



# Prader-Willi Alliance of New York, Inc.

## Advocacy • Support • Hope

### SUMMER 2009

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

## President's Message

*by Amy McDougall*



"Advocacy, Support, Hope"- a brief statement of purpose for PWANY, but these three words have taken on renewed meaning for me since being elected to serve as President of PWANY. For those of you whom I have not yet had the opportunity to meet,

my name is Amy McDougall. I live in Central New York, north of Syracuse, with my husband and three children. My daughter Noelle is 7 years old and has Prader-Willi syndrome (PWS).

In the few short months since our Annual Conference, there have been several issues that have required advocacy on the part of PWANY. In June, we learned that there was a bill pending in the New York State Legislature that would have made growth hormone a controlled substance, a move that would have created barriers to access of this needed treatment and caused a noteworthy burden and cost for individuals and families. However, thanks to a quick response from our organization, in conjunction with the efforts of other groups that would be affected, the wording of this legislation has been changed so that GH will not be included.

Another issue of concern is the need for statewide coordination of services to be made available to those with PWS. Given that PWS is a low-incidence diagnosis, providers often do not have the knowledge as to how to treat PWS as they tend to have with more commonly occurring diagnoses such as Autism and Downs Syndrome. The same holds true for those coordinating services for the disabled, as their caseloads are heavily weighted with higher-incidence disorders. As a result, they simply do not have the time to dedicate to remaining abreast of current research and knowledge of the services available for people with PWS statewide, rather than the very limited resources in their own geographical area.

In recognition of this concern, several years ago a group of parents worked with OMRDD to establish a position for a statewide Prader-Willi Coordinator. Given the current economic climate, OMRDD had indicated that they

intended to revert back to the model of having local DDSO PW coordinators take the lead, and thus eliminate the statewide position upon Ms. Vadney's retirement. The leadership of PWANY had advocated with Associate Commissioner Stephen Smits that it is essential to have one person at OMRDD who could act as a central repository for information and data in addition to being a contact person for resources in order to promote efficiency and cost-effectiveness for PW efforts statewide.

We also proposed that a statewide coordinator could maintain a statewide list of eligible PW candidates for placement in a PW group home and available openings in order to ensure that placements are fair, equal, and balanced.

**PWANY  
20TH ANNUAL CONFERENCE  
April 29 - May 1, 2010**

I am pleased to share that OMRDD is receptive to our concerns. They have designated Lisa Pesante (well known to many PWS families downstate) to serve part/time in this capacity, starting in the near future.

The need for PWS-specific training through OMRDD for providers, professionals, and parents is also being addressed, with work already starting on organizing a training module. I would like to take a moment to thank Commissioner Diane Jones Ritter, Deputy Commissioner Gary Lind, Associate Commissioner Steve Smits, and Director Janis Steven for their willingness to consider creative and cost-efficient ideas to meet the needs of those with PWS in New York State.

On a grassroots level, I would like to encourage each of you to continue to find ways to be involved in advocating, supporting, and spreading awareness of Prader-Willi syndrome. We may be a low-incidence diagnosis, but it is through building a unified voice that we will continue to create more opportunities for our loved ones. ■

## Conference 2009 - Much Better!!

I have to admit that after attending the conference in "2008", I was pretty done with the Best Western Sovereign Hotel. The rooms were shabby, the carpets dusty and everything had an overall run-down feel.



Not really the best foot for the Alliance to put forward. I was wondering that perhaps it was time to move to another hotel, or even another city.

Well Best Western heard our concerns, and they really deserve credit for the improvements they have made. The difference in cleanliness was visible upon entering the lobby. Carpets were clean, dust was conquered and light fixtures sparkled. The improvements continued on into the guest rooms.

