



Prader-Willi Alliance of New York, Inc.

2970 Beltagh Avenue Wantagh, NY 11793

Conference, "2005" Edition

15th Annual Conference of the Prader-Willi Alliance of NY, INC.

The 15th annual Prader-Willi Alliance of New York Conference will be held at the Best Western Sovereign Hotel in Albany, NY on Friday, May 20th and Saturday, May 21st, 2005. 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 at a special conference rate of **\$82.00** per night, single or double, **\$87.00** 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 **May 1st 2005**, 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.

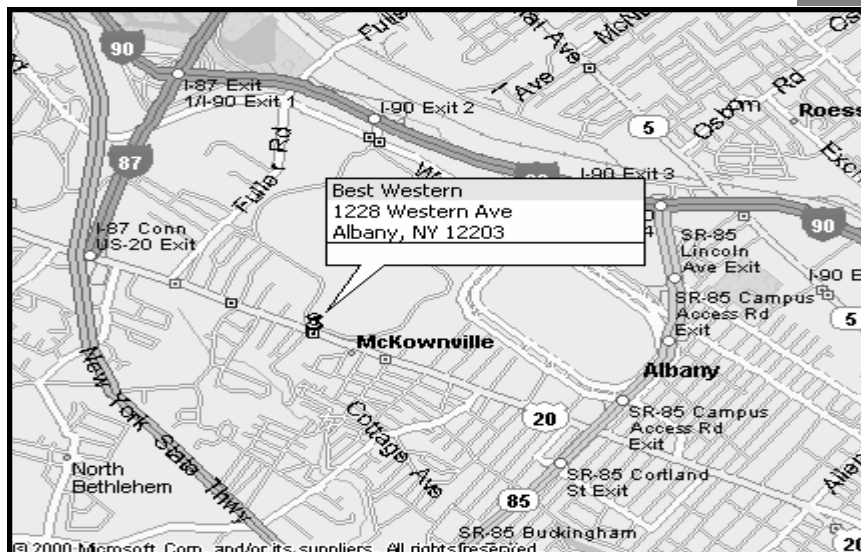
The Developmental Disabilities Planning Council has provided the Alliance with a grant to help defray the cost for those who can't afford to attend the conference. For information please call 1-800-442-1655 or E-mail us at alliance@prader-willi.org

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
"2005"
May 20th May 21st**

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)

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&
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PRESIDENT'S MESSAGE Hon. Daniel D. Angiolillo



The Alliance Conference Committee has been working tirelessly planning, scheduling and arranging presenters for our 15th Annual Conference. This year's conference will be held at the Best Western Hotel in Albany on May 20th and May 21st. Please take time to look over the details contained in this newsletter regarding this annual event.

The speakers will present to parents and care-givers the most current and reliable material and information on Prader-Willi Syndrome available to date. Our speakers are nationally recognized and hail from Missouri, Florida, Indiana, Minnesota, Massachusetts and of course New York. They will highlight their expertise, their research and their treatment for Prader-Willi Syndrome.

Pertinent issues from *infancy to adulthood* will be addressed.

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 look forward to seeing you in Albany and 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!

Why Should I Attend This Conference? By Harry Persanis

I am often asked this question, "Why should I attend this conference? If you've been to one you've been to all." As someone who has attended all the Alliance Conferences I can tell you this one will be exceptional.

Let me explain:

- How often will you as a parent/caregiver/provider have the opportunity to hear, discuss and consult with **Merlin G. Butler, M.D., Ph.D., F.F.A.C.M.G.** who is the PWSA(USA) Scientific Advisory Board Chairman, Chief, Section of Medical Genetics and Molecular Medicine William R. Brown/Missouri Chair of Medical Genetics and Molecular Medicine, Professor of Pediatrics, University of Missouri-Kansas City School of Medicine, Children's Mercy Hospitals and Clinics. Dr Butler is a world renowned researcher of PWS, who is devoted to the task of understanding and treating PWS, particularly in younger children.
- Have you ever been to a conference where a presenter such as **Janice M. Agarwal, P.T.**, who has 15 years of pediatric physical therapy experience, with emphasis on young hypotonic children, demonstrates both Neuro-developmental Training (NDT), and Sensory Integration (SI) techniques that have shown to be tremendously successful with children with PWS. She will not only demonstrate these techniques but teach parents with young PWS children how to apply them.
- Have you considered becoming a guardian for your child? Most parents do not even think about it until their disabled child reaches the magic age of twenty-one when the law says that he/she can now make their own legal decisions without your input. Can you as a parent foresee the day when your child, who is now an adult and twenty-one years old says to you "I can go where I want to go! Eat what I want to eat! And you can't stop me." Believe me, it has happened! You can hear more about this from an expert, **Patricia W. Johnson, Esq., Assistant Counsel to the NYS Commission on Quality of Care for the Mentally Disabled.** Ask her questions, so that you can prevent this tragedy from happening to your family.
- What do you know about the benefits that are available for your child? If you are like most of us, very little. This year we have an expert, **Michael Dinneen, Field Representative at the Social Security Administration** who will explain these benefits, such as SSI, Retirement Survivor Disability, Medicare and Health Insurance for the Disabled. What is available for your child that you're not getting?
- What is Medical Services Coordination? Is your child entitled to the service and how do you go about getting it? All these questions will be answered by **Linda LeTendre, LMSW, and Executive Director of Community Living & Advocacy Supports, Inc.** A Service Coordinator does more than just coordinate medical services. Find out what more a Service Coordinator can do for your child.
- If you have read this far and you are a provider you are probably wondering, "What's in this conference for me?" Take a closer look at the Program on page 4. There is a panel on **Managing Behaviors in Group Homes** for providers only. There is the presentation **Menu and Diets in a PW Group Home**, along with lots of other presentations that will understand PWS.

Whether you are a parent/caregiver, provider, or a medical professional, this conference has something for you. Come and join us at our conference where you can enjoy the company of others who share your experiences. Please help us to help you.

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www.prader-willi.org
Editor:
Harry Persanis

OUR CONFERENCE PRESENTERS

Thomas A. Maul, Commissioner, NYS Office of Mental Retardation and Developmental Disabilities

On June 13, 1995, the New York State Senate confirmed Governor George E. Pataki's nomination of Thomas A. Maul as Commissioner of the Office of Mental Retardation and Developmental Disabilities (OMRDD). Commissioner Maul is responsible for overseeing services to approximately 130,000 New Yorkers who have developmental disabilities.

Merlin G. Butler, M.D., Ph.D., F.F.A.C.M.G., Kansas City, Missouri

PWSA(USA) Scientific Advisory Board Chairman, Chief, Section of Medical Genetics and Molecular Medicine William R. Brown/Missouri Chair of Medical Genetics and Molecular Medicine, Professor of Pediatrics, University of Missouri-Kansas City School of Medicine, Children's Mercy Hospitals and Clinics

Janalee Heinemann, MSW – PWSA(USA), Executive Director, Sarasota, Florida

Past President PWSA(USA). Parent of an adult son with PWS; Masters in Social Work from Washington University in St Louis, MO; volunteer for PWSA (USA) for 16 years prior to becoming Executive Director in 1997. Past Professional Experience: 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.

Patricia W. Johnson, Esq., Assistant Counsel to the NYS Commission on Quality of Care for the Mentally Disabled

Ms Johnson counsels the State's Surrogate Decision-Making Committee Program enacted as N.Y. Mental Hygiene Law Article 80. SDMC Committees are an alternative approach to the court system for obtaining an informed decision about major medical treatment for clients with mental disabilities in residential facilities and programs operated, licensed, or funded by an office of the Department of Mental Hygiene. A graduate of Brooklyn Law School, she received her Bachelor of Science in Special Education and Liberal Arts at Syracuse University. Ms. Johnson will be available to answer questions.

