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PWSA U.S.A.

The Gathered View

National Newsletter of the Prader-Willi Syndrome Association (USA)

# Imagine . . .

*by Teresa Kellerman*
*1/29/97*

## what it would be like if you were born with Prader-Willi Syndrome

***Imagine*** that your desire to get food is so strong that you would do ANYTHING to get it, even crawl out of your bedroom window in the middle of the night to walk to the store several miles away.

***Imagine*** that you are hungry all the time, and that you are on a diet, all the time, and that you can only eat about half as much as everybody else, not to lose weight, but just so you don't gain weight. Imagine that if you do gain weight, you will have to go on an even stricter diet, getting about as many calories in one day as there are in just one cheeseburger and fries. Boy, would you like to have a cheeseburger and fries! But that's not in your diet. You are told that your diet is very important, because if you gain weight you could get really sick and die, because your heart can't handle the burden of obesity.

***Imagine*** that everybody in your group is going on a hike, and you want to go, but you know you will get tired easily, because your muscle tone is not really good, but you don't want to be left behind, so you go along, and it's really hard for you to keep up with everybody. And when you stop for lunch, the person next to you has a big sandwich with mayonnaise and cheese and roast beef and five cookies and potato chips, and the person sitting on the other side of you has three granola bars and trail mix with nuts and a candy bar. And you have two skinny slices of diet bread with mustard and a thin slice of ham, and a rice cake, and a teeny apple. You think that candy bar looks really good, and you watch that candy bar, because maybe it will get set down, and maybe you can get your hands on it, and maybe it would taste soooo good, and you can't think about anything else but that candy bar.

***Imagine*** that you find a $20 bill laying on the ground, and you pick it up and put it in your pocket and don't tell anybody, because maybe you can buy some candy bars with it some time when no one is looking. But you get found out and you are accused of stealing, and nobody believes that you just found it.

***Imagine*** that when you see a little scab on your arm, you just have to scratch it, you can't help it, you just have to! And when it bleeds, you get in trouble. And you try really hard to leave it alone, but you can't! And sometimes it takes over a year for sores to heal.

***Imagine*** that when you want something to eat you have to ASK, and then you usually get told NO or you get carrot sticks, and you can't eat what you want because there is a lock on the refrigerator and on the pantry too.

But you know if there were no locks, you would get more food, and gain weight and get sick. So you really don't mind if the food is locked up. At least you don't have to worry about getting food like you used to before there were locks, and you would wait until the middle of the night to get up and go get food without anyone knowing. You feel safe with the food locked up.

***Imagine*** that there's something you like to do and you're really good at it, like working jigsaw puzzles. And you have one that is a THOUSAND pieces, and you've been working on it for days, and you want to put it together all by yourself, because it's YOUR puzzle and you know where all the pieces go, and then someone else puts pieces in for you, and you take it all apart to start over, and you get yelled at, and you are told you are STUBBORN, but it's YOUR puzzle, and you just want to work it yourself.

***Imagine*** that you are going to the movies, and everybody else is getting popcorn and candy, but you can only have a diet pop, but you have to sit there and smell everybody else's popcorn and chocolate, and watch them eat, and hear them munch. You really wish you could have a giant tub of popcorn like that guy over there! And you see a piece of popcorn that someone dropped and you pick it up and someone tries to grab it from

*Continued on back page*

*inside*



**SPECIAL INSERTS**

PWSA (USA) Membership Survey, Board of Directors Candidates & Election Forms, National Conference News

## The Prader-Willi Syndrome Association (USA)

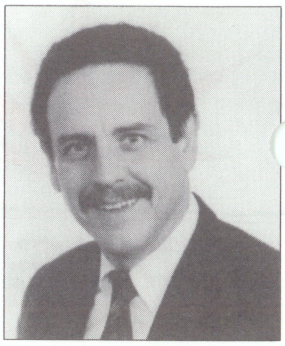
2510 S. Brentwood Blvd., Suite 220
St. Louis, MO 63144-2326
1-800-926-4797
Local: (314) 962-7644, Fax: (314) 962-7869
8:00 a.m.–4:00 p.m. CDLST

**PWSA (USA) on the Internet:**
**http://www.athenet.net/~pwsa_usa/index.html**
E-mail: pwsausa@aol.com




# Out of the Office

by Russ Myler, Executive Director



Included with this issue of *The Gathered View* is the first-ever PWSA all-member survey. Historically, the leaders of the Association learned the needs and wants of the members through informal conversations and contacts. As the Association has grown, with members now spread across all parts of the country and the world, this type of informal needs assessment has become almost impossible and certainly inadequate. After more than 20 years, it's time to take stock, in a systematic and comprehensive way, of how our members view the Association and its work today. The member survey is our first step in this assessment process.

