



# The Gathered View

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

Dr. Suzanne Cassidy was recognized for her service to PWSA. Her award: a PWSA baseball jacket, which she promptly donned.



## The Spirit of St. Louis

The largest PWSA (USA) convention of our 18-year history convinces us it is the cornerstone of the organization. It proves not only to parents but also to professionals the need for interaction and support from those who are knowledgeable of and sympathetic to the Prader-Willi syndrome. We sincerely thank conference co-chairs Paula Kollarik and Jerri Evetts, conference secretary Judy O'Leary, Barbara Whitman and Bruce Scott, who coordinated the scientific and service providers' meetings, and the entire St. Louis team of volunteers for all the time and energy it took to put on this year's conference. Special gratitude to Jan Wallis and all the youth program volunteers, who spent four days with our special children in unforgiving situations. Possibly a monument at the base of the St. Louis Arch would be sufficient recognition for the job you've all done.

This conference achieved many milestones: size (nearly 900 registrants!), scope, participation of professionals and service providers, and—most important—first-time conference attendees. Our Association is growing through our own outreach efforts and the increased professional recognition of the syndrome. It is exciting, and we as parents all know the need! The success of the national organization ties in directly with our recent accomplishment in acquiring research funding. We all must realize this is a *long-term* goal of our organiza-

tion. The funding and successes through research require years and should make us ever more committed to PWSA (USA).

Seeing the commitment at the national level through the officers, board, the hosting St. Louis chapter and its volunteers gives us renewed energy in achieving new goals at the state level with the "Spirit of St. Louis."

—Jerry Park  
PWSA (USA) President



Board member Gail Overton pitches products (above). Election winners Pauline Parent, Fran Moss, Jim Kane, and Paul Alterman (right).



Leonard Hacker coaches chapter presidents on the art of lobbying (left). Executive Director Russ Myler and Ricky Lacy (right) were primed for the big dance on Friday night.



## inside

Association News .....	3
Latest Research on PWS .....	4
Social Relationships and Understanding:	
Early Findings in a Study of Children .....	6

Calendar of Events .....	8
Camphill: Josh's Success Story .....	9
Publications .....	10
"My Ragdoll Girl," a Poem .....	11



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## Out of the Office

by Russ Myler, Executive Director



I was able to pass on some wonderful news at the national conference in St. Louis. The news was important enough that I felt those of you not able to attend should hear it as well.

Last year, Leonard Hacker—Association member, grandfather of a person with the syndrome, and our Legislative Relations Committee chair—and I began looking into the availability of federal funds for PWS research. Leonard discovered through his Washington contacts that the National Institutes of Health funded \$776,000 worth of grants for PWS research in 1993, but that the budget for PWS research in 1994 and 1995 was 10 percent less. As we explored ways to boost that funding level, Leonard discovered H.R. 1010, a House of Representatives appropriations bill designating supplemental NIH funds for research on birth defects over a five-year period. The bill was created as a supplement to the Americans with Disabilities Act and was sponsored by a long list of organizations, headed by the March of Dimes Birth Defects Foundation and including the National Organization for Rare Disorders. This was clearly our vehicle!

Leonard arranged to have PWSA (USA) added to the bill's list of cosponsors, and \$2.5 million of the funding designated for PWS over the five-year period, in exchange for our assistance in getting the bill passed. In May of last year, President Clinton signed into law the Birth Defects Prevention Act of 1995, and in July of this year we can already savor the results of our effort. A private report from the Congressional Research Service reveals that NIH grants for PWS research in 1995 totaled \$1,628,599—more than double the \$700,000 originally allocated. Last year's grants went for nine projects at six institutions, including four projects at Vanderbilt University. We should expect similar funding through the remainder of the five-year period covered by the Act, and Leonard assures me that this is only the beginning.

Over the years, PWSA (USA) itself has distributed more than \$75,000 to fund research on Prader-Willi syndrome. These grants, while small, have supported important work that has benefited those with PWS and stimulated interest in the professional community. The fact that many of these projects have been published in professional journals gave us more credibility on Capitol Hill and at NIH. The projects we select for grants are those viewed by our parent-professional board of directors as most important for the future of persons with PWS. Our research priorities should serve as a guide for researchers regardless of their funding source.

Despite the increase in federal dollars, we continue to be approached for grants by researchers throughout the United States and Canada. Your support of PWSA's Research Fund is more important than ever in helping the Association lead the way.

