

THE GATHERED VIEW

Newsletter of PRADER-WILLI SYNDROME ASSOCIATION

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PRESIDENT'S CONFERENCE REPORT

This is the tenth year that this organization has responded to a need defined by Gene Deterling, to exchange knowledge of Prader-Willi Syndrome. However, it is thirteen years since Gene created this organization. Ever since the inception of this group the primary goals have been to increase knowledge of Prader-Willi Syndrome and to maintain a viable organization capable of carrying on that task. Another important goal of this organization was also crafted by Gene with the establishment of the Prader-Willi Syndrome Fund. This recognized our dual goals and assigned their importance from the fiscal standpoint.

Over the past eight years over twenty homes have been created that are designed to meet the specific needs for survival of the Prader-Willi Syndrome person. This represents uncountable hours of donated time and hard work by Prader-Willi Syndrome families and friends. The overall success of these efforts is outstanding. Their success pointed up a need for a center that could serve to solve crisis needs, train specialists in the unique support structure for Prader-Willi Syndrome persons, centralize the management structure of the organization and focus the concerns and products of research in this Syndrome.

Research itself has become an integral part of the annual conference in the form of the scientific sessions. Now in its third year, once again it is supported with the full weight of an academic institution. Professionals recognize this as an appropriate forum for the dissemination of knowledge and query concerning our concern, Prader-Willi Syndrome.

Seen from the viewpoint of one of nine persons who attended the organizational meeting at Dr. Vanja Holms' office in Seattle twelve years ago, these successes seem almost staggering. Our membership now numbers over 1400. The number of chapters has grown to twenty-three. The annual budget calls for an expenditure of eighty thousand dollars. The organizations net worth is over a quarter of one million dollars. These certainly are proud achievements to mark the tenth anniversary of the conferences.

President's (cont.)PWSA

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With growth, however, comes stress. It is quite apparent from review of the operation of the corporation that there are problems to be solved. There is no glaring deficit, but there are weak spots. The most serious problem lies in the organizations total dependence on the ability of the executive director to accomplish her daily duties. In spite of the size of our budget there is no conceivable way that we could currently afford to buy the talent to replace the lady that glues the Prader-Willi Syndrome Association together into its present structure. Some day in the future this task will become mandatory to our survival and planning for it must be accomplished. As a step in this direction the official offices of the organization have moved out of the proverbial "Wett basement" into genuine leased office space, above ground.

Over the past two years another symptom has shown up. Individual members are identifying needs from the organization that they feel are unanswered. I cannot tell you how happy I am to see the symptom of discontent. The medical profession has long recognized that the patient is in the recovery phase before the complaints begin. In the military leaders have been taught that the squad that is without complaint is without spirit. For several years I have been deeply concerned because all of the questions, ideas and drive seemed to be coming from the top with little response back from the roots. The lawn was watered but the grass didn't grow. Committee tasks were assigned and accepted and only a few responded. This years meeting of the committee of Presidents was an excellent record of grass roots effort.

Three years ago was not only the first scientific session but it was the first meeting of the Council of Presidents and the first time anyone registered a real complaint from the floor at the annual meeting. This type of input is what is needed to challenge the leadership. Let me give you a personal anecdote. My daughter, Sarah, was transferred in to the high school this year from a private special education school. She complained that she wasn't getting any English instruction as she had been receiving at the Health Council. This was transmitted to her teacher and she was given an hour with an English resource class. Not only is she learning long new vocabulary lists but is being challenged with written assignments. Last week she came home and exclaimed, "I wrote my final exam in English. I never thought that I would take a course that had a written final exam!"

Challenge is important and controversy can be good. The first step to solving a problem is recognizing that a problem exists. Each of us sees the world just a little differently. If we respond to our world as we see it our solutions will be different from that of our associates. If you see a problem it is your responsibility to clearly identify the nature of that problem and to seek a solution. The complete definition frequently requires the viewpoints of others. Similarly, the correct solution can often be found through the process of group discussion and group thinking. It is with great pleasure then that I give you your tenth anniversary meeting, but with one caveat; When you present your problem, bring with it your solution.

I would like to take a minute now to review some of the changes that have occurred over the past year, the challenges that have been met and some of the challenges that will require your involvement and assistance to achieve.

