

The Gathered View

Newsletter of the
Prader-Willi Syndrome Association

MAY-JUNE 1990

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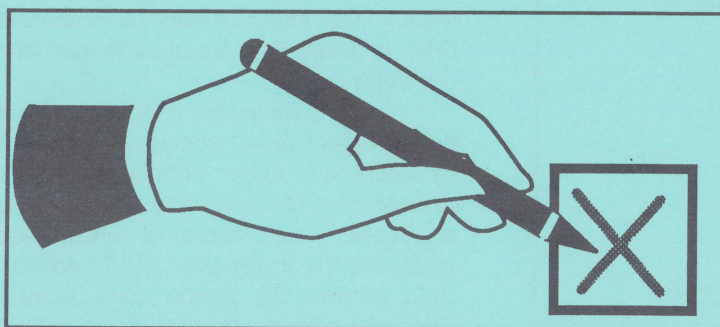
Conference Time is Also Election Time

The Prader-Willi Syndrome Association is operated on the structure headed by a 12-person Board of Directors. These Directors are elected by the general membership at the annual conference to serve a 3-year term. Board action taken in December, 1989, established a Nominating Committee charged with the responsibility of presenting a slate of candidates for the midyear election of this board. The committee was composed of five persons, two present board members and three additional members from the membership at large. This committee contacted the present Board members whose terms were expiring to determine if they wished to run for re-election, and then checked Board minutes and made inquiries to determine if that person was an active board member. As there were two board members who have elected not to run for re-election, the committee then proceeded to find candidates to present as a slate for the July, 1990 general membership meeting. The floor will also be open for nominations as it has been in the past. If no further nominations are made, a motion to accept the slate will be entertained. Candidates running for re-election and any new nominees will be given the opportunity to submit a photo and a couple of paragraphs of

general information about themselves to be included in this or the next issue. An opportunity will also be given any candidates during the actual meeting, voting is then accepted until Saturday morning.

Members who are not able to attend the conference are given the opportunity to cast a proxy ballot. Proxy means you are asking someone else to represent you because you cannot be present to vote yourself. Your proxy ballot may be given to the person you have asked to represent you, or it may be mailed to the national

PWSA office. If sent to PWSA, the extra votes are turned over to the person at the conference. Members present at the conference are given their ballots at the registration desk following the general meeting. As a member you are allowed one



ballot as an individual paid member, or one ballot as a paid organization. Family memberships are entitled to receive two ballots (but cannot be voted by one person). You are entitled to cast one vote for each board vacancy (there are three seats up for election this year) but you may cast only one vote for each candidate of your choice. In other words, your three votes may not be cast for one person. The actual proxy ballot will be found on page 11.

Prader-Willi Syndrome Association

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 Office Hours: 8:30 to 4:30

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Message From the President

Last fall the Exxon Valdez ran aground and spilled large quantities of crude oil that contaminated the environment. Immediately the press reported the incident and emblazoned the name Hazelwood, captain of the ship, as the cause. The FAULT was pinned on him. Indignant environmentalists found a new scapegoat to hang FAULT on. Now the trial by jury has taken place and his peers have acquitted Hazelwood of any significant FAULT.

Not infrequently when something happens that we had not expected it as a possible outcome of our action we cry out in pain and name the FAULT. Depending upon our individual sense of guilt, or our sense of moral outrage, the finger of FAULT can be pointed inward at ourselves or outward at frequently an unsuspecting, weakly defensive person, place or thing. This creates in us, the injured individual, a temporary loss of function. We become incapable of functioning in our usual manner, the manner that permits us to carry on our daily life. Occasionally we become frozen to that concept of FAULT to the point that it consumes our lives and then we need to seek help.

As most of you know by now, I spend my workdays in the surgical operating rooms conducting anesthesia on people who need their hearts repaired. Many years ago I started to employ a gimmick to prevent FAULT from paralyzing the minds and function of the team while they are caring for a patient and have the need to remain as sharp and capable as they can be. When a new person comes into the team we start a game. Today is Sam's day of FAULT. Anything that doesn't follow the expected pattern is blamed on Sam. On the next day, the new person gets to be the goat. Everything that follows an unplanned course becomes Dr. X's FAULT. And the following day Nurse Y will get the blame for being at FAULT for all of the normal unplanned events of the day. This little gimmick or game very neatly directs people away from forming false causes for an undesirable event and allows them to carry on without loss of uselessly wasted time, to do the job that they know how to do, the job that they need to do and makes it the job that they want to do. This is a way of minimizing loss of efficiency at a critical time, at a time that we need to give of ourselves to the fullest extent of our ability.

