



Prader-Willi Alliance of New York, Inc.

267 Oxford Street • Rochester, N.Y. 14607

NEWSLETTER • April 2000

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10th Annual Conference Scheduled for May in Albany

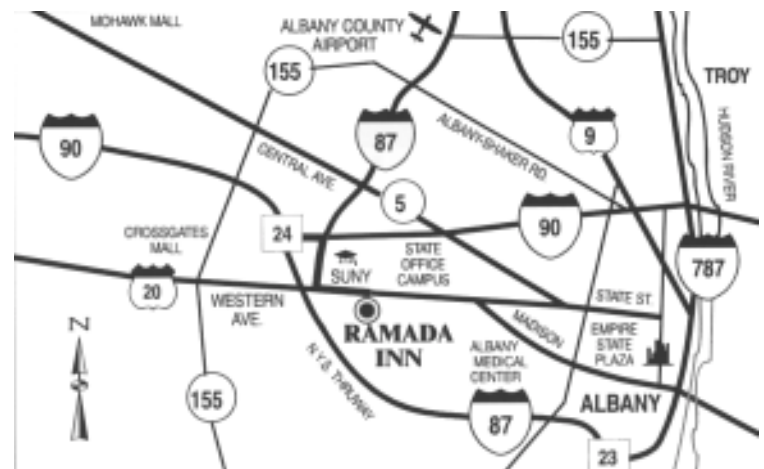
The 10th annual Prader-Willi Alliance of New York Conference will take place on Friday and Saturday, May 5th and 6th, 2000 at the Ramada Inn in Albany. The complete schedule is published on page 2, and you will find registration information on page 7.

The Ramada is located at 1228 Western Avenue, Albany, New York 12203. We have reserved a block of rooms for Thursday, Friday and Saturday nights at a favorable rate of \$70.00 per night, single or double. The rate includes breakfast. Children 18 and under stay free, but their breakfast costs \$1.99. An extra adult will cost \$5.00, which will include breakfast. The Ramada also has an indoor swimming pool. Reservations may be made by calling the hotel at **(518) 489-2981** or on the web at **www.ramada.com**. Ask for the special conference rate. You must make your reservation by **April 21, 2000** to obtain the special conference rate.

The 2000 Conference will also include plenty of time for parents and providers to separate into small groups and share information and concerns among themselves. And you will discover that some of the most valuable time at our conference is spent sharing in small groups, talking and meeting at lunch, and at our informal hospitality on Friday night. Save the dates *now* — and join us for what we're sure will be the best PWS conference you'll ever attend! ☘

Directions:

Exit 24 on N.Y. State Thruway (I-90), follow Exit 1-S to the end, left on Western Avenue (Rt. 20)



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

2000 Conference Program

Thursday, May 4

8 to 10 p.m. Registration

Friday, May 5

8 a.m. Registration

8:45 a.m. Opening Remarks & Welcome

9 a.m. **THOMAS A. MAUL**, Commissioner, New York State Office of Mental Retardation and Developmental Disabilities. After the Commissioner's address, there will be a question-and-answer period.

9:45 a.m. **LINDA LeTENDRE & DEE RIDER. *The Role of the Medicaid Service Provider.***

10:30 a.m. Morning Break

10:45 a.m. **ELISABETH N. DYKENS, Ph.D., *Behavior and Development in Prader-Willi Syndrome.***

12:15 p.m. Lunch

1:30 p.m. **ELISABETH N. DYKENS, Ph.D.; DANIEL J. DRISCOLL, M.D., Ph.D.; and B.J. GOFF, Ed.D. "Ask the Experts."**

3 p.m. Afternoon break

3:15 p.m. **SESSION A)** Daniel J. Driscoll, M.D., Ph.D., leads an overview session for parents of newly-diagnosed children. Question-and-answer session.

