



The *Gathered View*

April 1997
Volume XXII, Number 2

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

Come join us for ...

"Life Under the Palms"

The 19th Annual National PWSA Conference

July 17-19, 1997, Orlando, Florida

July 16 — Scientific, Service Providers Meetings



The PWSA conference in Orlando promises to be one of our best ever. The Florida chapter sends us the following highlights and urges members to register early!

Conference Sessions/ Speakers

Program highlights include:

- Keynote speaker, the Rev. Don Roberts, CEO of Goodwill Industries and a national speaker, presenting "Standing Tall—Moving Beyond a Disability"
- "Latest Findings on Obesity," presented by Dr. Dan Driscoll

Other topics to be explored:

A Humorous Look at the Impact of
Diet on the Family
Grief Issues
Positive Aspects/Acceptance
Overview of the Syndrome
Nutrition
Dental Issues
Dealing with Behavior Issues
Psychotropic Medication

Growth Hormone
Education—Inclusion
Sibling Issues
Sexuality
Employment
Living Alternatives
Legal Issues
Legislation
Reflections on Attending a First
Conference ... and more!!!

Youth & Adult Activity Program (YAAP) Update

Welcome news came with PWSA (USA) board of directors approval to fund a professional nonprofit organization, K.I.D.S. By The Sea, to help our parent volunteer coordinator, Debbie Stallings, organize and run the YAAP program. This organization has many years of experience in programming for large groups of children with disabilities, including experience with PWS. A day at Sea World, a carnival, the traditional banquet with a unique DJ for the dance, a Popeye-impersonator bingo caller, and many more fun experiences

await all of our young people attending—siblings included. Siblings and adults with PWS will travel in their own groups for the activities program and will have scheduled times for discussion and peer support.

There will be something for everyone, including a steel drum band at the adult banquet and an optional family event, "Arabian Nights," voted the No. 1 dinner show in Orlando.



Come join us at the Sheraton World Resort. Make your reservation now (rooms are limited) to obtain our special conference rate of only \$75 per night. Make sure you say you are with the PWSA conference.

**Call 1-800-327-0363 (outside
Florida) or 1-800-341-4292 (within
Florida).**

*Look for your conference
registration packet coming
soon in the mail!*

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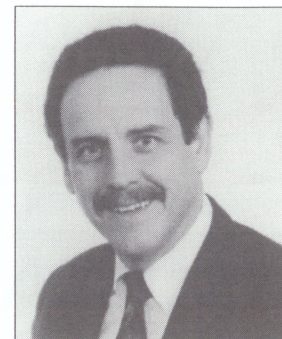
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Out of the Office

by Russ Myler, Executive Director



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Since I have been with the Association, this topic has been one of the most volatile for parents and service providers alike. There are strong opinions on both sides. I think both sides are right. (How's that for a position?)

I found a quote attributed to Dr. Suzanne B. Cassidy in an office file the other day I think should be shared here:

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In my 30 years of working with people I've learned that choices made by one person for another can be enforced in only two ways: coercion or cooperation. Parents or care providers may think they have made their "decision" stick because the other person is willing to cooperate and go along. When our children are small enough, we can enforce our will with the use of coercion ("GO TO YOUR ROOM"), but kids get bigger! The truth is that decisions are made in a relationship. Relationship calls for discussion, sharing, caring, learning about the other, and compromise.

My hope is that our exploring this topic will lead us all further along in gaining the cooperation of one another in a relationship of loving care.

See pages 4 to 9 for articles on the issue of choice and control in the lives of people with Prader-Willi syndrome.

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Opinions expressed in *The Gathered View* are those of the authors or editors and do not necessarily reflect the views of the officers and board of directors of PWSA (USA). *The Gathered View* welcomes articles, letters, personal stories and photographs, and news of interest to those concerned with Prader-Willi syndrome.

