

# The Gathered View



July - August 1992  
Volume XVII  
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National Newsletter of the Prader-Willi Syndrome Association

## Effectively Communicate with Your Physician

Have you ever left the physician's office frustrated because there just didn't seem to be time to ask your questions? Or when you did ask, you were not given an answer? To be your own and your child's best health care advocate, it is up to you to assist your physician in providing the best care. Here are six tips to aid the process:

**One: Be familiar with the history.** Keep records of whom you have seen for what and when. If you don't understand what the doctor tells you, have him/her write it in your record book. Keep track of all tests, and be sure to get the results.

**Two: Keep a list of medications in your record book.** In an emergency, it could be critical to know what medications the patient is taking. Also keep track of the effects and/or side effects the medications have.

**Three: Before going to the doctor, write down the questions you want to ask.** This will help you remember them, and you will be able to note answers. If the physician cannot answer all of them, ask for a reference where you can find an answer. Don't be frustrated with the response "Time will tell," because

in some instances that is the only way to find out, but do ask how much time it could take.

**Four: Give the physician a specific explanation of the symptoms and the course of time.** For example, if you are taking Johnny to the doctor because you suspect a hearing loss, relate when you first noticed a change and give specifics of what you have observed. For instance, three weeks ago you noticed every time you called Johnny to come in for dinner, he didn't respond. When you asked Johnny if he heard you calling, he told you he did not. Or you may have noted in the past month Johnny seems to be yelling all the time.

**Five: Find out if a specialist is recommended, and don't be afraid to get a second opinion.** Most responsible physicians will be happy to refer you. This could be especially crucial for your child with PWS since it may be necessary to see someone more familiar with the syndrome. Also request that your physician consult with a leading professional, if you are not able to travel to one.

**Six: Trust your instincts; listen to yourself.** If your physi-

cian is a world renowned specialist but doesn't talk to you, are your needs being met? If your physician makes you uncomfortable, it's unlikely you will be fully utilizing his or her expertise. If your physician seems inappropriate in comments or actions, change doctors. There are many concerned, considerate and competent physicians available. Also make sure your physician is willing to learn and research on your behalf.

National has state listings of physicians who are familiar with PWS. Recommendations from friends are also a good way to find a trusted physician.

### In This Issue...

President's Message 4

Placement Success 6

Conference Notes 9

Fund Raisers 11

## Prader-Willi Syndrome Association

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## A New Brochure for PWS Employers

PWSA announces the publication of a valuable new brochure entitled *Management of Prader-Willi Syndrome in the Work Setting - A Guide for Employers and Supervisors*.

Information in the brochure, which emphasizes careful supervision and consistency as the keys to success, was provided in large part by Anne Marie Saparito, Vocational Counselor at The Rehabilitation Institute of Pittsburgh, and a presenter at the past two conferences. Her contribution is greatly appreciated.

The areas outlined include: Communication/Planning; Employer/Staff Education; family and care provider involvement; Behavioral Management, Tips, Techniques, and Necessities; and Work Skill Development with the use of cognitive and behavioral strategies.

In addition, the brochure finally gives a brief overview of the syndrome highlighting these common characteristics which may affect job performance of the person with PWS:

- Insatiable Appetite
- Food Stealing
- Hoarding Possessions
- Tantrums
- Stubbornness/Rigidity
- Limited Attention
- Perseveration

This brochure, and all others are now available for:

U.S.	Cand/For
1-20 .25	.30
21-100 .20	.25
101+ .15	.20

Included in the brochure is this success story of a young man who works for Goodwill industries.

## A Success Story



*"Even though I have PWS, I feel like I'm out working with the rest of the world."*

Sam works in a sheltered workshop and a mobile crew at Goodwill Industries. "The people are nice and polite, it's a nice atmosphere," says Sam, who gets to and from work from his group home by bus each day.

Some of Sam's responsibilities include inspecting and packaging skids of books, assembling and taping boxes for swimming pool supplies, and packaging compact discs.

