



Prader-Willi Alliance of New York, Inc.

267 Oxford Street • Rochester, N.Y. 14607

NEWSLETTER • January 2000

Telephone (716) 442-1655
In N.Y. State (800) 442-1655
Fax (716) 271-2782

OFFICERS & DIRECTORS

Henry Singer, CPA
President, Brooklyn

Beth Ann Lynch
Vice President, Rochester

Daniel J. Maillet, Jr.
Vice President, Irvington

Hon. Daniel D. Angiolillo
Secretary, West Harrison

Volena Howe
Treasurer, Rochester

Elinor G. Baller
Director, Larchmont

Gloria Cox
Director, Manhattan

Kathy Jornov
Director, Valatie

Harry Persanis
Director, Wantagh

Sharon Spink
Director, Buffalo

Sheldon L. Tarakan
Director, East Hills

10th Annual Conference Scheduled for May in Albany

The 10th annual Prader-Willi Alliance of New York Conference will take place on Friday and Saturday, May 5th and 6th, 2000 at the Ramada Inn in Albany. Still in its planning stage, the 2000 Conference promises to rekindle a flame that was lit at last year's conference, when over 128 people — parents of children of all ages, from infants to adults, as well as health professionals and service providers — joined us at Saratoga Springs for our best conference to date. We hope to surpass last year's event and establish yet a *new* standard for regional Prader-Willi conference excellence.

Even at this early date we can confirm an array of outstanding professionals who will address the conference. Commissioner Thomas A. Maul of the New York State Office of Mental Retardation and Developmental Disabilities, will deliver the keynote address and will be available to answer questions on Friday, May 5th. Elisabeth N. Dykens, Ph.D., will speak that day on "Behavior and Development in Prader-Willi Syndrome." Dr. Dykens is an Associate Professor of Psychology in UCLA's Neuropsychiatric Institute, co-director of the Prader-Willi Syndrome Clinic at UCLA, and a member of the scientific advisory board of the Prader-Willi Syndrome Association (USA).

Daniel J. Driscoll, M.D., Ph.D., will speak on Saturday, May 6th. Dr. Driscoll is an Associate Professor of Pediatrics and Molecular Genetics at the University of Florida Medical College, co-chair of PWSA(USA)'s clinical advisory board, as well as a member of its board of directors. His clinic follows over 75 individuals with Prader-Willi syndrome. Also featured on Saturday is Edmund G Haddad, Ph.D. who will once again address sibling issues. There will also be sessions on nutrition and on the role of the service coordinator.

The 2000 Conference will also include plenty of time for parents and providers to separate into small groups and share information and concerns among themselves. As you will see from reading Nancy Finegold's article about the 1999 conference (page 3), some of the most valuable time at *any* conference is spent sharing in small groups, talking and meeting at lunch, and at our informal hospitality on Friday night.

(continued on page 5)

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

Message from the President

by Henry Singer

This has been a year of tremendous growth and change for the Prader-Willi Alliance of New York. Last Spring we held our best-attended conference ever when more than 128 people joined us in Saratoga Springs. Among those attending were a significant number of parents with children under 5 years old with Prader-Willi syndrome. They got a chance to meet and network with other parents, as well as service providers. Many forged relationships that still continue — the true sign of a conference's success. We were pleased to add Jay McCarthy, whose son just turned one, to our Conference Planning Committee. This newsletter includes articles written by parents of very young children.

I emphasize *young parents* because more and more the calls for help are coming from parents or service providers of infants. With early diagnosis, there is so much hope for a brighter future. Please reach out for help because it is *there* for you. We are also able to help if the situation involves an older child or relative in crisis. See our "help Network" listing on page 6 of this newsletter.

The opening of the new IRA on Long Island is good news. I believe a new residence for people with PWS is being planned in Brooklyn. If that happens, it would be only the second in New York City.

All of the Alliance officers, as well as some of the Directors, are up for election at the 2000 membership meeting on May 6. I hope that some of you will consider taking on leadership roles in the Alliance. Like all organizations of its type, the Alliance will benefit from a massive infusion of new blood.

