



# Prader-Willi Alliance of New York, Inc.

267 Oxford Street - Rochester, N.Y. 14607

Conference, "2004" Edition

## 14th Annual Conference of the Prader-Willi Alliance of NY, INC.

The 14th annual Prader-Willi Alliance of New York Conference will be held at the Best Western Sovereign Hotel in Albany, NY on Friday, April 30th and Saturday, May 1st, 2004. This is the same location as last year's conference. 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, and at a special conference rate of **\$80.00** per night, single or double, **\$88.00** 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 15th 2004**, 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.

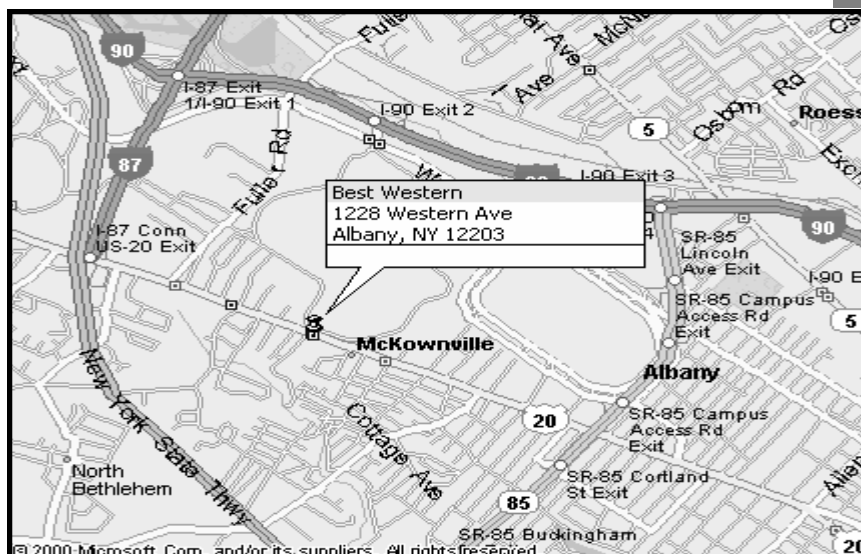
The Developmental Disabilities Planning Council has provided the Alliance with a grant to help defray the cost for those who can't afford to attend the conference. For more information please call 1-800-442-1655.

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

**ATTENTION  
REGISTER NOW  
ALLIANCE CONFERENCE  
"2004"  
April 30th-May 1st**

### DIRECTIONS

Exit 24 on N.Y. State Thruway (I-90), take Exit 1-South to the end, make a left onto Western Ave. (Rt. 20), hotel on right Side of Rt. 20.



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

# A MOTHER'S RESPONSE

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**Editor:**  
**Harry Persanis**

One of our parent/members (Helen McCleary) recently responded to another parent whose child with Prader-Willi Syndrome (PWS) was in crisis. It is a response worth sharing:

There are different levels of genetic testing necessary for the chromosomal diagnosis of PWS. The one that detected my son's is called FSH I.

I am just a parent of one particular 4 year old boy with PWS. There are support groups for parents of such children. You should probably contact your local group. You can find them through the PWSA (USA) whose website is [www.pwsausa.org](http://www.pwsausa.org). Please promise me you will call them as you sound like you need help right now!

In addition, if you have not already done so, you should also call your local early intervention office to arrange for therapies for your child. Mine received speech therapy, occupational therapy, physical therapy and special education from the age of 3 months. In NY children age out of such a program at the end of the calendar year in which they turn three, so take what you can get while you can get it for your child! I think my son enjoyed and benefited from these therapies (well, he hated physical—it was hard!)

My son is also being treated with growth hormone by a pediatric endocrinologist/geneticist. It is worth a consultation with such a doctor as the growth hormone fosters more lean muscle mass development as well as height acquisition. You do not mention if your child has fallen off the growth chart—mine did. Our doctor is in Mineola NY and I would heartily recommend him. His name is Dr. Moris Angulo (516 663 3090).

I am not an expert on behavioral modification, only a parent. I can only share with you what I think has been working for our family...I say family, because having such a child in your house impacts everyone in the house.

First, you may need to accept that you have to change the entire approach to food in your house. In mine, eating is now a very structured activity. We eat at set times. We have established a portion control system, whereby my son is given 1/3 of a full portion (for him) up front, so he can come back for "seconds" and "thirds". No one eats when the child with Prader-Willi is not eating. If you have a drink, he has a drink. We drink a lot of water and diet soda. All follow the rules. No candy is allowed in the house. The door to our kitchen has a lock. We do not reward or punish with food.

