

Sexuality

The following has been taken from an article written by Linda Thorton in "Pickwick Papers," the New Zealand PWS newsletter.

Because it is a known fact that sexual development in PWS is not complete and that there have been no known instances of reproduction, sexuality in PWS is often overlooked or brushed aside. Sexuality, at the best of times with a normal child, is often not the easiest of subjects to broach, but with more enlightened attitudes these days, the subject is now wide open.

So, how do we now explain to our sons and daughters with PWS that yes, it is possible and normal to have sexual feelings, wet dreams, erections, periods (to a lesser or greater degree), that babies are made through sexual intercourse but, no you probably won't experience intercourse and no, you won't have a baby and you more than likely won't marry?

Answer? With a great deal of difficulty. You might wonder why discuss sexuality in a population where males are impotent and have very small external genitalia, where females rarely menstruate, where neither sex develops more than rudimentary secondary sex characteristics and none are known to reproduce.

But sexuality covers more than just that. Sexuality is also about feelings, about being male

or female, about cultural attitudes and value systems and the roles. It covers subtleties that are often overlooked in today's fast pace "dating games." Sexuality is also an expression of our love and care for another person, and although few adolescents or adults with PWS are physically able to participate in the more intimate sexual activities, they nevertheless need guidance about appropriate sexual behaviors.

Those with PWS may lack strong sexual drives, but they verbalize and fantasize (albeit a little unrealistically) about marriage and parenthood. Those with daughters will often find that even as a young child, babies (real and substitute dolls) play a big part in their lives. They want to have a baby. They want to give their love and receive love back from a baby. And those with sons will often tell of friendships developing into engagements and heading hopefully towards marriage.

If we recognize all these yearnings and fantasies, then we must recognize that their sexual dimension is very real to them, even though to our thinking it is not "reality."

Sex, like food, is here to stay! It's visible in the majority

of television programs, magazines, and books, visible in school, and visible with siblings. Our children from an early age are quite aware of what's going on. Watching a younger sister or brother overtake you in the sexual development stakes can be a difficult and painful process for those with PWS.

The parental role in helping children achieve sexual maturity cannot be underestimated. Parents need to discuss with all children their own concepts of values and/or morals. Treat the handicapped child the same way as you would the normal child by answering the questions of where babies come from, what a wet dream is, what masturbation is, what sexual intercourse is, etc.

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The tough part comes with the later questions: will I have a baby?, Will I get married? This is the time to be realistic, no matter how hurtful it will seem to begin with. It's not helpful to keep putting the questions off with "maybe" answers. It's more helpful to give the direct answer and then begin to help the child/adolescent/adult adapt (e.g., Not everyone has a baby, many people are unable to produce eggs or sperm which makes the baby, but that doesn't mean that you can't help look after other people's babies--and lots of people don't get married these days, but it doesn't mean to say that you can't live in the same home as someone you really like).

Encourage your son/daughter to enjoy social activities with the opposite sex. It's healthy and stimulating to have boy and girl friends. Encourage them to go to and enjoy dances. When friendships develop, teach them the appropriate interactions, i.e., what is and what is not socially acceptable (e.g., marriage does not automatically follow a week's friendship).

Looking at all of the above from a parent's point of view, it can all seem a little daunting. This is where the role of the professional comes in. Today there are more and more professional counselors, social workers who are aware that sexual expression is a relevant aspect of life for the developmentally and intellectually handicapped. Specialized counseling, teaching, group facilitating, etc., are more available. Find a professional counselor who is skilled in this area. Ask your own doctor if he/she would feel comfortable discussing the issue with your

child.

The professional's role in assisting those with PWS to be comfortable with their own sexuality has four dimensions:

1) professionals must understand the syndrome's characteristics and acknowledge this population's limitations and potential for sociosexual activity.

2) Parents and primary care givers need to be incorporated into any learning process since their attitudes and acceptance play a major role in how, when and where sexuality is expressed. When parents collaborate with professionals to nurture sexual awareness, the process becomes legitimized. And of course, both sides hear the same story!

3) There is a need for honest, uncomplicated sex education programs open to discussion of sexual issues. This helps fill in the gaps from the day-to-day on-going sex education that parents provide by their own role modeling.

