



Prader-Willi Alliance of New York, Inc.

Advocacy • Support • Hope

WINTER 2011

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CONTACTS:

Phone:
800 442-1655

Fax:
585 271-2782

E-mail:
alliance@prader-willi.org

Web Site:
www.prader-willi.org

List-Serve:
PWS-NY@yahoogroups.com

Editor:
Harry Persanis & Tammy Reals

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

President's Message

by Amy McDougall



Today is a big day in the McDougall household. Noelle and I need to meet with a psychologist at the Developmental Disabilities Service Office (DDSO), after receiving a letter stating that staff was

not able to render a determination as to whether my child has a developmental disability and is eligible for services through the Office for People with Developmental Disabilities (OPWDD). I admit that I am angry, frustrated, and worried at the moment, emotions that I am sure that many of you can relate to. The bottom line is that Noelle is diagnosed with Prader-Willi syndrome, which, with its genetic cause, will impact her functioning for the rest of her life. It does not matter what adaptive skills Noelle learns, because her overwhelming desire for food will interfere with her ability to use those skills, necessitating high levels of external control of her environment to ensure her safety, and thereby substantially handicapping her ability to function normally in society.

I am not writing, however, to share my personal story. I am writing due to the fact that what my family is facing today is representative of the situation for each and every individual affected by Prader-Willi syndrome in New York State. New York is in the midst of a financial crisis, with decision/ policy makers at all levels of government and agency administration seeking to cut costs and be fiscally responsible. We should expect to shoulder our fair share of cuts, but the reality is that as a low-incidence diagnosis, those with PWS will be disproportionately affected. Policy decisions that seem on the surface to be equitable to all disabilities will have an inordinate impact on those with PWS.

For example, OPWDD recently informed PWANY that there will be no new group homes built in NYS, beyond the few currently in development, PWS-specific or otherwise. PWANY lauds

OPWDD's intent to address individual needs in the least restrictive setting possible; however, this would be counterproductive to effective and fiscally responsible service provision for those diagnosed with PWS, as well as being a regression from the centralized approach to placement and service provision previously effected. An effective service plan for individuals with PWS acknowledges the unique complexities of the syndrome. Divergent from the majority of the population that OPWDD serves, individuals with PWS have a need for absolute food security, along with appropriate environmental modifications, behavioral interventions, staff training and enhanced supervision. One could argue that it is possible to provide each of these in an individualized setting, yet I would point out that to modify every setting in which an individual with PWS resides, provide appropriate levels of staffing/ supervision, and then train the staff in each of these sites would cost OPWDD an exorbitant amount of capital and would not meet the appropriateness standard for PWS residences. As financial resources are limited, this leaves only two choices: not provide individuals with PWS with appropriate services or centralize PWS-specific services. The first "choice" is not an acceptable option. To suggest that fiscal responsibility dictates the end of proven interventions and the decentralization of services for those with PWS is inaccurate, short-sighted, and places the needs of those with PWS below those of other groups with disabilities in NYS.

Medicaid service coordination, Medicaid services, and school districts are also being impacted by cuts. Medicaid service coordinators have been assigned higher caseloads and asked to tier their clients into levels of need, which means less face-time for many of those receiving services. Funding for Medicaid is being scrutinized. Aid to school districts is being cut at the same time that Governor Cuomo seeks to cap off funding that districts can raise through property taxes.

Continued on Pg. 6

Why I Joined the Prader-Willi Alliance of NY, Inc.

by Rachel Johnson

I was asked to write about what being a part of PWANY means to me. I had to take some time to really think about how to answer this question. This is a group that I never thought I would be a part of but a year and half ago I was thrust into this life by the discovery of a "random" deletion. My beautiful daughter, Ellie, was diagnosed with Prader-Willi Syndrome on May 8, 2009 when she was just over 2 years old. Although we were relieved to finally know what we were up against, we were now facing the battle of our lives.

Joining PWANY made me realize that we were not in this battle alone. There are amazing families right here in New York that know what we are going through and can provide support and advice about how to navigate this new road we are now traveling. Within a week of learning of Ellie's diagnosis I was in contact with at least 3 different PWS families that gave me hope and support in a way that only another PWS family could provide. You have to live it to "get it".

Once I got past the initial shock of the diagnosis I decided that the only thing I could do for my daughter was to become involved in the

various organizations that have been created to help our PWS angels live to their fullest potential. I didn't know what I could do or how I could help, but I knew it was the only thing I had control over in this new world we were living in.

Becoming an active member of PWANY has provided me with knowledge that I had no idea I didn't know. I have my master's degree in special education and I thought I knew all of the acronyms...until PWS entered my life. I realized on my first PWANY conference call that there is a whole world of supports that I never knew existed. These supports are going to make all the difference in Ellie's future. I now have the chance to help shape Ellie's future. I look forward to using this opportunity to learn about the supports that New York has to offer. I want to make sure that these supports provide people with PWS every possible opportunity for independence.

I urge you to join the PWANY, and to attend the 21st Annual Conference this coming April. I'll see you there. ■

OFFICERS & DIRECTORS

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Jeffrey Covington *Residential Supports Advisor*

Have You Checked The Label ?

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 not a member for 2011, won't you please join with us now?