SESSION B) Sharing Session — Service providers

SESSION C) Sharing Session — Parents and family members — children under 18

SESSION D) Sharing Session — Parents and family members — 18 & up

7:30-10 p.m. **OPEN HOUSE** hosted by the Prader-Willi Alliance of New York

Saturday, May 6

8:30 a.m. Registration

8:45 a.m. Opening Remarks

9 a.m. **DANIEL J. DRISCOLL, M.D., Ph.D. *Medical & Genetic Issues in Prader-Willi Syndrome and Research Update.***

10:30 a.m. Morning Break

10:45 a.m. **MARY BENNETT, R.D. *Prader-Willi Syndrome and Nutrition.*** After a short talk, there will be a question-and-answer period.

12:00 p.m. Lunch

1:15 p.m. Alliance Membership Meeting & Election.

1:45 p.m. **EDMUND G. HADDAD, Ph.D. *Family and Sibling Issues.*** Video and discussion.

3:15 p.m. Conference Ends

**The Alliance would like to thank the
New York State Developmental Disabilities Planning Council and
The Prader-Willi Foundation for their financial support of this conference.
The DDPC grant is specifically awarded to help New York State families attend the
conference. If you need financial assistance, please call the Alliance
at (800) 442-1655. All calls are strictly confidential.**

Message from the President

by Henry Singer

As I look over the program for our upcoming conference, I am filled with pride. I believe it will be our best conference yet! Our opening speaker, **Commissioner Thomas A. Maul** of the New York State Office of Mental Retardation and Developmental Disabilities heads the state agency with the most responsibility for caring for people with Prader-Willi syndrome. He has held this position since the end of 1993 with the responsibility of overseeing services to nearly 100,000 New Yorkers who have developmental disabilities. Last time Commissioner Maul addressed our conference, he not only answered general questions, but also held private discussions with individual families and addressed their specific concerns. After the conference, his staff followed-up, providing the families with requested information.

We're also pleased to have on our program **Linda LeTendre, CSW**, and **Dee Rider**, who will address the role of the Medicaid service provider. Ms. LeTendre is the founder and Executive Director of Community Living and Advocacy Supports, Inc., one of the first agencies in New York State to provide service coordination as its only service, allowing the agency to act in total autonomy on behalf of their employers. Ms. Rider is Director of Service Coordination for Pathways, Inc. She has 24 years of experience, 5 of them with people with Prader-Willi syndrome.

Elisabeth N. Dykens, Ph.D. will address the conference, focusing on behavioral issues. Dr. Dykens is Associate Professor of Psychology at UCLA's Neuropsychiatric Institute and co-director of UCLA's Prader-Willi Syndrome Clinic. She is a member of the Scientific Advisory Board of the Prader-Willi Syndrome Association. **Dr. B.J. Goff** is no stranger to Prader-Willi conferences. She is a regular featured speaker all over the United States, and has her own disabilities consulting practice in Springfield, MA and teaches psychology and education courses at Westfield State College.

We are also proud to present **Daniel J. Driscoll, M.D., Ph.D.**, who will address the medical and genetic issues in Prader-Willi syndrome. Dr. Driscoll holds over one million dollars in NIH grants for research in Prader-Willi syndrome. He was recently appointed Haywood Professor of Genetics Research at the University of Florida. This is an endowed chair by the Haywood Foundation and the State of Florida. His clinic follows over 75 people with Prader-Willi syndrome in Florida and southern Georgia.

Mary Bennett, R.D., will speak about the crucial issue of nutrition. Ms. Bennett has been a dietician for 19 years and has been employed by Pathways for 9 years. Her work is focused on people with PWS living in ICF and IRA facilities. Our final speaker will be **Edmund G. Haddad, Ph.D.**, a specialist in family and sibling issues. Dr. Haddad, who holds a Doctorate in Special Education, works as a consultant, and is an adjunct associate professor.

As I said, we are certain that this will be our best conference ever, and hope that people will recognize the depth and range of expertise being brought together in one place on May 5th and 6th. That place is Albany, and we hope all of you will join us!

I'd like to extend my best wishes to **Harry Persanis**, an Alliance founder and board member, who is well on the road to recovery after surgery. Harry, as everyone who knows him will tell you, is one of our most dynamic and energetic board members, a hard worker and an equally hard taskmaster. I am certain that Harry will want to continue his duties as a board member, but with the election coming up it is another reminder that we are not growing younger and we need new blood. I sincerely hope that some of you reading this message will step forward and join and/or replace the "old guard" on the Alliance Board. The Alliance is 10 years old, and too much of the work is still being done by the founders.

