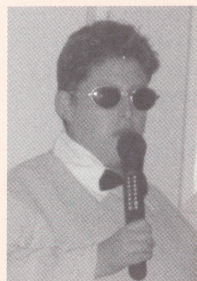




The *Gathered View*

May-June 2004
Volume 29, Number 3

National Newsletter of the Prader-Willi Syndrome Association (USA)



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'Down Under' 2004

Attending the PWS International Conference

By Janalee Heinemann, Executive Director

We flew for 26 hours to attend a "family" reunion. In April, New Zealand's Prader-Willi Association hosted the 5th International and 9th Australasian PWS Scientific and General Conference in Christchurch.

For Pam Eisen and me it was a special time because we could reunite with many friends we met in Italy, United Kingdom, Argentina, Israel, Taiwan, Belgium, South Africa, Switzerland, Norway, Austria, Malaysia, Romania, Japan, Germany, Australia... and New Zealand, of course. We also met friends from China, Zimbabwe, and other countries with whom we have been corresponding; now we could see their smiling faces for the first time.

PWSA(USA) was well represented by the following speakers: Dr. Dan Driscoll and his wife, Dr. Marilyn Dumont-Driscoll, Dr. Suzanne Cassidy, Dr. Merlin Butler, Dr. Tony Goldstone, Dr. Jim Locker and his wife Carolyn, Janice Agarwal, Dr. Ann Scheimann, Dr. David Allen, B.J. Goff, Barb Whitman, David Wyatt, Ken Smith, Jim and Joan Gardner, Pam and me. Presenting a poster was Dr. Linda Gourash, and IPWSO webmaster Steve Lundh was acting secretary for the General Assembly.

Special thanks go to Linda Thornton and Cindy Adams-Vining for co-hosting this event and for the years of hard work they put into making this successful conference. It was well organized, the speakers were interesting, and they allowed good time for sharing. The food was excellent and we especially



Janalee Heinemann, Urith Boger of Israel and Pam Eisen in New Zealand

enjoyed the New Zealand custom of morning and afternoon tea.

At the General Assembly meeting, Thomas Gross from Germany put in the bid that was accepted for Germany to host the next international conference in 3 years. Most exciting was when our USA Pam Eisen was elected to be the next IPWSO president.

Pam Eisen Now IPWSO President

Pam Eisen, PWSA(USA) Parent Delegate to the International Prader Willi Syndrome Organization (IPWSO), has been elected president of IPWSO. She succeeds Giorgio Fornasier, who now becomes IPWSO's immediate past president.

Her enthusiasm for connecting with different cultures lends itself well to her new mission as IPWSO's president. "I relish the opportunity to work on behalf of PWSA and IPWSO, because I particularly have a passion to help the children and families

New Zealand & Eisen continued on page 7

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Our Mission: Through the teamwork of families and professionals, PWSA (USA) will improve and enhance the lives of everyone impacted with Prader-Willi syndrome (PWS) and related conditions.

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26th Annual Prader-Willi Syndrome Association (USA)
National Conference

“Explore the Possibilities”

June 30 – July 2, 2004

Conference Registration only: www.pwsausa.org/conference

Phone: 800-926-4797 or 941-312-0400

WEDNESDAY, JUNE 30

Scientific - \$125.00

Care Providers Day only - \$100.00

Care Providers plus General \$175.00

(covers the costs of meals)

Chapter Presidents Day

THURSDAY-FRIDAY, JULY 1-2

General Sessions

(Early Years, School Age and Adult)

Registration Fee:

(Includes all meals except Banquet)

Members - \$150

Non-members - \$185

Banquet - \$15

Youth/Infant Program - *Ages 0-9*

Registration - \$75

Banquet - \$10



Conference Site and Hotel Registration

The **Lodge at Sawmill Creek** is the headquarters hotel for the PWSA(USA) Conference. This recently renovated, year-round resort features indoor & outdoor pools, Tom Fazio Championship Golf, bonfire and hayrides, exercise room and many more activities.

PWSA (USA) has secured a block of rooms at the discounted rate of \$99 a night for up to four in a room.

To avoid any overcharge or problems with registration, please make your room reservations by contacting Globetrotter Travel at 800-322-7032 (press 2) or via e-mail pwsa-usa@globetrottermgmt.com.

Hotel reservations may also be made online by contacting www.globetrottermgmt.com/pwsa-usa. All reservations require a credit card guarantee or a check deposit of the first night's room and tax (checks should be made payable to Globetrotter Travel). This deposit is non-refundable if canceled within 72 hours of the arrival date.

For special airfare and car rental rates, please call Globetrotter Travel at 800-322-7032 (press 1) or e-mail to pwsa-usa@globetrottermgmt.com to take advantage of the special airfare and car rental discount rates.

Conference attendees can save up to 15% on airfare and receive discounted car rental rates.

For program updates check the PWSA website at www.pwsausa.org



President's View

My Journey With Julie

Lota Mitchell

Daughter Julie, age 34, lives in a designated Prader-Willi syndrome group home near Scranton, Pennsylvania — the far eastern side of the state — while my husband and I live in Pittsburgh, the far western edge. Several weeks ago we drove the 300+ miles across Pa. to visit her.

It turned out to be a weekend that echoed Elizabeth Dykens' research showing that behavior problems decrease when the person with PWS reaches her 30s and 40s. Now the trick for parents is to survive that long! My own personal untested hypothesis is that just as toddlerhood seemed to go on forever (or at least Julie's did), adolescence is prolonged... and prolonged... and prolonged.

Except for one brief period of perseveration, when she got hung up on something I can't even remember, her behavior was almost without fault. She even had a major victory. We went out to dinner at Cooper's Seafood House, a restaurant and pub which lists on its menu a roster of celebrity customers that includes Bill and Hilary Clinton. After the (typical at Cooper's) 45-minute wait for a table, during which Julie perused the extensive menu with great interest, we were at last seated.

Her choice was fettucine with shrimp, scallops and clams. When her order arrived, my heart sank as low as the bowl, which looked big enough to be a birdbath, was piled high. But experience has taught that once food is in front of the person with PWS, taking some of it away is tantamount to starting World War III in miniature. But incredibly, two-thirds of the way through, she said, "I've had enough," and pushed it away. I cranked my jaw back up into place and

Julie and PWS have brought many blessings and enriched my life.... My hope is that PWSA(USA) has benefited as much as I have

congratulated her heartily on her accomplishment while she beamed proudly.