Member 2011
Joe & Jane Smith
22 Main St.
Every town, NN 12333-4444



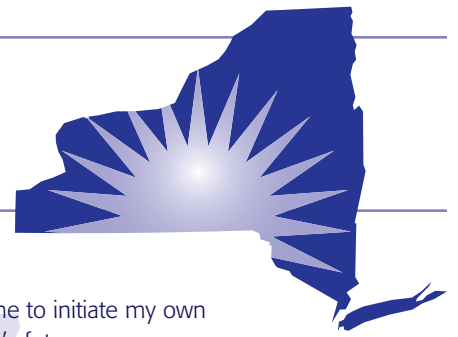
The "Alliance" is a tax exempt organization, which means any donation to the "Alliance" is tax deductible. The "Alliance" has NO paid staff and our income is derived from you, our members. The more members we have, the more powerful our voice.

Our expenses continue to grow. For example, the cost of printing and mailing this newsletter has increased, and we cover travel and accommodations for our excellent guest speakers at our annual conference, both of which have 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 we can continue to advocate for people with PWS.

Please don't wait to join us! ■

Why Am I A Member of the Prader-Willi Alliance of New York, Inc.



by *Elinor Baller*

As a parent of a middle aged adult with Prader-Willi Syndrome, I have been actively involved with the Prader-Willi Alliance of New York (PWANY) for almost twenty years. The Alliance has been of vital importance to both me and my daughter Louise. In the late 1980's when I worried about where my daughter would live and how she could have an independent life, the founding members of the Alliance were already negotiating the development of one of the first Prader-Willi group homes in our area (Westchester, NY). Through the Alliance I found the support among other parents who were looking for the same thing: a group home that would understand and address the many needs of a Prader-Willi young adult. Under the auspices of the Alliance, the parents of 10 young adults came together to work through the living arrangements for our children at the newly designed Todd Road residence run by The Community Living Corporation. These parents became family as we all worked to improve the lives of our children as they moved out of their childhood homes.

As I became more involved with the Prader-Willi community through the Alliance, I learned more about the Syndrome. Each conference run by the Alliance taught me something new, from the genetic profile of PWS and various health related issues to effective strategies for handling difficult situations with food and behaviors. The more I learned, the easier it was for me to talk to other parents who were struggling with the same issues in raising their children. The conferences provided a vast education for me about PWS so I could knowledgeably address and understand my daughter's needs. It was the conference sessions on trust and estate planning for a special

needs child that forced me to initiate my own planning for my daughter's future.

I can still remember the first conference that I went to with Louise. She was proud that she was controlling her diet and was determined to help anyone that she could. At that time she had only known one other person with PWS at her school. As we drove into the hotel parking lot for the Alliance conference in Boston, Louise started noticing others with PWS. She was so excited to find others who, like herself, struggled with diet and exercise. At the conference, Louise found a place where she could easily belong. Each year she loves to return to the PWANY conference to meet old friends and new ones and to show how successfully she has grown up with PWS.

Most important, the Alliance has provided me with a community that shares my concerns and through the Alliance I have derived much satisfaction from using my experience to help others who are new to PWS. The Alliance has done so much to help the families of PW children. I am very proud to be an active member because there is still so much that needs to be done. ■

Advocacy • Support • Hope

We recognize that it's so much easier to do things online. As a result the **Prader-Willi Alliance of NY, Inc.**

IS NOW ONLINE

Use your ***Credit Card*** for Conference Registration, Alliance Membership and Donation

Go to **www.prader-willi.org**

Medicaid Service Coordination: A Crisis is Building

by Rochelle Hutchings

Medicaid Advocates for the Disabled Inc. was established in 2004 as an independent Medicaid Service Coordination Agency. It was created to provide an alternative to Service Coordinators who were employed by a department within a residential /day program agency. It was thought that independence from other agencies might offer an advantage to consumers, since their advocates could act in their best interests without constraint.

The most highly qualified social work candidates were sought and retained as MSC independent contractors. They were paid on a contractual basis and supported by our agency, while having the freedom to set their own schedules, thereby coordinating with their clients' needs. They could choose the number of people that they served. Therefore, each professional could give the maximum time to each consumer. Medicaid funds were used to pay each Service Coordinator for each individual they served. (Fee for service) Over the past year, due to budget cuts, OPWDD, the new name for OMRDD, redesigned Medicaid Service Coordination, both payment and structure of service. The goal was to simultaneously retain essential services provided by Service Coordinators, but save money.

In addition to some changes, rather than the previously tiered system of payment, the Agency would be paid a flat rate for their MSC services and would be paid either for 6 months for consumers living in 24/7 supervised settings, 10 months for those in supportive apartments and 12 months for those living at home. It was left to each agency employing Medicaid Service Coordinators to distribute the payments to their Service Coordinators.

Individuals with PWS within our agency fall into the category of 6 months of payment, since they live in supervised settings. These individuals, although they reside in supervised homes, require advocacy and monitoring of the services they receive more than those living at home. We did not want to create a situation where these individuals would lack the oversight previously provided and which we believed necessary to their well being. The problem was how to pay for this level of service.

Our Board of Directors (one Board member is diagnosed with PWS) met. We agreed that we would redistribute the State monies in order to maintain the tiered system and to cut administrative costs. Sadly, we needed to cut the payment to our valued Service Coordinators. We maintained a reasonable level so that our MSC's would not be forced to overburden themselves by providing for so many consumers that services would suffer in order for them to earn a living wage.

We presented the Board's decision to a meeting of the Service Coordinators where all nervously awaited the outcome. All present graciously accepted the reduced fee and were gratified that they might be able to maintain an acceptable level of quality. A necessary component to make this budget work was an appeal to Board Members, parents and friends for financial help. And those who knew our work were generously forthcoming.

Our quality team is straining to provide the best and most comprehensive service possible in this economically impoverished environment. ■

In New York State we have two PWS Statewide Coordinators at the NYS OPWDD. Lisa Pesante is the coordinator for down state and Judy Herlihy covers upstate NY.



