

THE GATHERED VIEW

Newsletter of PRADER-WILLI SYNDROME ASSOCIATION

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NUMBER 1

PRESIDENT'S MESSAGE

Responsibilities beget rights, and rights provide the opportunity to carry out our responsibilities. In conjunction with the last two conferences, both the membership of the Prader-Willi Syndrome Association and the elected Board of Directors have become more acutely aware of the effect growth has had on the ability to communicate ideas from individuals to various segments of the total organization. Individual persons with specific needs from the Association have become aware of the geographical and time spread that can block a prompt response to that need. Similarly, the Board has desired to move ahead on various projects, but has been frustrated by their inability to reach out to each of you for the input that is necessary to arrive at a reasonable consensus. At the December meeting of the board, this problem was recognized and your president was directed to extend the message in the January-February newsletter to define the rights and responsibilities of the membership during the annual meeting of the membership, conducted at the annual conference. The actual statement was refined by the Chairman of the Board, Lota Mitchell.

The first responsibility of the membership is to determine the composition of the governing body by nominating and electing persons from among their group to be their representatives on the Board of Directors. The Committee of Presidents was formed in part to establish recognition to these important members of our organization in the hope that their exposure to problems at a national level would increase awareness and desire to become board candidates at future conferences.

An active and interested membership will recognize from time to time that the governing Bylaws of the Association may not reflect their guiding concepts. The Board has just completed a reorganization and titling of the Bylaws. Changes can be initiated by the membership and voted upon at the annual meeting. Proposed changes need formal submission with seconding and publication at least three months prior to the annual meeting. It has been the feeling of the Board in general that the Bylaws should reflect the goals of the Association and provide for the mechanisms necessary to accomplish those goals. On the other hand, it has been felt that the Bylaws should not be cluttered with fine definitions of every action that needs to be taken. Actions of the Association directed at specific problems are better managed by motions.

Thus the third area of responsibility and right for the membership acting at the Annual Conference is action items in the form of a motion. Again it is necessary that such motions be clearly stated and seconded with publication three months prior to any Annual Conference Membership meeting. Useful motions will carry with them not only the plan of action but also the means for carrying out the action. It is not appropriate to create tasks and expect someone else to do the work or find the funds

President's Message, cont.PWSABoard of Directors

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Cardinal Glennon Hospital

that will permit the action to take place. Also in this group of actions are motions brought to the membership by the Board. The Board is empowered and held responsible for the proper management of the incorporated Association by the laws of the state in which it is incorporated. In our case, these are the laws of the State of Minnesota. The Board is acutely aware of this responsibility, but from time to time this concern dictates that the Board seek the counsel of the membership. This can be accomplished by the Board submitting a motion at the Annual Meeting of the Membership in the same manner that an individual would act.

At the Annual conference the treasurer will submit an audited report of the financial status. It is characteristically the task of the membership of a corporation to accept or reject the auditors selected to oversee the financial business of a corporation and this practice will be introduced at future meetings.

As you can see, life becomes more and more complex as we grow as an organization. Growth is, however, essential to our continued existence and consonant with the goals outlined in the Bylaws. Only through the increased dues income of added memberships can we obtain the funds necessary to carry on the business of being an Association.

This letter is being written before the holidays but will arrive afterwards. May all of you receive the blessings and goodwill of this season. Start now to make your plans to join us all in Kentucky at the next annual conference. Your associates from Kentucky have been working hard for over a year in anticipation of your attendance in June.

Board Chair clarification of the Rights and Responsibilities of the Membership.

“The rights and responsibilities of the membership at the annual meeting consist of discussion, following recognition by the presiding officer, to nominate from the floor, candidates for the Board of Directors. And, the casting of a written ballot for the following purposes:

- ...to elect, annually, the members of the Board of Directors
- ...to approve, if necessary, the organization's auditors
- ...to vote on changes to the Bylaws initiated by members
- ...to vote on previously submitted and seconded membership motions
- ...to vote on motions considered by the Board of Directors as appropriate for approval by the membership

Only those motions submitted and seconded in writing three months prior to the annual meeting will be eligible for voting by the membership at the annual meeting.”

Delfin J. Beltran, MD

President

C.I.T. UPDATE

We thank the members who responded to our last issue regarding the use of our C.I.T. funds. Visits were made to the Rehab. program at Pittsburgh, the American Institute at Vineland and suggestions were presented to the Board in December. We will continue to investigate the best potentials in order to meet the goals originally set when this fund was started. The membership will be notified when decisions can be made.

We were extremely impressed by the program in operation at the Rehabilitation Institute of Pittsburgh in Pennsylvania. They have served over 75 people in crisis situation already and will continue to do so in the future. Their program is set up for those in need behaviorially as well as weight. If you have a child in a crisis situation, please contact Bea Maier, Program Coordinator, either by mail or phone and investigate their program.

Rehabilitation Institute of Pittsburgh
Bea Maier, Program Coordinator
6301 Northumberland St.
Pittsburgh, PA 15217
(412) 521-9000

We were also impressed by the potential for a program of longer intervention care at the American Institute in Vineland, NJ. This organization will be developing a proposal for PWSA and we hope we will be able to work with them in the second stage of serving crisis needs.

A third visit was made to the Sparks Center at the University of South Alabama and we hope they, too, will be interested in expand their service area.

In the meantime, we will continue to search for ways to meet the crisis level needs, develop more potential for research, and continue to assist in the opening of more homes.

INSURANCE

We have been informed that if given a choice between regular insurance programs and HMO programs, members have fared better with the programs other than HMO's because of the special needs of our children. If you have a choice, you may keep this in mind.

HIGHLIGHTS OF DEC. BOARD MEETING

Guidelines were accepted for investment of PWSA funds in order to preserve capital but earn more interest.

A discussion was held on fund raising and long range plans with further work to be done before next meeting.

Further research was requested regarding PWSA developing a Foundation for more assistance to people with PWS.

Grants Committee suggestion for awarding a conference grant was accepted. (See article regarding this.)

Permission was given to chapters to sell fund raising articles at conferences. Contact national for regulations.

Guidelines were approved for details of Scientific Day presentations at conference.

Standard Operating Procedures Manual should be completed by June.

Changes were made in donation designations (see Money article).

Conference bid for 1989, Calgary location, was accepted. Members will be contacted regarding later date for future conferences.

Membership rights and responsibilities discussed (see President's message).

Dr. Cassidy will pursue WHO funds for foreign scientific meeting.

Board meetings at conferences shortened in order to allow members time to meet and talk with other attendees.

Treasurer will develop a proposal related to improving the revenue of PWSA.

Details of publication of "The Management of PWS" are being worked out -- hope to have available before next conference.

(If any members have any question on any of the above items, please contact PWSA office and we will be happy to supply further information.)

Board members are elected at the annual conference. More information will follow regarding procedures to nominate and elect these members as the conference approaches.



THAT UNFAVORITE SUBJECT -- MONEY



Many of our readers are very well aware of how PWSA started, how Gene ran out of "spare time" to continue operating it alone (as they say, with a little help from his friends), and how we eventually had to turn from volunteer to a little paid staff. Those unpaid years built up a little reserve in the general operating fund, and that is why the Board of Directors were just able to pass an unbalanced budget for the coming year. Operating in the "red" is facing the fact we do not take in enough money in dues, material sales profit, donations to operating, and interest to pay the bills to continue to run the organization. Our operating budget does not allow us the luxury of spacious offices, well-paid staff, opportunities to start new projects and it does not face the future when things will need to be higher, but at the moment it is where we are.

As you know, in addition to the operating budget we do have special funds. These funds are designated as the Research Fund, the C.I.T. (crisis & intervention fund), and the Conference Fund. This month your board made a change in how these funds will be handled, the motion stated: "Hereafter undesignated gifts to PWSA will be split 50% to the Research Fund and 50% to the general operating fund. If the gift is designated, it will go 100% to wherever stated." In other words if you send a check and do not say which fund it is for, then it will be divided as operating and research. If you want the entire amount for one fund, then that must be specified with the donation.

This is the budget that was approved:

PRADER-WILLI SYNDROME ASSOCIATION

APPROVED BUDGET, 1988

INCOME:

Membership Dues	32,000.00
Operating Donations	7,500.00
Material Sales	15,000.00
Interest	4,000.00
Conference	18,000.00
Total Income	76,500.00

EXPENSES:

Salaries/Taxes	25,000.00
Travel	3,000.00
Rent	6,000.00
Printing	3,900.00
Postage	4,700.00
Supplies	2,300.00
Telephone	1,200.00
Publishing	15,000.00
Service Contracts	1,600.00
Capital Equipment	2,000.00
Committees/Chapters	300.00
Conference	16,500.00
Total Expenses	81,500.00
Net Income	(5,000.00)

Those who donated in November and December.