Sam also works part time at the Humane League where he cares for animals. He loves working with animals. Sam says, "I am saving my money to buy aquarium and tropical fish, and I'd like to see me get a job in the zoo." With proper support, Sam's hopes of working competitively may someday be a reality.

## Election Results

A special note of thanks to all our members who sent in their proxy votes for the election of our new board members. At the membership meeting, two candidates were nominated from the floor, bringing the final ballot to seven candidates for five three-year Board positions. Two candidates were incumbents running for re-election, and three vacancies were created by the stepping down of current Board members: June Smith (1989 - 1992), Lota Mitchell (1980 - 1992), and Frank Moss (1990 - 1992). **Wholehearted thanks go to these members who have committed several years, numerous hours, and boundless energy to serving PWSA and its members.**

A total of 171 ballots were cast. The five elected were incumbents D.J. Miller and Mildred Lacy, and new members elected were Annette Ruiz of Arizona, Pauline Parent of New Hampshire, and Paul Wissmann of California.

Floor nominees were Rita Welch of New York and Virginia Rupprecht of New Mexico; write-in votes were cast for Henry Singer and Rhett Eleazer.

***Congratulations to our re-elected and newly elected members of the Board of Directors.***

## Report from the Board of Directors July Meeting

The following actions were taken by the Board of Directors:



\* The price of materials was raised effective July 15, 1992, to more truly reflect the cost of development.

\* The Chairperson of the Board may serve up to a total of six one-year terms, and first preference shall be a parent or immediate family member.

\* The name for the scientific advisors of PWSA was officially adopted as the Scientific Advisory Board. Four new members were selected by Chairperson, Vanja Holm, M.D., and approved by the PWSA Board: Suzanne Cassidy, M.D., Phillip Lee, Ph.D., Rob Nicholls, D. Phil., and Jeanne Hanchett, M.D.

\* The following conference bids were accepted: Phoenix, Arizona in 1993;

Atlanta, Georgia in 1994; Seattle, Washington in 1995; and St. Louis, Missouri in 1996.

\* Lota Mitchell was recognized for her work as Chairperson of the Board from 1987 to 1992. Recognition was also given to D.J. Miller for her efforts and energy as Chairperson of the 14th Annual Conference.

\* The new Chairperson of the Board elected by a majority of the Board is Mr. Curt Shacklett. Mr. Shacklett, the parent of a 23-year-old son with PWS, is a practicing attorney from Oklahoma.

\* The Board approved a balanced budget for the remainder of 1992, and began intensive work on a long range plan for the organization.

# President's Message

by Janalee Tomaseski-Heinemann

Matt, Al, and I had just completed lunch at the lovely Radisson Hotel in Philadelphia when a young woman unfamiliar to us stopped at our table. Observing the untouched pickle and onion on Al's plate, she asked, "Do you like pickles?" Al said, "Why, yes I do," and proceeded to pick up the pickle and eat it. She continued to stand there and then asked, "Do you like onions?" Having no intention of eating a raw onion slice and knowing there are few calories in an onion, Al offered it to her, and the young woman casually strolled off eating the onion. It was at that moment we knew for sure we were at the 1992 Prader-Willi Syndrome Association national conference.

There probably is no more significant time or event that reminds us of our common bond with PWS than the national conference. This year, at the conference, the theme of needing to work together came through clearer than ever. When we are scattered across the nation and world for 51 weeks out of the year, working together is certainly a challenge—but with FAX machines, our 800 number, and conference calls it is not impossible. The spark that lights our flame of enthusiasm and commitment and rekindles it every year is the conference. Here we can meet face-to-face, not only to passively learn the latest information in the medical field, but we can also challenge each other and have brain-storming sessions. Most important, we can share personal stories with people who can grieve with us,

laugh with us, and get outraged with us—because they truly understand what we are going through.

During the Chapter Presidents' Day, common concerns, frustrations, and potential solutions were addressed to myself and the Board through your chapter president or state representative. This year we had an excellent working session. I only wish we had more time together to continue the process. I would like to share with you some of the topics and suggestions.

## Long Range Planning

The objective was to provide input to the long range planning committee of the National Board of Directors.