Some other notes: the Prader-Willi Alliance is now on the World Wide Web at www.prader-willi.org. The site is being maintained by Alliance board member **Shelly Tarakan**, who also donated the domain name. Anyone wishing to comment on the web site can e-mail Shelly at webdirector@prader-willi.org.

And finally, I would like to mention that **Rita Welch** passed away recently. Rita was one of the pioneers in the early days when very few people — physicians included — knew much at all about Prader-Willi syndrome. In 1998 the Alliance presented Rita with a citation that reads: "This fifteenth day of October, 1998. From her friends in the Prader-Willi Syndrome Community. In recognition of her tireless efforts on behalf of people with Prader-Willi Syndrome. As a result of her crusading advocacy, all of us have benefited from the increased identification, diagnosis and treatment of Prader-Willi Syndrome. Furthermore, it was through her persistent efforts that the first residence for people with Prader-Willi Syndrome was established in New York State. Thank you, the Prader-Willi Alliance of New York, Inc." ❧

Conference Calendar

Please mark your calendars and plan to attend the following Prader-Willi conferences:

PWSA (USA) Conference

July 20-22, 2000
Pittsburgh, PA
(800) 926-4797 for information

PWSA New England

October 13, 2000
Lexington, MA
(508) 991-6705 for information

Alliance Elections

The Prader-Willi Alliance of New York will hold elections for all officer positions and some at-large board positions at its Annual Meeting, Saturday, May 6. Officers serve a 2-year term and are automatically board members as well. Please forward your nominations to the Alliance office (267 Oxford Street, Rochester, N.Y. 14607), or give them to us by phone (800-442-1655), fax (716-271-2782) or by e-mail to nominations@prader-willi.org. Volunteers are eagerly sought and encouraged!

Articles Wanted!

This is *your* Prader-Willi Alliance, and this is *your* Alliance newsletter. In order for it to represent *all* of us in New York State, we must have input from our membership. Please send us letters and articles — from parents, siblings, people with Prader-Willi syndrome and caregivers. Please send articles to the Alliance Office at 267 Oxford Street, Rochester, N.Y. 14607, or send e-mail to newsletter@prader-willi.org

We're on the Web at
www.prader-willi.org

A Message From Barb Dorn, President of PWSA (USA)

I am asking you today to take the *first* steps in showing that you care — care about persons with Prader-Willi syndrome.

If you are not a member of PWSA (USA) become One. Your membership really does count. If you are already a member — take the challenge. Find 1 person you know who is not a member and convince them to become one. PWSA (USA) needs your help. Your membership helps our organization to grow stronger and more influential in educating and advocating for children and adults with Prader-Willi syndrome.

The more voices we have, the louder we will be heard.

A family membership costs less than 10 cents per day. Some of the Benefits of being a member include:

- You will receive a bi-monthly newsletter, *The Gathered View*, which keeps you updated on the latest information and research related to Prader-Willi syndrome.
- You will be invited to attend the world's largest conference on Prader-Willi syndrome sponsored by PWSA (USA).
- You can receive an array of publications published and distributed exclusively by PWSA (USA) at a reduced price.
- You can receive information, support, networking and resources. Help is just a phone call away.

For more information on becoming a member contact:

PWSA(USA)
5700 Midnight Pass Road, Suite 6
Sarasota, FL 34242
1-800-926-4797

Web site: www.pwsausa.org

**Show you care . . .
become a member of PWSA (USA)**

One And a Half

by Nancy Finegold, Queens

(reprinted from *The Gathered View*, newsletter of the PWSA (USA))

One of the hardest challenges facing any parent of a child with a disability is having the strength and the insight to view them as a whole person, a complete human being. For myself, this is a concept that I knowingly struggle with every day. In a strange, almost unexplainable way, the fact that my daughter isn't as active as most other babies, doesn't cry like they do, doesn't reach milestones at the same pace, and doesn't demand as much attention diminishes her worthiness in my eyes. I know this sounds like a terrible thing to have to admit, but if I'm really honest with myself, and really dig down deep within myself, I know that it is true. This is most likely true for the majority of "normal" people's view of the disabled world in general. When we see people with a disability, no matter what form that disability takes, we feel that they are missing some essential part of themselves that should have been rightfully theirs. We feel sorry for them, and this pity makes us uncomfortable. This results in a strong tendency to want to avoid disabled people, to not want to have to deal with them. When our own children evoke these kind of feelings, we feel guilty and ashamed, but the feelings are still real.

