THE GATHERED VIEW

Newsletter of PRADER-WILLI SYNDROME ASSOCIATION

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PRESIDENT'S MESSAGE

The Fourth International Meeting of the Prader-Willi Syndrome Association has been held, and for over one hundred and thirty registrants and sixty children a beautiful thing has happened. The setting and support was high quality and the kudos go to Eleanor Watson and Betty Schultze.

The organization is maturing, and as I reported to the Board Meeting on Friday morning, it can be characterized best by the word "alive." Gene Deterling discussed the financial status which included a graphic demonstration of growth in both the budgetary and membership size. The accuracy with which Gene has annually predicted these numbers continues to amaze me. The membership in seven years has grown to the third power, from only nine to over eight hundred. It has been pointed out by professionals working in several genetic disorders diagnostic centers that Prader-Willi Syndrome now numbers as one of the more common diagnoses seen after the most common problem which is Down's Syndrome. It can be expected that the organization and the need for its services will continue to grow.

With the growth of an organization, it can be expected that problems will also arise. The annual meeting is not capable of satisfying the needs of local clusters of Prader-Willi families, consequently local chapters are being formed under the umbrella of the National Association. This is evidence of healthy growth, and the administrative problems were discussed extensively over the past year by the Board and in conjunction with the members present at this year's Board meeting.

Two serious administrative problems surfaced during the past year and were approached at the meeting. At previous meetings when nominations for election to the Board were called, it was identified that sufficient interest in the organization to attend the Board meetings was the only requirement. The Board, during its executive session, discussed the problem of non-attendance, and voted to implement a rule that failure of the board member to attend two meetings during their term of office constitutes a resignation from the responsibilities of the office.

A closely related problem exists in the committee structure. Several years ago, Shirley Neason identified for us several areas of concern and proposed their solution by the appointment of committees. In the absence of a suitable roster of candidates, we utilized sign-up sheets, and asked for volunteers from the general membership. Some committees have established communication between members, defined the problems and the goals to be achieved, and moved forward to accomplishing the task. Unfortunately, the serious problem of distance between members impairs communication, and the majority of the committees have essentially ceased to exist. Two committee chairman are no longer members of the Association. The other causes of communication failure include the inability of a chairman to identify the problems to be solved and the goals of the committee activity. The most important failure has been the lack of response of committee membership.

President's Message (Cont).

The easiest way to belong to an organization is to send your name and pay the dues, then wait for the newsletter or monthly journal. The next step up is to write to the editor; complain if you believe in your "rights," add to our knowledge if you feel "responsible." If you are really serious about being a member, work for your local chapter, and be represented at the Fifth International Meeting of the Prader-Willi Syndrome Association, San Diego, CA, June 1983.

Delfin J. Beltran, M. D. President

PWSA CHAPTERS

Forming official chapters of our organization has been in the planning and development stages since last year's annual conference. The Board, groups that have been meeting, and finally the members that attended this year's conference, have had an opportunity to read and comment on the development of guidelines and rules to officially form chapters.

Due to the complicated issue of non-profit organizations, incorporation, tax exempt status etc., the board decided to look into further advice about all of the legality of this issue.

In the meantime, it was decided application can be made by groups that are meeting and we will complete the process of making them chapters of PWSA. Some of you have already received copies of the application form, some of you may want another complete copy of the chapter proposal, or whatever stage of decision you may be at present, you may now let the national office know what ever you need and they will furnish these forms. The next issue of the GV will be welcoming our first official chapters.

TRI STATE AREA OF PA

Lota Mitchell of the Tri State area group is meeting with Doris Jane Miller and Isa Breneisen to start investigating the possibility of getting a group home in PA. Would anyone with a child over the age of 15 that is interested in a group home, please send the child's name, age and address to Lota before the 15th of October.

They are interested in hearing from people from PA, NJ, OH, NY, DE, MD OR WV.

Lota Mitchell
844 Foxland Drive
Pittsburg, PA 15243

CO MEMBERS

Two Colorado members are interested in starting a group in their state for the purpose of opening a proper residence for their children. If you are interested, please contact Helen Tobin, 13261 Sheridan Blvd., Broomfield, CO 80020.