○ Lobby in Washington, D.C. & coordinate these efforts with the State Chapters. (Possibly a workshop topic at next year's conference could be on how to effectively lobby.)

○ Have a national spokesperson. (This has been attempted but so far with no success.) Have a national awareness campaign.

○ Develop packets on siblings, the younger child with PWS, the older child and older parents, education, and one for new parents that includes tips on how to talk to them about PWS.

## National Office Issues & Ways that National can meet the States' Needs

The objective was to foster more unity and communications

between National and State Chapters.

○ Explain the CIT funds regarding how they are being spent. New members are confused on the issue.

○ National should share their operating manual with State Chapters. States are not aware of policies and procedures of national. Need history of national.

○ Provide persons interested in forming new chapters a copy of guidelines to become a chapter and a sample copy of by-laws.

○ Chapters were concerned by one report of what appeared to be a disproportionate amount of money being spent by national on administration costs, when in actuality this is not at all true. (To clear this up, a more detailed report will be published in the near future.)

○ Determine how to give states that don't have chapters more support. *We are working on establishing a special relationship with the California Foundation and would like feedback from our California members.*

○ Have a more open attitude on alternatives in living situations. (This has begun to be addressed through sessions at the 1992 conference.)

○ Provide more written information regarding siblings. We also discussed several potential sessions for siblings for next year's national conference.

## Problems and Concerns at the State Level

☐ Keeping members involved after their child is placed in a group home.

☐ Balancing the needs of parents of younger children with those of the parents of older children.

☐ Keeping members of a scattered population feeling connected and informed.

☐ Developing a state chapter is still an issue for many states.

## Chapter Incentives

The objective was to find a means to motivate people to become members of national in addition to being a State Chapter member.

☐ Have mutual membership dues, i.e., if they join national they automatically join the state chapter. (Membership dues would be split.)

☐ Have a waiver on the membership application to national so they can release names to states more freely.

☐ Continue to work on awareness of what national does for state chapters.

☐ Any more ideas?

## Fund Raising

☐ Have mutual fund raising events between national and states. (Have na-

tional PWS awareness day. On that day, each state would have their own fund raiser, with a portion going to national.)

☐ Put all donors on the newsletter mailing list. This will be a reminder for them for future PW donations.

☐ Apply for grants (state, federal, and private donations).

☐ Do a letter writing campaign.

☐ Sell magazine renewals.

☐ Get local groups to sponsor a fund raiser for PWS. (i.e. Rotary Clubs, VFW, Lions, Elks, Kiwanis)

☐ Have a dance, Bingo night, Bowl-a-thon, Walk-a-thon, etc.

We also had a good session on topics for next year's conference that we don't have room to share here. A complete summary of the ideas generated will go to your Chapter President or a State Representative through the Chapter President's Quarterly Newsletter.

If your state doesn't have a chapter and you would like to be a representative for your state to get more involved, please let us know.

*My home address is 12198 Sage Meadow, St. Louis, MO 63043, or call national.*

Our highest compliments go to **D.J. Miller, Isa and Jere Breneisen, Vicki Turner, and all the folks from PA** who worked tirelessly in putting together an outstanding conference.

# Attention All Californians

The California Foundation will have its Annual Meeting on Sunday, November 15th. This half-day meeting includes well-known speakers, the membership meeting, and lots of time to share experiences with new friends and old. For more specific information, contact Fran Moss, coordinator of the California PW Project, at (805)389-3484 or in CA only 800-400-9994. In the next issue of *The Gathered View*, look for a specific write up on this exciting California PW Project.

## Mark Your Calendars

### Annual Conferences

**#15 in 1993: July 15 - 17, Phoenix, AZ**

**#16 in 1994: July 14 - 16, Atlanta, GA**

**#17 in 1995: July 15 - 17, Seattle, WA**

**#18 in 1996: July 16 - 18, St. Louis, MO**

## Placement Success Stories

The following are excerpts from letters we have received here in the National office regarding living situations for adult persons with PWS. This is a small sampling of the many types of living arrangements which are presently being used and explored. Please keep in mind these excerpts and ideas in no way fully describe or outline all the factors which play a significant role in the determination of a "successful placement."