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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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Communications regarding *The Gathered View* or PWSA membership should be directed to the national office of PWSA (USA), 2510 S. Brentwood Boulevard, Suite 220, St. Louis, MO 63144-2326. Telephone 1-800-926-4797, or (314) 962-7644 in the St. Louis area. Fax (314) 962-7869. E-mail: [pwsa\\_usa@aol.com](mailto:pwsa_usa@aol.com).



## Association News

### Elections, Staff Changes

• Incumbent board members **Paul Alterman**, **Jim Kane**, and **Pauline Parent** were reelected for three-year terms, and **Fran Moss**, administrator of the Prader-Willi California Foundation, was elected to fill the fourth seat on the PWSA (USA) board of directors.

• **Jim Kane** was elected by the new board to another one-year term as chairman of the board. **Bronnie Maurer**, president of the South Carolina chapter and wife of retiring board member **Stewart Maurer**, was appointed by the board in January to succeed **Viki Turner** and assumed the position of board secretary at the St. Louis meeting.

• **Terry Whitworth** replaced **Maureen Brown** as PWSA's office manager, effective May 1. Maureen worked as a full-time volunteer from May 1 through the end of the conference and will continue to pitch in until her family moves south.

### Board Actions

The PWSA board of directors' business meetings in St. Louis resulted in a number of actions, including:

- The week of April 27 through May 3, 1997, was established as the next national PWS Awareness Week.
- Board members approved Publication Committee proposals for new and revised PWSA brochures and new publications on

growth hormone and behavior management. They endorsed printing extra copies of the *GV* for member recruitment at the chapter level and agreed to publish a PWSA member cookbook.

• A draft policy statement on use of growth hormone in PWS was approved, and the board agreed to write a policy statement on food access for persons with PWS. (The growth hormone policy will appear in a future issue of the *GV*.)

• For ease of accounting, the board voted to reduce the number of separate funds to two—one for research grants, and one for all other programs and services of the Association.

### Chapter News

Two new chapters were recognized at the national conference in St. Louis. Congratulations to our members in:

• **Iowa**—Wanda Askelson, Chapter President, Rt. 6, Box 281, Decorah, IA 52101-9229, Tel.: 319-382-4106.

• **The Dakotas**—Becky Briggs, Chapter President, c/o Fraser, 711 S. University Drive, Fargo, ND 58103, Tel.: 701-232-3301

Chapter presidents met in St. Louis on Wednesday, July 17, in a full-day meeting chaired by PWSA President Jerry Park. Jerry urged chapters to continue striving for a strong national Awareness Week effort each year. Chapter leaders exchanged news and views and got a lesson in lobbying from our man in Washington, Leonard Hacker.

### Financial Notes

• PWSA (USA) reduced its deficit from \$56,693 in 1994 to \$5,953 in 1995. Treasurer Jim Gardner announced at the annual PWSA membership meeting in St. Louis. Sales of the hardback book, *Management of Prader-Willi Syndrome*, helped significantly last year, he noted. Although PWSA has struggled with a deficit for several years, 1996 may be a break-even year, depending on final conference costs. (See tables below for 1995 financial data.)

• The Association's 1995-96 Angel Fund drive was a tremendous success, bringing in some \$47,000—higher than in previous years.

• Conference sales of publications and merchandise produced \$21,000 revenue.

### In the Media

Doctors got exposed to PWS this summer via two pieces of free publicity:

• The July 15 issue of *Medical Economics* includes an article entitled, "Can you afford NOT to travel the Internet?" (p. 173). The featured example shows a search for information on Prader-Willi syndrome, turning up our PWSA Web page, and illustrates how easily one can locate the diagnostic criteria for PWS.

• An advertising brochure announcing the second edition of the *Physicians' Guide to Rare Diseases* shows a full page of information on Prader-Willi syndrome as an example of the information format used in the book.

#### PWSA (USA) CONDENSED BALANCE SHEET AS OF 12/31/95

##### ASSETS

Cash	\$168,341
Investments	96,755
Inventory	19,028
Other	1,223
<b>TOTAL ASSETS</b>	<b>285,347</b>

##### LIABILITIES

Payroll Taxes	\$1,247
Deferred Revenue	5,000
<b>TOTAL LIABILITIES</b>	<b>6,247</b>

**TOTAL LIABILITIES**  
**+ FUND BALANCES** \$285,347

#### PWSA (USA) CONDENSED INCOME STATEMENT FOR THE YEAR ENDED 12/31/95

##### INCOME

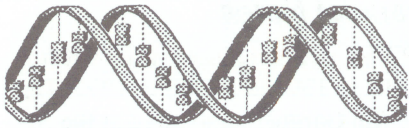
Earned Income	\$105,714
Public Support	106,191
<b>TOTAL INCOME</b>	<b>211,905</b>

