



THE GATHERED VIEW

Newsletter of PRADER-WILLI SYNDROME ASSOCIATION

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PRESIDENT'S MESSAGE

What is "appropriate education"? One of my favorite words is appropriate and as a parent, education is one of my greatest concerns. Education is many things but one of the most important is freedom. I remember being told by my father that I should take every opportunity to learn, to get an education, "whatever you learn can never be taken away from you, you may lose it, you may have things stolen, you may give knowledge to another, education will open doors that would otherwise forever remain closed, education will let you decide."

But how is it determined that a particular situation is the appropriate setting for the education of a particular individual? Testing, is the first response of many. But who selects the test, who administers the test, who interprets the test, who controls the test environment, what if the child is having an off day, what if the examiner is having an off day???? More questions. Some might say that only a skilled, experienced, professional can make a valid judgement, that testing is inadequate or invalid, or not appropriate, or just plain unavailable. Most would agree that no matter how great the situation, the task is not simple. Several months ago I had the opportunity to attend a conference on computer games and human development. One of the concepts I heard voiced was the unique potential of a computer to become involved in evaluating the level of educational achievement or learning impairment that might exist at a point in time with a given child. Wouldn't it be wonderful to have programming that could not only lure the student into a learning environment that would produce such a high level of motivation toward learning language techniques and arithmetic/mathematical skill that the child might not even realize that the fun they had was learning? What if they were able to become so self-motivated toward learning that they attacked learning with the same energy that we sometimes see devoted to MS PAC-MAN or FROGGER? What if, at the same time, that knowledge or learning techniques or communication skills or social skills were being learned, that the teaching machine would be able to compare progress from information stored about the student from prior encounters? Wouldn't it be wonderful if the machine could relate the skills used or the level of success achieved using a particular skill as compared to prior experience of the individual as sensed in similar situations? Wouldn't it be wonderful if all this feedback could cause the machine to select alternate courses that could be tested for greater appropriateness?

This past week, I learned of a strange encounter that caused me to think about appropriate education. Sarah, who is my 11 year-old Prader-Willi daughter, attends a special school. On alternate Thursdays, the children go either to swimming at an indoor pool used for rehabilitation of the neurologically handicapped person, or to vaulting. I observed her class in vaulting. I was amazed, 43" tall Sarah was in a class aimed at teaching her to make a leap from the ground onto the back of a moving

GUARDIANSHIP (TO BE OR NOT TO BE, THAT IS THE QUESTION)

Parents have questioned the need to legally go through the process of guardianship or conservatorship for their child with PWS. There are also less restrictive alternatives, such as "Informal Supervision or Protection", "Assistance from Social Service Agencies", "Appointment of Representatives Payee", "Establishment of a Trust", or "Establishment of a Joint Bank Account". This leaves the task of the parent determining what are the needs of their child and what are the possibilities of future change of needs.

From state to state, regulations vary. In the State of Minnesota a person reaches "adulthood" and is presumed to be "competent" at the age of 18. This means that a person is legally capable of exercising certain rights, such as the right to vote, marry, and contract, and his/her parents lose the legal power to control and make decisions for him/her.

The question of control comes into focus in the case of a person with PWS living in a situation with food control. You, as a parent, have determined this as the proper placement for your child. Your child, as an adult, may determine he/she prefers to live independently. Thus far we do not have any reports of these young people achieving independence and weight control successfully for a period of time. You have to determine if you want to allow your child to make the mistake that could literally cost him/her their life. The refusal of recommended medical treatment could also enter the picture.

Determination of the need for guardianship focuses on the person's behavior or functioning ability. I.Q. is an inadequate determinant. If a person's behavior demonstrates that he/she is unable to provide for their own needs, recognition of a need for a guardian or conservator may be necessary. Certainly if the child is mentally retarded the court process is less complicated, but guardianship can be achieved for higher functioning children.

A "guardian" is a person who has the legal authority and duty to care for the person and/or property of another (the ward), who, because of minority or disability is unable to exercise such care. A "conservator" is similar to a guardian in that the conservator has the legal authority and duty to care for another's person and/or property; however, a conservator's powers are generally not as broad as a guardian's, and the conservatee retains more rights than a ward, such as the right to vote and marry. Other alternatives involve providing assistance in various areas such as care, money management, but do not have any legal control.

