



Prader-Willi Alliance of New York , Inc.

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PRESIDENT'S MESSAGE

HON. DANIEL D. ANGIOLILLO



I am very pleased to report that fellow Board Member Harry Persanis and I recently met with Commissioner Thomas Maul of the New York State Office of Mental Retardation and Developmental Disabilities ("OMRDD") to discuss an ambitious agenda of issues affecting the Prader-Willi Syndrome Community in New York State. My letter of appreciation to Commissioner Maul is reprinted below. Specific agenda items and a synopsis of our meeting prepared by Harry Persanis, can be found on pages 2 and 3. Both Harry and I believe the meeting was a tremendous success and we believe that the Alliance is moving toward a successful partnership with OMRDD.

It was a busy summer. In addition to meeting Commissioner Maul, this past July I had the distinct honor of representing the Alliance at the National Conference and Chapter Presidents' Meeting of PWSA (USA). More than 1,000 attended the four-day conference in Orlando, Florida to network with and listen to scientific and medical experts, other professionals, and parents and relatives of individuals with Prader-Willi Syndrome. The conference was informative, enlightening and raised the spirits of those in attendance.

At the full-day Presidents' Meeting, National President, Lota Mitchell presented the welcoming remarks followed by keynote speakers Carlos Molinet, President, Chile Chapter and Giorgio Fornasier, President, International Prader-Willi Syndrome Association. The Presidents' Meeting focused on "Organizing Your Chapter," crisis intervention update from National Crisis Counselor David Wyatt, National "Parent Mentoring Program," and other topics. It was exciting to learn how other State Chapters are organized and operate and the many services provided by National.

Dear Commissioner Maul:

Thank you for taking the time to meet with Peter Pezzolla, Harry Persanis and myself on August 7, 2003 to discuss various issues concerning the Prader-Willi Syndrome community in New York State.

Both Harry and I believe the meeting was extremely productive and we appreciate your genuine interest and desire to help individuals with Prader-Willi Syndrome. We are excited about the many possibilities discussed at the meeting and your suggestions will be taken up at our next Board Meeting. Your willingness to meet with us periodically and your many other suggestions, such as drafting Prader-Willi Syndrome literature for distribution in hospitals, will assist us immeasurably in heightening the awareness of Prader-Willi Syndrome.

As stated in Harry's e-mail you are the "Can Do Commissioner." You gave us the opportunity to address a broad and ambitious agenda which included many of our concerns, for example, the DDPC Grant (funding a state-wide database and regional support centers), group home development, draft guidelines for residential facilities, and a crisis stabilization program to name a few. I understand that Peter Pezzolla will be summarizing our meeting in forthcoming correspondence.

On behalf of our Board of Directors and the entire membership of the Prader-Willi Alliance of New York, I thank you and look forward to a fruitful and cooperative partnership.

Sincerely,

Hon. Daniel D. Angiolillo, J.S.C.
President
Prader-Willi Alliance of New York, Inc.