Janice M. Agarwal, P.T., Zionsville, Indiana

Ms. Agarwal has 15 years of pediatric physical therapy experience, with emphasis on young children from birth to age 3. She uses both Neurodevelopmental Training (NDT), and Sensory Integration (SI) techniques. She was part of the neurodevelopmental evaluation team at Boston City Hospital and the early intervention team at St. Mary's Hospital for Children in New York. She has lectured on infant development and therapeutic intervention for hypotonic children for therapists in New York and for therapists and parents at PWSA(USA) national and IPWSO international conferences. Janice has previously served on the PWSA (USA) board.

Linda LeTendre, LMSW, Executive Director of Community Living & Advocacy Supports, Inc. (CLAS, Inc.)

Ms. LeTendre received her BA degree from SUNY Potsdam in 1977 and her MSW from SUNY Albany in 1987. She founded Community Living & Advocacy Supports, Inc. in 1993. Ms. LeTendre has worked in the field of disabilities for 28 years. She lives in Saratoga Springs, NY.

Michael Dinneen, Field Representative at the Social Security Administration, Albany, NY

Mr. Dinneen is a graduate of Notre Dame University and has twenty-five years of service with the Social Security Administration. Mr. Dinneen will be available to answer questions.

Monica Bienert, Director of Marketing and Vocational Development, Gilbough Program, Cape Cod, Massachusetts

Responsible for developing and implementing the very successful vocational programs for individuals with PWS at Gilbough Programs

Ann Marie Vadney, NYS OMRDD , Statewide Coordinator for PWS Services

Ms. Vadney will present on the PWS, DDPC Grant and be available throughout the conference for consultation.

Robin MacGillivray, St. Paul, Minnesota

Ms. Robin MacGillivray is 23 years old; she was diagnosed with Prader-Willi Syndrome when she was 17 years old. Robin has graduated from the University of St. Thomas in St. Paul, Minnesota in 2003, and has continued to take courses during the 2004-2005 academic year. Robin has a double major in elementary education and sociology, a minor in history, and has taken additional graduate level coursework in Special Education. Robin intends to work with children in an educational setting. Her hope is that her story will inspire other people with PWS, as well as their parents and caregivers.

Terry Colvin, QMRP, Pathways, Inc. Residential Programs, Corning, New York

Psychology and QMRP Coordinator for all Pathways, Inc. Residential Programs

John Porcella, PhD, Executive Director, Community Living Corporation, Mt. Kisco, New York

Dr. Porcella has more than 25 years of experience caring for people with PWS.

Barbara Scavarelli, LPN, Program Nurse, Sharon Henkel, Resident, Gilbough Program, Massachusetts

Tanisha Gomes, Staff, Gilbough Program, Mass.

Winner of the "2005 Award for Outstanding Work with Individuals and their Families," as given by, The Cape and Islands Citizen Advisory Board of the Massachusetts Department of Mental Retardation.

Richard Scott, Prader-Willi Coordinator, Taconic DDSO, Rick Conca, Psychologist, Taconic DDSO

Many years of experience caring for individuals with PWS at Othmer House and Stepping Stone, both are group homes in NYS for people with PWS.

Jamie Adella, Team Leader, Family Residences, Long Island, New York

2005 Conference Program

Thursday, May 19th

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

Friday, May 20th

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

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

Opening Remarks and Welcome

9:00 a.m. **Thomas A. Maul, Commissioner**, N Y S Office of Mental Retardation and Developmental Disabilities

Options for People Through Services or NYS OPTS

Progress For The Disabled Under N Y S Cares

The Role of Parents as Advocates

9:45 a.m. **Robin MacGillivray**

Reflections on Completing a College Education While Living With PWS, My Educational Journey

10:15 a.m.-10:45 a.m. **Break**

10:45 a.m. Concurrent Sessions:

Session a1) **Janalee Heinemann, MSW** – PWSA(USA), Executive Director

Prader-Willi Syndrome Twenty Five Years of Progress

11:30 a.m. Session a2) **Linda LeTendre, LMSW**, Executive Director of Community Living & Advocacy Supports, Inc. (CLAS, Inc.)