President's (cont.)

1. The Board of Directors has amended the ByLaws to include the Rights and Responsibilities of the membership at this Annual meeting.

"The rights and responsibilities of the membership at the annual meeting shall consist of discussion, following recognition by the presiding officer, the nomination from the floor of candidates for the Board of Directors and the casting of a written ballot for the following purposes:

- 1) to elect members of the Board of Directors;
- 2) to approve, if necessary, the organizations's auditors;
- 3) to vote on changes to the ByLaws brought before the membership; and
- 4) to vote on motions properly brought for consideration of the membership.

Only those motions submitted and seconded in writing three months prior to the annual meeting will be eligible to be voted upon by the membership at the annual meeting."

2. The Board of Directors in December 1987 provided for a grant that would provide funds for a member to attend this annual meeting. This was implemented and a person was selected.

3. A new textbook titled Management of the Prader-Willi Syndrome was edited by your Board member Louise Greenswag and her associate Randell Alexander. This effort was in part supported by research funds from the Prader-Willi Syndrome Association. There are 50 specially numbered copies for donors who contribute \$1000 to the PWS Association. To date four such donors have come forward.

4. There is a serious need to organize fund raising efforts on a national scale. The operating funds of this organization are below budget and are dependent on the dues from members. In order to avoid any dues increase it is necessary that a concerted effort be made by each of us to expand our membership to all of our Prader-Willi contacts, both relatives and professionals.

A unique opportunity was presented at the Presidents committee to obtain a major, widely known name person to represent our organization. Toni Campoy, president of Quest, the fund raising arm of the California Prader-Willi Foundation under the leadership of Anne Scott, will be seeking such a person through its honorary board. The annual cost of a public relations firm necessary to assure effective exposure of this spokesperson through the TV and broadcast medium is to be determined. It is estimated that for PWSA to benefit from this effort on a national basis it would require about \$3000 each month over a one year period. The chapter presidents encouraged this group to initiate the effort. When sufficient information becomes available it will then become necessary to commit the PWSA through its chapters to support the additional effort necessary to raise this amount of money. You will hear more about this as the program progresses.

5. The Board of directors has modified the ByLaws to recognize the serious threat to Board Members in the current highly litigious society we live in.

President's (cont.)

6. The Board has given approval to a new manual that includes a historical summary of the organization and contains an outline of how the organization works, its current ByLaws and other useful information necessary to the officers, Board members and chapters. It was compiled by Board member Janalee Heineman.

7. As mentioned previously the Association offices have been moved out of the Wett basement. A new telephone number has been added to the old one. The old number will also be carried for one year.

8. There is an additional opportunity to raise money for the Association also brought to us by the California Prader-Willi Foundation. Anne Scott has negotiated with the Maryland Bank National Association to create a Prader-Willi Syndrome Mastercard. This will pay the Association or Foundation one dollar for every person subscribing to a new Gold Mastercard and twenty-five cents for every transaction using this card. It will require a joint effort to subscribe six hundred total new cards under the Association and Foundation names. I plan to get two new cards, one for personal use and one for business use. I encourage every one of you and your associates back home to support this effort. It can prove to be a truly successful fund raiser for PWS needs.

9. I am sure that you have noted the emphasis that this year's conference has placed on meeting the information needs of the new and younger members of the association as well as the older Prader-Willi persons through specialized meetings.

10. Your Board has developed a new program that will provide funds for Prader-Willi persons in crisis need. Up to \$3000 dollars per case can be supplied for an acute crisis need. The funds will come from the interest generated by your donations to the Crisis Intervention Fund. Gene Deterling conceived of this useful way to put your donations to work for crisis situations until such time that it is possible to create the intervention center as originally planned.

Special thanks to Mildred Lacy, the Boss and all the Kentucky chapter for a successful meeting. Plan now for the First Internationally Sponsored PWSA Conference to be held in Calgary, Alberta, Canada in July 1989.

Delfin J. Boltran, MD

President

NOTE:

Clarification on Item #7: (612)926-1947 is our new phone number in our new office. The previous number is the Executive Director's home. Since she cannot be in both places at the same time, please use the new number between the hours of 8:30 - 4:30 CST. The previous number will be retained for one year to not miss calls until the new number is established.

