



The *Gathered View*

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

Off to a Great Start ... By Sue & Rich Cornell, New York

We'd like you to meet Chrissy, who just celebrated her second birthday on Feb. 26. She is a bright, vibrant, flirtatious, and charming little girl. After a rough start, we can't begin to tell you what a good feeling it is to watch her accomplish her goals. Chrissy just wants to do what others do and she does! That radiant glow once she accomplishes the task is just beautiful.

When she was born, she was so astonishing to look at. Her porcelain doll features were so pretty, along with her strawberry blonde hair and peaches-and-cream complexion. It was hard to believe our beautiful little girl could have a problem. That little "bird cry" was the doctor's first clue. After 36 hours, she'd had about two ounces of formula and was put in the Special Care Nursery. It was time to figure out why Chrissy couldn't suck and had such poor tone.

During her six weeks in the NICU (neonatal intensive care unit) in Utica and in Syracuse, she went through a series of diagnostic tests. She even had a muscle biopsy at three weeks. Every test was negative. Chrissy still couldn't suck but seemed to be "getting better." She was much more alert and being weaned from the tube to a bottle with a cross-cut nipple. Finally, the neonatologist and genetic specialist suggested another test. I remember signing a release for "Prader Something Or Other."

On April 1, 1997, I got a call from the geneticist. He wanted to see us the next day because the PWS test was positive. He told us all we wanted to know: it

was manageable and not fatal. I'm sure you all know the rest of the story.

She finally came home on April 8. Everyone involved in her care and treatment during her NICU stay was incredible. Even the social worker was on the phone to the New York State Early Intervention to get PT and OT started. Speech therapy has now been added. Her thera-

teness and simplicity, coupled with her million dollar smile, she has a way of making you reevaluate your own life. She's still tiny—16 lbs. She says a few words, but knows how to communicate through her own little language we like to call "Chrissy Speak." She's just as proud as any child would be when she does something that big girls do, like pushing her "babies" around in the carriage.

This story isn't complete without mentioning her brother, Andy. He is 3½ and just loves his "Chrissy Baby." And then there's Clancey, our Irish Setter. Most kids have teddy bears—not ours. Andy has "Don Duck"—no need to call him Donald since they're "tight!"—and Chrissy has Clancey and can't start her morning without checking him out at the foot of our bed.

Would our lives have been different without NICU's and social work's support? How different would life be without early detection and early intervention? We don't know but suspect things would be very different. We've read the stories: good, bad, sad, extreme, and helpful. What stays with us is what we've known from day one, and that is "it's manageable." We read and hear about the extremes. And while this shouldn't be ignored, there's a lot of good news out there. Early detection, early intervention, hope, research, and time are on Chrissy's side, along with a little luck and a few prayers. And if this isn't part of better management of PWS, then at least we'll know we tried. That's Chrissy's attitude, too!



Chrissy Cornell with big brother Andy and her beloved canine friend, Clancey

pists have done so much for her by making Chrissy think she's playing, rather than learning. And her daycare provider has been *extraordinary*.

Chrissy has such a wonderful way of teaching you about life. Through her gen-

inside

To Parents of Little Ones	3
Research Studies at the Conference	4
For Mothers and Fathers	5
Speech and Language Development.....	6

Special Pull-out Section:

"In Search of Angels," PWSA Annual Membership Meeting and Board Candidate Announcements, Proxy Voting Forms (*between pages 4 and 5*)

The Prader-Willi Syndrome Association (USA)

5700 Midnight Pass Road, Suite 6
Sarasota, Florida 34242

www.pwsausa.org

1-800-926-4797

9:00 a.m.—7:00 p.m. Eastern Time

Local: 941-312-0400

Fax: 941 312-0142

E-mail: pwsausa@aol.com

National Office Staff

Executive Director - Janalee Heinemann

Office Manager - Brenda Hagadorn

Officers

President - Barb Dom (WI)

Vice-President - Mary Lynn Larson (WI)

Secretary - Mary K. Ziccardi (OH)

Treasurer - Jim Kane (MD)

Board of Directors

Chair - Ken Smith, Pittsburgh, PA

Paul Alterman, Marietta, GA

Dan Driscoll, M.D., Gainesville, FL

James Gardner, White Bear Lake, MN

Don Goranson, Bristol, CT

Jim Kane, Towson, MD

Mike Larson, Appleton, WI

Wauneta Lehman, Merritt Island, FL

Daphne Mosley, Oklahoma City, OK

Fran Moss, Camarillo, CA

Pauline Parent, Manchester, NH

Barbara Whitman, Ph.D., St. Louis, MO

Scientific Advisory Board

Chair - Suzanne B. Cassidy, M.D.,
Case Western Reserve University

Chair Emeritus - Vanja Holm, M.D.,
University of Washington

Merlin G. Butler, M.D., Ph.D., Children's
Mercy Hospital, Kansas City

Elisabeth M. Dykens, Ph.D., University of
California, Los Angeles

Jeanne Hanchett, M.D.,
Children's Institute, Pittsburgh

David Ledbetter, Ph.D.,
University of Chicago

Phillip D.K. Lee, M.D., Children's Hospital
of Orange County, California

Robert Nicholls, D.Phil.,
Case Western Reserve University

Stephen Sulzbacher, Ph.D.,
University of Washington

Barbara Y. Whitman, Ph.D.,
St. Louis University

William B. Zipf, M.D.,
Ohio State University



At center, PWSA Board Chair Ken Smith stands between Gwen Moore (left) and Dr. Jeanne Hanchett (right), both of whom are retiring this summer. At far left is Dr. Jim Hanchett (Jeanne's husband), and at right are Dr. Linda Gourash (Jeanne's replacement) and her husband, Bob.

Transition at the Pittsburgh Prader-Willi Program

As the staff of The Children's Institute Prader-Willi program begins planning for next year's national conference in Pittsburgh, they are also preparing for some major staff changes. Dr. Jeanne Hanchett, who has been the physician for the Prader-Willi program since 1982, will retire in July, and Gwen Moore, one of the original architects of the PWS program, will retire in August.

