

The Gathered View

March-April 1992

Volume XVII

Edition 2

for the Younger Set

National Newsletter of the Prader-Willi Syndrome Association

Strategies for Those Pre-Speech Years: A Parent's Experience

- by Linda Stratman Keder -

I was glad to see in the last *Gathered View* Deborah Downey's article recommending early intervention for speech problems. As a parent whose three-year old is finally starting to speak understandable sentences, thanks to many hours spent with speech-language pathologists, I'd like to share some strategies with which my family has had success.

Early intervention begins with feeding skills.

The muscles that are used for eating and drinking are the same muscles that will be used for speech, and low tone can create problems in both areas. There are many simple things you can do to help develop oral motor control for feeding that will prepare the muscles for talking. By all means, consult a speech pathologist to assist in this area during your child's first year of life, if possible. At home, you can start your own early intervention program by introducing drinking from a cup and a straw and offering more textured foods that re-

quire biting and chewing. You can provide additional stimulation by using chapstick on the infant's lips and gently stroking towards the mouth with a dry wash-cloth or lotion covered hands before a meal.

A child of two needs a way to communicate.

Knowing that a child with PWS is likely to have a speech delay, begin early teaching your child one or more other tools for conversation. Sign language is excellent for a small vocabulary, but it has its limits for very young children and those with a lack of fine motor skills. To supplement sign language, you can make picture communication boards for your child so that he or she can point to pictures that represent people, places, wants, or needs. For example, you could group photographs or pictures of the child's favorite toys and let him/her point to one to choose an activity. Your child will stop using sign language or communications boards as soon as he can make himself understood verbally--speech is simply more efficient. Although Ms. Downey cau-

tions against teaching signs for food, I believe this is not an issue for a toddler who is not yet speaking. As long as you offer signs or pictures only for foods that are acceptable choices, mealtime can be a wonderful opportunity to "talk" with your child about what she wants and who's eating what today.

This is a synopsis of Linda's experience. If you would like the entire article which includes specifics on how to make your own communication boards and references for reading materials, please contact National and we will send it to you.

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Teaching Toileting Skills

Contribution by Barb Dorn, WI

Teaching toileting skills to a child with PWS can be a very challenging experience. Shortly after my son turned 4 years old, he decided that he no longer wanted to wear a diaper. He also did not show any interest in using the potty chair or toilet. I had my work cut out for me without much information.

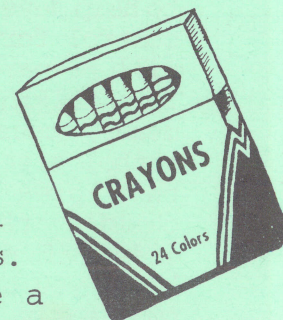
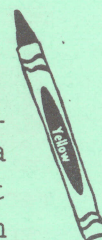
I began my new adventure by researching many books on the topic of toilet teaching. Tony was my first, so I had no previous experience. I ended up taking bits and pieces from several sources.

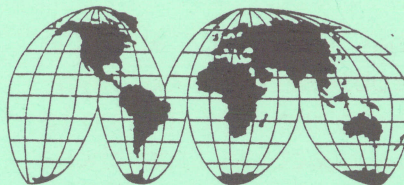
I began by purchasing several small toys and trinkets and placed them in a small box. Birthday party favors worked great. I also started a sticker chart. For Tony, stickers alone were not enough. Whenever Tony was successful in toileting, he was able to pick a toy from the "toy box", and he also placed a sticker on his sticker chart. When Tony earned 5 stickers, he was able to get a

larger toy. (i.e., chalk, coloring book, baseball cards, . . .)

At first Tony was very slow in catching on to "the game." We had two weeks with no successes. By that time, I was ready to call it quits. All of a sudden, however, it started to click. Soon we were having successes. I filled his toy box twice, and then we started using stickers alone. I had originally thought there might be problems with that transition; however, Tony proved me wrong. After about a week or two, we slowly raised the number of stickers he needed to be rewarded. After about one month, we eliminated the stickers, and Tony was successful on his own.