And while we're on the subject of leadership, we also need the assistance of some active, dedicated, committed people in several other areas of concern to our membership. First, we could use help in communicating with Spanish-speaking parents. Next, in order to have a successful newsletter, we need articles. Please consider either writing an article about your experiences with Prader-Willi syndrome, or help us locate professionals in all fields who can contribute to these pages. If you can assist, please call me at (212) 619-0181 and let me know of your interest. Your involvement is most appreciated! ✨

Please enroll me (us) as a member of the Prader-Willi Alliance of New York, Inc.

Enclosed are dues for 2000 (dues are \$15 per family, entitling the family 1 vote in Alliance elections. You may register as many family members as you wish for \$15 each) \$ _____

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

Total Amount Enclosed \$ _____

Name _____

Address _____

City, State, Zip _____

Telephone _____ Fax _____

E-Mail Address _____

Date _____ New Member Renewal

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

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

Child's Name _____ Child's Age _____ Age at Diagnosis _____

Where is Child Residing? _____

The 1999 Saratoga Springs Conference: A Parent Perspective

by Nancy Finegold, Queens

When my husband and I initially decided that we were going to attend our first Prader-Willi conference, we were both very nervous and very excited. There were other human beings with Prader-Willi Syndrome; other babies like mine; other mommies like me — I couldn't wait to meet them!

The first discovery we made about Saratoga Springs is that it is very far from Flushing, Queens! This fact hit home after about an hour-and-a-half into our trip when we discovered we had forgotten our big suitcase with all of our's and our daughter's shoes, clothing, and supplies. We had to turn around. A Freudian slip? Who knows. But arguing over whose fault this mishap was the whole rest of the trip helped to keep our minds off of our impending arrival at the conference.

For me, the next day-and-a-half had a surreal feeling to it. It was like I wasn't supposed to be there. Like I had been zapped into this curious affair to which I had no connection, didn't belong. Once I allowed myself to accept the reality that I *did* belong there, being with the other families in the same situation began to feel reassuring and comforting. Seeing other young babies and young children was therapeutic. Henry Singer, president of the Prader-Willi Alliance, told me that having so many young babies at a conference is a relatively new phenomenon. This means that our children are being diagnosed younger. This is really great news for those with PWS and their families. Most of the other mothers' stories were strikingly similar to mine. The initial experience in the hospital, the feelings, the pain; not knowing what could possibly be wrong with your baby, the tests, the fear. Then finally learning the realities of this strange syndrome. I felt like I was the only one. Yet we all went through it, we're still going through it. I felt a closeness and a bond to the other families and to the individuals with PWS themselves.

The conference was very multifaceted with a large array of different people. Foremost, I must say that those people running the conference were truly inspirational. Most of them have their own children with PWS. Grown children in their twenties. I found myself looking to them for their wisdom of experience and their dedication. They have lived through it and survived! Even without the conferences, without the support of an association, without growth hormones, without early

diagnosis, and before the availability of information that we have now. To me, they are the pioneers, the crusaders, and the heroes.

Also present at the conference was the most exceptional breed of human being — the righteous person who volunteers to raise those with disabilities, those with misfortunes. We had lunch with the mother who took in a young foster baby with PWS. Who loved him so much and so well that she decided to adopt him and take in children with many other ailments as well. People like this truly amaze me and should be a lesson in humility and self-sacrifice for us all.

Then there were the bitter ones — those who have just recently found out, just started reading, just started grieving. They are angry, scared, and everything *I* was just months before. Meeting them made me realize how my own grief had diffused. Here I was trying to comfort someone else! Trying to tell someone that it was going to be okay. Someone who didn't want to be comforted, wasn't ready to be reassured. I also met those individuals with dual-diagnosis. I like to call it Prader-Willi Syndrome plus. PWS + Autism; PWS + Mitochondria.