ATTENTION
MARK YOUR CALENDAR NOW!
ALLIANCE CONFERENCE
"2004"
April 30—May 1

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

Agenda - Prader-Willi Alliance - OMRDD - 8/7/03

- A statewide database of people with PWS and their needs must be put in place so that planning for future services needs can be established.
- The “Centers of Excellence” project spearheaded by Assoc. Comm. Peter Pezzolla and Ann Marie Vadney which has shown such great promise should be continued and expanded.
- We need more group homes and supervised apartments for people with PWS.
- As “PWS Group Homes” they must be designated as “special category group homes” with a rate commensurate with the extraordinary services required (behaviorist, nutritionist, cook, physical therapist, occupational therapist, speech pathologist and most important PWS training for management and staff) for their operation. These “PWS Group Homes” must house no more than six residents, each resident with his/her own room, with a minimum staff of four during hours when residents are awake.
- Operational and staffing guidelines must be established and enforced for all group homes under this PWS category.
- People with PWS are, in most cases, high functioning. Placing these individuals in a workshop setting is often counter productive causing them to behave inappropriately. With appropriate vocational training and job coaching many of these individuals “warehoused” in workshops can function well in society. Earning significant money helps to engender self esteem, and allows them to become partially self-supporting. This normalizing process which includes paying back some of the cost of their up-keep, saves the State money and also lets them provide for themselves the simple everyday conveniences we take for granted. We request that increased funding for vocational and job coaching opportunities be provided for people with PWS.
- The Governors’ PWS Ad-Hoc Committee must be reconstituted, again under the leadership of the OMRDD commissioner, so that all of the State agencies with a responsibility to address PWS issues (medical and educational) can do so with a coordinated multi-disciplined approach without duplication of efforts.
- People with PWS require an extraordinary number of medical appointments. This need exacerbates the ability of provider agencies to provide medical appointment transportation. According to the rules governing IRA’s, transportation to medical appointments is no longer covered by Medicaid on a fee for service basis. Homes that converted from CR’s to IRA’s lost this coverage and the transportation to medical appointments must now be paid by the provider agency with insufficient provision for reimbursement. Something must be done to relieve this crisis.
- Respite care is a long standing and a growing concern. Most people with PWS live at home and are cared for by their parents. With families where both parents work (more than 70% of households) and where there is just one parent, the need for respite care is an absolute necessity. We must identify where the need exists and provide it.
- Salaries for Direct Care Workers employed by Not For Profit’s must be enhanced to allow for the recruitment and retention of quality Direct Care Workers. Current salaries are abhorrent.

Pres. Daniel D. Angiolillo, PWA Meets With Comm. Thomas A. Maul, OMRDD

by Harry Persanis in cooperation with OMRDD

On August 7, 2003, in Albany at the Office of Mental Retardation and Developmental Disabilities (OMRDD) the Hon. Daniel D. Angiolillo, President of the Prader-Willi Alliance of N.Y., Inc., met with OMRDD Commissioner Thomas A. Maul. Also in attendance were Associate Commissioner Peter Pezzolla and Alliance Director Harry Persanis.

The meeting began promptly at 1:00 PM with introductions. The agenda (see pg. 2) was distributed and the discussion began.

The first order of business was the need for a database to identify on a statewide basis the people with Prader-Willi Syndrome (PWS) along with their current and future needs. This process will help OMRDD to better plan for the services they will require.

Comm. Maul advised of his support to develop a statewide database and that OMRDD was in the process of developing a Developmental Disabilities Planning Council grant that includes the identification and assessment of the PWS population as an initiative.

We discussed our Ad-Hoc Committee and how valuable it has proven to be in the past in the identification and resolution of issues. Assoc. Comm. Pezzolla pointed out that the project to develop "Centers of Excellence" which began with the Putnam County center operated by United Cerebral Palsy, was an idea offered by the Alliance at an Ad Hoc Committee meeting in Albany. Comm. Maul expressed his continued support for this project with the view towards expansion should the project prove to be successful.

Pres. Angiolillo spoke passionately about the need for a center, similar to the Children's Institute in Pittsburgh PA, where people with PWS who are in crisis can be treated by PWS experts so that their condition can be stabilized. A number of options were discussed and their feasibility will be studied by Assoc. Comm. Pezzolla with a report to Comm. Maul in the near future.

The great need for additional group homes was discussed. Comm. Maul asked for a list of people statewide in need of placement and will discuss these findings at a follow-up meeting to be held in approx two months.

Pres. Angiolillo and Mr. Persanis spoke about the extraordinary services required by people with PWS and how these services must be built into the "rate" when developing new group homes. The Alliance asked that a special category group home be established for people with PWS, with operational and staffing guidelines specific to their needs. Assoc. Comm. Pezzolla indicated that the special needs of the PW population have been and continue to be under discussion and review in order to identify best practices procedures that can be replicated and are programmatically and fiscally viable.