Given the amount of families that travel from the metropolitan and other down state areas, Albany really is the most central location for the conference to be. I am looking forward to the improvements that the Best Western has in store for the upcoming year and our 20th annual conference. ■

### OFFICERS & DIRECTORS

|                                  |  |
|----------------------------------|--|
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| <b>Dr. Moris Angulo</b>          | <i>Medical &amp; Scientific Advisor</i>              |
| <b>Nina Roberto</b>              | <i>Executive Director</i>                            |
| <b>Linda LeTendre</b>            | <i>Conference Coordinator</i>                        |

## 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 2009, won't you please join with us now?

Member 2009  
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. As examples, the cost of printing and mailing this newsletter has almost doubled, and there are increased costs of transportation and accommodations for our excellent guest speakers at our annual conference, 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!** ■

## The First International Conference on Hyperphagia June 4-5, "2009" Baltimore, MD



I felt honored as well as privileged to attend this conference and looked forward to attending. I am back in NY to report to you all on this extremely informative conference.

On my way to Baltimore, my flight was delayed due to the weather. I was stuck on the runway for close to 4 hours and came to the conclusion that maybe I was better off driving. The plane was the size of a VW Bug and claustrophobia became a fast approaching entity. It seems as though Mother Nature had plans of her own that didn't include us flying anywhere anytime soon. I began thinking after reading every magazine in the pocket in front of me and staring at my neighboring peers for a hint of interesting conversation; I began to refocus about the purpose of my trip which was to learn all I could about the condition that ails our children...the inability of feeling full, the insatiable appetite that goes with PWS. I grew eager and prepared myself to absorb the wealth of information waiting for me just hours ahead.

The purpose and the idea of this conference was to create an environment conducive to making connections and to foster discussions across all scientific disciplines. It is thought that anytime research is done, all unknown disorders should be included.

Researchers found that some individuals with PWS have particular foods that they will eat and there are some foods they won't, sweet, salty, sour, etc. Scientists are looking into possibly altering certain taste buds to some degree so that conceptually, our children may eat less because they won't be able to "taste" a certain food.

Research is also being done in mice that scientists are mutating with PWS. The downside is that these mice, because of the "failure to thrive stage" in PWS, live no more than one week thus hindering their research in determining when and why hyperphagia occurs. They are working on increasing their survival rate to do further studies.

There was also a study done regarding the famous rule of how important it is to eat breakfast. Individuals who skip breakfast were slightly heavier, having a higher BMI and tended to eat more fat. Skipping breakfast is equal to fasting which is equal to seeking higher calorie foods which may result in obesity.

Ghrelin was also discussed and how it may relate to gastric distention. There is a change in the brain because of ghrelin which causes an increase in food desire. This increase in ghrelin, mimics fasting which leads to the consumption of higher calories which could lead to gastric distention. Is ghrelin contributing to hyperphagia? This is still unknown.

The sheer brilliance in the room left the everyday lay person in the woods, yet at the same time, scientists explained it in such a way that one would truly 'get it'. As a parent, I was pleased, excited and amazed at the interest they've taken in our children and this gives me indescribable hope for their future. It made me think...five hours on a plane for a 40 minute flight...what do I have to complain about? My son never feels full! He will feel hungry every day of his life. Thousands of adults and children suffer from hyperphagia. What do I have to complain about? ■



## Silent Auction Makes a Big Noise!

by *Linda LeTendre*

Participants purchased tickets and placed them in decorative bags corresponding to the third annual silent auction for the PWANY conference. The auction raised fun and funds! The funds raised helped the young people with PWS have fun in our companion program while their parents and caregivers attended the conference.

Just before the Friday evening drawing, Harry Persanis made one more round of the guests and convinced them either to buy tickets if they hadn't already or purchase more if they already had. Actually he made two rounds....

Baskets included everything from cosmetics, to jewelry, to imported tequila, to candles and then some.

The young people who were part of the companion program drew the tickets and really knew how to milk the moment and keep everyone in suspense. We did make sure that those young people who drew the tickets for the baskets containing the tequila were over 21.

