

The Gathered View

*Newsletter of the
Prader-Willi Syndrome Association*

JANUARY-FEBRUARY 1990

VOLUME XVI, NUMBER 1

Year-End Board Meeting: A Report to the Membership

Your board met the first weekend in December, and some of the following actions were decided upon:

- Continued development of Foundation for Trusts
- Tentative date for International PWS meeting in Holland, May 3-5, 1991
- Approved guidelines for making Crisis grants and loans
- Approved new guidelines for conference Youth/Adult Activities Program
- Approved a vast undertaking in Education (for all professionals and parents)
- Appointed Sheldon L. Tarakan of New York as Public Relations Director
- Approved two grants for 1990 conference (*see article below*)
- Set terms for officers of PWSA (*see article below*)
- Approved grant for a drug study
- Established policy of using nominations committee for board candidates
- Approved screening of speaker's presentations for conferences
- Approved changes in policies for working with chapters
- Approved resolution to amend policy of board voting by mail
(to be voted upon by membership at next annual meeting)
- Approved 1990 budget (*see article on page 2*)

Two Conference Grants To Be Awarded

Two grants, up to a maximum of \$1000 per family, will be awarded to allow needy families to attend the next conference in Salt Lake City. Any member may submit a request to be considered for these grants. Need will be determined by a follow up phone call or contact, and two families will be chosen at random from those who qualify to receive this assistance. Please submit your request in the next couple of months.

Terms of Officers

PWSA President and Vice-President will be appointed by the Board of Directors to serve a term of three years with the possibility of them serving one additional term by a 2/3rds vote of the board. An annual review will be retained. The Secretary and Treasurer's position will continue to be reviewed each year.

The board felt a change of officers would give more members an opportunity to become more involved in their organization. A nominating committee procedure was also instigated by the board. A nominating committee, composed of five persons (with a maximum of three current board members), will be appointed to contact present board members whose terms are expiring to determine if they want to run for re-election and to also to determine if that person is an productive board member; to determine nominees to fit the criteria of the board needs (such as their expertise, wide representation of areas, mix of parents and professionals); and seek out interested people; determine qualified persons. This procedure will be used for the next board election in July.

PWSA

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Open Up and Say "Ah" . . .

. . . as in "Prahder-Willi" Syndrome! Yes, the verdict is in. It's pronounced *Prahder*, not *Prayder*. This, according to Dr. Prader himself, who has solved the dilemma once and for all! So, should you hear anyone pronounce it *Prayder*, just clue them in! And just in case there is any question whatsoever about how we pronounce Dr. Willi's name, it rhymes with "chilly." Need we say more?

1990 Proposed Budget

The new proposed budget includes an anticipated increase in income required in order for PWSA to grow, rather than continue operations at the present level. This will require an increase in donations. Additional funds would be used for such projects such as the newly approved Education Plan, efforts in Public Relations, efforts to increase membership, and improving our conferences.

PLANNED INCOME

Donations	\$30,000.00
Membership Dues	38,500.00
Material Sales	12,500.00
Interest	3,000.00
Miscellaneous	1,000.00
Total	\$85,000.00

PLANNED EXPENSES

Salaries/Taxes	\$52,000.00
Travel	6,000.00
Rent	6,000.00
Operating	
Committees/Chapters	6,000.00
Postage	8,000.00
Printing	6,600.00
Service Contracts	3,300.00
Supplies	3,000.00
Telephone	1,100.00
Special Grants	2,000.00
Capital Equipment	2,500.00
Material for Sale	7,500.00
Miscellaneous	1,000.00
Total	\$105,000.00
Projected deficit	\$20,000.00

The Executive Director's Year-End Report: A Synopsis

Due to the fact we never have any "slow times" anymore, we feel growth is continuing. Growth is measured by our membership numbers as well as services extended to many non-members. Our membership have reached 1647; 1348 of parents with older children and professionals and 299 parents of children under ten or professionals working with that age group. An Assistant Director, Barbara Harris, came on board the end of August and is presenting learning PWS as well as PWSA procedures. Judy Goff continues in her position of Office Secretary.