As I write this it is Easter Sunday Morning, and God rest my father's soul I didn't attend church. But I did have a religious experience by listening to Robert Schuller's sermon on incarnation, crucifixion, and resurrection. He made the analogy to business that has its incarnation when after a time period of conceptualizing and planning the entrepreneur sees the incarnation of the dream with the beginning of business, then follows the period hard work and struggle with a sense of impending doom and then when the bottom of the barrel is reached and all seems lost the fruits of labor cause the business to be born again.

Many of us went through a similar experience. There was the joy of discovering pregnancy, the planning of a future, the expectation of a new life, a new responsibility, a new and unknown source of joy and happiness. Then there was the discovery of an unexpected outcome. This new human that we have created is not what was planned on, joy was turned into sadness, hope became futility, and FAULT reared its ugly head. And FAULT paralyzed our lives. No, Prader-Willi Syndrome didn't do it -- we do it to ourselves. Looking for FAULT and shouting FAULT at the unknown paralyzes. Meanwhile a day of our lives slips by unnoticed except in a sense of failure and loss.

Just remember, tomorrow is Sam's day. It is his FAULT. So forget your blues. Be happy -- it's Sam's fault!

Melissa, We're Proud of You!

We are very happy to share another Special Olympics winner with our members. Melissa won a silver medal for softball and captured a gold medal for bowling. We're proud of Melissa and all of our other members who do well in this competition. Congratulations also to one of our members from Pennsylvania, who got a certificate from school for "Exemplary Academic Achievement in the 3rd Quarter". Keep up the good work, Julie.



Uneducated Doctors

"Uneducated Doctors." Is this a contradictory statement? Unfortunately not. We have in the past heard of, and continue to hear of, doctors who are not very knowledgeable regarding PWS, making statements to patients that should not be made. A recent comment to a set of young parents was, "Your son will become unruly and aggressive and his personality will change from the sweet cuddly child he is now." What does that do to a parent who knows nothing except the new diagnosis? Many of you have been in this position and know how hard this is to face, coming from a person you feel is an authority figure.

Prader-Willi Syndrome Association offers information on the Syndrome, and encourages parents to learn all about the Syndrome, but we also want to emphasize the fact that all of our children are individuals. In learning about all of the symptoms, please keep in mind that every child does not develop every symptom, nor do they all develop symptoms to the same degree. Making a statement that every child will



become unruly, aggressive and develop a personality that is a long way from the sweet baby, is very unfair for a parent to look forward to.

Our literature spends a great deal of space pointing out the possible symptoms, because they are important to know, but it is equally important to know the

many characteristics of our children that make them very exceptional. A couple of recent letters are very good examples: One young man walking his dog was followed by another pair of dogs and he could not return home before knowing these dogs were safely home again. (Aaron's mother shared the photo to the left with us.) Another young man, upon learning a relative's dog was dying of cancer, walked to their house each day to read the dog a story. It's always a good idea to remember terminology changes over the recent years, you have a child with PWS (not a PWS child), and he/she may have similar problems or characteristics of other children with the Syndrome but is always an individual.