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Raising Awareness of the Latest On Genetic Testing for PWS

From the calls we get in our national and chapter offices, and the information we read in other publications, it's clear there is still a great lack of understanding about testing for Prader-Willi syndrome. In all fairness, it's an extremely complicated issue and an area of new developments. To update our members, we share here some recent communications from our Scientific Advisors.

In the February issue of *Exceptional Parent*, a monthly magazine for families of children with disabilities, a full page was devoted to Prader-Willi syndrome in the magazine's "Ask the Doctor" column. The doctor's response to parents of a 10-year-old boy who was clinically diagnosed with PWS offered sound advice regarding the need for controlled diet, behavior management, and exercise, but was not current on the issue of testing.

The article said: "It probably is not necessary to get the chromosome testing if your son has most of the PWS features. Test results are not 100-percent conclusive. In a substantial number of instances, it is possible to have PWS with a negative chromosome test." While this may be true for high resolution chromosome testing, new tests are now available and should have been discussed.

Dr. Suzanne Cassidy, our Scientific Advisory Board chair, has written to update *EP's* scientific editors on the latest in testing for PWS. Following are excerpts from her letter:

"... the cause of Prader-Willi syndrome is now known to be the absence of normally active genetic material on the long arm of chromosome 15. It is always lack of the active DNA that should have been contributed by the father (the mother's copy of this genetic information is normally inactive) that causes Prader-Willi syndrome, and this absence may occur in three different ways. [The three ways are: a deletion on the paternal chromosome 15, a mutation on the paternal chromosome 15, and maternal uniparental disomy—i.e., both chromosome 15s from the mother and none from the father.] Also, accurate diagnostic testing

for all affected individuals with Prader-Willi syndrome is now available. The methodology is somewhat unique and does not usually involve chromosome analysis anymore. ...

"While ... chromosome analysis will only detect a proportion of patients with Prader-Willi syndrome, the newer molecular tests to identify the presence of a deletion (*fluorescence in situ hybridization*, or *FISH*) or uniparental disomy 15 (*polymerase chain reaction*, or *PCR*) will together identify about 99 percent of cases. [Editor's note: Uniparental disomy 15 is the cause of PWS in about 30 percent of the cases. When the PCR test is used to detect maternal disomy, blood samples from the affected person and both parents are usually required for the highest degree of accuracy.]

"*Methylation analysis*, which determines the parent of origin of chromosome 15q (which is always maternal in Prader-Willi syndrome) will detect virtually all cases of the disorder and costs about half that of a chromosome analysis. However, it is not available everywhere."

Dr. Cassidy recommends that "those who had chromosome analysis in the past [regardless of the results] should have the newer, more accurate testing done, both for management and for family planning purposes, since some causes can recur in a family, and prenatal diagnosis is available."

The bottom line: It is both possible and important to confirm the diagnosis of PWS through genetic testing and to find out whether your family carries an increased risk of recurrence (see box).

More on the Inherited Form of PWS

In the August 1996 issue of *The Gathered View*, we reported the findings of Dr. Robert Nicholls and colleagues concerning rare cases of PWS (about 2 percent or less of all cases) caused by an imprinting mutation on an apparently intact paternal chromosome 15, rather than a deletion or uniparental disomy.

A PWSA member wrote to us expressing concern about this transmittable form of PWS and asked whether siblings of a child with PWS should be tested to find out if they are carriers of such a mutation. Dr. Nicholls responds:

"Any family who has their child diagnosed with an imprinting mutation should seek professional advice from their genetic counselor and pediatrician, and if these are unfamiliar with the latest research, they should be referred to a center such as ours [at Case Western Reserve University] that works with imprinting mutations and the latest research. ...