"Our group home opened its doors one year ago, and although we are on our fourth manager, the clients (8 of them) have done exceptionally well. We have one client on insulin who is now taking one shot a day instead of two. Another client was admitted with a trachea which was removed in May because of his success in losing weight! We have now purchased a 15 passenger van to fulfill transportation needs of getting to work, going to the movies, trips for shopping, etc.; they are a busy bunch.

**To really show the success of weight loss here is a chart of those losses:**

*Total weight lost: 410.25 pounds  
(that averages 51.26 lbs per person)*

**Residents weight at admission  
vs. present weight**

224	vs.	172
295	vs.	170.5
191	vs.	140
191	vs.	106.75
174.5	vs.	124
128.5	vs.	124
132.5	vs.	111
138	vs.	116

- KY

"Our son, C. lived in an independent placement; the staff turnover rate was great. I don't think C. kept the same aide for more than three weeks. In the two years he lived in this sort of arrangement his weight escalated to 328 lbs., he rarely had any social outings, and his actions were pretty much dictated by his aides. After a visit then to the Pittsburgh Rehab Institute, C. was placed in a home with four other PW individuals. In two years time his weight is now at 170 lbs. In this home C. does not do his own cooking, but currently is doing his own medication, and he makes his choices as to his social activities. I think this current placement meets C's needs, and he is healthier and happier than ever before." - KS

"When we opened our group home, it was the decision of the Board of Directors that food never be used as a form of reinforcement or be used by staff to manipulate behavior in any way. We find it really helps our residents to be able to have their lives freed of the unnecessary strains and stresses which are present when the food is freely accessible. We think the ultimate key factor for any living situation for persons with PWS is to have a staff that truly understands all the aspects of the syndrome and is willing to treat each individual as an individual." - MN

"Because some individuals with PWS have already achieved independence and others are working toward that goal, the issue no longer is whether people with PWS will ever achieve independence; but

rather what we, as professionals and their support system are doing to help them achieve it." - KS

"I certainly do not want you to think that we are experts with individuals with PWS. We've worked with one person, one time, and we were fortunate that what we did worked. Most of the credit for that needs to go to the individual. I do believe, however, that allowing him/her to have the opportunity of choice made a difference." - IL

"Although total independence may be an impossibility especially around food management, both myself and my client's staff persons in her group home placement found that considerable independence could be encouraged. Even so, our client gained a considerable sense of pride when she learned to plan meals and make choices about them as well as when she actually was able to prepare whole meals for herself and other residents." - Calgary, Canada

"[It is my philosophy] to treat each person as an individual and allow them the opportunity for success, before assuming they will fail. It is our belief that every individual is responsible for his actions, and the consequences that may result. As an adult I am responsible for considering the consequences of my actions and acting accordingly; the same I believe to be true for the PW population." - Calgary, Canada

"I was initially monitored while washing dishes as he would lick the utensils, clean out the sink stopper, and pick at the garbage; he never experienced locked fridges or food pantries.

Initially his trips to the wash-room were supervised as he would walk the hall to the kitchen; he was given the responsibility to remain out of the kitchen when it was appropriate. Today J. weighs 141 lbs (the lowest ever). Another resident T. lives in a similar situation. T's money is budgeted weekly with our assistance, but she does her shopping and carries only enough money each day for her taxi ride to and from work. She follows a daily menu plan and enjoys the responsibility of checking off what she is allowed." - Calgary, Canada

**T** is a real joy to see him preparing his own meals, shopping, banking, attending classes, working in a local convalescent home, and enjoying a full social life involving church and community activities. A great staff from a state funded agency is providing assistance in developing this supported independent living skills and community integration." - CA