Judy Herlihy and Lisa Pesante

UPSTATE PWS COORDINATOR

Judith F. Herlihy, LMSW, SWS I
Coordinator of Family Support Services
Finger Lakes DDSO
620 Westfall Rd. Suite 108
Rochester, NY 14620
Office: 585-241-5726
Fax: 585-241-5767
judith.HERLIHY@opwdd.ny.gov

DOWNSTATE PWS COORDINATOR

Lisa M.E. Pesante
Placement Supervisor, PWS Liaison, OPTS Liaison
Metro NYDDSO
2400 Halsey Street
Bronx, N.Y. 10461
Office: 718-430-0474
Fax: 718-822-2592 fax
lisa.PESANTE@opwdd.ny.gov

In addition to the statewide coordinator, there are also PWS Developmental Disabilities Services Office Coordinators throughout the State. (See Page 5) Every county has one assigned. For any information on eligibility, entitlements, Medicaid, Medicaid Waiver programs, Family Support Services, etc., this is the place to call. If you need a Medicaid Service Coordinator, they will help you find one.

NYS OPWDD Prader-Willi Syndrome Coordinators

DDSO PWS Coordinator	Address	Telephone Number
BERNARD M. FINESON DDSO (Queens County) Deepa Nair Deepa.Nair@opwdd.ny.gov	PO Box 280507 Queens Village, NY 11428	(718) 217-6608
BROOKLYN DDSO (Kings County) Janet Strauss, Janet.Strauss@opwdd.ny.gov Izetta Weeks, Izetta.Weeks@opwdd.ny.gov Michelle Boyd, Michelle.Boyd@opwdd.ny.gov	888 Fountain Avenue Brooklyn, NY 11208	(718) 642-8548 (718) 642-8588
BROOME DDSO (includes Broome, Chenango, Delaware, Otsego, Tioga and Tompkins Counties) John Lishok JOHN.LISHOK@opwdd.ny.gov	Broome Developmental Services High Risk Births Clinic 305 Main Street, Binghamton, NY 13905	(607) 729-1295
CAPITAL DISTRICT DDSO (includes Albany, Fulton, Montgomery, Rensselaer, Saratoga, Schenectady, Schoharie, Warren and Washington Counties) Paul Partridge Paul.Partridge@opwdd.ny.gov	O.D. Heck DC 500 Balltown Road, Schenectady, NY 12304	(518) 370-7815
CENTRAL NY DDSO (includes Cayuga, Cortland, Herkimer, Lewis, Madison, Oneida, Onondaga and Oswego Counties) Fran Koon FRAN.KOON@opwdd.ny.gov	Onondaga County Service Office PO Box 1035 800 S. Wilbur Avenue, Syracuse, NY 13202	(315) 473-5063
FINGER LAKES DDSO (includes Chemung, Livingston, Monroe, Ontario, Schuyler, Seneca, Steuben, Wayne, Wyoming and Yates Counties) Judy Herlihy judith.HERLIHY@opwdd.ny.gov	620 Westfall Road Rochester, NY 14620	(585) 241-5726
HUDSON VALLEY DDSO (includes Orange, Rockland, Sullivan and Westchester Counties) Jackie Spring, JACLYN.SPRING@opwdd.ny.gov Richard McKeon, Richard.Mckeon@opwdd.ny.gov	PO Box 470 9 Wilbur Road, Theills, NY 10984	(845) 947-6059
LONG ISLAND DDSO (includes Nassau and Suffolk Counties) Akiva Karalitzky AKIVA.KARALITZKY@opwdd.ny.gov	Long Island Developmental Disabilities Service Office 415-A Oser Avenue, Hauppauge, NY 11788	(631) 434-6077
METRO NEW YORK DDSO (includes Bronx and New York Counties) Lisa Pesante lisa.PESANTE@opwdd.ny.gov	Bronx Service Office 2400 Halsey Street, Bronx, NY 10461	(718) 430-0474
STATEN ISLAND DDSO (Richmond County) Barbara Schubert BARBARA.SCHUBERT@opwdd.ny.gov	1150 Forest Hill Rd. Building 12-G, Staten Island, NY 10314	(718) 982-1904
SUNMOUNT DDSO (includes Clinton, Essex, Franklin, Hamilton, Jefferson and St. Lawrence Counties) Teresa Mahoney TERESA.MAHOONEY@opwdd.ny.gov	Clinton/Essex Service Office 159 Margaret Street, Suite 104, Plattsburgh, NY 12901	(518) 561-8190 ext. 230
TACONIC DDSO (includes Columbia, Dutchess, Greene, Putnam and Ulster Counties) Mark Searle Mark.Searle@opwdd.ny.gov	Dutchess County Service Office 38 Fireman's Way, Poughkeepsie, NY 12603	(845) 473-5050 ext. 151
WESTERN NY DDSO (includes Allegany, Cattaraugus, Chautauqua, Erie, Genesee, Niagara and Orleans Counties) Smart George SMART.GEORGE@opwdd.ny.gov	1200 East & West Road West Seneca, NY 14224	(716) 517-2198

Continued from Pg. 1

While less taxes may sound good to the individual in this struggling economy, the reality is that without the ability to raise capital through taxes, many school districts are now being faced with a cut in funding on two fronts, resulting in a loss of millions of dollars from their budgets. Here again, districts are forced to make decisions for the majority of their students that have a disproportionate impact on those with PWS, as our children tend to require costly services (special education, therapies, and 1:1 teaching assistants).

