

The Gathered View

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

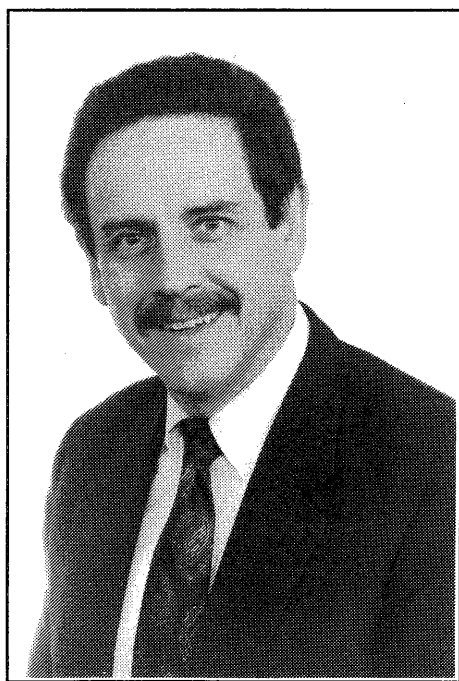


1994 and Beyond Leadership, Location Changes Chart a New PWSA Course

PRESIDENT'S MESSAGE

by Janalee Tomaseski-Heinemann
November 28, 1993

The 1994 New Year brings the promise of a new beginning for PWSA (USA). I am pleased and excited to announce three important decisions by the Board of Directors which I believe will help push our Association into a new era of growth and service.



Russ Myler
PWSA (USA) Executive Director

The first is that we have hired a new executive director, Russ Myler. Russ is currently the executive director of the Missouri Chapter of the National Association of Social Workers. Although I did not know Russ personally before, he has an excellent reputation within NASW. He has been in his current position seven years and, prior to that, he was director of social work at a home for emotionally disturbed children for 11 years.

Some of Russ's strengths are the following:

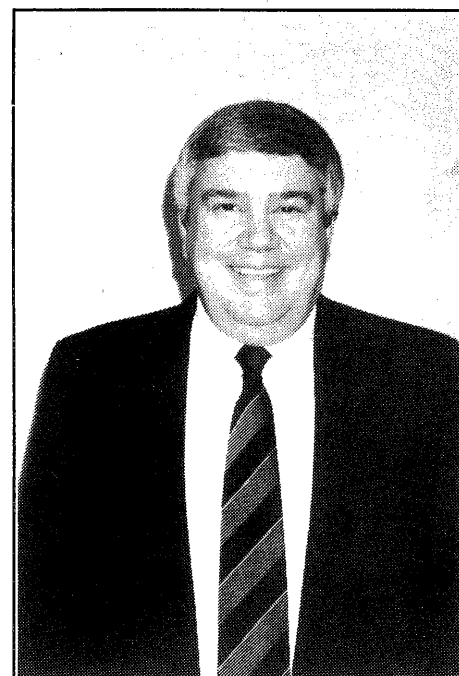
1) He is very personable, and I think everyone will find him very approachable. 2) He has strong writing and publication skills. Russ has compiled several brochures and packets of information for NASW. 3) Russ also has good managerial skills. In his current role, he works in a two-person office and deals with the entire spectrum of duties similar to what he will be dealing with in the PWSA office. 4) Russ currently works with a board of 25 people, to which he reports on a regular basis. He is well respected both by his board and the state membership. 5) Russ has political and fundraising skills. He was responsible for getting significant legislation passed in Missouri for social workers. 6) Russ has a strong social work background and spent his early career dealing with families in crisis or in need of special information and help. He has expressed a desire to get back into an area where he is more directly assisting families.

The second announcement is that the National Office will be moving to the St. Louis, Missouri, area around the first of January. An office location has already been approved. (See box on page 7 for the new address.) Missouri is centrally located, and there are major medical and university facilities available. There also is an active state chapter and four supportive living homes in the area. Unfortunately, Gretchen Gogel is unable to move with the office, so a new assistant director will need to be hired. Gretchen has been a tremendous asset to our association, and I regret losing her.

My last, but certainly not least, announcement is that Don Goranson has been approved by our board as our new vice president. Don is a parent of a 24-year-old son, David, with PWS and is the immediate past president of our Connecticut Chapter. Don worked for a city newspaper for 20 years and became managing editor. He is now serving as an editorial consultant for his state's department of education. Don is

also an active member of the PWSA public relations committee. I have found Don a pleasure to work with and a person with many excellent ideas to contribute.

Each year our New Year's resolution needs to be a renewed commitment to do the best we can for our families and friends of PWSA. I feel confident that the changes we are making will take us to a new level of professionalism with PWSA (USA) and broaden our ability to support all families. Over the years Tere Schaefer and, before her, Marge Wett have been an invaluable support for our Association in the role of executive director. I in no way want to diminish all of the good they have done for each and every one of us. Although we are branching out in many ways, let us never forget our roots. My sincerest thanks go to both of these committed women.



Don Goranson
PWSA (USA) Vice President

Prader-Willi Syndrome Association (USA)

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Culver, The Fieldstone Foundation
(matching grant for Culver), William &
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OPERATING FUND

Alberto Culver, MBNA, PWS Missouri
Association

Christmas Card Fund Raiser

In October, a sampling of members received a pack-
age of Christmas cards and were asked for a donation.
As of December 3, 293 donations were received for a
total of \$4,367.

If you're planning your retirement from PWSA involvement, please think again ...

A Message from Curt Shacklett, Past Chairman, PWSA Board of Directors

(from Curt's address to the PWSA general membership meeting, July 1993)

Our organization cannot continue to attempt to service our members and promote the quality of life for our children and adults with PWS without our individual involvement, without our energy, without our investment of time, emotional creativity, and financial resources. As a small organization we need everybody's help, everybody pulling together.