*What will this survey do?* you might ask. *Will it be placed into a large filing cabinet and forgotten? What if "they" don't like what I have to say? What difference will my response make?*

A polling of every member of an association seems to me to be basic to what an association is. We are a gathering of people who share interests and needs; we come together to have those interests and needs met. A survey can not only identify member needs, but it can help us understand what the association is doing right, where it needs to improve, and what new directions it must take to thrive.

This survey reflects the commitment of your board of directors to keep PWSA grounded in the mission and purpose that brings us together: to benefit the lives of people with Prader-Willi syndrome and those who love them. The board has a very real interest in hearing from you, and they will pay attention to your needs. This survey is important to YOU.

I urge each of you to take the time to complete the member survey and return it to the national PWSA office by mid-August. The results will be compiled and shared with the board of directors and you (through *The Gathered View*). More importantly, the results of this survey will help an association already committed to meeting your needs do so more effectively.

**SURVEY DEADLINE: August 15**
**Use the envelope provided or address your reply to the PWSA (USA) national office. Questions? Call 1-800-926-4797.**


***The Gathered View*** (ISSN 1077-9965) is published bimonthly by the Prader-Willi Syndrome Association (USA) as a benefit of membership. Annual membership dues are: $30 Individual, $35 Family, and $40 Agencies/Professionals for U.S. members and $40, $45, and $50 (US Funds), respectively, for members outside the United States.

Opinions expressed in *The Gathered View* are those of the authors or editors and do not necessarily reflect the views of the officers and board of directors of PWSA (USA). *The Gathered View* welcomes articles, letters, personal stories and photographs, and news of interest to those concerned with Prader-Willi syndrome.

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Communications regarding *The Gathered View* or PWSA membership and services should be directed to the national office of PWSA (USA), 2510 S. Brentwood Boulevard, Suite 220, St. Louis, MO 63144-2326. Telephone 1-800-926-4797, or, in the St. Louis area (314) 962-7644. Fax (314) 962-7869. E-mail: pwsausa@aol.com.

# 1997 PWSA (USA) Member Survey

**Please complete and return by August 15**

## Member Information

1. Which best describes your connection to Prader-Willi syndrome? *(check one)*

- ☐ Person with the syndrome
- ☐ Parent of someone with PWS
- ☐ Relative/Friend
- ☐ Service Provider
- ☐ Medical Professional
- ☐ Researcher
- ☐ Other:_____

2. What is the age of the person(s) with PWS with whom you live or work?

- ☐ Birth to 12 months
- ☐ 1 to 5 years
- ☐ 6 to 12 years
- ☐ 13 to 21 years
- ☐ Over 21 years

3. How long have you been a member of the Prader-Willi Syndrome Association (USA)?

- ☐ Less than 2 years
- ☐ 2 to 5 years
- ☐ 6 to 10 years
- ☐ More than 10 years

4. Are you a member of a PWSA chapter ? ☐ Yes ☐ No

5. In what state do you live?_____
*(If non-U.S., give country)*

## The Gathered View

6. Please rate *The Gathered View*, our national bimonthly newsletter, on each of these factors:

| *(check one for each item below)* | Excellent | Good | Fair | Poor | Don't Know |
|---|---|---|---|---|---|
| Content (scope and quality of information) | | | | | |
| Length of publication | | | | | |
| Frequency of publication | | | | | |
| Design/appearance | | | | | |
| Timeliness | | | | | |

7. What specific suggestions do you have for improving *The Gathered View* or making it more useful to you?

## Publications/Products

8. Besides the national newsletter, have you purchased/used any PWSA publications, brochures, videos, or other information products? ☐ Yes ☐ No **(If No, skip to 10.)**