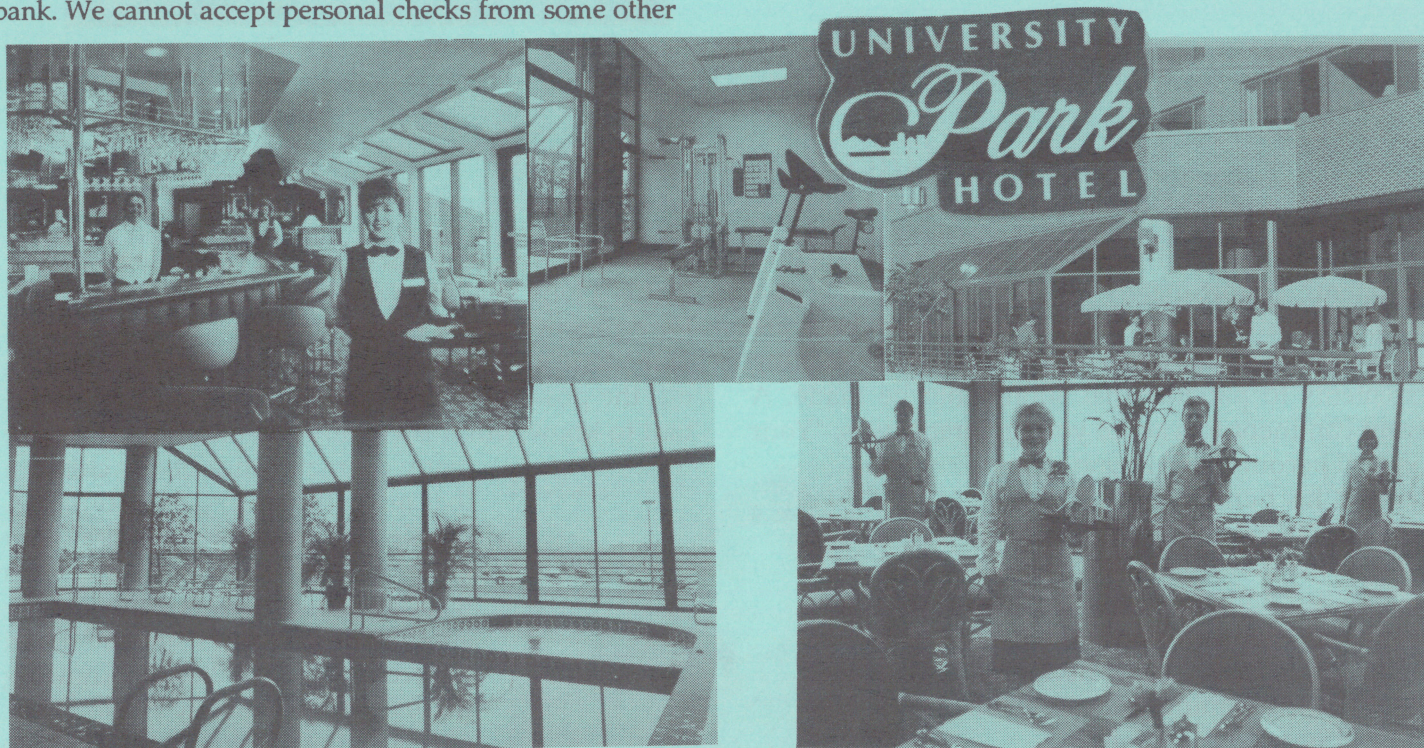
Conference Registration Time is Now!

Conference pre-registration packets went in the mail mid-March. If you haven't received yours, either we missed you or the mailman has let us both down! Please let us know if you need the forms to register.

It's the 12th Annual Prader-Willi Syndrome Association Conference -- Where: Salt Lake City, Utah; When: July 19-21, 1990 (pre-conference day July 18th); Hotel Contact: University Park Hotel, (registration card included with your pre-registration packet) 1-800-637-4390 or 1-801-581-1000; Any questions: PWSA 1-612-926-1947. Special Attention Canadian Members: Prices are in U.S. funds. We require the posted amounts in order to meet our expenses, therefore require that Canadians add an additional 18% if payment is made in Canadian funds. We cannot accept checks drawn on a Canadian bank marked, Pay in U.S. funds, or U.S. funds account. We can accept a Canadian check in U.S. funds if drawn on a New York bank. We cannot accept personal checks from some other

countries (England is an exception). (The bank charge is \$25 per check to collect those drawn on a Canadian bank.) The easiest method is to just use your regular checks and add the 18% difference.

We are happy to report registrations are already coming in. This assists the committee, particularly in planning the number of children/adults in the Activity Program. We needn't add photos to convince those who have attended a previous conference to come, but for those debating here's what you'll be missing in the facility and the agenda will let you know what great meetings and activities you will be missing. Hope to see all of you who can possibly make it in July. As many of you know the 1991 conference is booked for Chicago. The board will be discussing any bids for the 1992 and 1993 conferences. Someone asked the other day when we were coming back out east - Eastern Hosts, where are your bids?



Several views of the University Park Hotel, site of the 12th Annual Prader-Willi Syndrome Association Conference

Letters We Love to Receive!

"Dear Angels at National,

This is a Christmas gift from our family. We gave an equal amount to our local chapter. We have an auction at our annual family Christmas party. The proceeds go to the host/hostess' favorite charity. This year, we were the hosts and you are the recipients. Its a fun and easy fundraiser and might be of interest to other Prader-Willi families out there! (Bringing white elephants to other family gatherings could work also!) Please accept this check for \$82 and use it where you have the greatest need."

Ethnic Eating

Chinese: High-fat fried noodles, deep fried are out! Choose dishes that are boiled, steamed or lightly stir-fried in vegetable oil.

French: French onion soup is high in calories, especially when it's topped with bread and cheese. The rich sauces are just that -- very rich in calories! Ask for the sauce to be served on the side.

Greek: Seek dishes made with limited amounts of oil. Tzatziki, pita bread, feta cheese are good choices.

Italian: Pasta is good as long as it isn't filled with cheese or fatty meat. Wine sauces, marinara, chicken and fish are good choices. Italian ices are low-calorie.