Hopeful participants gave up a total of \$547, all of which supported the companion program for the 2009 conference.

PWANY is deeply grateful to the agencies and people who donated this year's fantastic baskets and to the people who bought tickets in support of the companions. ■

# Thank You Barbara McManus



Barbara McManus is well-known to many in the Prader-Willi community, given the numerous ways that she has worked to advocate for and support us. As her successor as President and as a representative of the Officers and Board of Directors of PWANY, I would like to thank Barb for her hard work, leadership, and dedication. Her efforts have benefitted not only her granddaughter Jessika, who has PWS, but all of us.

Barb's professional resume is reflective of her computer expertise and willingness to help others. In 2001, Barb was honored with the Daisy Award for her "leadership, initiative, and team contributions" by the local chapter of Zonta International. Prior to her retirement in 2005, Barb was a Senior Programmer Analyst at the Multidisciplinary Center for Earthquake Engineering Research.

The term "retirement" can only be used loosely, as Barb has certainly not stopped working! She has participated in Partners in Policymaking (an advocacy training program), overseen the development and

maintenance of the websites and databases for both PWANY and PWSA(USA), chaired the National Conference in 2006 (held on Grand Island), and served as President of PWANY. Barb recently moved from NY to Florida, where she continues to work closely with PWSA(USA) and holds the title of Director of Family Support. While Barb stepped down as President of PWANY subsequent to her move out of state, she graciously agreed to continue to serve in the capacity of Treasurer.

Barb is unfailingly generous with her time, knowledge, and expertise. As Nina Roberto, our Executive Director, recently pointed out, Barb "is always there when we need her." On behalf of all of us: thank you, Barb, for everything you do!!! ■

## Ad Hoc Committee Meets with OMRDD Commissioner Diana Jones Ritter July 7, 2009

**Attendees:** Commissioner Diana Jones-Ritter, Associate Regional Commissioner Stephen Smits, Janis Steven, Amy McDougall, Harry Persanis, Daniel Angiolillo and Nina Roberto.

Commissioner Ritter began by stating that she has "worked to embrace strategies to all affected with PWS".

On issues such as children being admitted to Pittsburgh, OMRDD has made revisions and worked in conjunction with the Department of Health, noting that there have been "significant streamline improvements". OMRDD will work with the DDSO's as to the execution of the process on how to improve the referral to Pittsburgh. We were asked to call OMRDD to let them know of any difficulties with the process and they will assist us to overcome them.

PWANY's proposition is to gather a group of educators to determine how to reconstruct PWS training across the state. We have the experts here and out of state that are willing to participate. We would like to collaborate with OMRDD. Comm. Ritter is looking into offering training via video webcasts making training more interactive. A team comprised of members from OMRDD and PWANY will be formed. The formation of this team has been designated as an "action item". We are working on forming this team.



Lisa Pesante, PWS DDSO Coordinator for the Manhattan and the Bronx

has been appointed interim PWS DDSO Statewide Coordinator. This position was previously held by Ann Marie Vadney. She will become a conduit of information to our audiences and will be networking with physicians and assisting DDSO PWS coordinators to find and acquire information pertaining to PWS, admission to Pittsburgh, training sessions, etc. Lisa Pesante will perform this role on a part time basis beginning in September, 2009.

A draft of the DDPC PWS Demonstration Grant final report is done. The grant Advisory Committee as well as PWANY will have the opportunity to see and review this report before it is published.

Dr. Moris Angulo would like to move forward in establishing a multi-specialty treatment facility for PWS (similar to Pittsburgh) to be located on Long Island. Deputy Commissioner Gary Lind, (Policy and Enterprise Solutions), indicated that while the NYS Department of Health would be the lead agency for such a project, he would be willing to broker an initial meeting amongst the relevant agencies. ■

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## PWS Focus Groups

# Updates from Around Our State

by *Nina Roberto*

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Our focus groups have been quite successful throughout the state. Here are some updates, information and progress reports.