On several occasions we have mentioned in *The Gathered View* and at conferences what we believe are some of the benefits of membership in PWSA. We have wanted to address the question: "What do I get out of my membership?" And rightly so that we should address this point. I am concerned, however, that there is another side of this issue that is being ignored. One of the cultural character flaws that I perceive in us

Americans is that we have a "me first" mindset—i.e., "What's in it for me?"

I am very troubled by one of the things I have seen as chairman of our organization, and that is the tendency of some of our members to simply ride off into the sunset never to be heard from again once their child with PWS has been placed in a residential facility or they have finally resolved the future care of their child. They no longer attend conferences to offer support, encouragement, and insights to younger families who are struggling; they no longer support the organization or their state chapter with their energy and financial resources. This is an incredible tragedy. We are too small an organization to let this happen; nor should it happen even if it were large.

We may attend a conference or become involved at the national or local level in our organization because we, as parents, experience a profound sense of personal need and yearn for help. This is clearly understandable. But once

some help is received, once we have situated our son or daughter in a "permanent" placement or living arrangement, if we then walk out the door of involvement with PWSA, what we are really saying is: "I did it all for me ... I did it all for my child, and frankly, I really don't give a hoot about someone else's struggles or problems."

There will be persons with PWS, yet unborn, and whose names are known only to God, who will enter upon our planet in future years. Who will be there to help those families? If we don't take the initiative now to provide for their future needs, who will? We have a responsibility to one another and those yet undiagnosed and yet unborn. Will you be there and help PWSA be there, or will you ride off into the sunset?

To paraphrase the words of former President Kennedy: **Ask not what your Association can do for you, but ask what you can do for your Association.**

The PWSA Leadership Structure

(summarized from the PWSA By-laws and Policies and Procedures Manual)

The Board of Directors, which is the governing authority and carries the control and responsibility for the affairs and business of the corporation, consists of 12 members elected by and from the membership at large for three-year terms. One member is elected to serve as **Chairperson** for a term of one year at a time, up to a maximum of six terms, which are not necessarily consecutive. The chairperson calls board meetings, prepares agendas, and conducts such meetings.

The officers are **President, Vice President, Secretary, and Treasurer**, all of whom are appointed by the board, attend all board meetings, but

have no vote. An officer may also be a board member, in which case he or she votes in that capacity. The president and vice president are elected for three-year terms, with a maximum of two terms. The secretary and treasurer are elected for one-year terms, with no limit on the number of terms because of the specialized skills required in these positions.

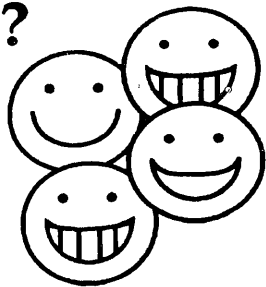
The **President** is the principal officer of PWSA, presides at the organization's membership meetings, and recommends the appointment and supervises the work of the executive director, among other duties. (Historically, both the president and the chairperson of the board of directors have been parents of children with PWS.)

Outgoing chairpersons and presidents are on the **Advisory Committee** for one year, along with Gene and Fausta Deterling, founders of PWSA and lifetime members of that committee. Advisory committee members are invited to attend board meetings but have no vote.

The **Executive Director** is employed by PWSA to manage the day-to-day operations of the organization, including support to families and chapters, publications, national conferences, training, fundraising, and public relations. The executive director hires and oversees the work of the national office staff.

How Many Are We?

We've all heard, or read, various occurrence rates for PWS—ranging from one in 8,000 to one in 25,000—but what exactly do those numbers mean? And why are they so far apart?



First, we need to define two terms—*incidence* and *prevalence*—that have very specific and distinct meanings in the science of epidemiology (that's the study of the distribution and determinants of diseases and injuries in human populations).

With respect to PWS, the *incidence* is the rate at which babies are born with the syndrome, expressed as the ratio of PW births to total live births. The incidence of PWS has been estimated by some to be as high as 1:8,000—one PW birth in every 8,000 total live births—and as low as 1:25,000. (By comparison, the incidence of Down syndrome is estimated to be around 1:800.) Since many cases of PWS are not diagnosed at birth, there's no sure way to arrive at a birth rate, which explains the wide range of estimates.

The *prevalence* of PWS is the ratio of existing cases, in people of all ages, to the total population. Recent epidemiological studies in the state of North Dakota and in the country of Norway both found a prevalence rate of 1:15,000—one

person with diagnosed PWS for every 15,000 in the population. If the prevalence rate really is 1:15,000 (all ages), then it seems unlikely the birth rate could be as low as 1:25,000 or even 1:15,000.

Based on the latest available U.S. population data, here's what the researchers' estimates translate to in real numbers:

U.S. birth rate: 4,179,000 Total (1990)*

1:8,000 =	522 PW births
1:15,000 =	279
1:25,000 =	167

U.S. population: 252,688,000 Total (1991)*

1:15,000 =	16,846 Total persons with PWS
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These same ratios can be used with the population of a single state or region to estimate the number with PWS in that area.

Even if these figures aren't precise, it's clear that we have a ways to go in reaching families affected by Prader-Willi syndrome. There's strength in numbers—let's all work harder in 1994 to expand our Association's reach and effectiveness.

The editors

**Source: Statistical Abstract of the United States*

Chapter Notes

The *Prader-Willi Syndrome Association of Wisconsin* got a local grant that enabled them to hold a sock hop earlier this year for 38 people with PWS. A disc jockey, dancing, prizes, and refreshments (of course!) all contributed to a fun and festive event. With a membership of 33 families and/or individuals, the Wisconsin chapter has undertaken another membership drive and received its 501(c)3 status. The chapter held its September meeting at Oconomowoc Development and Training Center, where residents of the two group homes for adults with PWS conducted tours, provided a panel discussion of their work environments and community interactions, and even helped with child care for visiting parents who needed it.