Japanese: Watch out for the deep fried sauces. Look for the word "yakimono," which means broiled.

Mexican: Request cheese and sour cream served on the side, otherwise most foods are low in fat. Refried beans can be cooked in lard.

Frozen Dinners

There's no doubt about it -- frozen dinners have become part of the American diet and in our homes. Supplementing side dishes of 100-200 calories can accomplish a balanced diet with calories in the 400-500 range. Here are some examples:

Weight Watchers Fillet of Fish au Gratin: add lettuce & tomato salad, 1 Tbsp. parmesan cheese, 1 Tbsp low-calorie dressing; 1/4 cantaloupe or nectarine or a baked potato with parmesan cheese and spinach.

Stouffer's Lean Cuisine Chicken Oriental: add 1 c. melon balls in 1/2 c. low-fat yogurt, or 1 c. cooked spinach or peach slices.

Le Menu Light Style Dinner Veal Marsala: add 1 c. raspberries with 1 Tbsp. low-fat lemon yogurt, or 2 tomato halves broiled with 1 oz. skim mozzarella.

Budget Gourmet Entree Pepper Steak with Rice: add 1 slice pumpernickel bread or 3 stalks of steamed asparagus.

Dining Lites Beef Teriyaki: add Oriental salad of lettuce, spinach, mandarin oranges, vinegar & oil, or 1 c. broiled Brussel sprouts & 1/4 c. water chestnuts.

Stouffer's Right Course Beef Dijon with Pasta & Vegetables: add fresh fruit mix: 1 sliced peach, 1/4 c. strawberries & blueberries, 1/2 c. melon balls or 1/2 cucumber & 1 sliced tomato in 1/2 c. low-fat yogurt.

Hans Zellweger, M.D. 1909-1990

With great sadness we wish to notify members of Prader-Willi Syndrome Association that Dr. Zellweger, international pioneer in medical genetics and professor emeritus of pediatrics at The University of Iowa College of Medicine, died at his home on February 24th. Born in Lugano, Switzerland, Dr. Zellweger was educated in Hamburg, Rome, and Berlin, and received his medical degree in Zurich in 1934. Following residency in pathology, surgery, and obstetrics in Switzerland, he joined Dr. Albert Schweitzer as a clinic physician in Lambarene, French Equatorial Africa where he remained until 1939. After serving in the Swiss Army during World War II, he returned to study pediatrics in Zurich (where the original "floppy baby" studies were done in PWS) and came to the U.S. as a Rockefeller Fellow. He subsequently served at the American University in Beirut, Lebanon. He visited Iowa City as a research scientist in 1957 and was named professor of pediatrics in 1959. During his career at Iowa he founded the Division of Medical Genetics, began one of the first clinical cytogenetics laboratories in the US to study human chromosomal abnormalities in 1960 and created Iowa's Regional Genetic Counseling Service.

Active in many professional societies, Dr. Zellweger contributed nearly 600 books, chapters, and scientific articles to medical and scientific literature. "Dr. Zellweger will be remembered as a role model for a generation of pediatricians around the world. His leadership in genetics and the care of children with handicapping disorders, and his profound respect for the simple dignity of a child will be missed by hundreds of families and his colleagues," says Dr. James Hanson, professor of Pediatrics at Iowa City. Many members of Prader-Willi Syndrome Association are familiar with the very special interest and concern Dr. Zellweger took in children with PWS and their families. He was a brilliant, courtly, compassionate, and gentle man whose passing will leave a void. — Louise Greenswag, R.N., Ph.D.

With Sympathy

We are saddened to express sympathy to Dr. Jack and Beth Gordon for the recent death of Lenore. Jack and Lee have been members of Prader-Willi Syndrome Association for many years, even though they lost their son, Joel, in 1986. Lee will be missed.

Letter Taken from "The Missouri View"

Why I Want to be in a Group Home

I've been living with my parents for 24 years and it's time to get away. The constant fighting with my parents will stop. (*Editor's note: Of course, John has nothing to do with precipitating these fights!*) It's lonely at home, I won't have to just sit in front of the T.V. Being around my parents makes me act like a kid.

I want to be around other people who have Prader-Willi Syndrome. When I see other people eating the food, I want the same thing. My food (at the group home) will be regulated. The last 100 pounds I want to get off. I'm having medical problems. At the group home I will get to go to movies, fun outings, work at the workshop, have more friends with the same hobbies. Then my parents can stop worrying about me. (We are happy to report that John is scheduled to enter a group home in the near future.)