Along with the toys and stickers, Tony was given verbal praise and hugs. This was quite a family project. I'll never forget the day;
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President's Message

by Janalee Tomaseski-Heinemann

An Australian View-- Bridging the Continents

The following excerpts are from a letter I received from my "pen pal," Dawn Taylor, from Hillary's, West Australia, whose six year-old son, Ryley, has PWS. Although half a world away, she expresses feelings and frustrations common to all of us dealing with Prader-Willi Syndrome:

"... I have to thank you yet again for your wonderful words of wisdom in the last newsletter. I felt the calm relief of being understood, and it is really such a wonderful feeling ... Ryley is going well at school and still hasn't put on that much weight. His behavior is erratic, and he struggles badly when in public to overcome his fear of the hustle and bustle of life, especially shopping centres and bust places. Tunnel vision does not allow you to reach out and explore

everything at once, and the whole scene becomes just too much for him to cope with. Must admit I couldn't blame him as I find them a bit over the top myself. (As you have guessed, we have just returned from Christmas shopping where Ryley stopped the whole centre calling me some rather colorful names at the top of his voice!) Silly me for taking him as I should have known better.

We had an interesting discussion the other day with nine specialist doctors from our mental health centre. It amazes me how very threatened they feel if they suspect that you know more about the syndrome than they do. Amongst the more "rational" comments were the following--I thought they might amuse you.

1. 'Oh, all children do that' (with reference to Ryley's greeting every time he gets off the school bus. He repeats four or five times, "What for tea, Mum? What for sweets?")

2. 'There are lots of PW people living independently and with families of their own-- We just don't know who they are.' (This was in reference to my comment that we had accepted the fact that Ryley will never attain total independence.)

3. 'Ryley may not be a PWS person!!'

4. 'The test showing part of no. 15th chromosome may not prove anything.'

5. 'There's a lot we don't know!' (Now that's an understatement!!)

I will leave it to your imagination as to my feelings on the aforementioned comments, particularly as I was led to believe that the reason behind the interview was to discuss Ryley's behavior. I don't want you to think that all the doctors here are like that. Our referring doctor was, in fact, embarrassed by the whole scenario. Nevertheless, it left me wondering how other people in the same situation may have coped. Implying that there may

be a possibility that Ryley did not have PWS and that others with PWS lead a normal (?) life. Almost makes you want to start imagining that he is completely normal and that it is all just my imagination that he has all (but a few) tendencies of a PW person. However, of course we will not get carried away with wishful thinking as it does not help you cope with daily life."

When I hear from Dawn, or other parents from different nations, it still fascinates me

that not only are the problems with the syndrome the same, but so is the reaction from those who do not live with PWS (i.e., professionals being threatened by parents' knowledge). Working with medical staff daily, I also understand that often they are trying to soften the blow to parents regarding their child's situation. What these professionals don't understand is that by minimizing the situation, they are either giving parents false hope or making them feel like over-reacting, neurotic

people. This is their way of avoiding parents' pain and anger at the time. As with Dawn, parents then question their own judgement and sense of reality. I think the most significant things we parents can do for each other is validate each other's feelings and concerns. Since we're all in this "PWS boat" together, there might be comfort in knowing that the boat is bigger and the number of people paddling is greater than ever. It might make the waves look a little smaller.

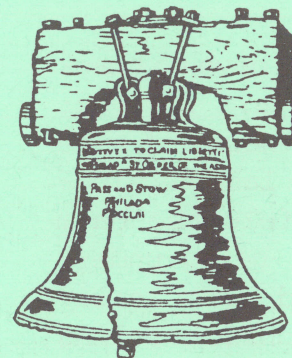
Philadelphia, PA July 16-18

Conference Packets Mailed

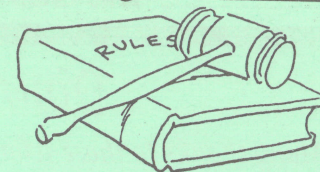
Conference packets were bulk mailed the beginning of March. If you haven't received your packet by **April 30th**, call us. We'll send you another one or discover why you didn't get yours.

