



THE GATHERED VIEW

Newsletter of PRADER-WILLI SYNDROME ASSOCIATION

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PRESIDENT'S MESSAGE

Organizations that are alive and well are like other living things: they need nourishment and love; they grow and have growing pains; there are good days and bad; some effort seems just like plain work while some is fun; there are times when we long for the rosy future, just as there are days when we look back in amazement. December 1st, 1984 was all of these and more.

Almost 9½ years ago, several of us met in Seattle in response to Gene Deterling's quest to help people with Prader-Willi Syndrome. That group became the officers and the Board of Directors of the Prader-Willi Syndrome Association. Every year since then they have met to carry on the business chores of a non-profit corporation, to determine where the organization was and where it was going. This has been accomplished during the Annual Conference each June. At this year's conference, it became apparent to several members of your Board of Directors that matters of concern would need attention without deferral to the following year. Chief among these was the charge to investigate the task of a National Developmental Center for Prader-Willi Syndrome.

Stewart Maurer is a member of the Board of Directors and has as his daily job the management of the Colony Square Hotel in Atlanta, Georgia. In June, he extended the Board and officers an invitation to hold the first PWSA Board of Directors interim meeting at the Colony Square Hotel on December 1st. As my faithful readers know, I get my injection of "survival" from attending the annual conference. This year I got two shots. I shall restrain myself from waxing poetic, but Stew demonstrated to the fullest the meaning of hospitality, and your Board closeted itself in one of the finest and most efficient demonstrations of a "work session" that I have had the pleasure of attending.

The concept of a National Development Center as introduced and supported in June is based in the belief that continued life of this organization can best be achieved if there is a focal point created for its activities. It is not meant by this that the focus of the organization is shifted from the Prader-Willi person but rather that this focus can best be served by establishing a permanent central office with personnel and facilities for supporting the organization and creating an identity that cannot be achieved in the back room of the Wett residence. As the demand for facilities to support the lives of Prader-Willi persons expands, there has developed a need to create a properly designed facility for an increasing number of persons that cannot obtain literally life-saving support in their own community or state. The product of a central facility is not only the residential considerations, but it can serve to further demonstrate the special needs of the Prader-Willi person, and teach the correct methods of managing those needs to persons that could go out to communities that

PRESIDENT'S MESSAGE (Cont.)

can afford to develop their own specialized residential facility. Thus the National Developmental Center for Prader-Willi Syndrome can bring together caring, research, educational, and administrative functions of this organization in a critical concentration that will provide on-going sustenance to the PWSA for the benefit of all its members.

The investigational phases have been started and the problems are more clearly seen. In order that our Executive Director can use her great organizational talents for N.D.C. matters, she has been directed to employ an assistant to carry on much of the necessary day to day tasks. Marge Wett will be communicating with private foundations and other charitable organizations with experience and expertise in the complex problems that need to be identified and solved to carry on a project of this magnitude. From time to time, each of you will be called upon to respond with supportive information and effort as well as an extension of your financial involvement. Projects such as this can only be achieved if each of us carries a personal sense of responsibility for placing a brick in the structure.

Delfin J. Beltran, M. D. President

REPORT ON RESEARCH FUND

July through December contributions to the Research Fund were as follows:

July	\$300.00	memorial donations;	\$1025.00	direct to fund		
August	\$10.00	"	"	\$10.00	"	"
September	\$90.00	"	"	\$54.42	"	"
October	\$170.00	"	"	\$35.00	"	"
November	\$37.00	"	"	\$45.00	"	"
December	\$245.00	"	"	\$169.42	"	"

With the above contributions, the Research Fund now stands at a total of \$11,301.08. We thank the following members and friends for their contributions over the past few months to this fund: Shoemaker, Rigsby, Lengacher, O'Connor, Coccozza, Kellstrom, Hower, Rowe, Streglel, Sojka, Uzendowski, Korte, Notbohm, DeHaan, Rasmussen, Ferris, United Way of S.E. DE, Dennis, Kent School, Staples, VanZomeren, Mitchell, Howe, Love, Corcoran, Barkeley, Lear Siegler, Fike, Castiglia, Gordon, Solitrin, Parole, Pieri, Spiller and Parent.