Julie loves going places and doing things. During my Scranton visits we have descended into the Lackawanna exhibition coal mine (chilly, depressing and informative), hiked the 3 ½ miles around Lake Scranton (the last hour in driving rain with one umbrella between us), taken a 45-minute ride on a little demo train, and visited the Steamtown roundhouse museum about steam engines. I did not expect her to be so interested in trains, but I got her to leave only because the place was closing and it was dinnertime. This trip I found the Everherd Museum, where

we enjoyed especially the outstanding collection of stuffed birds as well as looking at American paintings on display.

Back at the motel, out would come the cards, and she and I would shortly be deep into our double-solitaire competition. While I would have her normal in a heartbeat if I could, Julie and PWS have brought many blessings and enriched my life.

First I think of all the terrific people I've met and the wonderful and dear friends I've made over the years in PWSA(USA).

I've often joked that I could travel across the U.S. or down to Florida and never have to stay in a motel (OK, so I exaggerate a bit).

Then there is the personal growth I've experienced through PWSA(USA), with the privilege of



Julie Mitchell, 34, who has PWS, enjoys playing double-solitaire

serving for 12 years on the Board of Directors, being its chairman for five, and now completing my 3-year term as president. My hope is that PWSA(USA) has benefited as much as I have. Even more important is the sense that Julie's life has had meaning through me, that we have touched the lives of countless people we'll never know through my writing and service to the Association. Julie herself has personally contributed to the knowledge about the syndrome through her participation in research, the most important of which was being in the study that was definitive for uniparental disomy.

And last but not least is Julie, with the enjoyment I have in our card games, our travels together, and her obvious pleasure in my company. I am proud of her that most of the time she does the best she can with the hand she has been dealt. It is my wish for all parents of children with PWS that they, too, will experience many blessings from their little ones now or later when they are adults. Or both!

Peace.

Meet the National Office Staff

Diane Spencer: A PWSA Vital Resource

By Lota Michell, Associate Editor

PWSA(USA)
Support Coordinator
Diane Spencer

When you call the national office and talk to Diane Spencer, the friendly voice on the other end belongs to a pretty lady with short white hair softly waving around her face. Officially, her title is Support Coordinator. Unofficially, it means she does a lot of all sorts of things.

Outside the job she reads as much as possible, plays golf, and recently learned to fly fish. She is also a dynamite cook. For her, cooking is a stress reducer!

To her job she brings warmth, humor, tact, and all the experience her varied background has given her.

Born, raised and married in Ohio, she moved to Chicago in 1965 where her two children and six grandchildren still live. Using her degree in education from the University of Akron, she taught school for 20 years, with time off to have babies. Her teaching career covered all grade levels, kindergarten to college. She tells people she loves challenge and change. And both she has had. From

teaching, she got a real estate license in Illinois and then a separation and divorce. More change — she went back to school for computer programming and worked for Databroker Systems, where she became vice president of sales. When the company was sold in 1988, she moved to Sarasota.

And more change. She worked as a computer consultant for 2 years and then



Diane continued on page 11

Chapter View

I'd like to recognize some people who have stepped up to the plate on behalf of PWSA(USA), along with a round-up of what some of our busy chapters are doing. If you're not in a chapter, please consider joining one in your state — or starting a new one. PWSA(USA) will help you through the process.

The Board of Directors appointed **Henry Lee** as **Secretary for PWSA(USA)**, and he attended the January meeting of the Board. He takes minutes of all Board meetings, the annual general membership meeting held at conference, and all Board conference calls and email votes. Married to Marge for 17 years, he is the father of Sam, 13, with PWS and Ben, 11. He graduated from West Virginia University in 1999 after 18 years as an undergraduate with an Associates Degree in Electronics/Computer Technology. He manages the computer network and 450 workstations at WVU's College of Business and Economics. Lacking a chapter in W.Va. and living in Morgantown next door to Pittsburgh, the Lees helped re-form the Pennsylvania chapter in 1998, where first Henry was vice president and now is on its Board of Directors. In his spare time, he hunts, fishes, hikes with his boys and practices his pottery skills.

North Carolina Chapter's new president, **Sayward Schmehl**, is the daughter of past president Sally St. Johns. Sayward is starting grad school in August for school psychology. She wants to work with high school students and feels that having Elliott, age 20, with PWS, for her brother has shaped her goals in life. She remembers going to national conference and helping when Elliot was younger. Her undergrad major was international studies; last summer she went to Tanzania in Africa and she plans to go back to Africa this coming summer to spend five weeks in Malawi.

Wisconsin held its annual 2004 Hobby-Social & Training Day on April 24 — an all-day event offering hobbies and a dance, and speaker and sharing for parents and caregivers. Sounds like a great event—for more information, call toll free 1-866-797-2947.

Springtime and walking time arrive in **California** — Southern on April 25 and Northern on May 1. An immediate crisis concerning vital services for disabilities in the state was averted by strong advocacy by many, including PWS families, although uncertainty exists re future funding.

Michigan is walking, too, either 2 or 4.5 miles around Reeds Lake; proceeds benefit the 2004 National Conference.

Spring also brings golf outings, and **Pennsylvania** tees off on May 24. Co-chairing (with **Mike Azzara**) is **Mike Fabio**, recognized by his company, Cargill, Inc., as a Cargill Cares Award Winner for his work on these annual events. Each fiscal year Cargill presents up to 100 volunteers, retirees, and/or employee teams with awards for outstanding community service. Winners receive company-wide recognition and \$1,000 to donate to the nonprofit organization for which they volunteer. Way to go, Mike!

O'Leary's 8th Annual Charity Golf Tournament, on May 17, will benefit both the **Missouri** chapter and the Judevine Center for Autism. **Judy O'Leary**, whose brother-in-law's restaurant sponsors the event, is chapter president and mother of Tim, who has PWS.

Florida has scheduled its Spring Conference April 23 and 24 at the Westgate River Ranch with speakers Dr. Jennifer Miller and Susan Thompson, and a hayride, BBQ dinner, and the American Championship Rodeo. Sounds like fun for our PWS families!

Prader-Willi Alliance of New York also plans their 14th Annual Conference for April 30 and May 1, with speakers and presenters knowledgeable about PWS.

Mexico Conference 2003: It All Started With Jacobus

By Pam Eisen, IPWSO President/ Parent Delegate for PWSA (USA)

Janalee Heinemann and I attended the Third Latin American PWS Conference in Mexicali, Mexico, which was also the First Mexican PWS Conference. It all started with Jacobus. Diana Cota and Carlos Meza went to their doctor for help after their 14-year-old son Jacobus was diagnosed with PWS. From there the doctor's interest in PWS grew, and then dynamic Diana and Carlos started a support organization for Mexico. In 3 years it has grown from one family to a support system large enough to host this conference.