Then there was the couple struggling with their young child who is already very overweight. Already facing the ridicule, the pain of rejection, and the isolation from peers and adults alike that this syndrome can bring. She was learning too soon about the ugliness that can spawn from ignorance. For this child, the conference provided a respite. A haven of love and acceptance that she so desperately needed and deserved.

I also felt that I was in a haven of a sort. It felt so nice to be surrounded by those who understood what I was going through. People who enjoyed watching my daughter and loved her simply because they felt they knew her. She reminded them of their own young child. Most people were so encouraging and complimentary of my daughter Dina that I left the conference feeling a little more positive and optimistic that maybe she is doing okay, and will continue to do okay. These small compliments, words of wisdom, and advice from others were more important to me and more educational than the scientific information that the doctors had to share.

(continued on next page)

Meeting and speaking with adults with PWS was also very healing for me. It was difficult and painful at times, but beneficial. I found that I felt very proud of them and of their accomplishments. I also saw that they are valuable human beings who have good hearts and a lot to offer society, their families, and themselves.

The whole Saratoga Springs experience was very interesting for me. We were all so different from one another. We are from different places, have different coping styles, different lifestyles, and different beliefs. Yet fate gathered us up and joined us all in the most unexpected, unusual way imaginable. Who could've ever possibly predicted it? Yet there we all were in one place. Sharing, caring, laughing, and teaching each other.

Learning from each other's mistakes, and gathering strength from each other's tenacity and unyielding love of our children. The conference was short, only one and a half days, but for me those days were very meaningful. From the babies, to the adults with PWS, to their parents who have been where I am going, I feel I've gained a little from everyone. I try to carry these insights with me day to day, as I begin my own journey with my daughter.

To all those who worked so hard to make the conference possible, and to those who dedicate their lives and their time everyday to keep the association running and growing, I just want to say thank you. I'm looking forward to the next conference. ✨

"New York Cares" A 1999 Conference Report

by Elinor Baller

Note: Elinor Baller reports on a talk by Jim Moran at the 1999 Alliance Conference in Saratoga Springs. Since the conference, the legislation mentioned passed the legislature and was adopted as part of the New York State budget. Parents of children with Prader-Willi syndrome are fortunate in that we have in New York State many supporters, among them Governor Pataki and Thomas A. Maul, Commissioner of OMRDD, the developers of this historic "New York Cares" program.

Long-term planning has been a difficult and frustrating experience for parents of a disabled child because of the limited residential facilities in New York State. In an effort to show that "New York Cares," Jim Moran, the Director of Administration of the New York State Office of Mental Retardation and Developmental Disabilities (OMRDD), spoke at the 1999 Alliance conference about Governor Pataki's and Commissioner Maul's plan to expand residential and vocational placements for the developmentally disabled.

Moran described the State's plan to increase family support services over the next five years in an effort to place over 8,000 previously wait-listed clients in out-of-home services. Recognizing the need for these services, the State has budgeted about \$130 million to supplement the \$100 million coming from the Federal Government. These amounts contrast dramatically with the current State budget of \$26 million. Moran stated that he believes this issue in the budget will pass in the

legislature, because "Governor Pataki is committed and the legislature is supportive." The budget item passed the legislature, and was signed by Governor Pataki.

In an effort to streamline the process of providing adequate residential service, OMRDD has 13 district offices around the State to provide information and receive requests for services (see a complete list on page 6). Additional money has also been allocated to the district offices for services to clients not seeking residential service. Moran also noted that as people move into new services, former placements in respite and day care services will become available.

Moran acknowledged that most people with Prader-Willi syndrome will require specialized settings and emphasized the State's focus on "Person Centered Planning." One problem facing the development of more residential facilities is site selection. Currently, land purchases are not reimbursed by the State, although the State is considering being more flexible. Long Island, New York City and Westchester are difficult areas for site selection because of the high cost of land in these areas.