We will break even (or raise little) on the conference fund raiser. This year we decided to have a raffle with pocket calendars instead of selling actual tickets. We have not been successful in convincing our members they cannot get along without their PWSA calendar next year. One major frustration we have been encountering more recently than in the past is the fact there are more and more people in need that we cannot help. Money is extremely tight in most states and services are just not available. Does anyone have any ideas on our doing something at the federal or state level? Any suggestions would be greatly appreciated. To quote an old cliché, "we've come a long way baby", since our modest beginnings in 1975, and with the help of all of you we will continue to grow and serve our members, but if you have some suggestions on how we can do more, we would greatly appreciate them. -- Marge A. Wett

New Genetic Information

At the December board meeting Dr. Suzanne Cassidy shared information which was reported at the November American Society of Human Genetics meeting. Information included reflecting back to reports previously presented on the fact the chromosome #15 deletion, which occurs in persons with PWS, is located on the chromosome supplied by the father. If the deletion occurs in the maternal material, Angelman's syndrome is found instead. This is referred to as Genetic Imprinting. This indicated genes arriving from different parents may have a different effect. Geneticists are presently studying why this occurs. It is still very early in these studies, really the forefront of knowledge.

During the genetics meeting one laboratory presented four cases of PWS that did not have the #15 chromosome deletion but had typical symptoms of the syndrome. When examining the area where the deletion has occurred in other patients, these geneticists found that instead of having one maternal and one paternal chromosome in that

region, the patients had two maternal chromosomes. They had not looked to see if the whole chromosome is maternal, just the region of interest to PWS. Previously in studies of cystic fibrosis duplications of maternal chromosomes have been found. In this case the term used is maternal isodisomy as the chromosome is duplicated; in the case of PWS, it is being called maternal heterodisomy as both chromosomes are from the mother. This may be a case for explaining the presence of the syndrome when a deletion cannot be found. It is believed to be a sporadic occurrence, there is no screening to be able to predict this condition prior to birth. It is very possible this occurs on other chromosomes too but where it does not make any difference to the development of the child. Doctors still do not agree whether prenatal testing will verify the presence of PWS (the deletion can be very minimum).

It is very encouraging to hear of work being done, and such outstanding information be acquired.

President's Message

The first weekend of December is the time set aside by your Board of Directors to hold the annual interim meeting. Seventeen PWSA members selected by your vote meet to carry on the business and develop programs to find solutions to the needs of people with Prader-Willi syndrome and the people who care for them. At their own expense in time and dollars they arrived to a desert sunset of spectacular reds. Board member Dr. Suzanne Cassidy hosted a reception at her home and most then concluded the evening with a taste of the local chili and peppers that possess a strength that has made the area famous. By seven thirty the next morning chairperson Lota Mitchell had corralled the troops into formation and it was a day of energetic work. The long agenda that we felt would never be completed by noon Sunday was skillfully maneuvered by the chair to a successful and timely conclusion.

As you recall, the board at last year's interim meeting placed education as the leading responsibility among the list of goals for the administration of the organization. They recognized the importance of educating the professionals to make the diagnosis and to apply available knowledge in support. The educational thrust for parents would be supported by programs to provide us with current information that can help us in daily care and guide our planning for the future. The education of the person with PWS is controlled by their Individual Education Plan (IEP) according to Public Law 94-142. The success of an educational program depends upon the parents education about this law. Many of us never realized that our input guides the IEP and that our concerns regarding educations responsibility to include language evaluation and training, development of socialization skills, control of food environment both at school as well as on school transportation and that residential school placement and physical and occupational therapy may be included when they are necessary for the child to benefit from education.

This is a major undertaking of your board and is under the direction of board member Barbara Whitman who is associated with the St. Louis group. She has developed initial concepts for the program. These concepts will be expanded into the full program for presentation at our next PWSA Conference this summer in Salt Lake City. The full spectrum program will be designed to benefit all members of the PWSA. Part of the benefit each of us receives will be in direct relationship to the amount of effort

contributed to the task by your chapter and how much effort is contributed by you as a member. This is reminiscent of the old phrase, to get a letter, write a letter (nobody ever writes me a letter in response to my letters though!). But it will be true. This thrust to education is needed to benefit our persons with Prader-Willi and the degree to which each of us as members of the PWSA will benefit will be dependent on the amount of effort each of us commits to the common good.