Because Canadian and Foreign cannot be bulk mailed, we ask you to request a packet directly from us if you plan to attend the conference.

If you would like to come to the conference, but do not have the financial resources to do so--apply for a conference grant. See page 8 for specifics on how to apply.



Board Issues Decided in January



The Board of Directors met in January to discuss business again. The following actions were taken:

* The Name of our organization has officially been changed to Prader-Willi Syndrome Association (USA). The Board felt that the organization's name would then directly reflect the fact we are a national organization.

* The publication committee approved a new look for our letterhead.

* The by-laws changed to reflect a new procedure on Proxy Voting. "Resolved that proxy votes for elections be acceptable only by mail and received not later than fourteen days prior to the date of the annual membership meeting." (Slate of candidates and proxy ballots will be in the May-June issue of The Gathered View.)

* The powers and procedures of the Executive Committee were adopted as a standing committee of the Board of Directors. The Executive Committee consists of the Executive Director, President, and Chairperson of the Board, with a fourth Board member to be appointed for each issue of discussion.

* The organization formally adopted a mission statement:

"The mission of the Prader-Willi Syndrome Association (USA) is to provide to parents and professionals a national and international network of information, support services, and research endeavors to expressly meet the needs of affected children and adults and their families."

* The bid was accepted for the 1994 conference to be held in Atlanta, GA. **WE STILL NEED A BID FOR 1993.**

* A uniform policy of prices for brochures was adopted. First timers may have up to two of each brochure at no charge. Thereafter, each brochure is ten cents, and mailing charges of \$1.00 per hundred will be required.

* The current rebate system to Chapters was eliminated. New incentives for members to become a chapter and a national member will be discussed at the July Presidents' meeting.

* National Board members will each be assigned chapter presidents to contact two or three times per year.

* A special financial membership for hardship cases shall be offered by the Association. To qualify for that special financial membership, the non-paying members will be contacted by the Association. Any non-paying dues members may be dropped from the membership list at the discretion of the Executive Committee.

* The issue of raising dues and conference fees was committed to the Executive Committee for consideration.

* The Board will continue the undertaking of establishing a five year plan complete with financial perspective.

* A seven month budget was passed with a projected deficit of \$21,000. The budget will be reviewed again in July. This is the fourth year a deficit budget has been passed. Two of the past three budgets have broken even, but the 1991 operating deficit was approximately \$30,000.

(See the **Annual Report** on page 10 of this issue.)

Your Support is Essential to PWSA

Many thanks to those who supported PWSA in the months of January and February, and beginning of March.

Total Donations: \$8423 **Contributions to CFT:** Olson(2), Parent

Contribution to Conference Youth Program: \$1500 Westinghouse (Mitchell)

Contributions to Research: Margolis, VanZomeran, VFW Club Post #7564, Kennedy, Hesterberg, Hinson, Healy (Deterling), Boyd(2), Peifer, Gordon, Jenkins (2), Alterman (2), Meeks, Uzendowski, Marks, Pinerman (Singer), Patzik (Shutz), Maurer.

Contributions to Operating: Mitchell, Inland United Way, Wett, PW Kentucky Assoc.

Contributions as Memorials and Honorariums:

In Memory of Dr. Joseph Shacklett, father of member Mr. Curt Shacklett: Farrill, Bohling, LoVellette, Thompson, Smith, Levan, Warden, Sims, Bank of Oklahoma, Hoabe.

In Memory of William E. Bunker, Ms. Georgia Bunker's son with PWS: Rose, Bartell, Yeager, Burno, Stokes, Blair, Runnels.