**WESTCHESTER:** Nina Roberto

Our newest focus group has been established with the assistance of Harry Persanis as well as the help of Dr. John Porcella, the Executive Director of Community Living Corporation who attends the meetings and offered us a place to meet. Dr. Delores Lulgjuray a psychologist who works as a consultant at Community Living Corporation and at AHRC in NYC graciously volunteered to chair this group. She also has a lot of experience working with individuals with PWS as a crisis interventionist and as such is a wonderful resource.

**Next meeting:** Community Living Corporation Office in Mt. Kisco, 105 South Bedford road, Suite 300, Mount Kisco, NY 10549

**SYRACUSE:** Amy McDougall and Tammy Reals;

Have done a wonderful job bringing this group together. Topics discussed were, different services that they have received and the difference in services available in different parts of the state. They spent some time encouraging a family as to how to go through transition from EI to CSE and there was also a discussion about the benefits of attending the conference put on by PWANY. They also discussed different things they might like to see at conference. For more information, you may contact them at [amcdougall@prader-willi.org](mailto:amcdougall@prader-willi.org) or Tammy Reals at [fourhavei@yahoo.com](mailto:fourhavei@yahoo.com)

**WESTERN NY:** Jeannie Dickinson;

Is in the process of organizing this focus group which will meet at Parent Network 1000 Main Street, Buffalo, NY. For more information, you may contact her at (716) 773-3076. More details to follow.

**ROCHESTER:** Volena Howe

Judy Herlihy, from Finger Lakes OMRDD, invited Prader-Willi families

and friends to spend an evening sharing experiences and concerns in dealing with Prader-Willi individuals. Barbara McManus, Past President of the Prader-Willi Alliance New York, kicked off the first meeting and opened up a discussion. Parents, friends, and providers suggested speakers for future meetings, as well as a social for our Prader-Willi population! Come on out Rochester...and network with us!!! For more information, contact Volena Howe at [volenah@yahoo.com](mailto:volenah@yahoo.com)

**CAPITAL DISTRICT:** Nina Roberto

We've had several speakers from dietitians, behavioral specialists and social workers all discussing pertinent issues involving our children. We have gone over transitioning from CPSE to CSE, skin picking, behavior modification and a guest speaker from Parent to Parent of NYS. They discussed what type of organization they are, what they do, how they could help our children and how to advocate for our children with special needs. They are a wonderful organization where families of individuals with special needs and the professionals who serve them can meet and share information. You could check out their website at [www.parenttoparentnys.org](http://www.parenttoparentnys.org). **Next meeting:** September 15th at 5pm, 1 Park Place, 2nd Floor, Albany, NY

**METROPOLITAN AREA:** Nina Roberto

We discussed Therapeutic Brushing and how it is good for sensory stimulation, how it can reduce skin picking, and tantrums. We discussed how keeping the hands moist with hand cream, or Vaseline will help avoid damage done by skin picking. Last year, Prader-Willi Awareness Walk-a-Thons took place in two locations, Long Island, N.Y. and Queens, N.Y. and both were very successful. This year the Walk-a-Thons were held again. National's web site, [www.pwsausa.org](http://www.pwsausa.org) has suggestions on how to raise awareness. These are ideas that can be done easily and at little or no cost.

**Our next meeting:** September 22nd at 7:30pm, 120 Mineola Blvd, 2nd Floor (Dr. Angulo's office), Mineola, NY ■

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## OMRDD

# NYS Care at Home Medicaid Waiver Program

by *Nina Roberto*

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When we as a family first hear that our child has special needs, one of the first things that comes to mind is "What treatments is my child entitled to?" This is a question that may not be easily answered. Endless questions may lead to even more confusion.

One benefit our children may be entitled to is the OMRDD NYS Care at Home Medicaid Waiver Program. This program is set up to help families who have children with medical needs and/or are developmentally delayed. It is designed for children from birth to age eighteen. To qualify for this program, families can not be eligible for Medicaid. These services include but are not limited to Case Management Services, Home Health Aids, nursing home based therapies or PWS home modifications. These and other services are provided based on each individual child's needs.