Indicative of the culture, the people we met from Mexico were warm and gracious and there was a lot of extended family support.

Representing our own support from the USA, we joined other speakers such as Dr. Suzanne Cassidy and Dr. Moris Angulo, IPWSO scientific advisor for Latin America. Of course, our wonderful multi-lingual IPWSO Past President, Giorgio Fornasier, was there from Italy, along with his family and two Italian psychologists specializing in PWS.

Martha Lorena Suarez de Diaz, wife of the mayor of Mexicali, not only attended the entire conference, but also drove us around and joined us for meals. We educated her about PWS and she educated us on the realities of health care in her country. Unfortunately, we had to accept that growth hormone is not an alternative in their country due to the economics of Mexico. For this reason and because this was the first conference ever attended by most families, we all tried to focus on basic care, diet and behavior management. The professionals welcomed our printed materials, which they will translate into Spanish.

One special highlight was a mass we were all invited to attend. Giorgio sang from the choir balcony while his son Danielle, 28, who has PWS, served at the altar. Considering Danielle speaks only Italian and the mass was in Spanish, we were all impressed with how he handled the service with ease and confidence. Watching Danielle beam with pride as he looked up at his father singing, you could almost see a glow around him.

At the end of a wonderful three-day conference was a celebration dinner, including a performance of native dancers and singers. The highlight for us was when all of

the children with PWS and their siblings paraded up front with their sunglasses on and sang our PWSA(USA) rap song, "My Name's Not Willi" in Spanish. Appropriately so, on the last night, what all started with Jacobus ended with Jacobus — being "cool" while singing karaoke to the crowd.

Jacobus Meza is totally cool with "My Name's Not Willi"



Left: Giorgio Fornasier, Janalee Heinemann, Martha Lorena Suarez de Diaz and Pam Eisen attend Conference in Mexico; Below: Dancers entertain at the celebration dinner



PWSA (USA) gratefully acknowledges the printing and mailing of this newsletter is made possible by a grant from CIBC World Markets Corp./Miracle Day USA.

Those who have followed Pam's international work through reading *The Gathered View* know this was an excellent choice. Others elected to the IPWSO board were: Dr. Shaun Pei Lin of Taiwan, Eli Korth of Argentina, Diana Cota of Mexico, Christian Aashmer of Norway, and Kate Grussing of the UK.

Special event highlights included a spontaneous challenge to each country to sing a song from their country. Those from the USA sang "Yankee Doodle Dandy." Then Pam and I were invited to do a song and dance with our friends from Taiwan, represented at the conference by 10 people. Great fun! Members from the Maori tribe did their ritual dance for us, and at conference end, the youth program attendees performed their version of this traditional New Zealand dance.

Similar to our PWSA(USA) conference, the scientific component plays an important role in enhancing research on the syndrome. It brings together scientists from around the world, each with different specialties, but who share a special interest in the syndrome. They are thus able to bring new concepts and challenges to each other, which also fosters collaboration and cooperation on research projects. We will have more comments from the scientific conference in the next issue of *The Gathered View*.

Eisen - continued from page 1

throughout the world who are alone and have not yet heard IPWSO's voice," she said.

As the parent of Gabriella, her 24-year-old daughter with PWS, and two very supportive sons, Jeremy, 31, and Benjy, 28, Pam has worked tirelessly on behalf of families everywhere who are dealing with the challenges and stresses of Prader-Willi syndrome.

"PWSA has been a never-ending source of support in my life, from the time I first suspected Gabriella's diagnosis, through her many hospitalizations, through my husband's death from esophageal cancer, and especially through Gabriella's residential placement. Inspired by this fine group of people, I feel deeply committed to making life better for all those whose lives have been touched by PWS," she said.

Pam combined her education and professional work in child development and psychology with a personal commitment to community service. Her experience includes work with adoption of "hard to place" children, writing a manual for adoptive parents and developing parenting support groups for these families. She also developed toddler programs (emphasizing parent education and involvement), and designed and executed pre-school camps.

She became a full-time, stay-at-home mother after Gabriella was born, but remained active and took leadership roles in community service organizations. In addition to her work on behalf of PWSA and IPWSO, Pam has served on numerous boards, including the Children's Museum of Scientific Discovery in Pennsylvania, Canada's first Children's Museum, and United Cerebral Palsy.

NZ Scientific Conference Highlights

- In any suspect case of PWS, all children less than age 2 need a SNRPN DNA methylation test for diagnosis. This is because a deletion by chromosomal analysis or FISH will not distinguish between PWS and Angelman syndrome. At less than 2 years of age there can be significant clinical overlap between these two conditions. There have been numerous misdiagnosed cases using FISH alone at this young age. (Dan Driscoll, MD, Ph.D — USA)

- A small study to date has shown that although Somatostatin reduces Ghrelin in PWS, it does not change the appetite. Ghrelin and leptin may be the keys, but the lock does not work. The message of reduced ghrelin from the somatostatin treatment may not get to the brain, or it may be abnormal vagal activity, or a defect in the pancreas, or something else. More studies are needed to rule somatostatin in or out as a treatment for increased appetite in PWS. PWSA-USA is sponsoring such a study. (Tony Goldstone — USA, formerly UK)

- In a second study, psychotic illness was shown to be much higher in people in their 20s who have PWS and UPD. (Tony Holland, MD — UK)

- PWS is a syndrome of starvation in a food-enriched society. Eating, lying and stealing go together and are normal reactions to an abnormal hunger — behaviors like those of people living in a concentration camp. (Tony Holland, MD — UK)

- We do not have much good data on sudden deaths in PWS. We are becoming aware that respiration is a primary cause of death in children. Some possible reasons include: pharyngeal narrowness, chest wall restriction due to scoliosis, more REM sleep which means the arousal reflex is less than normal. Although the concern remains on starting a child on growth hormone who is significantly obese and has respiratory problems without recommended precautions being first made, on the whole, growth hormone has been shown to increase respiratory strength and increase CO2 response. (David Allen, MD — USA)