Operating funds: \$445.78, \$2055. (other additional funds were received thru contributing and patron dues)

CIT: \$625., \$1565.

RESEARCH: \$1081.63, \$395.

CIT Donors: Two donations: Sunde, Dixon, Sharp, Wett(Schaefer), E.Olson. Boyd, Sojka, Hambrick(Heniff), Dam(matching), Foley, Beltran, Stephens, Chase, LaBelle (Buckstein,LaBella), Notbohm, Wol Schon, Castle, Vermeulen (Heidel), Brewi(Posch), Parcell, Goff, Ziifle, Metzger,Gulling.

Research Donors: Sharp, Townsend, Mitchell(Echols), Hruska(Kramer), Healy, Corcoran(McKee), Maurer (3)(Shiflet,Colony Sq.Hotel, Maurer), Sojka, Vermeulen(U.W.), Cannon, Mook(Mook). Funds were also received indirectly from So.NV CFC & Nashville Community Chest. Two families designated memorials, Hinson and Budner. One of our member's son, Peter Haller, worked thru the Lambda Tau Chapter of Delta Sigma Pi and proudly presented a check for \$600. that was raised at local supermarkets. We supplied brochures, buttons, and posters and these young people not only asked for donations but also increased public awareness.

We thank all of these special people who do feel PWSA is worthy of their support.

REPORT-1A PWSA SURVEY-1

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Rec id	Sex	Birth id	Birth City	Birth Country	Birth Weight	Len gth	Preg Unsl	Preg Drug	Preg What	Labor Length	Preg Diff	First Csec	Delivery Position	Res Baby	Isa Used	Isa Len	Isa Day	Hypotonic Degree	Weak Dry	Plac enta	Alc Prog	Alcohol Amount	Seg Prog	Smoking Prog	Seg Amount	Seg Other	Still Birth	Miss Birth		
578	F	12/29/77	Severly	CA USA	5'2"	28"	N	Y	S	Y	N	N	N	N	N	N	N	Y	moderate	Y	N	N	N	N	N	N	0	0		
579	F	12/07/84	York	PA USA	5'5"	19"	N	Y	S	Y	N	N	N	N	N	N	Y	Y	severe	Y	N	N	N	N	N	N	0	0		
580	F	10/13/84	Lewisston	PA USA	5'5"	18"	N	Y	N	N	N	N	N	N	N	N	Y	Y	severe	Y	N	N	N	N	N	N	0	0		
581	F	01/22/80	Alhambra	CA USA	5'7"	19"	Y	Y	S	Y	N	N	N	N	N	N	N	Y	moderate	Y	N	Y	Y	light	N	N	0	0		
582	N	04/29/80	Phoenix	AZ USA	4'8"	23"	Y	N	S	N	N	N	N	N	Y	Y	Y	N	moderate	Y	N	N	N	N	N	N	0	0		
583	N	11/18/75	New Orleans	LA USA	6'	28"	N	Y	S	N	N	N	N	N	N	N	N	Y	moderate	N	N	N	N	light	N	N	0	1		
584	F	01/31/75	St. Murray	AT Canada	5'14"	21"	Y	Y	S	Y	N	N	N	N	Y	Y	N	N	severe	Y	N	N	Y	light	N	N	0	0		
585	F	09/12/86	Sioux Falls	SD USA	5'15"	16"	Y	N	Y	N	Y	breach	Y	Y	Y	Y	Y	Y	extreme	N	N	N	N	N	N	N	0	0		
586	F	05/29/81	Winnipeg	MB Canada	4'13"	N	N	N	N	N	N	N	N	N	Y	Y	Y	Y	severe	Y	N	N	N	N	N	N	0	0		
587	F	09/28/85	Arlington Heights	IL USA	6'0"	22"	N	Y	U	Y	N	N	breach	N	N	N	N	Y	extreme	Y	N	N	Y	light	N	N	0	0		
588	N	05/19/87	Lansing	MI USA	6'7"	28"	Y	N	Y	D	Y	Y	Y	Y	Y	Y	Y	Y	extreme	Y	N	Y	N	N	N	N	0	0		
589	F	04/15/84	Libby	MT USA	6'2"	28"	Y	Y	S	N	N	N	N	N	N	N	Y	Y	moderate	Y	N	N	N	N	N	N	0	0		
590	N	09/06/84	Loring	VT USA	4'12"	28"	Y	N	Y	D	Y	Y	Y	Y	Y	Y	Y	Y	severe	Y	N	N	N	Y	light	N	N	0	0	
591	N	01/08/77	Pittsfield	MA USA	6'3"	21"	N	Y	Y	D	N	N	N	N	Y	Y	Y	N	moderate	N	N	N	N	Y	Y	Y	0	1		
592	N	04/06/82	Simi Valley	CA USA	9'2"	21"	N	Y	D	Y	N	N	N	Y	N	N	N	N	severe	Y	N	N	Y	light	N	N	Y	0	1	
593	N	01/01/75	Springfield	MA USA	7'12"	21"	N	N	N	D	N	N	N	N	N	N	N	N	Y	severe	N	N	N	N	Y	moderate	N	0	0	
594	F	04/19/77	Philadelphia	PA USA	6'3"	19"	N	N	Y	L	N	N	N	N	Y	Y	N	Y	extreme	Y	N	N	Y	light	N	N	0	0		
595	F	03/13/81	Tacoma	WA USA	7'3"	21"	N	N	Y	S	N	N	N	N	N	N	N	N	moderate	Y	N	N	N	N	Y	moderate	0	0		
596	N	08/28/85	Atlanta	GA USA	5'12"	28"	N	Y	Y	S	N	N	N	N	N	N	N	N	Y	severe	Y	N	N	N	N	N	N	0	0	
597	N	03/21/84	Mashua	NH USA	5'13"	19"	Y	Y	Y	Y	Y	breach	Y	Y	Y	Y	Y	Y	severe	Y	N	N	N	N	N	N	0	0		
598	N	05/21/86	Boston	MA USA	7'15"	19"	Y	N	Y	D	Y	Y	Y	N	Y	Y	Y	Y	extreme	Y	N	N	N	N	Y	light	N	0	0	
599	F	12/06/81	Madison	WI USA	5'8"	19"	N	Y	Y	S	Y	N	N	N	N	N	N	N	moderate	Y	N	N	Y	light	N	N	Y	0	0	
600	F	12/21/84	Chicago	IL USA	4'10"	18"	Y	Y	Y	D	Y	Y	breach	N	Y	Y	Y	Y	severe	Y	N	Y	N	N	N	N	light	0	0	
601	N	05/18/84	LaPorte	IN USA	5'12"	21"	Y	N	Y	Y	Y	Y	breach	N	Y	Y	N	Y	extreme	Y	N	N	N	N	N	N	0	0		
602	F	08/17/88	Minneapolis	MN USA	5'8"	19"	N	Y	Y	S	Y	N	N	N	N	N	N	Y	moderate	Y	N	N	N	N	N	N	0	1		
603	N	07/17/85	Kirkland	WA USA	7'9"	28"	N	Y	Y	Y	Y	Y	Y	N	Y	Y	Y	Y	extreme	Y	N	N	N	Y	moderate	N	0	2		
604	N	05/22/85	Brenton	MA USA	9'2"	22"	Y	Y	N	N	N	Y	Y	N	Y	Y	N	Y	extreme	Y	N	Y	N	N	N	N	0	0		
605	N	04/09/78	Columbia	MD USA	6'1"	17"	Y	Y	Y	S	Y	N	N	N	Y	Y	Y	Y	severe	Y	N	N	N	N	N	N	0	0		
606	N	10/23/78	Muncie	IN USA	5'10"	19"	N	Y	Y	Y	Y	Y	N	N	Y	Y	Y	Y	severe	Y	N	N	N	N	N	N	0	0		
607	F	04/03/86	Spokane	WA USA	7'6"	28"	Y	Y	N	S	N	N	N	N	Y	Y	Y	Y	severe	Y	N	N	N	N	N	N	0	0		
608	F	04/06/88	Santa Clara	CA USA	N	N	Y	Y	D	N	N	N	N	Y	N	N	N	Y	severe	Y	N	N	N	N	N	N	Y	0	0	
609	F	10/18/88	Memphis	TN USA	4'11"	19"	N	Y	S	Y	N	N	breach	Y	Y	Y	Y	Y	severe	Y	N	N	Y	light	N	N	Y	0	0	
610	N	01/08/85	Hershey	PA USA	6'10"	19"	Y	Y	Y	D	N	N	N	N	Y	Y	Y	Y	extreme	Y	N	Y	Y	light	N	N	N	0	1	
611	N	04/07/84	Santa Cruz	CA USA	6'1"	23"	N	Y	Y	D	N	N	breach	Y	Y	Y	Y	Y	moderate	Y	N	N	Y	light	N	N	heavy	0	0	
612	N	05/31/83	Berkeley	CA USA	5'11"	23"	N	Y	Y	D	N	N	N	N	Y	Y	Y	Y	extreme	Y	N	N	Y	moderate	N	N	Y	0	0	
613	N	04/28/88	LaPlata	MD USA	5'9"	28"	N	Y	N	S	N	N	N	N	N	N	N	N	Y	severe	Y	N	N	N	N	N	Y	0	0	
614	N	07/28/84	Escondido	CA USA	5'10"	19"	N	Y	Y	Y	Y	Y	breach	N	N	N	N	Y	severe	Y	N	N	Y	light	N	N	0	0		
615	N	08/15/73	San Antonio	TX USA	18'7"	21"	Y	N	S	N	N	N	N	N	Y	Y	Y	Y	moderate	Y	N	N	N	N	N	N	0	0		
616	N	07/14/79	Summerton	TN USA	9'8"	19"	Y	Y	Y	D	Y	Y	Y	Y	Y	Y	Y	Y	severe	N	N	N	Y	light	N	N	0	0		
617	F	04/26/81	Toledo	OH USA	4'9"	18"	Y	Y	D	Y	Y	Y	N	Y	Y	Y	Y	Y	severe	Y	N	N	N	N	N	N	0	0		
618	F	07/14/73	Utica	NY USA	3'4"	18"	N	N	Y	D	Y	N	N	Y	Y	Y	Y	Y	severe	Y	N	Y	N	N	Y	moderate	Y	0	0	
619	N	12/04/81	Pittsburgh	PA USA	9'11"	22"	N	Y	Y	S	Y	Y	Y	Y	Y	Y	Y	Y	extreme	Y	N	N	N	N	N	N	0	0		
620	N	04/25/82	Birmingham	AL USA	7'6"	21"	N	N	Y	N	N	N	N	N	N	N	N	N	Y	severe	Y	N	N	N	Y	light	N	N	0	0
621	F	11/13/84	Montclair	NJ USA	7'	28"	Y	Y	L	Y	N	N	N	Y	N	N	N	Y	severe	Y	N	N	N	N	Y	heavy	N	0	1	
622	N	04/14/75	Birmingham	AL USA	5'12"	19"	N	Y	N	Y	N	N	N	N	N	N	N	N	Y	severe	N	N	Y	N	N	N	N	0	1	
623	N	04/12/88	Macon	GA USA	4'13"	17"	Y	Y	Y	S	Y	Y	Y	N	Y	Y	Y	Y	severe	Y	N	N	Y	light	N	N	0	0		
624	F	01/28/87	Boston	MA USA	7'11"	28"	Y	N	Y	D	N	N	N	N	N	N	N	N	Y	severe	Y	N	N	N	N	N	N	0	0	
625	F	07/12/88	Hartford	CT USA	6'3"	19"	Y	Y	Y	N	N	N	N	N	N	N	N	N	Y	extreme	Y	N	N	N	N	N	N	0	0	
Male = 372																														
Female = 363																														
Yes = 289 159 351 213 92 69 121 275 136 588 284 125 82 23																														
No = 92 293 98 149 376 28 206 125 82 23 79 462 399 385 262 256																														