There is a lengthy application process. Begin with your local DDSO for help with information on these services. Each DDSO has a Prader-

Willi Coordinator to give you that information. They will act as liaison to OMRDD. They will also provide information on enrollment so have your list of questions ready. Once you are approved, you will select an agency that will assign a Medicaid Services Coordinator (provided free) to your child to coordinate and select services. They will make sure everything that your child needs gets done and that you are satisfied with the services your child receives.

There are many services that our children are entitled to. We need to continue being strong advocates for our children so they can get what they're entitled to. These important services will not be handed to you. At the conference, many parents asked such important, vital and thought provoking questions regarding their children. I join you in continuing our efforts to find the best services and entitlements for our children, so that they may achieve the best quality of life which they rightfully deserve. ■

# Recap of the "2009" PWANY General Conference

As in years past, the 2009 PWANY Annual Conference provided numerous opportunities to learn about research, service provision, and ways to support our loved ones with PWS, while simultaneously being able to reconnect with friends and others who face similar concerns on a daily basis.

The General Conference opened with Associate Commissioner Stephen Smits as Keynote Speaker. Mr. Smits spoke about the impact that the current recession has had on services provided by NYSDD (the New York State Developmental Disabilities Office), formerly the OMRDD. He noted that there has been a hiring freeze for State employees and that numerous projects have been put on hold while cost analyses are completed. Emphasis remains on their goal to provide flexible supports for employment for consumers. Mr. Smits reported that PWS could be diagnosed either genetically or clinically in order to receive supports, and that a more streamlined process is being developed in order to access out of state programs. Associate Commissioner Smits encouraged us to stay involved as the State works to serve our children better.

*Several specialists spoke on medical issues related to PWS.*

- \* **Dr. Harold van Bosse** addressed orthopedic concerns, as outlined in a more detailed article "Scoliosis and the Prader-Willi Patient" to appear in the next newsletter.
- \* **Dr. Moris Angulo**, a pediatric endocrinologist, emphasized the use of growth hormone and diet control as the main treatments for PWS. He noted that he has seen vast improvement in height and muscle mass from the use of GH, and he has been adding sex hormones (testosterone and estrogen) to achieve more hormonal balance. The earlier one starts GH, the better chance there is to achieve adult height. Dr. Angulo also spoke of adrenal insufficiency in PWS and the need in such cases for glucocorticoid in medical emergencies when a child's system is experiencing stress.
- \* **Dr. Gregory Cherpes**, a psychiatrist at the Children's Institute in Pittsburgh, offered guidelines for treating behaviors and psychiatric disorders in PWS. Although appropriate psychiatric treatment can improve the quality of life for some individuals, he stressed that "there is no silver bullet without risk". Medication should be used as a last resort when behavioral treatment has proved inadequate. Effective treatment includes establishing a structured, predictable environment with food security. Dr. Cherpes talked at length about the use and effects of various medications such as anti-depressants, stimulants, mood stabilizers, and antipsychotic agents. Experience has taught him that PW individuals are more sensitive to the side effects of medication and need to be started at a low dose and monitored carefully. Most important, "treat all PW children and adults as individuals" when focusing on medication for specific conditions.

*Advocacy was a key theme in many of the presentations offered this year.*

Advocacy has been described as active support of an idea or cause. Having a working knowledge base and being able to speak on behalf of our loved ones with PWS is essential, as they often cannot truly advocate for themselves.