4) Finally, an awareness of sexual abuse is essential. There have been cases of sexual abuse in the PWS population (commonly bribed with sweets). This population is more at risk, more vulnerable to anyone who befriends them simply because they are outwardly friendly and chatty and susceptibility to food bribery. It is important as a parent to reinforce "stranger danger," the difference between a "good touch," and a "bad touch," and that it is OK to say "no." Much of this is covered in school programs, but will need constant reinforcing just the same.

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President's Message

by Janalee Tomaseski-Heinemann

We are fortunate in today's society to have so many helping agencies for our children with disabilities. But as I muddle through what seems like the 500th form A1 and I have filled out in the past month, my guess is that I'm not the only parent who has thought, "Save us from our rescuers!" Sometimes I wonder how many parents of a disabled child really have the time, energy, or money to get all of the help that their child needs.

My case in point: Matt came back to live with us full time again at the end of May. Within three months, while attempting to hold down our full-time jobs and give time and attention to our other children, we have had to deal with the following agencies/programs: SSI Medicaid, Regional Center, Productive Living Board, State Department of Mental Health, Judivine (a provider agency), SLARC (St. Louis Association for Retarded Citizens), MOD, Camp Wonderland, PWSA national conference, Special School District, and Lindbergh High School. This does not include all the medical groups such as primary physician, neurologist, psychiatrist, endocrinologist, ophthalmologist, audiologist, orthodontist, dentist, plus speech and physical therapy. Also, before Matt was 18, most services were on a sliding fee scale. Simply put, this means that if you aren't poor before you get all the services you need—you will be after!

Of course, each system has multiple forms that must be filled out and each caseworker wants to meet personally with you and your child. Most forms have "trick" statements such as, "We cannot process your application until..." These "untils" are what throw you—"until the immunization records are up-to-date," "until we

have income tax forms and all other verification of every dollar you have spent over the last 10 years" (only a slight exaggeration). The trickiest one is when you can't get services until you are formally accepted by another agency. Of course, each agency wants all records from all other agencies, doctors, and schools. It's a rare occasion, though, when one letter or one phone call actually gets the records transferred as planned. This requires duplicating release forms, making phone calls that don't get returned, and trying to figure out who really did get what.

Then there are various follow-up meetings, etc. For us, this is on the tail of an intensive two years spent attending many planning meetings, presenting to funding boards, and lobbying legislators to get our homes in Missouri approved. The "best" part is when you finally get through the system, only to find out that the agency had budget cuts and is out of money for this fiscal year and can't provide the services you fought to get approved. Another favorite of mine is when the worker you have spent three months working with so that he/she can get to know your family and your child's needs met, suddenly quits the agency, leaving you to start all over again.

Another dilemma for us personally is that Matt is 19 years-old and is his own legal guardian, which means he has to sign all forms and attend most meetings. This gets a little touchy when we are discussing such issues as behavior problems, while hoping the agency doesn't get a live example of a tantrum due to our answers to their questions. Matt cautiously reads all the forms he is signing, and if he doesn't like what they

say, he writes in the margins. You can picture the raised eyebrows of the worker who gets notes from Matt such as, "I not go Special School—I go regular school."

Al and I both have desks at home and at our work and can be reached by phone or beeper at any time. We also have access to fax machines, copy machines, and computers. We have the option of driving separate cars and sharing the responsibilities of completing the applications and attending meetings. To top this off, I am a social worker by trade. Yet, in spite of this, we don't always get everything done by the deadline and are often confused on which agency is still waiting for what information. I often wonder how a single parent with no car and no system to keep forms in order manages to meet the requirements to get the services needed. I suspect they don't. So often the people that need the services the most are unaware of what's available, and, even if they know, they are unable to wade through the system in order to be eligible. Then, if there is a problem with the system/agency, they certainly don't know how to pursue the appeal process.

The only solution I can come up with to deal with this maze of service systems, is that every parent of a child with a disability should be assigned a social worker whose whole purpose is to fill out forms for you, attend meetings for you, and fight for your rights, so you can go about the business of caring for your children and making a living. The problem is, of course, in order to get this social worker, you would have to fit their criteria, fill out several forms with attached verification, and attend a minimum of three meetings!

Plan Ahead

by Curt Shacklett, Practicing Attorney and Parent

Fact #1: Most people die without a valid Last Will or other sufficient trust or estate distribution plan in effect.