Male = 372
Female = 363Yes = 299
No = 92159
293351
98213
14992
37669
28121
286275
125136
62588
23

If you get out your magnifying glass you might be able to read some of the above chart. Actually, we didn't expect you to read it, we just wanted to show you an example of what is happening with the information that all of you have shared over the past few years in our questionnaire series.

We have divided the information into six surveys with related information. We have completed the entry of information from the first two surveys into the computer. The above minuterization is page 14 of report 1A of the first survey. When this was run, it included information from 737 people. Of those 372 were males and 363 females. Information such as this dispels inaccurate information such as the syndrome is more predominant in males (this was an early belief because more boys were diagnosed due to small genitals). 209 people said yes, and 92 people said no to the question of did this pregnancy seem unusual. When asked if drugs of any type were taken during the pregnancy, 159 said yes, 293 said no. Did the mother feel less movement of the fetus during pregnancy, 351 yes, 98 no. Several other questions were asked regarding the pregnancy. Was the baby hypotonic at birth; 588 yes, 23 no. This question brings up some interesting thoughts when we require hypotonia to be present to have the diagnosis. This survey also included other questions on the baby. The last section included questions on alcohol and smoking, with 197 mothers stating they did consume some alcohol during the pregnancy and 305 said they did not. 141 mothers reported they had smoked, 362 did not. Passive smoking, 260 others smoked in the household, 256 did not. Report 1B of Survey 1 included what is called memo questions. They are questions that are not answered in a few characters such as what drugs were taken, etc.

We are very excited to see this information being entered so it can be used. We certainly thank all of the people who took the time to fill out all those long, boring questionnaires. As mentioned elsewhere, we had a good response to the last GV in asking additional members to get involved. We added over 50 new people and filled in some missing information from some of our former respondents. If you had planned on returning the pink questionnaire but haven't gotten to it--it's not too late, we can use more, and we will be asking for additional information as we go along.

QUESTIONS????????

"My daughter is the most active in her classroom. She has adaptive P.E. on Mondays and is in adaptive after school P.E. on Tues. and Thursdays and has swimming lessons on Sat. Does she still require actual physical therapy, we'd have to pay for it privately?"

We often get the statement these young people are all individuals and obviously that is not clear enough in the printed literature. There is no way that you can state each child needs and have that fit every situation. If this child is "active", if she participates in the P.E., if she swims rather than stands on the side of the pool, if she is not overweight and if she does not have any physical need for a specific therapy, her program is probably adequate.

If you do have doubts and would like to ask the "experts" -- feel free to write anytime but give as much specific information as possible and if we can't answer the question from the office, it will be forwarded to someone who can.

"Why is very little written in the GV about the young people who are not retarded?"

The answer to that is two-fold. One, we write mostly what is shared with us, so if there is little written in this regard it is because we have little to share. The second part, is 95% of the people with PWS do have some degree of mental retardation. And of the 5% who do not, many if not all, are still functionally retarded, and what is written still applies. I do believe there are people with PWS that are never diagnosed because they do not have anything more than an eating problem and possibly a little behavior control problem. I, personally, know a nurse that has many characteristics of PWS. She obviously is not retarded, made it through the normal school system, through college and is living independently and working. She is in her 30's, is obese with the weight distributed midsection, can be a very unreasonable woman at times, very set in her ways and has a nasty temper at times. Does she have PWS????

"On your questionnaires you ask questions regarding smoking, drinking, drugs, illness etc.? Are you implying that these are the causes for PWS?"

We certainly don't want to imply any such thing. We feel our parents have had enough guilt piled on them from many sources already.

On the contrary I believe our questionnaires will prove that none of the above have any tie-in because the answers to these questions run the gamut from one extreme to the other.

We want to thank the many people (we lost count but believe we got approximately 200 pink questionnaires returned from the last GV) and this has brought our survey up to 745 participants. Many of the pink questionnaires were from new people, and many help fill in some of the blanks from former participants. As we continue to enter this information into the computer, you will be getting more questions from us.

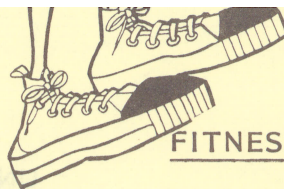
We have a sample page in this GV showing how impressive this information can be. We hope to obtain an interest from more researchers having this available.

Thanks again to your great response to this request and some of the other requests in the last issue.

"We have had knowledge of PW for two years now. Our family see-saws between acceptance and denial. When you are in denial it is hard to ask for help. Do other people have this same problem?"

There are many good books on dealing with feelings that apply to PWS as well as other syndromes. One parent wrote: "The hardest problem is to really know what is happening in your family. As I read the GV and see more information that compares with my child, it gives me a better understanding of her. It teaches us patience with things they can't help and gives us help for things we can."

Learning that your child is an individual, learning what might be but accepting what is. Living one day at a time is very old but it is very wise! Enjoy your child as he is, don't wait for things to change, you are not "condemned to a life of hell" unless you make that hell.



NOTE OF WARNING

Unfortunately, in our "let's sue" society, we all have to be a little more cautious in printed materials regarding PWS.

May we ask that any chapters or groups developing their own brochures or information sheets, please send a copy to PWSA before the final printing. Inaccurate information confuses everyone. Insensitivity can cause problems. We may be able to give some suggestions that will be of some help to you. (That's what we are here for!)

A TEXAS MOTHER SHARES:

"If anyone video taped the Sunday, Nov. 9th show 'Kids Like These', I would recommend a copy be shared with PWSA for their library and for showing at the next conference. It was incredible."

