

Gathered View

May - June 1992

Volume XVII
Edition 3

National Newsletter of the Prader-Willi Syndrome Association

On the Issue of Independence

The National office has been very involved with opening designated homes to serve PWS and many successful placements have been documented. However, national has very little documentation on the alternatives to designated group homes. Parents of adult-aged persons with PWS are very interested in obtaining this information, and being in contact with other parents whose PW adults have experienced alternative living situations.

Please send National the following:

1) The vital statistics of the PW individual. (name, age, sex, height, weight, interests, and activities)

2) Describe an average day in the life of the individual, and the type of placement.

3) Describe your requirements for a successful or unsuccessful placement. (Living on their own, maintaining weight, social life, costs, staff/supervisory care, community integration, and family involvement)

4) Provide a history of the placement. (When it began, supervision and for how many hours each day, any previous placements, number of aides and turnover rate)

5) Who suggested the placement? (A social service caseworker, your PW child, you as parents/guardians)

6) Please indicate if you are willing to have your name and address shared with these other parents.

What are Waivered Services?

States throughout the country receive waived funds by applying to the Federal Government. These funds were originally designed to provide services in family homes, thus allowing an individual to remain living at home in a least restrictive environment. The waived services do vary slightly from state to state, but these are the main ones.

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Case Management

This service is responsible for locating, coordinating, and monitoring social, habilitative, medical and other services to meet the needs of persons with mental retardation or a related condition and their families. This includes: assessing a person's needs and strengths, screening, developing individual service plans, arranging, analyzing and coordinating services, monitoring and evaluating the person's progress and service outcomes, and assuring that the rights of the person with mental retardation or a related condition are protected.

In-home Family Supports

Services include training of the person and/or family members in areas such as: behavioral needs, therapeutic activities, personal development, medically related services, and assistance to the family in dealing with supervision, monitoring, and stress management.

Respite Care

Short-term care designed to give the primary caregiver relief from the physical care of the individual. This service may be provided in the individual's home or in an out-of-home setting approved by the

county. This may range from one hour to 24 hours or more. There is typically a limit on the number of hours provided for respite care in any fiscal year.

Supported Employment Services

Employment of an individual who experiences a disability or disabilities severe enough to require ongoing training and support in order to retain and maintain employment in a position in which: the individual engages in paid employment in an existing business, industrial or other setting where persons without disabilities are also employed; public funds are necessary for the purpose of providing ongoing training and support services throughout the employment period; the individual will have social interactions in the work environment with individuals who do not have disabilities and who are not paid caregivers; and: adults who are eligible for waived services and were discharged from an ICF/MR facility; persons for whom supported employment services have been authorized by the case manager as part of an Individual Service/Habilitation Plan; persons who are not eligible for supported employment services from a vocational rehabilitation program under the Rehabilitation Act of 1973.

(continued on p.12)

Briefly on Prozac

The last issue of the newsletter contained a brief Quiz on Prozac. We received twenty-nine responses to our Prozac quiz. (If you still have it and haven't filled out please do so)

Here is a breakdown of that data:

- * Average age of person on prozac was 19
- * Average length of time taken was 8.5 months
- * Average Current Dose 19 mg/day
- * Average Maximum Dose 25 mg/day

Of those responding, 20 were Male, 9 Females; 15 lived at home, 9 in Group homes, and 5 in other facilities.

When asked if the individual was still taking the Prozac only 6 had not continued its use.

The primary reasons for beginning Prozac use were depression, acting-out behaviors, and temper tantrums.

Side-effects reported by seven respondents included excessive sleepiness and changes in sleep patterns.

Overall the comments were very positive:

Here were some of them:

"Prozac is a wonder drug for this individual"

"Never thought we'd be saying this, but Prozac made a desperate situation, liveable, bearable, and wonderful"

"Things seemed to be better, but it is so hard to tell whether it is the medication or how we are handling the behaviors right now"

"It has made a big difference in our daughter's life and consequently in ours"

Two respondents indicated they believe behavior was worse after starting Prozac.

Five indicated they didn't seem to think it made any difference.

There have been many questions and certainly a lot of media coverage regarding Prozac, primarily due to the efforts of Christian Scientist who oppose all medication for psychiatric purposes.

Many parents also have apprehensions about medications especially for teenage and younger.

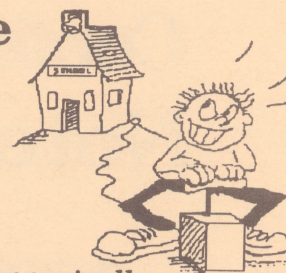
In the general population, approximately three million americans have taken Prozac. Ten to twenty percent have reported some headaches, anxiety, insomnia, and a decrease in appetite or weight loss.

The reasons why Prozac is widely prescribed: it is less toxic, fewer side-effects, and non-addictive.