Many chapters have had speakers share information on their state's requirements and regulations. We highly recommend finding out about this situation if your child is of legal age, or closely approaching this age. If you cannot afford an attorney, legal aid can be obtained without cost.

OAKWOOD TAPE

PWA of MN and PWSA, with funding from Edina High School, have completed a 36 minute video tape presentation of Oakwood Residence. The tape includes interviews with some of the key people that opened the residence, some of the staff and some of the residents. Viewing this tape could be particularly useful for groups interested in starting their own residences or existing residences seeking more information about the syndrome. The tape is available in VHS $\frac{1}{2}$ " and also in the $\frac{3}{4}$ " size. We would be happy to share this tape with others for a donation to cover the cost of packing and mailing.

TRAVELING

As representatives of the National Office, Dick and Marge Wett were able to make a swing east recently and meet personally with more PWSA members. They attended the Tri-State chapter's fall meeting in Mentor, OH and were able to participate in a panel as well as enjoy the other speakers that included Drs. Robert Danish and Robert Blinker of Cleveland Metro General. Co-chairpeople Marge Henderson and Peggy Ott were very pleased with the large attendance at this meeting.

A couple of days later in Rochester, NY, thanks to Volena Howe and Beth Rivers for arranging, the Wetts' met with a few members from the Upstate NY area, as well as making a call the next day on an 88 year-old mother and her 67 year-old daughter who has Prader-Willi. The mother, who has a remarkable memory, shared very interesting background information on her daughter, who she still cares for, in their apartment. It was also amazing to note so many of the same characteristics in the daughter that are so familiar in so many of our children.

The Wetts' then traveled on to Boston where they were able to visit Children's Hospital's Developmental Evaluation Clinic and meet with psychologists William Mitchell and Jim Bowman, as well as Margaret Van Gilder and Roseann Howard. It is very rewarding to meet professionals who are very dedicated to assisting families in the care of their children with this syndrome. An evening meeting of the Prader-Willi Association of New England chapter was arranged by new president Evans Tsoules. A particular thank you is extended to Bob Huffman for transporting the Wetts' from downtown Boston (which is no small feat during rush hour) to his suburban home for a lovely dinner prepared by his wife, Jackie, and Amanda Kavanaugh, and giving them a chance to meet with their chapter. A greater percentage of the meeting was donated to sharing information about group residences, which of course is a great concern of many of us.

1984 CALENDARS

As the 1983 kitchen calendar is replaced with the new 1984 one, be sure to add the dates of JUNE 21, 22, 23 as the time of the 6th Annual National Conference, to be held at the Thunderbird Motel in Minneapolis, MN.

The steering committee has already had their first meeting with the chef of the motel to furnish low calorie buffets for breakfast and lunch. The low cost of \$48. a day for the room (no charge for extra people) is also very appealing. Arrangements are also being made in order that all attendees may tour Oakwood Residence (the MN PW home).

Ask any member who has attended any of the previous national conferences--this experience can't be duplicated!!! Reserve the time now for a MN vacation this coming summer.

1983 CONFERENCE PAPERS

After many months of transcribing and typing, the copies of the 1983 Conference presentations are now available for purchase. Due to the number of pages (81 actually), we have divided them into two sets. Set #1 includes medical, educational, research, intervention, and sibling presentations. Set #2 includes nutrition, psychotherapy and residence presentations.

You may order either set for \$2.50 or the complete set for \$5.00. ^{US} We highly recommend this as a review for those who attended or a great amount of knowledge for those who were unable to attend. Send your order to the national office.

For your convenience, we have included an order form for our latest publications. If the mailing address is on the label below, enclose the whole sheet and do not bother to rewrite "order from" section:

_____ Annotated Bibliography \$2.00 (Overseas add \$1. for postage)

_____ 1983 Conference Papers (Information on page 11)
\$5.00 U.S., \$6.00 Canadian funds, \$8.00 Overseas for complete papers.

(If one set is desired, specify which set and half price.)

_____ Prader-Willi and You For persons with PWS, deals with feelings, diet, & activities. (Recommended for all ages.)

Order and check to: PWSA 5515 MALIBU DRIVE EDINA, MN 55436

Order from: _____

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