



# The *Gathered View*

February 1997  
Volume XXII, Number 1

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

## 1997 Calendar

### April 30

**National Prader-Willi Syndrome Awareness Day**, with activities throughout the week of April 27–May 3

### May 2–3

**Fifth Joint Conference of PWSA of New England and the Prader-Willi Alliance of New York**, Crowne Plaza Hotel, Natick, Mass. Keynote speaker: Merlin Butler, M.D.; sessions on sensory integration, wills and estates, nutrition and weight reduction, and a fitness program for people with PWS. Call 1-508-238-/825

### July 16–19

**19th Annual PWSA (USA) Family Conference and 12th Scientific Day on PWS**, Orlando, Fla. This year's theme: "Life Under the Palms." See pages 3–5 for conference information.

### October 16–18

**Third Annual Prader-Willi Syndrome Service Providers Conference**, Nashville, Tenn. Speakers: Merlin Butler, M.D., Ph.D., Ivy Boyle, M.D., and others. Call 1-800-358-0682.

**Note:** The 18th Annual International Conference on MR/DD, March 17–21 in New York, features on March 17 a presentation by Patricia Bruno: "Obesity and Behavior Management: A Specialty Service Model for Adults with PWS." Call 212-563-7474, ext. 140.

## President's Message

by Jerry Park

## Quality of Life

**T**he new year began, and with it a renewed interest in the planning aspect in each of our lives. Each of us as Prader-Willi parents views our child or adult "growing up" in a different light and with very different concerns. The parents of young children quickly move from feeding problems to dietary control; as our children age, IEPs, proper schooling, and behavior management are high on our lists.

When the person attains adulthood, the next obvious decision is the proper professional caregiver or a group home arrangement. The transition is dramatic from total dependency on us to "independent" living. It's a difficult transition from always assuming the person will be "joined at the hip" to having someone else care for and manage your child, possibly better than you can. Our homes are usually not a controlled environment, and with the best of circumstances our children with PWS will take advantage of us.

Whit, our 13-year-old son, has been in the Rehabilitation Institute of Pittsburgh and during his stay has lost 65 pounds, regained his self-image, and has a much better perspective on life. The separation has been emotionally difficult, especially during the holidays, but the

"quality of life" Whit has achieved through the wonderful caregivers of the Rehab Institute has been immeasurable.

The changes we have to make for our children are still our parental responsibility and always will be. The "freedom of choice" issue now being debated, and which we each will face, I feel does not apply to our loved ones with Prader-Willi. Whit, six months ago, did not care how much he ate or gained before entering the Rehab. He now is proud of what

he has accomplished. We as parents can establish the parameters and let our children have success and failures as any normal child would experience. The responsibility as parents is determining what degree of "quality of life" we so choose for our child.

The improvement of life for our children has been the cornerstone of **Awareness Day**. It gives all of us the renewed hope that today we can make a difference. We cannot count on the provisions we may leave or that governmental assistance will be adequate for the security and safe keeping of our children. We must decide that today is vitally important for Prader-Willi syndrome, and every year Awareness Day should be just that—a reason we become more aware of the future and what we can do about it today.

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*inside*

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## The Prader-Willi Syndrome Association (USA)

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[http://www.athenet.net/~pwsa\\_usa/index.html](http://www.athenet.net/~pwsa_usa/index.html)

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## Out of the Office

by Russ Myler, Executive Director



I had an opportunity to have dinner with an "empty nest" couple while I was in Cleveland last month. Their adult daughter (who has Prader-Willi syndrome) lives only a few miles from their home and visits them regularly. Being an almost empty-nester myself (both of my children are away at college), we spent the time talking about how life changes when the children grow up and leave. We talked about an almost guilty feeling of relief when the freedom returned that we had before children and we liked it. That does not mean we don't love our kids or are abandoning them. We are experiencing the feelings of success from the first major phase of parenting: preparing our children to take their place in the world.

Their daughter loves her home, where she lives with other persons with the syndrome. She works regularly and has been given more responsibility at her job site. She enjoys her visits to her childhood home but looks forward to going home after the visit. My daughter will graduate from college this spring and has not the slightest idea what she will do to make her way in the world. She, of course, waited until her senior year to panic and might end up moving back home for a while. (I'm personally rooting for graduate school.) The movement of our children into their adult lives is apparently never easy.

We agreed that possibly the hardest part of this new phase of parenting is reformulating the relationship into one of an adult parent to an adult child. I see it a lot like the first time I let go of the bicycle seat and let my baby go careening down the street all alone (she thought that the best way to stop the bike was simply to jump off—hard on both her and the bike). The problem with this letting go is that the trouble our kids can get into is more serious than before. Scary, but necessary if we are to help our children make it in the world.

*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.

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Communications regarding *The Gathered View* or PWSA membership and services should be directed to the national office of PWSA (USA), 2510 S. Brentwood Boulevard, Suite 220, St. Louis, MO 63144-2326. Telephone 1-800-926-4797, or, in the St. Louis area (314) 962-7644. Fax (314) 962-7869. E-mail: [pwsa\\_usa@aol.com](mailto:pwsa_usa@aol.com).



# 19th Annual National PWSA Conference

July 17–19, 1997

Sheraton World Resort, Orlando, Florida

July 16—12th Annual PWS Scientific Day,  
Service Providers' Workshop, Chapter Presidents' Meeting

## Conference Highlights

### Parent/Professional Program:

There will be presentations by the nation's leading experts in research, treatment, education, nutrition, and life planning. Many sessions will present topics specific to your child's age group. Dr. Dan Driscoll will be speaking on the latest findings in obesity research. All this and more presented in the fun, tropical theme of "Life Under the Palms."