We do appreciate this type of sharing and our tapes are borrowed and used frequently.

She also wrote: "Ms. Bintz article on behavior and training (Sept-Oct issue) was right on! Having taught for 3½ yrs. in High School Special Education, it is so apparent that in misplaced pity or perhaps guilt and fear many parents of handicapped children do not think of training their children in appropriate functional behavior." This parent also mentioned a "Learning in Functional Environments", a training program for parents conducted by Lou Brown of the University of Wisconsin-Madison. We will add this information to our educational material.

EXERCISE TAPES

One mother asked for a suggestion for a good exercise video. We might suggest "Senior Shapeup" Produced by Creative Fitness. Yablon Enterprises, PO Box 7475, Steelton, PA 17113. 49 minutes, \$29.95 + \$4. handling. It is recommended for any age and may be good for those overweight. Any suggestions from members?

FITNESS STUDY

In a study financed by the U.S. Public Health Service, researchers found most parents of children, ages 6-9, do not exercise with them and set poor examples.

The study also confirmed that children are fatter than they use to be. "The message to parents is that they need to make this (exercise) more a priority in their lives, and they need to allow it to structure their behavior with their children."

"One of the most important things in changing behavior or maintaining... behavior is a good role model, everybody seems to think it is not important, he's not going to, either."

These researchers found this information significant and cause for concern--which is even more true for children who really need a good exercise program.

ANOTHER COMMENT ON MARILYN'S ARTICLE ON BEHAVIOR

"Some of the specific methods I have used with my own children (including the two normal ones--they don't suffer from learning good manners, either) are to offer the SHOULDs rather than the SHOULDN'TS. By changing strictly to positive language, we have cut down the tantrums, the tears and improved the results. Some examples: Instead of 'Don't step on my toes!', step only on the floor. Please try to step AROUND me. Instead of 'Don't interrupt', can you wait til (the Person speaking) pauses? Then say your say! Instead of 'Don't spill your milk!'--walk carefully, steady with that milk.

There are some theoretical advantages to the positive speaking pattern other than the purely pragmatic ones of teaching someone to go something MORE to do, rather than taking away a behavior which they can do (albeit a behavior we don't want.) Most persons, in order to conceptualize a negative behavior, must first conceptualize the behavior, THEN negate it, THEN search for and find a substitute behavior, hopefully a more appropriate one. By using SHOULDs, you make this bypass for your child, giving him/her another way to please you.

COMMENTS cont.

I completely agree with Ms. Bintz that practicing the social situations helps a lot. We do that over and over in the car, taking turns. (the favorite is the phone). I'm getting a bit tired of 'Ring, ring' but, now when my son answers at least it gets to me rather than being hung up, laid down or him chattering on inappropriately. And we take turns as to which role we play. It seems to help to have him confronted with having to deal with his own inappropriate behavior. "

I was delighted this August when I received a compliment that both of my boys were the nicest and politest in camp. "After 8 yrs. that's success."

HEALTHY BBQ MEAT LOAF

1½ lb. extra-lean ground beef
 1½ c. whole-wheat bread crumbs
 (3 slices ground in blender, dry)
 2 egg whites ½ c. chopped onion
 ½ tsp. salt ¼ tsp. pepper
 1-¾ c. tomato sauce
 2 Tbsp. Worcestershire sauce
 3 Tbsp. mustard 3 Tbsp. vinegar
 ½ c. frozen unsweetened applejuice
 concentrate.

Combine meat, crumbs, egg, seasoning, half of tomato & worcestershire sauces. Shape into loaf, 7x11 dish. Cover with foil, bake 45 mins. at 350°. Remove from oven, drain fat.

Combine sauces, mustard, vinegar and juice. Pour over loaf. Continue to cook, uncovered for 15 more mins., basting every 5 minutes. 8 servings

215 calories as opposed to typical loaf at 360 calories. Diabetic exchanges, 0 milk, .4 fruit, .1 vegetable, .5 bread, 2.5 meat, low fat.

UNDERSTANDING THE "INITIAL" WORLD

Our parents are frequently dealing with M.D.'s, Ph.D.'s, R.D.'s, Ed.D.'s, P.T.'s, O.T.'s, etc.

If you have a question about nutrition, most people have always turned to their own M.D. and this may not be the best choice. Separate courses on nutrition are not medical school requirements. If the doctor is not that informed, he may give you a recommendation to someone who is but this is not always the case.

Nutrition courses at accredited colleges and universities are based on scientific principles. A bachelor's degree in nutrition requires 4 yrs. of full-time study to qualify for positions in dietetics or food service. A master's degree requires 2 more years. A doctorate (Ph.D.) is at least 2 yrs. of additional study plus a thesis. You can also see an educational (Ed.D.) degree in nutrition education. Registered dietitians (R.D.'s) are specially trained to translate nutrition requirements into healthy, tasty diets. This certification is usually sought by bachelor's and master's level nutrition graduates.

Because the titles "nutritionist" and "nutritional consultant" are unregulated, it is best to follow a few guidelines in seeking their help:

Question anyone who states everyone needs vitamin supplements.

anyone who suggest most diseases are caused by faulty nutrition.

anyone who suggests large doses of vitamins are effective against a large number of diseases and conditions.

anyone who suggests hair analysis determines the body's nutritional state or for recommending vitamins and minerals.

anyone who claims that a wide variety of symptoms and diseases are caused by hidden food allergies.

anyone who uses a computer-scored nutrient deficiency test for prescribing vitamins.

anyone who sells vitamins in his/her office.

Sound nutritional advise is very important for families with a problem like ours -- if in any doubt, get a second opinion.

SYNOPSIS OF ADDRESS GIVEN TO NEBRASKA JUVENILE JUSTICE ASSOCIATION:

Steve Sulzbacher, psychologist, University of Washington, recently wrote: "Ten years ago, the lack of knowledge about PWS caused serious problems in the schools. Today, the judicial system is faced with the same challenge to learn about this condition." (Taken from The Management of Prader-Willi Syndrome, to be published soon.)

There are over 3000 genetic syndromes; there are over 3000 additional conditions. We can't all be knowledgeable about all. One of the major problems with PWS is that it is unique in many aspects. Physical handicaps are easily identified -- when seen, typical characteristics can inform you of the problem, but with PWS problems cannot be identified by just looking at the person. At birth, the doctor is faced with a weak, pale, floppy baby and an immediate diagnosis is rare. Fortunately, testing and knowledge are expanding and diagnoses are made sooner now.

As Dr. Sulzbacher stated, schools are becoming more knowledgeable, other involved people are becoming exposed not only to the problems but also to the education needed to understand the problems, so proper treatment will follow.

The overview of the syndrome lists the major characteristics, but the two, compulsive eating and behavior are the most devastating to the caregiver. The statement, a person with PWS will do anything to obtain food is not an exaggeration. Weight must be controlled if you want to keep that person alive. Behavior must be lived with, and, believe me, it is not always easy.

I would like to address two specific areas; one, police/court involvement, and, two, guardianship. There are two distinct stages of this syndrome: one, the failure to thrive (ages 0-2), and two, the development of thriving too well (ages 2+). Rarely there is involvement in stage one with outsiders unless the physician questions the parent's ability to care for the infant because of the failure to thrive. Since the compulsion to eat generally starts between the age of 2-4, this is when "outsiders" begin to get involved with this child.

Areas of involvement include: one, charges of child abuse, stemming from complaints made to child protective agencies. These can be made by strangers observing a parent-child interaction in public which they deem inappropriate. It can be from examination of the child's bruises or skin picking scars, or it could be from broken bones. Two, running away from home or school. An indication that there are home problems. Three, shoplifting of food, toys, jewelry, etc. Even with careful supervision, this can occur and can involve police contact. Four, restaurant outings with no money to pay.

Our association advises parents to have preventative contacts with police and neighborhood shop owners to explain the syndrome and also suggests sharing pictures of the person for identification. Unfortunately, it is not uncommon for police to bring these children home and comment, "can't you keep track of your child". It is not infrequent to find PW homes where the locks are installed to keep people in rather than out. Locking of kitchens and food supplies are also encouraged.

Pre-teen and teen problems do not always involve police but when these young people are taken into custody, parents frequently come to pick them up and find them well fed during their wait. At this age these young people are usually very agreeable, easy to handle, but can be very manipulative. They would have no qualms in giving a very heart-rendering tale of not being fed at home. Occasionally further investigation is held to verify the true home situation.

As these youngsters age, changes can occur. The police or courts are no longer dealing with a child (who can be dismissed because of their age), but are now dealing with an adult. It would not be uncommon for an adult to build up anger, while waiting for the arrival of police, they can be very belligerent, they may even resent being touched, and may display temper.

