



Prader-Willi Alliance of New York, Inc.

267 Oxford Street • Rochester, N.Y. 14607

NEWSLETTER • April 2001

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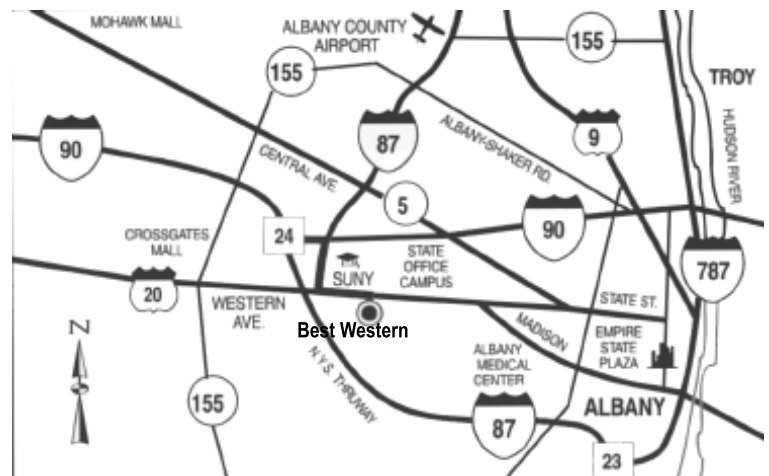
11th Annual Conference Scheduled for April in Albany

The 11th annual Prader-Willi Alliance of New York Conference will take place on Friday and Saturday, April 27 & 28, 2001 at the Best Western Sovereign Hotel in Albany. This is the same location as last year's conference — only the hotel has changed from a Ramada to Best Western. Registration information on page 7.

The hotel 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 \$73.00 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 hotel also has an indoor swimming pool. Reservations may be made by calling the hotel at **(518) 489-2981**. Ask for the special conference rate. You must make your reservation by **April 9, 2001** to obtain the special conference rate.

The 2001 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)

2001 Conference Program

Thursday, April 26

8 to 10 p.m. Registration

Friday, April 27

8 a.m. Registration

8:45 a.m. Opening Remarks & Welcome

9 a.m. **MERLIN G. BUTLER, M.D., Ph.D.** — *Hope For the Future*. Dr. Butler is a well-known and respected researcher who has contributed a great deal to the knowledge and understanding of Prader-Willi syndrome. He is currently Chief of the Section of Medical Genetics and Molecular Medicine at Children's Mercy Hospital and holds the William R. Brown/Missouri Endowed Chair of Medical Genetics and Molecular Medicine and Professor of Pediatrics at the University of Missouri-Kansas City School of Medicine. Dr. Butler is Chairman of the Scientific Advisory Board of the PWSA (USA). His talk is certain to appeal to families of people with PWS of all ages, as well as to the professional community.

10:30 a.m. Morning Break

10:45 a.m. **KEVIN JACKSON, Ph.D., CBA** — *The Five Most Important Things You Can Do To Improve the Behavior of Children and Adults With Prader-Willi Syndrome*. Dr. Jackson is Director of Behavioral Services at the ARC of Alachua County in Gainesville, Florida. He has been extensively involved in the development and growth of Alachua ARC's successful Prader-Willi syndrome treatment program, currently serving over 35 individuals with PWS.

12:15 p.m. Lunch

1:30 p.m. **PETER F. PEZZOLLA**, Associate Commissioner, OMRDD. Mr. Pezzolla will speak about the range of OMRDD services to people in New York State with disabilities and the professionals that serve their interests.

2:15 p.m. **ASK THE EXPERTS** — Q & A Session with Drs. Butler and Jackson

3:30 p.m. Afternoon break

3:45 p.m. **SHARING SESSIONS** — Breakout sessions for specific interest groups, including service providers, parents of young children, parents of young adults.

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

Saturday, April 28

8:30 a.m. Registration

8:45 a.m. Opening Remarks

9 a.m. CONCURRENT SESSIONS: Session A) **MERLIN G. BUTLER, M.D., Ph.D.** leads an overview session for parents of newly-diagnosed children. Q & A session.
Session B) **KEVIN JACKSON, Ph.D.** — sharing session on behavior
Individuals may group together to form their own specific interest sessions

10:30 a.m. Morning Break

10:45 a.m. **CATHERINE McHUGH** — *Preparing for CSE and CPSE meetings & the IEP*. Catherine McHugh is an educational advocacy trainer from the New York State Commission on the Quality of Care. She presents educational advocacy workshops for parents, teachers, service coordinators and other interested professionals through out New York State.