"With imprinting mutations, about half the patients (families) have a very small deletion in the region we refer to as the imprinting center (IC). The other half of the patients have no deletion, although this has just been referred to in passing in the literature. The imprinting center regulates the setting of imprints in the male and female germline, and it controls this for all imprinted genes in chromosome 15q11-q13. Thus PWS imprinting mutation patients, with either the tiny deletion or no deletion, have inactive paternally inherited imprinted genes. The half of these patients with a tiny deletion (referred to as a microdeletion in our published papers) [differ from] the typical deletion group, because the latter patients have a very large deletion that includes not only imprinted genes, but the Angelman syndrome gene and nonimprinted genes. For those families with an imprinting mutation which has a tiny deletion, we can offer 'at risk' testing and when necessary, prenatal testing."

Dr. Nicholls also notes that some of these mutations are not inherited but "arise as new mutations in the father's germline." He stresses that mutations are "no one's fault"; their cause is unknown.

The Ultimate Choice and Loss

by Betsy McCool, Poway, California

My son, Stephen, died last January [1996], and I would like to share his story. Stephen was diagnosed at birth, in 1976, with PWS. However, the diagnosis ended there with no education on what to expect or how to prepare. The main concern at the time was to put weight on him. Yes, on! A year after his birth we moved, and the doctor in the new location had not heard of PWS and gave us little help. In 1980, while living in Puerto Rico, a friend gave us an article on PWS from a California newspaper and asked if this was what Stephen had. It was the correct name, but the information included in the article was somewhat disturbing. It did mention the PWSA, and we got information from there. It was disheartening to say the least. How could we do this? Was there a choice?

Parenting a child with PWS presents quite a set of challenges. Parenting a child with PWS who is high-functioning and very highly motivated brings an additional package of challenges—some difficult to meet. Stephen began school in a “regular” kindergarten class. Speech therapy began then and continued until middle school when he refused to take it anymore. He stayed mainstreamed through high school, though he did have special education support in the form of a teacher who acted as a liaison when needed, or when he needed to take a test in a separate location, or when he just needed a friend. We had IEPs every year for 13 years, and in his last two years of high school, Stephen conducted his own and I was invited to attend. He graduated with a B average.

There were surgeries—the spinal fusion at age 6 when one of the staple holes scabbed and he managed to work it into a monumental and gaping wound. This was resutured twice and his picking hand/arm was put in a cast twice to allow healing. It

took four years to master that one!

There were the four years of Pro-tropin [growth hormone] injections that did increase his height and helped him come closer to “being like everyone else.”

There was the divorce of his parents when he was 12 that put him on Prozac for a short time. He was on it again his senior year in high school to help him with his obsessive-compulsive behaviors and make life more workable for him and those around him. I might note that it worked very well for him and almost immediately.

There were all the worries and heartaches over a child with no “after school” friends. Lots of friends at school, but no phone calls at home. Teachers loved his ability to stay on task, and his determination allowed him to do so. Teachers and adults were favored as friends for him.

And of course there were the phone calls from school about handling any given situation. “How do we ... ? What do we ... ?” When do we ... ?” Some answers were easy; most were not. Many times there was no answer at all for we were charting new territory, alone. One gets tired of saying “I don’t know,” but that was the answer more times than not. As Stephen got older, it became the answer of choice. Then there were the calls saying, “You need to do something about this.” As if I wouldn’t if I could. And of course, there was the well-intended advice from others. Most of it not even close to the mark. “Well, if he were my child ...,” “Have you tried ... ?” “If you’d only ...” Well intended, but painful. They missed the point that I would do anything to help this child, but there were few answers. Hardest of all

was a family that never really understood. Some treated him as if he were retarded. He was not. Some did not feel comfortable around him. It was known. Some were inconvenienced when he was around because of the care they had to take with food. Some were embarrassed to be seen in public with him as he got older and larger. The pain of feeling a child be rejected by his own relatives is almost too much to bear ...