Allow me to return to my personal story for a moment, given the parallels to the overall situation in NY. With the awareness that Noelle's genetics will result in an incurable hunger that impairs her ability to function normally in society, why should a diagnosis with PWS not have automatically resulted in a decision that she is eligible for OPWDD services? Noelle's application included evidence of her diagnosis, along with documentation as to her intellectual, academic, and adaptive functioning (at this point I should give kudos to Noelle's MSC and to the school psychologist who completed an extremely thorough re-evaluation). Instead, I lost a day of work, Noelle lost a day of school and therapy, and the tax-payers of NY lost the services of staff at the DDSO so that they could re-evaluate Noelle and further discuss her eligibility. I fail to see how this process was either efficient or cost-effective. Other families have wasted countless personal and tax-payer hours searching (in collaboration with their school district) for a residential educational setting for their child, only to find that they are unable to locate an appropriate setting that will accept their child in NY, and that being accepted at an appropriate school out of state does not mean that the placement will be approved by the State Education Department.

The question then becomes: what can we, as the representatives of those with PWS, do to hold our ground in the face of fiscal crisis and impending change? Advocacy becomes crucial at several levels. When each of us participates in an IEP or service planning meeting, we need to be aware of what constitutes an effective plan.

If you are uncertain what you should be asking for in those meetings, seek out an advocate to attend with you. Contacts need to be made with legislators and policy-makers to make them aware of the needs of those with PWS and the inordinate impact that their decisions have for a low-incidence diagnosis. We need to be making legislators, policy-makers, and educators aware of the issues specific to PWS: the reality that the incurable hunger those with PWS face will lead to extremely costly and life-threatening medical problems in the absence of appropriate services and supports.

Certainly changes are needed to make procedures and service provision more efficient and thereby more cost-effective. But services cannot be cut or be provided in a manner that seems "fair" to everyone. The mantra "fair isn't always equal" applies here. If someone walks into an emergency room with a gunshot wound, they should receive different treatment from the person with the flu. Of course each of those people should receive treatment appropriate to their presenting problem. We are not talking about having those with PWS receive some "gold standard of service" at the expense of others with disabilities in NY, we are talking about receiving appropriate services and keeping individuals with PWS alive.

As an organization, PWANY is hard at work on many fronts, advocating with legislators and agencies. We are also organizing our 21st Annual Conference. With the theme "Changes Ahead", we are focused on providing each of you with new information and strategies relevant to current issues in NY and the medical/behavioral needs of those with PWS. The reality is that many of the people who are going to make decisions affecting my daughter's future are well-meaning, but they do not live our day to day lives, nor do they understand the unique complexities of this syndrome. It does not matter how "high functioning" my child is if she will choose to eat herself to death. What I choose to say and do today will have a far reaching impact on what is available to my child in the years to come. It is essential that we advocate for our loved ones who cannot advocate for themselves. ■

Focus Groups Throughout New York State

by *Nina Roberto*

These valuable focus groups, (which I call mini workshops), continue to occur. At the Metropolitan area focus group we have had presenters talking about sleep disorders in PWS, scoliosis, Medicaid service coordination, guardianship and special needs trusts. Our latest presentation by Parent to Parent of NYS was on Education advocacy. We've also had presenters from our local DDSO's: Akiva Karalitzky from Long Island, Deepa Nair from Queens, Paul Partridge from the Capital District, Fran Koon from Central NY and Lisa Pesante from the Metro Area. They all shared extremely vital information on entitlements and eligibility for OPWDD services. This information is then shared at other focus groups throughout the state. I have also video taped speakers from the Metro group to show at the Westchester and Capital District Focus Groups because these are topics of most interest to parents.

Although we are attempting to make these groups as interesting and successful as possible, we are still struggling with attendance at the Westchester, Capital District and Central NY groups. If you have any suggestions for topics at these groups, please contact me at nroberto@prader-willi.org or 718-846-6606.

Thanks and see you at conference!





Annual PWANY Conference

April 29 & 30, 2011

Mark your calendars now! The 2011 PWANY Conference will be held April 29th and 30th at the Best Western Sovereign Hotel in Albany. Our theme this year is "Changes Ahead: Holding our ground and moving forward to meet the needs of our Prader-Willi population".

As I'm sure you know, our state is in financial crisis. Budgets are being slashed and services are being cut. While one can argue that a financial change is needed in New York State, we must be vigilant in making sure that these changes do not cause our loved ones to lose services or to diminish the many services that we have fought so hard over the past twenty years to attain. Any reduction of services will severely impact the very quality of life for people with Prader-Willi syndrome (PWS).

What can YOU do? Well, start by being informed.

Please join us at the 2011 conference to learn how you can better advocate for your child, or that person under your care, both now, and in the future.

Now more than ever we need to pull together and let our voices be heard. The fact that PWS is a "low incidence" syndrome, where there are so few of us lobbying for services, has caused many in Albany to think that services for people with PWS can be cut without any significant repercussions.

On Friday, April 29th at 9:00 a.m. OPWDD has committed to provide a keynote speaker from the commissioners office. This presents for us a golden opportunity to show him and those in charge of state spent dollars that when it comes to standing up for those for whom we care, we are second to none.

This Conference is the most important one that you will ever attend. Not only because of the information to be learned from our presenters, but also because we need you to be counted. We cannot and will not be ignored.

In unity and numbers there is strength.
See you at the Conference! ■



Annual Conference Fund Raiser, Gift Basket Silent Auction

by Linda LeTendre



The Alliance is pleased to announce our annual conference fund raiser; the Gift Basket Silent Auction. This event will be held on Friday, April 29th during the Dinner/Dance.