JUVENILE PRESENTATION cont.

From early on, parents are forced to assume the role of a policeman, their child literally has to be supervised 24 hours a day. "Burn out" occurs at different stages dependent on many circumstances. Police and courts may encounter a parent who states: "I've had it -- I've done everything I can. Now you can have him." In such cases, it is imperative for you to understand the needs of this person.

Some important points:

1. These are very vulnerable people. Although quite clever, devious schemes to obtain food occur also, they typically do not function at their I.Q. level. Poor judgement is common, sexual exploitation can also be a concern.
2. Not all professionals are PW experts. Very bad advice can be shared by those not understanding the syndrome.
3. Consider private counseling be ordered if you are aware the probation officer assigned does not have the time for counseling.
4. Consider a psychiatric unit in lieu of incarceration.
5. Know that no consistent benefit is derived from medication for behavior.
6. Know that limited success has been reported with foster home placement.

Regarding guardianship, most young people with this syndrome, remain in their homes until adults. Naturally there are exceptions--for example, if both parents work continued home placement can become impossible. Also, necessary complete food control and behavior control warrant seeking an out-of-home placement sooner in some cases.

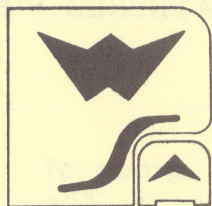
Personally, I recommend an out-of-home placement at the 14-16 year age level as best for the child, best for the parents and best for the home situation, but not all parents are willing to let go at this age. This can be a sense of obligation, guilt, an attitude this is my child, my responsibility and I am the only one who can meet his/her needs. The mother is frequently placed in the role from day one making it difficult to change.

Unless otherwise advised, many parents do not seek guardianship until their child is an adult. Some group homes require some type of guardianship before placement. If you are fortunate this guardianship will be handled by those knowledgeable about the syndrome or willing to learn. More frequently the case will be handled by attorneys and physicians who have never heard of PWS. An attorney who is a great advocate for "people's rights", a psychiatrist who feels this person is capable of making their own decision, can thwart your attempts to obtain this.

PWSA has been involved with parents who are not able to obtain guardianship. Therefore, we do recommend that this is sought before the child becomes an adult. We do receive calls from police, social workers, probation officers. The problem is we can tell them what the right placement is, what we can't tell them if where they can find it. A mixed facility (a facility serving a mixture of problems) will only meet the needs of a person with PWS if they are willing to accommodate their homes to this person. If they expect the person to adjust to them, it doesn't work. (When considering a placement, it doesn't take too many questions to find out what their attitude on this is.) That is why we are trying to assist in opening more PWS homes.

Without spending a great deal of time, there is no way for a speaker to really portray the effects of children on their homes. We hope people working with this syndrome are willing to learn so true justice for them is found.

Marge A. Wett



THE GATHERED VIEW

Newsletter of PRADER-WILLI SYNDROME ASSOCIATION

DELFIN J. BELTRAN, M.D., PRESIDENT
MARGE A. WETT, EXEC.DIRECTOR

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VOLUME XIV

JANUARY - FEBRUARY, 1988

NUMBER 1

PRESIDENT'S MESSAGE

Responsibilities beget rights, and rights provide the opportunity to carry out our responsibilities. In conjunction with the last two conferences, both the membership of the Prader-Willi Syndrome Association and the elected Board of Directors have become more acutely aware of the effect growth has had on the ability to communicate ideas from individuals to various segments of the total organization. Individual persons with specific needs from the Association have become aware of the geographical and time spread that can block a prompt response to that need. Similarly, the Board has desired to move ahead on various projects, but has been frustrated by their inability to reach out to each of you for the input that is necessary to arrive at a reasonable consensus. At the December meeting of the board, this problem was recognized and your president was directed to extend the message in the January-February newsletter to define the rights and responsibilities of the membership during the annual meeting of the membership, conducted at the annual conference. The actual statement was refined by the Chairman of the Board, Lota Mitchell.

The first responsibility of the membership is to determine the composition of the governing body by nominating and electing persons from among their group to be their representatives on the Board of Directors. The Committee of Presidents was formed in part to establish recognition to these important members of our organization in the hope that their exposure to problems at a national level would increase awareness and desire to become board candidates at future conferences.

An active and interested membership will recognize from time to time that the governing Bylaws of the Association may not reflect their guiding concepts. The Board has just completed a reorganization and titling of the Bylaws. Changes can be initiated by the membership and voted upon at the annual meeting. Proposed changes need formal submission with seconding and publication at least three months prior to the annual meeting. It has been the feeling of the Board in general that the Bylaws should reflect the goals of the Association and provide for the mechanisms necessary to accomplish those goals. On the other hand, it has been felt that the Bylaws should not be cluttered with fine definitions of every action that needs to be taken. Actions of the Association directed at specific problems are better managed by motions.

Thus the third area of responsibility and right for the membership acting at the Annual Conference is action items in the form of a motion. Again it is necessary that such motions be clearly stated and seconded with publication three months prior to any Annual Conference Membership meeting. Useful motions will carry with them not only the plan of action but also the means for carrying out the action. It is not appropriate to create tasks and expect someone else to do the work or find the funds

President's Message, cont.PWSABoard of Directors

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Edina, MN
Fausta Deterling
Orono, MN
Gene Deterling
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Dorothy Thompson, M.S.
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Baylor College of Medicine
Stephen Sulzbacher, Ph.D.
University of Washington
Louise Greenswag, Ph.D.
University of Iowa
Barbara Y. Whitman, Ph.D.
Cardinal Glennon Hospital

that will permit the action to take place. Also in this group of actions are motions brought to the membership by the Board. The Board is empowered and held responsible for the proper management of the incorporated Association by the laws of the state in which it is incorporated. In our case, these are the laws of the State of Minnesota. The Board is acutely aware of this responsibility, but from time to time this concern dictates that the Board seek the counsel of the membership. This can be accomplished by the Board submitting a motion at the Annual Meeting of the Membership in the same manner that an individual would act.

At the Annual conference the treasurer will submit an audited report of the financial status. It is characteristically the task of the membership of a corporation to accept or reject the auditors selected to oversee the financial business of a corporation and this practice will be introduced at future meetings.

As you can see, life becomes more and more complex as we grow as an organization. Growth is, however, essential to our continued existence and consonant with the goals outlined in the Bylaws. Only through the increased dues income of added memberships can we obtain the funds necessary to carry on the business of being an Association.

This letter is being written before the holidays but will arrive afterwards. May all of you receive the blessings and goodwill of this season. Start now to make your plans to join us all in Kentucky at the next annual conference. Your associates from Kentucky have been working hard for over a year in anticipation of your attendance in June.

Board Chair clarification of the Rights and Responsibilities of the Membership.

“The rights and responsibilities of the membership at the annual meeting consist of discussion, following recognition by the presiding officer, to nominate from the floor, candidates for the Board of Directors. And, the casting of a written ballot for the following purposes:

- ...to elect, annually, the members of the Board of Directors
- ...to approve, if necessary, the organization's auditors
- ...to vote on changes to the Bylaws initiated by members
- ...to vote on previously submitted and seconded membership motions
- ...to vote on motions considered by the Board of Directors as appropriate for approval by the membership

Only those motions submitted and seconded in writing three months prior to the annual meeting will be eligible for voting by the membership at the annual meeting.”

Delfin J. Beltran, MD

President

C.I.T. UPDATE

We thank the members who responded to our last issue regarding the use of our C.I.T. funds. Visits were made to the Rehab. program at Pittsburgh, the American Institute at Vineland and suggestions were presented to the Board in December. We will continue to investigate the best potentials in order to meet the goals originally set when this fund was started. The membership will be notified when decisions can be made.

We were extremely impressed by the program in operation at the Rehabilitation Institute of Pittsburgh in Pennsylvania. They have served over 75 people in crisis situation already and will continue to do so in the future. Their program is set up for those in need behaviorally as well as weight. If you have a child in a crisis situation, please contact Bea Maier, Program Coordinator, either by mail or phone and investigate their program.

Rehabilitation Institute of Pittsburgh
Bea Maier, Program Coordinator
6301 Northumberland St.
Pittsburgh, PA 15217
(412) 521-9000

We were also impressed by the potential for a program of longer intervention care at the American Institute in Vineland, NJ. This organization will be developing a proposal for PWSA and we hope we will be able to work with them in the second stage of serving crisis needs.

A third visit was made to the Sparks Center at the University of South Alabama and we hope they, too, will be interested in expanding their service area.

In the meantime, we will continue to search for ways to meet the crisis level needs, develop more potential for research, and continue to assist in the opening of more homes.