Another project of the board this is designed for the benefit of persons with Prader-Willi is the creation of a mechanism that will permit the PWSA to be designated for the provision of personal care and advocacy services. It will be the purpose of this plan to provide parents with a method of ensuring care and advocacy of the child with PWS after their death. One of the greatest fears that exists among parents of children with disabilities is the fear that after parents have died that there will not be someone to ensure that the child with PW will have someone who knows PWS will be available to make the decisions that they would have made based on their expert knowledge as parents. Consequently the PWSA is establishing a method whereby others parents and professionals that know PWS can be designated by a trust agreement to manage supporting funds for our children and to act on their behalf as we parents would have done were we alive to perform that function. This sounds complex, it is an attempt to answer the question, "What will happen to my child with PW when I die? No one knows them the way I do. Only another PW parent would understand." That is what your PWSA is attempting to create for you. IN effect parents will designate part of their estate to be paid to a trust managed by PWSA. These funds will be expended for the benefit of the designated person with PWS in accordance with an Individual Care Program established by the parents before their death. Obviously a complete description of this project cannot be accomplished in this letter, but I felt that such good news of a major commitment of your PWSA should be made available to you.

This letter is being written as our family gets ready for the holiday season and we fondly wish each and everyone the blessings of the season and a good and happy New Year.

Delfin J. Beltran, M.D.

A Gathering of Angels

Who cares how many angels can fit on the head of a pin? We want to know how many angels can fit on a page of *The Gathered View*! We are pleased with the results of the annual fund drive thus far. As we previously reported, one board member was able to obtain matching funds up to \$10,000 for this drive so this will make a considerable difference in our budget. We also thank the families for designating PWSA as recipient for memorial funds, and other members who have also been using the honor cards, which is greatly appreciated. Here's our latest roster -- all angels of the highest order!

HEAVENLY ANGELS: Trentacosta, Linonis, Notbohm, Foley, Fuller, Wett, Bintz & Beltran.

ARCH ANGELS: Brock, Faherty, Davidson, Nash, Wagner, Levikoff, Amalgamated Union, Shepard, Nanzig, Suppes, Cheng, Hicks, Weiss, Nanzig, Levine, Hadsall, Parcell, Pike, Weiner, Householder, Moore, Ziifle, Rose, Holm, Shadell, Metzger, Trinchi (ILGWU), Gardner, & Fick.

ANGELS: Weger, Thompson, Marchitelli, Kraft, Krebsbach, Braun, Braunreiter, Daly, Jorgensen, Luhman, Klatt, Hill, Wagner, Vermeulen, Horstein, Noordzy, Eisen, Pappas, Wilder, McDonald, Hamilton, Trentacosta, Veziroglu, Pfleiger, Donlon, Lakins, Lockwood, Marek, Heniff, Smith, Pauken, Magalee, Stutts, Newman, McManus, Castiglia/Cortelli, Hadsall, Becker, Boyd, Macdonald, Wachter, Sparks, Hughes, Ponti, Paolini, Forthman, Valliere, Krauss, Menzer, Womer, Whitman, Heidel, Howe, Tsai, Patel & Morgan.

CHERUBS: Henningson, Geller, Koch, Schroeder, Noll, Bolduc, Nicholls, Billedo, Scarloff, Simon, Bacigalupo, Gomeringer, Midthus, Maurer, Horrocks, Kropf, Hinds, McDonald, Snyder, Fankhauser, Sidlo, Dern, Werner, Dunn, Watson, Pesce, Vektor, Koerber, Sakurai, Lewis, Marik, Freeman, Gorman, Connelly, Schoepe, Svtoris, Duncan, Schmidt, Cabot, Conway, Carrier, Kvenvolden, Gordon, Houpis, Bukstein, Press, Newman, Schmehl, Ewish, Manning, Burton Ranck, Onopa, Black, Wett, Weakly, McKeon, Flanagan, Hansen, Snow, Merrill, Allan, Cooper, Abell, Klausen, Spsychalski, Kubichek, Peerson, Anderson, Kelly, Tsoules, Deisroth, Brisentine, Allsopp, Underwood, Wood, St. John, Mackey, Vermeulen, Anderson, McGuinness, Stickle, Ginn, Arstein-Kerslake, Schneider, Leveillee, Huibregtse, Dunne, Goudet, Roby, Burke, Schneider, Dodds, D'Alessandro, Schuster, Aydelotte, Thomson, Beck, Stone, Sherard, Murlas, Wyka, Satterthwaite, Leonard, Reed, Taylor, Kelleher, Warden, Herman, Brandstetter, Hiatt, Palmer, Minervini, Henderson, VanTuyle, Bryant, Mitchell, Heinricy, Dade, Turney, Bowles, Brewi, D., Schmehl, Randall, Vuz, Wallis, Shipley, Trope, Nicholau, McNamar, Grout, Petty, Barkedley, Saacks, Diamond, Sojka, Eager, Thompson, B., Martin, VanderMoortel, Johnson, Dixon, Jones, Falisi, Wagner, Katz, D'Elia, Mans, Posch, Farren, Watson, Mays, Sundell & Sheeran.