The *PWSA of North Carolina* boasts a membership of 105 families and supporters, which includes almost 50 people with PWS, and is still growing. Children attending the chapter's spring meeting were entertained by the firemen's auxiliary with a ride in a fire truck to a tour of the fire station. A highly active chapter with an impressive newsletter, North Carolina also reports progress toward the realization of their PWS group home project.

All across the country this past summer, large and small groups of PW families met for picnics, outings, support, and fun. The *Missouri Chapter* even had a weekend retreat for parents and kids at Wonderland Camp.

The *Prader-Willi Western Pa. Association (PWWPA)*, a support group, took the "PWS show" on the road in August,

when they had the opportunity to present a seminar for a meeting of 70 Western Pa. region base service coordinators. Jeanne Hanchett, M.D., pediatrician at The Rehabilitation Institute of Pittsburgh and a member of the PWSA Scientific Advisory Board, was featured, along with Melanie Grace, vocational professional, and several parents.

The *Prader-Willi Kentucky Association* dispensed with its usual business meeting in September to offer a program of speakers, featuring Barbara Whitman, Ph.D., a member of PWSA's Board of Directors, Scientific Advisory Board, and the Missouri Chapter. Local professionals on the program were Dr. Bryan Hall and geneticist Ron Cadle from the University of Kentucky.

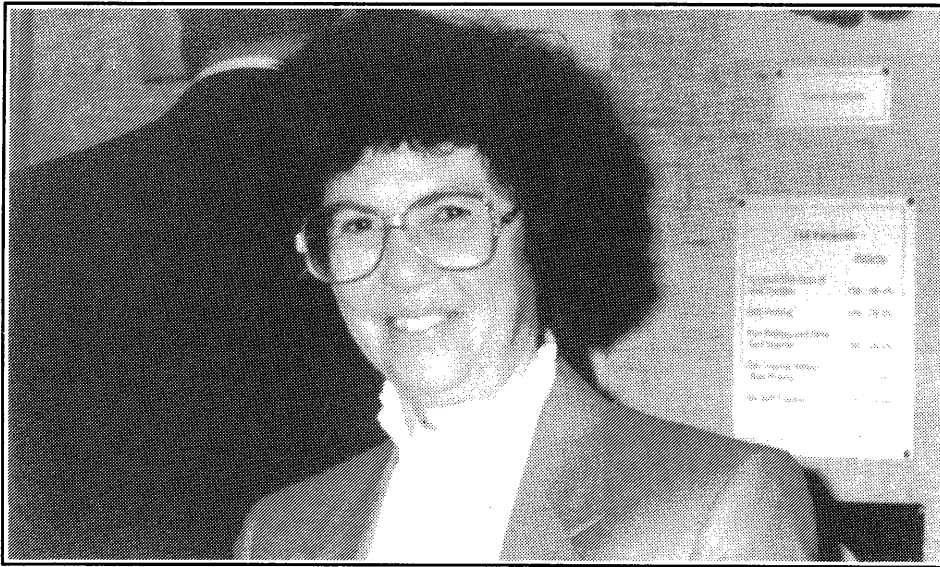
A low-fat, low-calorie brunch, games for all, and a gift exchange for persons with PWS were highlights planned for the midday holiday party on December 4 in East Lansing by members of *The Prader-Willi Syndrome Association of Michigan*.

The *Prader-Willi Association of Maryland*, until recently an inactive support group, has held several informal parent meetings in the past year and plans bimonthly meetings during 1994, the first to take place February 6 in Beltsville, Md. Meetings are open to anyone in the state of Maryland and in the entire Washington, D.C., metropolitan area. For more information, contact Linda Keder (301) 384-4955, or Peggy Baker (410) 799-7037. (Professionals and PWSA officials who are traveling to the Baltimore-Washington area also are urged to call.)

A Tribute to Bea Maier

by Lota Mitchell, M.S.W.
Co-Editor, *The Gathered View*

At our recent Western Pennsylvania mini-conference on PWS, Bea Maier, senior coordinator at The Rehabilitation Institute of Pittsburgh (TRI), was surprised with an award ceremony in recognition of her 25th anniversary with TRI and her many years of devoted service to the Prader-Willi community.



Bea Maier, senior coordinator at The Rehabilitation Institute of Pittsburgh

In presenting the award, John Wilson, president and chief executive officer of TRI, paid tribute to Bea's vision, her practical approach to bringing vision to fruition, her supportive manner with patients and their families, and her advocacy on behalf of those with PWS. The October 2 conference was held at TRI and attended by about 60 people from across the state.

For those who do not know Bea or her history with PWS, following is an edited version of my tribute to Bea, presented at the award ceremony on behalf of the parents who've been fortunate to work with her:

"The summer of 1980 I decided to start a parent group for PWS. I heard of a psychologist at TRI who had had a patient with PWS, and I called her, looking for a speaker for our first meeting that fall. She mentioned their

spina bifida summer 'camp' program and the possibility of a similar one for PWS. It was exciting to find myself soon afterward having lunch with staff in TRI's private dining room, discussing what would be needed in such a program. There I met Bea for the first time, the person who would be in charge of whatever was developed.

"Before the first parent group meeting in October, Bea asked me to come to

see her every few weeks. I thought she was looking for information; I discovered that what my visits were really for was to remind her and keep her going on the project since she is an expert procrastinator!