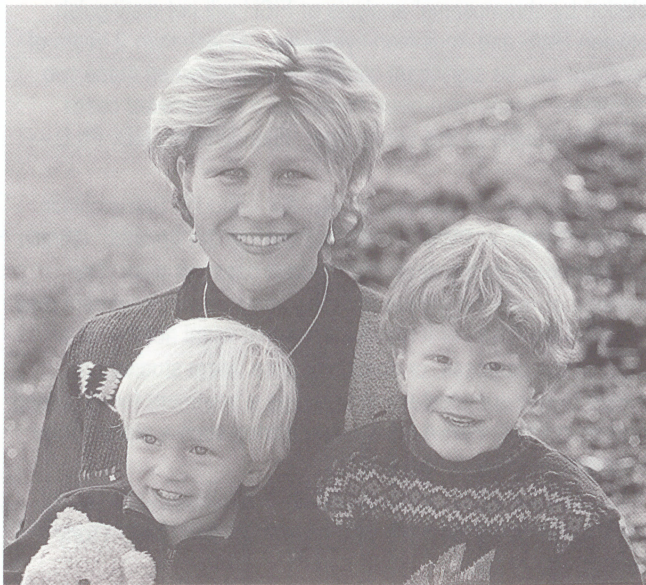
- In PWS, many of the aging issues are the same as in the general population of people with intellectual disabilities (ID), such as a high prevalence of mobility impairment, depression, loss of bone density, limited social networks and housing options. More prevalent in PWS are facial aging, osteoporosis, cardiovascular problems, frequency in mental illness (UPD), and an increase in compliance and a decrease in temper tantrums. (Susanne Blichfeldt, MD — Denmark)

- Growth hormone in adults deeply influences PWS subjects' quality of life and psychological well-being in a positive way. (Carlos Semenza — Italy)

- The insidious nature of cardiopulmonary deterioration in persons with PWS whose weight has reached the obese range is evident in the fact that cor pulmonale and hypoxia are frequently undiagnosed at the time of referral. Numerous case histories demonstrate that cardio respiratory decomposition often occurs seemingly without warning in patients who have appeared to be tolerating their obesity without imminent risk. (Linda Gourash, MD — USA)

Speech Therapy — When Should You Start?

By Janice M. Agarwal, P.T. and
Stacey Hiller, M.S., CCC-SLP



Janice Agarwal with her sons
Samuel, 3½, and Alexander, 4½, who has PWS

Speech-language pathologists can have a powerful impact on the early communicative development of babies with Prader-Willi syndrome. Beginning in their first year of life, children with PWS can benefit from oral-motor therapy and development of a total communication system.

A great deal of valuable therapy time can be wasted if therapy services are initiated only when a child begins to exhibit difficulty developing conversational speech. Issues such as weakness of oral (speech) muscles can be effectively addressed as early as 3-6 months of age. If appropriate therapy is initiated, our children may avoid developing many of the negative compensatory patterns and typical delays frequently seen in children with PWS, such as lack of verbal communication development or difficulty with mature eating skills.

Due to structural and physiological differences of speech mechanisms, hypotonia and neurofunctional patterns, most children with PWS have difficulty with speech intelligibility. These deficits can vary widely from case to case, making designing a treatment plan challenging for clinicians who are unfamiliar with this population. In addition, children with PWS can experience problems with articulation, fluency, resonance, vocal quality or hearing. Another frequently seen pattern is verbal dyspraxia, which is difficulty in voluntarily moving the muscles used for speech.

Traditionally, decreased expressive language and intelligibility have led professionals to underestimate the intelligence and capabilities of PWS children. Using sign language (or any alternative systems not requiring the use of

voice and/or mouth) can allow children with PWS to become successful communicators by the time they reach their first birthday.

Many parents fear that providing a child a non-verbal means of communication (e.g., sign language) will keep the child from talking. Research has proven exactly the opposite. Once a child experiences success with non-verbal communication, he/she becomes more motivated to do the often difficult work necessary to develop more mature forms of communication, such as talking.

Many of the underlying developmental problems in PWS are caused by sensory system abnormalities. Tactile defensiveness and eating difficulties are common. Clinicians should provide sensory integration therapy techniques

Sensory Integration Therapy Techniques

These can begin very early in children's lives:

- Tapping on or stroking the tongue
- Stimulating the cheeks with different materials, textures, or temperatures
- Using mouth massagers
- Applying ice on or around the lips
- Presenting strong tastes in or around the oral area (e.g. with glycerin sticks)

beginning very early in these children's lives. This type of therapy may include: tapping on or stroking the tongue; stimulating the cheeks with different materials, textures, or temperatures; using mouth massagers; applying ice on or around the lips; or presenting strong tastes in or around the oral area (e.g. with glycerin sticks). In addition, working on sensory reactions in the

rest of the body can help a child learn to calm and regulate him/herself and begin to feel more comfortable interacting with and exploring the world around him/her. Crucial fact learning activities include crawling on grass and a variety of surfaces, touching and mouthing a variety of toys, and tasting a variety of foods. Early in life, clinicians such as speech pathologists and occupational and physical therapists can help children master some of the sensory reactions and general skills that children will eventually need to develop appropriate oral language skills.

Because the same muscles used while eating are used for speaking, feeding is an excellent opportunity to work on sensory and motor issues around the mouth. Using different

Speech Therapy continued on next page

The First, the True, the Real Ally: Our Physiotherapist

By Nana Manolias Kyrzidis

She came one day to our house with a big warm smile on her face and that determination in her eyes. She did not ask much at the beginning. Slowly we got to know each other. I discovered a very professional woman.

She explained to us what the Bobath programme meant and was eager to present to us the methodology of her work. She showed us an evaluation form to be filled before starting the sessions and after certain milestones were met.

She explained that our boy was to be videotaped so that to record the progress and the timing of the progress. She asked for the phone numbers of all doctors that have seen our baby, then 4 or 5 months (and they were in fact quite many!) and she called all of them and talked about what she was about to start. She even visited the neurologist who was 4 hours away from where we live, so that to closely discuss the case of our baby.

That was the first meeting. She added that she follows babies at home so that they are kept as far away from viruses and infections as possible.

I was very happy about it. It was very convenient for me, since I would have to carry all around the therapy sessions my elder daughter then 3,5 years old. I was still in pain and confusion and she shed light to my heart and mind.

Speech Therapy - continued from page 8

food tastes and textures as stimuli during meals, children learn to move foods through the mouth and control tongue muscles. These same tongue movements will be necessary for the development of many speech sounds, such as "t" and "d". By learning to drink from a cup without a lid, children learn to retract their tongues, an important movement for many other speech sounds, such as "r" and "s".

