The Gathered View
for the younger set

Newsletter of the Prader-Willi Syndrome Association

MARCH-APRIL 1990 VOLUME V, NUMBER 2

Prader-Willi Syndrome in Australia

by Vanja A. Holm, M.D.

I had the privilege of being invited to be the keynote speaker at the 3rd National Biennial Conference of the Prader-Willi Syndrome Association of Australia, held in Perth, W. Australia. The program was impressive and included talks about genetics by Dr. A. Hockey and endocrinology by Dr. G. Bryne. Dr. P. Montgomery, who is with Irrabeens, their Authority for Intellectually Handicapped Persons, reviewed data accumulated on the syndrome in W.Australia. Exercise, dietetics, recreation, speech therapy, residential care and education were also well covered. An airline strike made travel difficult but people still came from as far away as New Zealand. A Haydn Williams Fellowship financed my trip. Dr. Williams is the founder and developer of Curtin University of Technology in Perth. He has a 6-year-old grandson with Prader-Willi Syndrome. Colleen Liston, steering committee member, organized my 6-week program (4 weeks in Perth, 4-5 days each in Adelaide, Melbourne and Sydney). A trip to Rotnest Island in the Indian Ocean outside of Perth was to be the post conference highlight. It was, but on a different scale than intended by the organizers. The island was named by the early Dutch seafarers who thought that the island quokkas (small marsupials) were rats. It has been used as a prison for aborigines and as a defense post during the two World Wars but is now a seaside resort. We traveled on a very windy spring day down under and many people got seasick on the trip over (except the persons with Prader-Willi Syndrome, of course).

Vanja A. Holm, M.D., and friend meet "down under"

In Perth I met with other parent organizations, gave grand rounds, talked to university students and visited many schools, organizations and facilities. Prader-Willi Syndrome Association in Adelaide, S. Australia, met from morning tea till afternoon tea. During lunch I had time to talk at some length with a set of parents who during my talk discovered that their daughter with the 15q deletion had Angelman Syndrome not Prader-Willi Syndrome.

In Melbourne, Victoria, I gave grand rounds on Prader-Willi Syndrome and spoke at a public lecture attended by parents and professionals. I also had an opportunity to meet with families and professionals in the Prader-Willi Syndrome clinic. Sydney, N.S.W., also has a Prader-Willi Syndrome Clinic, where I had an opportunity to sit down with their whole team and compare notes. There were many similarities. This meeting was followed by grand rounds on -- you guessed it -- Prader-Willi Syndrome. The neurologists wanted to hear about neurobehavioral aspects; the therapists, dieticians and pediatricians wanted to hear about weight reduction and diagnosis. The parent organization arranged an evening session on "Problem Solving," with group homes high on the agenda. Prader-Willi Syndrome was a big day in Sydney, rewarding to sense that professionals and parents worked closely for the benefit of people with Prader-Willi Syndrome.

This was mainly a professional visit, but the six fascinating weeks also provided a chance to cuddle koala

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Prader-Willi in Australia

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bears (as can be seen a somewhat intimidating experience), pet kangaroos and admire emus, wild parrots and lovely spring flowers. Australia is a friendly place. People are hospitable, the landscape is beautiful and the spring weather mostly "fine and 20 (centigrade)" as the weatherman usually described it. It was heartwarming to meet with so many people committed to Prader-Willi Syndrome on another continent.

In Memory of Scott

The loss of my brother, Scott has brought forth many inner feelings. Scott lived with and battled his Prader-Willi for 22 long years. During that time we, as his family, tried to give him all that we could to make up for the freedoms that we couldn't give him -- the ones that his Prader-Willi prevented him from receiving. But I've come to realize that he gave to the world much more than he received. He gave to those who knew and loved him a different perspective on the world and about themselves - a perspective that they wouldn't have had if they hadn't known him. All of the strangers, too, that he so readily struck up a conversation with were also surely affected.

Scott has left behind a legacy - a Prader-Willi Syndrome Group Home in Delaware - that is soon to open for which he provided the impetus. I must say that he was truly a success in his short lifetime. Many successful men in this world have not made such a lasting impression. The photo enclosed is of a loving person who had gained control over his Prader-Willi Syndrome (with the help of his program at the Woods School) and had lost over 100 lbs. Look at the smile on his face and you can see the pride he had in himself. We remember him with that same sense of pride. For all that he gave to the many he touched, now is his time to reap his rewards. With Love, from Scott's family.