Item #8: We will inform you when negotiations are completed on the Mastercard plan, with full details on how you can participate.

Item #10: A committee of Stewart Maurer, Dorothy Thompson and Gene Deterling will be setting guidelines for the awarding of crisis need's grants. If you have a need, submit your request through the national office and the committee will act upon it.

A committee will also continue work to develop a crisis and intervention program.

The President has shared the major accomplishments of the past twelve months. I would like to mention a few other happenings:

The National office was "there" to put out the six issues of the newsletter, issues
that can be the only information people have when they have just received a diagnosis.
that clear up the misinformation received from well-meaning but uninformed professionals.
that are the only contact some people have with those who understand.
 (many do not have support groups or can attend conferences)

Our newsletter is a written history of what families affected by PWS are living through; a history of those affected now and those who will discover us in the future.

The office was "there "
when many crisis situations arose. If someone couldn't answer a question they could refer you to someone who could or at least listen to the problem.
for others in addition to parents.
 It was not just "there" to send you dues notices, to beg for donations, which unfortunately is necessary to continue operating.

In this past year I have faced the fact many "outsiders" aren't going to rally to our needs. We aren't going to become another Heart or Cancer "biggy". What is going to be accomplished is what "we" do for ourselves.

There are some states or groups who are strong enough to stand on their own. Fortunately, most of them realize "national" is still essential for the best of all people affected by PWS.

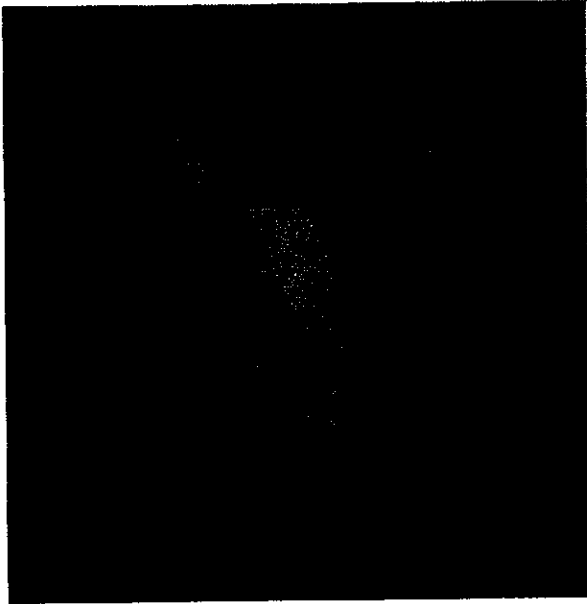
All of this has not been accomplished just this past year -- it has taken many years to develop. I just wanted to take this opportunity to thank all of the people whose loyalty has carried us through another year. (Especially Dorothy Thompson, who has stepped down from the board to make room for growth, but fortunately has not left us.)

Memorial day weekend found Judy and her husband, Loran, Dick and Marge Wett and their children and spouses, Dan & Kathy, Edie & Greg, Tere & Michael, Lisa and Andy, hauling over 50 cartons of files, books and supplies as well as furniture from the Wett's house to our new office -- an office in a medical building attached to a hospital, sublet through the generosity of Dr. Wett's anesthesia partnership. We feel this a giant step forward for PWSA and thank these people for donating these services to make it a move with no expense involved.

Unfortunately, this requires the new phone number (612)926-1947 and the new address, 6490 Excelsior Blvd. E-102, St. Louis Park, MN 55426. We will continue using up our imprinted supplies rather than waste them as mail can still be received at the Malibu address.

Another thanks goes to Judy for giving up a full week to work at the conference again this year. PWSA is fortunate to have people who care: board members, office staff, conference committees, chapter people -- who are all working to benefit all our members.

Marge A. Wett



Hi Marge, it was nice to see you in Chicago. I gave you a picture of me in my prom dress. I go to Kirk Center in Palatine, IL and we had a prom. We had dinner and a D.J. I danced all night long and had a great time.

Love, Annie

MEMBER REQUEST

One of our members has commented that it would be extremely helpful for younger parents if others would share information regarding education.

What programs were your children involved in this past school year? What type of class was available for them?

What worked, what didn't work? Did you have to get involved to obtain services for your child?