- \* In "IEP's and Me", Nina Roberto and Amy McDougall outlined how to understand the data incorporated into a student's Individual Education Plan, what should be included on that IEP, and discussed how to advocate with the school for a plan that truly addresses your child's unique learning needs.
- \* A panel of parents and providers (BJ Goff, Tony Zajchenko, Volena Howe, and Harry Persanis) discussed how having an understanding of the differing roles and responsibilities between the home and residential settings can promote collaboration.
- \* Dale LaPoint and Cindy Ferenedzo offered guidelines and suggestions on understanding the services that could be provided by a Medicaid Service Coordination and how to work effectively with your MSC.
- \* Another panel of parents and providers (Janalee Heinemann, Nina Roberto, Lisa Pesante, and Amy McDougall) spoke about how to obtain services and how to communicate your child's needs when others "just don't get it".

*Additional sessions focused on varied topics of concern.*

- \* Anne Rejack and Laura Spanbauer spoke about a partnership between behavior therapy and nutrition to effectively treat PWS, rather than relying solely on one or the other.
- \* In "Leaving the House but Not the Family", George and Susan Papaioannou (along with their daughter Susan who has PWS and is attending college) collaborated with Stacy Ward to discuss transitioning from home based to residential services.
- \* BJ Goff, Tony Zajchenko, and Jeff Covington offered practical suggestions and guidance to service providers on "How to keep your cool and effectively work with individuals with PWS".
- \* The always timely and important issue of future planning, including guardianship and trusts, was addressed by Edward Wilcenski, Esq. and Lee Ackerman.
- \* Janalee Heinemann presented on the results compiled through 1,774 medical surveys that have been collected through the PWSA(USA) website ([www.pwsausa.org/population](http://www.pwsausa.org/population)), which demonstrated that we need to know more in order to help those with the syndrome as they age. We currently have 128 people over age 40 in the collection, with the oldest at age 79. Mrs. Heinemann's presentation spoke of the many issues of aging which need to be researched further.

We would like to thank each of the presenters who offered invaluable information that can be used to better understand the needs of our loved ones with PWS so that we can better care for their needs and advocate for them! ■





# Annual PWANY Conference

## April 29 – May 1, 2010



The Prader-Willi Alliance of New York, Inc. (PWANY) is proud to be hosting our 20th annual conference on April 29th, 30th & May 1st of 2010 at the Best Western Hotel on 1228 Western Avenue, in Albany, NY.

*We can't believe it is twenty years already!*

Thanks to hard working parents and dedicated professionals like yourself we have a wonderful story of success and hope to tell at this twenty year anniversary. Our children are living longer with a much improved quality of life, not only for them, but for the families as well. People with PWS go to school, they are employed, they join community groups, they move into homes of their own; all the normal transitions of life.

Because this is such a momentous occasion we are getting an early start on the 2010 conference. We are sending out Request

for Proposal's (RFP's) now and requesting them back by October 31, 2009.

We hope that you will be part of our celebration of twenty years of progress by submitting a proposal and/or by joining us at the conference. Come celebrate the success you helped to create!

As always, please do not hesitate to contact the PWANY at 800 442-1655 if we can be of any assistance to you in this process, and please pass this invitation on to families and professionals who might be interested.

More information about the Conference can be found at our web-site; [www.prader-willi.org](http://www.prader-willi.org) ■

## Newly Elected Members to the PWANY Board of Directors



**Tammy Reals** is delighted to be one of the newest members of our board of directors. Eager to provide support to others who live with PWS, she has been working with Amy McDougall to set up a Focus Group in the Central New York area. She lives in Liverpool with Michael, her husband of 13 years, and their four children. Tammy works as a third grade teacher at the same private Christian school that her children attend. She is an active volunteer in her church and at school.

Mike and Tammy received the news that their second born son had PWS when he was only two weeks old. Tammy remembers the shock and confusion that came along with the diagnosis and would like to help others dealing with the same. She wants parents of young children to know that there is hope and that their child can be successful.