A special thanks goes to members who continue to support this fund by direct donations as well as obtaining matching funds from employers, having memorial directed to our organization, and who ask friends to honor them at special occasions such as wedding anniversaries. We also appreciate members who continue to contribute to other projects by paying contributing dues instead of the basic rate, and those who have directed their donations to the new club for the developmental center.

NATIONAL DEVELOPMENTAL CENTER (NDC) REPORT

The national office would like to sincerely thank the people who responded to our last issue requesting comments on the NDC concept. An overwhelming majority of the people who did respond, voted that we continue working to open this center. With the support of the Board of Directors, we are going to work toward this center. Some of the respondents had questions, we do not have all of the answers but we will attempt to answer some of them:

WHY IS THIS CENTER NECESSARY?

(1) PWSA - We feel an organization to meet the specific needs of PWS is essential. In order to insure a continuation of our organization, we need an office. This center would house that needed facility.

(2) PUBLICITY - No one cares about something they've never heard of. In order to make this syndrome a known entity that is recognized by professionals, we must continue to publicize our existence. A center would be an excellent means to be recognized.

(3) DESPERATE NEED FOR SERVICE NOW - In some states there is no possibility that a home strictly for this syndrome will ever be developed, many other states will only have one or two at the most. These facilities can not serve all of the young adults that need service. This center will be able to accomodate approximately 50 young people in need of immediate service. With a well-trained staff, we hope to develop programs for these residents and hopefully within a year or two they may be able to return to their home states for service in a residence that can be instructed in proper care. The same development will be used for proper work placement. Without this center many of these young people will never be served properly or will remain in their own homes until the parents can no longer care for them. Many are not working now because of the lack of knowledge in workshops. At the present time we are aware of over 50 people who need service and for many this center will be their only hope.

(4) RESEARCH - The fact that we have a large number of people in one location will interest researchers in this syndrome. We are not talking about these young people being used as "guinea pigs" to be poked and prodded by countless individuals, we are talking about trained staff being able to keep records in order that this syndrome can be understood. Most of us are aware that there are unique symptoms that accompany this syndrome and are not accepted when reported by parents.

(5) TRAINING - The high concentration of individuals will provide a place for professional training. This potential can be utilized by educational, medical, group home staff, workshop staff, and others. Successful programs are developed by people who are well informed. This center can provide this needed training.

(6) EMERGENCY - This center could also provide respite care in emergency situations. None of us plan our deaths or our incapacity to care for our children. This would not pose a problem to some but what about those who would have no alternative to having their children placed inappropriately in an institution for lack of another placement? This center could fill that immediate need.

FUNDING?

It was our original goal to have \$50,000 in direct donations from our members and \$100,000 in one or two donations from personal contacts through members by the end of 1984. We have received approximately \$24,000 directly so we are half-way to that goal. Only 116 members of our organization have felt it important to support this fund drive, consequently, we have not reached our goal. We also have not been successful in getting any large donations through personal contacts. There is no way of knowing if this is because so few people have tried, or if it is because no one is interested in our needs. All of us read of the large sums that are raised when people are convinced of the need. Our goal will never be reached if people do not try. Are you one of the 116 who care?

Five chapters have shown their support, two chapters have made pledges. That leaves five chapters that we have not heard from and hundreds of parents that have not responded.

The national office has been working on outside contacts and will continue to do so. An application was made for federal funding that would be available next year. We will hear in April if we have any chance of receiving that grant for \$100,000 or less. An application was also made to a Florida foundation for several million that would enable us to open several centers if approved. We have not heard from them. We will continue to make more grant applications as time permits. We frequently hear the comment there is a lot of money out there, unfortunately, it is not easy to obtain, but we will keep trying. We need all of you to keep trying too.