**"O**ur agency in 1989 moved our PW client into her own apartment with 24 hour supervisory staff available. Since this move she is her own boss, and she calls the shots for her life. It has also helped considerably that her family is extremely supportive, giving motivation not only to her, but for us, too, to keep us working extra hard on her behalf. We don't know how many people with PWS live independently, but she represents at least one who is doing just that. We also can't guarantee this good situation will last forever, but we'll do the best we can to help see that it does ... as she has been an inspiration to all of us." - SD

The concepts and philosophies surrounding the issue of "independence" and successful placements cannot be globally defined. However, there are clearly three significant points necessary for success in any type of placement. First, the philosophy of those providing services must be that they are customer service providers and that respect for their client's individuality and hopes are the top priority. Second, supervision and guidance are needed, but to what degree and how these are administered must be based upon the individual. Third, there must be a clear understanding that while there are a wide range of behaviors and food seeking, these are not learned or aberrant psychological processes; rather the fact that the brain of individuals with PWS physically does not function in the same way the brain of the "normal" population does.

If you are interested in the complete letters and reports which were received, please contact the National office.



## Sexuality in the PWS Population - A controversial subject

One of the many topics of discussion at this year's conference was sexuality. The opinions and ideas regarding this topic are wide spread and the questions surrounding it little explored. In order to gather information for an in-depth article, we are requesting that members write us with their input on the subject.

The views of those at the conference ranged from "... providing sex education allowing persons with PWS to pair up and do what comes naturally ..." to "... I fear they would be exploited and hurt by adult behavior they are not mature enough to handle ... If they were capable of handling adult sexual activity, they would also be able to control things such as management of their money, and personal grooming, etc ..."

Sex education programs have been developed for the developmentally disabled, but most of the feedback we have heard is that these programs are not adequate for persons with PWS.

Please take some time to provide us your input, experiences, and views regarding this subject.



## A Special Thanks to PWSA Donors

*Donations received in May through July.*

*Sincere apologies to several of you who donated in March and April and were not thanked in the May/June Issue of the Gathered View*

**CIT:** Beltran, Olson(3), UW Ventura (Moss), Tobin, Chase.

**Research:** Louis-Hortense Foundation (Greenswag), Fieldstone(Culver)(3), Culver(3), Kresbach, Van Zomeran, Travel Place, Boyd(2).

**Operating:** UW Grand Rapids (Riley, Potts), Keder, Eleazer, UW-MD (Jett), Parcell.

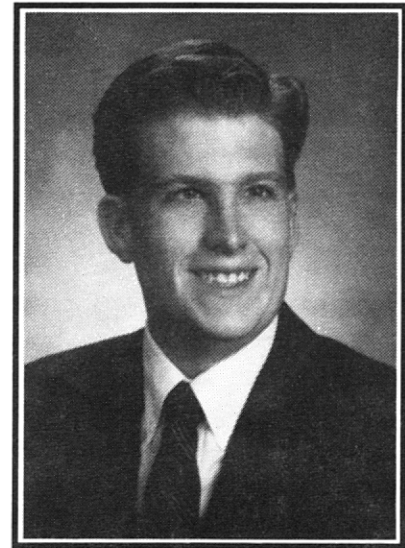
**Patrons Dues:(\$40-\$99)** Bartlett, Eisen, Daly, Weger, Endres, Clement, LaBossiere, Olson, Stickle, Underwood, Johnson, Foley, Smith, Kraft, Fuller, Post, Jackson, Lat, Bintz, Morgan, Braunreiter, Krueger, Switzer, Tarcia, Ingalls, Lousland, Ginn, Kowtna, Weingart, Lowney, Carton, Hutcoe, Ribes, Hendrix, Haller.

**Contributing Dues:(\$100+)** Tyler, Tarakan, Seal, Thompson, Antin, McCall, Holm, Kirchhoff, Jacobi, Eleazer, Deterling, Barkeley, Smith, Tyler, Tsai, Bennett, Berger.