Next Stop -- Salt Lake City!

The conference committee has been hard at work for some time now planning the next annual PWSA conference. The dates have been set: July 18 for the pre-conference (which includes Scientific Day Presentations, Chapter President's Meeting and a special Group Home day for providers). July 19-21 will be the regular three day conference. The location will be the University Conference Center near Salt Lake City. Get your vacations booked now so you may join us there. We guarantee you will not be disappointed in attending this meeting.

Dear Gathered View

"Sometimes, with children such as ours, the distance between positive events in their lives might seem almost infinite. We often must take what would be a minuscule accomplishment in the life of an unexceptional child (although I would fight to the death if you tried to call any of my children unexceptional), and celebrate it as a major accomplishment in the life of our child with PWS. Within the past month, two major events have occurred in the life of my son which I want to share, not simply for the joy of sharing, but also because both occurrences involved the utilization of the 'system'. Our son Adam, now 19, dropped out of school at 16 because it proved to be emotional torture for him to continue. For the past 2 years, he has been doing very little, except that he collects comic books and old-time radio tapes. He travels extensively to visit stores and other collectors. When he turned 18, we applied for S.S.I. for him. Despite his comparatively high level of functioning, we believed his emotional deficits would allow him to qualify. We had been reading about the nightmare of applying for benefits - that unless there was severe intellectual deficits and he could be labeled retarded - there was no hope that he would receive benefits without years of appeals. We began early building a solid case history with this single purpose in mind. We made his pediatric endocrinologist responsible for maintaining a comprehensive file rather than his pediatrician because expertise does count for something when justification is needed.

Adam was approved within four months. There was volumes of paper work which needed to be filled out several dozen times, but we kept our frustrations in check and developed a healthy adversarial relationship with the officer in charge of the case. As a result, Adam is receiving almost \$300 per month, backdated to the date of application. He is also eligible for medical and other benefits should he ever need them. At the same time, we opened an application for Adam with O.V.R. - Office of Vocational Rehabilitation - every state has one. It is a federally mandated program. He was approved for reimbursement for any appropriate training program after six months of

forms and aggravation. He had failed miserably at a sheltered workshop last year, again, because of the pressures in the social environment. He was referred by O.V.R. to a private agency which specializes in placement and follow-up of handicapped citizens, and within several months, he was found a full-time, but temporary job working for the Bureau of the Census. He will be an office worker and will earn \$6.00/hour for the duration of the program-about nine months to a year. He will be with normal people with whom he gets along far better than with socially disabled persons who are more likely to mirror his own social problems. Until funds come through for his job, he is volunteering for the future employer. The placement agency found a position that utilizes his assets - high reading level (he tests above 12th grade, though his comprehension is less), perseverance (he can stick to a single task for an unbelievable amount of time), good verbal skills (little do they know what he can do with them when he gets fixated on a subject).

For the first time in his life, Adam is in a positive catch-22. He is approved for S.S.I. when he isn't able to find a job, and he has the kind of job which could serve as a reference if his performance is adequate. Also, it is a job where food will not be a particular problem. Everyone packs lunch and he is not likely to be able to trade off with a group of adults who will be informed that he has problems in that area. Life with a PW affected adult is still difficult, but there is always hope that there will be these small rays of sunlight. They have to be enough. We do not live in the delusion that raising such a child is pleasant. It is not. But, there are no guarantees in life. How many parents have so-called normal children who take drugs, live far below their capacities, or just make life miserable for themselves and everyone around them?