STATE VS NATIONAL

There is no doubt in anyone's mind that a placement closer to home is the best for any child, but only if it is a good placement. The goal of the NDC is to develop programs for each individual and have them return to their own state or country. Some people may only need to be placed at the center for a year or two and then be able to move closer to home, others may take longer, and for some a permanent residence may be necessary. We hope with time that regional centers will be available in several locations throughout this country and other countries, to serve your children closer to home. This center is only step #1.

We do not intend the regional centers to replace smaller homes, we are not trying to steal your children from you, we want to insure the best environment for them. We hope parents will not confuse guilt of "sending their children away" with their responsibility of furnishing what is best for their child.

WHY A LARGE CENTER?

In order to accomplish the goals set forth we must be looking for a facility that will serve a large number of people. PWSA can not afford to pay a large rental fee, publicity would not be obtained from a small home, serving 10-15 people would not relieve the pressing needs of over twice that number of people seeking services now, a small residence would not interest researchers, training programs would be curtailed, emergency care could not be offered in a smaller facility. In other words, larger numbers are important. There is no way a smaller residence could become self-supporting, as we have hopes that this center can. We hope to develop a workshop that can contribute to the costs of operation. We are not talking about opening a PWS institution, we are talking about three units of 15-18 people located in the same building. Each of these three units could be assigned names, be like college dorms, and be treated as units so closer relationships of staff to residents can be developed. The current thinking is smaller is better, the current thinking does not recognize some of the needs of our children. One of the most successful homes that is presently serving our young adults with PWS is contrary to the current thinking, they have 15 residents. Smaller is not necessarily better in our case.

FINANCING?

Many states will not fund people across state lines; many countries will not fund people to a different country. We must rely on the funding that will be available for the residents no matter where they live, and from there we must find ways to pay the difference. We know it is impossible for most families to be able to make up the difference from available funding to actual cost. Because of the size of the facility, we also hope to obtain financial support from corporations and foundations but this will never be promised until the facility is in operation. This is why we need to proceed with our plans without having a fully developed and detailed long range plan. If we need all of the answers before we start we will never get to start.

What we do need is enough money to have start-up funding and up to 3 months of operating capital in order to proceed. We feel we could not start without at least \$300,000. That is Step #1, and until we have reached this money goal, no further development will be possible.

FIRST RESIDENTS?

How are we going to determine who will be the first residents? We do not want to restrict placement according to who can afford to donate the largest amount of money or privately pay for care, but we do need support in order to open this facility. If you can only afford a small donation and your fund raising efforts are not very successful, your child will have their name listed as a possible candidate because you did show support. In other words, it is not the amount of money, it is the effort and interest that is shown during our fund raising. If we have not received a letter from you requesting placement, nor received any donation from you designated for NDC, your child's name is not on the considered listing. If you want the name added, we must hear from you.

NDC COMMITTEE

The determination of how the center will operate, who the first residents will be, and other decisions of this type will be made by the NDC Committee, and your input will be requested. The committee is a group of volunteers who have no monetary interest in this facility, but who care about PW people. At the present time, the committee is spending all of its time on fund raising, because until the money is available, further plans are secondary. We had hoped for more support from the PWSA membership and their friends. But we fear that some members feel the center will not serve them personally, or they are immersed in another project and feel they cannot support both at the same time. This is not a home for a mere few -- it is a developmental center that will affect every person who has the syndrome.

Many parents have a younger child and do not foresee that their situation may become much more desperate in the future; some parents have an older child who fits well into their own home and does not need a placement. But what is going to be available for the young child when they get older or the older child if the need changes if nothing is started now? What happens to the older PW person when their parents are no longer available? And what happens to the child who is #13 on the list in a state when a facility opens and only serves 12 people? Can you feel the need for your fellow members? You can either do your best to help make the center happen, or sit by and see whether we make it or not, hoping someone else will make the donation that will make the difference.