##### EXPENSE

Program Services	\$170,280
Mgmt & General	32,010
Fundraising	9,568
Research	6,000
<b>TOTAL EXPENSE</b>	<b>217,858</b>

**INCOME (DEFICIT)** (\$5,953)





# Diagnostic Advances Hailed at 12th Scientific Conference

The 12th Annual Scientific Conference on Prader-Willi syndrome, held July 17 in St. Louis, featured presentations on PWS by researchers from across the nation. Drs. Suzanne Cassidy and Barbara Whitman summarized the research findings for attendees at the general conference on Saturday morning. Dr. Whitman concluded by announcing the recipients of the first "Vanja Holm Award for Excellence in Research on PWS" —Susan Christian and David Ledbetter, Ph.D. (formerly of the National Institutes of Health, now with the University of Chicago) for their research on diagnosis and prenatal testing. Named after PWSA's first Scientific Advisory Board chair, the new award was launched and funded by Dr. Whitman's clinic at St. Louis University.

Following is a brief overview of the latest research on PWS:

- Dr. David Ledbetter and colleagues found that DNA methylation analysis, one of the three basic diagnostic tests for PWS, can be used prenatally and that one of the two common probes used in this test (SNRPN) is very reliable, while the other (PW71) is less reliable for prenatal detection. For the small percentage of families with an increased risk of having a second child with PWS, **prenatal detection** is now possible.

- Susan Christian, of Dr. Ledbetter's lab, **improved the test for uniparental disomy** by developing and testing probes to reduce the number needed for reliable test results. (Uniparental disomy is the genetic cause of PWS in about 25 percent of cases.) Ms. Christian found that only four specific probes were needed for accurate results in the vast majority of cases—"an extremely valuable refinement in the diagnostic techniques," according to Dr. Cassidy.

- Dr. Robert Nicholls and colleagues at various institutions studied rare cases of PW and Angelman syndromes in which an **imprinting mutation** was found (the cause of about 2 percent or less of PWS cases). In these cases, the chromosome 15s are intact but the relevant genes are inactive because of an error in the activation, or imprinting, process. Dr. Nicholls reports that PWS and AS were found to have distinct imprinting regions in the same area of chromosome 15 and that this inherited form of PWS has roots in the genetics of the child's grandparents.

Imprinting is being studied by many scientists now, Dr. Cassidy explained, to learn whether genes that are present but inactive can be switched on.

- Dr. Peter Rogan and colleagues studied **imprinting in cases of uniparental disomy** and found that in some atypical people with PWS, some of the mother's genes that are normally inactive in PWS were active, or expressed, after all. This suggests there may be a "relaxation of imprinting" that may account for some of the variations in PWS.

- Dr. Cassidy and colleagues found that the average **age at diagnosis of PWS** was higher for those with uniparental disomy (average age 9), compared with deletion cases (average age 3–4).

- Dr. Merlin Butler reported findings on **atypical cases of PWS**: a higher percentage had uniparental disomy (UPD) than deletion of chromosome 15; and there was a higher incidence of asthma, benign tumors, and seizures among those with UPD.

- Dr. Butler also reported findings concerning the protein leptin, which was earlier found to be deficient in obese mice and which plays a role in satiety. Working with Amgen (the company that bought the rights to the "ob" gene, which prompts production of leptin), Dr. Butler reports that **leptin levels** are far higher in all obese people than in nonobese, and that nonobese people with PWS have more leptin than nonobese people in the general population. These findings indicate that leptin deficiency is not the cause of lack of satiety in PWS and that the potential use of leptin in treatment for appetite control is unclear, Dr. Cassidy notes.

- Dr. Moris Angulo reported that **growth hormone has a direct effect on penis length** and sexual maturation, independent of testosterone treatment, suggesting that growth hormone deficiency may in part be responsible for the small genital size in individuals with PWS.

- Dr. Jeanne Hanchett reported on **sex hormone levels** in 74 patients with PWS, ranging in age from 7 to 60, who were not receiving any hormone therapy. Testosterone in male patients was low, with the exception of some in the age 20–40 group who tested low-normal. No correlation was found between testosterone levels and aggression. Females had low levels of estradiol gener-

ally, but those who menstruated had higher levels than those who did not.