Group Home Placement

"I thought it may interest you to know our daughter is now living in a group apartment with two other retarded girls. All are in need of lots of help and care -- all have very little vocabulary. They have put a lock on their kitchen and the relief workers and live-in attendant have been able to keep her from gaining. She was 264 lbs. when she was 23 years old and went to a center for help. After she got to 150 lbs. she was transferred to this present location and her weight is now around 110 lbs. She goes to a day training workshop but she is not capable of doing any real work because she is indifferent or does not have the idea of time and finishing tasks. She comes home one weekend a month and sometimes it is very upsetting because she keeps begging for food and snooping in cupboards. I know she'd gain it all back in a short time if she'd come home to live."

The Benefits of Attending a Conference

We heard of a call from a teacher concerned about a new pupil diagnosed as having Prader-Willi Syndrome. The teacher wanted to know what Prader-Willi Syndrome was and how she could better prepare herself for serving his needs. That kind of concern creates warmth. The conversation continued that the parent was unwilling to become involved in dietary management, concern for social development skills, the IEP and the more subtle needs of this person. What a switch! How many parents have fought the school system to become involved in these areas.

A parent wrote of the first conference she attended and finding out the similarities and the differences in our children. Some children were raised without the benefit of a diagnosis, some were diagnosed at birth; some were severely retarded, others actually had an I.Q. level above the retarded level; some had gained some level of independence, others require very monitored environments. She pointed out the great variation that exists in how individuals meet their daily challenge and responsibilities of being a parent of a person with Prader-Willi Syndrome. This can be a delicate and painful as well as rewarding role. Each of us has a different capability to recognize our child's needs as they exist in daily life. Need assistance? That's what our annual conferences are. That's how we, as an organization, continue our "caring and sharing" theme.

Pre-Conference Day

For the July 18th Pre-Conference, Dorothy Thompson has agreed to chair the *Group Home* portion of this day, designed as an opportunity for providers to meet and share. In order to provide some structure to the day, Dorothy requests any attendee who would like to be a part of the agenda to get in touch with us in the near future.

Another portion of this day is devoted to *Scientific Sessions* presentations. A call for papers has gone out. If you are a professional who would like to present an abstract during this session and have not been contacted, please let us know so the necessary forms can be forwarded to you. Deadline for abstracts is the end of May.

We Get Requests

A teacher in Wisconsin writes: This child has been in my class for two years and I will have her for another year. I am very frustrated with no progress in behavior, in fact I feel we are losing ground. Would there be someone in my area that I could contact for information and support? A psychotherapist writes she is currently seeing two individuals with PW for individual therapy. I would like to talk with other professionals/parents about what they have found helpful. If other professionals have these same questions or feel communication would be helpful in working with their clients, PWSA would be most happy to start a referral directory to connect these interested parties.

Hot Off the Press!

When talking with younger parents, it is not difficult to encourage the "one day at a time" theory of dealing with your child because the past 5-7 years have been so encouraging in the field of genetics.

The most recent press release stated: After years of half-steps, missteps and fears that it could never be done, researchers have fashioned a strain of mouse harboring a specified genetic alteration in every cell of its body. Scientists can swap one form of a gene for another in mammals. This method offers limitless possibilities for devising therapies against disorders.

"This is one of the most exciting technologies in biology developed in the last 10 years," said Dr. Leroy Hood, a professor at the California Institute of Technology in Pasadena.

Researchers elsewhere are applying the new method to study genes that, among other things, have been implicated in brain cancer, leukemia, and the development of the nervous system.

Preventing Tragedies

A very good but rather long article titled, "My Problem and How I Solved it" was repeated in a Utah newsletter. The story told of a retarded boy who always caught his bus and appeared right on time but one day failed to appear. "Could he have been lured away from the bus stop by some unscrupulous person? Maybe he had to go to the bathroom and missed the bus. Perhaps he had been beaten up, robbed, raped, or murdered. Maybe he just wandered away and was mad at somebody, or even at himself. Thousands of thoughts went through my head." The story continued that the boy had gotten on the wrong bus and he was not located until 11 a.m. the following day for two major reasons: 1) they did not have a recent black and white photograph to share with authorities, and 2) he did not wear a wrist identification or carry with him a number to call in emergencies. The community officer that had picked him up politely told them if he had been carrying a card with emergency phone numbers listed he would have been back home around 8 p.m. instead of spending the evening in a jail, scared by people he had encountered. Lesson: Take some quality pictures of your child today -- studio-type portraits or close-ups of the face, preferably in black and white for good reproduction. Make sure your child/adult is wearing a wrist bracelet of carrying identification that indicates who to call when there is an emergency (more than one number would be best).