"Keep going she did. At that first meeting parents were told about the proposed 'camp' at TRI the following summer and asked if they would be interested, what they would want in such a program, and their children's ages. From that came a group of seven children with PWS between the ages of 6 and 12, which is why the first PWS summer camp at TRI in 1981 served that age range.

"It was successful on all counts. Bea had done her homework. The youngsters lost weight during their 28 days at TRI and had a great time as well. Parents received support and educa-

tion. All learned diet patterns. Bea had put it all together, but never sought the limelight. She just quietly saw that all went well.

"The next summer, because of the first year's success, there were two camps—one for 8-to-12-year-olds and one for teenagers. Soon another expansion occurred, which was crisis intervention throughout the year for all ages, mostly adults.

"Bea must have gotten hooked! She did her dissertation for her Ph.D. (in special education) on research she had done on the PWS population she had served. She has attended faithfully the meetings of the support group, helping with programs and providing guidance for problems with our children. The original group included parents from both Pennsylvania and Ohio, and Bea traveled to the Ohio meetings as well as the local ones. In addition, she became a board member of the Pennsylvania PWSA chapter, whose members and meetings are in the eastern and central parts of the state. Attending these has meant long drives and overnight stays. She also has gone to every PWSA national conference—sometimes to talk about TRI's program, sometimes to be a presenter, and sometimes just to be there.

"She probably knows as much—or more—about PWS as anyone in the entire country, yet that vast supply of knowledge is never pushed on anyone. It's just there when she is asked—and I suspect that none of us fully appreciates the extent of it and therefore never fully taps it.

"If other parents' experience with Bea has been like mine, to them she's not only TRI staff, educator, and support person, but also friend. I find her to be brilliant, a bit spacy (!), full of fascinating stories, warm and compassionate. For all the work, knowledge, and dedication she has put into PWS and its people, we are delighted that she is receiving this award."

(For a sampling of Bea's wisdom, see the Question Box on page 9 of this issue.)

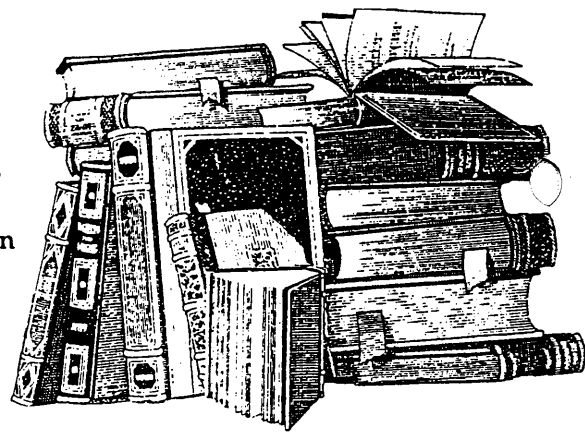
Supreme Court Rules in Favor of Private Schooling for Learning Disabled Child

Parents who place their child with disabilities in a private school because the public system has failed to meet their needs may be eligible for reimbursement under the federal Individuals with Disabilities Education Act (IDEA), even if the private school is not "approved" by the state, the Supreme Court has ruled.

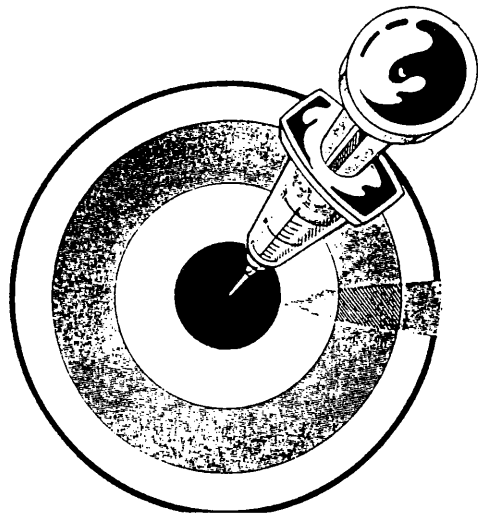
In a unanimous decision issued November 9 (*Florence County School District Four v. Carter*), the Court upheld a lower court's decision ordering a South Carolina school system to reimburse a family \$35,000 for their daughter's three years at a private academy for children with learning disabilities. The lower court found that the public school's proposed

program was "wholly inadequate" for the child, while the private school provided her "an excellent education in substantial compliance with all the substantive requirements" of IDEA, despite its lack of compliance with certain state standards. The child reportedly had dyslexia and attention deficit disorder.

While acknowledging that compliance with IDEA imposes a significant financial burden on schools, the Court states that the federal law "was intended to ensure that children with disabilities receive an education that is both appropriate and free," and that schools which carry out that mandate, whether through public education or in state-approved private



settings, "need not worry about reimbursement claims." Writing for the Court, Justice Sandra Day warned that parents who unilaterally remove their child from a public program run the risk of not being able to convince a federal judge that the public program was inadequate and that the private program was appropriate. Both findings are required in order to win reimbursement.



The formal presentation of President Clinton's Health Security Plan to Congress in October launched a debate about health care reform that is likely to continue for many months to come. At the heart of the President's plan is the principle of universal coverage, which clearly benefits all people with disabilities. No longer could a person be denied insurance benefits because of a "pre-existing condition." Clinton's proposal also includes "a significant new home and community-based care program," including "a broad range of personal assistance services." The bad news seems to be that outpatient rehabilitation services—physical therapy, occupational therapy, speech therapy, etc.—would be limited to recovery from injury or illness ("acute" needs) and would not be covered for people with

Health Care Reform: THE GREAT DEBATE BEGINS

"chronic" needs, such as people with PWS.