Dr. Hanchett, a member of PWSA's Scientific Advisory Board, joined what was then called The Rehabilitation Institute of Pittsburgh in 1977. She became involved with the Prader-Willi program after she met Bea Maier, who created the program, working with Gwen Moore and others, in 1981. When "The Rehab" became The Children's Institute last year, the PWS program was the only adult service that was retained. The Institute has a PWS outpatient clinic serving approximately 100 and the only in-patient crisis intervention program of its kind in the nation.

PWSA Board Chair Ken Smith, who is the Institute's case manager for Prader-Willi syndrome, writes: "Over the last 20 years, Dr. Hanchett has treated more people with Prader-Willi syndrome than anyone else in the world. ... She has become one of the national physician pioneers in the field." Dr. Hanchett has begun working with her replacement, Dr. Linda Gourash, and will continue to see clinic patients and to serve as a consultant after the transition, Ken reports.

The Gathered View (ISSN 1077-9965) is published bimonthly by the Prader-Willi Syndrome Association (USA) as a benefit of membership. Annual membership dues are: \$30 Individual, \$35 Family, and \$40 Agencies/Professionals for U.S. members and \$40, \$45, and \$50 (US Funds), respectively, for members outside the United States.

Opinions expressed in *The Gathered View* are those of the authors or editors and do not necessarily reflect the views of the officers and board of directors of PWSA (USA). *The Gathered View* welcomes articles, letters, personal stories and photographs, and news of interest to those concerned with Prader-Willi syndrome.

Editor: Linda Keder (keder@erols.com)

Associate Editor: Lota Mitchell (ljecholsm@juno.com)

Communications regarding *The Gathered View* or PWSA membership and services should be directed to the national office of PWSA (USA), 5700 Midnight Pass Rd., Suite 6, Sarasota, FL 34242. Telephone 1-800-926-4797, or in the Sarasota area 941-312-0400. Fax: 941-312-0142. E-mail: PWSAUSA@aol.com. Home Page: www.pwsausa.org

Dear Parents of the Precious Little Ones . . .

By Janalee Heinemann, May 2, 1999

Last weekend I attended the Florida chapter state meeting in Gainesville, and this weekend I attended and presented at a New York chapter (Prader-Willi Alliance) conference. While reading a book I brought along for the trip, *Tuesdays with Morrie*, I was struck with the words of Morrie to his student as he was in the final stages of dying from ALS (Lou Gehrig's disease). Morrie is talking to Mitch about the general selfish nature of our society, and states:

"The problem, Mitch, is that we don't believe we are as much alike as we are. Whites and blacks, Catholics and Protestants, men and women. If we saw each other as more alike, we might be very eager to join in one big human family in this world and to care about that family the way we care about our own. ... In the beginning of life when we are infants, we need others to survive, right? And at the end of life, when you get like me, you need each other to survive, right? ... But here's the secret: in between, we need each other as well."

In Morrie's words lies the beauty and profoundness of PWSA (USA) and our state chapters. We have been brought to our knees and learned that we do need each other to survive—and to care about each other beyond getting our own immediate needs met. There were many examples over the last two weekends of true love, and an open willingness to sacrifice for each other. I was hesitant to "give up" another weekend to go to the Gainesville, Florida meeting but went anyhow—and didn't regret it for a moment once I got there. Roda Guenther and her son, Chris, "gave up" their privacy to share a room with me and refused to take any money, because I had "given up" an evening to

write crisis letters to help get Chris into placement. The Kraurers "gave up" their time to plan the Florida meeting, and in New York, Henry Singer and his family "gave up" a great deal of time to organize their conference. I reflect back with pride on how our old St Louis chapter members pitched in and fought the system for two years to get our supportive living homes approved and opened. I also remember how the Florida state chapter members gave up a year of their life to put together

"I keep waiting for my child to get really bad like people have told me. I look at my little girl—she is so smart, and happy. And such a good little girl. Could it be that it's not going to happen to her? Are some children like my daughter?"

—Parent of a 2-year-old with PWS

the Orlando national conference. These are only a few small examples of common occurrences in our groups—but not a value that has been taught well to this generation in our American society—how to sacrifice for the good of each other, the good of society, and the good of our souls.

I watched the networking happening between the new young parents at the New York conference this weekend, and looked at the faces of their beautiful babies—and felt a warm glow knowing they were not only in the hands of caring parents, but also in the hands of a "community" that would care about them for the rest of their lives. I observed how delighted the parents of the older children were in just being able to look at or hold the little ones. Do they resent that they

had to struggle so hard to pave the way for this new generation of parents whose children will have opportunities that their children never had? NOT FOR A MINUTE! We "older" generation of PWS parents may not always agree on everything, but we learned long ago to live by Morrie's mantra, "Love each other or die."

Dear parents of the precious new generation of babies with PWS, we don't want you to feel our pain—we just want

you to gain our strength and tenacity in getting services for your little ones. We do feel your pain and understand your roller coaster of emotions. We wish we could protect you from all of the frightening literature and wish we could make our children look "prettier" and act "smarter"—not for our sake, but for your sake. Someday, we hope you can see beneath the veneer of our children's bodies—and see the beauty of their loving hearts and get the glimpses we get of the depth of their wisdom. In

Florida, I was talking to one of the teens with PWS, and he said, "Jan, the truth is I am alone most of the time. It's time for me to go into a group home, isn't it?" Another young man with "acquired PWS" said that he loved to put on his clown costume and make balloon animals for children—because then he didn't scare them with his size. In New York, I did the sharing group for our teens and adults with PWS. One young man said, "People laugh at us. I don't think they want to know us."

Dear parents of the precious little ones, we will continue to willingly work and fight for you, and hope someday that you can get beyond your own fears and be glad you got to know us and our children—and be ready to carry the torch for the next generation.

Research Opportunities at the July Conference

We are very pleased to announce that several researchers from around the country will be on hand in San Diego to work with interested children, adolescents, and adults with PWS and their families. A preview of these studies is summarized below. We hope that this information will help families decide if they would like to participate in any of these projects during the conference. All of these researchers appreciate your ongoing support and know firsthand that working together is the best way to promote new knowledge about PWS. More information and sign-up sheets for these studies will be available at the conference. In the meantime, if you have questions, please contact Elisabeth Dykens, Ph.D., at (310) 206-4633.