PRADER-WILLI SYNDROME RESEARCH FUND ESTABLISHED

A very important step for our Prader-Willi people was taken at our June 24th annual meeting. The Board of Directors approved the establishment of what is to be called "The Prader-Willi Syndrome Fund" which is a special fund dedicated primarily for research but also in certain cases to other projects in direct support of Prader-Willi people. It will at the same time provide some necessary funds for our operating expense but at a decreasing percentage as our operating working capital grows. It will allow for contributions to be made to a more specific cause in direct support of Prader-Willi persons themselves and will establish our organization as a leader among similar organizations for the percentage of contributions going directly toward the benefit of the people in need. As you must be aware in most of the larger charitable organizations in the world only a small percentage of the donations made actually go toward the direct benefit of their cause. In some cases it is as little as 10%. For the Prader-Willi Syndrome Fund a minimum of 75% of all contributions will go for research or other projects of direct support. This percentage will have the potential to increase to 100% providing we have an adequate reserve to assure continued operation of the organization itself.

The way our fund will work is that from now on until we have an operating reserve fund of $25,000 all contributions made to the Prader-Willi Syndrome Association will have 75% of the amount put into the Prader-Willi Syndrome Fund (for research and special projects) and 25% will go toward our operating expense. (This will not include dues and any special contribution designated for another purpose.) Once we have an operating expense reserve of $25,000, the percentage that will go toward the PWS Fund will increase to 80%. The percentage will increase 5% for every $25,000 increase in our reserve fund. If we ever achieve a $150,000 reserve for operating expenses, 100% of the contributions will go to the PWS Fund.

We must recognize, however, that our operating funds are still critical. Without operating funds, we wouldn't have our organization and then there wouldn't be any point in talking about other funds. It is through our national organization that all this is possible.

The PWS Fund, which as we mentioned above, will be primarily for research, will provide seed money for obtaining larger grants, or when the fund is large enough, provide grant money itself. The distribution of this fund will be at the recommendation of our Scientific Advisory Committee or other advisory committees designated by the board of directors but with the approval of our board of directors.

So now all of us should rest assured that there is no better place that we can invest our charitable contributions. (All contributions to the organization are definitely tax deductable.) We all need to do some planning for the future, and we should all consider modifing our wills to include the Prader-Willi Syndrome Fund. Every dollar invested in the fund will help make a better life for Prader-Willi people.

Many of you have increased your dues - your response has been great.
Many of you have sent small donations, memorials, etc. - these donations help our budget.
A very few dedicated members have made sizeable donations - this has been our growth.
Now we need all of you to consider making this fund a success. Let's <u>all</u> help the Fund grow.

Gene Deterling, Treasurer

PWSA (U.K.)

The second issue of England's newsletter announced their group has now become a registered charity and the Dr. B. M. Laurance has agreed to become their president. Ralph M. Williams is Honarary Chairman and his wife Janet is Honarary Secretary.

This group has been making terrific strides in forming a success group in their part of the world. Their third Annual Conference is in the formation stage for early November. We look forward to sharing information from them with our readers.

ANNUAL CONFERENCE

The 4th Annual PWSA Conference has been held. For the people who worked to prepare, organize and present it, the sigh of relief for a task completed is heard. It is now a matter of filing reports, balancing books, and making notes for the people that will take on the challenge of next year's conference. For the PWSA members that attended, we hope the feeling is very different. We hope they have gone away with a lot of newly acquired information that will assist them in seeking answers, aid them in solving problems, and the feeling of a togetherness from having the opportunity to meet with other parents and children.

Some of the attendees have been at all four conferences, some three, some two, and quite a few were attending for the first time. Every year it is heartening to hear the comments: "great conference", "so glad we came", and "can't wait until next year". To know these members had the opportunity to advance their knowledge, increase their ability to work with their children and very importantly that the young people with this syndrome were able to spend a few days together, makes all of the work very worthwhile.

The meeting was attended by over 130 adults and 65 young people (50 of these were PWS). Many excellent presentations were given, opportunities for socialization occurred. And by the way, the office does have certificates for attendance for those that did not pick one up after the last session. Write if you would like one for yourself or your child.