While we don't have the staff to scrutinize all 1,300-some pages of the President's proposal (not to mention the five or more other plans Congress is considering!), we'll make every effort to keep you posted on any major developments in health care reform. Meanwhile, we encourage you to get involved—read more about the plans, write to your legislators, help make sure our needs are heard, and help us stay informed. No doubt every disability organization will be watching the developments closely. In addition, there are a number of "umbrella" organizations that are advocating on behalf of all people with special needs. If you want to get more involved, you might consider contacting organizations such as those listed below, which have announced specific initiatives to advocate for health care reform that benefits those with disabilities:

Family Voices (c/o P.O. Box 769, Algodones, New Mexico 87001) is a newly formed organization of families and professionals advocating for children with special health needs to be

served with family-centered care; community-based, comprehensive, coordinated services; and parent-professional collaboration.

Association for the Care of Children's Health (ACCH, 7910 Woodmont Ave., Suite 300, Bethesda, Md. 20814, telephone: 1-800-229-1350) is an international nonprofit organization whose purpose is to promote policies and practices that meet the comprehensive health, developmental, and emotional-social needs of children and their families.

National Parent Network on Disabilities (NPND, 1600 Prince Street, Suite 115, Alexandria, Va. 22314) is a membership organization open to all agencies, organizations, parent centers, parent groups, professionals, and all individuals concerned with the quality of life for people with disabilities.

You can also follow the issues by reading *Exceptional Parent* magazine, which will be published monthly beginning in January (P.O. Box 3000, Dept. EP, Denville, N.J. 07834-9919, telephone 1-800-247-8080, \$18 a year).

A Glimpse of the Future

(excerpted from the President's Message in the North Carolina Chapter newsletter)

I cannot end this letter without commenting about the National Conference in Arizona. The scenery was beautiful, the conference informative, but ... I learned a lot more about my own child with PWS that I was aware of at the time. Karen Porter and her son, John, were my roommates. I received firsthand experience on daily living with a person, age 15, with PWS. My son, Steven, only age 6, does his thing on a small scale because he's younger. Realization set in when I returned home to find Steven's "small things" imitated John's much larger things. It seemed that all John's behaviors were "noticeable" because he is an older, much larger person, where Steven's behaviors sometimes go unnoticed at this moment in time because of his size and age. I realized Steven will be a

teenager one day, and I have John to thank for making me understand what growing up is all about for a person with PWS.

I enjoyed John's company. I hope he enjoyed mine. He's a very loving guy and has taught me more about PWS than books could say. I'll never forget dinner at the Japanese Steakhouse in Arizona, when food meant more to him than the cook's showmanship; however, at the Mexican restaurant, the music entertained him so that he didn't even notice the food. I know we can hardly live with them, but we surely can't live without them. We do have to admit they are a joy in our lives ... sometimes! Think about it—without our special people I wouldn't know you, you wouldn't know me and wouldn't life be a bore!

*Doris Oakley
President, North Carolina Chapter*

Assistant to the Executive Director Sought

A new assistant to the executive director will be needed for the PWSA(USA) office in Missouri after the new year. This position has considerable responsibilities with frequent member contact. Good phone presence needed. Among clerical duties are, preparing packets of information, laying out the bi-monthly national newsletter and the quarterly newsletter to chapter presidents, typing correspondence and performing light accounting and other office duties as required.

The ideal candidate will be familiar with computer operation, software packages of dBase, Aldus PageMaker, and Word Perfect. Additional qualities would include excellent written and verbal skills, and a good knowledge of PWS.

Salary Range in the mid-twenties.

Interested persons should send a resume to Russ Myler at 2510 S. Brentwood Blvd., Suite 220, St. Louis, MO 63144. PRIOR to January 1st mail to 1308 Kirkham Ave., St. Louis, MO 63122.

CLIP AND SAVE

PWSA(USA) New Address as of January 3, 1994:

2510 S. Brentwood Blvd.

Suite 220

St. Louis, MO 63144

Same toll free number: 1-800-926-4797

Work Adjustment

Third in a series of articles on work

by Melanie Grace, B.S., C.R.C., C.W.A.,
and Anna Marie Saporito, M.Ed., C.R.C.,
C.V.E.

During the vocational evaluation (see July-August issue of *The Gathered View*), "work adjustment behaviors" can be an area identified as either a strength or a weakness. Adults with Prader-Willi syndrome may present some unique difficulties in the area of work adjustment.

Work adjustment behaviors are the social/emotional/interpersonal skills necessary for a person to perform work successfully in a given work environment. For example, in a skilled work environment a person is required to interact with their peers/co-workers, floor supervisors, and general staff. Coping skills also fall into the category of work adjustment. How well can someone respond to supervisory feedback? Can they make the quick changes in routines or jobs that are common in sheltered work programs?

In professional vocational rehabilitation terms, when a "deficit behavior" is identified, it is discussed with the person to set goals to change the behavior. These goals are then written up as a behavioral program and worked on within the general program. Over a period of time the behavior is changed/achieved. Another behavior is then identified, and the process continues. But adults with Prader-Willi syndrome aren't always able to fit neatly into this model for behavior change. This is where difficulties can arise within a work program.

With help from the parents of adults with Prader-Willi syndrome to educate the rehabilitation professionals about the disability, an understanding can begin. From this understanding, realistic goals can be identified and a program implemented.

Management of identified behaviors is the key for adults with Prader-Willi syndrome. Goals may never be completely achieved, but they can be realistic and periodically readjusted. Management of behaviors then becomes an ongoing process for everyone.

An example of how a behavior might be managed is the case of a client who persisted in seeking the attention of a specific supervisor. The behavior manifested itself by the client not being able to follow directions from other supervisors and tantrumming unless the favorite supervisor became involved.