(1) Social Understanding in PWS

Kate Sullivan, Ph.D., & Helen Tager-Flusberg, Ph.D. (The Shriver Center and University of Massachusetts-Boston): "The broad goals of our research are to explore social understanding in individuals with Prader-Willi syndrome in an effort to understand the difficulties that PWS individuals often have in their social interactions with others. This year at the conference, we are interested in seeing adolescents and adults with PWS who are between the ages of 9 and 35. We plan to do two interviews to explore participant's understanding of themselves and their friendships. Together, the interviews should take approximately one hour, and they will be scheduled at the participant's convenience. Parents will receive a summary of their child's responses. We are also interested in interviewing as many parents as possible about their children's social and adaptive behavior."

(2) Jigsaw Puzzle Skills in PWS

Elisabeth Dykens, Ph.D., and the UCLA research team (Beth Rosner, M.A., Bob Hodapp, Ph.D., Tran Ly) all from University of California-Los Angeles, want to work with persons with PWS of all ages (6 to 60 years) who are particularly good at doing jigsaw puzzles or word search puzzles. We hope to discover how interests in puzzles might relate to visual-motor functioning, behavior, and possible interests in computers. We need an hour of time, scheduled at your convenience, to administer puzzles and other problem-solving tasks to persons with PWS, and an hour of time with parents to ask about puzzles and other behaviors. We will send parents individualized written feedback about their child's performance, and families will earn \$20.00 and a prize for their participation. We hope that you can join us for this fun project.

(3) Atypical PWS

Merlin Butler, M.D., from The University of Missouri-Kansas City School of Medicine and his colleagues at Vanderbilt University are searching for atypical persons with PWS with unusual chromosome/genetic findings such as translocations, imprinting mutations, and smaller than usual deletions. Dr. Butler and his colleagues will be on hand to talk to you about their genotype-phenotype studies and their need for these atypical PWS cases.

(4) Educational Needs of Students with PWS

Bob Hodapp, Ph.D., Tran Ly, Beth Rosner, M.A., and Elisabeth Dykens, Ph.D., from UCLA are examining the educational needs of 6- to 16-year-old students with PWS. Parents will be asked to fill out a questionnaire (takes 15 minutes) about their child's current educational placement, learning styles, and the degree to which the school program emphasizes different learning styles and approaches.

(5) School-to-Work Transition for Adults with PWS

Julie Seguin, M.A., and Bob Hodapp, Ph.D., from UCLA, are examining the transitions from school to adult services for young adults (aged 22-26) with PWS. They are interested in interviewing young adults with the syndrome about their experiences, as well as having their parents fill out some background information.

We all look forward to seeing you at the conference!

Parent/Provider Survey

Dr. Barbara (B. J.) Goff, whose survey form was published in the Jan-Feb issue of *The Gathered View*, is eager to hear from more of our members concerning their level of satisfaction with residential situations and parent/provider relations.

If you are a residential provider, or the parent of an adult with PWS who receives residential services, please take a few moments to complete and return this survey. If you need a new copy of the survey, please contact B.J. at 413-783-8192, or by e-mail: galagof@compuserve.com

Dr. Goff will be discussing her survey findings at both the service providers' workshop and the family conference in San Diego this July.

Attention: Conference Exhibitors

If you wish to present products or information about your organization at the 21st Annual PWSA (USA) National Conference at the Westin Horton Plaza Hotel in San Diego, Calif., on July 7-10, please contact:

Wauneta Lehman (board member)
Phone: 407-773-9503
Fax: 407-779-3031
E-mail: rwleh@aol.com

or

Fran Moss (conference co-chair)
Phone: 805-389-3484
Fax: 805-383-0899
E-mail: pwcf@msn.com

Exhibiting at our national conference is an excellent way for you to promote your services and products and to network with our members. A nominal fee will be charged, ranging from \$50 to \$200, depending on the type of display and space requirements. Please advise us as soon as possible about your desire to exhibit, as space is limited.

We thank you for your interest in our Prader-Willi syndrome population and families, and we look forward to working with you in San Diego!

IN SEARCH OF ANGELS ...

for the PWSA (USA) Annual Angel Fund Drive



Again this year we will be conducting our annual appeal for the PWSA (USA) Angel Fund. This is the primary fundraiser for our organization. In order for it to be a success, we need your help! Many people you know might be pleased to support our cause, but they've never been invited to help. We'd like to offer them the chance this year.

We ask you to send us the names of relatives, friends, and anyone else you feel might be willing to make a donation to PWSA or become involved with us as a member or volunteer. We will be contacting those individuals whose addresses you provide towards the end of this year, but we need to begin gathering names now.

Please fill in the following information and return this form to the national PWSA (USA) office by September 1st. If you need additional forms, feel free to make copies, or simply provide the requested information on a plain sheet of paper. When you've completed your list, send, fax, or e-mail your forms to:

**PWSA (USA) Angel Fund
5700 Midnight Pass Rd.
Sarasota, FL 34242
Fax: 941-312-0142
Email: pwsausa@aol.com**

We promise that these names will be used for no other purpose than to invite donations and support for the work of PWSA (USA). Please give us the opportunity to reach out to the angels you know. Thank you!



Your Name: _____ Telephone: _____

Name of Child with PWS (if applicable): _____

Please send the following people an invitation to support PWSA's Angel Fund:

Name: _____

Address: _____

City/State/Zip: _____

Relationship to individual with PWS: ☐ Grandparent ☐ Other relative ☐ Friend ☐ Other

Name: _____

Address: _____

City/State/Zip: _____

Relationship to individual with PWS: ☐ Grandparent ☐ Other relative ☐ Friend ☐ Other

(over)



**IN SEARCH OF ANGELS ...
FOR PWSA'S ANGEL FUND DRIVE**

Your Name: _____ Telephone: _____

Name of Child with PWS (if applicable): _____

Please send the following people an invitation to support PWSA's Angel Fund:

Name: _____

Address: _____

City/State/Zip: _____

Relationship to individual with PWS: ☐ Grandparent ☐ Other relative ☐ Friend ☐ Other

Name: _____

Address: _____

City/State/Zip: _____

Relationship to individual with PWS: ☐ Grandparent ☐ Other relative ☐ Friend ☐ Other

Name: _____

Address: _____

City/State/Zip: _____

Relationship to individual with PWS: ☐ Grandparent ☐ Other relative ☐ Friend ☐ Other

Name: _____

Address: _____

City/State/Zip: _____

Relationship to individual with PWS: ☐ Grandparent ☐ Other relative ☐ Friend ☐ Other

Name: _____

Address: _____

City/State/Zip: _____

Relationship to individual with PWS: ☐ Grandparent ☐ Other relative ☐ Friend ☐ Other

PWSA (USA) 1999 General Membership Meeting

Meeting Announcement

The annual membership meeting of the Prader-Willi Syndrome Association (USA) will be held on Friday morning, July 9, 1999, at the Westin Horton Plaza, San Diego, California, in conjunction with the PWSA (USA) 21st Annual National Conference (specific time and room number to be announced at conference registration). All PWSA (USA) members are invited to attend the annual meeting.