INSURANCE

We have been informed that if given a choice between regular insurance programs and HMO programs, members have fared better with the programs other than HMO's because of the special needs of our children. If you have a choice, you may keep this in mind.

HIGHLIGHTS OF DEC. BOARD MEETING

Guidelines were accepted for investment of PWSA funds in order to preserve capital but earn more interest.

A discussion was held on fund raising and long range plans with further work to be done before next meeting.

Further research was requested regarding PWSA developing a Foundation for more assistance to people with PWS.

Grants Committee suggestion for awarding a conference grant was accepted. (See article regarding this.)

Permission was given to chapters to sell fund raising articles at conferences. Contact national for regulations.

Guidelines were approved for details of Scientific Day presentations at conference.

Standard Operating Procedures Manual should be completed by June.

Changes were made in donation designations (see Money article).

Conference bid for 1989, Calgary location, was accepted. Members will be contacted regarding later date for future conferences.

Membership rights and responsibilities discussed (see President's message).

Dr. Cassidy will pursue WHO funds for foreign scientific meeting.

Board meetings at conferences shortened in order to allow members time to meet and talk with other attendees.

Treasurer will develop a proposal related to improving the revenue of PWSA.

Details of publication of "The Management of PWS" are being worked out -- hope to have available before next conference.

(If any members have any question on any of the above items, please contact PWSA office and we will be happy to supply further information.)

Board members are elected at the annual conference. More information will follow regarding procedures to nominate and elect these members as the conference approaches.



THAT UNFAVORITE SUBJECT -- MONEY



Many of our readers are very well aware of how PWSA started, how Gene ran out of "spare time" to continue operating it alone (as they say, with a little help from his friends), and how we eventually had to turn from volunteer to a little paid staff. Those unpaid years built up a little reserve in the general operating fund, and that is why the Board of Directors were just able to pass an unbalanced budget for the coming year. Operating in the "red" is facing the fact we do not take in enough money in dues, material sales profit, donations to operating, and interest to pay the bills to continue to run the organization. Our operating budget does not allow us the luxury of spacious offices, well-paid staff, opportunities to start new projects and it does not face the future when things will need to be higher, but at the moment it is where we are.

As you know, in addition to the operating budget we do have special funds. These funds are designated as the Research Fund, the C.I.T. (crisis & intervention fund), and the Conference Fund. This month your board made a change in how these funds will be handled, the motion stated: "Hereafter undesignated gifts to PWSA will be split 50% to the Research Fund and 50% to the general operating fund. If the gift is designated, it will go 100% to wherever stated." In other words if you send a check and do not say which fund it is for, then it will be divided as operating and research. If you want the entire amount for one fund, then that must be specified with the donation.

This is the budget that was approved:

PRADER-WILLI SYNDROME ASSOCIATION

APPROVED BUDGET, 1988

INCOME:

Membership Dues	32,000.00
Operating Donations	7,500.00
Material Sales	15,000.00
Interest	4,000.00
Conference	18,000.00
Total Income	76,500.00

EXPENSES:

Salaries/Taxes	25,000.00
Travel	3,000.00
Rent	6,000.00
Printing	3,900.00
Postage	4,700.00
Supplies	2,300.00
Telephone	1,200.00
Publishing	15,000.00
Service Contracts	1,600.00
Capital Equipment	2,000.00
Committees/Chapters	300.00
Conference	16,500.00
Total Expenses	81,500.00
Net Income	(5,000.00)

Those who donated in November and December.

Operating funds: \$445.78, \$2055. (other additional funds were received thru contributing and patron dues)

CIT: \$625., \$1565.

RESEARCH: \$1081.63, \$395.

CIT Donors: Two donations: Sunde, Dixon, Sharp, Wett(Schaefer), E.Olson. Boyd, Sojka, Hambrick(Heniff), Dam(matching), Foley, Beltran, Stephens, Chase, LaBelle (Buckstein,LaBella), Notbohm, Wolschon, Castle, Vermeulen (Heidel), Brewi(Posch), Parcell, Goff, Ziifle, Metzger,Gulling.

Research Donors: Sharp, Townsend, Mitchell(Echols), Hruska(Kramer), Healy, Corcoran(McKee), Maurer (3)(Shiflet,Colony Sq.Hotel, Maurer), Sojka, Vermeulen(U.W.), Cannon, Mook(Mook). Funds were also received indirectly from So.NV CFC & Nashville Community Chest. Two families designated memorials, Hinson and Budner. One of our member's son, Peter Haller, worked thru the Lambda Tau Chapter of Delta Sigma Pi and proudly presented a check for \$600. that was raised at local supermarkets. We supplied brochures, buttons, and posters and these young people not only asked for donations but also increased public awareness.

We thank all of these special people who do feel PWSA is worthy of their support.

[illegible]

If you get out your magnifying glass you might be able to read some of the above chart. Actually, we didn't expect you to read it, we just wanted to show you an example of what is happening with the information that all of you have shared over the past few years in our questionnaire series.

We have divided the information into six surveys with related information. We have completed the entry of information from the first two surveys into the computer. The above minuterization is page 14 of report 1A of the first survey. When this was run, it included information from 737 people. Of those 372 were males and 363 females. Information such as this dispells inaccurate information such as the syndrome is more predominant in males (this was an early belief because more boys were diagnosed due to small genitals). 209 people said yes, and 92 people said no to the question of did this pregnancy seem unusual. When asked if drugs of any type were taken during the pregnancy, 159 said yes, 293 said no. Did the mother feel less movement of the fetus during pregnancy, 351 yes, 98 no. Several other questions were asked regarding the pregnancy. Was the baby hypotonic at birth; 588 yes, 23 no. This question brings up some interesting thoughts when we require hypotonia to be present to have the diagnosis. This survey also included other questions on the baby. The last section included questions on alcohol and smoking, with 197 mothers stating they did consume some alcohol during the pregnancy and 305 said they did not. 141 mothers reported they had smoked, 362 did not. Passive smoking, 260 others smoked in the household, 256 did not. Report 1B of Survey 1 included what is called memo questions. They are questions that are not answered in a few characters such as what drugs were taken, etc.

We are very excited to see this information being entered so it can be used. We certainly thank all of the people who took the time to fill out all those long, boring questionnaires. As mentioned elsewhere, we had a good response to the last GV in asking additional members to get involved. We added over 50 new people and filled in some missing information from some of our former respondees. If you had planned on returning the pink questionnaire but haven't gotten to it--it's not too late, we can use more, and we will be asking for additional information as we go along.

QUESTIONS????????

"My daughter is the most active in her classroom. She has adaptive P.E. on Mondays and is in adaptive after school P.E. on Tues. and Thursdays and has swimming lessons on Sat. Does she still require actual physical therapy, we'd have to pay for it privately?"

We often get the statement these young people are all individuals and obviously that is not clear enough in the printed literature. There is no way that you can state each child needs and have that fit every situation. If this child is "active", if she participates in the P.E., if she swims rather than stands on the side of the pool, if she is not overweight and if she does not have any physical need for a specific therapy, her program is probably adequate.

If you do have doubts and would like to ask the "experts" -- feel free to write anytime but give as much specific information as possible and if we can't answer the question from the office, it will be forwarded to someone who can.

"Why is very little written in the GV about the young people who are not retarded?"

The answer to that is two-fold. One, we write mostly what is shared with us, so if there is little written in this regard it is because we have little to share. The second part, is 95% of the people with PWS do have some degree of mental retardation. And of the 5% who do not, many if not all, are still functionally retarded, and what is written still applies. I do believe there are people with PWS that are never diagnosed because they do not have anything more than an eating problem and possibly a little behavior control problem. I, personally, know a nurse that has many characteristics of PWS. She obviously is not retarded, made it through the normal school system, through college and is living independently and working. She is in her 30's, is obese with the weight distributed midsection, can be a very unreasonable woman at times, very set in her ways and has a nasty temper at times. Does she have PWS????

"On your questionnaires you ask questions regarding smoking, drinking, drugs, illness etc.? Are you implying that these are the causes for PWS?"

We certainly don't want to imply any such thing. We feel our parents have had enough guilt piled on them from many sources already.

On the contrary I believe our questionnaires will prove that none of the above have any tie-in because the answers to these questions run the gamut from one extreme to the other.

We want to thank the many people (we lost count but believe we got approximately 200 pink questionnaires returned from the last GV) and this has brought our survey up to 745 participants. Many of the pink questionnaires were from new people, and many help fill in some of the blanks from former participants. As we continue to enter this information into the computer, you will be getting more questions from us.

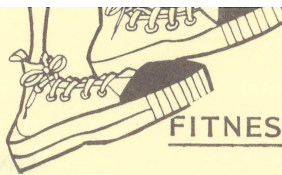
We have a sample page in this GV showing how impressive this information can be. We hope to obtain an interest from more researchers having this available.