A video tape was made with several parents participating in a discussion on the syndrome. This was shown to those attending. After this tape is completed it will be available for the use of the membership.

The Board of Directors held their annual meeting which included reports on activities occurring the past year, future projects being considered, and approving the budget for the coming year. Six nominations were made for the board election. The results are on the next page.

One fact came up several times during the three days -- "you are the PWSA Organization". It is not just an office in Edina, it is what you contribute that makes it what it is. The conference is living proof of that, without the contributions of Betty Schultze and Eleanor Watson there wouldn't have been a conference. Without the members attending, it would not have been a successful conference. Without the presentors there wouldn't have been anything to attend. Our success is caused and shared by all.

Several members commented on the cost of the conference. PWSA is not trying to make money by conducting conferences. Eleanor Watson spent a great deal of time trying to budget expenses so we could break even. Believe me, that is a difficult task to anticipate costs when we have no idea of what our income will be. Eleanor is preparing a report that will appear in the GV showing you the costs involved and how your money was spent.

The 4th Annual PWSA Conference has been held. Next year's conference is already in the planning stages. Put it on your calender right now -- JUNE, 1983 IN SAN DIEGO.

DONATIONS

One thousand dollars was donated by the students of Edina High School of Edina, Minnesota. This money was raised by the students in a week of activities called "charity week". PWSA was submitted as a possible recipient by one of the students who knew of PWSA and recently read a plea for help that appeared in the local paper. This was written by our director.

The funds will be used directly for projects for young people with this syndrome. The funds were divided as follows: $400 to the national; $300 to Oakwood Residence (the MN residence for PWSA); and $300 to the MN Chapter.

We sincerely thank these students for their concern for others.

CONGRATULATIONS!

The membership, by their presence and proxy vote, have returned Claire "Cellie" Ledoux to another board term at the 4th Annual PWSA Conference.

Stewart Maurer and Dorothy Thompson were elected to fill the two board positions available by the expiration of the board terms of Stephen Sulzbacher and Jean Janes.

We are pleased to have Cellie elected to serve another term, and proud to add two new members to the board. We are confident that Stu and Dorothy have much to offer in this capacity.

Six nominations were made during the business meeting and it was a very difficult choice to only vote for three since all six nominees would have made good board members. Betty Schultze, Ed.D. was a very close runner-up in the voting so she will serve as an alternate board member in the event a board replacement will be made during the coming year.

In Memory

PWSA gratefully acknowledges the donations of members and friends received this past month in memory of:

Esther Wambach, mother of Dr. Beltran.

Mrs. LeRoy Smith, mother of Mrs. K. Smith, grandmother of Mrs. S. Maurer.

Mrs. Harold Vance, friend of the Dalys.

PWS SUMMER CAMP

The Gilbough Center in MA is operating a camp this summer for PWS people. The camp session will extend from July 25 - August 14. Tuition for the 3-week session is $1,200; there is also a $25 charge for incidentals. 6 - 7 spaces still remain, so anyone interested in applying for admission can receive an application by writing: Nancy M. Drwal, Program Coordinator; Gilbough Center; Residential Rehabilitation Centers, Inc.; P.O. Box G; Brewster, MA 02631; or call (617) 896-5776 for more information.

ARC ALERT TO PARENTS WITH DISABLED CHILDREN

H.R. 6181, the Disability Amendments of 1982, will be scheduled for consideration by the full House in the near future. This bill must be defeated or substantially amended in order to protect the rights of mentally retarded and other disabled persons in need of SSI and/or SSDI benefits.

ARC recommends that people contact Tim Wirth, US House of Representatives, 312 Cannon Office Building, Washington, D.C. 20515 or your local representative and urge them to vote against this bill, or to vote for the amendment proposed by Rep. Harold Ford (D-Tenn) which would eliminate the danger of this bill affecting the benefits of disabled persons.