Comm. Maul was asked if he would recommend the placement of Pres. Angiolillo on the Governor's Advisory Committee. His response was very positive. When this appointment takes place it will be a great honor to the Alliance and to our President.

Although the medical appointments issue was not discussed in detail, Assoc. Comm. Pezzolla indicated that they were fully aware of this issue and its consequences. This issue will continue to be discussed for future resolution.

The issue of respite care was discussed in detail by Comm. Maul. With great insight he recognizes that respite care is an important tool that should be available for families of people with PWS who are living at home. He solicited recommendations from the Alliance to be presented at the next Ad-Hoc Committee meeting. Comm. Maul would consider a grant to the Alliance to develop a pilot respite care program.

The discussion turned to the dissemination of information on PWS to professional and non-professional groups, and how to go about it. Mr. Persanis recommended and Comm. Maul agreed that a letter would be prepared by the Alliance, appropriate to each group, which would then be mailed by OMRDD using mailing lists available only to them and to other NY State Agencies.

Comm. Maul was very supportive and acknowledged his awareness of these issues. He hopes to work with the Alliance in these times of fiscal constraints to pursue all avenues of support and services.

In closing the meeting Comm. Maul remarked that OMRDD "was created as a result of the advocacy of parents". With this and future successful meetings we are on the way to creating a better life for people with PWS.

**Commissioner Maul remarked
that OMRDD "was created
as a result of the advocacy of
parents"**

ADDRESSING THE CONCERNS ABOUT DEATHS AND THE RELATIONSHIP TO GROWTH HORMONE

By Janalee Heinemann, Executive Director PWSA,USA

I have been getting emails and calls of concern about a report of seven deaths worldwide of children who were on growth hormone. In the interest of our membership, I want to keep all parents and care providers updated with the latest on this issue. As always, I am committed to sharing with you honest and straightforward information. Having been very involved with this issue, I want to assure you that while there may be reason for concern, I believe there is no reason to panic.

We have been sending information on deaths known to us at PWSA (USA) to our medical boards and Dr. Martin Ritzen from Sweden. (For our newer members, Dr. Ritzen is considered one of the most renowned researchers in the world on growth hormone and PWS.) At PWSA (USA) we have followed 58 deaths from 2001 to March 2003. Of those, there is conjecture that one MAY be related to growth hormone treatment which is included in the two deaths reported from the USA. The other five deaths we have heard about were not from the USA. To keep this in perspective, we also know hundreds of children with PWS who have been placed on growth hormone (GH) without reported adverse effects and are doing well.

The following is a short summary of the issues, as I know them. Please keep in mind, I am not a medical physician, and PWSA (USA) is not making a formal statement. I have however asked four key physicians to review what I have written, and all agree that I have included all of the information available at this time. Dr Martin Ritzen responded, "It is well written and brings up the important note to all parents that respiratory problems may be a serious concern, with or without GH treatment."

1. While it is unclear what relationship growth hormone had, if any, with the seven deaths worldwide, keep in mind that almost all of the other deaths reported to us were of children and adults with PWS who were not on GH. These events have heightened our awareness that our children are at risk in general due to respiratory issues.

2. Respiratory issues combined with obesity appear to be a major risk factor for our children with PWS (See our article on this topic that was in the March-April 2003 edition of The Gathered View.) and the main risk factor identified in starting growth hormone (GH). It has recently come to light that there may be a slight risk in starting a child that is very

obese and already having apnea problems on growth hormone (the deaths were early in the start of the treatment) with the possibility of slightly increasing the tonsils to the point of obstruction and apnea.