Thanks again to your great response to this request and some of the other requests in the last issue.

"We have had knowledge of PW for two years now. Our family see-saws between acceptance and denial. When you are in denial it is hard to ask for help. Do other people have this same problem?"

There are many good books on dealing with feelings that apply to PWS as well as other syndromes. One parent wrote: "The hardest problem is to really know what is happening in your family. As I read the GV and see more information that compares with my child, it gives me a better understanding of her. It teaches us patience with things they can't help and gives us help for things we can."

Learning that your child is an individual, learning what might be but accepting what is. Living one day at a time is very old but it is very wise! Enjoy your child as he is, don't wait for things to change, you are not "condemned to a life of hell" unless you make that hell.



NOTE OF WARNING

Unfortunately, in our "let's sue" society, we all have to be a little more cautious in printed materials regarding PWS.

May we ask that any chapters or groups developing their own brochures or information sheets, please send a copy to PWSA before the final printing. Inaccurate information confuses everyone. Insensitivity can cause problems. We may be able to give some suggestions that will be of some help to you. (That's what we are here for!)

A TEXAS MOTHER SHARES:

"If anyone video taped the Sunday, Nov. 9th show 'Kids Like These', I would recommend a copy be shared with PWSA for their library and for showing at the next conference. It was incredible."

We do appreciate this type of sharing and our tapes are borrowed and used frequently.

She also wrote: "Ms. Bintz article on behavior and training (Sept-Oct issue) was right on! Having taught for 3½ yrs. in High School Special Education, it is so apparent that in misplaced pity or perhaps guilt and fear many parents of handicapped children do not think of training their children in appropriate functional behavior." This parent also mentioned a "Learning in Functional Environments", a training program for parents conducted by Lou Brown of the University of Wisconsin-Madison. We will add this information to our educational material.

EXERCISE TAPES

One mother asked for a suggestion for a good exercise video. We might suggest "Senior Shapeup" Produced by Creative Fitness. Yablon Enterprises, PO Box 7475, Steelton, PA 17113. 49 minutes, \$29.95 + \$4. handling. It is recommended for any age and may be good for those overweight. Any suggestions from members?

FITNESS STUDY

In a study financed by the U.S. Public Health Service, researchers found most parents of children, ages 6-9, do not exercise with them and set poor examples.

The study also confirmed that children are fatter than they use to be. "The message to parents is that they need to make this (exercise) more a priority in their lives, and they need to allow it to structure their behavior with their children."

"One of the most important things in changing behavior or maintaining... behavior is a good role model, everybody seems to think it is not important, he's not going to, either."

These researchers found this information significant and cause for concern--which is even more true for children who really need a good exercise program.

ANOTHER COMMENT ON MARILYN'S ARTICLE ON BEHAVIOR

"Some of the specific methods I have used with my own children (including the two normal ones--they don't suffer from learning good manners, either) are to offer the SHOULDs rather than the SHOULDN'TS. By changing strictly to positive language, we have cut down the tantrums, the tears and improved the results. Some examples: Instead of 'Don't step on my toes!', step only on the floor. Please try to step AROUND me. Instead of 'Don't interrupt', can you wait til (the Person speaking) pauses? Then say your say! Instead of 'Don't spill your milk!'--walk carefully, steady with that milk.

There are some theoretical advantages to the positive speaking pattern other than the purely pragmatic ones of teaching someone to go something MORE to do, rather than taking away a behavior which they can do (albeit a behavior we don't want.) Most persons, in order to conceptualize a negative behavior, must first conceptualize the behavior, THEN negate it, THEN search for and find a substitute behavior, hopefully a more appropriate one. By using SHOULDs, you make this bypass for your child, giving him/her another way to please you.

COMMENTS cont.

I completely agree with Ms. Bintz that practicing the social situations helps a lot. We do that over and over in the car, taking turns. (the favorite is the phone). I'm getting a bit tired of 'Ring, ring' but, now when my son answers at least it gets to me rather than being hung up, laid down or him chattering on inappropriately. And we take turns as to which role we play. It seems to help to have him confronted with having to deal with his own inappropriate behavior. "

I was delighted this August when I received a compliment that both of my boys were the nicest and politest in camp. "After 8 yrs. that's success."

HEALTHY BBQ MEAT LOAF

1½ lb. extra-lean ground beef
 1½ c. whole-wheat bread crumbs
 (3 slices ground in blender, dry)
 2 egg whites ½ c. chopped onion
 ½ tsp. salt ¼ tsp. pepper
 1-¾ c. tomato sauce
 2 Tbsp. Worcestershire sauce
 3 Tbsp. mustard 3 Tbsp. vinegar
 ½ c. frozen unsweetened apple juice
 concentrate.

Combine meat, crumbs, egg, seasoning, half of tomato & worcestershire sauces. Shape into loaf, 7x11 dish. Cover with foil, bake 45 mins. at 350°. Remove from oven, drain fat.

Combine sauces, mustard, vinegar and juice. Pour over loaf. Continue to cook, uncovered for 15 more mins., basting every 5 minutes. 8 servings

215 calories as opposed to typical loaf at 360 calories. Diabetic exchanges, 0 milk, .4 fruit, .1 vegetable, .5 bread, 2.5 meat, low fat.

UNDERSTANDING THE "INITIAL" WORLD

Our parents are frequently dealing with M.D.'s, Ph.D.'s, R.D.'s, Ed.D.'s, P.T.'s, O.T.'s, etc.

If you have a question about nutrition, most people have always turned to their own M.D. and this may not be the best choice. Separate courses on nutrition are not medical school requirements. If the doctor is not that informed, he may give you a recommendation to someone who is but this is not always the case.

Nutrition courses at accredited colleges and universities are based on scientific principles. A bachelor's degree in nutrition requires 4 yrs. of full-time study to qualify for positions in dietetics or food service. A master's degree requires 2 more years. A doctorate (Ph.D.) is at least 2 yrs. of additional study plus a thesis. You can also see an educational (Ed.D.) degree in nutrition education. Registered dietitians (R.D.'s) are specially trained to translate nutrition requirements into healthy, tasty diets. This certification is usually sought by bachelor's and master's level nutrition graduates.

Because the titles "nutritionist" and "nutritional consultant" are unregulated, it is best to follow a few guidelines in seeking their help:

Question anyone who states everyone needs vitamin supplements.

anyone who suggest most diseases are caused by faulty nutrition.

anyone who suggests large doses of vitamins are effective against a large number of diseases and conditions.

anyone who suggests hair analysis determines the body's nutritional state or for recommending vitamins and minerals.

anyone who claims that a wide variety of symptoms and diseases are caused by hidden food allergies.

anyone who uses a computer-scored nutrient deficiency test for prescribing vitamins.

anyone who sells vitamins in his/her office.

Sound nutritional advise is very important for families with a problem like ours -- if in any doubt, get a second opinion.

SYNOPSIS OF ADDRESS GIVEN TO NEBRASKA JUVENILE JUSTICE ASSOCIATION:

Steve Sulzbacher, psychologist, University of Washington, recently wrote: "Ten years ago, the lack of knowledge about PWS caused serious problems in the schools. Today, the judicial system is faced with the same challenge to learn about this condition." (Taken from The Management of Prader-Willi Syndrome, to be published soon.)

There are over 3000 genetic syndromes; there are over 3000 additional conditions. We can't all be knowledgeable about all. One of the major problems with PWS is that it is unique in many aspects. Physical handicaps are easily identified -- when seen, typical characteristics can inform you of the problem, but with PWS problems cannot be identified by just looking at the person. At birth, the doctor is faced with a weak, pale, floppy baby and an immediate diagnosis is rare. Fortunately, testing and knowledge are expanding and diagnoses are made sooner now.

As Dr. Sulzbacher stated, schools are becoming more knowledgeable, other involved people are becoming exposed not only to the problems but also to the education needed to understand the problems, so proper treatment will follow.

The overview of the syndrome lists the major characteristics, but the two, compulsive eating and behavior are the most devastating to the caregiver. The statement, a person with PWS will do anything to obtain food is not an exaggeration. Weight must be controlled if you want to keep that person alive. Behavior must be lived with, and, believe me, it is not always easy.

I would like to address two specific areas; one, police/court involvement, and, two, guardianship. There are two distinct stages of this syndrome: one, the failure to thrive (ages 0-2), and two, the development of thriving too well (ages 2+). Rarely there is involvement in stage one with outsiders unless the physician questions the parent's ability to care for the infant because of the failure to thrive. Since the compulsion to eat generally starts between the age of 2-4, this is when "outsiders" begin to get involved with this child.