The proceeds of this event go to support the conference companion program which provides care (including arts and crafts) to children and young people with PWS. This enables their parents to attend the conference where they learn valuable information and make important connections that will help to improve the quality of life for their children and their families.

You can help by donating, or arranging for a donation, of a gift basket. We just ask that there be no food items in the baskets (coffee & tea are OK) and that the basket be worth at least \$50. You can bring the baskets with you or have them shipped to the hotel.

Your support of this event will help to ensure the success of our conference!

If you have any questions or need assistance, please call our Conference Coordinator, Linda LeTendre at (518) 633-4781. ■

Childcare Registration Form

*This form must be attached to your Conference Registration Form if you are requesting childcare.
If you need childcare for more than one child, please photocopy this form and include one form per child.*

Child's Name _____

Parent's Name(s) _____

Date of Birth _____

Please list the name(s) of people who have permission to

Cell Phone Number (of Parent attending Conference): _____

take your child from the child care room: _____

**No food, sippy cups, or bottles are allowed in the child care room.
You will need to pick up your child and feed them in an alternate location.**

Are there any indications of vision or hearing problems? YES () NO ()

Describe your child's personality: _____

What is your child's favorite indoor activity? _____

What is your child's favorite toy? _____

Does your child normally nap at home? YES () NO ()

If YES, please list normal nap schedule and routine (ex. Goes to sleep with pacifier, or cries for a couple of minutes before settling down)

Is your child potty training? YES () NO ()

If YES, what words does your child use for use of the bathroom? _____

How much help does your child need in the bathroom? _____

Is there anything else you feel we should know in order to better care for your child? (Including specific behavioral concerns)

My signature below acknowledges that I have read, understand and will abide by the "Parents responsibilities at conference" article on Pg. 9.

Name _____ **Date** _____

Parent's Responsibilities At Conference

The PWANY's goal in organizing an Annual Conference is to provide a low-cost educational conference for families with a child with PWS and for the providers who care for them. For more than ten years the PWANY has provided companion care for children whose parents are attending the conference. With the recognition of how difficult it is to care for our children with PWS, we strive to employ companions who have experience in this area. However, each child with PWS has unique needs. As a result, we would ask that parents take an active role in meeting the following responsibilities:

- Provide complete and accurate information on the Conference Registration Form.
- Please complete and submit the Childcare Registration Form (Page 8)
- Help us to provide food security to all those with PWS at the conference. For example, snacks are not allowed in the childcare room as it would be upsetting to the others with PWS in the room. If your child needs a snack, he/ she should be picked up and provided with a snack at an alternate location.
- Provide supervision for your children, of all ages, in the halls and conference room areas of the hotel.
- Supervise your children during mealtimes and help them make choices as to the appropriate size of their meals. PWANY

has worked hard to provide a wide range of wholesome meals for both adults and children. However, there is no "one size fits all" when it comes to meals. Box lunches are available for very young children, while a smaller child's lunch portion is also available at no charge (suggested for children up to age 11). Our adult portions may contain too many calories for your child with PWS. As you know your child best, please decide what would be most appropriate for your child with regard to their nutritional needs and social concerns: to share your meal with your child, order a lesser calorie Children's Meal, or order them an adult size portion.



If you have any suggestions for improvement, please contact our Conference Coordinator Linda LeTendre at 518-633-4781

Thank you for your understanding and helping us make this conference as safe, stress-free, and low-cost as possible for our families. ■

Memories: PWANY CONFERENCE 2010



Prader-Willi Alliance of New York, Inc.

21st Annual Conference Agenda

Thursday, April 28

6:00 p.m. - 8:00 p.m.

Registration

Friday, April 29

7:30 a.m. - 9:00 a.m.

8:00 a.m. - 8:30 a.m.

Registration

Guilder Room:

Special Sharing Session for Parents of Newly Diagnosed Children:
Nina Roberto, PWANY Executive Director

8:30 a.m. - 9:00 a.m.

Squire Room Welcome:

Amy McDougall, President, PWANY

9:00 a.m. - 10:00 a.m.

Squire Room Keynote Speaker: OPWDD has committed to provide a keynote speaker from the Commissioner's Office

10:00 a.m. - 10:15 a.m.

Break

10:15 a.m. - 11:15 a.m.

Squire Room: Adrenal Insufficiency, Dr. Moris Angulo

11:15 a.m. - 12:15 p.m.

Breakout sessions

12:15 p.m. - 1:15 p.m.

Lunch: Executive Room

1:15 p.m. - 1:45 p.m.

PWANY membership meeting: Executive Room

1:45 p.m. - 3:00 p.m.

Breakout sessions

3:00 p.m. - 3:15 p.m.

Break

3:15 p.m. - 4:15 p.m.

Breakout sessions

4:15 p.m. - 5:15 p.m.

Breakout sessions

5:30 p.m.

Parents may pick up children's to-go dinners

6:30 p.m.

Dinner/Dance: Squire Room (Ticket required for admission)

Children's Entertainment: Guilder Room

Saturday, April 30

7:30 a.m. - 9:00 a.m.

9:00 a.m. - 9:15 a.m.

Registration

Squire Room Welcome:

Amy McDougall, President, PWANY

9:15 a.m. - 10:15 a.m.

Breakout sessions

10:15 a.m. - 11:15 a.m.

Breakout sessions

11:15 a.m. - 11:30 a.m.

Break

11:30 a.m. - 12:30 p.m.

Breakout sessions

12:30 p.m. - 1:30 p.m.

Lunch: Executive Room

1:30 p.m. - 3:30 p.m.