Message from the President

by Delfin J. Beltran, M.D.

Sarah recently had her 18th birthday and her parents have had an intense encounter with the collection of laws and administrators that surround the change from developmentally disabled daughter to adult. I have stated on many occasions that the true experts on Prader-Willi Syndrome are you, the parents. The daily experience of living with Prader-Willi person is an effective teacher. We learn partly because of our desire to know this problem which afflicts our children so that we can seek answers that will alleviate their suffering as well as our own discomfort. We also learn because we cannot do otherwise and survive the problems that life with a non-normal person causes. Through the years of growth we learn to sit in waiting rooms accepting the glances of normal persons who question our problem.

We learn to forego those leisure moments as husband and wife, spent away from family problems, to restore our energies and drive because we can't find a substitute caretaker that doesn't result in a week of trying to get back to normal. We learn to sneak a midnight snack after our Prader-Willi child is sleeping and can't see us do it and ask for a share that has to be denied. But at the age of 18 your child becomes emancipated, they are no longer under your jurisdiction, they have a legal right to make their own decisions. Today the legal system has tentacles that reach deeper than your pocket, deeper than your imagination, deeper than all your acquired expertise and deeper than your heart and soul.

We had always been aware that at some point we would have to contact our attorney to discuss conservatorship. We became aware of that as a potential additional legal cost as we paid the bill for the drafting of wills and establishing a family trust to minimize the impact of the IRS on anything I might have left over for the future after the annual Spring raid from the money gluttons in Washington. Hmmmmm! You don't suppose that there is a toxin in the air in Washington, DC that causes a variant of Prader-Willi Syndrome so instead of constantly seeking food these disabled creatures in government constantly seek the fruits of the citizens' labors. I would bet that I could get a grant to study that!! Back to the topic. We seem to have been so busy taking care of the daily problems that we forgot conservatorship needs. That is until last Fall during our IEP fight (mediation) with the school district when an administrator stated, "By the way, Sarah will be 18 in February, then she can decide for herself where she wants to go to school, or if she wants to be graduated under the waiver plan."

Gad Zooks! Sarah's 18th birthday was only a little over three months away. We then made a major financial mistake. We didn't search for a specialist in the problem of conservatorship for the disabled and instead financed the education of the probate section of a law firm that I have regularly done business with for 20 years. Three days after Sarah's day in court, we went to a lecture on conservatorship for the developmentally disabled only to discover a handful of facts we should have known and this expert in the field had a fee schedule one-third of what I am in the process of paying! There are people out there who have encountered these problems before and know the many factors going into your decisions that will determine the final wording and the nature of the documents related to the process and in much less time. Remember, when dealing with the law you pay for the time spent on the problem. If the problem is new to the lawyer you select, you pay for his education as well as your own. I now know. I just did it.

What will you need to know and what things have to be decided? Keep tuned. As we mentioned last issue, your Board is developing an education program. Part of that program will be related to the things that need to be known going into the various and sundry legal problems we encounter as parents of a developmentally disabled child with Prader-Willi Syndrome. No one individual in this organization has the knowledge or experience to touch on all the minutiae that we will need to include in our education program. It is necessary that each member, each chapter, every professional that pays dues and reads the Gathered View make the effort to relate their experience in a letter to the Association office in Minnesota. Remember, the strength of our organization is determined by the contributions of the members. You are the experts, share your experience and knowledge, help one another.

Where does the money go?

A relative asked us that question, and said, "I am enclosing a donation and have contributed in the past. What do you do with this money?"

Since she is wondering, maybe others are to, so, here's how it works:

All income and expenses are placed in and taken from four "pots," which are the *Operating Fund,* the *CIT (crisis) Fund, Research (research & projects) Fund,* and the *Conference Fund.* The *CIT Fund* is designated for crisis needs. Funds are not placed into this fund unless the donor specifies this is where the donation should go. Money is taken from this fund for crisis needs after applications are approved for specific purposes. The *Research Fund* is another designated fund. When donations are specified for research, the entire donation is placed in this fund; when donations are given to Prader-Willi Syndrome Association without any designation, half of the amount is placed in the *Research Fund* and the other half is placed in the *Operating Fund.* Money is taken from the *Research Fund* after approval of proposals for a research project or some other project that will directly benefit Prader-Willi Syndrome. These proposals are reviewed by the Scientific Advisory Committee and granted by the Board of Directors. The *Conference Fund* receives its monies from conference registrations and direct contributions (usually raised by the conference committee) and the conference expenses are paid from this fund. The *Operating Fund* is funded by direct donations, half of the non-designated donations, membership dues, and any profit on material sales. The following expenses are met from the *Operating Fund:* Salaries, taxes, travel, rent, committees/chapters, postage, printing, service contracts, supplies, telephone, capital equipment, materials for sale and miscellaneous expenses (in other words, expenses to operate the organization). The recent "Be An Angel" fund raiser (see next page) was designated to go into the *Operating Fund* in order for the organization to grow rather than operate at the same level. As a member you will be seeing the effects of this growth over the next three years as new projects are undertaken. If any member has a question regarding finances at any time, please feel free to ask. I hope the membership is comfortable that all paid employees and volunteers are very devoted to spending your money wisely and doing our very best to offer you the very best we can.

The Squeaky Wheel

Unfortunately all too frequently Prader-Willi Syndrome Association receives letters from parents who are aging and finding it difficult to continue to care for their adult with Prader-Willi Syndrome. Letters typically state, "Work is endless to take the best care of our Prader-Willi adult in our home. We love him dearly, but the older we get we find it harder to cope. We are now in our seventies, we get completely exhausted and discouraged. Where can we get help?"

We wish our organization could furnish the necessary information to relieve this situation but many times there is nothing to offer in the area where these parents live. Help must be obtained through the "system." That "system" is called different names in different areas, it may be the Department of Human Services, Department of Health, Department of Mental Retardation, or even the Department of Public Welfare, but whatever the name they must be contacted. The "system" assigns a caseworker to work with the parents. When you are not able to get services through this department, you may be forced to "go over their heads" and reach someone at the state level instead of the county level. If that fails too, you may have to go to your local state legislators. It's hard to accept that this must be the only way that parents can get the help they need, but as the saying goes, "The squeaky wheel gets the grease." If you sit quietly by waiting for help it may never come, it is going to be up to you to make it happen. There are also legal aid people, legal advocacy people, and even your local newsletter. You need help - raise the biggest fuss you can, make it impossible for them to ignore you. You are entitled to these services - and you deserve it - go for it.

Genetic engineering

Scientists injected immature donor cells into a foot muscle of a 9-year old boy hoping to prove they have found a way to treat muscular dystrophy by supplying correct genetic information.

The procedure, called myoblast transfer, is being tested by scientists at the University of Tennessee-Memphis facility. One doctor stated, "I think it is the opening salvo to what's going to happen in the 1990s, which I hope is going to be the successful treatment of many genetic disorders." There is hope!

Welcome to our newest Angels

We are happy to report a very successful fund raiser conducted by Prader-Willi Syndrome Association at the end of 1989.

We again thank all of our ***Heavenly Angels:*** Trentacosta, Linonis, Notbohm, Foley, Fuller, Wett, Bintz, Beltran, Kellerman, Carter, Tippie, Bell, Eleazer, Mleczewski, Miller and Alterman.

Thanks to our new ***Arch Angels:*** Chausow, Scheidegger, Schmidt, Mullen, Gulling, Mowrer, Hoffrichter, Gravallese/Margolis, Baron, Moran, Bush, Echols, Deterling, Johnson, Bennett, Smith, Taylor, Jornov, Herrmann, Evetts, Mears, Herman, Persanis, Castle, Means, and McAndrew.

Our newest ***Angels:*** Schmitz, Huether, Rangitsch, Robbins, Noll, Lat, Gross, Rasmussen, Kappler, Balinski, Smith, Ripley, Masterson, Regester, Seal, Whyte & Daly.

And last but not least, our new ***Cherubs:*** Giorgi, Gomez, Daly, LaPenta, Sunde, Steinmann, Reedy, Karlsson, Becker, Gerdes, Storey, Leonard, Gulling, Kandall, Hanrahan, DeMarsh, Schramm, Barret, D'Alessandro, Haney, Raniolo, Gonda, Hanley, Ferraco, Flaccavento, Ulland, Butler, Burdett, Moloney, Cicairos, Anderson, Sturm, Jones, Hetzer, Cornejo, Donnelly, Hartigan, Martin, McCoy, Weinberg, Peters, Echols, Prettyman, Trask, Gruen, Wyka, Lynch, Canova, Evans, Cohen, Umbaugh, Horrigan, Schneider, & Dorn.