3. The safest course would be to perform a sleep study test prior to receiving growth hormone if there is ANY respiratory concerns – and then repeating the study after a few months of being on growth hormone. (This advisory/ indication will come out officially in the near future.) Of course, many of our children should have a sleep study test with or without GH since we are finding that many have some form of obstructive respiratory problem. If obstructive apnea problems are added to the lack of central hypoventilation/ apnea response, then many of our children and adults are at risk with or without GH treatment. (Central hypoventilation is a disorder of decreased breathing rate or depth particularly during sleep.) In the case of a child who is obese with apnea, they should not only have a sleep study test, but also see an ENT to consider having tonsils and adenoids removed.

4. A child with PWS should begin a weight loss program prior to starting GH since obesity is a risk factor. The dilemma lays in the fact that weight loss is easier while on GH treatment, so waiting to start GH delays the success of a weight loss program. If it is important for parents to understand that GH is only an adjunct to diet and other external controls.

5. Based on the above, Pfizer Inc. (formally Pharmacia) changed the labeling to include the following contraindication and warning,

CONTRAINDICATIONS: Growth hormone is contraindicated in patients with Prader-Willi syndrome who are severely obese or have severe respiratory impairment.

WARNINGS: There have been reports of fatalities with the use of growth hormone in pediatric patients with Prader-Willi syndrome who had one or more of the following risk factors: severe obesity, history of respiratory impairment or sleep apnea, or unidentified respiratory infection. Male patients with one or more of these risk factors may be at increased risk. Patients with Prader-Willi syndrome should be evaluated for upper airway obstruction before initiation of treatment with growth hormone. If during treatment with growth hormone

Continued on pg. 5

Continued from pg. 4

patients show signs of upper airway obstruction (including onset of or increased snoring), treatment should be interrupted. All patients with Prader-Willi syndrome should be evaluated for sleep apnea and monitored if sleep apnea is suspected. All patients with Prader-Willi syndrome should have effective weight control and be monitored for signs of respiratory infections, which should be diagnosed as early as possible and treated aggressively.”

Recent data indicates that GH actually improves respiratory function in PWS. One study results states: “Peak flow rate, percentage vital capacity, and forced expiratory flow rate improved and number of hypopnea and apnea events and duration of apnea events trended toward improvement after GH intervention.” *Effects of Growth Hormone on Pulmonary Function, Sleep*

Quality, Behavior, Cognition, Growth Velocity, Body Composition, and Resting Energy Expenditure in Prader-Willi Syndrome (2003) Haqq AM, Stadler DD, Jackson RH, Rosenfeld RG, Purnell JQ, Lafranchi SH - Portland, Oregon. *The Journal of Clinical Endocrinology & Metabolism* 88(5):2206-2212.

In addition Dr. Martin Ritzen recently wrote to me, “I might add that we did a similar study in Sweden before and after GH, and found improved respiratory response (with GH) Lindgren AC, Hellström LG, Ritzén EM, Milerad J 1999 *Growth hormone treatment increases CO(2)-response, ventilation and central respiratory drive in children with Prader-Willi syndrome*. *Eur J Pediatr* 158:936-940.

PWSA (USA) would like to perform a more comprehensive study of the deaths of those with PWS who are reported to us. Our goal would be to apply for funding and hire a medical student or fellow to help us to analyze data including the study of autopsies, and get more detailed information on the medical history of the child or adult with PWS who died. As the only national membership organization for Prader-Willi syndrome, and with a bereavement program in

place, we have the data on deaths -- but do not have the time to perform an adequate review.

My greatest concern is that we may regress to the days when endocrinologists were reluctant to put a child with PWS on GH. So much positive about GH has occurred beyond height -- such as improved body composition, increased muscle function, and increased energy.

The fact that we have recently put our thirty -year-old son, Matt, on the PWS adult growth hormone study is the best example of my continuing confidence in the important role that growth hormone has in providing quality of life and improved health in our children and adults with PWS. (Matt was on GH from fourteen years of age to nineteen and then off ten years prior to the current adult study.) As I write, Matt has lost approximately thirty pounds in three months!

At this time, there is no recommendation to discontinue GH therapy in PWS.