On the caution side, anti-depressants do have a capacity to flip people into mania [the up stage of depression] if depression is not truly the difficulty.

More information regarding the use of psychotropic medications will be presented at the conference.

Got Those Brown-Bagging Blues?



Schools do not typically advertise the fact that they can supply your child with a special reduced calorie lunch. School meal programs are administered at the federal level by the United States Department of Agriculture (USDA). USDA reimburses schools for every meal served. Under USDA's Section 504 and child nutrition regulations, schools participating in federal meal programs are required to make a reasonable effort to provide, *at no extra charge*, special meals to students whose diets are restricted due to their disabilities [7 CFR Section 15b.26(d)(1)].

In order to be eligible for modified meals, a student must present a statement signed by a physician. The statement should include:

(a) A description of Prader-Willi syndrome, including the need for dietary restrictions to prevent morbid obesity; (b) the food(s) that should be omitted from your child's diet; (c) the caloric count you would like maintained, and the foods which would be acceptable to maintain it. [7 CFR Section 210.10(i)(1) and 220.8(f)].

The most effective way of getting special lunches for your child is to include it in your child's IEP, and notify the principal of your request.

Conference Notes

The PA Chapter will be holding a raffle at this year's conference, grand prize to be the print shown below. The print was donated by the award winning P. Buckley Moss of Warren, OH. Ms. Moss is dyslexic and in addition to painting has presented to special education teachers. Many of her paintings are donated to charities by the P. Buckley Moss Society. The framing of this print is being donated by Whispering Woods Gallery in Holand, PA.

Registrations are coming in slowly, we encourage everyone to register soon. Remember your hotel reservations must be made by July 1st, to assure you the special conference room rate which also allows up to four persons in the room at no additional charge. Every year the conference provides such wonderful opportunities for education, new tips and techniques, and most of all, having dinner with another family that understands why you are taking the french fries from your child's plate.

Hope to see you all in Philadelphia!



Espanol Anyone?

As our membership continues to grow worldwide, there is an ever increasing demand for materials in foreign languages.

If you know someone **who is fluent in a foreign language** and would be willing to take on a translating project, please let us know.

We especially need materials in Spanish and Italian. Call 1-800-926-4797.

A New Brochure

Do you have a neighbor who keeps giving your child with PWS an afternoon snack?

Do you have relatives who visit and get upset when the candy in their suitcase disappears?

Do others at school constantly annoy your teenage son? Would you like to educate their parents so their children can be taught to respect differences in others?

Have you ever looked for something to simply describe to your friends and neighbors what exactly is PWS?

Now there is a brochure which can help you do this. *Someone You Know has PWS* is the title, they are available for 10 cents each through the National Office.

A New Card for You and New Support for PWSA

In the January/February GV we mentioned the MBNA company would be sending you a mailing on a new credit card which would give royalties to PWSA for every new card issued and for every time the card is used. For unforeseen reasons what we thought was going to happen in February, took place the end of April.

PWSA hopes all of you will participate in this program. You can encourage your company and friends to sign up for a card too. Other notable features of the PWSA Gold or Silver MasterCard includes a competitive Annual Percentage Rate. Enjoy the advantages of using your PWSA Gold or Silver MasterCard without risk. The card is issued free of its \$40 (Gold) \$20 (Silver) annual fee for the first year. Extensive travel benefits and services also accompany the card: GoldPassage Travel Service; MasterAssist; MasterRental, a Supplemental Auto Rental Collision/Loss Damage Insurance Program; up to \$1,000,000 Common Carrier Travel Accident Insurance*; Supplemental Lost Check Luggage Protection and cash advance availability around the world through participating branches and Cirrus machines. In addition, Premium Access Checks are available for your convenience.

MBNA America is one of the world's leading issuers of the Gold or Silver MasterCard. Their commitment to customers' needs provides its clients with 24-hour, year-round Customer Satisfaction, one-hour processing for credit line increase requests, a lost card registration service, and an emergency replacement card service.

Please encourage your family, friends, business associates, neighbors, and even strangers to sign up for this special card and help PWSA(USA).

If you have not received the mailing or would like additional applications call 1-800-847-7378 ext. 5000

MBNA America, GoldPassage, and Premium Access Checks are federally registered Service Marks of MBNA American Bank, N.A. The account is issued and administered by MBNA American Bank, N.A. MasterCard is federally registered Service Mark of MasterCard International, Inc., used pursuant to license. *Certain restrictions apply to these benefits. The summary of credit card benefits accompanying the credit Premium Access Checks describe coverage items, conditions and limitations.

Donations as memorials or for other special occasions are essential to the ongoing operations of PWSA. Next time you'd like to acknowledge someone special, have PWSA send them a card. All you have to do is send us your check with the address of the individual to be acknowledged and we will do the rest.