Fact #2: This often causes increased expenses, court costs, delays, and frustration of the deceased person's real intentions.

Fact #3: No charitable gift(s) will occur unless you have provided for them in your Last Will, living trust, or other valid document(s) which the law of your state recognizes.

Fact #4: You can promote research for PWS and enhance the services of PWSA(USA) to families and persons with PWS by planning for a gift of a part of your estate to pass to PWSA upon your death.

A valid Last Will is one of the most basic estate planning documents. Whether simply written or more complex, the purpose is the same: to arrange for an orderly distribution of your remaining property upon your death. Many "bells and whistles" can be added and may even be needed, and in virtually all states you are free to include as a beneficiary of your Will one or more charities to

further the work or cause in which you believe.

The occurrence of PWS in the general population is low, but high is the trauma, stress, and impact experienced by the families, teachers, and caregivers of persons with PWS. Although

If a rocket lacks sufficient fuel to carry the payload into orbit, the whole attempt will fail -- the rocket will fall back to earth, accomplishing little. You can help boost the "payload" of research and services to persons with PWS by remembering PWSA(USA) in your Will or trust.

there exists no known cure for this syndrome, medical as well as care and management research will continue... maybe. You see, it takes money to provide grants for research, operating funds to provide services to families with the syndrome, informational literature and training for medical personnel and caregivers of adults with PWS, and so on and on. If a rocket lacks sufficient fuel to carry the payload into orbit, the whole attempt will fail -- the rocket will fall back to earth, accomplishing little. You can help boost the "payload" of research and services to persons with PWS by remembering PWSA(USA) in your Will or trust.

Some people give gifts in specific dollar amounts, e.g., "I give \$5,000 to the PWSA(USA), with offices at 6490 Excelsior Blvd E102 St. Louis Park MN 55426,

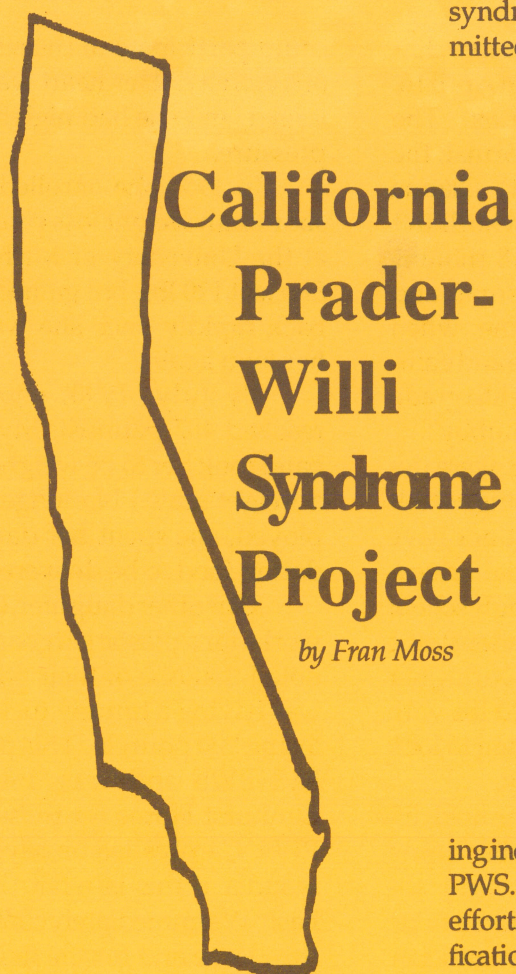
for medical research." Others give a designated percentage of their estate to the PWSA(USA). You can also designate the purpose for which you wish your gift to be used.

Even after your death, your estate tax deductible contribution, large or small, will be used to provide ongoing as well as future benefits. These benefits will assist current and those yet undiagnosed persons afflicted with the syndrome.

Frankly, those affected most by a particular trauma of life are most likely to personally and financially support the efforts to assist the lives of others similarly affected. Thus, families and friends of persons with PWS are most likely to be sensitive to the ongoing needs for financial support of our Association. Gifts given via Last Wills, trusts, etc., provide the fuel to keep the rocket of research and services climbing but how high and how far depends, to a very large extent, upon you.

