I still hoped, maybe it's just because he was early, there really can't be something wrong.

Words cannot describe the sick feeling in our stomachs as we heard the doctor's words: "Your son will most likely be obese, retarded and have severe behavioral problems." We were given a handout from 1975 that painted the most dismal picture. This is not what I wanted, but most of all I didn't want it for my daughter Meghan. I had never had a brother; this was not how it was supposed to be.

The community support was overwhelming. Everyone was trying to lend a hand, making food, offering babysitting, but their faces said it all: "Poor you!" Everyone felt as helpless and in just as much shock as we were. I think I was in a fog for three months before I could actually believe what had happened.

My husband Brendan has been an unbelievable source of strength. He sat me down and said, "This little boy didn't chose this. If we don't believe in him, no one will."

At that point, I knew it was time to go forward.

We continued to take Colin to healing masses and constantly prayed for him. We had hands-on healers come to the house. We began early intervention services and took as many services as were offered.

As the months went on, Colin became more responsive, alert and just a complete joy to be around. It was almost as though he had a halo over his head.

Colin's biggest stimulation is his sister Meghan. She jumps on him, plays with him constantly and loves him to death. We truly know why we were blessed to get Colin. He has taught us about patience, understanding and love, more so than anyone else could have ever done. We truly feel lucky to have him.

We certainly wish he didn't have Prader-Willi syndrome, but in some strange way we feel lucky because we really "get it." We celebrate every little thing he does and live with the philosophy that we are prepared for the worst and hope for the best. If we don't expect all of him, no one will.

When Colin was 18 months old he was put on growth hormone. Today at 3 years and 5 months he weighs 34 lbs. and is 3 ft. 4 in. tall. He has been walking for 8 months and is still getting therapy in all areas. Although he is considerably

delayed in speech and motor skills, he shows not sign of excessive appetite.

Colin has a very happy disposition and was able to attend a regular pre-school two mornings a week at age 2. This fall he will attend an inclusion program at a regular pre-school five mornings a week, where he will be provided an aide and all his regular therapies.

His sister Meghan, who is now 5, still provides him with love and stimulation and is his biggest supporter.

Colin has brought us nothing but happiness. If we had believed all of those dismal and outdated reports about Prader Willi syndrome, we would never be experiencing this truly remarkable little boy.

Anne and Brendan Moran live with their daughter Meghan and son Colin, who has PWS, in Katonah, NY.



Meaghan and Colin Moran

The Chuckle Corner

Being a Prader-Willi parent at holiday time is....

Not decorating your tree with stringed popcorn, or cranberries, or candy canes, or gingerbread men....
Janalee Heineman



Do you have a joke or funny story to share with readers about Prader-Willi syndrome? Send it to the PWSA (USA) office. Be sure to include your name, phone number and address in case we have any questions. We'd love to hear from you!

PWSA 2003 Annual Conference July 2-5



Fulfilling The Dream: Joining Together to Secure Brighter Horizons

**Mark your calendar NOW for the PWSA 2003 Conference
at the Sheraton World Resort in Orlando, Florida**

Outstanding Programs

July 2nd will be a day of outstanding programs for the scientific community and providers. The general conference program is July 3rd, 4th and morning of the 5th, with separate sessions for parents and caregivers of the 0-5 population, school-age children, and adults with PWS.

Our conference will also include a full Infants & Toddler Program as well as a Youth & Adult activities program for both those with the syndrome and their siblings.

Plus Fun for the Whole Family

On Friday, July 4th, we are planning a fun-filled family evening at Sea World, just a 5-minute walk from the hotel. A dinner at Sea World, a Shamu Show, and fantastic fireworks will be a great way to celebrate the 4th!

Convenient Orlando Location

The Sheraton is located on International Drive and is only minutes from Universal Studios, Disney World Theme Parks, award-winning restaurants and shopping.

This tropical landscaped resort features three outdoor heated pools, two kiddie pools and complimentary transportation to and from Lake Buena Vista Factory Stores and Walt Disney World Theme Parks.

Special PWSA Discounts for Accommodations, Rental Cars and Airfare

PWSA has secured a block of rooms at the wonderful discount rate of \$98/night for up to four people. To make reservations, call Globetrotters Travel at 800-322-7032 (press 2) or by e-mail to pwsa-usa@globetrottermgmt.com.

Special airfare and car rental discounts have also been contracted for PWSA through Globetrotter Travel. To take advantage of these offers call 800-322-7032 (press 1).

Check Our Web Site for the Latest Information

Keep checking the PWSA (USA) web site for the latest details regarding conference:
www.pwsausa.org.

