



# Prader-Willi Alliance of New York, Inc.

Advocacy • Support • Hope

## WINTER 2007

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A Chapter of the  
Prader-Willi  
Syndrome Association  
(USA)

## President's Message

Barbara McManus



As your President I pledge to you that this year, 2007, will be a year of growth and progress for the Prader-Willi Alliance of New York, Inc. (PWANY). As an example, take a look at our new website which has had a face lift ([www.prader-willi.org](http://www.prader-willi.org)) and is expanding daily with new information posted as it becomes available.

Our new logo and masthead reflects our hopes for a bright future for those we serve, the people with PWS. Please take the time to surf through the site and inform us if there are any changes or additions by e-mailing us at [alliance@prader-willi.org](mailto:alliance@prader-willi.org).

This edition of the Alliance Newsletter is our invitation to you to attend our annual conference which will be held on April 27th & 28th at the Best Western Hotel, 1228 Western Avenue in Albany, New York.

As always we will have a host of exiting and informative speakers coming from all parts of our State and Country that will cover a wide range of topics ensuring that no age group is left out. Additionally we have also scheduled specific sessions for the care giving professionals who attend (*See the conference schedule on Pg. 4*). Sign up early by filling in the registration form (Professional or Family) in this newsletter or by downloading either form from our website.

If you have never attended a PWS Alliance Conference before, you will be pleased with the informal format which gives all participants an opportunity to talk to the experts one on one.

All families, Care Providers, OMRDD or DOH staff, Physicians, Medical Professionals, Psychologists, Nutritionists and all others are invited. You will learn so much about our wonderful individuals with the Syndrome. ■

## Dr. Angulo's NY Metro Region PWS Support Group

Meeting 4/17/2007, 5/8/2007

The meetings will begin at 7:30 PM in Dr. Angulo's office,  
120 Mineola Blvd.

As always there will be a guest speaker with lots of opportunities for questions and answers. Refreshments will be served. Dr. Angulo, Monika Zack and Michelle Lamerson will be there.

It is important for your child's future that you attend. We all can learn more on what we, or others can do to help our children lead better lives. For more information call 516-663-3090, ask for Monica Zack.

To ensure the success of these meetings please let Monica Zack, [mzaptekar@yahoo.com](mailto:mzaptekar@yahoo.com) and Harry Persanis, [hpers@aol.com](mailto:hpers@aol.com) before each meeting that you will be attending. ■

Mark your  
calendar!

The Prader-Willi Alliance of New York (PWANY) through an OMRDD Family Support Services Grant (administered by Catholic Charities Disabilities Services) is pleased to announce the development of our "Listserv" and "Bulletin Board" at <http://www.prader-willi-alliance.org>.



We think these lists will prove to be an invaluable resource for information sharing and discussion about issues relating to Prader-Willi Syndrome (PWS) in New York State as well as on a regional and national level.

A "Listserv" is an e-mail list. You must have e-mail to get information from the list. Everyone on the list receives the announcement, article or whatever information is being disseminated. You can reply to messages from the Listserv after the moderator reviews it. This allows for discussion among members. When you delete Listserv messages from your e-mail it is gone. The Prader-Willi Alliance listserv is a free, moderated email discussion group. The purpose of the Prader-Willi Alliance listserv is to provide an electronic forum for sharing information related to PWS, its assessment, treatment and the learning, social and educational ramifications to children and adults with PWS as well as the issues that affect their families. Prader-Willi Alliance

Listserv is not a closed list; it is open to parents, therapists, educators, researchers and anyone else who wants to discuss and learn about PWS.

A "Bulletin Board" is web based and you do not need an e-mail address to access it. You can view it from any work station that has Internet access. Once you register you can post messages on the Bulletin Board and only the "poster" (the person posting the message) or the moderator can remove it. A Bulletin Board is better for announcements that you want anyone in the general public to see. Information can and is archived for longer periods of time.

There are two registration forms (one for families and one for professionals) currently posted on the bulletin board for our 17th annual conference. You can download the form and register early!