**Angel Fund:** Sheeran, Brewi.

**Memorials:** Sommers (Forthman); Wassel, LaGrotta, Harris, Davis, CPC, Armeli, Bomersbach (Pagliughi); Baldwin, McNamara, Moss, Jeff Nat'l, Carroll, Samedan Oil, Morrison, United Way (Kirk); Gordon, Pieri, Haimowitz (Gordon); Ingalls, Women's Fellowship, Sunlighters (Ingalls); Marsden (Vandemoortel); Judge (Pearson); Regan, Brennan, Pflieger, Dowbner, O'Brien, Kennedy, Moran, Murphy (Pflieger); Sherard (Jacobs), Mitchell, Gray, Alterman, McGee.

## Class of '92 Mark Collins

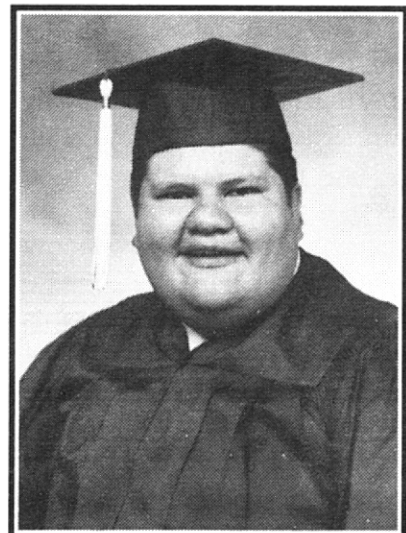


Stockton, CA

## Greg J. Ledsma of Bertram, TX

The Following was placed in the school yearbook:

*Sometimes life was hard, sometimes sad and the odds have been great. The road a little lonely. We held on so tightly, always a reason for tomorrow. May God and his Angels watch over you. Congratulations: We are very proud. Love, Dad, Mom, Leticia and Clarissa*





# Conference Notes

*"A top of the mountain experience in the midst of the valleys of PWS!"*

So said an enthusiastic attendee at the 14th Annual National Conference in Philadelphia, which provided the latest medical findings, information on care provision -- and most of all, an opportunity for parents to share their experiences and support for one another.

Attendance was excellent, with over 400 adults, and nearly 200 persons with PWS and their siblings. The pre-conference day featured special meetings for 30 medical/scientific professionals to review the most recent research findings. A providers day for nearly 100 care providers encouraged the exchange of information. The biggest discussion concerned "independent" and other alternative living arrangements. This day also provided the opportunity for the Presidents of 20 State Chapters to explore issues and provide input to each other and National.

**Here were some of the comments:**

*"I plan to change the basic programming and staff training at my facility" [from a professional care provider]*

*"I have been revived to work harder on weight management."*

*"I understand better the limited knowledge of PWS in the medical profession. Therefore, I will be more of an educator, provocateur and questioner to those that work with our PWS child."*

The conference provides an opportunity to recognize outstanding individuals for their

contributions to PWSA. This year's honorees were two outstanding professional women: Suzanne B. Cassidy, M.D. from Arizona and Louise Greenswag, R.N., Ph.D. from Iowa.

Most of you probably read Dr. Cassidy's article in the past Sept.- Oct. issue of *The Gathered View* on the advances in medical genetics and the understanding of uniparental disomy. She became interested in PWS at the University of Washington in 1982. In addition to her work with genetics, Dr. Cassidy is a member of the Board of Directors and Scientific Advisory Board for PWSA. Her personal commitment and energy is an inspiration to us all.

Louise Greenswag is co-author of what we affectionately refer to as "The Bible on PWS" [*The Management of PWS*]. She dedicated about three years to writing and editing this invaluable book. Louise became personally acquainted with PWS when her son married and gained a sister-in-law with PWS. Louise is a consultant for the University of Iowa, servicing families with PWS in that state and throughout the world. A member of the Board of Directors and Scientific Advisory Board for PWSA, she is currently working on a study regarding the use of psychotropics in the PWS population. A great deal of appreciation goes to Louise and we look forward to her continued work and writing on PWS.

The National office has compiled the conference sessions in the form of audio tapes to make them available to those who were unable to attend.