9. In general, how would you rate the PWSA publications/products you have used?

| *(check one for each item below)* | Excellent | Good | Fair | Poor | Have Not Used |
|---|---|---|---|---|---|
| Books/booklets | | | | | |
| Information packets | | | | | |
| Brochures | | | | | |
| Videos | | | | | |

10. What publications or information products would you like to see PWSA develop?

## PWSA World Wide Web Page (http://www.athenet.net/~pwsa_usa/index.html)

11. Have you visited the PWSA Web Page on the Internet? ❒ Yes ❒ No **(If No, Skip to 14.)**

12. How would you rate its:

| *(check one for each item below)* | Excellent | Good | Fair | Poor | Don't Know |
|---|---|---|---|---|---|
| Content | | | | | |
| Ease of use | | | | | |
| Design/appearance | | | | | |

13. What would make our Internet site more useful or interesting to you?

## National Office Help Line

14. Have you contacted the national PWSA office for information or help in the past 2 years? ❒ Yes ❒ No
**(If No, Skip to 17.)**

15. Please rate the national PWSA office response to your request(s) in terms of:

| *(check one for each item below)* | Excellent | Good | Fair | Poor | Not Applicable |
|---|---|---|---|---|---|
| Promptness of response | | | | | |
| Quality of information/answers | | | | | |
| Usefulness of referral (to professionals, service providers, parents) | | | | | |
| Sensitivity/courtesy shown | | | | | |
| Follow-up action (if callback or other follow-up was needed) | | | | | |

16. Do you have any suggestions for improving the Association's response to individual members?

## National PWSA Conference

17. Have you ever attended a national PWSA conference? ❒ Yes ❒ No **(If No, Skip to 22.)**

18. How many national conferences have you attended? ☐ 1 ☐ 2 ☐ 3 ☐ 4 or more

19. What was the last conference you attended? City:_____ Year:_____

20. Please rate the last national conference you attended in the following areas:

| *(check one for each item below)* | Excellent | Good | Fair | Poor | Don't Know |
|---|---|---|---|---|---|
| Relevance to you of session topics | | | | | |
| Quality of presentations/panels | | | | | |
| Opportunities to exchange information/support | | | | | |
| Opportunities to meet people/socialize | | | | | |
| Youth and adult activity program | | | | | |
| Conference location & accommodations | | | | | |
| Overall conference experience | | | | | |

21. Do you have any suggestions for improving our national PWSA conference?

22. **If you have <u>never</u> attended a national PWSA conference**, what is the major reason you have not?

☐ Time/other commitments
☐ Cost of conference or travel
☐ Health/inability to travel
☐ Not interested in attending the conference
☐ Not ready to meet other families
☐ Other:_____

## National Goals and Leadership

23. How would you rate the national PWSA's effectiveness in each of the following areas?

| *(check one for each item below)* | Excellent | Good | Fair | Poor | Don't Know |
|---|---|---|---|---|---|
| Providing current, accurate information and advice concerning PWS | | | | | |
| Developing effective publications/information products on PWS to meet various needs | | | | | |
| Responding to individual families who need assistance | | | | | |
| Supporting chapters in their efforts to serve families | | | | | |
| Raising awareness of PWS among professionals, service providers, and the general public | | | | | |
| Promoting the dignity and individuality of people with PWS | | | | | |
| Demonstrating sensitivity to the families of newly diagnosed children with PWS | | | | | |
| Advocating for legislation and services that would benefit people with PWS | | | | | |
| Promoting research into the causes of and treatments for PWS | | | | | |

24. What would you like to see PWSA (USA) accomplish in the coming year?

*(Please list no more than three goals—List the most important first)*

1. _____

2. _____

3. _____

25. What areas of research do you feel are most important for the future of people with Prader-Willi syndrome?

*(Please list no more than three subject areas—List the most important first)*

1. _____

2. _____

3. _____

26. Do you have any additional comments or suggestions for your national PWSA leaders?

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***Thank you for your participation!***

**May we contact you for further comments or ideas?** *(Optional)*

Name: _____

Phone: _____ Best time to call: _____

(Note: All survey responses will be held in strictest confidence and will be reported to the PWSA membership in summary form only.)