**Please join us to share information, resources, and suggestions! ■**



## OFFICERS & DIRECTORS

<b>Barbara McManus</b>	<i>President, Niagara Falls</i>
<b>Hon. Daniel D. Angiolillo</b>	<i>President Emeritus, Director, W. Harrison</i>
<b>Henry Singer</b>	<i>Vice President, Brooklyn</i>
<b>Harry Persanis</b>	<i>Vice President, Wantagh</i>
<b>Nina Roberto</b>	<i>Secretary, Queens</i>
<b>Jeannie M. Dickinson</b>	<i>Treasurer, Grand Island</i>
<b>Ann Baird</b>	<i>Director, Clinton, MA</i>
<b>Elinor G. Baller</b>	<i>Director, Larchmont</i>
<b>Gloria Cox</b>	<i>Director, Manhattan</i>
<b>Nancy Finegold</b>	<i>Director, W. Hempstead</i>
<b>Kathy Funk</b>	<i>Director, Ballston Spa</i>
<b>Volena Howe</b>	<i>Director, Rochester</i>
<b>Daniel J. Maillet, Jr.</b>	<i>Director, Irvington</i>

**Linda LeTendre** *Coordinator, Saratoga Springs*

## The "Alliance" Needs You

**Please check the label on the front of this newsletter.**

If you are a current member, or a recent member your last date of membership will appear above your name. (see label below). If you are a current member THANK YOU, if you are not a member won't you please join with us now?

Member 2006  
Joe & Jane Doe  
22 Main St.  
Every town, NN 12333-4444

The "Alliance" is a tax exempt organization which means any donation to the "Alliance" is tax deductible. The "Alliance" has NO paid staff and our income is derived from you our members. The more members we have the more powerful our voice.

Our expenses continue to grow. As an example, the cost of printing and mailing this newsletter has almost doubled and of course our annual conference where we had to pay for the increased cost of flying and accommodations for our excellent guest speakers has left our treasury in need of replenishment. That is why we urge you not only to join but to **DONATE** to the "Alliance" so that our good work will not end prematurely.

**Please don't wait to join us! ■**

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# The 17th Annual Alliance Conference Announcement

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**The 17th annual Prader-Willi Alliance of New York, Inc. Conference will be held at the Best Western Sovereign Hotel in Albany, NY on Friday, April, 27th and Saturday, April, 28th, 2007.**

This is the same location in Albany where we have had most of our conferences. The hotel is located at 1228 Western Avenue, Albany, NY 12203. For your convenience the Alliance has reserved a block of rooms for Thursday, Friday and Saturday at a special conference rate of \$84.00 per night, single or double, \$89.00 per night, triple/quad.

The rate will include breakfast (full or buffet). Children 18 and under stay free, but breakfast will cost an additional \$2.99 for each child. The hotel amenities include a large indoor swimming pool and in each room a hair dryer, ironing board & iron, free cable with HBO and a coffee maker.

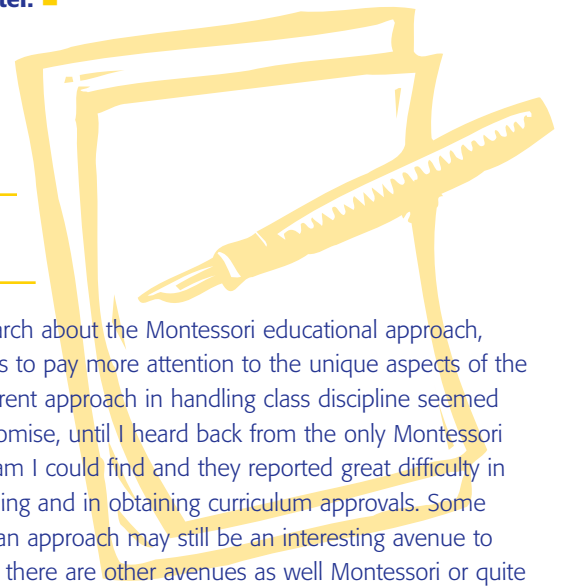
Reservations can be made by calling the hotel at (518) 489-2981. Ask for the Special Conference Rate. Your reservation must be made by April, 6th, 2007 to obtain the Special Conference Rate.