**#1-Synopsis of the Pre-Conference Day** (Scientific, Providers, and Chapter Presidents) 1 hr. \$5.00 Canadian \$7.00

**#2-Psychiatric Challenges** (Presented by Barbara Whitman, Ph.D., Louise Greenswag, Ph.D., and Herbert Cooper, III, M.D.) Examines the question of utilizing psychotropic medication in the PW population and the utilization of counseling. 1 hr. \$5.00 Canadian \$7.00

**#3-Nutritional Dilemmas** (Presented by Barbara Thomas, RD, Debie Demko, Mother, and Regina Brady, Mother) Examines dieting and the family issues surrounding its difficulties. 1 hr. \$5.00 Canadian \$7.00

**#4-Genetics** (Presented by Suzanne Cassidy, M.D., and Robert Nicholls, D.Phil.) Examines and explains the issues and current understanding of genetics as it relates to PWS. 1 hr. \$5.00 Canadian \$7.00

**#5-Questions and Answer Panel** (Presented by Louise Greenswag, Ph.D., Suzanne Cassidy, M.D., and Mildred Lacy, Mother) 1 hr \$5.00 Canadian \$7.00

**#6-Medical Overview** (Presented by Suzanne Cassidy, M.D.) Gives a general medical overview of PWS. 1 hr. \$5.00 Canadian \$7.00

## SAVE

The entire set of six tapes:

**\$20.00 plus \$3.00**

**shipping**

**Canadian/Foreign \$30.00 plus \$5.00 shipping**

# Money Matters

Everyone is all too aware of the escalating costs of everything. PWSA has experienced this also, at the same time that services have been increased – services such as the 800 number, more published materials, and a new Chapter Presidents' Quarterly Newsletter.

The result is that PWSA faced deficit spending in 1991 and possibly will again in 1992. The Board of Directors has made the following decisions to balance this year's budget:

1) Dues are raised in each membership category by \$1.00 effective August 1st, 1992.

2) Price of materials is increased, with charges added for shipping and handling.

3) At the end of August when Marge Wett retires from the National Office, replacing her will be deferred.

4) No proposed high expense projects will be undertaken for now.

5) Great care will be used in approving any Crisis and Training Funds and/or Research grants.

Such steps are part of the Board's effort to put PWSA on a firm fiscal footing so that tomorrow's members as well as today's may continue to benefit from its services.

The assistance of all our members is needed to achieve this. PWSA needs your financial commitment, your personal commitment, and your willingness to help the growth of our organization.

The following is the report which was presented at the membership meeting by treasurer, Jim Kane. If you have any questions regarding the report, feel free to call National.

## PRADER-WILLI SYNDROME ASSOCIATION FINANCIAL REPORT TO MEMBERSHIP

**HISTORICAL BACKGROUND:** The PWSA was organized in 1975 to assist families and professionals in the understanding and management of the syndrome. The Association is a Minnesota corporation, and is registered with the IRS as a tax exempt organization. Historically, the financial support for the Association's activities has come from membership dues, informational publication sales, earnings on investments and donations. The Association organizes its financial activities into four separate funds as follows:

Operating Activities:	Maintenance of national office, newsletter publication, informational literature publication, assistance to families and group home operators.
Conference Activities:	Organization and handling of the Annual Conference.
Research Funding:	Support of selected research projects.
Crisis Intervention and Training Activities:	Support for individuals and families during difficult periods, and the conduct of training activities.

**FINANCIAL DATA:** The following table summarizes various financial data for the Association:

	AS OF 12/31/91	AS OF 6/30/92
Cash and Cash Equivalents	\$ 166,400	\$261,900
Certificates of Deposit	95,000	25,000
Mutual Funds	58,400	58,100
Treasury Bills	55,000	45,000
Total Assets	\$ 374,800	\$390,000
	=====	=====
Fund Balances:		
Operating Activities	\$ 68,200	\$ 50,800
Conference Activities:	17,200	38,700
Research Funding:	24,200	36,900
Crisis Intervention and Training Activities:	265,200	263,600
Total Fund Balances	\$ 374,800	\$390,000
	=====	=====
	YEAR ENDED 12/31/91	FOR THE SIX-MONTHS 6/30/92
Operating Income and Donations	\$ 105,200	\$ 56,700
Operating Expenses	<128,700>	<74,200>
Conference Income and Interest	36,700	30,600
Conference Expenses	<38,000>	<9,100>
Research Donations and Interest	13,700	13,500
Research Expenses	<33,500>	<600>
Crisis Fund Donations and Interest	23,300	8,600
Crisis Fund Expenses	<5,800>	<10,200>
Total Association Income (Loss)	\$ <27,100>	\$ 15,300
	=====	=====