Growth Hormone Information Sought

A member reported that their young daughter was started on growth hormones in July 1989. The parents noticed a dramatic improvement in her behavior including a marked improvement in her stress level. Although their daughter grew well on the hormone, she developed scoliosis which forced them to stop using the drug. The parents believe that the six months their daughter was on growth hormones contributed directly to her improved behavior. They would like to compile information from other families to determine if others have had the same experience. PWSA would like to acquire the following information: 1. Name of drug used 2. Amount used 3. Weight of the child 4. How often the drug was given 5. Was the drug given the same time each day? If so, when? 6. Were there any behavior changes, yes or no. If yes, please explain. We feel that these types of observations could someday lead to a treatment for people with PW. We hope that anyone involved in a growth hormone therapy would take a few moments to comment on the above questions. Please return your response to PWSA. This information will be shared in a future issue of the GV. Thank you for your help.

Your Funds at Work

The RESEARCH FUND was established by the Board of Directors in June 1982, to be used primarily for research, but also including other special projects in direct support of people with PW while, at the same time, providing some funds for necessary operating expenses. In 1987 a revision was made that specifies when a donation is marked for Research, 100% goes into this fund and the fund will be used for Research and special projects only. At the present time, PWSA is sponsoring three separate projects: 1) "Orofacial and Dermatoglyphic Characteristics in Patients with PWS", evaluating 30 or more patients, to allow more clinicians to make an earlier diagnosis as well as help identify the most propitious time for orthodontic correction of malocclusions. 2) History and current use of psychotropic medications in patients with PWS, and 3) The development of an appropriate exercise program specific to the needs of people with PW (including a video and manual to be shared when project is completed).

The CRISIS INTERVENTION & TRANSITIONAL FUND (CIT) was first established in June of 1984, to actually open a Crisis Center for PWS with specific goals in mind. When unable to actually establish a center, the following criteria was developed as acceptable usage of this fund: 1) Continue to provide CIT funding to aid people in crisis to receive necessary services; a) travel grants to the nearest hospital or rehabilitation center; b) intervention grants for families facing crisis situations (help while waiting for

home placement, short-term respite care, educational travel, camping, as examples). 2) Funding travel expenses for experts to consult with primary providers for a) establishing programming and group homes; b) staff development and training; c) continued support; d) long-range follow-up. 3) Establish a mechanism for loan of CIT monies as collateral for startup funds in the development of quality designated group homes. A training session for ten individuals from across the country took place the end of April. This is the first step in developing additional people to be of assistance in opening new homes, training staff for homes, and problem-solving to keep homes meeting the needs of their residents. As many of you have experienced, getting a home off to a good start, having properly trained and informed staff, is paramount in developing a good designated home. We hope our members keep this fund in mind when a crisis situation does develop and PWSA may be able to help. The CONFERENCE GRANT FUND was established in December of 1987, to provide monies to PWSA members who cannot afford to attend the annual national conference without financial assistance. This year, the Board agreed to finance two grants which were recently awarded to a family from Connecticut and a family from Idaho. Almost a dozen applications were received for these grants, and we are pleased to be able to help two of the families. Hopefully in the future the number can be increased.

Money Problems

For members outside of the U.S., we sometimes have difficulty in methods of payment (for dues, materials, etc.). For Canadian members, we suggest just using your regular checks and adjust the payment to the amount in U.S. funds. (Canadian rates are listed on the membership renewal form and on the order form or you can use an increase of 18%.) For foreign funds the best arrangement is a Bank or Postal Money order drawn on a New York bank. We can accept English checks in pounds but we cannot cash checks from some of the other foreign countries. Unfortunately when checks are drawn on foreign banks (even with the notation to pay in U.S. funds or U.S. fund account), there is a \$25 fee to send this check for collection. We appreciate your assistance with this problem.

Your Contributions Keep Us Going!