With the support of our members, their relatives and friends, we will be able to go forward with our plans to "grow in 1990."

During this period (mid-December, January & the beginning of February) we also received donations from the following members:

RESEARCH FUND: Prouty, Hill, Kirchhoff, Hinson, Shoemaker, Saddock, Miller, Lennhoff, Coca-Cola Rochester, VFW-Krebsbach, Vermeulen, Leonard & Boyd (2). Additional Ingalls memorials: Starkey, Cavigioli, Ingalls (2), Red Door Corp., & Driscoll. Additional Eager Memorials: Eager (3), Anderson, Oman, Padgett, Wiitala, Halstead, Landine, Rosenberg, NW Distr., Johnson, Sturm, Pfeifer & Williams (2). McDougall Memorials: Johnson, Eager, Lutz & Black. Keeton Memorials: Buckner, Keeton, Wilson, Monaghan, Buckley, Rice, Fisher & Trarbaugh. Other Memorials: Reeves (Bush), List (Bliss), Firsco (Anchors), CT Chapter (Andersen) & Leonard (McCourt & O'Brien).

CIT FUND: Trachtenburg, Goff, Lundh, Harris, Paaren, Olson (2), Schaefer (Wett), & Rankin.

CONTRIBUTING DUES: Dillman, Gellatly, Ripley, Sidbury, Wertz, Hicks, Phillips, Schramm, Castelli, Chausow, & Lindsey.

PATRON DUES: Beltran, Mitts, Smith, Plashal, Schermerhorn, Alterman, Goranson, Greenswag, Metzger & Rose.

A child with a handicap is first of all a child -- the handicap is secondary

Over the past 20 years, developmental specialists have changed their views of infants. Now it is widely believed that infants develop through a continuing interaction between their inborn abilities and the stimulation they receive from their environment. The following principles summarize contemporary thinking about infant development, according to Lewis (1984), Hanson (1984), and Anastasiow (1986). While these principles are based on studies of infants without handicaps, we have included them to provide a basis for an understanding of normal development.

1. An infant's capacity to learn is present from birth. Research data from the last 20 years on early childhood development reveal that infants learn, respond, and interact from the moment they are born. Their capabilities and their sensory and cognitive skills are greater and more complex than researchers had thought possible. Even very young infants can process information and respond to it based on their experiences. For example, research and studies by R. Fantz in the 1960s demonstrated that newborns could see and process information and showed signs of visual preferences. When newborns were given a choice between simple and complex visual patterns, they preferred the more complex.

2. Infants learn through social contact. Infants begin their social contact by engaging in soothing bodily contact and eye contact with their parents, and later by smiling and making sounds. Infants like to look at faces and can understand facial expressions and tone of voice. A social smile and cooing are part of an infant's way of communicating and have an important role in social interaction between the parent and child. A large part of early learning takes place through play and other interactions between the parent and child.

3. Infants are active learners. Infants like to have an influence on the people and objects in their environment. Several researchers have demonstrated this principle by giving a group of infants control over what they see while other infants observe the same thing without having that control. In the Watson study, the infants who had control were able to move a mobile which was attached to their arms by a string. In the Siqueland and DeLucia study, infants could change the brightness of a projected picture by sucking a pacifier. In these and similar studies, the infants whose actions made a difference in what they saw were interested for longer periods of time and smiled more than those who can not affect what they saw. Similarly, infants like to produce an effect on people around them. When they make faces, they like someone to make faces in return; when they make sociable sounds, they like responses from those around them.

4. Infants affect their parents, just as parents affect infants. We think of parents as having the primary influence in the parent-infant interaction. More careful observation of play and other social interaction has taught specialists that just as the parent's attention, affection, requests, physical interactions, and warmth trigger a response by the infant, so also, do the child's responses affect the parent. For example, when a baby smiles, the parents smile in return and often talk to the baby. The baby, in response, may coo or gurgle and thrash around, which, in turn, causes the parents to continue the interaction. What is important is that each partner in the parent-child interaction influences the other and sets up a response to the reaction for the other. When interactions between infant and parent are strained and seemingly unrewarding, parents' feelings of self-esteem may be threatened, and a cycle of rejection may result. One author states that even though parents may feel like playing and talking less with their non-responsive infant, it is very important that they play and talk even more than they would if the infant were responsive. Although an infant may have some difficulty interacting with others, he or she may very much want to play and respond, but may not know how or be able to "signal" others to do this. The important point is to "listen to" and watch your infant to find out the unique signals or cues he or she uses to indicate a willingness or readiness to play and respond.