Board of Directors Election Information

The Prader-Willi Syndrome Association (USA) is headed by a 12-member board of directors. Board members are elected for three-year terms, and terms are staggered so that four terms expire each year. The Leadership Development Committee, which is appointed by the board, proposes a slate of candidates to fill the expired terms. In addition, nominations can be made by any PWSA member from the floor at the general membership meeting. In selecting board candidates, PWSA seeks to maintain representation by parents, professionals, and service providers on the board, as well as to represent various regions of the United States.

In 1999, all four board members whose terms are expiring have chosen to retire from the board. The Leadership Development Committee has proposed four new candidates, whose biographies and photos appear on the following pages. If there are no additional nominations from the floor at the general membership meeting, members in attendance may be asked to approve the candidate slate by a voice vote or show of hands. If there are additional nominations from the floor, voting will be by secret ballot during a designated time period July 9-10 at the national conference in San Diego, California.

Issues for Voting by the Membership

Only motions made and seconded in writing three months prior to the annual meeting are eligible for consideration at the annual meeting. No motions have been put forth for membership vote in 1999.

Voting Eligibility

Members of PWSA (USA) whose dues payments are current are eligible to vote in the annual election. Individual and Professional/Organization Memberships are entitled to one vote; Family Memberships are entitled to two votes—one each by two separate individuals from the same family.

Voting by Proxy

A member unable to attend the annual meeting may name another member who will be attending to cast a proxy vote. This is done by completing the official proxy form included in this mailing and returning it directly to the national PWSA office for receipt no later than June 25, 1999 (14 days before the annual membership meeting). No substitute proxies, letters, faxes, or telephone designations will be accepted. (Note that the bottom half of the official proxy form is a second proxy ballot to be submitted only if there is a second individual within a Family Membership who wishes to cast a vote by proxy.)

The completed proxy form must include:

- The name of an eligible voter who will be attending the national conference. (If you wish to vote and do not know any member who is attending, you may designate any PWSA board member or officer to serve as your proxy. These individuals are listed on page 2 of *The Gathered View*.)
- Instruction to the designated proxy (by a check in the appropriate box) either to vote for candidates marked on the form or to vote as the proxy sees fit.
- The name (clearly printed) and signature of the member completing the proxy form.

Please mail the original proxy form to:

PWSA Election, 5700 Midnight Pass Rd., Suite 6, Sarasota, FL 34242
(Proxies must be received at PWSA's national office by Friday, June 25, 1999.)

PWSA (USA) Board of Directors Election

July 1999

Information on the Candidates

The Leadership Development Committee has put forth the following slate of candidates for consideration by the membership. There are four nominees for four seats on the Board. All nominees were invited to submit a biography or statement and a photograph. Their submissions follow, in alphabetical order. Voting for candidates takes place in person at the national conference or by proxy form (enclosed).

Dorothy M. (Dottie) Cooper, PMP (Georgia)

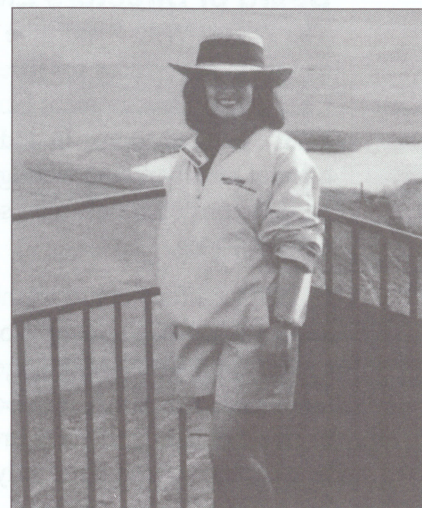
I am a Senior Operations Manager for METAMOR Information Technology Services (an IT consulting firm), having retired from BellSouth with 31½ years of service in 1996. I received my BA in Business Administration (summa cum laude) in 1996, and in April 1999 became a certified Project Management Professional (PMP). My husband, Dale, and I—married for 31 years—have a son, Chad (27), and a daughter, Shawn (23), who was diagnosed with Prader-Willi syndrome at age 11.

My PWS advocacy began in 1985, when I learned of my daughter's diagnosis and began consuming literature on the subject. In that year I joined the national PWSA, attended my first PWS conference, and hosted the first of two parent/medical professional "Southeastern Regional PWS Conferences" in Birmingham, Alabama. Upon moving to Georgia in 1988, I joined the local chapter and was very active in the chapter effort to work through political hurdles to establish the first PWS group home in the state of Georgia (1993).

As Georgia chapter president (1992-1994), I chaired the state chapter project to host the 1994 National PWSA Conference, held in Atlanta, Ga. With a creative, motivated, and dedicated membership, our planning committee introduced a number of new perspectives to the conference format. Most significant were an updated agenda (Newcomers/Old Timers, Grandparents Only, reception for medical and provider professionals, etc.), meeting facilitation, corporate fundraising/sponsorship (the "refrigerator" public relations folders, corporate grants, in-kind donations, etc.), telephone company Pioneer volunteers, and national publicity (*USA Today*, CNN, etc.). The conference agenda, staff and volunteer training, hotel accommodations, food service, and the YAAP program received very positive feedback.

I've been a member of the Georgia chapter Board of Directors since 1994 and have served as a resource on conference planning to other state chapters. I believe that teamwork is essential in accomplishing major projects, and I feel privileged to have been part of a great team effort that has achieved a number of such goals in the state of Georgia.