*We need **YOUR** help*

To make the 2003 conference a huge success and help offset the cost of conference, we need your help.

We are looking for donations/loans of many items needed for the conference, including the following:

- Copy machine rental
- Computers
- Walkie Talkies
- Printing of conference materials
- Office supply materials
- Toys for YAAP program rooms
- Prizes for YAAP program carnival
- Cribs
- Diapers, baby items
- Disc jockey for Thursday night banquet

If you or someone you know can loan or donate any of the above items, please call the PWSA office at 800-926-4797.

We also need volunteers for the YAAP program. If you can volunteer, please contact PWSA Conference Planner Kristin Gutierrez by e-mail at

pwsaconferenceplnr@hotmail.com
or by phone at 407-688-0235 for more information.

With your help, we can make the 2003 Conference the best and most fulfilling ever!

Learn How To Perform the Heimlich Maneuver

Because some reported PWS deaths have been associated with choking, we think it is important for parents and providers to have knowledge of the Heimlich procedures.

The most effective way to learn these methods is to take a CPR course that includes practice of the Heimlich procedures, so we encourage everyone to take such a course, along with frequent reviews. Check with your local fire department to see if there is a free or low-cost CPR course available.

If the victim is conscious and choking on something, you perform the Heimlich maneuver until the object is dislodged or the victim becomes unconscious.

In an unconscious victim, you always try to do a few quick rescue breaths to see if you can get air into the chest. Also, periodic attempts at a rescue breath are necessary even if you do not see the foreign body come out of the mouth. All of this is discussed in CPR training.

Please remember, it is important to dislodge the food prior to doing CPR. Here are instructions for saving a choking victim using the Heimlich Maneuver:

A choking victim can't speak or breathe and needs your help immediately. Follow these steps to help a choking victim:

- From behind, wrap your arms around the victim's waist.
- Make a fist and place the thumb side of your fist against the victim's upper abdomen, below the ribcage and above the navel.
- Grasp your fist with your other hand and press into their upper abdomen with a quick upward thrust. Do not squeeze the ribcage; confine the force of the thrust to your hands.
- Repeat until object is expelled.

If the victim is unconscious, or if you cannot reach around the victim:

- Place the victim on his or her back.
 - Facing the victim, kneel astride the victim's hips.
 - With one of your hands on top of the other, place the heel of your bottom hand on the upper abdomen below the rib cage and above the navel.
 - Use your body weight to press into the victim's upper abdomen with a quick upward thrust.
 - Repeat until object is expelled.
- If the victim is a choking infant:
- Lay the child down, face up, on a firm surface and kneel or stand at the victim's feet, or hold infant on your lap facing away from you.
 - Place the middle and index fingers of both your hands below his rib cage and above his navel.
 - Press into the victim's upper abdomen with a quick upward thrust; do not squeeze the rib cage. Be very gentle.
 - Repeat until object is expelled.

In all instances, if the victim has not recovered, proceed with CPR. Do not slap the victim's back, this could make matters worse. If the victim becomes unconscious, call 911.

The victim should see a physician immediately after rescue. The Heimlich Maneuver is fully illustrated on the PWSA(USA) web site at www.pwsausa.org.

In Honor Of

Callaghan & Reilly Hartnett
Mike and Linda Hartnett and
the Ford Motor Company of
Hamburg (*Skip a Lunch
Fundraiser*)

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Fraternal Order of Police,
Lodge 73, Evansville, IN

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Joanne Marie Williams
Linda A. Zick

Charles Trentacosta
James Trentacosta & Family

A Family Tragedy

We express our deepest sympathy to Elber & Rachel Brubaker of Lititz, PA, grandparents of Ethan Shenk, who had PWS. Five-year-old Ethan, his sister and his parents, were all killed in a small plane accident in August. Gerald & Julia Shenk of Elizabethtown, PA, were members of PWSA (USA). Our hearts and prayers go out to the family.

Acknowledgements

Our Sincere Thanks for Contributions Received in August and September 2002

Major Benefactors (\$500 or more)

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PWSA of Ohio (*Janet & Mike Gurney Fundraiser for Parent Mentoring Program*)
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Virginia F. Howkinson

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*In Honor of
continued on page 15*

Angel Fund Contributions August-September 2002

Arch Angel (\$250-\$499)

Sean & Elizabeth Schluntz (*in honor of Kerrigan Faith Mehner*)

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Bie Chuan & Lucy Ong
David & Jane Shoemaker

Cherub (Up to \$99)

Clarkrange United Methodist Women (*in honor of Becky Allred*)
Delores Heinemann
Sandra & Gary Kodish

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.