### Youth and Adult Program (YAAP):

A few of the YAAP highlights will be: Sea World, a carnival, clowns, arts and crafts, a bingo caller who goes by the name of "Ace Ventura," and the annual banquet and dance. We are also planning special sibling programs.

Although the YAAP Program is the biggest challenge of any conference, we want to assure all concerned parents that we are working hard to create a program that is safe, fun, and well-coordinated. Likewise, we need your co-operation with new conference rules requiring advance registration and complete medical information for each YAAP participant. (See page 4.)

*Conference registration packets will be mailed out 1 March. Register early!*

### Accommodations:

The conference will be held at the Sheraton World Resort in Orlando—in the backyard of Sea World and near Walt Disney World. The Sheraton World hotel is set in a tropical theme with three heated outdoor pools, poolside Gazebo bars, tennis courts, and a miniature golf course. Complimentary bus service to Disney theme parks is provided. Come a few days early, or stay a few days after the conference to make this a memorable family event.

### **Make your vacation plans now!**

Call the Sheraton World Resort for reservations at:

1-800-327-0363 (outside Florida) or  
1-800-341-4292 (within Florida).

To obtain our special conference rates of only \$75 per night, make sure you tell the reservation desk that you are with the National Prader-Willi Syndrome Association conference.

### Conference Grants Available

PWSA (USA) offers grants to families who want to attend the national conference but cannot afford the expense. Application should be made by letter to the Executive Director, PWSA (USA), 2510 S. Brentwood Blvd., Suite 220, St. Louis, MO 63144-2326, and must be received at the national office by **April 30** to be considered. Decisions on grant applications are made by PWSA's Conference Grants Committee.

Grant application letters must include:

- (1) the size of your family and age(s) of your child(ren);
- (2) an indication of your income and expenses;
- (3) a brief summary of difficulties your family is experiencing in dealing with PWS;
- (4) whether your family would need all conference expenses paid or only some expenses (e.g., just transportation or lodging); and
- (5) whether anyone in your family has attended a previous PWSA national conference.

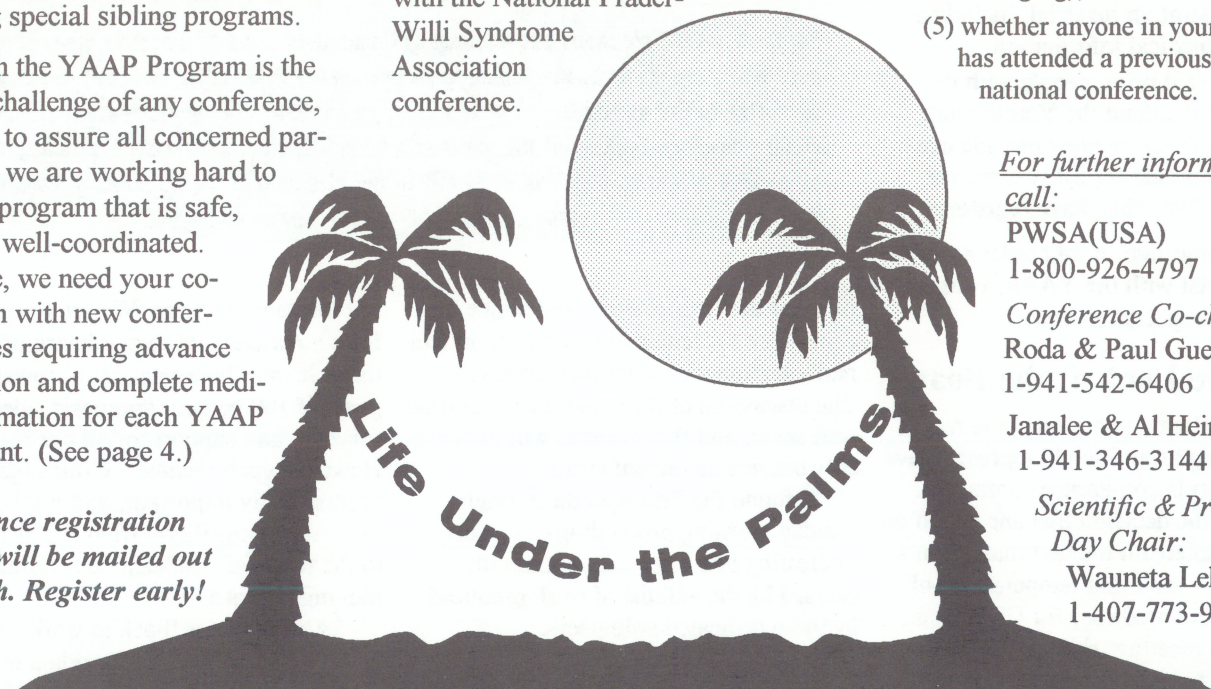
### For further information, call:

PWSA(USA)  
1-800-926-4797

*Conference Co-chairs:*  
Roda & Paul Guenther  
1-941-542-6406

Janalee & Al Heinemann  
1-941-346-3144

*Scientific & Providers' Day Chair:*  
Wauneta Lehman  
1-407-773-9503





## Board of Directors

### New Rules Set for Youth & Adult Program Participants

The PWSA (USA) board of directors has established a new, more stringent policy on registration for the Youth and Adult Activities Program (YAAP) at the annual PWSA national conference.

During the January board meeting in Cleveland, Ohio, PWSA's directors and officers discussed the growing concerns about safe management of the YAAP. Board chair Jim Kane explains that PWSA is unique among disability associations in offering such a program but that dramatically increasing numbers, unexpected registrants, and lack of medical information on some participants have created problems for program leaders in recent years. The new policy is designed to address those problems and ensure a safe and happy experience for all.