If elected to the National Board of Directors, I would offer passion and commitment to the goals of the organization, as well as professional project management and facilitation experience.



Pauline Haller (Maine)

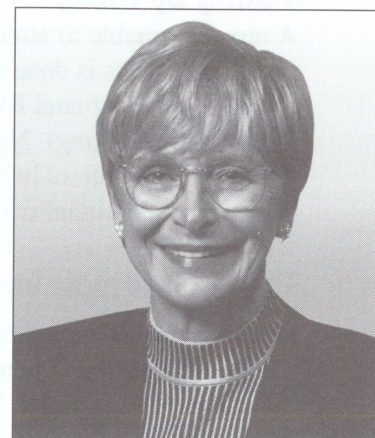
Hello, I am Pauline Haller from Presque Isle, Maine. My husband Erich and I have four wonderful children, two daughters and two sons. Our youngest daughter, Andrea, now 30 years old, was diagnosed with PWS at age 3.

Erich and I were the eighth family to join PWSA (national) in 1975. In addition, we are members of the Prader-Willi Florida Association.

The following is a list of several committees and boards on which I have served:

- Charter board member of Personal Services of Aroostook, which provides supported living, supported employment, waiver home services and peer group support for the mentally challenged in the greater Presque Isle area.
- Served on the board of directors for New Vocations, Caribou, Maine, an organization which seeks employment opportunities for the mentally challenged.
- Served on the committee that developed a group home in Presque Isle, in which our daughter resides. Also a board member of same for seven years.
- I enjoy working with people to identify problems and find solutions. I have experience as a volunteer in the following organizations: Hospice of Maine, Cancer Mount, Battered Women's Project, and a literacy volunteer program in the Naples, Florida, education system.

I have been working with parents, persons with PWS, and the organizations that support them since my daughter's diagnosis. I would consider it a privilege to devote my time to the PWSA as a board member. Thank you for your consideration.



Carolyn Loker (Michigan)

Who am I?

I am a Wife to Jim (a pediatric cardiologist and co-chair of the committee that is developing a Medical Advisory Board for PWSA).

I am a Mother to four beautiful daughters—Michele, 29 years; Ashley, 16 years; Breanne, 14 years; and Anna, 4 years old (see photo). Anna was diagnosed with Prader Willi syndrome at 17 months old.

I am a Medical Professional, as a pediatric cardiac echosonographer currently taking time off to spend more time with Anna.

I am the Co-President of the Michigan PWSA Chapter along with my husband. We have worked hard with the chapter to increase its enrollment as well as its activity on the national level. We also write the chapter newsletter.

I am the Co-Founder of Parent to Parent Resource Group of Southwest Michigan. This organization supports parents through mentoring, parent matching, attending IEP and IFSP meetings, and finding community and financial resources that best suit the family's needs.

I am Co-Author of the "Nutrition Guide for the Newborn through Toddler Child with Prader Willi Syndrome," which PWSA (USA) plans to publish this year.

I am a Parent Support/Mentor for PWSA (USA). I have been pleased to talk with many families from across the country with a child newly diagnosed with Prader Willi syndrome. I hope that my encouragement helps them through their difficult time.

If elected a member of the board of directors, I would be a strong advocate for the parents of young children with Prader Willi syndrome. I have never looked at "Who I am." I try to do what is in my heart and pray that my purpose will be fulfilled.



Pamela Tobler (Utah)

I'm sure many of you have seen those toy snow globes filled with water. You know the ones with the village scene and when you shake it, it "snows" in the village. On September 14, 1995, it snowed in our village when Nathaniel joined our family. Shock was my first reaction, but not for long. We soon realized that snow doesn't ruin things, it makes them look different, and usually more beautiful. We decided to do everything we could to make our son's life as rewarding and fulfilling as possible for him.

We quickly became involved with the Utah PWSA chapter with some fund raising ideas I had, and I was soon elected as the next president of the Utah chapter. We realized we were some of the very fortunate to have had a diagnosis for our son so quickly (12 days after birth), and we wanted to assist others in achieving that goal. With the aid of a student public relations team from a local university, I coordinated the implementation of a statewide awareness campaign and some fund-raising opportunities. We implemented quarterly educational meetings for the parents and continued quarterly parties for our children and their families. After a year of service, my term as president ended because of employment opportunities outside of Utah for my husband. [The Toblers have since returned to Utah.]

I realize that I am a newcomer to the PWSA arena, but newcomers bring new energy and new ideas. We have been PWSA (USA) members since 1996. The first conference we attended was in 1996 in Orlando. The knowledge gained has enabled us to assist our son and those we worked with in Utah to lead fuller, happier lives. We also realized how much more there is for us to learn.

With a bachelors degree in public relations and having worked in that field for several years for a prominent author and speaker, I have developed strong communication skills that will assist in more awareness activities and ideas. I know what it takes to obtain media coverage—I've made it happen for other issues.

With our son only 3½, we are dealing with many issues that parents of younger children with PWS are encountering. I see this opportunity of serving on the board as an opportunity to represent the younger families and individuals and to improve the quality of your lives. I want to assist my son, and in the process I want to assist your sons and daughters (and grandchildren) to have as rewarding and fulfilling a life as you and I enjoy. Together, we can make a difference!



Instructions for Completing the Proxy Ballot

(Note: The official proxy ballot is on the next page. Use this form to cast your vote if you are a PWSA-USA member in good standing, and you will not be present at the San Diego meeting to vote in person. Family memberships may submit two proxies.)

Your proxy form will be hand-delivered to the person whose name you write here (any eligible voter who is attending the conference, including any current officer or board member)

The state name will help us identify the member you've chosen as your proxy, if it is not a current officer or board member

Prader-Willi Syndrome Association (USA) 1999 SAMPLE PROXY

I hereby appoint _____ of _____ to
(print name of your designated proxy voter) (state of residence)
vote as my proxy at the PWSA (USA) Annual Membership Meeting in San Diego, California, July 1999.

Instructions to proxy voter:

☐ Please cast my vote as you see fit

OR

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

(Check no more than FOUR)

☐ Dorothy M. Cooper

☐ Pauline Haller

☐ Carolyn Loker

☐ Pamela Tobler

☐

(This space provided for a write-in candidate)

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

Name _____
(please print)

Signature _____ Date _____

If you wish to have your designated proxy voter choose board candidates, check the first box, and don't check any others on the ballot.