RECIPES

A couple of low-calorie summertime recipes for our membership:

Marinated Vegetables

1/3 cup safflower oil
1/2 cup wine vinegar
2 tbsp. minced green pepper
1 tsp. chopped parsley
1 tsp. salt
Fresh ground pepper
3 cups cauliflowerettes & broccoli flowers
1 cup carrots, sliced thin
1 cup cucumber slices
1 cup raw sliced green beans

Mix oil, vinegar, gr. pepper parsley, salt & pepper. Add vegetables and mix gently. Cover and refrigerate. Use within one week. Makes 10-12 servings. Each serving has 71 calories.

Frozen Pineapple Cream

1 (20 oz.) can pineapple chunks packed in unsweetened pinapple juice
2 tsp. fresh lemon juice
3/4 cup evaporated skim milk (1/4% milkfat)
4 dashes ground ginger
1 tsp. sweet sherry

Combine pineapple chunks with all but 1/4 cup juice, lemon juice, skim milk, ginger and sherry in blender. Blend on high speed for 1 min. Turn into freezer tray that has been rinsed in cold water. Place tray directly onto metal in freezer and freeze until almost firm, about 2 hours. Beat with electric mixer in tray until light. Or turn into food processor and process on/off 3 times with metal blade. Pour back into freezer tray. Return tray to freezer. This time do not place tray in direct contact with with metal. Freeze for 1 1/2 hrs. Finished dessert should be creamy and semi-soft. Makes 6 servings. Each serving has 59 calories, 9 mg. sodium, 13 gm. carbohydrates, and 2 gm. protein.

ANOTHER food idea from a member in ND: "...Zucchini has few calories and my son enjoys eating it cooked in water and sprinkled with garlic powder (no butter or salt). A large bowl helps 'fill-out' a meal for him...I freeze a good deal for winter eating."

LEFT-HANDED SUGAR--A NEW "ANTI-SUGAR"

Current chemical research is nearing a time when we will see a new "sugar substitute" introduced into the market. "Left-handed" sugar, unlike many of the current artificial sweeteners, is chemically identical to ordinary sugar; it looks, tastes, and can be used exactly like regular sugar. The only difference between this sugar and ordinary sugar lies in its molecular structure, left-handed sugar rotates to the left rather than to the right, as does ordinary sugar. For this reason, the body treats left-handed sugar differently; it is not absorbed by the body; human enzymes do not digest it, but rather pass it off as waste. This chemical fact means that left-handed sugar has no calories.

All types of sugar now exist, in small quantities, in a left-handed version. So, current research has only to develop a method of producing it in large enough quantities to be easily marketable. But, predictions say that it will still be several years before left-handed sugar will reach the market; it has yet to be approved by the FDA, and a cheaper method of production must be found to reduce the current price of approximately $5,000 a pound to a more reasonably affordable $2 a pound.

RESEARCH DIRECTIONS

Dr. Richard King, a Minnesota-based geneticist, recently spoke to the PW Minnesota group about a current direction of research with PWS. He has observed that several PW people he has dealt with have lighter hair and eyes than their family members, an observation which led him, along with Drs. Vince Riccardi, Helene Pittner, and John Crawford, to conduct pigment studies of 9 PW's. The study revealed that the PW people tested, all of whom had a deletion of chromosome number 15, a deletion found in some but not all people with PWS, evidenced fewer pigment cells in their skin, hair and eyes. In all those places, Dr. King pointed out, the pigment cells are derived from cells that migrated from a part of the brain known as the neurocrest. This fact lead the researchers to believe that this part of the brain might possibly be concerned in some way with the abnormalities involved with PWS. Neurocrest cells are also related to the hormones that control appetite, and to the cells that control the breathing pattern, two other areas affected by PWS. Dr. King is currently planning further study along this line, hoping to examin local PW people both with and without the chromosome deletion, testing the pigment levels, the breathing, and the hormone levels in the blood; he hopes to find more evidence for the theory that the neurocrest might be an origin of abnormality in PWS.

STARCH BLOCKERS

Some of our members have recently commented on products on the market known as "starch blockers." These products claim that their use eliminates calories from consumed starches thereby lowering caloric intake. These products were allowed on the market listed as a food suppliment rather than a drug. Due to reported adverse reactions, the FDA has determined that these are drugs and that they have to be removed from the market until several questions are answered. They question: their effectiveness, their active ingredients, their safety, and their long-term effects on the users.