The behavioral program that was created for this person was in the form of a written contract. The contract stated that the client would get to spend five minutes in the morning with the favorite supervisor. In that time, they reviewed daily objectives and exchanged pleasantries. The contract agreed upon was that the client would follow directions from the floor supervisor without difficulty. If this occurred without incident in the first two hours, the client could spend break time with the favorite supervisor. This program would continue for the lunchtime break and then the afternoon break. As the client became more comfortable with the floor supervisor, the time spent with the favorite supervisor was decreased. But, because of the disability, there were a few rough spots, so the original program resumed until things smoothed out for the client. The favorite supervisor never completely faded out; the morning contact was still maintained to review the daily goals and contracts.

This program required a lot of time on the part of the supervisory staff. Because the staff understood the nature of the disability, however, the program was realistic and based on the specific needs of the client.

In short, difficult work adjustment behaviors can be managed, but management needs to be on a continuous basis and realistic for the disability.

The Social Skills Problem

In the book, *Management of Prader-Willi Syndrome*, Dr. William Mitchell describes the serious problem of inadequate social skills among working-age persons with PWS:

"... PWS clients represent an exaggeration of a statement ... that 'more jobs are lost among developmentally disabled populations because of social behavior problems and deficits than because of lack of job skills.'"

"PWS clients not only lose jobs because of social skills deficits, but also are often precluded from consideration for work placement. The basic components of social interaction, such as eye contact, appropriate interpersonal distance, listening, turn-taking, and shaking hands are frequently missing from the repertoire of social behaviors of PWS clients. Even in supported work environments ..., social behavior deficits associated with PWS create problems for supervisors and coworkers accustomed to interacting with clients with other developmental disabilities."

Mitchell advocates direct social skills training in the home or residential setting to teach persons with PWS more acceptable behavior patterns. In a pilot staff training program described in the *Management* textbook, residential staff identified these areas as the most problematic: conversational skills—specifically, turn-taking and listening skills—and inappropriate behaviors such as emotional outbursts, verbal assaultiveness, and noncompliance. Training techniques found to be the most effective were role-playing, modeling, and game-playing.

For more information:

William Mitchell, "Social Skills Training for Prader-Willi Syndrome," p. 166; "Appendix F: Social Skills Training," p. 274; *Management of Prader-Willi Syndrome*, Springer-Verlag, 1988. (This book may be purchased from the National Office for \$35, which includes shipping and handling.)

"Social Skills," News Digest No. 6, National Information Center for Children and Youth with Disabilities (NICHCY), P.O. Box 1492, Washington, D.C. 20013-1492, telephone (202) 416-0300. (Single copies of this eight-page newsletter are free of charge.)

Ask the Parents/Ask the Professionals

(Editor's Note: The following letter from Lin Marchitelli asks for parent input on several important issues relating to teenage children. We decided to combine our columns and include comments from a professional as well. Interspersed with segments of Lin's letter are comments from Bea Maier, senior coordinator at The Rehabilitation Institute of Pittsburgh.)

Dear Editor:

I recently called PWSA regarding the challenges of a person with PWS who is higher functioning. I would like to see how others who have been in our situation have handled these problems.

● Driving

My son, Mike, will be 17 this month and has been begging to drive for a year. Mike's view of driving is that all students age 16 and over drive their own cars to school. I'm sure this is not the case, but I cannot convince him otherwise.

His ophthalmologist states Mike has no depth perception, and his neuropsychological tests show that his thinking is too "concrete" for the many decisions which must be made to drive a car. We recently took Mike to a rehabilitation hospital that has a program to test driving ability, and Mike did not pass the first of two evaluations. There were many reasons why he would not be able to drive (judgment, eye tracking problems, reaction time, understanding procedures), but the occupational therapist conducting the test told him he could try again in about four years.

I think having a professional show him the reasons why he cannot drive made it easier for him to understand, and that we have solved the problem of Mike wanting to drive, at

least for the time being. I would like to know if anyone else has been through this situation and how it was handled.

Bea's Comment: I think you handled this in a very thoughtful and savvy manner. Allowing him to retake the tests later is a wise course as it leaves hope and self-esteem more or less intact. The desire for a driver's license shows an awareness of one of the "rites of passage" which confer on young people adult status and a degree of independence. Many parents are concerned with this problem. Some get into an authoritarian struggle while others allow reality, failing either the learner's permit or driving exam, to resolve the problem. Young people with less academic ability usually cannot master the written exam. Disappointments in achieving a goal are part of many lives. Perhaps you can find some other activities for increased independence such as choosing clothing or budgeting and banking funds for optional spending.

● School

Mike tests normal for IQ, with areas where he is exceptionally bright and others where he is very low. This makes life difficult and frustrating for him since special education classes do not meet his needs, and regular classes are extremely challenging for him. At present, he is in a private Lutheran school. We've asked them for a lot (Mike has assumed the responsibility of discussing his needs with his teachers), and they are doing their best to help him. Mike sees a tutor twice a week who is experienced with children with learning differences. She and his teachers communicate on a regular basis to determine the best approach, both in the classroom and in tutoring.

Socially, Mike has difficulties because he wants to fit in, but does not always understand the proper way to do this. One day he will tell us how great the kids are, and the next day the story is that EVERYONE mistreats him.

I would like to hear from parents of persons with Prader-Willi who are high-functioning to see how they have handled high school. It is difficult to find an appropriate setting for a child who is neither retarded nor an average student.

Bea's Comment: You are providing Mike with a "normalizing" experience. The stresses he experiences from being different are usually very acute during teen years. Family support and reasonable expectations regarding social skills are helpful. Participation in community or church activities as well as in skill-based groups like swimming instruction or beginning computer instruction can be useful. His social awareness may need some direct coaching. Perhaps your community or school system has some counseling or recreation groups for young people classified as learning disabled. These may meet Mike's needs. Such groups are hard to find, but he is more likely to imitate peer behavior in a group than adult behavior. I think some counseling in the area of post-high school vocational education and activities is essential. Work-oriented skills and attitudes are an important facet of the transition to young adult status and semi-independence.