Cast your vote for chosen board candidates by checking the second box under "Instructions to proxy voter" AND checking the box next to each of your selected candidates

Please print clearly on the Name line, using the name that appears in our membership records, then sign your name on the Signature line the way you sign other legal documents

PROXY FORMS MUST BE RECEIVED AT THE NATIONAL OFFICE BY FRIDAY, JUNE 25, 1999

MAIL TO: PWSA ELECTION, 5700 Midnight Pass Rd., Suite 6, Sarasota, FL 34242

Prader-Willi Syndrome Association (USA)
1999 OFFICIAL PROXY

I hereby appoint _____ of _____ to
(print name of your designated proxy voter) (state of residence)
vote as my proxy at the PWSA (USA) Annual Membership Meeting in San Diego, California, July 1999.

Instructions to proxy voter:

☐ Please cast my vote as you see fit

OR

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

(Check no more than FOUR)

☐ Dorothy M. Cooper

☐ Pauline Haller

☐ Carolyn Loker

☐ Pamela Tobler

☐

(This space provided for a write-in candidate)

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

Name _____
(please print)

Signature _____ Date _____

This ballot to be used by
Family Memberships only.

Prader-Willi Syndrome Association (USA)
1999 OFFICIAL PROXY for Second Family Member

I hereby appoint _____ of _____ to
(print name of your designated proxy voter) (state of residence)
vote as my proxy at the PWSA (USA) Annual Membership Meeting in San Diego, California, July 1999.

Instructions to proxy voter:

☐ Please cast my vote as you see fit

OR

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

(Check no more than FOUR)

☐ Dorothy M. Cooper

☐ Pauline Haller

☐ Carolyn Loker

☐ Pamela Tobler

☐

(This space provided for a write-in candidate)

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

Name _____
(please print)

Signature _____ Date _____

THIS ORIGINAL PROXY FORM MUST BE RECEIVED AT THE NATIONAL OFFICE BY FRIDAY, JUNE 25

MAIL TO: PWSA ELECTION, 5700 Midnight Pass Rd., Suite 6, Sarasota, FL 34242

THIS ORIGINAL PROXY FORM MUST BE RECEIVED AT THE NATIONAL OFFICE BY FRIDAY, JUNE 25

MAIL TO: PWSA ELECTION, 5700 Midnight Pass Rd., Suite 6, Sarasota, FL 34242

For All the Mothers and Fathers

This year I am celebrating my 15th Mother's Day, and this will be the same anniversary for my husband in celebrating Father's Day. Little did we know how much being a parent would change our life. These past 15 years have been wonderful, exciting, challenging and adventurous (sometimes *too* adventurous).

We are all *special parents with special kids who have special needs who bless us with special gifts.*

As a parent, you can and do make a difference in your children's lives. I don't know about you, but this parenting stuff has been a bit "spooky" at times. I guess the magic or spooky part that I am referring to is also known as "mother's intuition." Dads also get pretty good at this intuition stuff but mothers are the pros. We sure get to know our kids ... their cries, their "off days," their needs at school, their illnesses, their challenges and their successes. We can tell when they are telling the truth and when they are not; when they "want something"—

even before they ask for it; and when something is bothering them. It is truly amazing.

Oh yes ... their successes. These are the gifts that we learn to APPRECIATE, TREASURE and CELEBRATE.

- I remember our son's first cry ... he was 3 months old. I remember not knowing what to do—"do we let him cry or should we pick him up?" (We picked him up.)
- I remember his first steps ... he was 2 years old. It really *did* happen.
- Our whole neighborhood remembers his first success at potty training. He was 4 years old. We proudly announced this big accomplishment to Dad, who was doing some work on the top of our roof.
- His successes at school ... his first birthday party—that HE was invited to ... his first sleepover ... his first dance. And now *he* can't wait for his first kiss. (*We* sure can.)

Yes, there have been challenges. It hasn't been easy. But no one has ever said parenting was going to be easy. Our parents just made it look easy. I have friends right now who are dealing with

"We all have our challenges—some bigger than others, some sooner than others."

their kids who are doing drugs and getting into trouble with the law, and they are fearful that their children will drop out of school. We all have our challenges—some bigger than others, some sooner than others.

Make sure to take time for yourself as a couple. We always make time for little league, soccer or hockey. We need to make time for each other. *The greatest gift we can give our children is to take care of ourselves as a couple.* Have a date once a month. Some dates may be big—a movie, a night out. Others may be small—cuddling on the couch after the kids go to bed. (I don't know about you, but I remember a few dates like that in my past.) Maybe you can meet your spouse for a quick lunch or breakfast after the kids are in school. My husband and I have "a date" once a month and our children think that is pretty neat.

Parents, you are special, powerful people. There has never been a group of people that has made so many positive changes for their kids in schools, in homes, and in the communities that we live in—no group like parents. Be proud and celebrate your gifts and your accomplishments. Happy Mother's Day and Father's Day to everyone.

TAKE CARE, and I hope to see and meet many of you in July.



The Chuckle Corner

Debbie Peaton of Florida shares a story about resorting to the old soap treatment to clean up her son's language. When she caught Rorri (16) using the "F" word, she made him take one bite of soap for every letter in the forbidden word. (It wasn't his first time.) ... When it was all over, Debbie asked, "How did you like it?" Rorri replied, "Actually, Mom, the Irish Spring tasted pretty good!" (by comparison with his earlier taste of Dial brand, anyway...)

Debbie Stallings, who brought this story to our attention, had recently made a pre-conference site visit to San Diego, where she and her husband, John, will be running the Youth and Adult Activities Program. In the conference hotel, she discovered "oatmeal and peppermint soap," which she reports "smells and looks very inviting." After hearing the Irish Spring story, she notes that "if we see any participants at the conference show up foaming at the mouth, we shall not panic!"

Speech and Language Development

By Mary Lynn Larson, MA, CCC-SLP
Pediatric Speech Therapist and Vice President, PWSA (USA)

Editor's Note: Mary Lynn Larson, who was appointed vice president of the association in January of this year, is the parent of a young son with PWS. She originally wrote this article on speech and language issues for the Wisconsin chapter newsletter. It is reprinted here with her permission.