The Conference Committee has purposely set aside valuable time for both parents and providers to separate into smaller groups where they can share information and concerns among themselves. All of our distinguished presenters will be available for these discussions. As many before have discovered, some of the most valuable time at our conference is spent at these impromptu discussions during lunch and breaks, and at our informal open house on Friday night.

The Developmental Disabilities Planning Council has provided the Alliance with a grant to help defray the cost for those who can't afford to attend the conference. For information please call 1-800-442-1655 or E-mail us at [alliance@prader-willi.org](mailto:alliance@prader-willi.org)

Please, save the dates and make your reservation now. We promise to make this a most enlightening and enriching experience.

**Reservation forms can be found as inserts in this newsletter. ■**



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## A Parent to Parent Letter

*By Helen McLeary*

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**Dear Parent,**

My name is Helen, my 7 year old son, Aaron, has Prader-Willi Syndrome (PWS) and is in 1st grade in a NYC Special Education 12:1:1 program. When he was younger, he had very few tantrums, and behaviorally did pretty well in school with the help of a full time Para-professional. Educationally, he has not done as well.

Lately, he has started to tantrum more frequently and with greater severity. At the same time, the attention that his school pays to him during the tantrums plays to his sense of theater and his behavior spirals out of control to the extent that they seek to suspend him. Having thrown one or more of these tantrums tends to increase the likelihood that he will throw more and so rather than abating, a cycle of severe tantrums feeds off itself.

I would like to explore whether there are enough parents with children with PWS to form a critical mass of interested parents to lobby for a program specifically geared toward our children and their issues in New York City's public schools. My instinct is that this will not be a program of inclusion as with mainstreaming, but rather one of drawing away from the no child left behind (high pressure) approach to teaching our children, in favor of something that allows them a little more leeway to learn in their own way and to recover from lapses in behavior with less attention on the negative, and more on the positive.

Preliminary research about the Montessori educational approach, whose premise is to pay more attention to the unique aspects of the child with a different approach in handling class discipline seemed to hold some promise, until I heard back from the only Montessori special ed program I could find and they reported great difficulty in maintaining funding and in obtaining curriculum approvals. Some aspects of such an approach may still be an interesting avenue to explore. I'm sure there are other avenues as well Montessori or quite possibly some approaches that you could share.

I invite any and all of you who have something to say, who are curious, interested, or concerned about our school age children to join in a dialogue with me and with other parents to see if we can come up with workable ideas to present to NYC's Department of Education or to a sympathetic private school for a program for which we might be able to attract NYC Department of Education funding. All of this in lieu of NYC's Department of Education already high costs in educating our children in not so ideal an environment.

Please contact Nina Roberto, Secretary of the Prader-Willi Alliance of N.Y., Inc. at [victorian\\_lace@earthlink.net](mailto:victorian_lace@earthlink.net) or **718-846-6606** if you want to join us in this exploratory dialogue to try to come up with some ideas and a plan that will help our children.

With best regards,

*Helen McCleary* ■

# 17th Annual Prader-Willi Alliance Conference Schedule

## Thursday, April 26th

8:00 p.m.  
to 10:00 p.m. Registration

## Friday, April 27th

8:00 a.m. Registration  
8:45 a.m. Opening Remarks and Welcome: Barbara McManus, President, PWANY  
9:00 a.m. Keynote Speaker  
9:30 a.m. Hormonal Evaluation in PWS: Moris Angulo, MD  
10:30 a.m. Break  
10:45 a.m. Concurrent Sessions  
    Session a) Behavioral and Cognitive Differences Between the Genetic Subtypes of PWS:  
                Jenifer Zarcone, PhD, URM, Deborah Napolitano, Ph.D., URM  
    Session b) Accepting, Growing and Thriving; The Stages of the PWS Family: Janalee Heinemann, PWSA(USA)  
12:00 p.m. Lunch  
1:00 p.m. Alliance Member Meeting and Election of Officers and Directors  
2:00 p.m. Concurrent Sessions:  
    Session a) Sleep Apnea in People with PWS: Mary Cataletto, MD  
    Session b) Q&A for Professionals Panel: Moderator, John Porcella, PhD,  
                Mary K. Ziccardi, DA QMRP, Gary Siegel, Exec. Dir., CCD  
                • OPTS Process  
                • Staff Training  
                • PWS Diet  
                • Staffing Levels for PWS Residences  
                • Medicaid Waiver Program  
                • Entitlements  
    Session c) PWS Behavior Management: The Early Years: Linda Gourash, MD  
3:00 p.m. Break  
3:15 p.m. Concurrent Sessions:  
    Session a) Self regulation: Linda Gourash, MD, Group Home Best Practices, BJ Goff, Ed. D  
    Session b) Q&A Session, Newly Diagnosed with PWS: Moris Angulo, MD  
    Session c) Benefits of Growth Hormone & Genetics of PWS: Michelle Lamerson, CNP, Monica Zak-Aptekar, MS  
5:00 p.m. Sessions End  
7:30 p.m. Alliance Reception