As I mentioned, Stephen graduated from high school with a 3.0 GPA, and he wanted to go to college and become a veterinarian (animals were always his best friends). He not only wanted to go to college, but to go away to college. Well no,

this could not happen. It was a ridiculous idea. He was determined and took tests and made applications. I was still hesitant. No, let’s be honest, I was totally opposed to this idea, but Stephen was 19 and I had no conservatorships. None. And stood no chance whatsoever of getting any—I

had checked. Life was not pleasant for a time as we argued. Then I remembered an article I read in *The Gathered View* about a father who let his son determine how he wanted to live his life and realized that was what I need to do. Was it easy? Not for a minute. Was it right? Absolutely! Stephen got what he had always wanted—a chance to be like everyone else.

So he went off to a small junior college and experienced life on his own. I would love to say it worked out well, but it did not. Academically he did well. Socially not so well, but there were a few good friends. Dietarily less successful, even with help. He came home for Christmas, and we had one of the best ones ever. He insisted on going back to school, so he did. Eighteen days later he went to bed and died in his sleep. No warning.



Community Mapping: Promoting Community Participation, Contributions

by Mary Ziccardi,
Regional Program Director
REM-Consulting of Ohio, Inc.

In 1992, the Cuyahoga County Board of Mental Retardation and Developmental Disabilities made a commitment to residentially support individuals with Prader-Willi syndrome. REM-Consulting of Ohio, Inc., was chosen as the service provider.

The first home for five people opened in November 1994, followed by a second home to support four individuals in September 1995. Consistent in both homes is the belief in and implementation of sound clinical models, which result in meeting individual needs while promoting independence and offering choices.

The cornerstone of a successful program is a well-trained and empowered staff who implement programming with consistency, yet offer and encourage individuality and choice-making.

Even though people who happen to have PWS must have many choices re-

stricted regarding food, a great number of opportunities are still available that promote independence and self-expression. The staff and supervisors in the programs in Cuyahoga County focus on a person-centered approach. This is, in part, accomplished through community mapping, a person-centered planning process, where the individual, and all those people important to him/her, meet in a relaxed atmosphere to actively plan and explore the path to helping the person in achieving his/her goals and dreams. Our role is to pave the way for the person we support to lead the richest and fullest life possible, focusing on the gifts and capacities of the individual.

A function of the person-centered approach is to assist the individuals to participate in their communities through pursuit of activities that are meaningful to them. This planning process can help guide all of us in helping the individuals to find meaningful connections in their

communities. Some of the individuals here have made significant contributions to their communities. For example, one of the young women belongs to the choir at her church, while another lady has joined a new church and regularly acolytes in Sunday morning services. Similarly, one person volunteers at the children's museum, while another man loves to attend community theater events. All of these activities are chosen by the individuals and supported by the staff.

Another area in which choice is supported is regarding the person's health care. Being able to choose community-based physicians promotes individuality and dignity. Individuals' preference for appointment times are discussed with them, and reminder cards or a calendar help them remember previous commitments, and avoid a "surprise" appointment. Opportunities are also made for as much control as possible about medication administration. With supervision, the individuals participate in self-medication programs, and in some cases, initial that they have indeed ingested the medication or completed the treatment. Lastly, the programs' nurse has made a commitment to teaching and certifying each individual in basic first aid and CPR.

Evidence of the success of the programs in Cuyahoga County is in the independence, increased self-esteem, improved health, and community contributions that have been made by the individuals receiving supports. Accomplishments, both large and small, are celebrated and shared. Poor choices and less than ideal days are quickly forgotten, and positive choices and achievements are consistently encouraged. The people who live in these homes have proved that the manifestation of a people-first and value-based philosophy are independent, caring, contributing members of our society. ▲

Loss—Continued from page 4

The legacy he left in memories is amazing—indomitable spirit, faced adversity head-on, tenacity, courage, faithfulness, diligence, willing to help, and on and on. He experienced life to its fullest (more so than some who are not handicapped)—running for student body office (he never won), homecoming dance, senior prom, voting for the first time (he actually read all the information he received so he would be prepared to cast his vote), becoming an Eagle Scout. In the college newspaper they quoted him as saying, "Hurry up! I'm growing old back here" while in the lunch line. He packed as much into his life as he possibly could.