It is believed that man is born with the innate ability to learn language. This means a built-in capacity to understand and learn the language of his environment, whether that is English, French, or Navajo. Unfortunately, when a child is born with Prader-Willi syndrome, the development of these skills is affected significantly by a number of factors, including, but not limited to, their level of cognitive skills, the degree of hypotonia, and the implementation of early intervention programming. Hypotonia and cognition are responsible for many of the difficulties seen with speech and language issues in individuals with PWS.

The hypotonia greatly affects a child's oral motor structures in ability and functioning, whether it relates to feeding or speech/language. Muscle weakness may be responsible for some of

the unintelligibility/imprecision in the child's utterances, which might also be referred to as an articulation or phonological disorder. Low tone may also contribute to the degree of hypernasality that might be noted in their utterance. Hypernasality is usually a direct result of inadequate velopharyngeal closure, or the inadequate closure of the oral and nasal cavities using the velum and pharynx. Closure of the velopharyngeal port results in directing airflow to the oral cavity and closes off the nasal cavity. Children suffering from hypernasality sound like they are "talking through their nose."

A delay in language development might be attributed to a cognitive delay or perhaps the child's inability to demonstrate their understanding of what is spoken to them due to a delay in their motor skills. How can a child demonstrate they understand a two-step directive such as "Put the cup on the table" if they do not have the motor skills to reach for the cup and perhaps the ability to balance while standing to place it on the table? How can a child explore their world and the wonderful objects about them if they have difficulty maintaining a sitting balance or difficulty with two-handed midline play?

Most of us explore new items with both hands in front of our bodies while perhaps using our fine motor skills to turn and rotate the object for visual (sight), tactile (touch), auditory (hearing), olfactory (smell) and sometimes oral (taste) exploration. It is often appropriate for the Physical Therapist/Occupational Therapist/Speech Therapist to work in joint sessions with the child to help them explore their motor abilities and language skills. As a child becomes more mobile, they might often put their language on hold until they are comfortable with their newfound mobility skills, and then after a period, you see gains in their language skills also. I often tell parents of the children I work with that children are a sponge and need to soak up what we are striving to teach them for a period of time and then, after a while, they show us that they *really were* listening and paying attention!

Our cognitive skills (sometimes referred to as our mental skills, problem-solving skills, or thinking skills) very closely match our language skills, as you cannot (or perhaps shouldn't) talk above the level of your knowledge base. In other words, you can't use language you don't know, referring to grammar, vocabulary, etc. ... A language delay because of a cognitive deficit requires working with the child on using these forms of grammar or vocabulary and modeling the use of these structures. It might include expanding their vocabulary base from 10 words to a more age-appropriate expressive vocabulary through modeling and exposure to age-appropriate vocabulary words and language structures. One of the issues with many children is their intelligibility—how easy or difficult it is to understand them when they speak. The most common issue affecting a child's intelligibility is their articulation skills. A child may not be using sounds correctly and often substitute easier

PEN PALS WANTED



E-MAIL

Krider17@aol.com

My name is Kerry. I am 23 and I have PWS. I like horseback riding and swimming and playing with dogs. I like birds, and I have a bird.



U.S. MAIL

Lance is looking for a writing pen pal (NOT e-mail), who is a young woman in her mid-20s. Lance lives at Laura Baker School in Minnesota. You can write to him at this address: Lance, Laura Baker School, P.O. Box 611, Northfield, MN 55057.

Continued on page 7

Foundation Funds PWS Conferences

The Prader-Willi Foundation announces that it will consider requests for funds of up to \$1,000 from state and regional PWSA chapters to hold conferences on Prader Willi syndrome. The Prader-Willi Foundation is a national public charity, incorporated in 1994 in New York to promote the cause of Prader-Willi syndrome.

PWSA (USA) expresses its gratitude to the Prader-Willi Foundation for donations of \$2,000 in 1999 family conference grants, \$3,500 for bus transportation for the 1999 conference youth program, and \$480 for a video duplicating machine.

For further information, or to apply for a Foundation grant, contact: Meg Comeau, 13 Oak Knoll Rd., Burlington, MA 10803, or e-mail comeaum@a1.tch.harvard.edu

New Handbook for Parents Available from PWSA

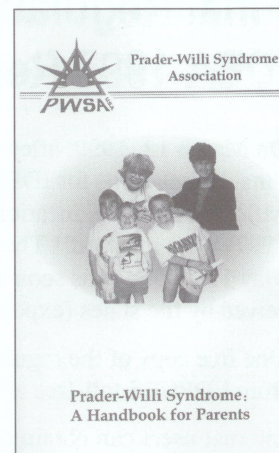
Updated and Full of Photos!

In 1978, PWSA published the first *Handbook for Parents* of children with Prader-Willi syndrome. It was written by one of the association's founders, Shirley Ann Neason, the mother of Daniel, to whom the book is dedicated. Although Daniel died at age 13 of a viral infection unrelated to PWS, Shirley's booklet has lived on and been revised several times since its original publication.

The 1999 edition retains the warm, parent-to-parent tone of the original writing and enriches the text with numerous photographs of our beautiful children with PWS, young children in particular. More importantly, the content is updated to reflect the latest knowledge of Prader-Willi syndrome—the genetics, the wide variability of characteristics, the best treatment and prevention strategies, and the importance of early intervention.

The professional editing and layout of this latest edition were accomplished by two more parent volunteers: Suzanne Wise Ceppos, a freelance writer and editor from Ann Arbor, Michigan, and mother of a 10-year-old daughter with PWS, updated the text; and PWSA Board Member Mike Larson, a mechanical engineer and technical writer from Appleton, Wisconsin, with a 6-year-old son, designed the layout. Our thanks to Suzanne and Mike for a superb job on a truly important booklet.

To Order: *Prader-Willi Syndrome: A Handbook for Parents* (75 pages), is now available through PWSA (USA) at a price of \$7.00 (+ \$1.50 shipping) for PWSA members and \$10.00 (+ \$4.00 shipping) for nonmembers. Send order with check payable to: PWSA (USA), 5700 Midnight Pass Rd., Sarasota, FL 34242.