## Saturday, April 28th

8:00 a.m. Registration  
8:45 a.m. Barbara McManus, President, PWANY  
9:00 a.m. Session a) 50 Years of Progress: Janalee Heinemann, PWSA(USA)  
                Session b) Developing a Training Guide for PWS Service Providers: Sally O'Leary, Director of HR & QA, CCDS  
10:00 a.m. Break  
10:15 a.m. Concurrent Sessions  
    Session a) Skin Picking and Sensory Stimulation in PWS: Patrice Carroll, Dir. PW Services, Advocates, Inc., MA  
    Session b) Maintenance and Enforcement of the IEP Document: Jennifer Monthie, Esq.  
    Session c) The Later Years: What Happens To Me Then? Gary Siegel, Exec. Dir. CCDS, BJ Goff, Ed. D: Group discussion.  
11:15 a.m. Session a) Wills and Trusts: Edward Wilcenski, Esq.  
                Session b) How Parents Can Influence the Opening of a PWS Group Home: Jeff Covington, CCDS  
12:15 p.m. Lunch  
1:00 p.m. Current Research in PWS: Jamie H. Bassel, D.C.  
2:00 p.m. Sharing Sessions  
    Session a) Ages 0-5 Moderator: Nina Roberto  
    Session b) Ages 6-15 Moderator: Janalee Heinemann  
    Session c) Ages 15+ Moderator: Barbara McManus

For the most current Conference Schedule information please go to [www.prader-willi.org](http://www.prader-willi.org)

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## Our Conference Presenters

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**Moris Angulo, MD, Director of Medical Genetics and Assistant Director of Pediatric Endocrinology at Winthrop University Hospital and Associate Professor of Clinical Pediatrics, SUNY at Stony Brook School of Medicine.** He follows more than 200 children and adults with PWS at his practice in Mineola, NY. He is a member the PWSA(USA) Clinical Advisory Board

**Jamie H. Bassel, D.C. P.C.** Became involved with PWS 9 days after his son Zakary (19 months) was diagnosed with PWS. He is an active member of the PWSA (USA) Scientific Advisory Committee.

**Patrice Carroll, Dir. PW Services, Advocates, Inc., MA:** Has many years of experience developing and providing services for people with Prader-Willi Syndrome.

**Mary Cataletto, MD:** She is the **Associate Director of the Division of Pediatric Pulmonology and Director of Children's Sleep Services at Winthrop University Hospital in Mineola, NY**, additionally she serves as Associate Professor of Clinical Pediatrics at Stony Brook University on LI. She has vast experience caring for people with PWS.

**Jeffrey A. Covington, Director of Residential Living, Catholic Charities Disabilities Services (CCDS); Panel members; Mary George, Parent, Joanne Green, Parent; Marianne Purrello, Individual with PWS, Kerry George, Individual with PWS, Ellen Bagge, Associate Director of Residential Living, Darlene Ginsberg, Site Supervisor; Carrie Woodard, Behaviorist.**

**BJ Goff, Ed. D, Associate Professor of Education at Westfield State College in MA:** She is also a disabilities consultant, specializing in PWS. Dr. Goff has first-hand experience opening and operating PWS group homes. She also serves as an educational crisis consultant for PWSA(USA).