In honor of Mrs. Sam Alterman's Birthday: Louise, Mr. & Mrs. Nathan Lipton, Alterman, Arvella, Jean, Mary, Willi, Mattie, Shirley & Izzy Weitz, and Mrs. Sylvan Makover.

In honor of Samantha Aalund's First Birthday: Aalund Party

In Memory of Ms. Donna Pagliuighi, with warm memories from her husband, David, Rebecca, her 10 year old daughter with PWS, and family: Elliot (2), Anderson, Pagliuighi, Campbell, McLane, Reynolds, Giger, Schoen, Hinkis, Dellert, Gura, Knorr Best Foods, CPC Co.(2), Chenarides, Zerbst, Nolfi, Keeter, Fekner, Bryant, Trentacoste, Hayes, Bailey, Strobel, Holmdel School, Carlisle, Lloyd School.

In Memory of Lucille Wehner, relative of member Debbie Shoemaker: Hackler, Gardner(2), Thomas(2), Shoemaker(2), Bunch, James, Gardner, Holcomb, Morris, Latty(2), Gibbs, Kennett(2), Means, Davidson, Frances, Fisher, Griffith.

Contributions to Be An Angel Fund Raiser: Total \$12,135

Names in parentheses indicate the name of the member who is family or friends with the contributor.

Cherubs (\$1-\$49): Kral, WKS, Fondell, Kerslake, Sheeran, Reep & McKenzie(Noordzy), Trask (Tobin), Singer, Snow(Ingalls), Bush, Stransky, Weinberg, Marciniak (Wyka), Ridling (Evetts), Williams (Burleigh), Larkin (Persanis), McDonald, Grout, Castle, Krebsbach, Harvey (LaBella), McGuinness, Baynard, Gomez, Gomeringer (Noll), Noll, Jones, Gardner, Posch (Brewi), Abramek (Sojka), Hill (Wett), Srnold, Schramm, Weiner, Prettyman, Watson, Zielske, Alt.

Angels (\$50-\$99): Pacheco, Benedikt, Ranberg, Means, Nash(Wett), Pappas (Boucher), Horrigan, Marchitelli, Wachter (Mitchell), McDonald & Schneider (Schneider), Saacks, Hawkinson, Lamberson, Olson, Roenigk, Huether, Wilder, Eager, Jones, Gross, Ranberg, Rogan.

ArchAngels (\$100-\$249): Leonard (Mook), Hoffrichter (Vermeulen), White, Thomas, Hinson, Berger, Moran, Warden, Stege, Lennhoff, Singer, Swenson (Sojka), Percy, Paterson, Lamberson, Lyon (Pick).

HeavenlyAngels (\$250+): Dietz, Bishop, Beltran, Versa Handling, Dolese Bros.(Park), Millipore Foundation (Margolis), Notbohm.

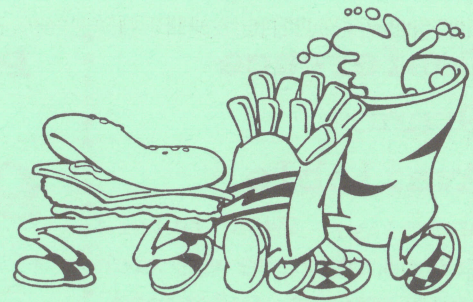
Great appreciation to our patron and contributing dues members:

Patrons (\$40-\$99): Schramm, Thom, Ipsen, Chausow, Deisroth, Percy, Welch, Weiss, Hicks, Sidbury, Gemar, Gootitz, Kremer.

Contributors: (\$100+) Greenswag, Metzger, Singer, Baron, Mitts, Cash, Beltran, Smith, Warner, Alterman, Maurer, Goranson, Miller, Rose, Hermann, Ceppos.

It's Another Fast Food Update

If Fast Food were your only choice for three meals a day, could you stay within your diet? The answer is Yes with the right choices. Remember these are calories based upon serving sizes at an average fast food place. The amounts may be much larger than what you provide at home.