Starting with this year's conference in Orlando, the following changes will be in effect:

- No one will be admitted to the Youth/Adult Activities Program after the deadline date for receipt of registrations publicized in the registration packet. This applies both to individuals with PWS and to siblings. No "walk-ins" will be accepted!
- No one will be admitted to the Youth/Adult Activities Program without *complete* registration material, including required medical information.
- Agencies that bring people with the syndrome to attend the Youth/Adult Activities Program *must* provide one YAAP volunteer for every three persons with PWS they have registered.

(Note: Siblings age 16 and older *may* volunteer to assist with the YAAP; volunteers pay no registration fee.)

### An Inside Look at the Board

Wauneta Lehman attended the recent board meeting as an invited representative from the Florida conference committee. (She claims the decision that she would go was based "solely on the fact that I own a winter coat!"—and that temperatures of 30° below were predicted for Cleveland.)

After the meeting, she wrote: "This was the first time the board had asked a

## Ask the Professionals

**Q:** There was an article in the Dec. 6 issue of the *New York Times* about neuropeptide Y (NPY). It reported that "mice with a flawed OB gene eat without restraint and become grossly fat, sterile, diabetic, and lethargic." When NPY is removed from the mice, they "slim down, become energetic and can even reproduce." What significance does this have for people with PWS?

*The following answer is provided by William Zipf, M.D., of Ohio State University College of Medicine and Columbus Children's Hospital, who has researched the role of small peptides in appetite control.*

**A:** NPY is a peptide found in discrete sections of the brain and in the nervous system of the gastrointestinal tract. In animal studies it has been shown to be the most potent of all the known biological agents for stimulating appetite and an important natural regulator of appetite. It is not known if there is an abnormality of the NPY system in PWS. The studies described with the ob/ob mouse are not immediately applicable to the PWS condition in as much as the ob/ob mouse has a gene defect preventing the production of the satiety hormone, leptin, also called ob protein. Recent studies show that individuals with PWS have normal to elevated levels of leptin. In the normal mouse, there is evidence that leptin inhibits NPY production; thus in the ob/ob mouse there is a large excess of NPY. In this situation, administration of an "anti-NPY antibody to inactivate the excess NPY leads to a decrease in appetite as would be predicted from this model. Since leptin levels are normal in the PWS, there is no reason, as yet, to believe that NPY is in excess and its production may already be inhibited to very low levels. However, since we know so little about all the controls for appetite and know even less about the cause of the increased appetite in the PW syndrome, it remains very possible that what we are learning about NPY and its relationship to appetite control might very well lead to new knowledge that is important for the individual with PWS.

## Call for Nominations for Board of Directors

For the July 1997 elections, the Nominating Committee requests that the names of members interested in, or recommended for, a seat on the PWSA (USA) board of directors be submitted to the committee no later than April 30, 1997. Recommendations should include a brief description of the member's qualifications to serve on the board. Send recommendations by mail, fax, or e-mail to the attention of the Nominating Committee Chair, c/o PWSA (USA) at the address or fax number shown on page 2.

member of the upcoming conference host committee to come and make a report so I really had no idea what they expected. ... The discussion of the conference was time well spent, and this exercise will undoubtedly become an annual event.

"I found the Friday night through Sunday morning proceedings extremely interesting and informative. I am impressed by the volume of work produced by these dedicated volunteers.

"It was exciting to view our directors in action, and I left inspired to come back

to Florida to do more. We are fortunate to have a national office and board of directors who are there to assist us toward the goals of 100 percent diagnosis, adequate services, and support for all our families. However, each member of this organization is vitally important, and it takes all of us working together—from the local level to the national—to keep our organization moving forward.

"And now it is 'back to work' to make the 1997 conference in Florida a memorable experience for all who attend."



# Recent Journal Articles on PWS

(See Gathered View, October 1996, for other 1996 articles.)

## MEDICAL

Arnbjornsson, E., Mikaelsson, C., Lindhagen, T., & Ivarsson, S.A. (1996) Laparoscopy for nonpalpable testis in childhood: is inguinal exploration necessary when vas and vessels are not seen? *European Journal of Pediatric Surgery*, 6(1), 7-9.

Harris, J.C., & Allen, R.P. (1996) Is excessive daytime sleepiness characteristic of Prader-Willi syndrome? The effects of weight change. *Archives of Pediatrics & Adolescent Medicine*, 150(12), 1288-93.

Robson, W.L.M., Shashi, V., & Norgaard, J. P. (1997) Water intoxication in patient with Prader-Willi syndrome treated with desmopressin for nocturnal enuresis. *The Journal of Urology*, 157(2), 646.

Schuster, D.P., Osei, K., & Zipf, W.B. (1996) Characterization of alterations in glucose and insulin metabolism in Prader-Willi subjects. *Metabolism, Clinical and Experimental*, 45(12), 1514-20.

Vgontzas, A.N., Kales, A., Seip, J., Mascari, M.J., Bixler, E.O., Myers, D.C., Vela-Bueno, A.V., & Rogan, P.K. (1996) Relationship of sleep abnormalities to patient genotypes in Prader-Willi syndrome. *American Journal of Medical Genetics*, 67(5), 478-82.

## PSYCHOLOGY AND BEHAVIOR

Dykens, E.M., Leckman, J.F., & Cassidy, S.B. (1996) Obsessions and compulsions in Prader-Willi syndrome. *Journal of Child Psychology and Psychiatry*, 37(8), 995.

Gault, J. (1996) Food as a motivator in a client with Prader-Willi syndrome. *Nursing Times*, 92(41), 38-9.

Thompson, T., Butler, M.G., & Joseph, B. (1996) Prader-Willi syndrome: genetics and behavior. *Peabody Journal of Education*, 71(4), 187.

## GENETICS

Arrieta, I., Nunenz, T., & Martinez, B. (1996) A case of Prader-Willi syndrome associated with mosaicism: cytogenetic and FISH study. *Genes & Genetic Systems*, 71(1), 31.