So much for procedure. There are other aspects to working with such a child...they can be very manipulative to get what they want...they tend to develop habits which can be hard to break...I consider any conditioned response to be a habit. Screaming can become a habit as well as a pure expression of frustration. You want to minimize such a response as much as possible because it is hard on you, and it makes the child socially unacceptable, and it doesn't promote the development of better communication skills. Ignore briefly and redirect after a short respite. This usually works with my son. Sometimes it doesn't. Luckily I have faith. I usually pray for strength when my son is especially difficult. Then I tell my son, "I don't know why I love you, but I do!" And then I kiss him.

If your child is like mine, he enjoys it when you get angry or excited. Avoid getting him hooked on getting an adrenalin rush from getting you angry since I unscientifically think this may result in your child's brain getting more hard wired to seek such a response for enjoyment like a kind of backwards positive reinforcement!. Speak to him as rationally as possible. Even as a toddler, he may enjoy confrontation.

He may be developmentally delayed, but try to speak to him on a level he may understand in a civilized way. If it doesn't work, back off temporarily, then come back and redirect. My son also tries to push his 8 year old brother's buttons. He is usually successful. The 8 year old then gets a side-bar about dealing with his PWS brother. I acknowledge the 8 year old's frustration with a hug, and try to make sure he gets separate attention and lots of "lovin."

Establish other purposes for meals—foster the idea by repetition in word and deed that meals are for hanging out with your family as well as eating. Reassure him that no one will eat or remove his food until he is done by your reassuring word and deed (and never using food as reward or its removal as punishment). Sit at a table for meals and snacks as a family to reinforce the social aspects of eating.

Give him things to "crinkle" in his hands when not engaged in meals so that he may continue to derive sensory input from crinkling a plastic bag, a paper towel, etc. It may help take his focus away from hunger. These are just a few suggestions. As you search the web, attend conferences and talk to other parents you will discover many more. This is just the first of many steps you will take to ensure your child's success and happiness.



The Alliance Conference Committee has been working tirelessly planning, scheduling and arranging presenters for our 14<sup>th</sup> Annual Conference. This year's conference will be held at the Best Western Hotel in Albany on **April 30<sup>th</sup>** and **May 1<sup>st</sup>**. Please take time to look over the details contained in this newsletter regarding this annual conference.

The speakers will present to parents and caregivers the most current and reliable material and information on Prader-Willi Syndrome available to date. Our speakers are outstanding. They will highlight their expertise, their research and their

treatment for Prader-Willi Syndrome. Pertinent issues from *infancy* to *adulthood* will be addressed.

I look forward to seeing you in Albany. The annual conference provides a wonderful opportunity to meet parents and professionals, ask many questions and share diverse experiences. I am confident you will come away from this conference having made new friends and gained knowledge to better meet the needs of our loved ones with Prader-Willi Syndrome. I hope you plan to attend. Please complete the attached registration form and return it as soon as possible! Together we will make this our best Conference ever!

## OUR CONFERENCE PRESENTERS

**Cheryl Adamec**, is the Public Affairs Representative at the Social Security Administration, Albany, NY. Cheryl will present on Medicare, SSI, Retirement Survivor Disability and Health Insurance for the disabled.

**Linda Gourash, M.D.**, a Developmental Pediatrician who serves as the Program Medical Director of the Prader-Willi Syndrome/Behavioral Program at the Children's Institute in Pittsburgh, Pennsylvania. Dr. Gourash will discuss obesity and behaviors associated with Prader-Willi Syndrome.

**Jim Loker, M.D.** is a Pediatric Cardiologist and Medical Director of Pediatrics at Bronson Children's Hospital in Kalamazoo, Michigan. Dr. Loker, a father of a nine year old with Prader-Willi Syndrome, has written many articles for PWSA (USA) and will discuss sleep disorder and Prader-Willi Syndrome.

**Carolyn Loker**, is Vice President and Board Member of PWSA (USA) and coordinator of its Parent Mentoring Program. Carolyn will bring us up to date on PWSA (USA).