Enclosed is my gift

☐ in memory of:

☐ in honor of:

I would like my contribution:

- ☐ To be used wherever needed
- ☐ To support research efforts
- ☐ To support Crisis and Training efforts

Please acknowledge:

Address:

President's Message

by Janalee Tomaseski-Heinemann

Recently, while listening to an appeal to the Productive Living Board of St. Louis County by parents regarding their concern about the very specialized services their children needed, I heard statements such as, "When our children are young, seeing older children with this disability is too painful"... and, "Jeffery is always finding a new and innovative way to destroy our lives"... and, "Most service providers really do not understand our children's unique needs and cannot handle their behavior problems."

I've heard these statements many times before, but the interesting aspect was that these were not Prader-Willi parents, they were the parents of children with autism. I wrote in the last newsletter how I was struck with the similarity of PW issues from nation to nation. This meeting brought home the parallelism between our children with PWS, autism, and perhaps other brain damaged children.

I remember when the movie, Rain Man, (starring Dustin Hoffman as an adult with autism) also brought home these analogies with PWS. It made us laugh and cry with empathy, and

brought out the chronic grief we parents have tucked away for the child that will never be. Although I've mentioned some of the similarities of dealing with autism and PWS before, it's never struck me as much as it did at that board meeting. Tedious is the word that encompasses a broad realm of idiosyncrasies of many special needs children including:

1) Repetitiveness -- Our children can go over the same story or ask the same question over and over and over again. What PW parent hasn't said under their breath, "If he asks me that question one more time!..."?

2) A sense of urgency -- where even minor issues seem very important to them. In our children's minds, it needs to be done -- and needs to be done now! They can't discriminate between major and minor issues. A member of our PWS group, Timmy, has been known to be upset for hours and "fire" trashmen for coming late to pick up their garbage.

3) A need for routine -- which is usually workable until it's a holiday or you go on a trip. This is well depicted in the movie when Hoffman (Raymond) travels across the country with his

brother, Charlie (played by Tom Cruise). There are the scenes where he has to have the bed near the window, and the scenes where they are frantically looking for a television every afternoon because Raymond had to watch Wheel of Fortune. To some people, I'm sure, this scene seemed exaggerated, but try to convince one of our young people with PWS that lunch will be at 1:00 rather than noon!

4) Stubbornness -- A classic trait of our young people with PWS from early childhood on. Even now at nineteen, if Matt decides he looks better in long sleeve shirts in the summer, no amount of logic, including the sweat dripping down his forehead, is going to convince him otherwise. With Raymond it was, "K-Mart is the best place to buy underwear," and his brother learned not to attempt to use logic to explain alternatives!

5) Lack of a sense of humor -- When someone cracks a joke at our house and Matt says very seriously, "What you mean?", we know trying to explain is futile. The subtleness of humor seldom fits into his world of concrete facts. Since we feel a sense of humor is important, we keep working at it, as did Charlie, who finally got Raymond to say jokingly, "K-Mart sucks!"

We parents and careproviders also have traits in common. Like Charlie, we grow in depth as people because of our relationship with our children. A smooth life can create a shallow person (No problem for us!). Hopefully, we learn patience, tolerance for differences, a sense of humor (if you're going to survive), compassion, and a strength that even we don't appreciate at times. I have witnessed mothers who may have never left the kitchen, become public speakers, political advocates, and accomplished writers. I have known fathers who admit that under different circumstances they would have spent their spare time in front of the TV, who have now learned to share their feelings at group meetings, take their children to the "multiple clinic" appointments, and advocate for other families' rights.

Whether our child has Prader-Willi syndrome or autism, their needs are great and we parents all struggle for ways to help make the world work for them. Like steel we are tempered by the fires of adversity, but also like steel we can form ourselves into what we need to be in order to support and advocate for our children.

Your support is Essential to PWSA

Many thanks to those who supported PWSA in the months of March and April.

Total Donations: \$3,226

Contributions to CTF: Olson

Contributions to Research: Nolfi, Central MI, Trentacoste, Hackler, Gardner(2), Thomas(2), Shoemaker(3), Bunch, James Jr., Holcomb, Morris, Latty(2), Gibbs, Kennett(2), Means, Davidson, Strobel, Keeter, CPC, Fekner, Bryant, Carlisle, Lloyd School, Patzik, Fisher, Carlson, Walker, Rueland, Widmer, Bodensteiner, Donlan, Boyd(2), Pinerman, Uzendowski, Boston Pizza, VanZomeren, Casuccio, Crawford, Calhoun, Schermerhorn, Culver, Fieldstone Foundation, Strathmore (Sweeney), Browne

Contributions to Operating: Nanzig, Lyon, Rogan, McGinn

Contributions as Memorials:

In Memory of Ms. Donna Pagliughi, with warm memories from her husband, David, Rebecca, her 10 year old daughter with PWS, and family: Globus, Jones, MacDonald, Niles, CPC, Holmdel High School

Great appreciation to our patron and contributing dues members:

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