Moran stressed the need to register clients with Prader-Willi syndrome as soon as the child is diagnosed so that the State can plan accurately for future needs. Eventually, all adults with Prader-Willi syndrome will need some help through the State. Parents are urged to register their child by contacting the district office of OMRDD for the "New York Cares" representative in each district. ✨

Off to a Great Start

by Sue & Rich Cornell, New Hartford

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

We'd like you to meet Chrissy, who celebrated her second birthday last Feb. 26. She is a bright, vibrant, flirtatious, and charming little girl. After a rough start, we can't begin to tell you what a good feeling it is to watch her accomplish her goals. Chrissy just wants to do what others do and she does! That radiant glow once she accomplishes the task is just beautiful.

When she was born, she was so astonishing to look at. Her porcelain doll features were so pretty, along with her strawberry blonde hair and peaches-and-cream complexion. It was hard to believe our beautiful little girl could have a problem. That little "bird cry" was the doctor's first clue. After 36 hours, she'd had about two ounces of formula and was put in the Special Care Nursery. It was time to figure out why Chrissy couldn't suck and had such poor tone.

During her six weeks in the NICU (neonatal intensive care unit) in Utica and in Syracuse, she went through a series of diagnostic tests. She even had a muscle biopsy at three weeks. Every test was negative. Chrissy still couldn't suck but seemed to be "getting better." She was much more alert and being weaned from the tube to a bottle with a cross-cut nipple. Finally, the neonatologist and genetic specialist suggested another test. I remember signing a release for "Prader Something Or Other."

On April 1, 1997, I got a call from the geneticist. He wanted to see us the next day because the PWS test was positive. He told us all we wanted to know: it was manageable and not fatal. I'm sure you all know the rest of the story. She finally came home on April 8. Everyone involved in her care and treatment during her NICU stay was incredible. Even the social worker was

on the phone to the New York State Early Intervention to get PT and OT started. Speech therapy has now been added. Her therapists have done so much for her by making Chrissy think she's playing, rather than learning. And her daycare provider has been *extraordinary*.

Chrissy has such a wonderful way of teaching you about life. Through her gentleness and simplicity, coupled with her million dollar smile, she has a way of making you reevaluate your own life. She's still tiny — 16 lbs. She says a few words, but knows how to communicate through her own little language we like to call "Chrissy Speak." She's just as proud as any child would be when she does something that big girls do, like pushing her "babies" around in the carriage.

This story isn't complete without mentioning her brother, Andy. He is 3½ and just loves his "Chrissy Baby." And then there's Clancey, our Irish Setter. Most kids have teddy bears — not ours. Andy has "Don Duck" — no need to call him Donald since they're "tight!" — and Chrissy has Clancey and can't start her morning without checking him out at the foot of our bed.

Would our lives have been different without NICU's and social work's support? How different would life be without early detection and early intervention? We don't know but suspect things would be very different. We've read the stories: good, bad, sad, extreme, and helpful. What stays with us is what we've known from day one, and that is "it's manageable." We read and hear about the extremes. And while this shouldn't be ignored, there's a lot of good news out there. Early detection, early intervention, hope, research, and time are on Chrissy's side, along with a little luck and a few prayers. And if this isn't part of better management of PWS, then at least we'll know we tried. That's Chrissy's attitude, too! ✨

10th Annual Conference

(continued from page 1)

The Ramada is located at 1228 Western Avenue, Albany, New York 12203. We have reserved a block of rooms for Thursday, Friday and Saturday nights at a favorable rate of \$70.00 per night, single or double. The rate includes breakfast. Children 18 and under stay free, but their breakfast costs \$1.99. An extra adult will cost \$5.00, which will include breakfast. The Ramada also

has an indoor swimming pool. Reservations may be made by calling the hotel at (518) 489-2981 or on the web at <http://www.ramada.com>. Ask for the special conference rate. You must make your reservation by April 21, 2000 to obtain the special conference rate.

Save the dates *now* — and join us for what we're sure will be the best PWS conference you'll ever attend! ✨

OMRDD Developmental Centers & Disabilities Services Offices

(as of September, 1999)

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

Attention — Individuals and Families Affected by Prader-Willi Syndrome

Note: We recently received a fax from Dr. Suzanne B. Cassidy regarding an exciting new research project, funded by the March of Dimes, which she will undertake. Following is the complete text of the fax.