It is difficult to read of these products and not have them available for our children now, but with lifetime use a necessity for people with PWS, we can readily see the need for extensive study before this type of product is used.

SOUTHERN NEW ENGLAND

The topics of discussion during the Southern New England PWS group's last meeting, held May 5 at Newington Children's Hospital, included funding a group home and the CT PWS clinic. The group discovered that their plans to submit a grant application to the Vocational Rehabilitation Department of DMR had to be cancelled because that particular grant would not have benefitted them. The first PWS clinic at the U of CT Health Center was successfully held, another is planned for June 18; the clinic is being supervised by Suzanne Cassidy, M.D. and Carrie Mukaida, R.D. The group has scheduled their next meeting for July 21, 1982. Contact Secretary Jean Antin, 92 Five Mile River Road, Darien, CT 06820 for futher information.

PW TEXAS ASSOC., METROPLEX BRANCH

This newly formed group met June 26th at the University in Dallas. Speakers Mary Jo Harrod, Ph.D. and Patricia Howard-Peebles, Ph.D. were included as part of their meeting.

Grady Hendrix of Arlington is the Chairman, Board of Directors of the new PW Texas Assoc.

HOMES & SCHOOLS

Margo Thornley, Seattle, Washington has written us that Camelot Society has just opened two new homes near Seattle for young adults with Prader-Willi. Wiser Institute is on the threshold of establishing a residential school exclusively for the 12-21 age group for adolescents with this syndrome.

We have some brochures for anyone interested in this school, or you may contact Margo directly, for information.

Margo L. Thornley, Executive Director
P.O. Box 55223
Seattle, WA 98155 (206) 364-5545

RIVERBROOK SCHOOL

The GV has received some recent information about Riverbrook School, a PWSA member, currently serving two women with PWS. Riverbrook is a private, year-round residential facility located near Stockbridge, MA. The school houses 25 moderately mentally handicapped girls ages 12 and on. There is no upper age limit; residents may stay "as long as their general health is good." The school provides its residents with individualized academic programs emphasizing Math, Reading, and Language Arts. They also stress the development of skills necessary for independent living.

The GV would like to caution its readers that this is not necessarily a recommendation for the school, but a sharing of their program with the membership. Any member who may wish to find out more about the school and its programs should write to:

Mrs. Joan S. Burkhard, Director
Riverbrook School
Ice Glen Road
Stockbridge, MA 01262

BOOKS ON HOUSING FOR DD PEOPLE

The DD Program--Metropolitan Region XI has added the following titles to their library which may be of interest to many of our chapters or other PWS groups.

Planning Community Living Arrangements for Developmentally Disabled Persons in Indiana. John Hagen, Marilyn Krull, Susan Jensen. Northern Indiana Health Systems Agency, Inc. "The purpose of this document is to determine and plan the appropriate supply mix and capacity of resourcers for community living residences that ought to be made available to all developmentally disabled citizens in Indiana."

Housing and Handicapped People. Marie McGuire Thompson, Washington, D.C. "The purpose of this study is to identify major problems in housing for mentally retarded, physically handicapped, or developmentally disabled adults, and to suggest ways to improve the quality of their lives by making available to them a variety of options in community-based housing."

Housing for the Handicapped and Disabled. Marie McGuire Thompson. Washington, D.C. "A local action guide that serves as an immediate, useful resource for state and local communities as they expand their housing activities to better serve handicapped and disabled persons."

FOR OUTSTANDING PARENTS

TASH is seeking nominations for its Distinquished Parent Award, an award presented to an outstanding parent for his or her contributions toward bettering the lifestyle of the severely handicapped. Send the name (s) and a description of the contributions of possible nominees (by October 1, 1982) to:

Linda Pelkey
The Association for the Severely Handicapped
7010 Roosevelt Way, N.E.
Seattle, WA 98115

UPCOMING CONFERENCE

The 9th annual TASH conference will be held in Denver, Colorado this year, at the Hilton Hotel. The conference will be Nov. 4-6 and any interested member seeking more information or registration materials should contact Dueretha Williams, Conference Coordinator, The Association for the Severely Handicapped, 7010 Roosevelt Way N.E., Seattle, WA 98115, (206) 523-8446.