Here's the menu:	Calories
Breakfast: 3/4 cup Wheat Flakes with 4 oz. skim milk	120
Lunch: 1/8 of 12" Cheese Pizza	140
Dinner: Grilled Chicken Sandwich	265
8 oz. Skim Milk	90
6 oz. Orange Juice	85
8 oz. Low Cal. Hot Chocolate	100
Total for the day	800 Calories

You may be asking, "What about the salad bar instead of a sandwich or pizza"? Salad bars are good, but be careful. The calories can pile up fast. You may be money and calories ahead with a slice of pizza and small lettuce salad.

Typical Salad Bar	Calories
1 cup Lettuce and Tomato Salad	20
1/2 cup Potato Salad	130
1/2 cup Coleslaw	100
1 tbsp. Regular Italian dressing	70
1 tbsp. Reduced calorie dressing	15
1 tbsp. Imitation Bacon Bits	30
1 tbsp. Sunflower Seeds	50
1 tbsp. Chopped Egg	15
1 tbsp. Grated cheese	25
1 tbsp. Croutons	15

If you were to have everything but the potato salad and regular dressing, and put 3 tbsp. of reduced calorie dressing, the total is 300 calories. Remember also there isn't much in one tablespoon.

The biggest fast food danger is on the side:	Calories
French Fries	235
Large Baked Potato	220
Corn-on-the-cob	155
8 Onion Rings	275

Believe it or not, you'd be calories ahead and about the same in fat with a brownie or cookies rather than the onion rings.

Brownie	245
2 oz. box Chocolate Chip Cookies	235
Fried fruit pie	265
Strawberry Sundae	270
3 oz. Cone, low-fat frozen yogurt, vanilla	102

Dieting is difficult in our food oriented society. Plan for times of enjoyment, parties, holidays, and compensate for them over the next few days. However, a lax attitude can be dangerous. Dieting for a child with PW is not just a matter of health and looks, it is a matter of life and death.

Conference Grants Available

Annually, PWSA offers grants to those who wish to attend the conference, but cannot afford the expense.

HOW DO I APPLY?

Send PWSA a letter giving the following information:

- * The size of your family.
- * An indication of your income and expenses.
- * The age of your child with PWS, and a brief summary of what the greatest difficulties you, as a family, are experiencing in dealing with PWS.
- * Whether or not you/your family would need all your expenses paid or just need some assistance.
- * Whether you (or family) have attended a conference in the past.

WHAT IS THE PROCESS?

Your letter will be reviewed by a committee of the Board, which will make the determination. All information is kept confidential.

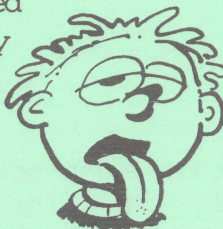
Applications must be received by FRIDAY, MAY 15, 1992.

Any applications received after this date will not be considered.

Parent Asks Good Question

Q Molly got into the picnic cooler that we forgot to empty two weeks ago. She ate sandwiches that had mayonnaise, cheese, and some left over milk. All these items left unrefrigerated are highly susceptible to spoilage, which might poison a child.

What shall I do?

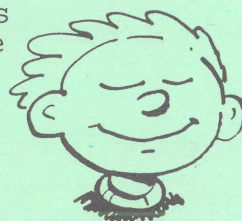


A There is no clear answer whether a child with PW would be poisoned by this, but it is probably better to be safe than sorry. A trip to the emergency room may be in order, so check with your local poison control center. In the emergency room, it is traditional practice to give the child a dose of Syrup of Ipecac to cause vomiting, which removes the toxins from the body. As all PW parents should know, Syrup of Ipecac has no effect in inducing vomiting in children with PW. If a poisonous substance had been ingested, stomach pumping has been the only alternative.

Now there is a potential alternative!

A new treatment when something potentially poisonous has been eaten: Activated Charcoal. No, this doesn't mean to feed your child the briquettes from the grill. Activated Charcoal is a chemical compound developed for medical uses.