- Dr. Louise Greenswag reported preliminary data from a study of **52 adults with PWS age 35 or over**. Weights ranged from 92 to 268 pounds; those in designated PW homes had lower weights. Significant health problems were related to weight. About two-thirds had been hospitalized during the year for physical health problems, and 15 percent for behavior problems. Nearly half (47 percent) were taking psychotropic drugs to alter mood or behavior.

- Dr. Barbara Whitman reported that tests done as part of a growth hormone research project in St. Louis revealed that 73 percent of patients had bone ages that exceeded their chronological ages, and that 27 percent had **"advanced" bone age**. Advanced bone age was significantly correlated with weight and might disqualify subjects from GH treatment (if bone age was over about 14 years). Dr. Whitman stressed the importance of early weight control to prevent advanced bone age, shorter growth period, and possibly exclusion from GH treatment.

- Bruce Bakke reported a study of **negative behaviors** in eight adults with PWS over five years and results of trials using various **foods as a reinforcer for exercise**. The extra food was found to be neither an incentive for exercise nor a factor in negative behaviors. The identified behaviors remained stable over the five-year period.

- Drs. Robert Hodapp and Elisabeth Dykens studied stress and support in 42 families of children with PWS, ages 3 to 18. They found that **PW families have higher levels of stress** than families in general and families of children with mental retardation (non-PWS), and higher levels of pessimism. Although social supports exist, they often live at a distance from the family; few families listed professionals as sources of support. Stress in PW families is most often caused by negative behaviors displayed publicly (i.e., aggression, tantrums).

—Linda Keder

*Note: PWSA (USA) members may obtain photocopies of the Scientific Day abstracts for personal use only. Call the PWSA office at 1-800-926-4797 for information and price.*



## PWSA (USA) Research Priorities

### 1. Investigations of the biologic basis of PWS

- Finding genes/mechanisms of imprinting
- Metabolism and physiology of obesity
- Abnormalities in neurotransmitters
- Neuroimaging
- Causes and effects of sleep abnormalities

### 2. Delineation of the natural history through a collaborative registry

- Spectrum of disease
- Genotype-phenotype correlations
- Development/behavior
- Medical problems
- Effects of living situation

### 3. Determination of the effects of interventions, such as:

- Growth hormone
- Sex hormones
- Psychotropic medications
- Weight control medications

### 4. Improving diagnostic testing

- Value of testing
- Screening mechanisms
- Testing all hypotonic infants

*(Approved by the PWSA-USA board of directors, July 1996.)*

## Research Grants Available

Funding for research on Prader-Willi syndrome, particularly for pilot or start-up projects, is available from the PWSA (USA) Research Fund. Grant requests are reviewed by the Scientific Advisory Board and voted on by PWSA's board of directors, based on the recommendations of the SAB.

For more information and applications, contact Russ Myler, Executive Director, PWSA (USA), 2510 S. Brentwood Blvd., Suite 220, St. Louis, MO 63144-2326. Tel.: 1-800-926-4797 or 314-962-7644. Fax: 314-962-7869. E-mail: pwsausa@aol.com.

## Research Notes

*Three research projects* were ongoing at the national PWSA conference, with the approval of the Scientific Advisory Board. Two were questionnaires developed by researchers at Vanderbilt University, which is conducting a five-year, multidisciplinary study of PWS. The Vanderbilt surveys covered self-injurious behaviors and other behaviors common in Prader-Willi syndrome. The third project was a study of craniofacial patterns in PWS, conducted by Dr. Judith Allanson, a geneticist from Children's Hospital of Eastern Ontario, Ottawa. Dr. Allanson took a series of 21 head and facial measurements of a number of children and adults with PWS. She hopes to develop a "pattern profile" of Prader-Willi syndrome that may help in the diagnosis of PWS through such measurements.

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*A research grant* of \$5,800 was approved by PWSA's board of directors at its July meeting for a proposal by Dr. R. Wevrick of Canada: "Identification of imprinted genes involved in the Prader-Willi syndrome." As part of a larger research laboratory project by Dr. Wevrick on PWS, this grant will aid in isolating novel genes in the PWS common deletion region and assessing the expression pattern in a set of human tissues of those genes that are imprinted.

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*A set of research priorities* for PWSA grants was recommended by the Scientific Advisory Board and approved by PWSA's board of directors at the July meeting. (See box at left.)