**Peter Pezzolla, Associate Commissioner OMRDD**, heads the Upstate Regional Office, which oversees all of NY State's DDSO's, except for OMRDD offices in NYC. Special Populations and Children's Services also report to him. Comm. Pezzolla will speak about the range of OMRDD services available in NYS for people with disabilities.

**Gary Siegel**, Executive Director, Catholic Charities Disabilities Services, Latham, NY. Gary has been a provider of services to the disabled for more than twenty years and presently operates two residences for people with PWS.

**Robin Stone**, Privacy Compliance Officer, Family Residences & Essential Enterprises (FREE), Old Bethpage, NY. Come hear the achievements of six friends from FREE. Listen to them express their experiences. They will be sharing with you what it was like for them at first and what their lives are like now. This will prove that struggling over the years has only made them stronger. Anything can be accomplished as long as you set your mind to it. FREE operates two residences for people with PWS.

**Ann Marie Vadney**, is the NYS OMRDD Coordinator for PWS Services who will be moderating a panel and will be available throughout the conference for consultation.

**David Wyatt**, the Crisis Intervention Counselor for PWSA (USA), will speak on crisis intervention and on legal issues. He will be available to meet privately with attendees (call David for an appointment (800) 926-4797)

**Tony Zajchenko**, Assoc. Executive Director, Pathways, Inc., Corning, NY. Tony has been a provider of services to people with PWS for more than twenty-five years. At present his agency operates two residences for people with PWS.

# 2004 Conference Program

## Thursday, April 29th

8:00 p.m. to 10:00 p.m. **Check in and Registration**

## Friday, April 30th

8:00 a.m. **Registration**

8:45 a.m. **Hon. Daniel D. Angiolillo**, President , PWANY  
**Opening Remarks and Welcome**

9:00 a.m. **Assoc. Comm. Peter Pezzolla**, NYS Office of Mental Retardation and Developmental Disabilities  
**Partners Into the Future**

10:00 a.m. **Carolyn Loker**, Vice President and Board Member of Prader-Willi Association, (USA), [PWSA,(USA)]  
and its Parent Mentoring Program.  
**PWSA,(USA) Today**

10:15 a.m. **Break**

10:30 a.m. **Jim Loker, M.D.**, Pediatric Cardiologist and Medical Director of Pediatrics, Bronson Children's Hospital  
in Kalamazoo, Michigan.  
**Sleep Disorders And People With Prader-Willi Syndrome**

12:00 p.m. **Lunch**

### Concurrent Sessions:

1:30 p.m. Session a) **Jim Loker, M.D.**  
**Question And Answer Session Newly Diagnosed And Very Young Children With PWS**

1:30 p.m. Session b) **David Wyatt**, Crisis Intervention Counselor, PWSA(USA)  
**Police Related Legal Issues For People With PWS.**

2:00 p.m. Session c) **Dr. Gourash, M.D.** Developmental Pediatrician, Program Medical Director, of the PWS /Behavioral Program  
at the Children's Institute, Pittsburgh, PA.  
**Behavioral And Psychiatric Issues Found In PWS**

3:00 p.m. **Break**

3:15 p.m. **Concurrent Sessions:**

Session a) **Panel will be Moderated by Ann Marie Vadney**, OMRDD  
**Gary Siegel**, Executive Director, Catholic Charities Disabilities Services, Latham, NY  
**Robin Stone**, Privacy Compliance Officer, Family Residences & Essential Enterprises (FREE), Old Bethpage, NY  
**Tony Zajchenko**, Assoc. Executive Director, Pathways, Inc., Corning, NY  
**Minimum Standards For Operating Group Homes For People With Prader-Willi Syndrome.**

Session b) **David Wyatt**, **Issues for Parents of School Age Children**

Session c) **Sharing Session: For Parents of Pre-School Children**

4:00 p.m. **Sharing Session: For Parents of School Age Children**

7:30 p.m. **Alliance Reception**

## Saturday, May 1st

8:00 a.m. **Registration**

8:45 a.m. **Hon. Daniel D. Angiolillo**, President , PWANY  
**Remarks**

9:00 a.m. **Concurrent Sessions:**

Session a) **Panel of Group Home Residents From Family Residences & Essential Enterprises**  
**Power Willingness Success, What PWS Means to Me**

Session b) **Sharing Session: Carolyn Loker, Facilitator**  
**Advocating for Your Child: For Parents of Pre-school and School Age Children**