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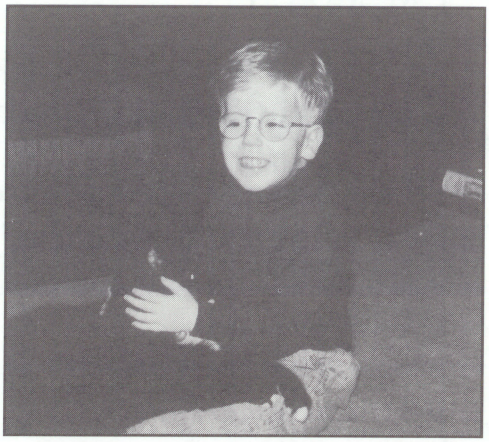
**Please return this survey by August 15 to:**
**PWSA (USA), 2510 S. Brentwood Blvd., Suite 220, St. Louis, MO 63144-2326.**
*(For your convenience, a return envelope is enclosed with this mailing.)*

## Support Across the Miles



Robbie at 3½ with feline friend, Bogie.

Our son, Robbie, [was] 4 years old on April 10, and, with the exception of a very stressful first year, we have enjoyed watching our son develop into a beautiful, loving child. When he was very young, I researched as much as I could about PWS and in my search found some articles written by Janalee [Tomaseski-Heinemann]. I was so inspired by her words that I wrote a letter to let her know how much I appreciated her words of encouragement that came out of a sea of negative literature. Parts of that letter were published in an issue of *The Gathered View* [Vol. 19, No. 1, 1994], and we were very proud to have a picture of Robbie shown to your readers.

A few months after that letter was published I received a birthday card for Robbie from a stranger in Israel. Margot had read about Robbie and was inspired to write to me as her son, Guy, was born with PWS a month before Robbie. She had read my words and felt such an affinity to what we were experiencing, although we live on opposite sides of the world. Since that time, Margot and I have shared many letters, some faxes and a phone call, and we look forward to meeting one day!

We live in completely different worlds but share so much. We both pour our hearts out in very lengthy letters and share our innermost feelings about our sons and life with PWS. Margot has four older children, while Robbie was our first child. Margot and her family live on a kibbutz in Israel, and we live in Vancouver, B.C., on the West Coast. Although our lifestyles are different, our feelings, concerns, and hopes for the future are the same.

I think our letters have provided a level of support for each of us that most people don't have. Both Margot and I have very supportive husbands and families but still share those incredible emotions that only mothers can have. We probably make PWS more a part of our life than we need to, worry too much about behaviors that may or may not be part of the syndrome and think more of the long term than we should at this early stage of our sons' lives. Our husbands both have the enviable ability to enjoy the moment and not to make a mountain out of a molehill with every unusual situation.

Our communication allows us to compare the services our communities provide, the successes and difficulties that Robbie and Guy encounter, and provide an outlet for our feelings and concerns. We share a good laugh at things that happen with the boys and are amazed at their similar personalities—especially things like their love for elevators and incredible memories for people's names. We share great empathy in the day-to-day reminders of PWS and our concern for the future.

Having Margot as a pen pal has been such a positive experience for me. Writing long letters to her is a catharsis for me and reading her letters reminds me that I am not the only one feeling the way I do. We share so much, and I look forward to the day our families can meet.

I would encourage your readers to find someone to share their lives with as we do. We all have so much to share and can benefit from the support of others living with PWS.

Thanks again for the great work you do with *The Gathered View*.

*—Cindy Armstrong*
*Vancouver, British Columbia*

## Smoothing a Transition

Another transition is approaching for my 13-year-old son, Crosby, who has Prader-Willi syndrome. In September, he will be in junior high—a new school, a new paraprofessional, and the dilemma of after-school care.

As we parents of special needs children all know, the after-school care for this age group is very limited. I have heard of a child with special needs who had a wonderful experience at our local YMCA's after-school program. At some point this may be an option for Crosby, but being that part of PWS is difficulty adjusting to new situations, I wanted something familiar for him his first year in junior high.