Many of you know of a "pet rock type" of idea that has made a great deal of money. Many of you have witnessed publicity that has helped others. Our committee would appreciate ideas. Many of you have seen a chain letter or are aware of an older fad called a pyramid. We would like to propose a chain letter be started to ask for donations for our center. It may not make a million like some schemes but it may be a start. The idea is to send the following letter to ten people that you know (friends, relatives, neighbors, or whomever). In the meantime the committee and the national office will continue to work on other ways and means of achieving these funds. Following the letter is a listing of the members who have shown their support, and we sincerely thank them. ARE YOU WITH US?

Dear

The demands of the holiday season have ended for another year. We can all settle down for a few moments of tranquility. Well, at least some people can settle down. Unfortunately, there are some people whose lives are in turmoil twelve months of the year. I am writing about families that are sheltering a young adult with Prader-Willi syndrome that are in desperate need of help. This syndrome is one of those "orphan" conditions that most people hear very little about unless they are lucky enough to be chosen on programs such as Quincy, 20-20, etc.

In order to obtain the services necessary for these families, people in direct contact are the only ones who can get things started. This country is great for publicizing needs in other countries but there are people here whose needs are equally as devastating that are not able to get that needed publicity.

I am writing to you as a friend and asking your support of a very important project for these young people with Prader-Willi syndrome. I am also asking you to send a copy of this letter to ten friends of yours and asking them to do the same. It's not the old-fashioned chain letter that threatens bad luck if you break the chain, it's a 1985 letter asking for your help in opening a National Developmental Center for this syndrome.

If you help by sending your donation, and others do too, you will read about the development of this center in the news and you will know that through your efforts this badly needed center became a reality.

I'm only asking for a little bit of your time to have this letter copied and to mail it out to ten friends. I'm only asking for the size donation that you can afford, but for these young people that need this service, you are giving them a new lease on life. For some you will even be saving a life because several young people died last year for the lack of a proper placement.

Prader-Willi syndrome -- the neglected malady -- that needs your help. Please send your tax deductible donation to:

Prader-Willi Syndrome Association
5515 Malibu Drive
Edina, MN 55436

We sincerely thank you,

Climb the Mountain

THE PEAK ACHIEVERS (TPA'S) Donations of \$5,000 or more

SMITH

CROSSING THE FACE (CTF'S) Donations of \$1,000 to \$5,000

HUFFMAN BURLEIGH ROBBINS (Olson) WETT DANIEL NEASON MEMORIAL FUND (Neason)
EAGER BINTZ MITCHELL

THE CREVASSE JUMPERS (TCJ'S) Donations of \$500 to \$1,000

ROBERT WATSON MEMORIAL FUND (26 contributors) BOUCHER NANZIG NOTBOHM
MIDLANTIC CHAPTER

UP & COMING ACHIEVERS (UCA's) Donations of \$100 to \$500

WHITLOCK KREBSBACH WESTBROOK (Graham, Wyble) LEVINE STEGE (Stege) NELSON
INGALLS (Snow, Flex-Con) BROCK PW TEXAS CHAPTER WYKA ABELL PW COLORADO CHR.
CHASE HARRINGTON BLAIR CASTLE KARNIK BRINDISI VAN ZOMEREN (Diehl) ZORN
WESTMAN MILLER HENDRIX BATES KING MC KEEN MAREK ROBINSON RIESENMAN
ANDERSON VEZIROGLU HERRMANN (AMER.M.S.) ZIIFLE SOJKA CARLYON PLATNER
HUTCHINS WHITE PW KY CHAPTER FOLEY