Is this all due to initiating small doses of GH? We think it is due to a combination of GH and a new exercise routine of walking a school

track 4-6 laps daily. But, we know from experience, that prior to the growth hormone, he could walk the track all day and not have that kind of success!

At this time, there is no recommendation to discontinue GH therapy in PWS. The multiple beneficial effects of GH therapy in children with PWS are well documented. The company which has approved labeling for GH therapy in children with PWS, Pfizer (Pharmacia), and the Lawson-Wilkins Pediatric Endocrine Society, the major pediatric endocrine group in the U.S., have both reviewed the available information and are expected to issue summary statements. PWSA USA will keep its membership informed of this progress.

We will keep our members updated with as much objective information as we can for the health and well being of all of our children with Prader-Willi syndrome. Meanwhile, those who have specific questions regarding GH therapy in PWS are advised to discuss them with their physician. If your physician has additional questions, they can contact Pfizer Medical Information at 800-323-4204.

Our quarterly newsletter is mailed first class to more than nine-hundred recipients. Needless to say not all recipients are members of The Alliance”. Our fifteen dollar annual membership dues have not been raised in over ten years. Membership dues, our annual Skip-a-Lunch fundraiser and our conference grants are our only source of income. Our annual conference, this newsletter, our “800” number and other minor administrative costs come out of this one pot. Our Officers and Directors are all volunteers and we have no paid staff.

MEMBERSHIP

Won't you please complete the membership form on page six and become a member of the Alliance. Remember your membership and contribution are tax deductible.

Note: An asterisk (*) next to your name on the mailing label identifies you as a current “2003” member.

A Father Offers Hope For Those With Newborns Diagnosed With PWS

By Tom Patrick

After a dramatic pause, my two-year-old son pushed off from the top of the slide and splashed into the plastic wading pool, laughing as his sister plunged in behind him. He stood, slowly lifted each leg over the flimsy side of the pool, and pulled himself up for another run. The leaden skies and rain of the past weeks had lifted, giving way to a blue-sky, sun-drenched day.

I mention this backyard moment only because the sun breaking through seemingly impenetrable clouds seems an apt metaphor for discussing the days and weeks that followed my son's PWS diagnosis. If you are the parent of a newborn or toddler who has just been diagnosed with PWS, take heart, better days, fun-filled days, await. At some point, this same weak and sleepy child, likely being nourished primarily with tube feedings, will be guzzling milk from a sippy cup, casting a mischievous smile your way, and goading you into a game of chase. Your child, no longer a stranger, will fill your life and the lives of those fortunate enough to meet him or her with joy. His formidable people skills will impress you.

I hesitate to make rosy predictions like the one above, especially since I don't know your unique circumstances, and there are no doubt many challenges ahead.

I recall too that I didn't always appreciate it when well-intentioned folks, who learned that my son was in the neonatal intensive care unit (NICU), said they were sure that "everything would be just fine." (I fought the urge to tell them that they ought to go spend some time in a NICU where, of course, everything doesn't always turn out "just fine" at all.) I was asked to write this article, though, and the deadline looms, so I'm hoping you'll cut me some slack.

My son arrived with low muscle tone ("floppy") and a weak cry after his due date and was quickly moved to the NICU. I remember his tiny eyes flitting around as he lay in his steel crib, feeding tube coursing down his nose, heart and respiration monitors hooked to his body. My wife and I spent hours urging him to suck his bottle, prodding his cheek with a finger while pushing his chin up. It was often a futile effort and most of his sustenance was delivered via tube.

More difficult was the emotional roller coaster of not knowing why he was so weak and the varying hints and suggestions—sometimes uplifting, sometimes not—from doctors and nurses. Testing, scans, and difficult blood draws ensued. The first time we heard the word Prader-Willi was a mere 13 hours after his birth. An excellent neonatal doctor told us that he thought there might be some subtle chromosomal abnormality or gene defect. It could, he said, be any one of several relatively rare syndromes. I pressed the doctor to make his best guess.