12 p.m. Lunch

1 p.m. Alliance Membership Meeting & Election

1:30 p.m. **B.J. GOFF, Ed.D.** — *Educating the Child With Prader-Willi Syndrome: School Issues*. Dr. Goff 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.

3 p.m. Conference Ends

Message from the President

by Henry Singer

In past messages, I've stressed the importance of parents of young children with Prader-Willi syndrome becoming more actively involved with the Prader-Willi Alliance. I have actively sought parents of young children to serve as Alliance officers and board members. I'm happy to announce that last year Susan Cornell and Kathy Funk, both mothers of 4-year-old daughters, joined the Alliance Board and immediately demonstrated their enthusiasm and commitment by volunteering to help arrange this year's Conference.

It is crucial that we continue to get parents of young children to become members of the Alliance. It is equally crucial that we urge them to serve as officers, board members, and volunteers for various committees and projects. Without an influx of "new blood," our ability to expand, and even *maintain*, our services is woefully limited. With the enthusiasm and commitment demonstrated by our two newest board members, our future glows with the prospect of higher levels of service to families in New York State. One of our major goals this year, and well into the future, is to help establish local parent support groups and other networking opportunities for parents and the professionals who serve our children. If you want to become more involved, please do not hesitate to contact me or any other Alliance officer or director. We can be reached by mail, e-mail, fax or telephone — whatever your favorite means of communication, we'll be at the other end to talk with you, meet with you, and get you involved.

I'd like to relate a story that points out just how valuable an ally the Alliance can be to a person with Prader-Willi syndrome when trouble strikes, as it inevitably does. Recently, a young man in Westchester County, a student in a residential school, injured someone during a tantrum. The incident attracted the attention of, among others, the Westchester County District Attorney. I asked Alliance board member Harry Persanis, who had success in a previous situation in Queens, to try and help this young man. For about a month Harry spent many long hours consulting with school officials, a physician from the local office of OMRDD (Office of Mental Retardation and Developmental Disabilities), the young man's attorney, and an assistant district attorney. Harry, with the assistance of Janalee Heinemann, Executive Director of PWSA(USA), had a tremendous impact on the outcome of the case. The young man faced the possibility of court supervi-

sion for as much as 17 years and possibly at a psychiatric facility. The end result was 1 year's supervision at an OMRDD facility — not necessarily an inappropriate placement. When it comes to crunch time, it's good to have a relentless advocate like Harry available.

I'm happy to report that Heritage Center, a Buffalo-based voluntary agency, will be opening a 5-person IRA on McKinley Parkway in Hamburg. The house will be home to 5 women, 3 with PWS and 2 with compulsive eating disorders.

And finally, a fond farewell — and a warm welcome! At last year's conference, Patricia Bruno, who had been our liaison at OMRDD for more than 10 years, announced that she was moving on to a new position within that agency. Patricia has served us extraordinarily well during her tenure, and every family in New York State that has a member with Prader-Willi syndrome can remember her as a solid advocate, a person who really got things done. Our thanks, love and best wishes go out to Patricia.

Also at last year's conference, Patricia Bruno introduced us to her successor, AnnMarie Vadney. On February 27 of this year, Alliance Vice President Shelly Tarakan, Treasurer Volena Howe and Directors Harry Persanis and Kathy Funk met with AnnMarie in Albany to discuss many of the issues that are important to families of people with Prader-Willi syndrome. We look forward to a long and enjoyable relationship with our new OMRDD liaison.

The 11th Annual Alliance Conference will bring together some of the most knowledgeable people in the country — top professionals who want to share with you their extensive knowledge of and experience with Prader-Willi syndrome. Take a look at the schedule on page 2 and imagine just how much you could learn from these experts. In addition, think of how valuable the networking experience can be. You will be among friends — families and individuals who share your concerns, your fears, your hopes, and your life experiences.

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. I hope to see all of you in Albany.

Having Another Baby: Courage or Insanity?

by Nancy Finegold, Queens

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

My first thought when my daughter Dina was born was that I would simply have another baby as soon as possible and somehow make the disappointment and the tragedy of Dina's birth seem less severe.