I became most aware of this shortcoming in myself a few weeks ago when someone at work, whom I hardly know and doesn't really know me, asked if I had any children, I casually replied "yes, I have two." As the words left my mouth I felt that I wasn't being totally honest with this woman. I had to fight back the urge to explain further. I wanted to say "I've given birth to two babies, but due to unfortunate circumstances, I really only have one and a half." Of course I kept this last part to myself, but it was there, hovering over me like a dark cloud, and I believed it sadly and strongly to be true. On some level, in

my eyes, she is less than whole because she isn't what I expected her to be, what she should've been. I realize that this feeling is at the root of many strong and difficult emotions that I have towards Dina. I feel that she is somehow not as important as my son, who is a healthy and rambunctious 3-year-old. I feel that she does not need or deserve as much attention, time and love as he does. The money I spend on her baby-sitter, doctor bills, and daily care is somehow on some level not as well-spent as the money I spend on my son. The time I spend with Dina playing with her, reading to her, and just trying to love her somehow seems to require more energy. There is always this little voice in the background asking, "What if I'm wasting my time?" I try to keep these feelings below the surface, to block them out and not recognize them. But these subtle and painful feelings do surface at times, and their existence shocks and angers me. This is how I feel about my own flesh and blood! What kind of mother am I?! A mother is supposed to love her children no matter what, unconditionally. The road that lies ahead of me is long. It will no doubt be a lifetime struggle to see my daughter as whole and perfect just the way she is. I need to believe in my heart that with all of her imperfections, she is just the way she was meant to be. She is her own individual person, beautiful, special, and worthy. Worthy of mine and everyone else's money, time, love, and respect. There are times when I look at her and for a brief moment I really believe all this to be true. I really know that she is her own beautiful talented little person, and that my life is so much more full and enriched with her in the world, despite the pain and challenges, and that I really do have two whole children. Those moments feel so good! ✨

The Prader-Willi Alliance Help Network

If you are the parent of a child with Prader-Willi syndrome and you need to talk with another parent who shares your concerns, please call one (or more) of the people listed below. These parents are eager to help, to offer advice, share their experiences, and do their best to comfort you in a time of great need. Don't for one minute hesitate to make contact — we are here for you.

- Elinor Baller: 914-834-4804
- Gloria Cox: 212-988-7350
- Volena Howe: 716-271-5332
- Kathy Jornov: 518-758-9753
- Daniel Maillet: 914-591-6425

- Harry Persanis: 516-783-7508
- Henry Singer: 718-783-0181 (home);
212-619-0185 (work)
- Sharon Spink: 716-823-3095
- Sharen Tarakan: 516-621-1596

OMRDD Developmental Centers & Disabilities Services Offices

(as of September, 1999)