Christian, S.L., Smith, A.C., Macha, M., Black, S.H., Elder, F.F., Johnson, J.M., Resta, R.G., Surti, U., Suslak, L., Verp, M.S., & Ledbetter, D.H. Prenatal diagnosis of uniparental disomy 15 following trisomy 15 mosaicism. *Prenatal Diagnostics*, 16(4), 323-32.

Dittrich, B., Buiting, K., Korn, B., Rickard, S., Buxton, J., Saitoh, S., Nicholls, R.D., Poustka, A., Winterpacht, A., Zabel, B., & Horsthemke, B. (1996) Imprint switching on human chromosome 15 may involve alternative transcripts of the SNRPN gene. *Nature Genetics*, 14(2), 163-70.

Ferguson-Smith, A.C. (1996) Imprinting moves to the centre. *Nature Genetics*, 14(2), 119-21.

Fischer, K.M. (1996) Genes for Prader Willi syndrome/Angelman syndrome and Fragile X syndrome are homologous, with genetic imprinting and unstable trinucleotide repeats causing mental retardation, autism and aggression. *Medical Hypotheses*, 47(4), 289.

Ishikawa, T., Kibe, T., & Wada, Y. (1996) Deletion of small nuclear ribonucleoprotein polypeptide N (SNRPN) in Prader-Willi syndrome detected by fluorescence in situ hybridization: two sibs with the typical phenotype without a cytogenetic deletion in chromosome 15q. *American Journal of Medical Genetics*, 62(4), 350-2.

Lindgren, V. (1996) Genomic imprinting in disorders of growth. *Endocrinology and Metabolism Clinics of North America*, 25(3), 503-21.

Mayo, M.A., & Tunnessen, W.W. (1996) A floppy infant: making a whale of a diagnosis. *Contemporary Pediatrics*, 13(6), 107-113.

Monaghan, K.G., Van Dyke, D.L., Feldman, G., Wiktor, A., & Weiss, L. (1997) Diagnostic testing: a cost analysis for Prader-Willi and Angelman syndromes [letter]. *American Journal of Human Genetics*, 60(1), 244-7.

Rachmilewitz, J., Elkin, M., Looijenga, L.H., Verkerk, A.J., Gonik, B., Lustig, O., Werner, D., de Groot, N., & Hochberg, A. (1996) Characterization of the imprinted IPW gene: allelic expression in normal and tumorigenic human tissues. *Oncogene*, 13(8), 1687-92.

Saitoh, S., Buiting, K., Rogan, P.K., Buxton, J.L., Driscoll, D.J., Arnemann, J., Konig, R., Malcolm, S., Horsthemke, B., & Nicholls, R.D. (1996) Minimal definition of the imprinting center and fixation of chromosome 15q11-q13 epigenotype by imprinting mutations. *Proceedings of the National Academy of Sciences, U.S.A.*, 93(15), 7811-15.

Schuffenhauer, S., Buchholz, T., Stengel-Rutkowski, S., Buiting, K., Schmidt, H., &

## Scientific Day 1997

**PWSA has mailed information and the call for papers for the 12th Annual Prader-Willi Syndrome Scientific Day, to be held Wednesday, July 16, 1997, in Orlando, Florida, in conjunction with the PWSA annual national conference.**

**To attend or present research at the 1997 Scientific Day, please contact the PWSA (USA) office for the announcement packet—**

**Telephone: 1-800-926-4797**

**Fax: 314-962-7869**

**E-mail: pwsausa@aol.com**

Meitinger, T. (1996) A familial deletion in the Prader-Willi syndrome region including the imprinting control region. *Human Mutation*, 8(3), 288-92.

Stein, C.K., Stred, S.E., Thompson, L.L., Smith, F.C., & Hoo, J.J. (1996) Interstitial 6q deletion and Prader-Willi-like phenotype. *Clinical Genetics*, 49(6), 306-10.

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Wevrick, R., & Francke, U. (1996) Diagnostic test for the Prader-Willi syndrome by SNRPN expression in blood. *The Lancet*, 348(9034), 1068-9.

White, L.M., Rogan, P.K., Nicholls, R.D., Wu, B.L., Korf, B., & Knoll, J.H. Allele-specific replication of 15q11-q13 loci: a diagnostic test for detection of uniparental disomy. *American Journal of Human Genetics*, 59(2), 423-30.

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*Sources:* MEDLINE database, National Library of Medicine, and Uncover database, Colorado Alliance of Research Libraries. Each cite shows: *Journal*, *Volume* (Issue), *Page*. This listing does not include articles in languages other than English nor articles published in *Prader-Willi Perspectives*, a quarterly journal devoted to PWS. For an index to articles in *Prader-Willi Perspectives*, contact the publisher, Visible Ink, Incorporated, at 1-800-352-0627



# BASIC ESTATE PLANS

by William L.E. Dussault  
Seattle, Washington

*In the last issue of The Gathered View, Mr. Dussault presented basic information about wills as a first step in estate planning for families of children with Prader-Willi syndrome or other developmental disabilities. In this second article, he discusses guardianship and financial planning, including various forms of trusts that can be set up for a child with PWS. Mr. Dussault is an attorney who specializes in estate planning.*

**T**here are several basic estate plans (with variations) which parents or relatives and their attorneys should consider. The plan should address at least two and possibly three primary issues:

- (1) **personal planning for your surviving family members;**
- (2) **financial planning for your estate;** and possibly
- (3) **estate and inheritance tax planning,** depending upon the size of your estate and the state in which you reside or hold property.

Issues (1) and (2) should be included in any estate plan. Issue (3) should be included as appropriate, based upon the advice of a competent professional.