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*The need for brain and other tissues* from individuals with PWS remains critical for researchers to make advances in understanding why PWS affects the body as it does. Dr. Cassidy reminded conference attendees about the Brain and Tissue Banks for Developmental Disorders, which can counsel families about tissue donation and arrange for proper collection of the tissues at the time of a scheduled surgery or death. It was noted that even simple surgeries such as a tonsillectomy could produce tissue of value to researchers. The hypothalamus portion of the brain, of course, is of greatest interest in the study of PWS.

The Brain and Tissue Banks, located in Maryland and Florida, have printed information and telephone counselors to answer family questions and guide them through the preregistration process. Individuals who are registered for tissue donation receive donor cards to carry with them, similar to those for general organ donation. Preregistration is not a commitment to carry through with tissue donation; it simply offers the best possible chance to retrieve tissue in usable condition for research purposes, should the family member with PWS die unexpectedly. For more information, families are urged to contact any of the following persons:

- Ann C.M. Smith, Genetic Counselor at NIH and PWSA's liaison with the Brain and Tissue Banks, 301-402-2011. Ann can refer families to a PWS medical advisor and to the appropriate bank.
- Sally Wisniewski, Project Coordinator at the Maryland Bank, 1-800-847-1539
- Elsa Robinson, Project Coordinator at the Florida Bank, 1-800-592-7246

□ □ □

*MEDLINE*, the National Library of Medicine's premier database of biomedical articles—more than 7 million of them—is now available through the World Wide Web to anyone who registers and pays the search fees. For the past 10 years, people who wanted to search the database had to buy and install on their computers a cumbersome software package called "Grateful Med." Internet Grateful Med, unveiled this past spring, changed all that. Full details can be found at the Web site—the address is: <http://igm.nlm.nih.gov>. MEDLINE lists and summarizes articles from more than 3,600 journals around the world and adds about 30,000 new citations each month. A separate NLM database called SDILINE lists only the citations from the most recent complete month in MEDLINE.



# Social Relationships and Social Understanding in Children with Prader-Willi Syndrome

by Helen Tager-Flusberg, Ph.D., University of Massachusetts at Boston

Research Collaborators: Kate Sullivan, Ph.D., Jenea Boshart, Jason Guttman, University of Massachusetts;  
Karen Levine, Ph.D., Children's Hospital Boston and Spaulding Rehabilitation Hospital

*This article is based on a presentation made at the 1996 meeting of the Northeast Regional Conference of the Prader-Willi Syndrome Association April 26, 1996, Albany, N.Y.*

*For the past several years our research lab has been conducting research on social understanding in different groups of children and adolescents with mental retardation syndromes. By middle childhood many*

*children with developmental disabilities have great difficulty making friends and sustaining positive relationships with peers. Exactly what the sources of these difficulties might be are not yet well understood, and it is likely that for different groups of children, the source may vary considerably.*

*Recently, in collaboration with Karen Levine, Ph.D., we have begun*

*studying Prader-Willi syndrome; however, since our work is still in its early stages, we still have more questions than answers about this interesting and unique group of children.*

*In this article, I will present the basic approach that we are taking in this study, briefly describe some of the tasks that we are giving the children, and offer a preliminary view of our findings.*

## Background on Social Cognition/Theory of Mind

In recent years there has been considerable interest in the field of developmental psychology in what has come to be known broadly as "social cognition"—the development of the child's *knowledge about and understanding of* the social world. This type of understanding is believed to be one key ingredient in the child's ability to engage in mature relationships with others. At the heart of our research is the exploration of the children's social cognitive abilities, which we hypothesize may place a constraint or upper limit on the abilities of the older children and adolescents with PWS to engage in peer relationships.

Theory and research on social cognition has taken a strong *developmental* approach: at each stage children's social understanding becomes more advanced, and along with these developmental changes come changes in the types of relationships that children engage in. The

foundation of social cognition in very young children comes in the preschool years as children develop a very basic understanding about people. They come to understand that people are quite distinct from other things in the world—people's behavior is goal-directed (or *intentional*) and is caused by mental states such as desires, knowledge or beliefs. This understanding of people as mental beings, or as individuals with minds, is the crucial first step in social cognitive development.

At the next stage, by age 4, children are able to understand that everyone has different mental states—their beliefs and knowledge may not all be the same. The child now is able to understand that people may have different perspectives on things—they see and interpret the world in different ways. Because children at this stage understand the relationship among different mental state concepts (e.g., desires, beliefs, emotions) and use these mental states to predict and explain human action, this type of knowledge of the mind has come to be called a *basic theory of the mind*.