<p>Bernard Fineson DC P.O. Box 280507, Queens Village, N.Y. 11428 (718) 217-4242</p>	<p>Janet Wheeler, Director</p>	<p>County served: Queens</p>
<p>Brooklyn DC 888 Fountain Avenue, Brooklyn, N.Y. 11208 (718) 642-6000; 642-6151 DDSO located at DC</p>	<p>Usha Venkataraghavan, Director</p>	<p>County served: Kings</p>
<p>Broome DC 249 Glenwood Road, Binghamton, N.Y. 13905 (607) 770-0211 DDSO located at DC</p>	<p>Richard J. Thamasett, Director</p>	<p>Counties served: Broome, Chenango, Delaware, Otsego, Tioga, Tompkins</p>
<p>Capital District DDSO Balltown & Consaul Roads Schenectady, N.Y. 12304 (518) 370-7331; 581-3006</p>	<p>Helene DeSanto, Director</p>	<p>Counties served: Albany, Fulton, Montgomery, Rensselaer, Saratoga, Schenectady, Schoharie, Warren, Washington</p>
<p>Central New York DDSO Box 550, Rome, N.Y. 13442-0550 (315) 336-2300</p>	<p>Stephen M. Smits, Director</p>	<p>Counties served: Cayuga, Cortland, Herkimer, Lewis, Madison, Onondaga, Oneida, Oswego</p>
<p>Finger Lakes DDSO Parkside Commons, 5259 Parkside Drive Canandaigua, N.Y. 14424 (716) 394-7140 (800) 452-4256</p>	<p>Sylvester P. Zielinski, Director</p>	<p>Counties served: Chemung, Livingston, Monroe, Ontario, Seneca, Schuyler, Steuben, Wayne, Wyoming, Yates</p>
<p>Hudson Valley DDSO Administration Bldg., Ridge Road Thiells, N.Y. 10984 (914) 947-6100</p>	<p>James Whitehead, Director</p>	<p>Counties served: Orange, Rockland, Sullivan, Westchester</p>
<p>Long Island DDSO 45 Mall Drive, Commack, N.Y. 11725 (516) 493-1700</p>	<p>Marvin L. Colson, Director</p>	<p>Counties served: Nassau, Suffolk</p>
<p>Metro New York DDSO 75 Morton Street, New York, N.Y. 10014 (212) 229-3000</p>	<p>Hugh Tarpley, Ph.D., Director</p>	<p>Counties served: Bronx, New York</p>
<p>Staten Island DDSO 1150 Forest Hill Road, Staten Island, N.Y. 10314 (718) 983-5200</p>	<p>Robert Witkowsky, Director</p>	<p>County served: Richmond</p>
<p>Sunmount DC 403 Park Street, Tupper Lake, N.Y. 12986 (518) 359-4485 DDSO located at DC</p>	<p>Barbara A. Hawes, Director</p>	<p>Counties served: Clinton, Essex, Franklin, Hamilton, Jefferson, St. Lawrence</p>
<p>Taconic DDSO R.R. #1, Box 27, Wassaic, N.Y. 12592 (914) 877-6821</p>	<p>David Sucato, Director</p>	<p>Counties served: Columbia, Dutchess, Greene, Putnam, Ulster</p>
<p>Western New York DDSO 1200 East & West Road, West Seneca, N.Y. 14224 (716) 674-6300</p>	<p>Thomas Zielinski, Director</p>	<p>Counties served: Allegany, Cattaraugus, Chautauqua, Erie, Genesee, Niagara, Orleans</p>

The 10th Annual Prader-Willi Alliance of New York Conference
May 5 & 6, 2000 • The Ramada Inn
1228 Western Avenue • Albany, New York

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

Family Registration: \$35.00 for 2 days • \$25.00 for 1 day
(Up to *THREE* family members may attend for the 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: Dues-paying members of the Alliance may deduct \$5.00 from the total due. You may join *NOW* (see application on last page) and receive the Conference discount.

Lunch: \$14.00 per adult • Children's lunch (ages 5-10) is \$10.00

We have worked closely with the Ramada Inn to provide healthful and appropriate meals.

The 10th 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

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 age(s) _____

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

I would like to make an additional tax deductible contribution to help offset the cost of the conference: \$ _____

Total Amount Enclosed: \$ _____

Please complete this form and mail it, along with your check, to:

Prader-Willi Alliance of New York • 267 Oxford Street • Rochester, N.Y. 14607

For further information, call the Alliance at (800) 442-1655.

Prader-Willi Alliance of New York, Inc.
267 Oxford Street
Rochester, N.Y. 14607



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 2000 \$ _____

Here's an additional tax-deductible contribution \$ _____

Total Amount Enclosed \$ _____

Name _____

Address _____

City, State, Zip _____

Telephone _____ Fax _____

E-Mail Address _____

Date _____ New Member Renewal

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 Age _____ Age at Diagnosis _____

Where is Child Residing? _____

Please make your check payable to the Prader-Willi Alliance of New York and send it to:
Prader-Willi Alliance of New York, 267 Oxford Street, Rochester, N.Y. 14607