## PERSONAL PLANNING

### Guardianship Designation

Regardless of the estate plan options that you chose, your will should include an express acknowledgment that one of the family survivors is disabled. This establishes a factual basis in the will for the special planning you will want to include. Then, based upon that acknowledgment, some provision should be made for both

guardianship of minors as well as disabled adult children. The person you name as testamentary guardian should be carefully selected, because that individual will have the direct responsibility for seeing to the day-to-day care of any surviving minor children, whether disabled or not. A "testamentary guardian" is one named within a last will and testament.

In addition to naming a guardian for minor children (including your child with PWS), you should consider nominating a successor guardian as a continuing or limited guardian or conservator on behalf of your adult child with PWS, in the event of your death. Only a court can appoint a guardian on behalf of a disabled adult. The court must be asked to confirm appointment of the individual you nominate.

The selection of an individual to serve as a guardian can be very difficult. The named individual should be someone who is likely to live as long as your child with PWS, because the adult guardianship will survive as long as your child lives. Therefore, the person named in that capacity should be about the same age as the person with PWS. This is not always possible, and it may be necessary to name several successive persons to serve as guardians. Because the designated guardian will have direct responsibility for the care and maintenance of your child with PWS, he or she should be someone known to the person with PWS. It is advisable to name at least one alternative. While it is possible to name someone as a guardian who does not live in the same state as your child with PWS, that is often not advisable since it is difficult for a guardian to exercise the necessary personal supervision over long distance.

## FINANCIAL PLANNING

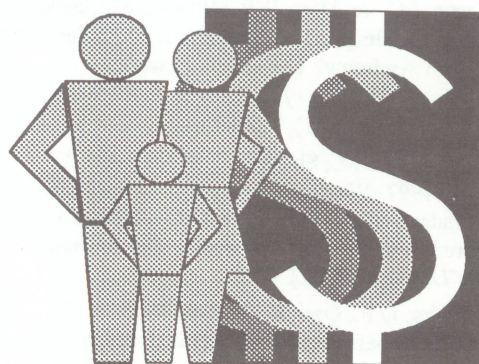
### Simple Will Designed to Exclude the Person With PWS

Under this plan each spouse executes a will which provides that upon the death of the first spouse, that spouse's entire estate is to be distributed to the surviving spouse. If there is no surviving spouse, then the estate may be distributed equally to the children, excluding the child with PWS. The child with PWS is specifically acknowledged and excluded from inheritance by the will. Disinheritance of a child for any reason must be explicit. The

following is suggested language:

"I expressly leave nothing to John Doe, my child with PWS, except my love and affection knowing that he will be adequately cared for otherwise."

In some states the validity of a provision disinheriting a dependent child may be challenged. Your attorney should advise whether or not a provision disinheriting a dependent child is valid in your state.



This type plan may be advisable for young parents with very limited assets which would be required after their death for the maintenance of their other children. This plan would usually be changed to one of the other suggested plans once assets increase or the needs of the nondisabled children decrease. The plan may also be considered where there is a desire to distribute all assets to a nondisabled adult child who the parents believe will use them fairly for the sibling with PWS.

However, parents should be aware of the possibility that greed, mental illness, death, or disability of the nondisabled adult child or their spouse may frustrate that intent. Funds directed to such child will be subject to the claims of that person's creditors, claims by an unhappy spouse in a divorce proceeding, and the payment of income taxes on income generated from the inherited property. The possible negative consequences must be carefully weighed when leaving all or a significant portion of the estate to the sibling of a disabled child rather than utilizing a carefully drafted trust to benefit the child with PWS directly.

### Will with Testamentary Trust Provisions

Under this plan, each spouse executes a will which provides that the estate of the decedent spouse is to be distributed to the



other spouse if surviving. Upon the death of the surviving spouse, the estate is to be divided into shares: one share to be held in trust for the benefit of or distributed to the nondisabled children until they reach a certain specified age and then to be distributed outright to them; and the other share to be held in a separate trust for the benefit of the child with PWS for his or her lifetime. The trusts included in the will are known as "testamentary trusts." They do not become effective until the death of both parents.

The assets in the trust for the nondisabled children will be held, managed, invested, and expended for them just as the parent would manage the funds if the parent remained alive. Possible uses could include housing, health care, general support, and education. At a suitable age, (e.g., 23, 25, or older), the remaining assets in the trust would be distributed outright to the child(ren).

However, the trust for the child with PWS must be designed to protect the trust assets and income from the claims of creditors, including the state, and to prevent the person with PWS from becoming ineligible to receive SSI (Supplemental Security Income), Medicaid (medical assistance), and other government financial assistance and program services benefits.

This kind of trust is designed to be primarily for the benefit of the person with PWS, to insure that there will be a friend, advocate, or protector of that individual's legal rights, to insure that supplemental funds will be available to assist the individual in developing maximum desired potential, and to allow that individual to achieve a reasonable degree of independence and happiness. It is *not* the principal purpose of these trusts (as contrasted to the trusts for nondisabled children) to pay for food, clothing and shelter, or medical, dental, and hospital expenses which could otherwise be provided from some other source. The trust must explicitly be determined to be a *supplemental discretionary spendthrift trust* and must contain the strongest possible spendthrift provisions.

Testamentary trust provisions are not normally designed to become effective until the death of both spouses. The plan offers great flexibility by permitting the surviving spouse during his or her lifetime to eliminate the trust, to amend its provi-

sions, or to change the portion of the estate that will be held in trust for the benefit of the child. The ability to change is important, especially if the law, governmental programs and policy with respect to persons with developmental disabilities, the needs of the child, or the trust laws of the state change during the lifetime of the surviving spouse.

## Living Trust

Unlike a testamentary trust, which does not become valid until the death of the person who makes the will and trust, another type of trust, known as a "living trust," can be created [and become valid] prior to an individual's death. The main distinction is that with a living trust, funds may be placed into the trust upon its execution, and the trust becomes effective as soon as funds are transferred to the trust. The trust provisions for the child with PWS under a living trust plan should be the same as the provisions set forth in a testamentary trust.