Areas of involvement include: one, charges of child abuse, stemming from complaints made to child protective agencies. These can be made by strangers observing a parent-child interaction in public which they deem inappropriate. It can be from examination of the child's bruises or skin picking scars, or it could be from broken bones. Two, running away from home or school. An indication that there are home problems. Three, shoplifting of food, toys, jewelry, etc. Even with careful supervision, this can occur and can involve police contact. Four, restaurant outings with no money to pay.

Our association advises parents to have preventative contacts with police and neighborhood shop owners to explain the syndrome and also suggests sharing pictures of the person for identification. Unfortunately, it is not uncommon for police to bring these children home and comment, "can't you keep track of your child". It is not infrequent to find PW homes where the locks are installed to keep people in rather than out. Locking of kitchens and food supplies are also encouraged.

Pre-teen and teen problems do not always involve police but when these young people are taken into custody, parents frequently come to pick them up and find them well fed during their wait. At this age these young people are usually very agreeable, easy to handle, but can be very manipulative. They would have no qualms in giving a very heart-rendering tale of not being fed at home. Occasionally further investigation is held to verify the true home situation.

As these youngsters age, changes can occur. The police or courts are no longer dealing with a child (who can be dismissed because of their age), but are now dealing with an adult. It would not be uncommon for an adult to build up anger, while waiting for the arrival of police, they can be very belligerent, they may even resent being touched, and may display temper.

JUVENILE PRESENTATION cont.

From early on, parents are forced to assume the role of a policeman, their child literally has to be supervised 24 hours a day. "Burn out" occurs at different stages dependent on many circumstances. Police and courts may encounter a parent who states: "I've had it -- I've done everything I can. Now you can have him." In such cases, it is imperative for you to understand the needs of this person.

Some important points:

1. These are very vulnerable people. Although quite clever, devious schemes to obtain food occur also, they typically do not function at their I.Q. level. Poor judgement is common, sexual exploitation can also be a concern.
2. Not all professionals are PW experts. Very bad advice can be shared by those not understanding the syndrome.
3. Consider private counseling be ordered if you are aware the probation officer assigned does not have the time for counseling.
4. Consider a psychiatric unit in lieu of incarceration.
5. Know that no consistent benefit is derived from medication for behavior.
6. Know that limited success has been reported with foster home placement.

Regarding guardianship, most young people with this syndrome, remain in their homes until adults. Naturally there are exceptions--for example, if both parents work continued home placement can become impossible. Also, necessary complete food control and behavior control warrant seeking an out-of-home placement sooner in some cases.

Personally, I recommend an out-of-home placement at the 14-16 year age level as best for the child, best for the parents and best for the home situation, but not all parents are willing to let go at this age. This can be a sense of obligation, guilt, an attitude this is my child, my responsibility and I am the only one who can meet his/her needs. The mother is frequently placed in the role from day one making it difficult to change.

Unless otherwise advised, many parents do not seek guardianship until their child is an adult. Some group homes require some type of guardianship before placement. If you are fortunate this guardianship will be handled by those knowledgeable about the syndrome or willing to learn. More frequently the case will be handled by attorneys and physicians who have never heard of PWS. An attorney who is a great advocate for "people's rights", a psychiatrist who feels this person is capable of making their own decision, can thwart your attempts to obtain this.

PWSA has been involved with parents who are not able to obtain guardianship. Therefore, we do recommend that this is sought before the child becomes an adult. We do receive calls from police, social workers, probation officers. The problem is we can tell them what the right placement is, what we can't tell them if where they can find it. A mixed facility (a facility serving a mixture of problems) will only meet the needs of a person with PWS if they are willing to accommodate their homes to this person. If they expect the person to adjust to them, it doesn't work. (When considering a placement, it doesn't take too many questions to find out what their attitude on this is.) That is why we are trying to assist in opening more PWS homes.

Without spending a great deal of time, there is no way for a speaker to really portray the effects of children on their homes. We hope people working with this syndrome are willing to learn so true justice for them is found.

Marge A. Wett

OVERSIZED CLOTHING

An Alabama mother shared: "At last togs for overweight boys, girls, in trendy styles. For catalog, send \$2. to: AT LAST, INC., 60 N. Main St., Dept. P, Natick, MA 01760.

COMMUNITY SERVICE LISTING

We have a Kansas parent who is attempting to get a listing for PWS in all of the state's telephone directories. Many yellow pages have a special listing in the front of the book. We would prefer to have the national organization listed in order for us to send full information, but some may require a local number.

Recently an Idaho mother had her phone listed for information and received three calls. We do like to warn you that listing a phone and address may sometimes be inviting unwanted calls or attention, and therefore do recommend the national listing.

We are happy to have publicity ideas shared, every little bit helps.

CONFERENCES

Now that you are looking at January, 1988, be sure to write down JUNE 23-25 for the next annual conference in Louisville, KY. We have many "old faithful" members who attend as often as possible, and we receive many letters stating the first conference was great. Join the crowd this year in KY.

The board has also accepted the bid of the B.C., Canada group for the 1989 conference. Since a change of dates was necessary, we will keep mentioning these dates frequently. The Calgary conference will be JULY 20-22, our FIRST International Conference. The later date was necessitated by late school closing and the famous Calgary Stampede. Before the next conference we will be asking your opinion if the later date should be continued so all schools will be closed before our conferences.

An example of a letter received: "Thank you for the fine conference that PWSA held

this past summer in Houston. This was my first conference, and I learned so much it was almost overwhelming. I enjoyed meeting and talking with parents of PWS people of all ages. I wouldn't have missed the conference, but it was difficult for me. The conference experience forced me to face the tough reality of what it is to raise a PWS child. (My two year old was diagnosed in June, 1986 at the age of 8 mos.) However, I was impressed by the hope, humor and love that was evident among the participants. It was an experience of a lifetime, and one I hope to repeat soon.

Thank you for all the good work you do all year long to make life easier for PWS people and their families."

TRAINING CENTERS

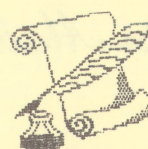
We are hearing more and more of special training centers aimed at assisting parents with special kids. One recent brochure stated there are 26 parent resource training centers in VA, WV, and MD. These are centers to educate parents regarding special education.

The one mentioned in this brochure was "Instructional Resources Center, 3651 Hartford St., Portsmouth, VA 23707." An inquiry in your own area may well give you references to those available to you.

SHARING LETTERS

It's hard to find the time (and the money) to acknowledge every letter that we receive from parents sharing information on their child. PLEASE know these letters are all very much appreciated and if they don't make it into the GV, they are still shared in phone conversations and stored for reference.

This is your newsletter, what you share makes it helpful -- keep the letters coming.



CONFERENCE GRANT APPROVED

It has been suggested that PWSA set up some mechanism of financial assistance for people who want to attend the conference but cannot afford the entire cost. Your board has approved a grant suggested by an appointed committee. The first grant will be awarded in the amount of \$500.00 to a parent, guardian or primary care giver of a person with PWS, in order for them to attend the Kentucky conference.

If you are interested in applying for this grant, you may contact your local chapter president or the PWSA office. Eligibility will be based on financial need, with a random drawing to choose the recipient. In the future, we hope to expand the amount, the number of the awards and eligibility as resources do allow.

PUBLICITY WE ALMOST GOT

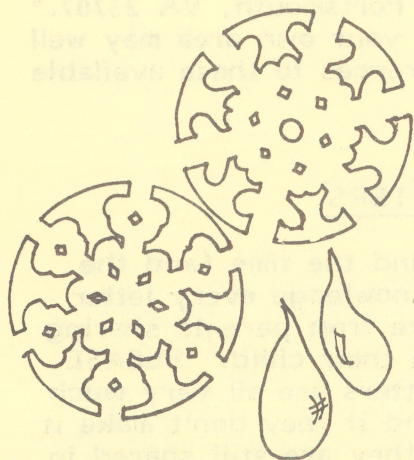
The March issue of Good Housekeeping was scheduled to review our PWSA brochure (submitted by member Anne Hill of Ohio), but it was "cut" due to space.

Write to Marcy O'Koon, Good Housekeeping, The Better Way, 959 8th Ave., New York, NY 10019 and request that our review make the next issue. It may encourage the editors to not cut it the next time and we can certainly use the publicity. Numbers do make a difference, one letter can be ignored--a dozen letters will make an impression. Just a note today may bring in 100 new members tomorrow.

We thank Anne for submitting our brochure to this editor, let's hope for a future publication.

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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 the PWSA. Duplication of this newsletter for distribution is prohibited. Quotations may be used if credit is given to PWSA. Membership dues are \$20./year Individual, \$25./year Family, and \$30./year for Agencies/Professionals. (U.S.Funds) Send dues and change of address to: PWSA, 5515 Malibu Dr., Edina, MN 55436.
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