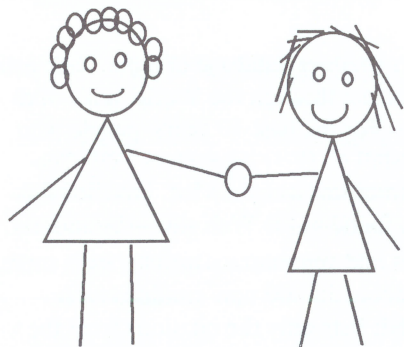
By the age of 6, normally developing children can begin to reason about one person's thoughts about another person's thoughts. This type of thinking, known as *second-order reasoning*, may represent a more advanced theory of mind and plays an important role in how we interpret many social situations. By middle childhood (ages 7–8), normally developing children are able to interpret other peo-

ple's behavior using even more advanced social concepts. For example, they begin to understand that personality traits are enduring qualities of a person that can be used to predict how a person might behave in new situations.

By late childhood/early adolescence they begin to view people, themselves and others, in terms of their internal qualities (the type of person they are, their talents, etc.) rather than simply in external ways (the types of clothes they wear, their skin color, gender, etc.). They understand the moral dimensions of interpersonal behavior and begin to frame their relationships with others on this newly emerging awareness of these more advanced social constructs.

## Factors Producing Developmental Change

One question that developmental psychologists ask about social cognition concerns the factors that are critical in accounting for these developmental changes. Our current view is that a number of important factors account for developments in social cognition. First, social knowledge is a specific and independent cognitive domain—developmental changes in this domain are related to underlying changes in the brain to the specific brain regions that process information about the social world. There are also general cognitive processes that are related to social cognition as well as to other aspects of cognitive functioning.





At each new stage of development, important reorganizations of the child's knowledge take place into more advanced or sophisticated theories. Thus, we can view development in social cognition as representing changes at each stage in their *theory of mind*. These changes or reorganizations seem related to general cognitive processes. Other factors, too, play important roles in children's social understanding and in their social abilities. These include memory, language and communicative abilities, social experience, and adaptive functioning. Thus, we have portrayed here a complex, multi-faceted picture of social ability—competence in this domain will require the integration of developments in all these areas of functioning.

### Research on Prader-Willi Syndrome

Our current work on PWS focuses on this view of social functioning. Our goals are to trace developmental changes in each of these areas of functioning and to explore how they might be related to the child's social understanding and current social experience. The particular set of tasks and tests each child is given are chosen to be appropriate for their developmental level. We see each child individually and test them in their home for several testing sessions. Ultimately we are interested in group performance and do not report on individual children, but we do provide each family with a summary of their own child's performance on our tasks.

### Preliminary Findings

At this point we have only completed testing a small number of children with PWS, and they span a wide age range from 5 to 12. Nevertheless, we can begin to say a few things about our data thus far.

First, there is considerable variability among the children. Their general cognitive abilities vary considerably. Some are close to their chronological level; the cognitive level of others lags behind one or more years. Cognitive abilities themselves show quite an uneven profile, with greatest weakness in auditory short-term memory. We also find uneven and variable language skills, confirming other reports in the literature. Among children in the age range we have studied, articulation difficulties and limitations in both comprehension

and production of semantic/grammatical aspects of language are present; however, knowledge of words stands out as an area of relative strength.

On parent report measures—the Vineland and the CBCL—the children with PWS are delayed relative to their age-matched peers on the development of adaptive behaviors such as daily living skills. As a group, the children aged 5 to

12 do show some problems in social functioning and in attention or thought. A smaller number of the children are also exhibiting problems with anxiety and withdrawal.

Performance on the social cognitive tasks also suggests variability among the children. Some children in the younger group (ages 5 to 9) are passing most of the

## The Research Methods

*All children receive a series of tasks that tap:*

- **general cognitive abilities** (Differential Abilities Scale)
- **auditory short-term memory** (Digit Span)
- **language and communication** (Peabody Picture Vocabulary for word knowledge, and the Clinical Evaluation of Language Functions for comprehension and production of semantic concepts, grammar, and uses of language)
- **adaptive functioning** (Vineland Adaptive Behavior Scales—parent report measures)
- **maladaptive behavior** (Child Behavior Checklist—completed by parents)
- **social cognition/theory of mind**—experimental tasks

### Younger Children

The social cognition tasks in this battery are designed to tap the children's *basic theory of mind*—their knowledge of basic mental states and their use of this knowledge to explain or predict behavior.