PWSA has been asked in the past to make suggestions for I.E.P.'s. This is an impossible task because of the great variance in the ability and functioning level of our children. Parent's sharing experiences may only apply to some children, but is very valuable for those with limited experience with the educational systems.

PWS ASSOCIATION IN SWEDEN

This association reports they produced their first PWS brochure in Swedish and that it has been very well received. Mass orders have been received from doctors, authorities, teachers, parents and others.

Their association has some 47 families as members now, after just two years. They estimate that there are probably some 100 in Sweden. Efforts are being made to locate others and plans are being made to research needs and develop some appropriate educational material.

One study that they are aware of is a DNA study that has just been started.

Their most exciting event of the year was the Nordic expert conference on PWS held in Norway in April. Sweden, Norway, and Denmark sent four experts to give papers. Finland and Iceland sent observers. It was a wonderful opportunity to meet each other, exchange experiences and plan collaboration between our countries for future projects.

The president mentioned they are looking forward to a World Conference.

PWSA (UK) is planning the "Old King Cole Ball" for November 2nd, as a fund raiser for their association. Their aim is to raise £500,000 over a period of 5 years. We certainly wish them well.

November 12th will be the date for their next annual conference, which will be held at Guildford Technical College. The May newsletter had grown to 24 pages with a very new attractive print.

5th ANNUAL CANADIAN CONFERENCE September 24th - 25th, Toronto

Speakers include Drs. Lefeure, Hollan, Bar-Or and Zlotkin. For further information: Pat Eaton (613) 727-5104; or Janet Slater (416) 624-3967.

ACTION TIME

In November, 1987 the Development Disabilities (D.D.) program bill was reauthorized by the President. Due to a great amount of lobbying by the United Cerebral Palsy group in Washington, it was mandated that the National Association D.D. Council develop a survey (basically a Consumer Satisfaction Survey) to particularly reach the un-served and the under-served D.D. population. Through the state planning councils, the D.D. Center at Temple University developed a survey that was shared throughout the country and the final draft of the instrument was due to be completed the week of June 19th. It was determined that 300 volunteers would be sought in each state to answer the survey to seek information on services. Some states will not be using the set survey but developing their own to obtain the information.

It was suggested by a NY member that PWSA become involved (to raise the awareness of PWS). What can you do? Call your own state's D.D. council and volunteer to be one of the 300 persons in your state to fill out this survey. If you can't locate your D.D. council, drop us a line, we will be happy to help you find them. This is another opportunity for us to stand up and be counted - do it today before you forget.

A CANADIAN MEMBER SHARED:

Some airlines recognize that some handicapped people are not capable of traveling alone and have offered a half fare rate for the person accompanying them. It's worth looking into if you need to travel to a medical appointment or next year's conference.

The Journal of International Research into Developmental Handicaps is having a call for papers. For further information, contact: Geoffrey Willott, 620 Hunterston Cres., Calgary, Alberta, Canada T2K 4N2.

SHARING THROUGH THE MAILS

After getting a second opinion, our daughter is wearing a Boston brace rather than a Milwaukee brace for her scoliosis. (It's easier to wear.) She's doing great - check all options.

Our son was diagnosed at the age of two. Following 5½ years full of medical appointments, testing, pre-school, etc., his first year of regular school found him the square peg in the round hole. The school is taking the extra effort to determine exactly which program is appropriate for him. If I can give any parents any advice, it would be to just become aware of their rights in education as our children are special and do deserve the best they can possible get.

Our son does have a weight problem, he manages to find food in the most bizarre places. The temper is another area we are having problems but fortunatley it does embarass him so he does try to control it.

I enjoy the GV, there is always something new to me in each issue. I really appreciate the recipes that are shared. I particularly need help getting through the holidays.

Our son was diagnosed at 22 months. We were first told that he had cerebral palsy. He started physical therapy at 6 months, sat at 11 months, rolled everywhere until 21 months, then had enough strength to crawl and walked a short time later. He just turned three and is in a head start pre-school. His speed is almost up to his age, his gross motor is up there except for the lack of strength. He is in tap dancing lessons and loves it. He is 34" tall and only weighs 24 lbs. We really watch his diet and feel fortunate we found out at a young age. He is very personable and adorable and we are very proud of him and his 6 year old sister who helps stimulate him.