He is gone now, but thought of often. We just celebrated the first Christmas without him and recalled his enthusiasm for the season and the care he put into each gift. There will be many memories both good and bad, but as time goes on the good will outweigh the bad, and our "Stephen" memories will inevitably produce more chuckles than tears.

Was it difficult being Stephen's mom? You bet it was! Are there things I wish I had done differently? Of course. But giving him the chance to fulfill his dream is not one of them. ▲

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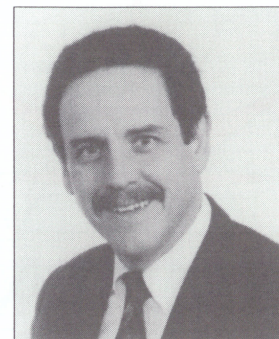
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by Russ Myler, Executive Director



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February 1997
Volume XXII, Number 1

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

1997 Calendar

April 30

National Prader-Willi Syndrome Awareness Day, with activities throughout the week of April 27–May 3

May 2–3

Fifth Joint Conference of PWSA of New England and the Prader-Willi Alliance of New York, Crowne Plaza Hotel, Natick, Mass. Keynote speaker: Merlin Butler, M.D.; sessions on sensory integration, wills and estates, nutrition and weight reduction, and a fitness program for people with PWS. Call 1-508-238-7825

July 16–19

19th Annual PWSA (USA) Family Conference and 12th Scientific Day on PWS, Orlando, Fla. This year's theme: "Life Under the Palms." See pages 3–5 for conference information.

October 16–18

Third Annual Prader-Willi Syndrome Service Providers Conference, Nashville, Tenn. Speakers: Merlin Butler, M.D., Ph.D., Ivy Boyle, M.D., and others. Call 1-800-358-0682.

Note: The 18th Annual International Conference on MR/DD, March 17–21 in New York, features on March 17 a presentation by Patricia Bruno: "Obesity and Behavior Management: A Specialty Service Model for Adults with PWS." Call 212-563-7474, ext. 140.

President's Message

by Jerry Park

Quality of Life

The new year began, and with it a renewed interest in the planning aspect in each of our lives. Each of us as Prader-Willi parents views our child or adult "growing up" in a different light and with very different concerns. The parents of young children quickly move from feeding problems to dietary control; as our children age, IEPs, proper schooling, and behavior management are high on our lists.

When the person attains adulthood, the next obvious decision is the proper professional caregiver or a group home arrangement. The transition is dramatic from total dependency on us to "independent" living. It's a difficult transition from always assuming the person will be "joined at the hip" to having someone else care for and manage your child, possibly better than you can. Our homes are usually not a controlled environment, and with the best of circumstances our children with PWS will take advantage of us.

Whit, our 13-year-old son, has been in the Rehabilitation Institute of Pittsburgh and during his stay has lost 65 pounds, regained his self-image, and has a much better perspective on life. The separation has been emotionally difficult, especially during the holidays, but the

"quality of life" Whit has achieved through the wonderful caregivers of the Rehab Institute has been immeasurable.

The changes we have to make for our children are still our parental responsibility and always will be. The "freedom of choice" issue now being debated, and which we each will face, I feel does not apply to our loved ones with Prader-Willi. Whit, six months ago, did not care how much he ate or gained before entering the Rehab. He now is proud of what

he has accomplished. We as parents can establish the parameters and let our children have success and failures as any normal child would experience. The responsibility as parents is determining what degree of "quality of life" we so choose for our child.

The improvement of life for our children has been the cornerstone of **Awareness Day**. It gives all of us the renewed hope that today we can make a difference. We cannot count on the provisions we may leave or that governmental assistance will be adequate for the security and safe keeping of our children. We must decide that today is vitally important for Prader-Willi syndrome, and every year Awareness Day should be just that—a reason we become more aware of the future and what we can do about it today.

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honor of their granddaughter
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