Sharing sessions

Prader-Willi Alliance of New York, Inc. Conference Breakout Sessions

Friday, April 29	Session	Presenter
11:15 a.m. - 12:15 p.m. Squire Room Town Room Loft Room	Effective Advocacy Transitioning from School Age to Adult Services Sleep Issues In PWS	Jeff Covington Amber Villines Guilda Hertz, MD
1:45 p.m. - 3:00 p.m. Squire Room	Behavior Panel: Managing Behaviors of Adults Panel: Jonathan Lukens, Kim Schultz, Michael Marchese, Wendy Bernard and Stacy Ward	Moderator BJ Goff, Ed.D.
Town Room	Functional Behavior Assessments (FBA'a) of school age children	Glenda Criss-Forshey and Tracy Menapace
3:15 p.m. - 4:15 p.m. Squire Room Town Room	Psychotropic Medications Understanding the New State Mandated Individualized Education Plan (IEP)	Dr. Ivy Boyle Amy McDougall
Loft Room	Your Unanswered Questions About PWS	Janalee Heinemann, MSW
4:15 p.m. - 5:15 p.m. Squire Room Town Room	Creative Housing Solutions What makes a good residential school, and why & how would you choose one for your child	Sandra Van Eck Jonathan Smith
Saturday, April 30	Session	Presenter
9:15 a.m. - 10:15 a.m. Squire Room Town Room	Current Medical Research Creating an Individualized Service Plan	Janalee Heinemann, MSW Mary Jo Hebert
10:15 a.m. - 11:15 a.m. Squire Room	Special Needs Trusts, Wills and Estate Planning for Families of People with Disabilities	Edward Wilcenski, Esq.
Town Room	Medicaid Service Coordination Redesign	Eric Pasternak
11:30 a.m. - 12:30 a.m. Squire Room	Guardians, Trustees and Other Important Roles that Advocates Can Play	Edward Wilcenski, Esq.
Loft Room Town Room	Managing Classroom Behaviors Working With Adults With PWS In A Residential Setting	Patrice Carroll BJ Goff, Ed.D.
1:30 p.m. - 3:30 p.m. Squire Room Guilder Room Loft Room Town Room Albany Room	Sharing Session Ages 0-5 Sharing Session Ages 6 -12 Sharing Session Ages 13 -21 Sharing Session Ages 21 + Sharing Session Grandparents	Nina Roberto Janalee Heinemann, MSW Jeff Covington BJ Goff Ed.D. Barbara McManus



PWANY 21st Annual Conference Presenters

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

Wendy Bernard: Wendy graduated from Dowling College with a Bachelor's degree in psychology. She has been an employee of FREE for 4 years since January 2007 acquiring various skills while working with dually diagnosed individuals with a range in diagnoses. For the past 2 years, she has worked at the Hempstead ICF serving individuals with Prader Willi Syndrome.

Dr. Ivy Boyle, is a child and adolescent psychiatrist and for the last twelve years has been the Medical Director at Bellefaire JCB in Cleveland, Ohio. Her specialties are Autism and children with disabilities. Dr. Boyle has a child with PWS.

Patrice Carroll, is a member of PWSA USA Provider's Advisory Board and has 12 years of experience working with people diagnosed with PWS. Patrice is currently working at The Latham Centers as Manager of Prader-Willi Syndrome Services and has extensive knowledge and experience working with children and adults diagnosed with PWS who have severe behavioral challenges..

Jeff Covington, BA, is the Director of Residential Services for Catholic Charities Disabilities Services in Albany, NY. He has worked with individuals with PWS for over 10 years and in the field of developmental disabilities for over 15 years. Jeff is a member of the PWS associations of New York, New Jersey, and New England, and is also a member of the PWSA(USA) Provider Advisory Board

Glenda Criss-Forshey, BA, MS, is the Community Outreach Coordinator for the Early Childhood Direction Center (ECDC) at Syracuse University. She has a BA in Early Childhood Education and MS in Instruction. Glenda has 15+ years experience working with young children with challenging behaviors in daycare and preschool settings. She is also the parent of a child with special education needs and a typically developing child.

B.J. Goff, Ed.D., is an 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 serves as educational crisis consultant for PWSA(USA).

Mary Jo Hebert, is the Regional Coordinator with the Capital District office of Parent to Parent of NYS. She is an instructor of Training and Development Programs for OPWDD. Mary Jo is a member of the Capital District DDSO's Family Support Council. As the parent of a child with developmental disabilities, she is a frequent contributor of articles on the challenges faced by parents of children with special needs.

Janalee Heinemann, MSW, is the parent of an adult son with PWS and has her Masters in social work from Washington University in St. Louis, Mo. She is the former executive director of PWSA(USA) and presently serves as the Director of Research and Medical Affairs.

Gila Hertz, PhD D-ABSM, Currently the Director of the Center for Insomnia and Sleep Disorders Diplomate, American Academy of Sleep Medicine, a Licensed Psychologist and Certified, in Behavioral Sleep Medicine (CBSM)

Jonathan Lukens, Director of Residential Services at Community Living Corporation Westchester, NY. Over 25 years of innovation, leadership and support to persons with developmental disabilities (including PWS). Provides Supervision and oversight to 36 residential programs in Westchester County.

Amy McDougall, M.S., has ten years of experience as a school psychologist in both elementary and preschool settings. She is currently the CPSE Chairperson for an upstate NY district. Amy has three children, one of whom has PWS, and serves as the President of the PWANY.

Michael Marchese, MA, LMHC, is the Director of Adult Services at Latham Centers Inc., and has been responsible for managing Latham's Prader-Willi Syndrome services since joining Latham in 2003. A licensed mental health professional, he has 30 years of clinical, supervisory and program management experience in the mental health and developmental disabilities.