● Adult Living Arrangements

The issue which I think will be the most difficult in the future will be to find a suitable living arrangement. I think the concept of a 24-hour supervised apartment complex with roommates of opposite strengths and weaknesses sounds like it would give more independence to individuals like Mike. Unfortunately, I do not know of any that supervise food. We have tried Overeaters Anonymous, which did not work, and have had Mike tested for participation in the Eating Disorders Clinic (which has helped persons with Prader-Willi), but the nutritionist felt he would not be open to the concept of the program.

Bea's Comment: The letter does not indicate how hard it is to control his weight. He might manage in a supervised apartment if he is not a severe food seeker. I do know of a number of high-functioning young people with PWS who are living in supervised apartments. The degree of weight control and supervision varies. Most gain some weight. This is not always a successful experience,

Continued on page 10

but each person has a right to fail. Prior to moving into an apartment, it would be good to make your son aware that a weight gain of more than "X" pounds will require some change in life style. Be sure that one of the supervisors weighs your son every week so he has plenty of feedback on weight management. I know of a parent in Michigan who is trying to develop a supervised apartment life style for a daughter now attending a community college.

I would be open to talking to parents of other high-functioning adults and adolescents to share with each other on these and other issues.

Yours very truly,
Lin Marchitelli
Houston, Texas

Editor's Note: We would be happy to publish parent responses in The Gathered View, or interested parents may contact Lin through the PWSA National Office.

We are still looking for parent responses to questions raised in the last issue:

- What kind of locks and alarms are best, and where do you get them?
- How do you get your insurance company to pay for growth hormone?
- How do you stop a person with PWS from stealing?

In Sympathy ...

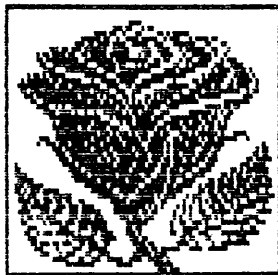
While *The Gathered View* focuses on supporting the struggles and celebrating the successes of those who are coping with Prader-Willi syndrome, we would be remiss if we did not also acknowledge the battles lost. Unfortunately, premature death remains a fact of life for some percentage of our loved ones with PWS, as evidenced by the memorials in recent issues of our newsletter. We will publish death notices and remembrances as space allows, and we urge our readers not to feel discouraged by these but to find in them inspiration to continue the struggle and search for the joys.

The editors

**"Life has meaning only in the struggle.
Triumph or defeat is in the hands of the Gods ...
So let us celebrate the struggle!"**

*Swahili warrior song
(from the opening frames of the movie, "Lorenzo's Oil")*

Remembering Renee



Renee Davis

**Georgetown, Tennessee
July 4, 1967 - June 1, 1993**

What a gift to our family! God's special gift to Toni and Jim—a precious baby girl, but so weak that she could hardly take nourishment from that bottle. Would she live, would she walk, be able to cope with public

school, learn to read? Yes, with God's help and careful nurturing from her parents, she—in time—did all of these things and much more.

He blessed her with seemingly endless patience and the will to keep trying, to never give up until the goal was reached—an optimistic outlook on life that enabled her to overcome handicaps that would have destroyed many people. We were all inspired by her courageous example of longsuffering.

During those early school days she had a happy, sparkling, bright-eyed smile, and a wonderful sense of humor. When she got tickled at something funny, she laughed all over. Those were happy days and we will all treasure those memories of a cabin in Natchez Trace State Park, fishing and more fishing, happy Christmas times together—special family times together.

Her faith never wavered. When others would have been questioning God's love by asking "Why do I have to have diabetes? Why can't I be like other teenagers?" Renee was gently, quietly adjusting to more

and more problems. She was also spending time every summer helping residents in the nursing home in a cheerful, happy way. She loved needlework and once again demonstrated to us her patience by carefully making each stitch just right even if it had to be corrected many times. Bright colors, cute animals, and happy designs were her choices. She wasn't content to have idle hands, but kept busy with a variety of crafts that were so satisfying to her to see unfold. She was making a special friend a cross-stitched picture, her favorite teacher a Christmas ornament, and her mother a hand-painted plate.

When Paul in his letter to the Galatians described the fruit of God's Holy Spirit: love, joy, peace, longsuffering, gentleness, goodness, faith, meekness, and temperance, I think of Renee and know that God's Spirit was abiding in her life because those words accurately describe her sweet spirit. We loved that wonderful spirit and will sorely miss her.

Love to Renee,
Pauline Highsmith
(Renee's grandmother)

Holiday Treats to Enjoy All Year

Lemon Cheese Chiffon

Barbara Gallagher, Montoursville, PA

- 1 package (4 servings size) lemon sugar-free jello
- 1 Tbl. sugar
- 3/4 cup boiling water
- 1 cup ice cubes
- 1 package (3 oz.) cream cheese, softened

Combine jello, sugar, and boiling water in blender. Cover and blend at low speed until jello is dissolved (about one minute). Add ice and stir until partially melted. Add cheese; cover and blend at high speed until smooth, (about one minute). Pour into individual fancy glasses. Chill until set, (about 30 minutes). Top with a little cool whip. Serves 5, approximately 75 calories per serving.

Note: This is as satisfying as cheese cake and is a very pretty dessert, especially with some canned cherry pie filling on top.