I inquired about him staying at the after-school program at his elementary school and hoped they could make him feel like a helper, as a junior aide, assisting younger children with various tasks—for example, taking attendance, reading stories, and chaperoning them to the bathroom. So often our children are the ones getting all the help; what a self-esteem boost for them to give of themselves! The staff at the after-school program was more than willing to do this. So Crosby not only is looking forward to junior high but feels proud that he will be returning to his elementary school's after-school program because he has a "JOB TO DO."

*—Cathy Mook*
*Nashua, New Hampshire*

## Death at an Early Age

A member has brought to our attention that *The Gathered View* publicizes the deaths of people with PWS without explanation as to the cause of death. We apologize for leaving some of our readers mystified, and we appreciate the reminder of the need to explain.

PWS is not a terminal illness, but it ***is*** life-threatening: The combination of food obsession, slow metabolism, and poor exercise skills in people with PWS can lead quickly to obesity if the diet is not closely controlled. Over time, obesity leads to heart and/or respiratory failure—the usual causes of death in the lost battles we report and grieve together. *—The editors*

*Imagine*—*continued from page 1*

you but you are faster then they are and you eat it, and they get mad at you, but it was worth it because that one little piece tasted so good. Better than the air-popped stuff.

***Imagine*** that you have a hard time expressing your feelings and you get mad easily, but only when things aren't fair. Only when someone breaks a promise. Only when you're not getting what you think you need or deserve. Imagine that when you can't say what you want to say you scream and hit. You wonder why you get in trouble for hollering when everybody else is hollering too! Or sometimes you just sit and REFUSE, and nobody can make you move. You know you feel better when you take your medicine, but you don't want to take your medicine. You don't know why, you just don't want to take it. When you refuse to take your medicine, you get in trouble. But when someone in charge forgets to give you your medicine and you lose control, then you are the one who gets in trouble.

***Imagine*** that you have family and friends who understand you. Imagine that your teacher, your case manager, your care provider, your doctor, all understand PWS. They know you are different, but they know you are special too. Imagine how lucky you would be!

❖ ❖ ❖

*Editor's Note:* Teresa Kellerman is the mother of Karie, who has PWS. She is also treasurer of PWSA's Arizona chapter, editor of PWSAA's newsletter, *Prader-Willi Nilli News*, and the creator of the chapter's World Wide Web page (reachable through PWSA's Website or directly at the following location: *http://www.azstarnet.com/~tjk/pwsaa.htm)* "Imagine" appeared in the April issue of the Arizona newsletter and is the inside text of a new Arizona chapter brochure. It is reprinted in *The Gathered View* with Teresa's permission.

## Research

### Call for PWS Patients with Atypical Clinical Features

Dr. Robert Nicholls and colleagues are interested in identifying PWS patients with a typical or larger deletion (detected by chromosome analysis or molecular results) or uniparental disomy (UPD), in whom there may be atypical clinical features, particularly more severe characteristics. Recent genetic studies in mice suggest a possible explanation for differences in severity in some cases of Prader-Willi syndrome.

Dr. Nicholls is a member of the PWSA (USA) Scientific Advisory Board.

For information, please contact:

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University Hospitals of Cleveland
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Fax: 216-368-3432; E-mail: rxn19@po.cwru.edu

### New Study on Behavior Change Medications Needs Participants

Dr. Barbara Whitman of St. Louis University School of Medicine is seeking to update information regarding the use of behavioral change medications in persons with Prader-Willi syndrome. She hopes to gather systematic data on the administration, effectiveness, and side effects of behavior change medications.

Dr. Whitman is seeking caregivers of persons with PWS (parents or direct care staff) to participate in this comprehensive study during the next several months. She hopes to collect information on at least 100 persons who take or have taken behavior change medications. Caregivers will be asked to respond by telephone to a 20-minute structured survey inquiring about these medications. In addition, for those who are willing, prescribing physicians will be contacted for copies of medical records. Caregivers who agree to the review of medical records will receive release forms needed to authorize release of the records. Dr. Whitman will pay all necessary postage and copying costs related to acquisition of medical records.

Dr. Whitman is a member of both the PWSA (USA) board of directors and its Scientific Advisory Board. She and colleague Dr. Sue Meyers are currently conducting a two-year study of growth hormone in persons with PWS.

Results of the drug survey will be shared with study participants (parents and other appointed caregivers), doctors of the individual subjects, and PWSA (USA).

For information, please contact:

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