**Linda Gourash, MD:** A Developmental Pediatrician who graduated from Georgetown University Medical School in Washington DC. As the medical director of the P. W. and Behavioral Disorders program of the Children's Institute of Pittsburgh she worked for more than five years, almost exclusively with children and adults with PWS.

**Janalee Heinemann, MSW – PWSA(USA):** Executive Director and Past President PWSA(USA). Parent of an adult son with PWS; Masters in Social Work from Washington University in St Louis, MO; Oncology Pediatric Medical Social Worker at St Louis Children's Hospital-10 yrs.; Hospice Social Worker-3 yrs.; Child Abuse & Neglect Social Worker-6 yrs.

**Michelle Lamerson, CNP,** is a Certified Pediatric Nurse Practitioner working in the Pediatric Endocrine and Genetics Center at Winthrop University Hospital since 1999. She graduated cum laude from Adelphi University with a Bachelor of Science Degree in Nursing in 1991. She is involved in the evaluation and management of children with Prader-Willi Syndrome, and varying endocrine disorders. She is a member of several nursing Societies and the National Association of Pediatric Nurse Practitioners.

**Jennifer Monthie, Esq., attorney at Disability Advocates, Inc., in Albany, New York:** She practices in the areas of Education Law and Civil Rights Law. She is a founding member of the Special Education Task Force dedicated to educating advocates and parents on Special Education.

**Deborah Napolitano, Ph.D.:** Senior Instructor of Pediatrics, University of Rochester Medical Center, Strong Center for Developmental Disabilities. Graduate School University of Kansas. Postdoctoral Fellowship

**Sally O'Leary, Director of HR & QA, CCDS:** Worked in the field of developmental disabilities for over 25 years. She is director of HR and QA for Catholic Charities Disabilities Services.

**John Porcella, PhD, Executive Director, Community Living Corporation:** John Porcella is the Executive Director of Community Living Corp. (CLC) located in Mt. Kisco, NY. CLC has operated a residential program for people with Prader-Willi Syndrome since 1991. He has more than 25 continuous years of experience with PWS and was responsible, in 1980, for developing the first residential school program in New York for children with PWS.

**Nina Roberto, Secretary, PWANY, Parent Mentor, PWSA(USA):** Has many years of experience as a Certified Phlebotomist Technician, CPT, IV Technician and parent of a PWS child.

**Gary Siegel, Executive Director, CCDS:** Has been in the field of developmental disabilities for over thirty years. Developed Catholic Charities Disabilities Services in the Capitol District over twenty years ago. Helped to found and organize the PWANY more than twenty years ago. Opened the first of several group homes for people with PWS in the Capitol District over ten years ago.

**Edward Wilcenski, Esq.:** is a co-owner/manager of Jones & Wilcenski PLLC. He is a Trustee of the NYSARC Pooled Trust, serves as a Trustee of the Wildwood Pooled Trust, which serves individuals with learning and developmental disabilities throughout the Capital Region. He practices in the areas of Elder Law, Special Needs Estate Planning, and Trust and Estate Administration. He lectures frequently to attorneys, agency staff and families on elder law, special needs trusts and other legal issues.

**Monika Zak-Aptekar,MS:** Senior genetic counselor at the division of Human Genetics at Winthrop University Hospital, Long Island, NY. She administers the activities of Dr. Angulo's Metro. Support Group.

**Jenifer Zarcone, PhD, Associate Professor of Pediatrics at the University of Rochester Medical Center:** She currently has an NIH funded grant focusing on compulsive behavior and appetite in Prader-Willi syndrome.

**Mary K. Ziccardi, DA QMRP, Administrator at REM Ohio, Inc.:** Developed and implemented residential services to people with PWS for more than a decade. Has served as a member of the PWSA(USA) board of directors for six years.

**Since the initial paper on Prader-Willi Syndrome (PWS) in 1956 by Drs. Prader, Labhart, and Willi describing the clinical characteristics of nine individuals there have been over 1000 studies published to date on the syndrome.** Because PWS is caused by abnormalities in a specific chromosome, researchers are interested in the syndrome because the direct effects of specific genes can be evaluated in relation to physical and behavioral outcomes. Research into the characteristics of individuals with PWS and other Neurodevelopmental disorders (e.g., Fragile X syndrome, Down syndrome, autism) is an area of great growth over the past 10 years and the focus of much research.