Thank you for the opportunity to share. After all the years we have been in the association, this is the first time I felt the need or desire to do so. But, it is nice to know you are there. The enclosed check is a small contribution to the general fund. Keep up the good work. Sometimes, it is the best way to say, "Thank you!"

Aggression and Other Problems

A member reports that her teen-aged daughter has shown aggression towards babies and animals. She felt it important to share with other parents because her family found this difficult to discover and hard to accept. She felt the acts of aggression followed times when the girl was unhappy about things in her life. She reported pinching babies, killing two gerbils, locking a small dog in the trunk of a car and strangling a neighbor's cat. Unfortunately this has been reported by other parents as well. This mother recommends that parents not immediately replace a family pet if there was some question of cause of death.

Our office has been asked if people with PW should be allowed to baby sit. Naturally our children are individuals and we always have to remember this when making statements, but it has been our opinion there is enough question of adult responsibility that we do not recommend baby sitting. This mother would appreciate any comments from other parents as she questions if her child would be capable of seriously harming someone's child.

A group home operator asked us to share other information with our parents. He stated, "Even though these may be unpleasant subjects, it should be the duty of our organization to talk about these things with parents so they know they are not alone." One of the items was rumination. A few years ago one of our researchers did look into the practice of rumination (bringing up food into the mouth, reawaking and swallowing again). Her study reported that this did occur more frequently than was previously reported. Some parents reported it more frequently when the child was upset. We have not had any suggestions as to how to eliminate this practice.

Another item was it has been reported that children do remove stool from their rectums. Sometimes parents and doctors have been very puzzled by sores in the rectum, and finally discovered they were made by the children themselves. This may be a practice associated with constipation, and then again it may not. When this becomes a problem, it may well be a good policy to not allow the child the privacy of the bathroom.

The third matter, are drugs sometimes necessary for people with PW to treat behavior, depression, psychotic episodes? PWSA does not advocate continued usage of drugs, particularly for behavior problems alone. We have had more cases of true depression and psychotic episodes reported and drug treatment was necessary.

Drugs by Mail

A member recently shared a sample of Sudafed, a nasal decongestant, which arrived in the mail. She stated her daughter loved to walk a short mile to our mail box and plowed through it very well each day. She could well receive samples that we would never even know about. Maybe the 4 tablets of 30 mg. each would not have any disastrous effects, but we would hate to see drug companies start a practice of mailing such samples which may well be consumed by the person with PWS. If any member receives such samples in the mail, please write to the company that supplied them and explain why this could be a dangerous practice.

Seeking Foster Home

The Iowa Dept. of Human Services is seeking a foster home for a 14 year old girl, high I.Q., with PWS. She is presently living in a group home. They are seeking a home in Iowa if possible. For further information, contact Sherry Spowe at (712) 255-2717.

Parent Seeking Information

A parent is seeking information regarding the successes or problems of persons who have had cosmetic surgery for removal of skin flaps following massive weight loss. She would also like to know if anyone obtained insurance or medicare funding etc. to cover costs. Please direct your responses to the national office and we will share it with all of our members.

Our Sympathy

We extend our sympathies to the families of Elwin Ingalls and Alice Fox. Elwin and Alice have been parent members of PWSA for a number of years and we are sorry to hear of their deaths.

Placement Questionnaire

We thank the couple of dozen people who took the time to fill out and return the placement questionnaire from the last issue. How much more complete would be the information if a few other hundred people bothered to do the same thing. It's not too late.