There are various ways parents can interact with an infant who is slow to respond that are mutually pleasurable and rewarding. Siblings, grandparents, and other adults who are comfortable with the baby can initiate and participate in these activities, as well, and should be encouraged to do so. Some of these activities include simple, spontaneous interactions, such as stroking or gently touching the baby; talking or singing in a quiet, soothing voice; or holding and rocking or swaying the baby. These activities can occur during day-to-day interactions, when your baby is being fed, dressed, or bathed. Remember that an infant who is

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A child with a handicap

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slow to respond may need to interact more often and continue the activity longer than other infants. Whenever possible, keep your baby where the action is in your household, rather than secluded in a separate room. Take your baby on as many outings as possible, and with other people, for added stimulation. Try to maintain contact with others to expose yourself and your baby to common, everyday experiences. Although your baby may not be able to participate in the same way the other infants do, try to make his or her everyday experiences as normal as possible. Parents need to respond to a baby with special needs the same way they would to any baby, and should encourage others to do the same. While it may seem that your child is developmentally delayed, it is important to remember individuals vary. Many inborn abilities may not be seen in the first few years of life, but may unfold as time goes on.

As a parent, you can help your child mature and grow by focusing on your child's strengths and worth as a human being and, more importantly, by giving your child what every child needs: acceptance and a sense of belonging to a family and being valued and loved. As much as possible, try to focus on your baby's positive qualities, and concentrate on the potential your child has for experiencing joy, love, and the security of the closeness of his family and those around him. It is also important to keep in mind that you are a valuable and important asset to your child, and that your child's sense of identity originates with you. Your attitude toward your child and yourself is vital to your ability to put the situation in perspective.

It is important that parents confront and manage any negative feelings they may have about themselves and try to rid themselves of any guilt they might feel over their baby's problems. Parents who are able to let themselves experience their infant as a separate being rather than a negative extension of themselves, and who can recognize the unique qualities that make their infant an individual, have begun to take the first steps toward growth and survival as a family. The needs of an infant with handicaps are the same as every child's needs, but there may be more of them. The infant with special needs may require help and attention more often and in different ways than do other infants. Meeting these demands is often difficult for parents to handle alone, and they may need more support and encouragement that those around them can give. Association with people who can share experiences and feelings and empathize rather than sympathize can help. Even if your baby isn't developing normally in every aspect, you will want to strive to make his or her everyday experiences as normal as possible. (Certainly the word child may be substituted for infant in many places in this article.)

Special education tests

Prader-Willi Syndrome Association has frequently heard from parents that not all evaluation tests are appropriate for someone with Prader-Willi Syndrome. Pacer Ctr. is offering a handbook for parents and professionals examining special education tests used by schools to assess children. The book is edited by E. Jean Hosterman, school psychologist and licensed consulting psychologist, helps to understand what kind of assessment their child is being given, qualities the tests evaluate, what else might be appropriate. To Order: Assessment Handbook, Pacer Center, 4826 Chicago Ave. So., Minneapolis, MN 55417; cost $4.00.

Richer lives for kids who are disabled

This title was used by a parent-minister, in a recent paper editorial. He told the story of meeting the parents of one of his child's classmates in a bowling alley, just an ordinary meeting except his daughter is profoundly handicapped and despite her handicap made friends while being mainstreamed into a regular school class. He also stated, "Mothers and fathers of handicapped children are really very normal. We like to take our kids out in public so that the world can see how beautiful and how courageous they are. And we enjoy talking about them with other parents or anyone else who will listen. Moms and dads of disabled children are called upon to be very deeply involved in every phase of their children's lives, and their education in particular. Parents help to establish with teachers goals for their children to accomplish through individual educational plans (IEPs)."

Editorials such as this one reminds us how much progress has been made in the acceptance of "differences."

A matter of (dis)agreement

A parent states that she and her husband do not agree over the needs of their child with Prader-Willi Syndrome. They do not agree with what the future can hold. They do not agree with the effect on the other children in the family. The letter also asked that more information on group homes be included in the newsletter. Answering the above questions, furnishing all that is asked would take more than a whole issue of this newsletter, but a brief answer will be attempted.