One of the hallmark characteristics of PWS is excessive eating (sometimes called hyperphagia). This includes not only consuming a large amount of food but also eating contaminated food from the garbage or inedible food such as frozen bread rolls or powdered drink mix (Butler & Thompson, 2000). Researchers have found that individuals with PWS will eat up to 3000 calories if given the opportunity. In addition, they will report that they are beginning to feel hungry again within 20 minutes after consuming a large meal while comparison individuals will not report feeling hungry even four hours later (Holland et al., 1993).

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Researchers are attempting to understand the biological and psychological factors affecting the excessive hunger and food-seeking behavior in individuals with PWS. Is it the case that there is a breakdown in communication between the digestive system and those areas of the brain that tells us we are hungry or full? Specific hormones or neuropeptides that affect appetite may be altered in individuals with PWS. For example, ghrelin is a hormone that increases appetite and regulates energy. Individuals with PWS have extremely high ghrelin levels and this has been proposed as a possible source of the excessive appetite (Del Parigi et al., 2002). Other hormones and peptides such as peptide YY, oxytocin, and leptin are also being examined to determine how they may be different in individuals with PWS compared to people who don't have PWS. This may serve as a link for better understanding obesity in the general population.

In our research, we are trying to understand the brain mechanisms linked to food intake may be different in people with PWS. The brain mechanisms related to hunger were studied in healthy weight individuals and people with PWS. We found that healthy weight individuals showed more brain activity when looking at pictures of food when they were hungry whereas people with PWS showed more brain activity when looking at these same pictures only after they had eaten a meal. Why would this be?

It is possible that those mechanisms that regulate hunger aren't working correctly and eating any amount of food primes the brain and makes people with PWS even more focused on food? Further research is needed to examine the possible mechanisms in the brain that affect hunger and eating need to be studied to truly understand what is happening.

In 2000 the Food and Drug Administration approved growth hormone treatment for children with PWS. This hormone will help children grow taller and have stronger muscles, which is a major problem for them. This milestone may change the future for children with the syndrome not only because growth hormone increases height, but it also improves body composition, energy expenditure, muscle strength, physical agility and heart function (Hoybye, Hilding, Jacobsson, & Thoren, 2003).

As a result, individuals with PWS avoid the psychological burden of being short and falling behind their peers developmentally. Whitman, Myers, Carrel, and Allen (2002), demonstrated several positive physical and psychological effects of growth hormone treatment with 35 children and adolescents with PWS. Additional studies are continuing to look at other positive behavioral as well as physical outcomes of growth hormone.

Treatment of PWS falls into the areas of medication management (including growth hormone therapy described above) and/or behavior management. Appetite suppressant and obesity medications have been used in an attempt to curb hunger but have generally been ineffective or have had mixed effects. Medications also are being used for the treatment of skin picking, anxiety, and compulsive behavior in individuals with PWS. Antidepressants and antipsychotic medications have been successful in the treatment of non-food related behavior problems and continue to be the most commonly prescribed medications. Stein D.J., Keating J., Zar H. J. & Hollander E. (1994) A survey of the phenomenology and pharmacology of compulsive and impulsive aggressive symptoms in Prader-Willi Syndrome. *Journal of Neuropsychiatry* 6, 23-9.

Behavior management for compulsivity and maladaptive behaviors include: providing a structured, predictable routine; providing extra help and time with transitions; and family support (Dykens, Leckman, & Cassidy, 1996). Additional data have been published that show differential reinforcement for the absence of food stealing and a response cost were effective in reducing food stealing in a controlled setting for three persons with PWS (Page, Stanley, Richman, Deal, & Iwata, 1983). Unfortunately, there are very few other studies explicitly describing effective behavior management programs to both decrease food intake and provide support for other symptoms (e.g., skin picking) displayed by individuals with PWS. This is clearly an area in need of research.