You may designate your gift to:
The Deterling Research Fund *or*
The Wett Crisis and Training Fund *or*
The PWSA(USA) Operating Fund

PWSA(USA)
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The California Prader-Willi Syndrome Project was established to assist individuals with Prader-Willi syndrome (PWS) and their families in obtaining required services and support from both government and private sectors in the state of California. Funding for the pilot one-year project was provided by a state Program Development Fund grant and a matching grant from the Prader-Willi California Foundation. (The Prader-Willi California Foundation is an independent, nonprofit organization with more than 300 member families in the state of California. It was incorporated in 1979 to promote residential

placements and research to benefit persons with Prader-Willi syndrome.) An advisory committee was established, consisting of representatives from state departments to assist in coordination of services. An administrative committee oversees the project, and I serve as the project coordinator responsible for the day-to-day activities.

The specific goals of the project were defined as: educating professionals and state organizations on PWS; establishment of a state-wide resource network; information dissemination and training; needs assessment; coordination of services; the establishment of a comprehensive data base profiling individuals in California with PWS. The combination of these efforts will promote early identification, diagnosis, and intervention; referral; governmental agency and educational system involvement; parental support; appropriate residential placement; and, most important, prevention of the debilitating effects of PWS.

We began our outreach effort by contacting the 21 regional centers in California that serve the developmentally disabled. The project was initially introduced to the executive directors through letters and project brochures to be distributed to their case managers. We then tried to identify a regional center staff person and a parent in each of the 21 areas to be a resource/contact person (liaison). To date, we have scheduled in-service/training sessions at 17 of the cen-

ters. At each center, the "Medical Overview of PWS" video was shown, and selected materials published by PWSA were distributed. Also, each liaison was given a binder of information relevant to the project, Prader-Willi syndrome, and state services.

In addition to training regional center staff and parents, we sent letters and appropriate brochures to a targeted group of physicians and related personnel in California; all school districts; SELPA districts (Special Education Local Plan Areas); LPA's (Local Planning Areas—which are involved with California's early intervention programs); rehabilitative specialists; Area Boards; and mental health directors. Our plans for the future include contacting the state developmental centers, California School Nurses Association, University Affiliated Programs, sheltered workshops, and care providers, and participating in information fairs and seminars.

The results of our project networking and education have been extremely encouraging. Approximately 800 people have attended the training sessions; calls have been received from most areas of contact and from out of state; new families are being identified (30 in the last few months); and the waiting list for appropriate placements grows.

Anyone interested in knowing more about the project may contact me,

Fran Moss, Project Coordinator
5141 Verdugo Way
Camarillo CA 93012
(805) 389-3484, and
in CA only (800) 400-9994.

Dianne's Story - A Story of Hope and Life

*Adapted from the account by
Maria Arnodouse*



May 1992

The second of our five children, Dianne, was born April 16, 1951, weight 7 lbs. 9 oz. The pregnancy seemed normal, the delivery fast (face first). Dianne was a very quiet baby who didn't walk until she was 18 months old. She remained small and thin until she was nine, when she began eating more and gaining weight. By the eighth grade she was definitely "chubby".

Her school years were delayed by her slow reading, which I believe today might not have happened with special education programs. By high school graduation (a "C" student), she was 5'1" and 140 lbs. During her senior year she lost 20 lbs with the incentive of wanting to look good in the year book.

In high school she held different part-time jobs doing nurses' aide work. Next she took and passed a course to receive her license as a beautician. But jobs were hard to find, and because she couldn't get enough hours, she returned to being a nurses' aide.

At that time she had no serious health problems except shortness of breath due to excess weight. Tired of our continual harping about food, she purchased a mobile home and moved out of our home when she was 25. Still working, she lived alone taking care of her own transportation; paychecks went for food.

We kept investigating methods to lose weight. We sent her to a special weight loss camp in California (at age 30, 300 lbs.); they sent her home after 10 days because they didn't think she

could participate in the strenuous activity. Her heart was enlarged, and she had high blood pressure.

In 1985 she enrolled in a six-month weight loss program at the University of Michigan. She lost 120 lbs. but gained it all back rapidly once she was on her own again.

By July, 1990, she had reached 487 pounds! (My husband took her to be weighed on a freight scale.) No longer employed, she spent her days ordering food to be delivered.