Motor activities that assist a child in developing oral-motor strength and stability (and are still fun!) include blowing bubbles, horns and whistles and using straws. Imitation can be facilitated through activities such as rounding lips, throwing kisses, or clicking the tongue. Breathing exercises strengthen respiration (and the diaphragm) and lengthen the duration of exhalations, which positively impacts speech development by improving breath support and trunk stability.

Many of these activities can easily be incorporated into a home program and don't require large amount of isolated time for families. By giving a child an adapted straw to use for all drinks at home, the child will work on improving oral-motor strength every time he/she take a drink.

Implementing an approach that incorporates direct oral-motor therapy, language stimulation techniques, alternative means of communication, and sensory activities) is the best way to have a significant positive impact on the verbal, linguistic, and cognitive abilities of our children. By beginning speech intervention at a very young age, we give our kids the best chance to be all they can possibly be.

Mrs.
Theocharopoulou
Vlahogianni Fani,
physical therapist,
works with
Konstantinos,
who has PWS,
while his sister
watches.



I realized that after all, what happened to us was not the most dramatic thing and that there were solutions.

"Solutions" is the key word for me. When something can be fixed, why worry about it? I said to myself: Work, work and work. See what you can do every single day. Just concentrate on the work and the results will come. Of course I had a vision. Of course, this woman was the first and only one that gave me this positive vision. Work without vision is like wondering around without beginning or end.

So she took me by the hand, she explained to me very clearly, she gave me the tools and I was eager enough to absorb everything that was said or done.

She gave me orders. Yes, this is the right word. In these issues there is either black or white. "This is the right way to feed this baby." Or, "This is the proper way to hold your son. You have to change the tone of your voice, make it louder, more theatrical. Put mirrors all over the house." This is right, this is wrong.

Our baby walked independently at 24 months, immediately after the eye surgery for the correction of strabismus. Till then we had followed a very strict programme of Bobath positions and exercises, every day, every hour, every minute of his and our life. We had incorporated the Bobath philosophy to our everyday life and she was there to ensure that we properly follow the right steps.

I am proud of our son. I am proud of our selves. I feel honoured and privileged that in the middle of nowhere, perhaps my tears and prayers brought to out life our physiotherapist, a real Lady: Mrs. Theocharopoulou Vlahogianni Fani.

I hope that the rest of the therapy team that have entered our life in the meantime prove themselves to be as fruitful and result-oriented as she was and still is.

Nana Manolias Kyrzidis, mother of two, lives in Larissa, Greece.

The Decision to Adopt: Parenting Multiple Children With PWS

By Vicki Knopf

When people hear that my husband Dave and I are parents to seven children, we often get a response of "Wow!" or "That's great!" But when we further explain that three of those children have Prader-Willi syndrome, there is often a look of disbelief followed by questions like "Why?" or "Oh, I'm sorry," because many think that we have had the misfortune of giving birth to three children with the rare disorder.

Nothing could be further from the truth. In 1994 we did give birth to a child with Prader-Willi syndrome, the youngest of our five boys, and we were given a very bleak diagnosis. We were told to expect David to be mentally retarded, morbidly obese, and have horrible behavior problems, that he would pretty much be a monster. We took our baby home from the NICU with a feeding tube and braced ourselves for the worst. In 1994 the Internet was not what it is today and we didn't even have a computer in the house, so I had a friend who is a doctor go to the medical library at our local hospital to try to find some more encouraging information. She was only able to give us a very clinical article copied from a medical journal that gave us little to go by.

As the months passed and David finally started to wake up and become aware of his surroundings, we were amazed at his accomplishments. He met all his milestones on his own time frame, but he met them nonetheless. He blossomed into an inquisitive toddler and continued to surprise us all.

In July 1999, when David was 4, we became aware of a baby boy who was in foster care waiting for an adoptive family. When Dave and I discussed this baby, we knew right away what we would do. After David was born, we had discussed adoption and had decided that if we ever had the opportunity to adopt, it would be a child with special needs. We felt that we had much to offer and found it so rewarding to see David thriving that we knew we could help other children. Ben came home to us when he was 5 months old and our family was complete... or so we thought!

We were busy raising six boys. There were ball games, scout meetings, school functions, doctor appointments and therapies. Life was full. Life was good. David was doing well in school, and Ben was a perfect fit to our family; he even looked like our other boys! We were blessed.

In April 2001 I took a phone call that would change our lives forever. I work for a parent mentoring group called PATH (Parents Available To Help).

I took a call from a woman whose newborn had low tone, feeding issues, and was being tested for PWS. We spoke a lot over the next few weeks, but the family was not equipped to handle the issues that PWS brings. After the diagnosis they decided that the best thing for the baby was an adoptive placement. Having gone through the adoption process with Ben, I offered to help them look for placement for baby Caroline.

In the meantime Dave and I decided to offer some respite care for the family. They accepted, and Caroline came to stay with us a week later. The hunt for an adoptive family continued, but there was just no interest anywhere.

Caroline had been with us for several weeks when Dave and I started to talk about adoption. We were already raising two children with PWS, we knew all the ins and outs of the syndrome, we had the connections and most of all, this little girl had stolen our hearts. In April 2002, just shy of her first birthday, Caroline Grace Elise Knopf became an official member of our family. Now I can say our family is complete.

What makes us think we can raise three children with PWS when some have such difficulty with one? I'm not sure I can answer that. What I do know is that what we are doing works, and it works well. We have set up a structure that works well for the three with PWS as well as the four who don't. We have given our other children the opportunity to see what a difference they can make in the lives of others. They know that their siblings have different needs than they



The Magnificent Seven:
Ryan, 15; Alex, 13; Aric, 11; David, 9,
Jacob, 8; Ben, 5; and Caroline, 3

Knopf continued on next page

do, but they have never been denied anything because of their siblings' issues. Sometimes it is a give and take, but that is how a family works. There are no guarantees in life and nobody is perfect.

Our kids treat David, Ben and Caroline like any other kids treat their siblings; they fight sometimes, they get mad when the little ones get into their things, and they sometimes get aggravated that they have to help out. But isn't that how it is with any siblings — special needs or not? They also play together, do things for each other, and stick up for each other, like other siblings do — special needs or not. My other boys have learned compassion for differences, patience, unconditional love and acceptance. They are great kids and we are very proud of them.

Dave and I work as a team with the kids. When you have a large family, it is imperative to have the support of your spouse. We share the work, and we have learned to take time for us as a couple as well as time off for each of us individually. We have found a good balance, and that is what it takes to be successful with what we do.