BASE CAMP SUPPORTERS (BCA'S) Special Gifts & the \$1.00 a week members

VAN HOUTEN (Rosenberg) BUCHANEN MUELLER BATTERSBY MC INTYRE KEENAN BAKER
JOHN LA MONICA MEMORIAL FUND (LaMonica) SHEERAN MANNING PARENT BURTON DALY
MILANA MARCHITELLI DE HAAN KOWTNA KLINDWORTH FOX (Phelan) SIDLO BRAUN
JODI DAMON MEMORIAL FUND (Gandara) JURGENSON CANOVA GULLING REGESTER LACY
GIBSON VICKERY MAURER WEGER BUDNER COSTA KRAFT GUNNISON GROUT HINDS
DUNN IOVEN KRUEGER NASHVILLE MORENO ALLAN HARTIGAN MC ANDREW THOMPSON
CORCORAN TOBIN GARFINKEL MENZER THOMAS PARCELL STURGIS JANES EGGERS
AUL VIRNIG DETERLING KINNEY HANSEN KIMBERLY WALSH AYOTTE COMPTON
HUIBREGTSE LEVIKOFF PW NE CHAPTER JACKSON ROSETTE PIKE

PLEDGES: FICK MEANS SUNDE GOTTSCHALK FOX TRIMBLE PW MO CHAPTER HEINEMANN
ATWOOD SHARP

\$23,766.78

\$300,000.00

A Very Special Thanks to all of You !!!!!

MAKING HEADWAY

Whenever an individual or a group accomplishes something for this syndrome in their area, this can affect all of us. Rita Welch is asking your support for the things their group is working on in the State of NY. Rita has two requests for our members:

PROFESSIONALS: Please address letters to Clarence J. Sundram, State of NY, Commission on Quality of Care for the Mentally Disabled, 2 World Trade Center, 55th floor Room 5578, New York, NY 10047, asking this agency to continue investigating the lack of services to persons with PWS. While investigating the death of a NY girl with this syndrome, the state found she was receiving appropriate care. This girl had been placed in a psychiatric center, had remained there for three years, was allowed to weigh over 200 lbs., and lacked supervision which was contributory to her death. Rita needs letters from professionals disagreeing with their findings.

PARENTS: Please address letters to Senator Lowell P. Weicker (R-CT), Subcommittee Chairman and Margaret Heckler, Secretary, supporting the 1985 HHS Appropriations Bill, which will provide the needed funds to monitor all institutions with 300 or more residents. Helping to get such bills passed will help in obtaining appropriate placements for our children. Federal monies can be withheld from states if the states are not providing appropriate programs. As parents of a syndrome that is badly in need of appropriate placements, we must help to support such programs.

Please address the letters as stated above, but mail to: Rita Welch, 6-12 160 St., Beechhurst, NY 11357.

FIRST CANADIAN CONFERENCE ON PWS

The Ontario PWSA held their first conference in October at McMaster University in Hamilton Ontario. Jack Slater, Co-Chairman, reported that under the guidance of the Continuing Medical Education branch of McMaster University, their one day programme produced very gratifying results. Attendance of 68 adults (parents, friends, and professionals) and 21 children (12 with PWS), made it a very successful day. Plans now include having a repeat preformance in the spring.

ANOTHER PARENT WRITES

Our 14 year old son is now in a self-contained classroom with EMR children and is happy and doing very well for the first time in his life. He was unable to cope with the pressures and frustrations of a normal classroom, and it took all these years of fighting to get him into this placement at last. It's a joy to hear him singing and eager to go to school. His whole mental attitude has changed completely.

I would also like to add I agree with the parent who wrote regarding allergies in a previous issue. Our son also has problems with artificial colors, flavors, and additives, as well as regular milk. She wrote they used Alka-Seltzer to eliminate the reaction, we have had the same results with Pepto-Bismol. We have also noted that he seemed to build up a tolerance as he has gotten older and the reactions are not so severe now.

We find the parent sharing in the GV very valuable to us.

OUR THANKS

The Board of PWSA extends their thank you to Betty R. Schultze, who recently cited personal reasons that forced her resignation from the Board of Directors.

Betty has been a board member for several years, has been very active in working toward our goals of bettering the present and future of our young people with this syndrome, and will be missed.