Here are some additional Angels who have donated to our fundraiser: *Heavenly Angel*: Miller; *Arch Angel*: Gravallesse (Millipor Fd.); *Angels*: Lyon, Wolcott, & Smith; *Cherubs*: Beck, Dietz, Gales, Stickle, Armstrong & Thomas. During this period (mid-February, March & mid-April) we also received donations from the following members: *Research Fund*: Furr, Burmeister, Gerdes (Luhman), Barret, VanZomeran (4), Willinsky, Boyd (2), Needel, Mines, Leonard, Sojka, Levy, Weiner, Briar Cliff College, Gordon, Winnebago UF (Doolittle), Notbohm, Mitchell (Solomon). Gordon memorials: Gordon, Parola, Scheps, Silverman, Perrick, Spivak, Podlin, Bodoff, Rothman, Parker, Reider, Lenetsky, Richman, Miller, Rosenholtz, & Solitrin. *Operating Fund*: Burmeister, Krebsbach (2), Gerdes (Luhman), Barret, Needel, Mines, Westman, PWSA-KS, Daly, Dolese Bros. Co., Briar Cliff College, Winnebago UF (Doolittle), Burleigh, Notbohm, & Smith. *CIT Fund*: Olson (2), Beltran, Shoemaker & Matza. *Contributing Dues*: Fick, Hamill, Bartlett, Pflieger, Coleman, Dixon, Feldman, Krautwurst, Ziifle, Carraher, Sturm, Stenger, Lovsland, McHargue, Sunde, Eggers & Scheidegger. *Patron Dues*: Parcell, Singer, Baron, Cheng, Burleigh, Levikoff, Lehman, Whitehead, Menzer & Luhman.

"Thank You" to some special people: Penny Park, chair of the 1989 fundraiser, for designing and producing the angel flyer and obtaining \$10,000 in matching grants (two matching grants were from the Dolese Brothers and Roy Smith); Tere Schaefer, for donating a weekend and saving us \$500 in conference printing costs; Dick Wett, for donating the wallpapering of the PWSA office and a new printer for the computer, (\$2000); Westinghouse Electric Corporation, for the \$1500 grant for the YAAP/1990 conference; Sheldon Tarakan for editing and formatting each issue of our newsletter; and a thank you that is surely not adequate to Judy Goff, office secretary, who retired after five years of employment. For those who know Judy, she has been far more than an employee and it will be very difficult to replace her devotion and loyalty.

The Winners:

Congratulations to Jud Bell of Florida, the February winner of the conference fundraiser. The third and final winner was Ruth Levikoff of Pennsylvania. We thank all the winners and others who supported this event.

Pens Wanted:

"I need more old pens -- my offer is \$5 for any old fountain pen and \$25 for each one that is 50 years old and restorable (undamaged)." - Judson Bell, Catamaran 2231, 2400 S. Ocean Drive, Fort Pierce FL 34949. Jud, a member, has offered a contribution for each pen received from a PWSA member.

A Member Writes:

"My husband and I would like to extend our gratitude and appreciation to all those people instrumental in making The Gathered View possible for all our Prader-Willi members to read. We've been receiving this newsletter for nine years now and because of the valuable information made available to us, we are constantly kept abreast of all that is occurring in our special organization. Unfortunately, my husband and I have only been able to attend one national meeting in Connecticut, because of various reasons that do happen in a family; but, now that all my children are married, we hope to be in Utah this July. We would like to give special mention to Dr. Beltran, who is so faithful in writing letters to the association. They are not only informative, but also very realistic and oftentimes very sensitive and funny. He made us aware in our January-February newsletter how little credit we give to those who do so much for our organization. Thank you, Dr. Beltran, for all you do. Thank you again to all of you on our Prader-Willi Board and again to all those who make *The Gathered View* possible. God bless all of you!"

Westinghouse Grant:

For the second year in a row, Westinghouse Electric Corporation gave PWSA a grant for our Youth/Adult Activity Program planned for our conference. We would like to know if any PWSA members are employed by Westinghouse. If you are, please write us a quick note. We need these numbers to work on next year's grant.

Analogy Submitted

A parent submits this for our enlightenment: "This analogy may be of interest to other parents. I can't vouch for its scientific accuracy but it seems to be correct as far as I know. Perhaps the medical experts would like to comment; they are welcome to do so.

Having Prader-Willi Syndrome is a lot like starving. The hypothalamus is an older part of the brain and it regulates a lot of the automatic functions of the body. It seems that this is the part of the brain primarily affected by getting that unopposed maternal chromosome. When a normal person stops eating, first we feel hungry. Then hungrier and hungrier. After a week or more, hunger goes down a bit. But lots of other interesting things happen during that first week. First, you start burning up your sugar (you hardly feel hungry till that's gone -that's overnight.) Then you start in on your muscle and towards the end of the week, you start living off your fat. Meanwhile, your metabolism goes down. You use up less energy just to stay alive, your body gets more efficient. You lose energy. You just want to sit around. You sure don't want to go out and jog! But you can still, of course. And food! Your mind is completely on food. Someone named Laura makes you think of Scuders potato chips, the letter M is for M & M's etc. If you have lots of will power, you can fast a whole week and go about your daily business, but any mention or sight of food sorely taxes you. And your body is so efficient that you don't lose much fat that first week, either. It makes you want to sleep more, too. Now imagine if you were born that way...that you felt like you were starving all the time - even stuffing yourself only turned down the feeling a little while - and your body lays in the fat but you still feel like you're starving. And you are just a little kid. You don't have grown ups willpower to go about your day and hang on. You're starving, and you want to eat!!!! And 'they' lock up the food and want you to learn to read and count and subtract and stuff like that but you're STARVING and when's lunch? cause YOU ARE STARVING and if you don't eat soon you are going to DIE and you don't care what 2 minus 1 is. YOU ARE STARVING! And YOU WANT TO EAT! Think about it.