Tracey Menapace, MS, is the Director for the Early Childhood Direction Center (ECDC) at Syracuse University. Tracey has an MS in Educational Psychology. She has 25 years experience working with children and families of young children. She is the parent of three children, two with special education needs and one without.

Eric Pasternak is the Statewide Coordinator of Medicaid Service Coordination for the Office for People with Developmental Disabilities. A social worker by trade and education he has been in the human services field for 17 years. He started with OPWDD ten years ago as a service coordinator and recently assumed the role of statewide coordinator.

Kim Schultz is an Associate Divisional Director for Family Residences and Essential Enterprises. Kimberly has over 15 years experience in the Human Service field. She has been working with individuals with Prader-Willi for the last 7 years.

Jonathan Smith, LCSW, is the Director of Children's Services at Latham Centers. He has over 30 years of experience working with parents and individuals with PWS as well as host of other issues, in residential, hospital and community based programs. He has extensive experience working with "aging out youth" and the transition challenges that they and their families encounter.

Sandra Van Eck, MS, is the Director of Innovation and Design for The Arc of Rensselaer County. Ms. Van Eck has 25+ years experience supporting individuals with disabilities in residential settings in a variety of roles ranging from direct care to senior management. She has a Master Degree in Organization Development from Antioch Graduate School. Sandy has specialized in creating highly innovative alternatives to the traditional community residence model.

Amber Villines, Is currently RSE TASC Transition Specialist at OCM BOCES and has worked as a Consultant at OUHSC, Preschool Coordinator at OSDE and Special Education at OKC. She is a graduate of the University of Central Oklahoma.

Stacy Ward CCDS, Associate Director for Residential Services. She has been working in the field of developmental disabilities for over 15 years and with individuals with PWS for at least 6 years.

Edward Wilcenski, Esq. is a co-owner of the law firm of Wilcenski & Pleat PLLC in Clifton Park, New York. He practices in the areas of Special Needs Estate Planning, Elder Law and Trust and Estate Administration ■

The 21st Annual Prader-Willi Alliance of New York Conference

**April 29th & April 30th - Best Western Sovereign Hotel
1228 Western Avenue - Albany, New York**

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

Family Registration (Up to THREE family members may attend for one fee!):

\$35.00 for two days - \$25.00 for 1 day

\$15.00 for each additional family member (good for 1 or 2 days) (Example 4 family members = \$50, 5 = \$65, etc.)

Discount: "2011" paid members of the Alliance may deduct \$5.00 from the total due.

Lunch: \$14.00 per adult – A Children's size (smaller) lunch is free for ages 11 and under.

We have worked closely with the Best Western to provide healthful and appropriate meals.

Hotel reservations can be made by calling the hotel at (518) 489-2981.

Ask for the Special PWANY Conference Rate.

Please Note: ONE form per family. PLEASE PRINT LEGIBLY!

Name(s): _____
(List all names for whom you want a name tag)

Address: _____ City: _____ State: _____ Zip: _____

Home Phone: () _____ Work Phone: () _____

Fax #: () _____

E-mail: _____

No. in Attendance: Friday _____ Saturday _____
No. of Lunches: Friday: Adult _____ Child(ren) _____
Saturday: Adult _____ Child(ren) _____

Do you require companion care for an individual with PWS, or a sibling(s)?
Please complete and attach "Childcare Registration Form" on Page 8

No _____ Yes _____ Age(s) _____

Comments/Special needs: _____

Please indicate amount enclosed:

Registration Fee: _____ = \$ _____

Lunches: _____ Total No. of Adult Lunches _____ X \$14 = \$ _____

Tax deductible donation: _____ \$ _____

Membership Dues (\$30 person or family of 3): _____ \$ _____

Sub total: _____ \$ _____

Deduct \$5 if a member in "2011" _____ \$ _____

Total amount enclosed: _____ \$ _____

ADULT'S LUNCH MENU

Choice of one, each day, for each paid lunch

FRIDAY

Chicken Noodle Soup
Tuna Salad/Kaiser Roll
No. _____

SATURDAY

Vegetable Soup
Roasted Vegetable Wrap
No. _____

Chicken Noodle Soup
Roasted Turkey Wrap
No. _____

Vegetable Soup
Grilled Chicken/Hard Roll
No. _____

Apple Harvest Chick. Salad
Roll/Butter
No. _____

Chicken/Spinach Salad
Roll/Butter
No. _____

CHILDREN'S LUNCH MENU (11 & under free)

Offerings are the same for both days.

Grilled Chicken
Over Garden Salad
No. Fri _____ No. Sat _____

Child's Box Lunch
(ages 2-6)
No. Fri _____ No. Sat _____

Garden Salad
No/Bun Turkey Burger
No. Fri _____ No. Sat _____

Garden Salad
Turkey Wrap
No. Fri _____ No. Sat _____

Office Use Only

Current Member Y N

Amount Due \$ _____

Please send payment along with this registration form to:

Prader-Willi Alliance of New York, Inc., PO Box 222, Baldwinsville, NY 13027

If you are registering after April 23rd or have questions, you must call our conference coordinator Linda LeTendre at (518) 633-4781.

The Sovereign Best Western Hotel is located across from SUNY Albany's Western Ave. entrance.