Peppermint Meringues

Barbara Gallagher, Montoursville, PA

- Whites of 2 large eggs at room temperature
- 1/8 tsp. salt
- 1/8 tsp. cream of tartar
- 1/2 cup granulated sugar
- 2 peppermint candy canes (preferably red & green) crushed

Arrange racks to divide oven in thirds. Heat oven to 225 degrees. Line two cookie sheets with foil. In a large bowl, beat egg whites, salt, and cream of tartar with electric mixer until soft peaks form when beaters are lifted. Gradually beat in sugar, beating five to six minutes until mixture is very stiff, smooth, and glossy. Drop teaspoons onto prepared cookie sheets, close together. Lightly sprinkle crushed candy over tops. Bake 1 1/2 hours. Meringues should be dry and white. Turn off oven. Keep oven door ajar and let meringues cool. Store loosely covered in cool dry place. Makes 48 drops at 13 calories each with no fat

Cranberry Jello Salad

Leona Smith, Phoenix, AZ

- 1 large (6 oz) package raspberry sugar-free jello
 - 1 (16 oz) can jellied cranberry sauce
 - 2 cups boiling water
 - 1 cup no fat sour cream
 - mustard greens
- Dissolve jello in hot water. Add cranberry; mix until dissolved. Add to sour cream, beat until creamy

and smooth. Pour into oblong pan and chill overnight. Serve squares on mustard greens. Top with dollop of lite or no fat miracle whip/mayonnaise if desired. Makes 12 servings

Carrot Spread

Leona Smith, Phoenix, AZ

- 5 or 6 large carrots, grated
- 8 ozs. Healthy Choice no fat cream cheese, softened
- 1 Tbl. grated onion
- 1/2 cup lite or no fat miracle whip
- 1 Tab. Worcestershire sauce
- Several dashes of tabasco or hot sauce

Combine ingredients and chill. Serve on whole wheat, low fat crackers. **Note:** This is healthy, delicious and LEGAL.

The following three recipes are from the PWS AZ Association newsletter.

Tasty Cranberry Sauce:

Mix a can of cranberry sauce, a can of unsweetened applesauce and a can of unsweetened crushed pineapple. It looks pretty, tastes sweet, is only 80 calories per half-cup serving—and easy to make!

Sparkling Cranberry Punch:

In a punch bowl mix a large bottle of lo-cal cranberry juice cocktail, a can of unsweetened grapefruit juice, and a 2-liter bottle of diet 7-Up. Add ice. Cheers!

This dip for veggies is only 20 calories per tablespoon: Blend 1 cup low-fat cottage cheese, 1 teaspoon garlic salt, 1/4 cup parsley, 1 Tablespoon dill pickle juice.

Serve lots of fresh cut veggies with a lo-cal ranch dressing for dipping. Serving the veggie tray while the turkey is cooking is sure to appease anxious appetites. This will help fill up that tummy and make it easier to not over eat on the more fattening dishes.

Lota Mitchell

Pittsburgh, PA sent in our last two recipes

Another delicious dip for the veggies: Mix a 16 oz. (2 cups) carton of plain yogurt with an envelope of reduced calorie ranch dressing.

And a fruit dressing that mimics its high-calorie cousins: In the blender, process whatever quantity you want of low fat cottage cheese until smooth. Sweeten to your taste with a bit (go slow and check—it doesn't take much) of Equal or Sweet 'n Low.

Free ASHA Brochures

How Does Your Child Hear and Talk?, a free brochure available from the American Speech-Language-Hearing Association, features a checklist of developmental milestones in hearing and speech from birth to age 5 with guidelines to help parents determine if their child has a problem in this area. A number of other ASHA brochures might also be of interest: *Speech and Language Disorders and the Speech-Language Pathologist*; *Speech-Language Pathologist in the Schools*; *Do Your Health Insurance Benefits Cover Speech, Language, and Hearing Services?*; and various titles in the *Answers About* series (*Articulation Problems*, *Child Language*, *Stuttering*, *Voice Problems*). To request free brochures or other information related to speech and language, including referrals to speech-language pathologists, call ASHA's Information Resource Center at (800) 638-8255.

New Numbers for NICHCY

Since our article in the July-August *Gathered View*, NICHCY—The National Information Center for Children and Youth with Disabilities—has changed hands and can no longer be reached at the telephone numbers we published. Their new local number is (202) 416-0300, in Washington, D.C., and they promise to return long-distance phone calls until their new toll-free 800 line is established. NICHCY's mailing address remains unchanged.

1994 Calendar

Jan. 14-16 PWSA Board of Directors mid-year meeting in St. Louis, Mo.
For information, call the PWSA National Office: (800) 926-4797 or, in Minn., (612) 641-1955.

April 29-30 Prader-Willi Alliance of New York and Prader-Willi Syndrome Association of New England second joint conference in Albany, N.Y. For information, call the Prader-Willi Alliance office: (800) 358-0682 or, in N.Y., (516) 621-2445.

July 21-23 16th Annual PWSA (USA) National Conference in Atlanta, Georgia, sponsored in conjunction with PWSA of Georgia. For information, call the PWSA National Office: (800) 926-4797 or, in Minn., (612) 641-1955.

The Gathered View is the official newsletter of the Prader-Willi Syndrome Association and is sent to all members. The opinions expressed in *The Gathered View* represent those of the authors of the articles published, and do not necessarily reflect the opinion or position of the officers and Board of Directors of PWSA (USA). Duplication of this newsletter for distribution is prohibited. Quotations may be used if credit is given to PWSA (USA). Membership dues are \$21 per year Individual, \$26 per year Family, \$31 per year for Agencies/Professionals (U.S. Funds). Send dues, change of address, and letters to: 1821 University Ave., W., Ste. N356, St. Paul, MN 55104-2803. Any questions? Call us at: 800-926-4797 or 612-641-1955 or Fax 612-641-1952.

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