The lack of response, the initial difficulty bonding and the stress and disappointment that Dina caused upon her arrival into this world provoked in me feelings of intense confusion, fear and loss. At the time, I mourned the loss of the baby I was expecting and the child I knew I would never have (from this birth).

During those early months with Dina I received great advice from my Rabbi. He told me that I should wait long enough to bond with Dina before thinking about getting pregnant again. "No child can ever replace another," he advised me. "A new baby must add to Dina and to your family, not replace her."

I decided that I would wait long enough to love, cherish and accept Dina in my life before I would try to have another baby. This did not take long. Once Dina began to open her eyes and look at me, and move around and call to me, the bonding and the love came naturally.

Do I still have many fears about the future? Of course I do. Do I still get pangs of heartache for my daughter and her fate? Of course I do. But I feel that I have accepted her for whoever she is and for whatever she will become. I admire her for her motivation and tenacity and for her drive to be independent. She is easy to love because she gives so much love. Her hugs, kisses and coos melt the hearts of everyone around her, especially mine.

Once the love and bonding issue was behind me and I no longer felt the urgency to replace my baby with another, the idea of having another child came to the forefront of our lives. And along with it came a whole new and unexpected set of dilemmas.

Dina is our second child. What if life with Dina as she grows is so stressful and all-encompassing that yet another child to take care of will just be too much to handle? How will being the middle child sandwiched between to healthy siblings affect Dina? What if we have another baby with disabilities? This would surely do me in. Can I take that chance? Won't the issue of having to hide food be so much more difficult and chal-

lenging with two other children in the home? Do I give up my dream of having at least three children because of Dina's problems and my fears?

I honestly do not know if it's courage or insanity that drives us moms to keep pushing on despite our obstacles and fears. I think it must be a little of both.

I am now 8 months pregnant with my third child. Ironically, this baby is due on Dina's birthday in June. Dina will be two years old. We are all so excited about having a new baby, including Dina. I have a feeling her maternal instincts will kick in at the age of two and she will be a great big sister. Dina already cradles, hugs and tries to feed all of her dolls.

My amniotic tests all came back negative and all seems to be fine this time, but until I see the baby with my own two eyes in the hospital, I will not be completely convinced or at ease.

Having another baby after giving birth to a child with any kind of serious disability is a leap of faith and courage for any parent. It's a challenge which many families choose to bravely face and conquer every day.

Sometimes when I feel that "thump, thump" sensation inside of my abdomen, I don't know for sure if it is my baby kicking or simple giant butterflies inside of me from nerves. I think it must be a little bit of both.

Editor's note: Sarah, Nancy Finegold's third child, was born on Dina's second birthday. Nancy reports that Sarah is a "beautiful, healthy little girl, and Dina is very happy her birthday present."

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

Growth Hormone Therapy: A Letter From PWSA(USA)

Editor's Note: This letter, although sent out last year, is important enough to reproduce here unedited, with the permission of PWSA(USA).

July 12, 2000

Dear PWSA(USA) Member:

As we have all been aware, for years there has been no medication specifically approved for individuals with Prader-Willi syndrome (PWS). Now, finally, there is some good news. We are pleased to inform you that the U.S. Food & Drug Administration (FDA) has just determined that PWS is an "indication" (eligible condition) for treatment with Genotropin™ (somatropin rDNA for injection), which is a form of growth hormone manufactured by Pharmacia Corporation. Previously approved to treat "growth hormone deficiency" in children and adults, Genotropin is now the only treatment approved specifically for "growth failure in children with PWS."

This does not mean that there is a problem if your child is on another brand of growth hormone. In general, growth hormone therapy has been approved for some time — but now, Genotropin specifically has been approved for treating PWS. Genotropin's approval for PWS was issued by FDA under the Orphan Drug Act. This designation is only given to treatments for which the potential patient population is under 200,000. Orphan Drug status entitles Pharmacia exclusivity in marketing the drug for this purpose for the next seven years. FDA approval should make it easier for families to appeal to insurance companies for coverage and should help with Medicaid coverage. Also, under the FDA ruling, growth hormone deficiency testing will no longer be required for children with PWS and growth failure

who are being considered for GH treatment.