10:00 a.m. **Break**

10:15 a.m. **Linda Gourash, M.D.**  
**Obesity and Prader-Willi Syndrome.**

11:15 a.m. **Linda Gourash, M.D. and Jim Loker, M.D.**  
**Ask The Experts**

12:00 p.m. **Lunch**

1:30 p.m. **P W Alliance Membership Meeting and Elections**

2:00 p.m. **Cheryl Adamec**, Public Affairs Representative, Social Security Administration, Albany, NY  
**Medicare, SSI, Retirement Survivor Disability & Health Ins. For People With Disabilities**

**A "Certificate of Attendance" will be issued to attendees upon request.**  
**( Please check "Yes" on Registration Form)**

# The 14th Annual Prader-Willi Alliance of New York Conference

## April 30th & May 1st - Best Western Sovereign Hotel

1228 Western Avenue - Albany, New York

### Registration Fee Schedule (all prices are in U.S. funds)

**Family Registration:** \$ 35.00 for two days-\$25.00 for 1 day  
 (up to *THREE* family members may attend for one fee!) \$ 10.00 for each additional family member (good for 1 or 2 days)

**Professional Registration:** \$ 50.00 (good for 1 or 2 days)

**Discount:** "2004" paid members of the Alliance may deduct \$ 5.00 from the total due. You may join the Alliance **NOW** (see application last page) and receive the Conference discount.

**Lunch:** \$ 9.00 per adult- Children's lunch (ages 5-13) is \$ 6.00  
 (The low cost for lunch is due to a grant from Pfizer)

**We have worked closely with the Best Western to provide healthful and appropriate meals.  
 Hotel Telephone # (518) 489 2981**

# The 14th Annual Prader-Willi Alliance of New York Conference

Type of Registration:  Family (How many in family will attend? \_\_\_\_\_ )  
 Professional

Attendance:  Friday only  Saturday only  Both days

Lunches (how many) Friday: \_\_\_\_\_ Adult \_\_\_\_\_ Child  
 Saturday: \_\_\_\_\_ Adult \_\_\_\_\_ Child

LUNCH MENUS	
<i>Choice of one, each day, for each paid lunch</i>	
FRIDAY	SATURDAY
Chicken, baked, stuffed No. _____	Chicken Marsala No. _____
Tuna Salad Plate No. _____	Chefs Salad No. _____
Vegetarian "Prima Vera" No. _____	Vegetarian "Stir Fry" No. _____

Name(s) of People Attending: \_\_\_\_\_

Agency (if applicable): \_\_\_\_\_

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

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

Home Phone: \_\_\_\_\_ Work Phone: \_\_\_\_\_ Fax: \_\_\_\_\_

We will require **free** companion care for a person with PWS, age \_\_\_\_\_; sibling(s) age(s) \_\_\_\_\_

Registration Amount Due: \$ \_\_\_\_\_ Amount for Lunches \$ \_\_\_\_\_ Total Fees Due: \$ \_\_\_\_\_

I would like to make an additional **Tax Deductible** contribution to offset the cost of the Conference \$ \_\_\_\_\_

"Certificate of Attendance"  Yes How many? \_\_\_\_\_ Total Amount Enclosed: \$ \_\_\_\_\_

Please complete this form and mail it, along with your check, to:  
**Prader-Willi Alliance of New York, Inc.- 2970 Beltagh Avenue- Wantagh, NY- 11793**

**Prader-Willi Alliance  
Of New York, Inc.**  
2970 Beltagh Avenue  
Wantagh, N.Y. 11793



**ALLIANCE CONFERENCE ISSUE "2004" April 30th-May 1st**

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

Dues are \$15 per person or family. Your membership entitles you to one (1) vote in the organization. You may enroll as many members' of your family as you like at \$15 per person.

Enclosed are dues for 2004

\$ \_\_\_\_\_

Here's an additional tax-deductible contribution

\$ \_\_\_\_\_

Amount Enclosed

\$ \_\_\_\_\_

Date \_\_\_\_\_

New Member

Renewal

Name \_\_\_\_\_

Address \_\_\_\_\_

City, State, Zip \_\_\_\_\_

Telephone \_\_\_\_\_ Fax \_\_\_\_\_ E-Mail Address \_\_\_\_\_

- Check this box if we have your permission to share your name with the PWSA (USA)
- 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, 2970 Beltagh Ave. Wantagh, NY 11793**