There are many other areas of research aimed at better understanding the syndrome that includes the development of a mouse-model, comparing the behavior of individuals across each of the genetic subtypes, as well as understanding the source of compulsive and problem behavior. While we may be able to manage the syndrome to a large degree, there is still much that we need to learn about the effects of the syndrome. ■

## Current Research in Prader-Willi Syndrome

(Continued)

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## I Have a Dream

By Rose Burns

My daughter Rose is in fifth grade. had to write a composition in honor of Martin Luther King Day. I wanted to share with you what she wrote.

Sybil Burns in NJ

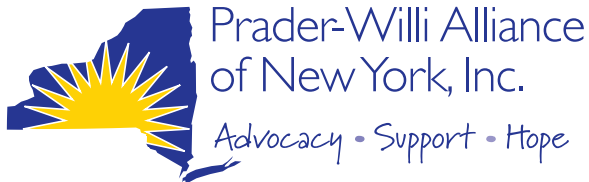
### I Have A Dream

*I have a dream. My dream for the world is that in all countries they should try to find cures for all diseases and disabilities. This is my dream because I have a disability and it is called Prader-Willi Syndrome. I am so desperate for a cure for what I have and for all the other people out there who have something because they are desperate too. This is my dream for the world.*

*is another part of my dream. I want my dream to come true because I feel their pain and I know how they feel. If I were with these people that have disabilities, I would tell them to hang in there and not give up. I would tell them that whatever they have can't rule their life, even though it seems like it. I'm saying this to everyone because giving up isn't good. When I give up on something, it's not like I can be like, "all right, I give up." I have to urge myself and push myself to do it. Also, in my life kids haven't liked me and have teased me. They have done this just because I look and act different. Ever since 1st grade everything started to go wrong, even before that. My parents have fought to get me into the school that they wanted me in. Then in 1st grade the kids bullied me. I only have one friend. Even the teachers were mean to me and they had no time to teach me. I was held back. So then my family moved from Woodbury, NJ to Cherry Hill, NJ. I redid that grade. Once again, kids were mean to me. One kid never listened when I talked, one accused me of doing things, and another kid annoyed me. This happened in second grade. That year though my teacher was really nice and she liked me. In third grade, the teachers were nice. The kids were still mean and there was too much pressure on me. I left that school and I didn't like getting pulled out.*

*So, that's why I'm at Orchard Friends School. My teachers Miss P., Miss Weisman, Miss McMahan, and Mrs. Topiel have been the best help to get me ready to return to Cherry Hill for middle school which is either going to be Beck or Rosa. I have learned to let go of things sometimes. You have all taught me a lot. Thank you for all your help.*





Prader-Willi Alliance of NY, Inc.  
2970 Beltagh Avenue  
Wantagh, N.Y. 11793

**Please enroll me (us) as a member of the Prader-Willi Alliance of New York, Inc.**

Dues are \$20 per person or family of three. Your membership entitles you to one (1) vote in the organization. You may enroll as many additional members of your family as you like at \$20 per person.

Enclosed are dues for 2007 \$ \_\_\_\_\_

Here's an additional tax-deductible contribution: \$ \_\_\_\_\_

Amount Enclosed: \$ \_\_\_\_\_

Date: \_\_\_\_\_  New Member  Renewal

Name: \_\_\_\_\_

Address: \_\_\_\_\_

City: \_\_\_\_\_ State: \_\_\_\_\_ Zip: \_\_\_\_\_

Telephone: \_\_\_\_\_ Fax: \_\_\_\_\_ E-Mail: \_\_\_\_\_

- Check this box if you do not want to share your name with the PWSA (USA)
- Check this box if you do not want to share you name with OMRDD
- I would like to become active in the Alliance. Please call me to discuss my involvement.

**Parents of Children with PWS:** Please give us the name, age and living placement of your child. *This is optional, and will be used only for purposes of "parent-to-parent" networking:*

Child's Name: \_\_\_\_\_ Child's Date of Birth: \_\_\_\_\_ Age at Diagnosis: \_\_\_\_\_

Where is Child Residing? \_\_\_\_\_

**Please make your check payable to the Prader-Willi Alliance of New York Inc. and send it to:  
Prader-Willi Alliance of New York, Inc., PO Box 1114, Niagara Falls, NY 14304**