MINIMIZING CALORIES

A recent newspaper article gave some tips for the times when for speed, economy, or availability, it is necessary to indulge in fast food purchases. You can minimize the calories, fat and sodium by ordering with nutritional sense. For example, while a milkshake could provide some calcium, it also provides 400-800 calories (Burger Chef, choc 403, vanilla 383; Dairy Queen, malt 600; Hardee's 391; McDonald's choc. 383). By ordering regular milk, you cut that intake to 160 calories and still get calcium. A fruit drink would eliminate the calcium but add vitamin C. You can save 100 calories on a Whopper-style hamburger by ordering it without mayonnaise, cut the sodium by holding the pickle, add vitamin C by adding extra onion. Leave on the lettuce and tomato, that may be the only fiber and vitamin C you get. Make up for the lack of vitamins by having a salad with the meal or add several vegetables and fruits at another meal. Whenever you have fast food for one meal, be sure to broil, boil, or steam your next meal to make up for the high fat content of the hamburger. Leave out the butter from your vegetables, skip high sodium foods such as canned soups and pickles, and don't add salt at the table.

While reading these tips I couldn't help but think of the advantages of an early diagnosis and getting your young person in the habit of some of these substitutions. Our own daughter was trained to order fish whenever possible in a restaurant and it was only later that I found out the fish in the fast food shops had more calories than the hamburger. Some of these calories can be eliminated by removing the breading from the fish but more calories can be eliminated in regular restaurants by ordering the fish broiled.

The food and drug administration has a pamphlet entitled, "What About Nutrients in Fast Foods" and this can be obtained free from Consumer Information Center, Dept. 529M, Pueblo, CO 81009.

HELPFUL HINTS

Carry sugarless gum and sugarless candies in your pocket or purse to "trade off" for offered treats when you are shopping in stores, stopping at the bank, etc. It has been mentioned before that this kind of trade can be used for substituting school treats or at halloween time, in order to save those valuable calories.

1984 CONFERENCE PAPERS

We now have the 1984 Conference Papers available for our membership. We have also added a copy of the presentation made by Dr. Prader at the banquet. In order to get your copy from PWSA, please send \$9.00 U.S., or \$12.00 in Canadian funds or for Overseas mailing. (This is a corrected price from the last issue.)

HEALTH NEWS

We appreciate members continuing to share news clipping with us. Many of these articles appear in a limited number of papers so are not seen by a great many people.

A recent article which appeared in the LA times, gave an interesting account of a discovery of a chemical called cholecystokinin. Until recently this was believed to be present only in the intestinal tract but its presence is now noted in the brain. Researchers have found obese mice had 1/3 as much cholecystokinin as their thin littermates. Eventually (and it does take years), human studies will be done.

Another article stated, "In addition to the health problems fat people already face, nutrition experts say the obese may now have to worry about extra high levels of toxic chemicals being stored in their bodies." The article talks about an increase of toxic chemicals being stored in fat, more toxic wastes being ingested because of larger quantities of food being eaten, higher quantities of fish being eaten, and fast reduction of weight which releases a larger quantity of chemicals into the blood stream. Suggestions include bringing the obese person down more slowly to ideal weight; removing the skin of fish as this eliminates most of the fat soluble toxins; boiling and roasting fish and meat rather than frying, which not only removes excess calories but also removes stores of potentially hazardous chemicals.

The Journal of the American Medical Association, October 5th issue, contained an article entitled, "Outbreak of Diarrhea Linked to Dietetic Candies - New Hampshire." The article reported case histories of children aged 5 to 13 that have suffered acute abdominal pain and diarrhea from eating 3 to 16 pieces of hard dietetic candies. Each piece of candy contained 3 g. of sorbital as a sweetener. Sorbital, a hexahydric sugar alcohol, acts as an osmotic laxative. Other articles cited have reported sorbital being responsible for both acute and chronic diarrhea in adults and children. Ingestion of 10 g. of sorbital caused bloating and flatulence in most of the 7 volunteers in one study. Higher doses caused more severe problems.

In unexplained cases of acute or chronic diarrhea, a careful dietary history may possibly show a larger than normal ingestion of sorbital (particularly when dieting).