We also love what we do. For both of us, it's all about the kids and not just our kids. Dave runs our local Youth Football league and often jokes that from August to November every year he is parent to 175+ kids! He also coaches the first-year kids and is little more than a big kid himself on the field! I help out with football by doing the books for the league and by running the concession stand. You may think it crazy that being the mother of three with PWS I would run the concession stand, but what better way to stay in control of the food issues than to run the stand?

All seven of our kids are doing well. Our oldest is a freshman in high school this year, and Caroline will be entering pre-school in the fall. We have quite a spread. David is far from the morbidly obese, mentally retarded monster they told us he would be. He is 9 years old, in the third grade, learning how to read; he is a wiz at math and so smart! He is thin and happy and just an awesome kid. There continue to be ball games, school functions, doctor appointments, therapies, piano lessons, youth group meetings, etc.... Life is full, life is good.

Diane - continued from page 5

for 6 years as executive director of the Siesta Key Chamber of Commerce. In August of 2001 she and her partner bought an auto body shop that rehabbed trucks and cars to be sent to the Middle East and Latin American countries. Really bad timing — 9/11 sank their fledgling business, and in March 2002 she came to work for PWSA(USA).

Diane says, "I love being at PWSA(USA), especially the telephone friendships that develop. I love working as Chapter liaison and on the Parent Mentor program with my two wonderful mentors, Lota and Carolyn. I am the triage e-mail person. Problems I can't handle get sent upstairs to

The Parent Mentoring II Program



Vicki Knopf

The Parent Mentoring II Program (PM II) is modeled after the Young Parent Mentoring Program (PMP) for parents of newly diagnosed infants and very young children, initiated and led by Carolyn Loker. The PM II, headed by Vickie Knopf, offers free educational materials, free membership and support to parents of children with PWS diagnosed

after the second phase of the syndrome has set in, usually between 2-5 years old.

Started in 2002, the PM II offers support to parents of children with PWS who have had a diagnosis for some time but are experiencing behavior, food, and/or weight issues for the first time and need help with coping skills, or handling school-related issues.

Upon referral from National, Vicki contacts the family to find out more of their needs, then she may refer them to a mentor family or handle the call herself. Many of these families, she says, just need guidance and some reassurance that they aren't alone.

Vickie is President of the Connecticut Chapter, serves on the PWSA(USA) Chapter Presidents Day Committee and Publications Committee. She has lobbied in Connecticut for Birth to Three services and testified twice before the State Appropriations Committee on behalf of Birth to Three.

A plaque that hangs in my dining room says "Where there is room in the heart, there is always room in the house." You just never know what tomorrow will bring.

Vicki and David Knopf live with their seven children in Salem, Connecticut.

David or Janalee. I am a treasure trove of trivia after answering and researching some 40-60 e-mails a day!

"I handle most printed media (except the newsletter) published in and out of house. I am proudest of our cookbook and have two new publications I am helping work on to be published this summer.

"I coordinate the Valentine Research Fund project, and the Conference grant applications. I am doing my first conference awareness booth for PWSA(USA) in April for the Pediatric Endocrinologists Nurses Society in Las Vegas. I did many conferences when I worked for Databroker (real

Diane continued on page 13

The Sibling View

Attitude Adjustment

By Diane Spencer, Support Coordinator

In March of 2003, a mother called me for information regarding the Orlando conference. She explained that she had three daughters and they were not getting along. Well, hey, what's so unusual about that?

It seems that two of the sisters were being especially unfeeling toward their youngest sister, who has PWS. The mother said they had tried everything and the girls just wouldn't cooperate. Everyone hated everyone else, no solutions were working... home was not a happy place to be. Mother wanted to know if I thought the conference could help this situation. I suggested they give it a try.

After the conference, mom wrote me a lovely note telling me how much the family had gotten out of the conference. Megan especially had a change in attitude, and Lindsay, well she was 16 years old after all. Six months later Lori, their mother, wrote to me about a wonderful essay Lindsay had done for her college entrance application. It speaks for itself. And now, Lindsay is doing a video documentary for a senior project: "What is it like to live in a family where someone has Prader-Willi syndrome?" I, for one, will be eager to see the video, how about you?

Lindsay Reddinger's essay...

Be Positive, Tolerate Differences, Admire Courage

No one has ever asked me to identify one person who has influenced my life until now! The person who has had the most influence on my life is a 13 year old named Chelsea. She is my youngest sister and she was born with a rare disorder called Prader-Willi syndrome. PWS affects 1 out of 15,000 births in the United States. It's caused by a defect in chromosome 15.

The syndrome is very rare and has not been researched very thoroughly, but the bottom line is, there's no cure! Living with my sister has taught me to be less judgmental, positive, and also has taught me the real meaning of courage.

Chelsea happened to be that very special 1 out of 15,000 chosen to carry such a burden; nevertheless she has proved that she is no different than anyone else. As she's growing older, it's heart wrenching to watch her come to the realization of the meaning behind the stares and whispers from her peers. Needless to say, it has not slowed her down. Sadly, there may be some things that Chelsea may never be able to do... and this can be difficult to accept. But this is what makes Chelsea so special — no matter the situation or circumstance, she's always smiling. Her positive outlook on her unfortunate situation is such an admirable trait and has taught me that life doesn't always go the way I planned. She has showed me there's a reason for everything and as long as I stay positive, I can surpass any of life's obstacles. Without this important lesson, I would have never gotten through the ups and downs of growing up.

Secondly, Chelsea has taught me about the way society passes judgment on people who they view as "different." I feel the society we live in is very judgmental. If they see a person who looks or sounds differently, they automatically pass a judgment, whether they think of them as stupid or

sometimes retarded. But the thing people tend to forget is, these people have feelings and they are just as easily hurt. We are taught not to judge a book by its cover, but yet the majority of our society never seems to remember what they were taught. Although Chelsea looks different, speaks differently, and is mentally different, she is still a person with feelings and a big heart. All Chelsea or anyone like her desire is the feeling of belonging, but by treating them differently they feel different. It's hard enough knowing you're not the same, but having to be constantly reminded makes it so much harder to find that sense of belonging.

Perhaps the greatest lesson Chelsea has taught me is about courage. I could never imagine having to wake up every morning and face the challenges she faces; yet you would never know she's struggling. She can enter a room and change the opinions of everyone with just her smile. She's never afraid to speak with someone she's never met, she's far from shy, and most importantly she's a joy to be around. Smart, funny, and caring are just a few words to describe her, she is truly remarkable. Her courage is something that cannot be put into words, but some how, I have done it.