Our other daughter, Carol, works for a plastic surgeon. She noted that one of their patients was having a tummy tuck after losing 200 pounds. This person had PWS and was living at Elmhurst Home for those with PWS. Carol called us, saying, "I wonder if this is what Dianne has!" We immediately contacted the Home and for the first time learned about PWS and the possibility that this was Dianne's problem.

Jan Hutchinson from the Elmhurst Home called Dianne to ask her if she would let Jan take charge. Dianne had no choice; she finally acknowledged she needed help. Jan took all the food out of her trailer, and Dianne gave her what money she had. Then Jan brought Dianne her meals everyday, 1,000 calories a day.

We went to work trying to get her into The Rehabilitation Institute (TRI) in Pittsburgh. Her doctors were reluctant to recommend the program, admitting

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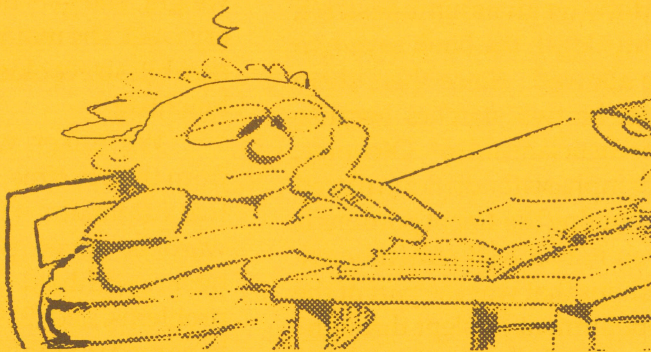
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Barbara Whitman for Phil Miller

Rosalie Tillmann for Dan Peters



**"Do you have trouble hearing?"
asked the teacher of a youngster who
sat dreamily at his desk.**

"No Ma'am," replied the boy.

"I have trouble listening."

**Dianne's Story-
Continued**

they knew nothing about PWS. But finally, in August 1990, already having lost 40 pounds under Jan's supervision, she was admitted. There she lost another 125 pounds in six months on a 600-calorie diet; then she entered Elmhurst Home on an 800-calorie diet.

Dianne had so many health problems when overweight — enlarged heart, high blood pressure, kidney stones, frequent headaches, backaches, bladder infections, arthritic pain in her knees. Now her heart is normal size, and blood pressure is normal.

Thanks to the efforts of Jan, TRI, and Elmhurst, she lost 327 pounds in 22 months and now weighs 160 pounds! When she gets down to 140, she will have a tummy tuck and later surgery on her thighs, arms, and neck.

We are so happy for her new self-esteem and her ability to work at her present job as well as pursue her studies at Jordan College, where she's not too far from an AB degree.

We will always be grateful for the saving of Dianne's life. My husband and I went to the convention in Chicago in 1991 and learned so much. How tragic that we didn't know about PWS until Dianne was 39. What pain, frustration and anguish all of us would have been spared!

A Farewell to Marge

Something is missing in the National Office. Rather, someone is missing--someone who has been there since the National Office was a space in the Wett basement.

That someone is Marge Wett. Marge was appointed the organization's first Executive Director in 1980, when PWSA had 300 members. Daughter Lisa, now 27, has PWS, so this has been a project near and dear to her heart, and she was frequently assisted by husband Dick, who provided computer expertise.

For many years she served long dedicated hours without pay and only accepted a minimal salary when the Board insisted, realizing this had to be built into the budget for the future. There might not now be a PWSA had not Marge been there to answer the phone, write the newsletter, oversee the hundred and one details of national conferences, and do the work no matter how tedious.

In 1991, Marge chose to step down to become Executive Secretary, and Tere Schaefer became her successor. At that time, the Crisis and Training Fund was named in the Wetts' honor. Still in the office, she continued to work for PWSA. On August 31, 1992, she went into full retirement, to enjoy her home on the lake and other interests.

Every member of PWSA owes a debt of gratitude to Marge, for her untiring devotion to a cause she passionately believes in, a devotion which has kept PWSA alive and growing as it moves into what we all hope will be an even more successful future. We wish you well, Marge!!

If you would like to drop Marge a note to wish her well or thank her, send it to the National Office marked for her attention.

From the Home Front . . .

The Dietician Said So!