Another article wrote about the compound Dehydroepiandrosterone, DHEA for short, a chemical compound, related to human sex hormones, that may offer new hope for hereditarily obese humans and diabetics. These researchers found that a genetic abnormality causing obesity also caused over-stimulation of the insulin-producing cells of the pancreas, which can lead to diabetes.

Another member commented on the studies being conducted on the drug naltrexone, commercially called "Trexan", which is on the market for the treatment of drug addicts. While testing is not complete, it is being done with this syndrome.

A TV report recently gave a tremendously encouraging report on an enzyme study that well could be the answer for our children in not only eliminating the eating compulsion but also raise a person's I.Q.

The important thing to remember is that when we read of these reports, we must remember that these studies not only take years to complete but frequently do not relate from animals to humans as researchers hope. The more accounts like this that we read, the more we hope one of these discoveries will eventually be the answer for some of our children.

NEW RESOURCE DIRECTORY AVAILABLE

A new resource booklet, "A Guidebook for Parents of Children with Emotional Disorders" is available from the Pacer Center, 4826 Chicago Ave., Mpls., MN 55417. This booklet was written to offer guidance to parents about three general topics: 1) how to know when a child's problems should receive professional attention, 2) an overview of the mental health profession, and 3) a look at the kinds of services and programs available in Minnesota. Although the last section would be specifically applicable only in MN, the booklet's publishers said that the other sections would be of use to parents in all areas. Also, they added, even the material on MN services and programs could serve to suggest to parents the kinds of resources they might want to inquire about in their own areas. The booklet is available for \$6.00 U.S. funds.

SUGGESTIONS FROM A PARENT:

In response to a previous article in the GV, I would like to share the experiences with my child. Regarding the teeth grinding, gold crowns can be placed on the back molars to eliminate grinding. With my daughter, juice and water did not help her dry mouth condition, we had to use the artificial saliva treatment, but we were happy we did this as it also improved her speech.

PWSA

One of our very important functions as a national office is to be able to furnish information to persons that can help this syndrome. The survey that many of you are participating in right now will be of tremendous help. Having a complete listing of all of the members that have children, and data on children who have died, will also be of great benefit. If you do not recall signing a consent form in the past, will you please take a few moments, fill in this form and return it to us:

NAME (person with PWS) _____ Birth Date _____

We have two listings of people with this syndrome. One is the National Listing that will be available for research statistics, etc. This list will never be given to anyone indiscriminately, but will be used when it can be helpful. The second listing is entitled non-consent. This listing will be compiled in order that we have a record of all known cases of the syndrome. This list will never be shared without your permission. Could we add your child's name to one of these lists?

National Listing _____ Non-Consent Listing _____

If your child has died, it would help us a great deal to have the following information:

NAME _____

AGE _____ WEIGHT _____ HEIGHT _____ (At time of death)

Cause of death _____

Your signature

1985 NATIONAL MEETING

Now that we have the brand new calendar facing us, it is time to write JUNE 20, 21, 22 to be spent in Connecticut at the 1985 ANNUAL NATIONAL CONFERENCE. The committee has been working, in fact they actually started prior to the last conference, and are hoping to offer the membership the best conference that can be assembled. The meeting agenda was formulated by committee head Dr. Suzanne Cassidy, and is pretty well set already. We are sure that every member will find many sessions of interest. In addition to the professional presentations, all attendees will have an opportunity to add their expertise in workshops that will be set up as working task forces. The products of these task forces will benefit all of our members. Another committee, headed by Tony LaPenta, is working hard on formulating the Youth Activity Program. The success of these programs is proven in the number of people in attendance, it is growing each year.

We will follow our usual pattern of getting a pre-registration packet in the mail to you some time in March. Start planning now for this trip -- we guarantee you will not regret your decision.

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 \$15.00 per year for U.S. \$20.00 per year for Canada and overseas. Send dues & change of address to : PWSA, 5515 Malibu Dr., Edina, MN 55436.

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