MAY & JUNE DONORS WILL BE THANKED IN THE NEXT ISSUE. WE DO APPRECIATE YOUR CONTINUED SUPPORT.

"THE BOOK" that we have been waiting for has been promised for delivery mid-July. We are pleased to be able to offer this to you, and at such a reasonable price, due to the generosity of the editors and contributors. You may use the form below, and shipment will be made as soon as available.

A practical and relevant handbook...

Management of Prader-Willi Syndrome

Edited by
Louise R. Greenswag and Randell C. Alexander,
 The University of Iowa, Iowa City, IA

This comprehensive sourcebook on Prader-Willi Syndrome discusses the characteristics, etiology and diagnosis of the syndrome and offers practical, common sense guidelines for management. Its chapters are written by professionals in many different health and allied specialties, who provide an interdisciplinary perspective on clinical, social, familial, and community issues relating to care.

Health and education specialists in academic, clinical, and community settings will find **Management of Prader-Willi Syndrome** an indispensable source for information about the syndrome and for pragmatic management strategies.

From the foreword by Hans Zellweger: "The book gives useful directions to all of those involved in the care of children and adults with PWS; not least to the parents. It may not only help to provide a sophisticated treatment program for PWS, it may also help to get the specialists closer together in a collaborative effort to help PWS individuals and their families carry their lot."

Contents:

Preface, D.J. Beltran. Foreword, H. Zellweger. Introduction, L.R. Greenswag, R.C. Alexander.

Physiologic and Genetic Considerations
 Prader-Willi Syndrome: An Overview, R.C. Alexander, J.C. Hanson. Differential Diagnosis, H. Zellweger. Hypogonadism and Oligospermia, K. Rubin, S.B. Cassidy. Genetic Counseling Issues, E.R. Thomson.

A Case Presentation

A Chronology of Hope, J. Sherman, G. Eric

The Interdisciplinary Process

A Team Approach to Case Management, L.R. Greenswag, R.C. Alexander. Medical and Nursing Interventions, R.C. Alexander, L.R. Greenswag. Dental Manifestations and Treatment, A.J. Nusuk. Nutritional Management, D.E. Downing. Psychological and Behavioral Issues, S.B. Sulzbacher. Educational Concerns,

M.H. Lupi. Speech and Language Development, J.H. Munson-Davis. Physical Therapy and Occupational Therapy, M.D. Minor, T. Carr. Vocational Concepts, J.T. Inwood. The Role of the Social Worker, J.F. Porter.

The Socialization Process

Social Skills Training, W.B. Mitchell. Understanding Psychosexuality, L.R. Greenswag. A Parent's Point of View, J. Tomaszewski-Heinemann.

Delivery of Services

Advocacy Services, R. Newbert. Residential Planning, D.G. Thompson, L.R. Greenswag, R. Eleazer. Parent Support: The Prader-Willi Syndrome Association. Glossary of Terms. Suggested Bibliography. Appendices. Index.

1988/approx. 312 pp., 35 figs./cloth

Order form

Please send me _____ copy(ies) of *Management of Prader-Willi Syndrome*, Greenswag, Alexander, eds.

_____ \$27.50 for members of the Prader-Willi Syndrome Association

_____ \$32.00 for nonmembers

Prices include postage and handling. Payment must accompany order.

Send to:

Name _____

Address _____

City/State/Zip _____

Return to: **Prader-Willi Syndrome Assoc.**

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NATIONAL CONFERENCE

Another conference has concluded, that can be a happy time for those involved in all of the planning and execution and a sad time for those who wished it could have gone on for another week at least. The tapes are being listened to, and pertinent information will be shared in the GV as well as available in typed papers in the future. Forty-four parents, 12 professionals and 6 relatives returned our evaluation forms and from these and remarks made at the meeting we can conclude the conference was a big success. Comments, such as "Excellent, well-planned and well-executed conference", "Smooth flowing, lots of good time for conversations", "Met wonderful people, very informative. The hard work that was put forth was shown by excellent presentors and workshops", are examples of what was shared. One parent wrote, "We attended our first conference this year and really benefitted from it. We had never talked with any other parents and it was so reassuring to learn our young daughter was not any different from others her age."