I would like to share an experience we have had with our son with PWS and dieticians. Trevor, now 17, is being encouraged to take more responsibility for his diet and actions. At this year's annual hospital visit, he said he would like to talk to a dietician. This sounded encouraging. Unfortunately, the appointment was scheduled for 12:30, and his preceding appointments were running late. During the planned lunch break from 12:00 to 12:30, he was still seeing his doctor. Lunch was postponed! Needless to say, it appeared the dietician had less than his full attention.

However, he did seem to pick up some new information and came home with his own diet reference material. Our high functioning son frequently uses his new diet--perhaps not as the source had intended! Where we had always given him one starch at breakfast, the book says two are allowed. Since then, there must be two starches because "the dietician said so". Of course, the emphasis the dietician placed on limiting the size of portions is often not so well remembered. Perhaps that was the part of the appointment he slept through.

Thank you for the job the Association continues to do. The knowledge and experience shared through the newsletter improves the quality of our life by making our expectations more realistic and allowing us to see the humor in some of our experiences--even those involving dieticians. Harriet Thom, Prince Rupert B.C.

The Yogurt Plan

Daughter Julie, 22 and 4'9", has never been excessively heavy, due to constant monitoring, but each year her weight would creep up a few pounds. Then I came up with the "Yogurt Plan," which might interest other parents.

Every week she lost a pound, she earned a frozen yogurt cone. She could stay on the same level for three weeks before having to lose another pound to get the yogurt. It has been incredibly motivating for Julie. I'm sure Prozac (4x/week) has helped also, by increasing energy and decreasing--slightly--her appetite.

Saturday morning weigh-in, sans clothes and before breakfast, is really important to her. She is much more aware of her weight and what she eats. Of her own accord, she has worked up to 18 miles a day on her exercise bike (the plus side of compulsivity!). Now that she is ten pounds (102) below her top weight, she gets her yogurt every week she maintains and can earn bitesize cookies for her daily lunchbag.

We tinker with the plan from time to time, but there are two essentials: (1) that the reward be given promptly and never withheld for behavior problems, and (2) that the terms be agreed upon ahead of time. A contract could even be written, perhaps for a special period, to be signed by both parties and posted on the refrigerator.

Lota Mitchell, PA

We invite you to send in letters with your news and views for consideration for publication in the Home Front. We want to hear from YOU!

New PWSA Price List**BOOKS**

	U.S.	Canadian/Foreign
Management of PWS, Greenswag, Alexander. Comprehensive management information, hardcover text.	32.00	42.00
Handbook en Espanola, Neason	4.00	5.00
Directions	5.00	6.00
Sometimes I'm Mad Sometimes I'm Glad	4.00	5.00
PW & You-Feelings, Duno, During & Jeffers	4.00	5.00
Overview of PWS, Mitchell	4.00	5.00
"PWS" Current Problems in Pediatrics reprint	6.50	7.50
Development of Proper Placement for PW's	10.00	11.00
Directory of Services	6.00	7.00
Bibliography, Annotated (1956-1992) Dr. V. Holm	15.00	18.00

INFORMATION PACKETS

Past GV Articles		
#1 Mental & Physical Development. Treatment & Clinics	4.00	5.00
#2 Diet, Recipes, Nutrition, Weight & Food	4.00	5.00
#3 Research, Vocational Plcmnt, Adult PW's	4.00	5.00
#4 Publications, Residences, Education	4.00	5.00
#5 Parenting, Camps, Family Life	4.00	5.00
#6 Behavior, Exercise & Activity, Health & Medical	4.00	5.00
#7 Case Histories	4.00	5.00
Behavior Issues	4.00	5.00
Educational Issues	4.00	5.00
Guardianships	4.00	5.00
Wills	4.00	5.00
Misc. Subjects. (Marriages, Families)	4.00	5.00
Publicity Poster	2.00	3.00
Past Conference Materials		
Papers from Past Annual conferences. (1980-1985)	6.00	8.00
1986 Medical, education, advocacy placment. 134 pages	10.00	12.00
1987 Services, genetics, behavior, parent's rights. 105 pages	10.00	12.00
1988 Group Homes, employment, behavior, stress, questions. 55 pgs	10.00	12.00
1989 Nutrition, intervention, education, group homes. 103 pages	10.00	12.00
1991 Conf. Audio Tapes (Tape 1- PWSA/Gov. Benefits & Estate Plan. Tape 2-End Benefits/Laughter Tape 3-Medical/Speech Tape 4- Finding Services/Employment)	5.00/Set of 4 \$15.00	7.00/Set of 4 \$17.00
1992 Conf. Audio Tapes (1-Synopsis Pre-Conf. Day; 2- Psychiatric Challenges; 3-Nutrition; 4-Genetics; 5-Question/Answer; 6-Genrl. Medical Overview)	4.00/Set 6 \$20.00	6.00/Set of 6 \$30.00