PWSA Video Available in PAL Format

"Searching for Solutions," PWSA's professional video released in 1998 as a general introduction to Prader-Willi syndrome for all audiences, is now available in the European PAL format. The price of this video is the same in both formats—\$20 for PWSA members, \$25 for nonmembers, plus shipping charges (\$4 to U.S. and Canada, \$10 to other countries). Specify US or PAL format. *See above for order address.*

Speech and Language—continued

sounds in their place; for example, they might say "tup" for "cup." A therapist might refer to a child's articulation difficulties as a "phonological processing" disorder. This refers to a child's learning the "rules" or classification of sounds. For example, some sounds are made in the front of your mouth, (like /t, p, d, b/) where some are made in the back, (/k, g/). A child might not always recognize this rule and use some of the "front" sounds for "back" sounds. Some sounds might be described as "long" sounds (as therapists, we refer to them as *contin-uants*—/s, z, Th, sh, f, v/—because they continue) while others are "short" sounds

(these are referred to as *stops*—/p, d, t, k, b, g/). If a child does not know the rules of sounds, they will not know when to use each of these different classes. Using sounds from another class makes it difficult for us as listeners to try to figure out what the child is saying. If a child uses a different sound than needed but it is from the same class, it is much easier to guess what they are trying to tell us. Knowing why the articulation problem occurs (e.g., not knowing the rules of sounds) helps the therapist identify approaches that enable the child to make the most progress.

One of the many questions parents ask is what they can do for or with their child at home. Depending on the nature of the problem the child is experiencing,

carryover/home activities can vary dramatically. Some basics include modeling language you want your child to imitate, using gesture or visual cues to help their understanding, and rewarding or praising them when language is successful! Talk with your child's therapist to get some ideas for home carryover that are appropriate to the situation.

But remember, you are the parent, not the therapist, and they look to you to love them and "make it all better" when things go wrong. Many parents find that their child does not respond well to them taking on the therapist role. Try to avoid doing the activities in a drill routine and try to incorporate them into everyday conversational activities. ▲

Final Regulations for IDEA 1997 Released

On March 12, 1999, after numerous delays, the Final Regulations for IDEA 1997 (the Individuals with Disabilities Education Act Amendments of 1997) were released!! The regulations take effect May 11, 1999, or as soon as federal funding is received by the states (expected July 1).

One free copy of the regulations can be requested from EDPUBS toll-free at 877-433-7827.

Internet users can obtain copies of the Regulations online through a number of Websites:

- <http://www.ed.gov/legislation/FedRegister/finrule/index.html>
- <http://www.ed.gov/offices/OSERS/IDEA/getregs.html> (U.S. Office of Special Education and Rehabilitative Services)
- <http://dssc.org/frc/regs99.htm> (Federal Resource Center)
- <http://www.pacer.org/idea/idea.htm#idearegs> (PACER Center)
- <http://www.ideapractices.org> (IDEA Practices)

For information about the IDEA Amendments of 1997, including general information, a copy of the law you can download, and several important memos and letters from the U.S. Department of Education, go to:

- <http://www.ed.gov/offices/OSERS/IDEA/index.html>

For a short summary of the changes, go to:

- <http://www.cec.sped.org/pp/idea-a.htm> (Council for Exceptional Children) OR
- http://www.pacer.org/idea/pacer_idea97.htm (PACER Center)

NICHCY's Publication on IDEA 97

The National Information Center for Children and Youth with Disabilities (NICHCY) publishes many useful summaries on special education. The revised version of NICHCY's News Digest 26, "The IDEA Amendments of 1997" (June 1998), is now available on-line in both text-only and PDF formats on NICHCY's Website: <http://nichcy.org>.

You can also call toll-free 1-800-695-0285 and request one free copy of the News Digest.

March and April Donations

1998-99 Angel Fund

Angel

(\$100-\$249)

John B. and Mary Ann Danese
Linda L. Hartnett (*in celebration of Callaghan McCulley Hartnett*)
Lynda & Marvin Helton
Alan Inselbuch
James A. & Susan F. Judge
Teresa Kellerman
Mitch Menzer & Wendy Wolf

Cherub

(Up to \$99)

David & Darlene Endres
Stephen Felder
Margaret Hollingsworth
Mike & Susan Trogan
Bruce & Bebe Whyte
Loraine & Dale Zarr



Other Donations

Patron Memberships (\$100+)

Cinda & Curt Ball
Case Western Reserve University
Donald & Peg Goranson, Jr.
Louise Greenswag
Melinda Marie Morrow
Anthea Richardson

Contributing Memberships (\$50-\$99)

Kevin & Michelle Donaldson
Kathy Funk
Su Glesner

Research Fund

Fredna & Marler Bennett
Stuart R. Boyd

Operating Fund

Shirley Burnett (*for recovery of grandson, Mathew*)
Shirley Burnett (*in honor of Walter Kane's 75th birthday*)
Raymond and Phyllis Fuja
Bryan & Karen Juncosa
Evelyn Krebsbach
Lane & Phyllis Loyko (*in honor of Amanda Diaz*)
J. McCarthy & A. McGovern

Operating Fund—continued

Brook & Joanne Parker
Robert W. Place
Raymond Sheeran
Laurie Smalling
Cliff & Wanda Strassenburg
United Way
United Way of Orange County
Dave & Cori Witte

MEMORIALS

VERA W. BAKER
R. Nieman

JASON BOND
(AND IN HONOR OF
JEFF BOND)
Peggy Outen

FLORENCE DOBRING
Evelyn Krebsbach

LEONARD LEVINE
Judy and Sidney Block
Ernest & Lillian Blumberg
Melvin Comak
Jack Darman
William Doughty
Sylvia Gordon
Mindy and Fred Hirsh
Jason L. Levy
Ruth Lutzky
Richard Marson
Sue Meyer
Edward and Ruth Needel
Rita & Bill Needel
Barbara and Stuart Packer

PRISCILLA B. SMITH
Eleanor Bloomer
Thomas Bloomer, Sr.
Harry and Ann Burt
S. Edwin Hallagan
Helen Hamilton
Ruth Maurer
Lota E. Mitchell
Robert W. Place
Maurice Strobbridge
Eleanor Stuart

LYNN TILL
Jean Till

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.