Some questions that were presented to a medical panel included:

In answer to a question relating to Ritalin treatment, one doctor stated, "It is well recognized now that children who were treated for attention deficit and hyperactivity, that there are a couple of serious side effects in the use of Ritalin. #1: psychosis has been described; #2: the potential, on a long term usage, to cause depression; #3: potential growth deceleration; #4: motor jerks (tics) may have been predisposed and just started earlier by the medication.

What has been the experiences of the use of anti-depressants with PWS? "There are some people with PWS that truly have depression. Some times they will respond to any drug used as an anti-depressant. A study last year stated there were few cases of depression in PWS. I, personally, have not heard of any one drug that worked more effectively or of any that did not work."

One parent recommended that we should all be careful about using sedatives with our children as her daughter had a severe reaction to Vallum.

One parent questioned the use of testosterone. One doctor stated she felt treatment was controversial because there is little good data to support conclusions on either side but she did recommend it for the following reasons: Treatment in the 12-14 year age mimics puberty. Testosterone will help develop body hair, enlarge the penis, masculine the appearance and make the child appear more "normal". Testosterone helps put calories into muscles rather than into fat. The more active the child becomes, the more likely weight control can be achieved. Treatment has to be balanced against the potential problems relating to behavior. Monitoring should be done so behavior changes will be noted. (The comment was made that it was her opinion PWSA was against testosterone from articles she had read in the GV. This may have stemmed from articles regarding surgery to bring down the testes. PWSA has never taken a stand on estrogen/testosterone treatment because there is not enough information available.)

One doctor stated she has 10 males, ranging in age from 12-40 and she has not seen any sexual acting out with testosterone treatment.

Cosmetic surgery for breast tissue removal in the male was questioned. One doctor has heard of two cases of surgery; two parents reported their sons had benefitted psychologically. No negative effects were reported.

One parent questioned leaking of urine in her 29 year old obese son. Doctors suggested constipation may cause pressure on bladder, as well as obesity causing this. They did not feel any difficulty with the syndrome would cause the problem.

QUESTIONS (cont.)

One parent commented on the use of "Silvadene" successfully on picked areas but doctors were reluctant to prescribe. One doctor said silvadene facilitates new skin growth so it would make sense to use it. He could only guess the reluctance was "mindset" as this drug is used for burns and clearly there are situations where a drug can be used in more than one situation. Another parent had been told to use it for 2-3 days and then discontinue for a week or so as skin darkens. Another doctor thanked the parents for sharing and said if enough doctors tried it it could be put into the literature to make it easier to obtain. (A parent commented that she was frustrated because she had mentioned this to national several times and they had "done nothing about it." We would like our readers to know when information is shared by parents we do welcome the opportunity to pass it on. Since picking is a great problem to many, we can't imagine how something like this got by us "several times".)

Another parent suggested covering the sores with "Duoderm" patches, as she found this effective. A short discussion was held on whether the skin picking was actually caused by irritation or by brain dysfunction. No conclusions were drawn.

A parent questioned the use of drugs instead of proper behavior management treatment. He requested something in writing from people who were acquainted with PWS to assist parents in refusing drugs in group homes. Until an organized drug control study has been done, it is difficult to say anything in the literature without being inflammatory or ridiculed for reporting an uncontrolled study. There are rules and protocol about what will be published. Some medications work for some people, some short treatment helps people retain their placement in a group home. The trick is to use it and then get rid of it rather than continue chemical restraint. It is very important to first try non-chemical treatment, individualized programs.

A parent questioned diagnosis on basis of chromosome deletion. Doctor response, deletion is not a sure correlation of PWS. Certainly with the deletion the patient is followed closely. In the Scientific session Angelman syndrome, which has a similar deletion was discussed. PWS and AS usually have distinct and distinguishing clinical features, but both syndromes have been shown to have similar chromosome 15q12 deletions. Though some features overlap, many symptoms of AS are very unlike PWS, i.e. lack of speech, seizures, unprovoked laughter, stiffened legs, lumbar lordosis, uplifted arms. The doctor also questioned where the chromosome testing had been done because some people have not had much experience with it. Another doctor stated you still need the clinical features of PWS for a diagnosis.