Regarding group homes, we do have two specific issues of *The Gathered View* -- the issue for younger children is mailed to homes while the child is under ten; after that age the regular issue is sent. Many articles are repeated in both issues but group home articles usually appear in the older issue only.

Disagreement over the needs of the child, planning for the future, how should the handicap be handled, etc., are very serious issues when the parents do not agree. Counseling and reading are highly recommended before major disagreements affect the marriage. Two books that can be borrowed from our library are *A Difference in the Family, Life with a Disabled Child,* by Helen Featherstone and *Some Just Clap Their Hands, Raising a Handicapped Child,* by Margaret Mantle. These are just two of many books available on the subject. Our own book, *Management of Prader-Willi Syndrome,* edited by Greenswag and Alexander, and *Sometimes I'm Mad, Sometimes I'm Glad...on being a Prader-Willi Family,* also deal with these questions and are aimed specifically at Prader-Willi Syndrome.

Another book, *Living with a Brother or Sister with Special Needs,* a book for sibs, by Meyer, Vadasy and Fewell can also be borrowed from our library. Regular libraries also have many informative books. (This mother stated her reading time was limited because of the family. It may be easier to say than do, but there comes a time when you must rank your necessities.)

What will the future hold for our children? Should parents of a child under the age of 10 be making group home decisions now? Tremendous strides have been made just the past few years in the field of genetics. There is no way anyone can know what the future holds for our children. Can you imagine how needs would change if you eliminated the problems of the compulsive appetite and behavior? As hard as it may be, the old adage "one day at a time" applies, now is not the time for the parents of a young child to be worrying about what respite care may be available for adults and if the adult should remain in the home or a group home found. But it is the time to work out disagreements that pertain to the present. Your happiness and marriage may well depend on handling these problems now.

SSI and the SSA

"There may be hundreds of thousands of low-income, severely disabled children who need SSI but don't get it, largely because the federal rules are unfair and illegal," say the American Medical Association, the American Academy of Pediatrics, and others.

Those groups are challenging the rules in Sullivan v. Zebley, which is about to be decided by the U.S. Supreme Court. If they win, many more disabled children not only will get about $300 a month in cash benefits, but, often more important, they'll get Medicaid-paid health care. A family of four with one wage earner could have an income as high as $22,000 and still have a child qualify for SSI and Medicaid. The heart of the issue is whether the Social Security Administration (SSA) should conduct individualized functional assessments to determine eligibility or continue its current policy of comparing children's impairments to a list of 57 subsets of qualifying disorders. The AMA, AAP, and NORD argue that it's unreasonable to restrict the universe of disabling conditions to 57. NORD has documented more than 5,000 disabling diseases and conditions.

Another bill narrowly failed in the last congressional session which included provisions to require individualized functional assessments of children beyond the medical listings, make children under 4 with genetic disorders presumptively eligible for SSI if it was probable that medical evidence eventually would show impairments, and mandate revision of the impairment listings and criteria to meet current medical standards."

Two drugs recently discussed

From a Sydney, Australia medical paper, Selikowitz, Sunman, Pedergast, and Wright: (Abstract) A double blind study was conducted to determine the effect of fenfluramines (Ponderax) on the weight and behavior of patients with Prader-Willi Syndrome. Fifteen subjects, aged 5-1/2 to 27 years, received the placebo and the active drug, each for a period of 6 weeks. (A double blind study means that half of the patients were given the actual drug while the other half are given a pill that looks exactly like the drug. In the case the "fake pill" contained just lactose. Patients or parents do not know which group they are in.) The dose of fenfluramine varied according to the age of the patient. Treatment with fenfluramine was associated with significant weight loss, improvement in food related behavior, and a decrease in aggressive behavior directed towards others. Skin picking and other self mutilation were unaffected by the drug. None of the subjects suffered from any side effects while taking the drug.

These findings suggest that short term treatment with fenfluramine may have a role in the management of some patients with Prader-Willi Syndrome. It could be used during periods when exposure to large amounts of food cannot be avoided and aggressive behavior is particularly difficult to contain. It may also be useful in those whose lives are threatened by the complication of obesity.

Another drug mentioned recently in connection with Prader-Willi Syndrome, is fluoxethine (Prozac). A few parents have been pleased with the results of this new antidepressant drug, while others have reported no results. One of the differences is that Prozac acts on the brain chemical serotonin, and is designed for long-term use (to elevate both mood and energy levels), while other drugs such as Valium, Librium, Ativan, Xanax, are common anti-anxiety drugs, slowing down the rest of the nervous system and become addictive as well as the patient develops a tolerance (so they no longer work). Another doctor felt Prozac would lose its effect after 6 months to a year. Side effects to Prozac have been reported by one group and the number of adverse reactions listed by the FDA have been relatively high.