Living trusts can be "funded"—that is, money or assets can be placed under the supervision of a trustee by transferring the designation of ownership on the assets from the person who makes the trust to the trustee. This can occur at a bank, for instance, by designating a bank account as a trust account. Similarly, a stock brokerage account can be registered in the name of the trust(s), or the title to real property can be held in the name of a trustee. Parents can place money aside in trust accounts for children with PWS, and if the trust document is properly drafted, that set-aside money should have no impact on the child's eligibility for government benefits.

If the trust is made to be irrevocable, (i.e., one that, once signed, cannot be amended or revoked), it may provide added security to a predeceasing spouse who has concern about the ability of a surviving spouse to manage the estate during the surviving spouse's lifetime. It also removes any concern that the surviving spouse would favor the nondisabled children to the detriment of the child with PWS or vice versa. Additionally, it deals with those concerns that might arise concerning remarriage of the surviving spouse. Living trusts are often recom-

mended in situations where estate tax savings are desired. Compliance with federal tax codes is critical, and for that reason, such trusts should be drafted only by attorneys who are competent in this field.

## Other Trust Plans

There are entirely different trust plans which parents can consider. A few parents may believe that the trust assets will be so large that the income and principal of the trust will pay all costs of care for their child's lifetime. Other parents may believe that the trustee should be directed and given discretion to expend the income and/or principal of the trust to supplement their child's own earnings, if any, regular Social Security (not SSI), and Medicare (not Medicaid) benefits for basic costs of care.

Your child's eligibility for Social Security disability or survivor's benefits and Medicare is not affected by personal assets, unearned income, or the trust. However, before parents decide to use trust plans other than discretionary spendthrift trust plans, they should consider the risk of rather rapid depletion of the trust assets before the death of their child if creditors, including the state, can reach the income or principal of the trust, or if the child should lose eligibility to receive certain means-tested government assistance benefits. For example, it is extremely difficult to predict for the beneficiary's entire lifetime: (1) what the future costs of foster, group home, or other residential assistance may be, especially if inflationary trends continue; (2) the possible future amounts of Social Security or Medicare benefits or the eligibility requirements or periods of eligibility and ineligibility; (3) the beneficiary's future state of health (it may be good today, but sometime in the future astronomical medical and hospital or long-term nursing home expenses, which may not then be covered by Social Security and/or Medicare, might be incurred); or (4) your own estate's may be quite large today and much smaller upon the death of both parents. ▲

*(Editor's note: In a comprehensive article on estate planning, Mr. Dussault offers many specific recommendations on trusts and trust provisions. His full article will be included in a new publication on legal issues now being developed by PWSA. Watch *The Gathered View* for announcement of its availability.)*







## A Message of Hope for Families of Young Children

*The mother of Tyler, below, sent the following letter "with the hope that it will somehow speak to the parents of younger children with PWS." The essay "Welcome to Holland," which was incorporated in her letter, is reprinted separately on the next page.*

Last week we celebrated my son's fourth birthday. Since that day, I have found myself thinking back on his birth and the difficult days and months that immediately followed. I found myself recalling those terrifying days of uncertainty when I was torn between desperately hoping the doctors would find a diagnosis, and hoping even harder that there was no diagnosis to be found. My most vivid memory, though, is of the overwhelming fear I experienced when we were finally told that our son has Prader-Willi syndrome. In some irrational and unexplainable way, I became almost fearful of my son himself, and even more so of the life he would live. And in the rare moments when I allowed myself to be completely honest about my feelings, I had to admit that I

was afraid of how I was now going to have to live my life. My child was born with a syndrome that would alter his life as I had pictured it, and I didn't know how to deal with that. It was not only not what I had planned, but not even something I had considered to be within a reasonable realm of possibility. My husband and I were young and healthy. How could we not have a healthy child?

It was about this time that I happened to catch the tail end of a movie on TV about a mother (played by Tyne Daly) and her experience raising a son with Down syndrome. She gave a speech which I have since seen in writing in an old Dear Abby article entitled "Welcome to Holland" by Emily Perl Kingsley. (See page 9.)

Those words have a very deep emotional effect on me each time I read or hear them; however, each time I hear something new in them. What was at first an eloquent and comforting message is now an incredible speech of wisdom and experience. What it says to me is that life with a "special" child may be different than we'd planned, but it can be wonderful in its own unique way. And in the instance of a child with PWS, I think it is very much up to the parent to see their own child as unique from all the other children with PWS in the world. We must remember to see our children as individuals rather than a piece of the syndrome. I know in the early months and years the information about the syndrome can be overwhelming. Each new characteristic or behavior we hear about we immediately apply to our child either

saying he, too, will do that or be that way—or denying it so vehemently that even we can't quite believe ourselves. It is so easy to do this, and in the process we frighten and worry ourselves about the days and years ahead.

My son is only 4 years old, so I don't know what it's like to raise an older child with PWS, and I couldn't even pretend that I do. I can, however, tell you how much joy I have been able to find in my son since I began to let go of some of those fears. I have stopped trying to plan for every possible eventuality, and I have begun to look for the windmills, the tulips, and

even the Rembrandts. And although sometimes I have to be very patient in my search for these things, I do find them. Maybe what is even more important than that is just the simple fact that I'm able to enjoy my child so much more when I'm looking

for the beautiful possibilities that lie within his grasp. He, like ANY other child, will do some things in his life that I will not be thrilled with. Like any other child, he will do things that anger me, upset and embarrass me ... but he will also do things that will make me smile and laugh, he will do things that will fill my heart with joy and cause it to overflow with pride. (I know this because he already has done all these things!) In many ways he will be just like any other child, but he will also be unique, not because he has PWS, but because he is his own person. He has his own personal traits, his own strengths, and his own destiny, and I owe it to him to remember that as I raise him. For by doing so, I will be able to help him to see the "windmills," "tulips," and "Rembrandts" within him.