Results from the studies submitted to the FDA reveal that growth hormone treatment improves growth and body composition in children with PWS, including stimulating skeletal growth, decreasing the amount of body fat and increasing lean body mass (muscle). Given the many issues faced by families affected by PWS, we believe the increased availability of growth hormone will be of benefit to many members of our community by helping to reduce some of the major medical problems often inherent in this syndrome. Please note that you should consult with your physician as to whether growth hormone therapy is appropriate in your particular case, since it may not be beneficial for every child with PWS.

By the end of the year, PWSA(USA) will publish a new booklet for parents and guardians, designed to help you make informed decisions about growth hormone treatment. When it is available, we will inform you through our newsletter, *The Gathered View*. Meanwhile, you can log on to our Web site at www.pwsausa.org. If you would like more information specifically about Genotropin or its use in PWS, please feel free to visit the Genotropin Web site, www.genotropin.com, or call 1-800-645-1280.

It is a new era for Prader-Willi syndrome with many encouraging things on the horizon! We are enclosing further "cutting edge" information on growth hormone therapy, and will do all we can to keep you informed of all new treatment options.

Sincerely,
Janalee Heinemann, MSW
Executive Director, PWSA(USA)

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
- Susan Cornnell: 315-733-8105
- Gloria Cox: 212-988-7350
- Kathy Funk: 518-583-4115
- 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

Bernard Fineson DC P.O. Box 280507, Queens Village, N.Y. 11428 (718) 217-4242	Janet Wheeler, Director	County served: Queens
Brooklyn DC 888 Fountain Avenue, Brooklyn, N.Y. 11208 (718) 642-6000; 642-6151 DDSO located at DC	Peter Uschakow, Interim Director	County served: Kings
Broome DC 249 Glenwood Road, Binghamton, N.Y. 13905 (607) 770-0211 DDSO located at DC	Richard J. Thamasett, Director	Counties served: Broome, Chenango, Delaware, Otsego, Tioga, Tompkins
Capital District DDSO 500 Balltown Road Schenectady, N.Y. 12304 (518) 370-7331; 581-3006	Helene DeSanto, Director	Counties served: Albany, Fulton, Montgomery, Rensselaer, Saratoga, Schenectady, Schoharie, Warren, Washington
Central New York DDSO Box 550, Rome, N.Y. 13442-0550 (315) 336-2300	Stephen M. Smits, Director	Counties served: Cayuga, Cortland, Herkimer, Lewis, Madison, Onondaga, Oneida, Oswego
Finger Lakes DDSO Parkside Commons, 5259 Parkside Drive Canandaigua, N.Y. 14424 (716) 394-7140 (800) 452-4256	Sylvester P. Zielinski, Director	Counties served: Chemung, Livingston, Monroe, Ontario, Seneca, Schuyler, Steuben, Wayne, Wyoming, Yates
Hudson Valley DDSO P.O. Box 470 Thiells, N.Y. 10984 (914) 947-6100	James Whitehead, Director	Counties served: Orange, Rockland, Sullivan, Westchester
Long Island DDSO 45 Mall Drive, Commack, N.Y. 11724 (516) 493-1700	Marvin L. Colson, Director	Counties served: Nassau, Suffolk
Metro New York DDSO 75 Morton Street, New York, N.Y. 10014 (212) 229-3000	Hugh Tarpley, Ph.D., Director	Counties served: Bronx, New York
Staten Island DDSO 1150 Forest Hill Road, Staten Island, N.Y. 10314 (718) 983-5200	Robert Witkowsky, Director	County served: Richmond
Sunmount DC 403 Park Street, Tupper Lake, N.Y. 12986 (518) 359-4485 DDSO located at DC	Barbara A. Hawes, Director	Counties served: Clinton, Essex, Franklin, Hamilton, Jefferson, St. Lawrence
Taconic DDSO R.R. #1, Box 27, Wassaic, N.Y. 12592 (914) 877-6821	Helene DeSanto, Director	Counties served: Columbia, Dutchess, Greene, Putnam, Ulster
Western New York DDSO 1200 East & West Road, West Seneca, N.Y. 14224 (716) 674-6300	Thomas Zielinski, Director	Counties served: Allegany, Cattaraugus, Chautauqua, Erie, Genesee, Niagara, Orleans

The 11th Annual Prader-Willi Alliance of New York Conference
April 27 & 28, 2001 • 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 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 Best Western to provide healthful and appropriate meals.

The 11th 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 2001 \$ _____

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