One doctor, speaking for a widespread number of physicians who prescribe Prozac with little fear of its side effects stated: "Those of us who prescribe it are responsible for the patient, and nobody would do so, so frequently if he saw these problems cropping up".

Fat substitutes under FDA review

Fat substitutes, Olestra and Simplesse, are under FDA review. Olestra, also known as sucrose polyester, is a calorie-free substitute made from sucrose (sugar) and edible fats and oils. Olestra provides the same taste and cooking properties as full-calorie fats and oils, but contains no cholesterol. It may be substituted for up to 35% of fat in home cooking oils and shortening and for a maximum of 75% of the fat used in commercial frying and snack foods.

Simplesse is a reduced-calorie fat substitute fabricated from natural egg white protein or milk using a patented cooking and blending process known as microparticulation. This process was developed by the Nutra-sweet Company. This product provides the taste and texture of fats with reduced calories and no cholesterol. One gram of Simplesse has 1-1/3 calories compared to 9 in a gram of full-calorie fats. Simplesse may be used in dairy products such as ice cream, butter, sour cream as well as oil-based products such as salad dressings and margarine, but cannot be used in frying or cooking. The status of GRAS (Generally Recognized as Safe) is under review by the FDA.

Chemicals added to foods fall into 4 categories; Food additives, GRAS substances, prior-sanctioned substances and color additives. The category an ingredient falls into determines which regulatory requirements apply.

Volunteers are needed

One of the approved expenditures for some of the Crisis Fund monies is to provide experts to assist in developing group homes, work with group homes in need, train staff, etc. in order that these homes serve our children in the very best way. Up until this time, there has only been two people available out of the national office to offer these services. As many of you know, Dorothy Thompson has been offering her services for many years. Our Director, Marge Wett has also traveled for this purpose. Since these two people will not be available "forever", it was felt other people should be available, maybe living closer also, to meet these needs.

Prader-Willi Syndrome Association, in conjunction with the Oakwood Residence, will conduct an intensive training session for people who feel they would like to learn more about the operation of a good designated Prader-Willi home, and then be willing to share their expertise with others. The first training session is scheduled for April 26th, 27th, & 28th. We are seeking 6-8 volunteers from across the country. Expenses will be paid for the training session, and also paid when the volunteer goes forth when needed by the homes. Since the better airfares are limited, we will need to hear from you right after receiving this newsletter. Further information can also be supplied to you if you need more details before volunteering.

San Diego home

On a recent trip to San Diego, your director was able to spend some time with the treasurer, Bud Bush, meet with staff from the Governor's Council and also visit the home Corte Maria, a designated Prader-Willi home for 6 young adults. It was very enjoyable to meet some of the residents and have an opportunity to talk with the staff.

Summer program

The Institute of Logopedics, Wichita, KS, is offering a special summer program, ages 6-22, 7 week program June 25 to August 10th. Fee is $4500. For further information, 1-800-835-1043.

Response on rumination

In response to your article on rumination, our solution is a piece of candy or some gum. It controls the ruminating and sweetens the breath immediately, especially in close quarters like a car. Also, we take our son to a gastroenterologist for chronic esophageal reflux which aggravates the ruminating. He takes Zantac which reduces the stomach's acid production. Reglan helps the stomach contract and keeps the contents (food) down.

Questionnaires

Prader-Willi Syndrome Association maintains very valuable information from parents in a computer. Since we have many new members since this questionnaire series was completed a few years ago, we would like to add additional participants. After a reorganization of the 7-part survey, we will be mailing a copy to members who did not have an opportunity to be involved. Statistics not only keep us well informed but encourages research. We appreciate your assistance.

A parent shares

A New England Journal article reported on a study conducted by Dr. Franco Salomon of St. Thomas Hospital in London, involving 24 adults who did not produce enough growth hormone. The growth hormone promotes muscle growth, which in turn helps burn calories faster.

Unfortunately, it only works on those deficient in growth hormone, and most reports have stated few people with Prader-Willi are truly deficient. The more muscle a person has, the more calories the body will burn, but a doctor at the Rockefeller University suggested that a person wanting to gain muscle and lose fat would be better off exercising than injecting themselves with this hormone, which can also increase chances of developing diabetes.