Family Stress Tips

From Curran, *100 Ways to Reduce Family Stress*

1. Learn to distinguish between things you can change and those which are beyond your control.
2. Recognize that stress is temporary, sometimes even positive.
3. Expect some stress as a normal part of family life without considering yourself a failure.
4. Work together on solutions to minimize the stress.
5. Remember how you have successfully dealt with stress in the past.
6. Find solutions to problems rather than blaming someone or something else.
7. Be realistic. Don't expect perfection of yourself or others.
8. Don't bottle up anger or frustration, but learn to express desires and opinions on important issues.
9. Reward yourself occasionally for a job well done. Go to a double feature or splurge on an ice cream sundae.
10. Remember a large part of stress may be created from your reaction to a situation rather than the situation itself.
11. Look for other ways to handle problems. If plan A doesn't work, try plan B.
12. Find a support group to share your problems, put them in perspective and generate new solutions.
13. Find help when you are overwhelmed and unable to deal with stress on your own.
14. Seek support from friends and relatives when you need it.
15. Allow each family member a measure of freedom time for favorite activities or a private place to be alone.
16. Look for workshops or seminars offered by community groups.
17. Laugh at yourself and with others and keep a good sense of humor.
18. Give of yourself by doing things for others at work or in the community.
19. Take care of your health by eating a balanced diet and getting enough rest.
20. Reduce stress by walking, jogging or participating in some sort of physical exercise or in stress relieving techniques such as deep breathing or stretching.
21. Avoid overindulgence in food, drugs, alcohol, caffeine and nicotine.
22. Think positively. A positive attitude about situations and yourself is your most important asset in coping with stress.

And Most of All . . .

Please remember that you, as the parent or caretaker for a special needs child, are a special person, too. Be kind to yourself, watch out for burn out. Danger Signs: Feeling of "knowing it all," or "having been through it all." Stubbornness, change in resistance. Cynicism. Less efficiency-takes longer to complete the same task. Feeling indispensable. Excessive number of hours devoted to caring for others. Instantaneous irritation. Quickness to anger. Taking more risks. Feeling imprisoned -- can't get away from... Increased use of tranquilizers, alcohol, cigarettes, etc. Insomnia, headaches, ulcers -- can't get things off of one's mind. Feeling guilty. Can't get along with others.

Keep in mind that: You are human. You can not give 100% all the time. You need recognition. At times, it is normal to feel that you can not cope with life. You need time alone. You need a variation. You belong to a larger family. You have a choice in all things. You are responsible for energy out go. You need to feel that you are in charge of your own life to some degree. You can say "I don't care." You can be angry and share frustrations with friends. You need time off from being a caregiver without feeling guilty. You can not make taking care of others your whole life. You need a sense of responsibility. You are not alone.

Congratulations Karie!



Karie was 15 years old in December. To celebrate a very successful year, her parents took her out to dinner and allowed her to order a regular adult meal with DESSERT! Karie earned this by maintaining a healthy weight (presently 85 lbs.). Karie's mother wrote: "Hurray for Karie and hurray for everyone else who has been supportive of her diet, even when she looks like she doesn't need to diet. Earlier this year Karie made a wish on a wishbone and believes she was granted her wish - to be 'normal' and not to suffer from Prader-Willi syndrome anymore. I realized after awhile that she actually believes she has been cured, denying evidence to the contrary. We all know how difficult it is to use rational logic with our kids sometimes. They think what they want to think, no matter what. So Karie believes she is 'normal', and I gave up arguing with her about it and put her beliefs to constructive use. Her belief has been a strong motivator in avoiding problem behaviors. She has had better control over her temper, her picking has diminished to the point that it is no longer worrisome. Plate licking and crumb picking can be stopped just with a reminder that 'normal people don't do that'. The biggest area of improvement has been in the noticeable decrease of food snitching incidents. Of course, Karie still is argumentative (but she doesn't think so) and has emotional outburst and tries to get extra food. But her problems definitely are easier to manage since the wishbone incident. The power of faith is strong indeed. Maybe in some way Karie's wish did come true!" Karie's mother also offered to share their experiences with a Milwaukee

brace for scoliosis if anyone is interested, inquiries to PWSA will be shared.

Request for Photographs

Board Chair Lota Mitchell was able to obtain an additional grant to further our work on additional brochures. Two brochures, one for younger parent of newly diagnosed children and one for more detailed medical information, are nearing completion.

We would appreciate it if members would share photos of their children with the national office so we may include these as new publications are developed. Black and white reproduce the best but color is acceptable also.