**INVESTMENT ACTIVITY:** The Association maintains an investment portfolio of high-grade income-producing assets. The investment objectives are maintaining a current yield sufficient to generate real growth while preserving, at all times, the principal balance.

- HAPPY BIRTHDAY -



## Announcing the PWSA Birthday Club

Tired of trying to remember too many birthdays? Tired of having to remember to get those cards in the mail? Here is a simple solution that also benefits PWSA. **Join the PWSA Birthday Club!**

Here are the simple steps to join the club:

1) Send PWSA the names, addresses, ages, and birthdays of those to whom you want cards and a small age appropriate gift sent.

2) Enclose a contribution of \$25 for each individual you are enrolling.

### And that is all there is to it!!!

Or... if you would like to brighten the life of an individual with PWS, you may contribute without designating a recipient for the card. Your card will then be sent to a person with PWS who has no living family or who would normally not receive any mail or birthday cards. Remember when you were young what a thrill it was to get something in the mail? Now, you can bring this thrill to a person with PWS.

The Birthday Club is simple... provides joy to people's lives... and helps PWSA help people with PWS. **Special bonus: join the Birthday Club before December 1st and receive a free Angel lapel pin.**

### Fund Raising for PWSA Needs You

Our annual fund raising campaign in 1992 will again be "Be An Angel." Several years ago when this campaign began, members were asked to submit the names and complete addresses of individuals they felt might also contribute to the campaign. You sent names of relatives, friends, and neighbors to add to our mailing list. These additional names have assisted greatly in the success of our campaigns. **Therefore, we are again requesting that members send names and addresses for this year's campaign.** Our campaign is just one mailing during the holiday season, no annoying phone calls, no follow-up letters, and no identification of who submitted their name. It is a simple request which comes but once a year.

We also suggest that our members check with their employers regarding the possibility of matching funds. Many companies will send a check in the same amount as yours, thus doubling your contribution to PWSA. We also encourage members to submit names of any organizations which contribute to charitable organizations such as PWSA.

## Thinking of the Future

Alice Parcell of VA wrote about her experience that she wanted to share with anyone else who might benefit.

"When my aunt died three years ago, she left Caroline [Alice's daughter with PWS] \$5,000. Even though she was a legal secretary, she did not phrase the use of the money restrictively but merely left it for her benefit and education with me as the distributor. I put some in a CD and some in a money market account so that we could use it as needed. I put it in a trust for her with me as the guardian (we have guardianship of Caroline).

This turned out to be a major mistake as this money made her ineligible for SSI. I know what my aunt intended the money for but the people at SSI saw it as money Caroline could use for everyday needs.

In the end what I did was to cash in the accounts and pull out all my records to show we had spent on her (well over \$5,000) since she turned 18. I recently received a letter saying she qualified as of the first of this month.

My advice to anyone in similar situations would be to put the money under your own name and pay the taxes each year while you use it as it was intended to be used."

# Conference Audio Tapes Designed for the Age of the Person with PWS You May Know

## Adolescents (Age 12-18)

This three hour session is presented by **Dorris Tinker, Ph.D. and Marsh Lupi, ED.D.**

The session covers the various issues regarding sexuality and education.

**Cost \$10.00 Canadian/Foreign \$12.00**

## Adults (Age 18+)

This three hour session is presented by **Louise Greenswag, Ph.D., and Dorris Tinker, Ph.D.**

The session presents facilitated discussions of residential alternatives and sexuality.

**Cost \$10.00 Canadian/Foreign \$12.00**

*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 call: 800-926-4797 or 612-926-1947 or Fax 612-928-9133.

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