These lessons are the number one reason I'm proud to say she's my sister. From the day she was born I knew she was special, I just never understood why until now! I thank God every day, because I'm truly blessed to have someone so special in my life.

The Reddinger sisters, Megan, 15,
Chelsea, 13, who has PWS,
and Lindsay, now 17,
live in Annville, Pa.



We welcome writings from siblings and family members for *The Sibling View*. Send to the PWSA(USA), Attention Lota Mitchell, Assoc. Ed., or e-mail at ljeholms@juno.com.

View From The Home Front

Let Santa Help Raise PWSA Funds

By Bill Vucci

Yesterday was a success with the neighborhood! Santa came for a surprise visit and brought all the families together in our neighbors' basement, which was all set up for a video and photo session. It's a blessing to have good neighbors like Joy and Steve Sharp, who did most of this on their own out of the goodness of their hearts.

Upstairs, we had punch, cookies, cakes, fruit drinks, and the like. At the front door was Maria's large poster board to greet guests as they entered, which describes what PWS is and how PWSA(USA) helps our children.

On a table were brochures and packets of information to educate our neighbors and tell how our Association helps children with this syndrome. Also available were Angel Fund envelopes for neighbors to send with donations in honor of Maria Christine Vucci.

Anne and I greeted new neighbors we'd never met before, as well as immediate neighbors we've known. Both of us were busy introducing people to Maria and her older sister Angela and meeting their children. It was a great way to meet people in a large development you would not normally get a chance to see. After the introductions, we began mingling with our neighbors describing what PWS was and how PWSA(USA) helps in medical research and development, crisis intervention and education.

All the children went downstairs in the finished basement rec room to play while the adults chatted upstairs. Then all of us went downstairs to see Santa magically arrive through the back door to meet and hug the children.

Santa picked up Maria and introduced her, announcing to all that Santa makes certain special trips during the holidays and this trip was in honor of this very special girl named Maria Christine Vucci, who has Prader-Willi syndrome. Santa sat down with Maria on his lap and said "I want this very special girl to see you all, and I want photos with each and every one of you on my lap."

The Vucci girls, Angela and Maria, who has PWS, with Santa



The first to talk with Santa about Christmas was Maria and then Angela.

This is an original idea which I think could have a lot of potential around the country during the holiday season and even at other holidays throughout the year. It's a way for families having a child with PWS to meet other families in a neighborhood to introduce them and share what PWS is all about. The awareness alone is the most important part, but having educational brochures helps, too. As for fund raising, this is really not focused on having neighbors donate, but does give them the opportunity to do so by having envelopes available for them to take with their brochures.

Consider this idea also. All around the country every mall has a Santa photo area, where people pay money in cash for their children's photo with Santa. I think a great fund-raising strategy would be for PWS members to ask mall managers to hold these Santa photo sessions, with a portion of the profits to be given to PWSA(USA). I believe many mall managers would be open to this idea to support our cause in saving our children's lives.

Bill and Anne live with daughters Maria Christine and Angela in Brookeville, Md.

Diane - continued from page 11

estate State conferences), so I feel like I am getting back in the harness."

As liaison contact for the Chapters and Affiliates, Diane is the person who keeps all their records in order — no small task — and bugs the officers for their annual documentation, all the time worrying about being as tactful as possible. All that background experience comes into play, but with the warmth and caring that is part of her personality.

For many years she has kept a "spill" book in which she records her thoughts and feelings at least every year on her birthday. One of her favorite entries is this: "Life is about not knowing, having to change, taking the moment and making the best of it without knowing what's going to happen next."

Shop & Share Benefits PWSA

In Illinois, we have a program available to us called Shop & Share through Jewel/Albertson's Grocery Store. The store provided me with vouchers that could be used on certain dates and I distributed them. For every voucher turned into the cashier at the checkout, 5% of the total order would go to our association — an easy way to raise money without anyone having to spend any extra money.

Unfortunately, when I received the vouchers, it was a trying time in my home and I did not get them all distributed, but still we generated \$114.75. I plan on trying this again in the summer and getting it out to more people.

Due to our own personal financial situation, we are not able to make donations very often, so I feel a need to find other ways to support the association.

Thank you all, for all your help and support.

Angela Krambeer Crystal Lake, IL

We Remember...

Richard (Dick) Wett, M.D.

From Gene Deterling, one of the founders of PWSA(USA)

We are saddened to report the passing of one of our long time organizational friends and members, Richard (Dick) Wett, M.D. Dick died March 8, 2004 in Minneapolis after a brief illness following a heart attack on December 29.

Dick was a former chairman of the Board of Directors of PWSA(USA). He became a member in 1977 during our formative years along with his wife Marge, our first executive director, and contributed significantly in the perpetuation of our organization. Lisa, one of his seven children, has PWS. Another daughter, Tere, served as PWSA executive director in 1992 and 1993.

In addition to serving as a Board member from 1978 to 1990, he chaired the board for the longest period of any to date. Dick was also active in the founding of Oakwood Residence, one of the first group homes dedicated to people with PWS, and served on their Board of Directors as a member for more than 10 years, during a part of which he chaired the Board. In addition, he was active in the formation and perpetuation of the Minnesota PWSA chapter.

Dick was a physician specializing in anesthesiology and was part of the Medical Anesthesia, Ltd. group in Minnesota until his retirement in 1992.

PWSA has lost a great friend and contributor to where we are now as an organization. We extend our sincerest sympathies to all of the Wett family.

From Janalee Heinemann, executive director, PWSA(USA)

I have been involved with PWSA(USA) for 23 years in various capacities, and am very proud of what an ethical organization this is and how much it does to support families and research. Much of the thanks and admiration goes to Dick and Marge Wett, who along with the Deterlings, were the rock this foundation was built on. Probably few people besides my husband Al and I, who

Tragic Loss To Our Board Member

In March, Mark Ryan, PWSA (USA) board member from Newhall, California, lost his mother and brother-in-law in a house fire during a robbery.

Mark's sister Mary, who has subsequently moved in with Mark and Linda and their family, is trying to cope with losing her husband, her mother, her home, all of her possessions, and her livelihood (their business was in their home.)

Mark states that their son Trevor, 14, who has PWS, has been very sensitive to Mary's needs and will say things such as, "Aunt Mary, I think you need a hug today."

A big hug from PWS families around the world and our most heartfelt prayers go out to Mary, Mark and their families.

— Janalee Heinemann

followed in Marge and Dick's footsteps, can appreciate how much they gave of their lives to make this happen.