CHILD PLACEMENT

One common dilemma for parents with older PW people concerns the placement of their child in a living situation other than their own home. Whether it be in a group home or a residential school, putting a child in an institution away from home is a tough decision for a parent to make. But, as many parents know, the time comes when some families realize that such a placement is best both for them and their child. The following is an excerpt from a letter written by a mother who recently was faced with this decision. The letter has been edited to eliminate any reference to the names of the people involved and to the facility concerned.

"...My friend and I toured the center...At the end of the tour, my friend said...'I'd like to take the steps necessary to place my son here.' I was totally amazed! Although the place was beautiful, the staff caring and they know PWS, it just seemed a cop-out to place a child in an institution...On the way home I wept for my friend and her son and myself and the whole situation. Within a few months I realized it was the only way to go for now...For the last few months my hard job has been to talk to my daughter about living away from home. I've taken her to pick up my friend's son a few times so she knows it's beautiful there and the people are nice. It's especially hard to change some of the 'free' concepts I had instilled in her before the diagnosis. Early diagnosis is so important. I know I'll always be looking for ways to educate people about PW.

"Every parent must go through the steps of letting go. I've noticed at meetings often the fathers do not really understand the problem as well as the mother who must usually deal with it 24 hours a day...I found PW mothers a great support group. Almost a sisterhood...Thanks for everything you've done!"

"A LOOK BACK"--PART THREE

The second part of this series led the reader from Part 1's review of the roots of the Association in 1975, through the growing pangs of 1976. The typical 1976 issue of the GV was described in Part 2, along with sample articles from some now-established experts in PWS: Peggy Pipes and Vanja Holm, M.D.

Moving ahead in time, 1977 was a year of growth both in membership and the structure of the Association itself. Membership jumped to 193 members by March of 77, a boost brought about by the increasing national attention of the media, most especially an article printed in Good Housekeeping magazine. The response to that article was so enormous that the Sept. 77 GV contained an apology from Gene Deterling for falling behind in answering correspondence. By July 77 another important change had taken place. The former "Prader-Willi Syndrome Parents and Friends" officially became the "Prader-Willi Syndrome Association." The incorporation papers were filed, and a first nation-wide meeting was held on May 27 in Seattle, WA to adopt formal bylaws, elect a board of directors, and approve the Articles of Incorporation.

Official publications other than the GV soon appeared from the newly incorporated PWSA. "The Prader-Willi Syndrome--A Brother's View," written by Robert Amren, became the first publication published by the PWSA, and Shirley Neason's Handbook for parents was just going to press, to appear in mid 1978.

The GV itself also expanded in 1977. In Jan., articles such as the following comments about Intelligence Testing from Beverly Vanderveer, Ph.D. appeared alongside the regular columns such as "A View of Who's Who," "The Book View," and "The Gathered Exchange."

> "Intelligence tests for younger children are age scale tests. The child is given questions to answer and tasks to perform, and his performance is compared to other children of various ages. The result tells us his mental age..."
> "Intelligence tests for older children compare the child to a large sample of children his own age and rate him on a scale. On this scale, a score of 100 is considered to be the mid-point of the range of intelligence. An I.Q. of 80 to 120 is average, and about 2/3 of the population fall within this range. 1/3 of the population are either above or below average in intelligence as measured by this method. The whole idea behind intelligence testing originally was to predict how well a child would do in school with traditional teaching methods being used. As a result, the tests are not designed to pinpoint specific abilities and weaknesses an individual child may have..."

Concerns about education in Mar. 77 prompted a "Memorandum to Teachers of Children with PWS," with suggestions for special educators written by Stephen Sulzbacher, Ph.D. and Jeff Snow, M.A. This memorandum included the following suggestions about reinforcers:

> "We suggest dividing the lunch into bite-size portions...The child could then be instructed that he would get one 'chunk' of his lunch after he completes each portion of his daily work. For example, he might get a bit of his sandwich after finishing three pages in his Sullivan reader..."

Or the educator might, instead of giving out candy as a reinforcer for these children: "Use small slices of celery, carrot, or dill pickle...as reinforcers. Our nutritionist informs us that the children may have as much of these three foods as they wish..."