As reported in *Healthline*, at the University of Buffalo, over a two year period, 70 children were studied who came into the Children's Hospital Emergency room for treatment of mild to moderate oral poisoning. One group was treated with Syrup of Ipecac and Activated Charcoal, and the other with Activated Charcoal alone. The group that received only Activated Charcoal spent less time in the emergency room and kept the remedy in their systems longer than the group that received syrup and activated charcoal. Keep this in mind if you are faced with a trip to the emergency room, as individuals with PWS have been overdosed on Syrup of Ipecac.



Looking for some free advice on Nutrition?

The National Center for Nutrition and Dietetics is offering help via a toll-free hot line.

Call 1-800-366-1655 from 9 a.m. to 4 p.m. (Central Time) Monday through Friday. You can listen to pre-recorded messages or talk with a registered dietician. These individuals would not be trained specifically in understanding the difficulties with PWS, but they would be able to answer basic questions you may have to help maintain a diet.

Questions such as: How many calories does a certain food have? Does a recipe have fewer calories baked or broiled? What is a good source of fiber?

Wanted: A Video About PWS That Everyone Can Relate To Introducing TV Clips II

January 16th aired The Maury Povich Show, half of which was dedicated to PWS. Appearing on the show were Penny Townsend (NC) and her 16 year-old daughter, Beth, and Eileen Klein (NY) and her 10 year-old son, Billy. Providing a professional commentary was Dr. Jack Sherman, who has seen PW patients in the NY area.

The end of the show gave our number for people to call for more information. In two months, the Association has received over 900 phone calls from across the nation. People called who were just interested in having additional information, others thought they knew someone who might have the syndrome, and some had children with the syndrome who didn't know anyone else in the world was dealing with the same situation.

As a result of PWSA representatives appearing on this TV show and on the Jerry Springer Show in October, the national office is now happy to offer

TV CLIPS VIDEO TAPE 2, \$25.00 or available for Rental at \$10.00. TV CLIPS II has the Deadly Hunger news series from St. Louis, The Jerry Springer Show, and The Maury Povich Show. This is an excellent tape to provide support in explaining aspects of the syndrome others may not understand, and conveying need for services in your area.

I would like
to order

TV Clips II

Name:

Address:

Enclosed is
my check for
\$25.00 or
check for
\$35.00 to
rent.*

*\$25.00 deposit returned
upon receipt of rental tape.

PWSA FINANCES: 1991 Annual Report

PWSA operates finances on a system of four major funds.

They are:

**Deterling Research Fund
Wett Crisis Intervention
& Transitional Fund
Conference Fund
Operating Fund**

The Deterling Research Fund, established in 1982, to be used primarily for research and including other special projects. A 1987 board directive determined all non designated gifts to PWSA would be split 50% to this fund and 50% to operating. If the gift is designated to research 100% is placed in this fund. **The year 1991 ended with a balance of \$28,835.77 in this fund.**

Applications for grants for these funds are submitted to our Scientific Advisory Committee, and then approved or rejected by our Board of Directors.

The Wett Crisis Intervention & Transitional Fund was established in 1984, to open a National Developmental Center. Due to the inability to establish this crisis center, the following criteria was developed as acceptable usage. Crisis aid to families, travel expenses for establishing group homes, staff development and training, and as collateral for start-up funding for designated group homes.

The Executive Director screens applications, making appropriate comments, and then forwards them to a Board of Director's committee for approval or disapproval.

The balance in this fund at the end of 1991 was \$265,675.59.