- **visual perspective taking**—ability to understand that people have different visual views of pictures
- **emotion matching**—ability to label and match facial expressions of emotions
- **explanation of action**—use of mental states such as desire, emotion, cognition, to explain behavior
- **false belief**—understanding that person may hold false belief about the contents of a familiar container or the location of an object

### Older Children

- **second-order belief**—what does one person think another person believes or knows
- **moral understanding**—understanding that if a person makes a commitment to do something, he then has a moral obligation to carry it out
- **lies and jokes**—testing the ability to distinguish when someone is lying or just joking (not intending to deceive)
- **personality traits**—use of information about traits as clues to intentional behavior
- **self-understanding interview**—an interview with the child asking a series of questions, e.g.: What are you like? What kind of person are you? What are you not like? What do you like most about yourself? What type of person do you want to be?
- **friendship interview**—after telling the child a story about a conflict involving a friendship triangle, we ask the child a series of questions about the conflict, addressing issues of what friendship is, how one forms friendships, how to handle conflict among friends, etc.

*Continued on next page*



tasks we give them, demonstrating their knowledge of a basic theory of mind. At the same time, some aspects of the tasks seem more difficult. For example, in the emotion matching task we find that many of the children have difficulty distinguishing between the sad and angry facial expressions (this is also true for young normally developing children). They also do not provide many explanations using mental state terms on our explanation of action task—this may be more related to the language difficulties they have since this is a task that requires the child to formulate a novel verbal response. Among the younger children we have a little evidence to suggest that their performance on the theory of mind tasks is associated with their general cognitive abilities.

Among the older children we also find variability, but by-and-large, we are finding that almost all the children with PWS have great difficulty with the social cognitive tasks. We should note here that these difficulties are strikingly *similar* to our findings on other groups of children with developmental disorders (e.g., autism, mental retardation of unknown origin, Down syndrome, and Williams syndrome). We are finding that after acquiring a basic theory of mind, the children show particular limitations in developing more advanced social concepts—they are very delayed in reorganizing their social knowledge into more advanced theories of mind.

Exactly what the source of these delays might be we do not yet fully understand. We have identified a number of important relevant variables, but in order to tease them apart and know how each contributes to these social cognitive deficits will require a much larger sample of subjects. We also do not know how severe the delay is—we need to test adolescents between the ages of 13 and 17 to explore their performance on these tasks.

Nevertheless, we are finding that the older children are showing delays in the social cognitive development beyond what we would expect from their general cognitive level. This means that, although they may function relatively well in school subjects, their age-matched peers have a more advanced understanding of the social world. The child with PWS has

*social concepts* (including an understanding of personality traits, self, and particularly friendship) that are significantly less advanced than their normally developing peers, which makes peer relationships so difficult for them. We believe that these delays in social cognitive development place a severe constraint on the social functioning of the child or adolescent with PWS.

### Future Direction of Research

We still have much to learn about social understanding and social relation-

ships in children and adolescents with PWS. We do not yet know much about the complex interactions among the domains of functioning that we discussed earlier. To what extent do general cognitive abilities influence the social domain? What effects do the language deficits associated with PWS affect social functioning? How do the changes in adaptive and maladaptive behavior affect family and peer relationships in PWS?

We hope that as our work progresses we can begin to address some of these questions.▲