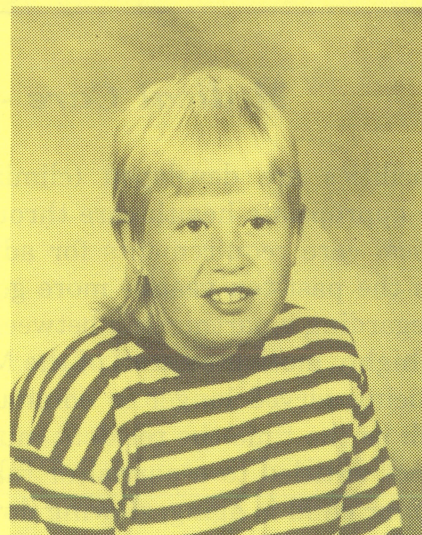
You May Be Contacted

A grant was approved to obtain further information on drug treatment for people with PWS. Since so many patients are treated by individual doctors, we felt it was important to accumulate data to be shared with our membership in this very important area.

Pen Pal Wanted!

Hi my name is Heather Rivers. I'm 12 years old. I like reading, rughooking, bowling

and skiing. I would love to have a pen pal. Please write to me at 256 Webster Road, Webster, New York 14580



Basic Survival Strategies

Richard Aronoff, Child Psychologist

Surviving children has never been an easy task for parents. It requires every ounce of our energies, and every bit of ingenuity we can muster. How then can the parent of a child with a handicap ever survive? There are no simple answers, however, with some basic survival strategies it can be a little less stressful. First of all, children, both handicapped and normal, all need to feel secure. The easiest way to make children feel secure is to provide them with structure. This basic foundation of security is not easy to establish with any child, and potentially much more difficult to establish with a handicapped child.

Structure does not mean rigidity, but refers here to a basic set of rules and expectancies that can serve as a foundation in building a child's sense of security. These structures are most effective when they are simple parts of the child's daily routing. The simple act of establishing a bedtime routine will let the child know that at the end of each day they will go through a safe, and hopefully loving, set series of steps from which they can gain comfort and security.

Other basic daily routines can also add to our children's feelings of security. The simple act of having a reserved regular seat at the kitchen or dining room table both adds to the child's security, and gives them a sense of

respect from others, who do not violate their right to that chair or place at the table.

Handicapped children should not be exempt from helping out in the home. All children can do some helpful tasks. It may be as simple as moving something from one spot on the table to another, setting the plates around the table, or helping to dry off a nonbreakable utensil.

The act of being able to help gives a child value, and knowing that their parents see them as capable of helping, as being a useful human being, builds self-confidence and self-esteem. It doesn't matter what the task is, but rather that they can contribute, and are expected to contribute, that is important to developing good feelings within the child.

Discipline is another important part of building up a child's sense of security. We've all heard that we shouldn't pity the child with a handicap, for it will just make them feel more inferior. But we need to go further and expect from them all that they are capable of doing. That includes as much appropriate behavior as they can demonstrate. Thus, setting firm, but not overly demanding, limits and behavioral expectancies will build their sense of value and provide them with the security of knowing that their parents won't let them act inappropriately, when they are capable of better behavior.

Medical Care - Work Regulations

As more facilities are developed (eliminating institutions) more people are looking at providing more appropriate health care through community physicians. The body of knowledge about the medical care requirements for adults with developmental disabilities has improved substantially in the past ten years - more good systems for application are being developed. A recent article regarding a partnership between the Division of Developmental disabilities in New Jersey and the highly motivated staff of the Morristown Memorial Hospital is most encouraging. As adults are being served longer in community residences, hopefully a look will be given to regulations such as the time the resident must spend outside of the home. As our children age, are they, too, not entitled to a partial or full retirement? It may be something you may want to look into if your child is aging, slowing down, or might appreciate more relaxation time than employment time.