Recently, Dr. Suzanne Cassidy of the Center for Human Genetics, together with a number of collaborators at Case Western Reserve University and University Hospitals of Cleveland, have received funding from the March of Dimes Birth Defects Foundation to conduct vital research on Prader-Willi syndrome. Entitled “Prader-Willi Syndrome: Genotype/Phenotype Correlations,” this research is aimed at advancing our understanding of the genetic basis of the manifestations of PWS, specifically what molecular changes may be responsible for the different physical and behavioral findings seen in affected individuals. It is our hope that such research will contribute to an improvement in the understanding, management and future treatment of this very complex disorder.

To do this research, we need your help and participation! We are looking for 100 individuals who are willing to participate at some point over the next three years. Participants should be an age over the age of three years. Participants do not need to be patients of Dr. Cassidy’s, or to switch their ongoing clinical care in any way. They simply have to have a confirmed laboratory diagnosis of Prader-Willi syndrome. Additionally, not choosing to participate in this study will not affect the care your adult or child receives.

By appointment, each participant with a parent or care provider will be invited to the Clinical Research Center located in Rainbow Babies and Children’s Hospital in Cleveland, Ohio, for a 2½ day stay. During the stay, a thorough evaluation will be conducted by various specialists on the physical, nutritional, cognitive, speech, behavioral, and endocrine aspects of the disorder. X-rays for scoliosis, bone age and bone density will be taken. Blood samples will be drawn for genetic, hormone (including growth hormone) and other testing. Parent and grandparent blood samples will also be obtained, when possible. Each patient will have his or her own private room, with sleeping accommodations for a parent or care provider. All meals for the participant and their care provider will be provided. Much personal attention will be devoted to the participant throughout their stay. While we cannot pay participants for their time, we do make any useful results available to the family and physicians, as well as validate parking. Additionally, anyone can choose to go home or elsewhere for the evenings and/or night; if needed, funds are available to reimburse some travel expenses.

If you are interested in learning more about the study, or making an appointment to participate, please call Shauna Heeger, Study Coordinator, at (216) 844-7213. And please pass the word. Together we must continue to make advances to help all individuals and families affected with Prader-Willi syndrome. ✂

The Prader-Willi Alliance Help Network

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

- Elinor Baller: 914-834-4804
- Gloria Cox: 212-988-7350
- Volena Howe: 716-271-5332
- Kathy Jornov: 518-758-9753
- Daniel Maillet: 914-591-6425
- Harry Persanis: 516-783-7508
- Henry Singer: 718-783-0181 (home);
212-619-0185 (work)
- Sharon Spink: 716-823-3095
- Sharen Tarakan: 516-621-1596

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



F.R.E.E. Opens Long Island Residence

by Robin Stone, Senior Program Director

On November 3, 1999, Family Residences and Essential Enterprises, Inc. (F.R.E.E.), opened its second Prader-Willi program, the Prospect IRA. Situated on a quiet street in Central Islip (Suffolk County, Long Island), the IRA (Individualized Residential Alternative) has six bedrooms, two baths, a recreation room and two lovely patios for the residents to relax on. Several of the residents who moved into the Prospect IRA have graduated from our existing Hempstead ICF.

The individuals are going to be on an intensive exercise regime, and will be working on goals to ensure that they become as independent as possible. Prospect has an open kitchen with the exception of designated cabinets and a refrigerator that will remain locked. Each individual will be maintained on a specific calorie diet

that the staff will implement in conjunction with a nutritionist, who will provide training and assistance in teaching healthy eating skills. The program has a behavioral specialist who will work directly with the residents to train and assist them in coping with daily stresses, two direct care counselors on a shift, and one overnight awake counselor. There is a two-person management team and a registered nurse.

F.R.E.E. is thrilled to be part of this venture. As an agency, we are determined to make this program as successful as our existing Hempstead program. We have watched the individuals we serve learn the skills needed to help them move on in life. We take pride in their growth and we always strive for the individuals to be the best they can be. ✂