Seizures were questioned. One doctor stated the statistics show 15%. (balance of statement was not understandable). One parent reported her daughter started having seizures at age 16 and she was the only one at the clinic in Chicago with seizures. (It may also be noted we do have some reports of lack of speech in some of the younger children, but this is rare.)

One doctor reported that even if a chromosome abnormality may not be present in a cytogenetic study, it may be detectable by using molecular genetics techniques. Even though this work is rather young, it does look promising.

Upon questioning, one doctor recommended calcium supplements for adolescent females to prevent osteoporosis.

SEXUAL DEVELOPMENT

Questions are frequently asked regarding sexual development in our children. One mother recently asked for assistance because the residence where her daughter lived insisted on putting her on birth control pills and they had given her medical complications in the past. She could not get a doctor to sign a statement that she could not get pregnant. In this "suing world" people are forced to be cautious. The statement can be made that our knowledge no girl/boy with PW has been reported to be fertile, but what would happen if someone made that statement as fact and then the person (who did not truly have PWS) became pregnant or fathered a child?

We have been informed that boys have emissions but the emissions do not contain sperm. It has also been reported that boys do masturbate but naturally we do not know if this is for sexual gratification. It is our belief that many things occur socially rather than sexually. One doctor reported his 17-year old male patient with PW was having sexual intercourse on the average of twice a week. We asked where this information came from and he stated the boy had told him and that made it a fact. Unfortunately, many of us have witnessed our young people attempting to be "normal" by repeating things that have happened to others as something of their own.

INSERVICE IN CHICAGO

Michael Reese Hospital, Chicago, is planning on hosting an inservice for multi-disciplines on PWS in October. More information will be available at a later date. Contact Grayce Seidenberg for more details.

MEMBER ASKS

Please inform your members that PWSA is a non-profit, 501C-3 corporation so they will know this when they approach an attorney to place this organization in their will.

This is also true for tax deductibility.

Many organizations survive only because of donations. This is true of PWSA, we need to be remembered.

SEXUAL EDUCATION

Naturally, sexual education is just as important for our children as it is with others, but some parents have found this a difficult area for their children to grasp. Sexual discussions seem to fall in the area of abstract thinking - making it difficult to assimilate and retain. It is very important for your child to be aware of the possibility of sexual abuse. Parents have reported camping experiences, one of exposure and one of touching. Other times could present themselves although our children are fairly sheltered.

One girl was involved in a discussion on menstruation, came downstairs later (during a parent's dinner party) minus any clothes, and asked, "What was the name of that pad that is used for menstruating?" Another girl, 22, insisted that she was pregnant although she knew what was required for that to happen and had not had intercourse.

Child sexual abuse, primarily from known parties now numbers 1.6 million - do not neglect this part of your child's education.

ANOTHER PROBLEM AREA

Temperature regulation has been mentioned as one PW problem. Unexplained fevers have been reported, frequently the cause is never found. The young people can wear very warm clothing in heat, or very little in extreme cold, and not appear to be uncomfortable. One parent questioned a doctor for suggestions on keeping her "overheated" daughter cooler in hot weather. The doctor suggested the wearing of a light T-shirt which could be "watered down" with a spray type cleaning bottle containing water. This mother commented her daughter lost all interest in doing anything when she was warm.

CONGRATULATIONS !

Stewart Maurer and Louise Greenswag were returned to the board for another three year term by the election at the conference. Two new board members were added: Penny Park, Oklahoma City, OK and Barbara Whitman, St. Louis, MO. As the President stated, voting was extremely difficult because such a great slate of candidates were available. Any of the nominated people would have made a very good addition to the board.

We are also happy to announce the winners of the fund raiser to help offset conference costs. The winners were Margaret Trentacosta of Fraser, MI, Troy Toby of Gilbertsville, KY and Neil Mellesmoen of Royal Oak, MI. All three winners made donations to PWSA after their big winnings.

Because of the longer-than-usual President's message, this issue is being sent to all members this month. The conference always renews our knowledge that this is a two-phase syndrome and the needs of younger parents are different. We need more information to share with younger parents ⁴ help us out, share your problems, experiences, and solutions so we can build a better "for the younger set" GV.

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