Brochures

My child has PWS Now What (Newly Diagnosed), Medical Alert (professional guide/related conditions), Behavior & Wt Mngment (tips for everyone), Shelly (General info, obesity for non-believers), Scotty (General info, goals of PWSA), Someone You Know has PWS (general info. for friends/neighbors), Education for Parents, What Educators should know (teachers/ school), Late Teens & Young Adults (Issues & Needs), PWSA (USA) (About the Organization & PWS), Guide for Employers & Supervisors (Vocational guidelines), Speech & Language (Basic understanding of communication skills) 1-20 .25 Each, 21-100 .20 Each, 101+ .15 Each (Canadian/Foreign add .05 to price listed)

AUDIO VISUAL

Slide Presentation (Tray w/accompan. audio)	95.00	110.00
Overview (12 min.)	20.00	30.00
Medical Overview (17 min.)	25.00	35.00
Oakwood Residence (36 min.)	25.00	35.00
TV Interviews (120 min.)-Retaped, poor quality	20.00	30.00
TV Clips II (80 min.)-Provides good stories & Overview	35.00	45.00
News Special "A Deadly Hunger", Jerry Springer, and Maury Povich Shows		
Exercise for PWS - Exercise only (30 min.)	20.00	30.00
Exercise & Instructor's Manual (60 min.)	35.00	45.00
PWS for Teachers (Audio Casette only-10 min.)	5.00	7.00
Designated Age Group Audio Tapes 3-hrs (Presented at 1992 Conference)	10.00 each	12.00
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Calling All Questions

In the next issue of *The Gathered View* the National Office will inaugurate twin columns *Ask The Professionals* and *Ask The Parents*.

Ask The Professionals will address a question from the membership to the appropriate professional. For example, questions might be about medical concerns, behavior, nutrition, SSI eligibility, some aspect of group homes, early development.

Ask The Parents will also use a question from the membership, but answers will come from other parents. A question will be published in *The Gathered View* in the preceding issue; then as many responses as possible will be in that column. This is a chance to share your successes and perhaps help someone else. You may also find out how other parents have dealt with a situation you face.

Send your questions by phone or letter for *Ask The Professionals*. Send your questions by phone or letter for *Ask The Parents*.

Now, to get the *Ask The Parents* column underway, here is the first question:

How do you handle routinely scheduled snack times at places outside of your home? Do you provide written materials? Do you provide your own snack. Ask for the individuals with PWS be removed? Or just compensate calories?

Send your answer by phone or letter, no later than November 13, keep it as brief as possible, and indicate if we may use your name and state if your response is chosen for publication.

Materials and Brochures Available in Foreign Languages

Thanks to the efforts of many members and organizations such as the California PWS Project, PW Vereniging, Edie Chrisostomo, and others, many PWSA materials are now available in foreign languages.

Available in Spanish:

- *The Parent Handbook
- *Medical Alert Brochure
- *PWSA General Brochure (Describes characteristics, the organization, and has a membership application on the back.)

*What is PWS? Information and Suggestions for Parents (An article applicable to those of a Spanish culture.— \$ 2.00)

*The Overview of PWS

Available in French:

- *The Overview of PWS
- *My Child has PWS—Now What? brochure

Available in German:

- *PWSA General Brochure

Available Only in Danish:

- *A Common Sense Approach to Dietary Management
- *Teaching Children with PWS—Some Notes for Teachers
- *A Fact Sheet for Teachers and School Personnel

Available in Hebrew:

- *The Parent Handbook

The PWSA general brochure is being translated into Italian. If there is another foreign language you would like to see materials in, please let us know.

These materials may be ordered through PWSA. See the publications list on page 9 for prices.

MBNA Credit Cards Helping PWSA

As all of you know, MBNA has been marketing the members of PWSA to open a MasterCard with their company. Many of you may have doubted that they would actually live up to their promises.