Tyler Johnston, age 4

Patty Johnston  
Ames, Iowa



# Welcome To Holland

by

Emily Perl Kingsley

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I am often asked to describe the experience of raising a child with a disability—to try to help people who have not shared that unique experience to understand it, to imagine how it would feel. It's like this ...

When you're going to have a baby, it's like planning a fabulous vacation trip—to Italy. You buy a bunch of guide books and make your wonderful plans. The Coliseum. The Michelangelo David. The gondolas in Venice. You may learn some handy phrases in Italian. It's all very exciting.

After months of eager anticipation, the day finally arrives. You pack your bags and off you go. Several hours later, the plane lands. The stewardess comes in and says, "Welcome to Holland."

"Holland?!?" you say. "What do you mean Holland?? I signed up for Italy! I'm supposed to be in Italy. All my life I've dreamed of going to Italy."

But there's been a change in the flight plan. They've landed in Holland and there you must stay.

The important thing is that they haven't taken you to a horrible, disgusting, filthy place, full of pestilence, famine and disease. It's just a different place.

So you must go out and buy new guide books. And you must learn a whole new language. And you will meet a whole new group of people you would never have met.

It's just a different place. It's slower-paced than Italy, less flashy than Italy. But after you've been there for a while and you catch your breath, you look around ... and you begin to notice that Holland has windmills ... and Holland has tulips. Holland even has Rembrandts.

But everyone you know is busy coming and going from Italy ... and they're all bragging about what a wonderful time they had there. And for the rest of your life, you will say "Yes, that's where I was supposed to go. That's what I had planned."

And the pain of that will never, ever, ever, ever go away ... because the loss of that dream is a very very significant loss.

But ... if you spend your life mourning the fact that you didn't get to Italy, you may never be free to enjoy the very special, the very lovely things ... about Holland.

(Published in its official version with permission of the author)



## Some Helpful and Hopeful 'Guidebooks' for Families with Young Children

*Directions: Help for Parents of Young Children with Prader-Willi Syndrome*, PWSA (USA), 1991. 1-800-926-4797.

*The Child with Prader-Willi Syndrome: Birth to Three*, by R. Wharton, K. Levine, M. Fragala, and D. Mulcahy, Prader-Willi Perspectives, 1995. 1-800-358-0682

*In Time and with Love: Caring for the Special Needs Baby*, by M. Segal. Newmarket Press, 1988. 1-212-832-3575.

*Deciphering the System; A Guide for Families of Young Children with Disabilities*, by P. Beckman and G. B. Boyes. Brookline Books, 1993. 1-800-666-BOOK.

*Parenting A Child with Special Needs: A Guide to Readings and Resources*. The National Information Center for Children and Youth with Disabilities (NICHCY), 1993. 1-800-695-0285

*A Parent's Guide to Accessing Programs for Infants, Toddlers, and Preschoolers with Disabilities*. The National Information Center for Children and Youth with Disabilities (NICHCY), 1992.

*After the Tears; Parents Talk about Raising a Child with a Disability*, by R. Simons. Harcourt Brace Jovanovich, 1987. 1-407-345-2000.

*Hope for the Families; New Directions for Parents of Persons with Retardation or Other Disabilities*, by R. Perske. Abingdon Press, 1973. 1-800-251-3320.



## Ask the Parents



**M**y daughter is 9 years old and in a 4th grade special education class. Academically this is the right class for her. However, all the other children in the class, aside from needing some extra help academically, are normal (physically, socially, behaviorally). My daughter is different from them, and they notice it. She participates in many activities outside school (Girl Scouts, Hebrew School, dance class) and is usually treated kindly. However, these children are not her friends even though she considers them so. They do not want to socialize with her outside of that particular activity. She is a sweet, smart, friendly child. Where can she find friends? I see this becoming more and more of a problem as the years pass and the differences between her and her peers become more obvious.

Judy Livny

42 Thomas Drive, Manalapan, NJ 07726

e-mail: ytml@worldnet.att.net

**Friendships seem to be difficult for many of our children with PWS, and social skills do not come naturally. Parents, teachers, and others who are close to the child need to help. What has worked for your child? Do you have some experience or thoughts on the subject of friendships that you'd like to share?**

**Please write to us at The Gathered View, in care of the national PWSA office.**

*Here's some advice from the Beach Center on Families and Disability:*

### How To Encourage Friendships Between Children With and Without Disabilities

To help facilitate friendships, you must be open to friendship development, flexible, and persevering. Orient toward the child's strengths and allow the child to make his or her own choices, because the ability to make respected choices develops ... independence.

With younger children, you might have to teach the child with a disability how to interact with his or her peers in play. You will also need to educate the peers. Start by discussing the child's disability with playmates. Ask for questions. This encourages tolerance and understanding of individual differences. If the child has a communication disability, tell playmates ways to communicate with the child with a disability.

Studies indicate that group size influences social play ... Two or three children play better with a child with a disability than larger groups. Another tip is to vary the children in the group. More sophisticated children will be role models and have better communication skills. Less sophisticated children allow the child with a disability to exhibit more leadership and problem solve.

... Some toys (balls or board games) promote play with other children. [Others] (such as books or crayons) encourage solitary play. Organize materials to promote interaction

and have them in a defined area with sufficient space to play. ...