You can register on-line by going to: www.prader-willi.org/conference

The 21st Annual Prader-Willi Alliance of New York Conference

**April 29th & 30th - Best Western Sovereign Hotel
1228 Western Avenue - Albany, New York 12203 - (518) 489-2981**

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

Professional Registration: \$60.00 For 1st Day, plus \$20.00 for 2nd Day

Discount: "2011" paid members of the Alliance may deduct \$5.00 from the total due

Lunch: \$15.00 per adult

Membership Dues: \$40 - per person (**not** per agency)

**We have worked closely with the Best Western to provide healthful and appropriate meals.
Hotel reservations can be made by calling the hotel at (518) 489-2981.
Ask for the Special PWANY Conference Rate.**

Please Note: ONE registration form per person - NO group registrations. PLEASE PRINT LEGIBLY!

Name: _____

Organization/Agency: _____

Address: _____ City: _____ State: _____ Zip: _____

Work Phone: () _____ Fax #: () _____

E-mail: _____

Attendance: Friday Saturday

Comments/Special needs: _____

Please indicate amount enclosed:

Registration fee: _____ = \$ _____

Lunches: _____ \$15 X no. of days _____ = \$ _____

Tax deductible donation: \$ _____

Membership Dues: \$ _____

Deduct \$5 if a member in "2011" \$ _____

Total amount enclosed: \$ _____

LUNCH MENU	
Choice of one, each day, for each paid lunch	
FRIDAY	SATURDAY
Chicken Noodle Soup Tuna Salad/Kaiser Roll No. _____	Vegetable Soup Roasted Vegetable Wrap No. _____
Chicken Noodle Soup Roasted Turkey Wrap No. _____	Vegetable Soup Grilled Chicken/Hard Roll No. _____
Apple Harvest Chicken Salad Roll/Butter No. _____	Chicken over Spinach Salad Roll/Butter No. _____

You can register on-line by going to: www.prader-willi.org/conference

Send payment, along with this form, to:

Prader-Willi Alliance of New York, Inc., PO Box 222, Baldwinsville, NY 13027

If you are registering after April 23rd or have questions, you must call our conference coordinator Linda LeTendre at (518) 633-4781.

The Sovereign Best Western Hotel is located across from SUNY Albany's Western Ave. entrance.

Office Use Only	
Current Member	Y N
Amount Due \$ _____	

Dinner & Dance

An "Official" PWANY Conference Event



Last year's dinner/ dance was such a hit (our young folks really know how to "cut a rug") that we decided to do it again! Though we'll be more informal than last year with a toned down menu and a DJ rather than a live band, there is no doubt that this will be a wonderful time together— and that the dancing will be every bit as exuberant, if not more so!

While the adults and older children enjoy dinner together, there will be a children's program with great entertainment. Following rave reviews from children and adults alike last year, we are fortunate to have "The Magic Trunk" returning. To ensure food security in the children's room, yet provide a convenient means for families to feed

their children prior to the start of the entertainment, children's meals will be packaged "to-go" for pickup earlier in the evening. When the dancing starts, the children are welcome to join us for the festivities.

We're excited to offer this evening of dinner and dancing for \$20 per adult. A to-go children's meal will be available for those who want to feed their child before attending dinner, at a cost of \$5 per meal for those 11 and under. Don't miss out on your opportunity to join us! Complete the "Registration Form" below and we'll make sure that you're on the list! ■

Dinner/Dance Registration Form

Friday, April 29, 2011 • 6:30 p.m.

Please Note: ONE form per family. PLEASE PRINT LEGIBLY!

Name(s): _____

Address: _____ City: _____ State: _____ Zip: _____

Home Phone: () _____ Work Phone: () _____

E-mail: _____

Number in Attendance: _____

Dinners: Number of Adult(s) _____ X \$20 = \$ _____

Number of Children _____ X \$5 = \$ _____

Sub total: _____ \$ _____

Total amount enclosed: _____ \$ _____

Please note number of children attending the

Children's Entertainment Program: _____

Please send payment along with this registration form to:

Prader-Willi Alliance of New York, Inc.
PO Box 222
Baldwinsville, NY 13027

If you are registering after April 23rd or have questions, you must call our conference coordinator - Linda LeTendre at (518) 633-4781

DINNER

Choice of one for each paid dinner

Entrée Choice

All Include House Salad,
Vegetable Medley & Baked Potato

Chicken Marsala No. _____

Salmon Bourbon Glazed No. _____

Pasta Primavera with Marinara Sauce No. _____

With Assorted Rolls, Herb Butter
Coffee, Tea, Decaf, Unsweetened Ice Tea

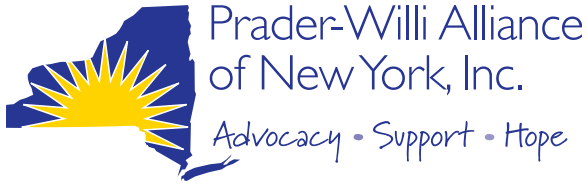
Dessert

Strawberries with mixed berries topped with
fat free, sugar free whipped topping

Children's To-Go Menu (includes dessert) 11 and under

Garden Salad with Grilled Chicken No. _____

Baked Chicken Nuggets
With carrot & celery sticks No. _____



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First Class Mail
U.S. Postage
PAID
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Rock Island, IL

PO Box 222
Baldwinsville, NY 13027



Enroll Me As A Member of the Prader-Willi Alliance of New York, Inc.

Dues are \$30 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 \$30 per person. Professional Dues are \$40 per person.

Enclosed are dues for 2011 \$ _____

Here's an additional tax deductible contribution \$ _____

Here's an additional tax deductible contribution designated for RESEARCH \$ _____

Amount Enclosed \$ _____

Date: _____ New Member Renewal

Name: _____ Organization: _____

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 your 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 222, Baldwinsville, NY 13027**

Go to www.prader-willi.org online and use your *Credit Card* for Conference Registration, Alliance Membership & Dinner/Dance.