PWSA received its first royalty check from MBNA for \$47.10. This amount was generated from only 27 cards.

Think if only 10% of our membership had these cards, the check might have been for \$470.10, which would mean an additional income to PWSA of \$1880.40 per year.

Doesn't seem like much:

☐ It is memberships for 90 individuals who normally couldn't afford to be members.

☐ It is the production of a new video tape on how to open a group home.

☐ It is the payments for the 800 line, so everyone across the country has access to the most information possible and access to experiences of others across the country.

☐ It is several trips by the executive director or president, to educate others on the best care and needed services throughout the country.

☐ It is the publication of a new brochure.

☐ It is the updating of previously printed materials.

☐ It is the creation of new handbooks for parents.

Let us all make the effort to contribute to PWSA through this special offer.

Call MBNA at 1-800-847-7378 ext. 5000 to get your contributing card today.

It's Calendar Time Again

The 1993 PWSA Calendar is now available. The 11"x17" sized calendar features many photographs of members' children, and explores the uniqueness of PWS.

Also included are holiday recipes, poems, inspirational quotes, and helpful hints for a happy life for you and the individuals with PWS you know.

The calendars also make great Holiday gifts for those hard to buy for people. All orders received by **November 27** will be filled in time for holiday giving.

One complimentary calendar will be mailed to Patron Dues (\$40-\$99) and Contributing Dues (\$100+) members.

It's a great stocking stuffer!

L · I · F · E

with Prader-Willi Syndrome



1993

A Calendar for Family and Friends



1993 PWSA Calendar

Please send me _____ Calendars.

The cost is \$6.00 each (\$7.00 for Canadian/Foreign)

Name:

Address:

Mail this with payment to PWSA(USA)

Memorials and Honoraria

Donations as memorials or for other special occasions are essential to the ongoing operations of PWSA. Next time you'd like to acknowledge someone special, have PWSA send them a card. All you have to do is send us your check with the address of the individual to be notified and we will do the rest.

Enclosed is a gift from:

☐ in memory of:

☐ in honor of:

I would like my
contribution:

- ☐ To be used
wherever needed
- ☐ To support
research efforts
- ☐ To support Crisis
and Training efforts

Please send
acknowledgement card to:

Address:

Sexuality continued from page 2

Conclusion

Those with PWS are not asexual. They have drives and interests and will develop strong gender role identification. Individual family, religious and social values play a major part in how their sexuality is expressed.

Development of sexuality (psychosexuality) occurs at a later age compared with a person of normal intelligence, and sexual interest tends to remain lower where intellectual functioning is lower.

Sexual maturity in PWS is usually indefinitely delayed even though other developmentally disabled persons reach puberty at the same age as normal persons.

The sexual activity of most individuals with PWS is basically innocent in nature. Genital manipulation and masturbation are often fostered by boredom, lack of activities, and a failure to understand what is acceptable public behavior.

It is common for teenagers to express a desire for companionship and dating, and ask sex-related questions. They have the same needs for intimacy, privacy

and relationships as anyone else.

Ongoing support and understanding is needed as individuals become more aware of how different they really are from their normal peers. When encouraged to deal with the realities of their limitations early in life, most can learn to adapt. These are the realities:

a) Most individuals with PWS know that they are "different." This reality produces increased stress in adolescence and needs to be addressed.

b) many individuals with PWS have the capacity for some measure of sexual expression.

c) Society today is very accepting of females in non-maternal roles, that females elect to remain childless and there is no longer anything out of the ordinary about not being able to have children and in no way are you any less "female" or any less "male" because of it.

d) As parents and caregivers we have a responsibility to teach those with PWS about their sexuality and the facts of life.

References: Management of PWS, L. Greenswag, and Raising a Handicapped Child, Charlotte Thompson, MD.

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. Duplication of this newsletter for publication is prohibited. Quotations may be used upon credit given to PWSA. Membership dues are \$21 for an individual, \$26 per family, \$31 per agency/professional. Send dues, change of address, or letters to: 6490 Excelsior Blvd. E102, St. Louis Park, MN 55426-4797. Questions or comments regarding this publication or PWS should be directed to the National Office. Telephone: 800-926-4797 or 612-926-1947 or Fax: 612-928-9133.

Prader-Willi Syndrome Association

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