Budget crunch

State governments from California to Maine are running on empty this year, forcing legislators to shove social issues into the back seat while they hunt for ways to raise-or save-money. A few states, particularly in the Pacific NW, have managed to avoid fiscal pitfalls but a majority around the country have fallen victim to an unexpected plunge in tax revenues.

AP reports from all 50 state capitols indicate budget problems will be the top issue in more than 20 states this year, and will be among the main issues in most others. Most legislative sessions are in session now.

Potential deficits include $1.5 billion in NY, $500 million in MA, $400 million in CT, $80 million in NH, $67 million in ME, and $30 million in MD.

If any of our members have some input or unique ways on how money is being saved for DD services in their area, you may share them with Prader-Willi Syndrome Association and we in turn can share them with members who are fighting with the legislature to fund services.

Pre-registration for July Conference

The Pre-registration packets for the conference should be in the mail very shortly. If yours does not arrive by the middle of April, please let us know if you need a copy. As always, we are very pleased with the preliminary work accomplished by the conference committee. The Conference will take place in Salt Lake City, Utah, on July 18 (pre-conference day) and July 19-21 (conference days).

A call for papers has gone out for the Scientific Day presentations; the chapter presidents will have a opportunity to meet again as well as group home providers on the pre-conference day. We look forward to hearing from some of our Prader-Willi experts again as well as some new people who have information to share. Sessions will be geared to parents of infants through adulthood. Topics will include education, medical, Prader-Willi first-phase problems, behavior, emotions, family stress, cutting calories, legal aid as well as rap sessions, questions time and all of the other many things offered. A treat for parents will be an opportunity to hear the Mormon Tabernacle Choir practice as well as the usual banquet night.

Not on the agenda but of the utmost importance is your opportunity to meet with other parents and professionals. One of our last year attendees from England wrote: "I did enjoy all the sessions but the best part was meeting and talking to other Prader-Willi people and their families." The committee is also working very hard on formulating a great Youth/Adult Activity Program. New innovations will be tried this year which we are certain the attendees will enjoy.

We are certain everyone will enjoy their stay at the beautiful University Park Conference Center. Help lighten our load - register early!

Conference grants

You still have a couple more weeks to submit a request to be considered for receiving a grant to attend the Salt Lake City conference. $1000 maximum per family will be allotted to two families to help offset their expenses. All you need to do is submit a written request stating why this financial assistance is needed. We will follow up with a phone contact, and those determined to be eligible will be included in a random drawing to be held the end of March.

Summer program

The Rehabilitation Institute of Pittsburgh informs us they continue to have a very active and successful program for person with Prader-Willi Syndrome. This summer they will again have two special programs for children and teenagers: Program I 6/18 to 7/13 for teens, 13-21 and 7/23 to 8/24 for children 6 to 13. They write: " Our goals are to provide an enjoyable experience away from home in a highly structured active program that facilitates weight control/loss, improvement in motor skill and physical stamina, intensive speech-language stimulation and improvement in social skills and adaptive behavior. Parent training in nutrition and behavior management is part of our program as well as a comprehensive parent conference with all members of the team."

Group homes

Some parent groups and areas are fortunate to have new designated Prader-Willi homes opening.

- Delaware - opening soon
- Maryland - opening in the next few months
- New York - second one soon, another within a year
- Illinois - second one soon
- Pennsylvania - one opened, talking of second
- Missouri - working on second
- Indiana - opening soon
- Michigan - talking of 3rd
- California - children's home opening soon

Unfortunately these homes do not just automatically become available, they are usually obtained because many people work for their approval. Prader-Willi Syndrome Association is frequently consulted when placements are made into these homes. Be sure you have your name in our file if you are looking for a placement.

And after all this time, too!

It's hard to believe but it was almost two years ago that Prader-Willi Syndrome Association moved into "a regular office," located at 6490 Excelsior Blvd., E-102, St. Louis Park, MN 55426. The move also necessitated a new phone number, which is (612) 926-1947. Some of our members have continued to use the Malibu address and the former 933 exchange phone number. You have been able to continue reaching us this way because this was the director's home address and phone. In the near future, *HOPEFULLY*, Dick and Marge will have their new home completed and they will be moving. To avoid the delay of forwarded mail, now is the time to jot down the correct address and phone number above.

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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