In the years following 1977, many other milestones, such as the first annual PWS conference, were gained by the PWSA. "A Look Back"--Part Four will recall this and other additions made to the Association in 1978 and 1979.

EMOTIONAL REACTIONS TO DISABILITIES:

We've "borrowed" a few ideas from the Institute for Information Studies' guidebook titled, "Learning to Live with Disability..."

Emotional responses to disabilities vary but it helps when families understand what they have felt, or are now feeling, and what could be considered "normal" reactions to a difficult or stressful situation. Recognizing, understanding, and expressing the emotions associated with living with someone disabled, enables greater mastery of daily inconveniences and obstacles.

DENIAL: Denial is the most common initial reaction. People use denial to shield themselves from the overwhelming emotional pain which full recognition of a disability brings. This initial reaction is somewhat overcome with parents of Prader-Willi children because they very seldom receive an immediate diagnosis of a disability.

Usually, denial cannot be maintained. Families will normally feel depressed for many months following the recognition of a permanent disability.

LOSS: Any disability always involves loss. The parents of a developmentally disabled child see the child's inability to meet the normal milestones of infancy and childhood and may feel the loss of autonomy and independence as they foresee long years of struggle ahead.

Another level of loss is loss of a fantasy, plan, or dream for the future. The family experiences the loss of an image of having a "perfect" child.

Loss encompasses a painful constellation of feelings. Deep sorrow and grief are often accompanied by anger and rage, as well as a sense of betrayal as expressed in the words, "why me?" Sometimes feelings of bitter disappointment arise. These can be turned outward as revenge onto society or other family members, or inward as self-condemnation.

It is important not to hold back or bury feelings. Our society seems to value emotional control, but suppression can psychologically harm the family.

ANGER: Anger gives many people difficulty. It is very difficult to adequately express and then let go of anger toward disability, because it seems so unfair. Anger is a normal and natural response to disability -- to being hurt. And it is felt by the entire family. It is important for the family to acknowledge their anger without resorting to blaming each other or using other indirect avenues of anger expression.

Sometimes it is very beneficial to ask someone to just sit and listen to your angry thoughts and feelings. If no one can be found, use a tape recorder or write your anger on paper. It's essential to express it, even if it seems irrational. After all, there's nothing rational about disabilities.

FEAR: Another feeling which everyone has at some times but which becomes particularly pronounced with disabilities is fear. Different fears are associated with different disabilities. The adjustments which the family must make that are required when living with a child with this syndrome, often without sufficient support and information, can have the same intense quality as when the child was newly diagnosed.

Generally, these very deep fears diminish over time as reality, experience and practice aid in replacing them with action. Fears do occasionally surface, and this is entirely understandable given the very real difficulties that have to be faced in the long period of adjustment.

GUILT: Guilt is one of the most complicated and devastating of human emotions.

EMOTIONAL REACTIONS TO DIABILITIES, cont.

It is important to uncover and analyze the sources of excessive guilt feelings. Parents will often feel overwhelming guilt over wishes that their child had not lived. They are often unable to express these thoughts to one another, and they become deeply buried. Or they can feel that God is punishing them for past misdeeds by giving them a handicapped child. These deep feelings of shame and guilt, if not directly expressed, can lead to suppression or misdirection of anger, conversion of guilt to excessive fears and worrying, emotionally induced illness, or overprotection of the child.

Families can help uncover guilt feelings, whether warranted or unwarranted, by permitting family members to communicate freely about their guilt feelings. Sometimes even bringing up the topic of guilt by such "exercises" as having family members write out their responses to statements beginning with "I feel (felt) guilty when..." and discussing their responses, can help.

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THE GATHERED VIEW is the official newsletter of the PRADER-WILLI SYNDROME ASSOCIATION and is sent to all members. Duplication of this newsletter for distribution is prohibited. Quotations may be used if credit is given to PWSA. Membership dues are $15.00 per year for U.S. members; $20,00 per year for Canada and overseas members. Send dues and change of address notices to: PWSA, 5515 Malibu Drive, Edina, MN 55436.

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