He said Prader-Willi, but that it was speculative and more tests were needed. A combination of characteristics led him to this diagnosis: low muscle tone (hypotonia), poor sucking and swallowing, undescended testicles, and his thin toes and fingers.

I had never heard of PWS, and was distressed to find out from the doctor that newborns with it tend to need a g-tube installed in their stomach to supplement their feedings. Later, the problem would be an insatiable appetite, an inefficient metabolism, obesity, and as if that wasn't enough to send two sleep-deprived parents into mild shock, we were informed that those with PWS were usually mentally retarded, short, and slow in the motor-skills department.

It was a lot to take, and I amplified my anguish by surfing the Internet for even more distressing PWS-related information. Based on my reading, I was convinced that the doctor's diagnosis was correct. Insomnia ensued for the next few days.

This first doctor's speculation, though, was not one shared by other doctors on the staff. Several said straight out that they doubted he had PWS or any other chromosomal anomaly, but that they wanted to rule it out. The initial chromosome test came back normal, but they indicated that they wanted to send another sample to a different lab that would test specifically for Prader-Willi.

My wife and I both had the impression that the doctors didn't expect confirmation of this disease, and several made other encouraging comments. For a moment, I allowed myself the fleeting thought this nightmarish ordeal might be at an end, despite my confidence that the first doctor had made a well-informed diagnosis. The slight hint, the merest insinuation, that maybe all our baby's problems would just vanish in time, or that they didn't appear too severe, provided a welcome emotional lift.

Twenty-four days after his birth, a doctor with a soft but matter-of-fact tone confirmed that the latest test results showed that our son did, in fact, have PWS. It was disheartening news, but at least we now knew the problem. In addition, our son would now not have to undergo a planned muscle biopsy to test for neuro-muscular disorders. Instead, we could focus on learning how best to help him.

When he was one, his Mickey button (which replaced the less convenient g-tube) which proved not to be so horrible after all was removed. He also began growth hormone treatment, which is helping his growth and gross motor skills. A physical therapist and a speech therapist also continue to work with him a couple times a week. Shortly after he turned two, he began to walk and is now happily careening around the house.

I confess that, even now, I recoil at the word "Prader-Willi," perhaps because it evokes the initial despair I felt. Now, I don't think of my son as a child with PWS. To me, he's just a remarkable and fun little guy with some unique challenges to overcome. Medical research and early intervention offer him and others with PWS the prospect of brighter days ahead.

"Medical research and early intervention now offer others with PWS the prospect of better days ahead"

A Comprehensive Team Approach To The Management Of ***Prader-Willi Syndrome***

EFFECT OF GH THERAPY ON PWS BEHAVIOR

With regard to the effect of GH therapy on PWS behavior in the setting of behavioral difficulties and refractoriness to psychopharmacologic agents, surveys of parents indicate that some behaviors improve and none deteriorate. Since the behavior of children with PWS tends to deteriorate over time, the absence of deterioration is, in fact, a positive outcome.

Specific behavioral benefits of GH therapy, as reported anecdotally by parents, included increased energy, increased activity without the need for encouragement, improved personal hygiene, less "annoying" behavior, increased assumption of responsibility, and less perseveration. In addition, attention span and compliance seemed to improve and anxiety, depression, and obsessive thoughts decreased, although there was no impact on obsessive-compulsive behavior or improvement in school performance.

Growth hormone therapy also produced positive effects on physical appearance, usually within 3 to 6 months of patients' starting treatment. Appearance of the hands, feet, and trunk normalized in all GH recipients, and appearance of the head normalized in 81%. Such changes may positively affect patients' social interaction. Furthermore, 97% of patients had more energy and 83% spontaneously increased their level of physical activity without parental prodding.

IMPROVING QUALITY OF LIFE IN PATIENTS WITH PWS: DIET, EXERCISE, AND LIFESTYLE CHANGES

Surveys performed in the United Kingdom in 1989 and 1999 have provided useful information about the impact of lifestyle changes on PWS.