We now serve more than 3,000 members and three times that many non-member professionals who are support people to the families. We have a crisis program, new parent mentoring program, chapter support program, bereavement program, medical support program, and are starting a teacher mentoring program. We also support people from more than 30 nations and have created more educational materials on PWS than any other entity in the world — which we freely share with the rest of the PWS world.

None of this would have happened if the Wett family had not devoted years of their lives in the initial phase of the organization. Marge was the first executive director for PWSA (USA) and Dick was the first Board chair. The first office was in their home. We will be forever indebted to them and the love they have shown for all children with Prader-Willi syndrome through their devotion.

From Lota Mitchell, president, PWSA(USA)

When I attended my first conference (the second national one), Dick Wett asked me if I would run for the Board. I had written a paper on PWS for a class in graduate school and sent it to the fledgling organization, which then had no publications but a newsletter. The paper became *The Overview*, and Dick's invitation was the beginning of my long-time involvement in PWSA(USA). I firmly believe that without the time, talents and treasure contributed so generously by Dick and Marge, the organization might not exist today.



Richard (Dick) Wett, M.D.

PWSA(USA)'s bereavement follow-up program is coordinated by Volunteer Norma Rupe. We have articles that we send to our members free of charge, along with envelopes for memorial contributions. For more information about these and other materials, contact the PWSA(USA) National Office.

Angel Fund

Angel (\$100-\$249)

Devine Family *Honor-Victoria*
 Mike & Audrey Dickey *Honor-Jace Coltrane*
 David & Sharon Doherty
 William & Gloria Doherty
 Donald & Michelle Dulevich *Honor-Leslie Torbert*
 Michael & Susan Evans
 Debbie & Michael Fabio
 Dan & Sue Falk
 Alan & Deborah Feldman
 Gary Ferdig
 Barry & Sara Formslag
 Franklin Foster *Honor-Ashley Fender*
 Maryanne & Edmund Funai
 Norman Gerou
 Pres On Products, Inc. *Honor-Lea Capraro*
 Jerome & Carol Gloekler
 Valerie & James Grabicki
 Jon & Tasha Graham
 Lisa & TJ Graziano
 Wendy & William Grey
 Daniel & Nancy Gulling
 Joan Hadsall
 Erich & Pauline Haller
 Lee & Jack Hancock
 Laurie & Ron Hanson
 Jo & Floyd Hatcher
 Thomas & Barbara Haverfield
 Ozmer L. Henry Jr. *Honor-Mr. & Mrs. Everett Henry*
 Lonnie & Judy Hicks
 Angela Hill
 Jennifer Hill
 Willie Hinson
 Michael & Karen Hipskind
 Donald & Patricia Horrigan
 Susan J. Houff
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 Ann Murphy Hunt
 J & K Auto Parts & Salvage
 Donna & Mike Jallick *Honor-Jack Martin Bevacqua*
 Mary Lou & Otis James *Memory-Louis Jay Ribes*
 David & Phyllis Jeffery *Honor-Peter Frazin*
 Karen & Timothy Jobe
 Elaine & Stanley Katz
 Sean & Patricia Keating *Honor-Brennen Keating*
 David & Tammy Kenney *Honor-Julia Kenney*
 Kevin A. & Julia Kipka
 William Klein, Sr.
 Mark Krinsky
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 George & Lee Ann Kuntz
 Mary L. Lagana
 Nelson & Hope Leonard
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 Monroe & Constance Levy
 Sharon Lewis
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 Larry & Robin Lovelace
 J. Mark & Linda Lozier
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 Patrice & Charles McCleary
 Bernice & James McKean
 Barbara & Michael McManus
 Eugene & Jean Alice Metzger
 John and Margaret Miller, IV
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 Bob & Cathy Mook
 John Mook & Family
 Dennis & Darlene Mull
 Sal Nicrone
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 Eric & Tammy Stratton
 Kathy Stroup & Family
 Rick & Jonna Svabek
 John & Carol Talanian
 Tara Materials, Inc.
 Jean Till
 Guy & Lorryn Tomicchio

Heather & Richard Valeo *Honor-Isabella Valeo*
 John & Wendy Van Elk
 Ventnor/Margate Lioness Lion Club
Memory-Claudia Pasco
 Don & Betty Vincent *Honor-Abbey Seelig*
 John I. Vucci Santa Awareness
 Proj.-*Honor-Maria Christine Vucci*
 William & Anne Vucci
 Anne Warchol
 Lenora R. Watson
 Eleanor & Richard Weiner
 Charles Welch
 Wayne & Karen Wendel *Honor-Ashley Fender*
 Richard & Marge Wett
 Laura & Dan White
 Karin & Rick Willson
 Richard & Denise Wolcott
 Elsa Woods

Cherub (Up to \$99)

Donald & Glenda Grimm *Honor-Jacob Soncarty*
 Leslie & Laurence Hall
 Mark & Sharon Hall
 Roger & Mary Hanke
 Matthew & Claire Hanrahan
 Claire & John Harrington
 Linda Hartigan
 Anne R. Hartley
 Karen T. Haug
 John & Sue Heybach
 Jan Hsien-Chenge Ho
 Charles & Barbara Johnson
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 John & Susan Lachance
 Evelyn Lamm
 Theresa & Harold Lauer
 Shawn & Amy Lemmons *Honor-Brock James Lemmons*
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 Victor & Vivian Marcovici
 Lawrence Mattson
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 Jim & Carol McIvain
 Marian Melenbrink *Honor-Donald Crawford*
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 Ileen Morris
 Cathleen Morrison
 Regina R. Murphy
 Rita & Bill Needel
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 Elizabeth Prochazka
 Samuel & Barbara Rader
 Warren & Dorothy Ramsdell
 Robert & Lisa Ranieri
 Delores Rica *Memory-Gary Rica*
 Linda Rollings
 Marc & Elyse Russman
 Troy E. Shingleton
 Laverne Sidlo
 Marilou Singson
 Shirley Small
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Rosemary Vayda
 Carl & Patricia Walker
 Adele Weinberg
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 George & Mary Kay Brice
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 Deborah & Michael Capraro
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Prader-Willi syndrome (PWS) is a birth defect first identified in 1956 by Swiss doctors A. Prader, H. Willi, and A. Labhart. There are no known reasons for the genetic accident that causes this lifelong condition, which affects appetite, growth, metabolism, cognitive functioning and behavior. The Prader-Willi Syndrome Association (USA) was organized in 1975 to provide a resource for education and information about PWS and support for families and caregivers. PWSA (USA) is supported solely by memberships and tax-deductible contributions.

