



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.

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, issuesthat 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, Holland, 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:

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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.

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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."

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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 Osteoporosis, K. Rubin, S.B. Cassidy. Genetic Counseling Issues, E.R. Thomson.

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

The Interdisciplinary Process

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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

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Prices include postage and handling. Payment must accompany order.

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