With older children, research shows that peer tutoring, cooperative learning, and disability awareness training help children with and without disabilities to socialize, play, and just "hang out." Strategies that have proven to be successful are:

**1. One-to-one matching.** Here, in a formal volunteer program (such as Best Buddies, Natural Ties), a similar-aged peer, often as an academic course requirement, is matched with a similar-aged peer with a disability. Many long-lasting friendships emerge from these formal matches.

**2. Existing or formal networks.** In the McGill Action Planning System (MAPS), the child and family are asked to look closely at their environment and plan for a better life by examining the child's current relationships and coming up with ways to expand and improve those connections. A related method is Group Action Planning, which brings together family, friends, and community members to regularly problem solve for and with the child with a disability. For those who have few or no relationships, Circle of Friends is a method where peers are invited to make a commitment to a child with a disability. Often this is done in the school setting and can be part of an existing club or a new one. Promoted to students as an extracurricular activity, this "friendship club" should allow members to choose the relationship they want to develop, such as

### Winning Strategies

- Find opportunities to bring children together. A key trait of friendship is close proximity and frequent opportunities to socialize.
- Highlight the child's strengths and gifts.
- Have the physical environment accessible to the child with a disability.
- Encourage independence. Follow the child's lead.
- Collaborate with regular ed teachers.
- Present information on disabilities to others to promote understanding.
- Teach social skills. Talk to your child about how to make and keep friends.
- Expect people to accept the child.
- Have the child attend his or her neighborhood school.
- While planning the child's school goals, include community activities and developing relationships.
- Give the child time to spend with friends.
- Invite community members to participate in your family's life.
- Prepare the child to answer questions that others typically ask [such as "Why can't you eat everything we're having?"].
- Consider how the child can make the best possible first impression in terms of clothes, hair style, or greetings.
- If the child has communication difficulties, offer meaningful comments on behalf of the child to emphasize similarities.
- Be open to different types of relationships.
- Encourage the child to make friends with others who have empathy—who can "stand in the shoes" of another.
- Get information on Circle of Friends, Group Action Planning, or other person-centered future planning approaches.
- Realize that true friendship needs some basis for exchange (reciprocity).

in-school or after school, and make sure the child with a disability is regarded as a peer at all times.

**3. Community activities.** Many programs in the community actively encourage people with disabilities to participate. These include the Young Men's Christian Association (YMCA), Boy and Girl Scouts of America, 4-H (which offers more than just agricultural offerings), park and recreation programs, community theater groups, and volunteer organizations.

(Reprinted in edited form with permission from The Beach Center's *Families and Disability Newsletter*, 1996, No. 3.)



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*Continued, p. 12*

*God's Special Child*, reviewed in the last *Gathered View*, can be ordered directly from the authors/publishers at: Harvest Publications, 1928 Oxbow Road, Minneapolis, KS 67467. Send check or money order for \$11.95 (\$18.95 for 2), which covers postage.

## The Sibling View

### A Salute to Siblings

by Janalee Tomaseski-Heinemann

Florida Conference Co-chair and Former PWSA President

I recently ran across a poster that our daughter, Sarah, made when she was 9 years old. In one corner was a section for things she didn't like. Along with a picture of peas, clams, and a poisonous jellyfish, was a scribbled-out portion where Sarah had written "My brother Matt."

Our concern for her regarding the impact of being a sibling dealing with PWS was an issue then and became even more so as she entered those "wonderful" early teen years. I also remember when Tina, my oldest daughter from a previous marriage, met Matt and was appalled by his obesity and behavior. Now, 15 years later, we no longer live near Matt, and Tina and her family have become his main family support and advocate, with Sarah as backup.

When Sarah attended her first national PWS conference, she became fast friends with two other young girls who had siblings with PWS. While eating smuggled-in pizza, they commiserated over the anger and embarrassment of having a sibling with PWS—and had many good laughs over conference capers. These same two girls, Katie Alterman and Sarah Northcraft, who have since been volunteers at several conferences, are now young women. Both recently wrote to offer their services and willingness to take on significant responsibilities for the July 1997 Youth and Adult Activities Program (YAAP) in Orlando. Shortly thereafter, I received a call from another 29-year-old sibling, Kimberly Thinel. A physical therapist, she also offered to play a major role. So, with the conference committee's blessing, each of these siblings will have prominent positions of leadership in coordinating the different age groups under the guidance of Debbie Stallings, our Florida conference YAAP director.

For the parents of siblings going through the turmoil years, I hope you can take heart in the fact that many of us have walked in your moccasins—and survived. We all worried about the impact of PWS on our children. But as I have said in the past, although our children will be partially damaged by the struggles that come hand-in-hand with PWS, they will also be greatly enriched. It warms my heart to see some of our siblings come full circle in becoming compassionate and responsible adults—not in spite of being a sibling dealing with PWS, but *because* of it.

### To read more on friendships:

*Families and Disability Newsletter* (free subscriptions), Beach Center on Families and Disability, 3111 Haworth, University of Kansas, Lawrence, KS 66045.  
Telephone: 913-864-7600  
E-mail: BEACH@DOLE.LSI.UKANS.EDU

*A Guide to Thoughtful Friendship Facilitation for Education and Families*, by C. Beth Schuffner and Barbara Buswell. PEAK Parent Center, 6055 Lehman Drive., #101, Colorado Springs, CO 80918.

*Friendships and Community Connections Between People With and Without Developmental Disabilities*, edited by Angela Novak Amado, Paul H. Brooks Publishing Company.

## It's Not Too Late!

You can still include your favorite recipes in the PWSA (USA) member cookbook, scheduled for publication in time for this year's national conference.

We've received more than 50 recipes so far, but we'd like more—in every category—to make this a truly useful tool for every Prader-Willi kitchen.

Recipes should be low in fat and calories, of course, and will be computer analyzed for nutritional content.

Send your recipes, with your name, address, and phone to:  
**Pauline Parent, 159 Walnut St., Manchester, NH 03104**



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