The Editor responds: I did think about it and I guess I want to be the first to respond -- hopefully others will too. The problem that I see with the above analogy is if I truly believed that my daughter felt that way she would probably not be alive today. Compulsive, yes. Mind set on thinking of food constantly, yes. But can we assume that people with this syndrome feel or look at things the same way that we do. Discussions have been held in the past whether persons really do experience true hunger or is the desire to eat a compulsion only? Some parents state their child is truly uncomfortable because they are hungry. If a child finds that stating this fact will get him food, isn't he going to use it? How can a mother refuse to feed a child that convinces her he is truly in pain if he doesn't get food? On the other hand, if the child is compulsive and only wants to eat because he knows the food is there, isn't it easier to say no, you can't have it because you are gaining weight? We certainly all have noted a difference in emotions in our children. Many never truly cry, they fake a protest cry if they feel it is the thing to do. Some never cry tears. They laugh when people around them laugh because it must be the time to laugh. (Naturally this is not true of everyone.) I agree certainly their mind is on food constantly, but do they truly feel they are starving? That's how I would feel but I find it hard to believe we can know how they feel. Accepting the analogy makes me feel it is alright to let them overeat, and I'm afraid I can't accept that. A member recently sent an article from one of the tabloids, picturing a baby from China who weighs 103 pounds at the age of 25 months. The article states, "the first thing he did was start squalling for food. When he was just 6 months old he was eating 15 bowls of hot noodles in one day. Now at 25 months he gobbles up eight or nine pounds of fish, rice and noodles a day." His mother stated, "But at least our baby doesn't throw his food around and make a mess like most children do. He's very careful not to waste a bite." As parents we do have to make our choices, our choice was to control our daughter and she is now alive at 25 (and I believe quite happy). I don't believe the above parents are going to be able to say the same thing for their son. If I had believed my daughter felt she was "starving" all her life, I don't believe I could have made that decision."

Proxy Voting

What is a proxy ballot? A proxy ballot gives you the opportunity to vote even though you cannot be present at the conference. How do I pick my proxy? Anyone who is going to be at the conference can act as a proxy for you. This can be a board member, an officer, or any member of PWSA. For your convenience, the board and officers are listed on page two. Why should I submit a proxy? This is your opportunity to be an active member. If no proxies are submitted, just the members in attendance will make the decisions. Can I tell my proxy how to vote? Yes, you may direct him/her how you want your ballot cast, or you may let him/her choose. What do I do with my proxy ballot? Give it directly to the person you choose, or mail it to PWSA and they will give it to your proxy at the meeting.

A motion was passed at the December board meeting requesting the membership of PWSA to amend the Articles of Incorporation so as to authorize the Board of Directors to take action and make decisions by mail by a 2/3rds vote. Present policy states mail vote must be unanimous. This policy can restrict our ability to accomplish some of the necessary business between board meetings. If you feel this change should be made you may mark your proxy ballot by requesting your proxy to vote yes. If you feel the present method is better you can request your proxy to vote no. Or you may ask your proxy to vote as he/she chooses for you.

Proxy Ballot

I would like the following person to act as my proxy in all voting transpiring during the 1990 general meeting (including vote for board members, issue of changing mail voting by board, and any other matters that may come before the board during the general membership meeting):

Name of Proxy: _____

Please vote on my behalf or follow these guidelines: _____

Date: _____

Signature(s): _____

Must be returned to PWSA before July 1, 1990. THIS IS YOUR OFFICIAL PROXY and the only legal acceptable medium to be used (reproductions in other newsletters or phone calls are not legal).

New Brochures

The Brochures Committee members have just completed three additional brochures. We are happy to report that they are now at the printers and we will announce when they are available in the next *Gathered View*. The first brochure is a Medical Alert for doctors and other health professionals. It includes a diagnosis guide and a reference guide on PW. We are certain our members will find this brochure tremendously helpful in educating professionals. The second is a brochure designed for parents of younger children and includes questions and answers on several topics. This brochure is developed with the sensitivity needed when parents first receive a diagnosis of PW. Finally, the third brochure contains information in many areas concerning PW in late teen years and young adulthood.

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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