Yearly conferences operate on a pay-for-itself basis. Since Host Committees have been able to obtain local grants to offset costs, and we have been fortunately to have a large number of attendees each year, we have accumulated a positive balance in this fund. **The year end balance in this fund was \$16,860.57.**

Organizations have expenses to operate, therefore, it is necessary to have an operating fund. Our **Operating Fund** consists of membership dues, direct donations, 50% of non designated donations and any profits (there are little) from materials sold. Expenditures from this fund are all of the necessary costs of operating a professionally equipped and staffed office. **As of the end of 1991, there had been an accumulated positive reserve total of \$50,919.03.**

These numbers would lead members to believe PWSA has a great amount of wealth, remember the above funds are designated for specific purposes. Especially focusing on the Operating Fund, it appears to have a comfortable balance. Do not be deceived at our present rate this reserve will be gone in two years. **The 1992 operating budget for the first seven months projects a deficit of \$21,000.00.**

Remember we need your continued support, not only

for operating, for the other funds as well to continue to grow in serving the needs of our members.

The balance sheet for 1991

1991 Income

Crisis Donations	\$545
Crisis Interest	\$15,587
Conference	\$34,414
Conference Intrst	\$1,237
Research Dontrs	\$10,398
Research Interest	\$2,148
Material Sales	\$17,476
Membership Dues	\$39,170
Operating Dontrs	\$40,610
Operating Intrst	\$4,768
Misc.	\$846

Total Income \$167,199

1991 Expenses

Crisis Expenses	\$5,856
Conference	\$38,049
Research	\$33,589
Materials	\$7,395

(Direct printing only)

Postage	\$11,060
Printing	\$6,500
Rent	\$6,000
Salaries	\$45,467
Service/Contracts	\$9,110
Supplies	\$2,329
Taxes	\$21,919
Telephone	\$3,038
Travel	\$10,928
Capital Equipment	\$5,377
Misc.	\$107
Total Expense	\$197,614

**Total Operating
Deficit for 1991
\$30,415**

Prozac Quiz

The national office would like to collect written information on the effectiveness and possible side effects of Prozac (fluoxetine) when taken by people with PWS. We have heard of success and failure with the use of Prozac, but at this point they are merely stories. If we have written information from those who are using it or have tried it, it would be helpful in knowing for whom to prescribe it, what can be expected, and other effects to look for. It could also be of help in getting financial reimbursement for its use from insurance companies and state agencies.

If you have a child/adult in your care who has tried or is taking Prozac, please take a moment to answer this informal quiz.

The information will be kept confidential.

Circle Appropriate Response Where Available

Age of person taking Prozac _____

Sex F M

Living Situation: Family Home Group Home Other: _____

Person Completing form: Parent/Guardian Group Home Worker Psychiatrist/Psychologist
Physician Other: _____

Length of time Prozac taken: _____ Months _____ Years

Still being taken? Yes No If no, why: _____

Maximum Dose Tried: _____ mg per day **Current dosage:** _____ mg per day

Major Reason Prozac started: Temper Tantrums Other Acting Out

Obsessive-Compulsive behavior (skin picking) Depression Other: _____

How helpful was Prozac in dealing with the following problems?

Tantrums

Acting Out

Obsessive-Compulsive

Depression

Other

Any Side Effects Noticed: No Yes If so what _____

Comments:(Attach additional pages as needed)

If deemed useful, we would be grateful for your permission to contact you for additional information.

Name: _____

Thank you for your valuable help. Mail this to: PWSA, 6490 Excelsior Blvd E102, St. Louis Park MN 55426

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my husband was up on the roof doing repairs when Tony had one of his first successes. Tony and I proudly and loudly announced his success to his Dad (and the entire neighborhood). Everyone was excited for Tony.

At the present time (Tony is almost 7), Tony is completely successful in his toileting

skills during the day, but he continues to have bedwetting problems at night. Just as there is a great deal of variance in teaching children without developmental delays, so there is variance in teaching toileting skills to children with Prader-Willi Syndrome. This is just one method that worked for us.



*** Note:** Tips which have been effective for night bedwetting: If your child goes to bed hours before you do, wake him/her to go to the bathroom before you turn in for the night. Or set an alarm clock during the night to wake the child. Allow no liquid after 8 o'clock. Continue your reward system for success overnight.

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