From the standpoint of diet, two distinct phases of PWS are apparent: initial failure to thrive and subsequent obesity.

Failure to thrive results primarily from hypotonia, which makes sucking difficult during infancy, and nasogastric tube feeding may be necessary for as long as 2 months to meet energy requirements.

Signs of poor feeding in infants with PWS include changes in the voice or cry, coughing while swallowing, excessive drooling, frequent vomiting, constipation, respiratory infections, irritability during feeding, slow intake, and poor weight gain. For infants who are able to suck, specially designed nipples can reduce the energy expenditure. Early weaning to soft food will reduce energy requirements; introduction of solids is accompanied by a lessening of appetite for milk. However, some 33% of older infants with PWS are unable to eat soft food normally acceptable at 1 year, and children with PWS typically lag far

behind children without PWS in their transition to solid food, with 42% of children with PWS unable to chew some solid foods at the age of 5 years. The change from failure to thrive to hyperphagia generally occurs between 2 and 4 years; there seems to be a recent shift toward the younger age. Despite their reduced energy requirement, these children are obsessed with food and engage in food seeking and food stealing.

Overeating may be due to the prolonged eating drive that results from their disturbed feelings of satiety. The vast majority of parents of children with PWS have attempted to control their children's weight, but dietary compliance is poor.

Severe caloric restriction for short periods at home or for longer periods in the hospital setting may be helpful, but most families feel that no intervention will help.

Increased physical activity can increase energy expenditure, promote negative energy balance, raise the post exercise metabolic rate, build muscle mass, prevent osteoporosis, improve scoliosis, and enhance the overall sense of well-being. However, very few patients with PWS seem to participate in a structured exercise program. Aerobic exercise, toning and strengthening, flexing and stretching, and formal physiotherapy are all useful for patients with PWS.

Activities they may find acceptable include bicycling, skating, jumping on a trampoline, dancing, and ball playing.

Lifestyle changes that can be implemented certainly include control of food seeking and food-stealing behaviors but also must encompass social integration and independence. Specific environmental controls designed to limit hyperphagia include locking places where food is stored, restricting access to money or credit cards, and prohibiting participation in food preparation.

Unfortunately, many of these impositions and limitations may actually discourage social integration and independence.

SUMMARY AND CONCLUSION

Because of its many physical and behavioral manifestations, PWS should be managed in a multidisciplinary setting that emphasizes comprehensive care. Clinical trials confirm that GH treatment of children with PWS normalizes linear growth, promotes an increase in lean body mass, and decreases fat mass.

However, the long-term benefits of GH can be maintained only in conjunction with dietary control and counseling, physical therapy, and psychological and educational evaluation and support.

The above article was excerpted with permission from the web-site of the International Prader-Willi Syndrome Organization (IPWSO). (www.ipwso.org)

**Prader-Willi Alliance
Of New York, Inc.
2970 Beltagh Avenue
Wantagh, NY 11793**



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 2003

\$ _____

Here's an additional tax-deductible contribution

\$ _____

Amount Enclosed

\$ _____

Name _____

Address _____

City, State, Zip _____

Telephone _____ Fax _____ E-Mail Address _____

Date _____ New Member Renewal

Check this box if we have your permission to share your name with the PWSA (USA)

I would like to become active in the Alliance. Please call me to discuss my involvement.

Parents of Children with PWS: Please give us the name, age and living placement of your child. This is optional, and will be used only for purposes of "parent-to-parent" networking:

Child's Name _____ Child's Date of Birth _____ Age at Diagnosis _____

Where is Child Residing? _____

Please make your check payable to the **Prader-Willi Alliance of New York, Inc.** and send it to
Prader-Willi Alliance of New York, Inc., 2970 Beltagh Ave. Wantagh, N.Y. 11793

PLEASE JOIN THE "ALLIANCE" TODAY