Our Supporters

The end of October, November and the first half of December added \$16,381.76 to our Research, CIT & Operating Funds. We would like to report this is our usual income for that period but unfortunately that is not the case. As you know we are in the middle of our annual fund raiser right now and we also have a few families that have graciously appointed us to receive their memorial donations. Our Angel fund is well on it's way to qualify for the matching fund of \$10,000 which has been designated. We hope our members will continue to support our efforts for PWSA to grow in the coming year. Donors for the various funds were:

RESEARCH: Henningsen (Howe), Tobin, Spencer Monday Club, Alterman, Krocka, Boyd, Castle, Wilkes, Hinson (Noon), Rochester Coke, Tankovich, VanZomeren, Matza, Nanzig, Prader-Willi KY Assn., Culpepper, Folley, McMurdow, Gatto, Solitrin/Pieri, Francavilla & Ledoux; Ingalls Memorial contributions were received from: Jones, Lamoreux, National Letter Crs, Belgarde, Ingalls, Morrison, Starky, Robinson, Atwood, Cook, Flex Con, Putnam, Markey, Jones, Spencer P O, Fastnight, Lammi (2), Smith, Spencer Lodge, Reid, Steptoe Church, Mercy Ctr., Cardin, Young, Lowe, Beer, McDonough, MacMillan, Tolis, Bell, Olmsted, Snow, Howard, Meloche, Mass Elec., Paradise, Letendre, Cole, Spencer Monday Club, & Dwelly. Gordon Honor contributions were received from: Spiller, Braw, Parker, & Ford. Fox Memorials were received from Plashal & Hilgenberg.

CIT: Jones, Wett, Parent & Olson.

OPERATING: Haller, Corcoran, Nashville Comm. Chest, Alterman, Schneider.

CONTRIBUTING MEMBERS (Members submitting \$40 or more for dues): Toby, Parker, Johnson, Lubrant, Lockwood, McAndrew, Reynolds, Braun, Wicks, Letcher, Hansen, Houtman, Lehman, Blumberg, Deisroth, Yoder, Gelb, Janes, Willensky, Townsend, James, Magalee, Forest, Robertson.

PATRON MEMBERS (Members submitting \$100 or more for dues): Miller, White, Hanchett, Mleczewski, S hacklett, Rooney, Groenboom, Maurer, DiCosimo, Hadsall, Warden, MacKinnon, & Olson.

To the Association

"I would like to say 'Thank you' for all of the things that have happened in my life because of there being an association. My daughter is one of the six persons now calling the PWS home in PA their home. It has been such a great thing for these persons to now have a chance to a more productive life. She is very happy in this environment and our home is starting to belong to her step-father and me. I would like very much to help with raising some funds through the sale of the pocket calendars, and am enclosing four checks totaling \$140, for fourteen more books which I have sold. I hope that this fund raiser will help raise the knowledge of PWS, so that more of the general public will become aware of it.

Thank you again for all that you have done to make our burden of coping with the tribulations and frustrations of being a parent of these challenging individuals, a little lighter and brighter."

"Senior" Member Shares

A Community Trust Act (which provides for handicapped) was passed in the State of New Jersey in 1986. Not all attorneys are aware of this information. (PWSA is hard at work developing a Foundation which will address the problem of taking care of the person with PWS following the death of the parent.)

"We are in our late 70's, our daughter is 47, and we are still hoping to get her established in a group home. It was only 6 or 7 years ago that we finally became acquainted with PWSA and finally understood our problems. I wish I could relate many of the stories we often discuss how it felt to be pioneering with a rare syndrome. It would take a heavy, heavy book. Tell the 'movers' in PWSA to keep up the wonderful work - it has meant a great deal to many, many people."

The Terms They Are a'Changing!

An ARC group stated, "Because mental retardation is difficult to measure in the population, there is not much agreement on how many people are mentally retarded (M.R.). Estimates of their percentage in the U.S. population range from .67% to 3%. At any point in time, however, approximately 1% of the population is estimated to be M.R. This translates to between 2 and 2.5 million people who are M.R. Estimates vary by age and definition used.

There are four different degrees of M.R., which are categorized by IQ and social functioning. People with IQs under 20 are considered to be profoundly M.R. (1.5% of all M.R.). Severely M.R. are people have IQs between 21 and 35 (3.5%). Moderately M.R. individuals have IQs between 36 and 50 (6.0%). The large majority are people who are mildly M.R. with IQs between 51 and 70 (89.4%). An additional 2.5 million are borderline (70-80) or low normal (80-90) in IQ."

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 \$20.00 per year Individual; \$25.00 per year Family, and \$30.00 per year for Agencies/Professionals (U.S. Funds). Send dues and change of address to: PWSA, 6490 Excelsior Blvd., E-102, St. Louis Park, MN 55426. Any questions? Call us at (612) 926-1947.

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