**Nancy Behringer** is mom to Peter, 3, with PWS. She is currently a stay at home mom. While pregnant with Peter, Nancy obtained her MSEd at Fordham University in School Counseling and worked as a Career Counselor in Westchester. Nancy obtained her undergraduate degree from Hofstra University and spent twelve years in corporate marketing. Her past positions include Global Marketing Director for the Wall Street Journal, Vice President at Chase Manhattan Bank and North American Marketing Manager for TNT Worldwide. Nancy had previously served on the Junior Advisory Board for the Make-A-Wish foundation and was also a volunteer wish granter. Nancy currently lives in Wantagh, NY with her husband, Chris and Peter.



**Cathryn "Catt" Maczko** is mother to Julia (15), Jack (12), and Thomas Jersey (4, PWS/ UPD). She has lived in the Binghamton area for more than twenty-five years. Catt works in Real Estate Development, mostly student housing. In addition to being a member of PWANY and PWSA(USA), Catt is also a member of the Foundation for Prader-Willi Research (FPWR) and a parent member of the OMRDD sub-committee for Broome County. She has attended training specific to parent advocacy in Early Intervention and is a mentor for Parent to Parent. Catt shares, *"I believe with all my heart that God has a cure for the blasted hunger in Prader-Willi Syndrome- and it's our job to find it!"*

# 2nd Annual Long Island Walk for Prader-Willi Syndrome

by Nancy Behringer



Over  
\$12,600  
raised for  
PWSAUSA

The rain may have dampened our clothes, but not our spirits because the 2nd Annual Long Island Walk for PWS was a huge success. On May 17th, over 70 people came out to Wantagh Park to support our children and adults with PWS. Although the weather did not cooperate and one of our tents fell victim to the wind, everyone came ready to walk and show support for their loved ones.



We are proud to report that the walk generated over \$12,600 for PWSAUSA. What a wonderful accomplishment for our second year. In addition to the donations from family and friends, we received generous support from local and out of state companies to help organize the walk. This included bottled water, balloons and prizes for our top fundraisers.



This year we welcomed five women from Curry Street House, a group home in Westchester and seven local families with children who have PWS. Grandparents, aunts, uncles, cousins and friends braved the bad weather to be a part of this annual event. We thank everyone who walked despite the weather and all those who provided generous donations and support.



*We look forward to your support again next year! ■*



# Queens Walk for PWS a Huge Success!

by Nina Roberto



**Top Fundraisers:**

**Henry and Sue Singer**  
**\$1,970**

**Friends of Finnerty**  
**\$1,155**

**Nina Roberto**  
**\$1,985**

I wanted to thank you all for showing your support towards the 2nd Annual PWS Queens walk 2009 (in spite of the rain). It was wonderful seeing the dedication, spirit and love in everyone who joined us in our effort to raise funds, show support and to help us spread awareness. Families were holding signs, as well as children, showing support for their loved one with PWS. There were several teams such as "Walking for Joseph", "Sonny's Team" and those rooting for Josh. Many walkers wore red as well showing a sense of unity and support among us all.

Thank you so much to all who participated in this year's walk. Because of your dedication and love, we have raised over \$5,000 and donations continue to come in.

I would also like to thank Christina Santucci from the Courier Sun and also the Richmond Hill Times for covering our walk and for putting us on the front page. This publicity will certainly help us spread awareness to over 2,000,000 Queens residents.

*We look forward to seeing you next year hoping for it to be the biggest event ever! ■*



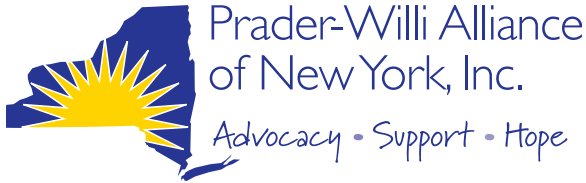
# PWANY 19th Annual Conference - Albany, NY



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

Dues are \$20 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 \$20 per person.

Enclosed are dues for 2009 \$ \_\_\_\_\_

Here's an additional tax deductible contribution \$ \_\_\_\_\_

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

Total 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 you 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**