Medicaid Service Coordination Is More Than Coordinating Services:

What You And Your Medicaid Service Coordinator Need To Know

10:45 a.m. Session b) **Panel, Terry Colvin, Facilitator** , Pathways, **John Porcella, PhD.**, CLC, **Richard Scott**, OMRDD, **Rick Conca**, OMRDD

Managing Behaviors in Group Homes (For Providers Only)

12:00 p.m.- 1:15 p.m. **Lunch**

Concurrent Sessions:

1:15 p.m. Session a1) **Janalee Heinemann, MSW** – PWSA(USA), Executive Director

Medical Crisis Prevention And Intervention followed by Q & A

2:00 p.m. Session a2) **Barbara Scavarelli, LPN**, Gilbough Program Nurse, **Tanisha Gomes**, Gilbough Staff, **Sharon Henkel**, Resident

What Are We Eating Today? One Agency's Approach To Menu & Diet In It's PWS Group Homes

1:15 p.m. Session b) **Merlin G. Butler, M.D., Ph.D., F.F.A.C.M.G.**

Question And Answer Session, Newly Diagnosed And Very Young Children With PWS

2:45 p.m. - 3:00 p.m. **Break**

Concurrent Sessions:

3:00 p.m. Session a) **Parent/Provider Panel, Q & A, Ann Marie Vadney, Facilitator**, OMRDD, **Elinor Baller**, Parent, **Volena Howe**, Parent,

Tanisha Gomes, Gilbough Staff, **Jarnie Adela**, Team Leader, Family Residences

Role of Parents in Prader-Willi Group Homes

Session b) **Janice M. Agarwal, P.T.**

Physical Therapy, Making Sense of Sensory Integration, for parents of children 4 to 14 years old.

Session c) **Sharing Session for Parents of Children, Infants to 3 years old. Janalee Heinemann, MSW, Facilitator**

4:30 p.m. **End of Friday Session**

7:30 p.m. **Alliance Open House**

Saturday, May 21st

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

8:45 a.m. **Hon. Daniel D. Angiolillo**, President , PWANY, **Ann Marie Vadney**, OMRDD

The PWS Developmental Disabilities Planning Council Grant, It's Purpose and It's Progress

9:00 a.m. **Merlin G. Butler, M.D., Ph.D., F.F.A.C.M.G.**

Current Understanding of Cause and Diagnosis of Prader-Willi Syndrome

10:30 a.m.-10:45 a.m. **Break**

Concurrent Sessions

10:45 a.m. Session a) **Michael Dinneen**, Field Representative at the Social Security Administration, Albany, NY

SSI, Retirement Survivor Disability, Medicare, and Health Insurance for the disabled

Session b) **Janice M. Agarwal, P.T.**

Physical Therapy, Making Sense of Sensory Integration, for parents of infants to 3 years old.

Session c) **Sharing Session for Providers**

12:15 p.m.-1:30 p.m. **Lunch**

1:30 p.m. **Patricia W. Johnson, Esq.**, Assistant Counsel to the NYS Commission on Quality of Care for the Mentally Disabled

The Pros and Cons of Guardianship: An Overview of Guardianships, Wills, Trusts and Alternatives to Guardianship

2: 30 p.m. **Alliance Membership Meeting**

Review of Progress Made, Plans for the Future and Election of Directors

4:30 p.m. **Conference Ends, See You Next Year**

The 15th Annual Prader-Willi Alliance of New York Conference

May 20th & May 21st - Best Western Sovereign Hotel

1228 Western Avenue - Albany, New York

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

Family Registration: \$ 40.00 for two days-\$30.00 for 1 day
 (up to *THREE* family members may attend for one fee!)
 \$ 15.00 for each additional family member (good for 1 or 2 days)

Professional Registration: \$ 50.00 For 1st Day, \$20.00 For 2nd Day

Discount: "2005" 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: \$ 12.00 per adult- Children's lunch (ages 5-13) is \$ 8.00

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

The 15th 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 |
| Filet of Scrod No. _____ | Filet of Sole No. _____ |
| Roast Turkey with Dressing No. _____ | Chicken Parmigiana No. _____ |
| Vegetarian Stir Fry No. _____ | Vegetarian Prima Vera 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 "2005" May 20th - May 21st

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 2005 \$ _____
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 you do **not** want 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