## Calendar of PWS Events

- |                     |  |
|---------------------|--|
| <b>Sept. 21</b>     | <b>PWSA of Michigan</b> services seminar, 10:00 a.m. to 12:00 noon, public library on Abbott Rd., East Lansing, MI. Topics include residential options, respite, how to access your community mental health system, and services available from Michigan's PWS consultant team. Open to all interested families. Contact: Helen at 810-626-8995 or Jim at 517-332-2651.              |
| <b>Sept. 22</b>     | <b>PWSA of Maryland and Metropolitan D.C.</b> family picnic. Columbia, MD. Contact: Linda Keder at 301-384-4955.   |
| <b>Oct. 11-13</b>   | <b>Prader-Willi Florida Association</b> fall conference. Sheraton World Resort, Orlando, FL. Facility tour and planning for the 1997 PWSA (USA) national conference. Contact: Roda Guenther, 941-542-6406.   |
| <b>Oct. 19</b>      | <b>Prader-Willi California Foundation</b> annual meeting and program. 10:00 a.m. to 4:00 p.m., Capital City Baptist Church, 4840 Fruitridge Rd., Sacramento, CA. Topics will include: early intervention, special education, vocational transition, residential options, and more. Activity program for youth and adults with PWS. Contact: Fran Moss, 800-400-9994 or 805-389-3484. |
| <b>Oct. 19</b>      | <b>PWSA of New England</b> 2nd annual fundraiser dance. Fall River, MA. Contact: Diane Hight, 508-238-7825.  |
| <b>Oct. 25-26</b>   | <b>Ontario Prader-Willi Syndrome Association</b> annual conference. ITT Sheraton Four Points Hotel, Mississauga. Keynote speaker: Merlin G. Butler, M.D., Ph.D.; sessions on nutrition, education, crisis intervention, individualized funding, physiotherapy, and social services. Contact: Nita Goldband, 416-481-8657.  |
| <b>Nov. 1-3</b>     | <b>6th Australasian PWS Conference</b> , Auckland, New Zealand. Features speakers from Australia, New Zealand, Denmark, United Kingdom, and United States. Contact: Linda Thornton, PWSA (NZ) Inc., P.O. Box 143, Masterton, NZ. Fax: (+84) 6.370.9117.  |
| <b>1997</b>         |  |
| <b>Apr 27-May 3</b> | <b>3rd Annual U.S. Prader-Willi Syndrome Awareness Week</b>  |
| <b>July 17-20</b>   | <b>19th Annual PWSA (USA) National Conference.</b> Sheraton World Resort, Orlando, FL.   |
| <b>1998</b>         |  |
| <b>May 15-18</b>    | <b>3rd International Conference on PWS</b> , Seville, Spain. Sponsored by the International Prader-Willi Syndrome Organisation (IPWSO).  |



# Camphill: *Where Dreams Do Come True*

*Marie Meshok of Myerstown, Pennsylvania, writes of a unique and successful way of life for her son, Josh, and her battle to get it for him. She asserts, "The hand that rocks the cradle rules the world," and signs herself the "Mother of Joshua John Chase, a very happy, healthy, normal kid."*

**J**osh was born July 12, 1978, a typical lethargic baby with PWS and hyaline membrane disease. The crises of those first six weeks, then months, then years are a nightmare to remember. We went through gavage feeding, undescended testicles, inguinal hernia, infant stimulation classes, programs for the developmentally disabled, speech therapy, Intermediate Units, psychologists, psychiatrists, counselors, teachers, evaluations, the psychiatric ward (another nightmare), the body brace he wore for two years for scoliosis, and finally a spinal fusion.

Why then did it take 10 years for a diagnosis of Prader-Willi syndrome?

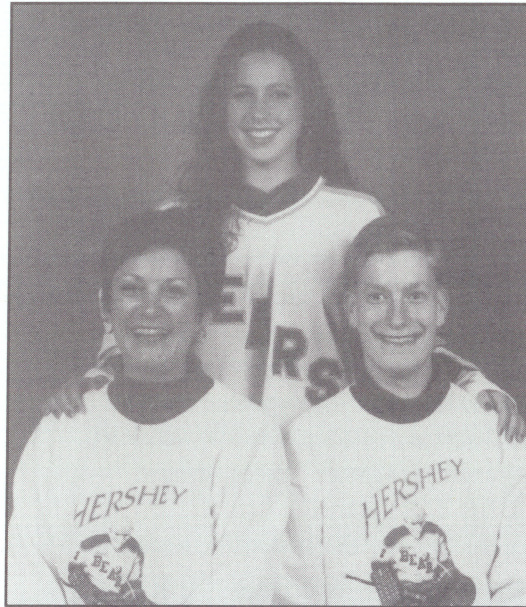
At first I was relieved to have a name for his "condition" (at least now I knew I wasn't crazy); then I was furious. To think of all the suffering, torment, agonizing, and depression that not only he went through, but the whole family, which included his younger sister. I remember him at the age of 9, asking me to "Please find a doctor who can HELP me." Now who wouldn't like a child who was so sensitive? Oh, but there were times, many of them, that I didn't like him or me or his sister or our life. Looking back, I guess poor Josh was struggling just as much trying to fit into our society with all its rules.

Around the pre-adolescent stage he was becoming fairly large and the tantrums more fierce. Once again I was losing my mind, yearning for an escape and hoping it would come soon.

School had been a bad experience from Day One. The I.U. moved its classroom to a different school (space available) every year. Drivers came and went, and every aspect of the coming day made Josh so anxious there was war every

morning just to get him off. By noon the pressure had built to the explosive stage, and I constantly got calls at work telling me to come intervene before the mental hospital got there. (If I did not respond immediately to a call from the school, staff from the local mental hospital would be called to transport him to their facility. This actually never happened as I always responded, but it was the overhanging threat.)

The day I saw my son in a straitjacket was the straw that broke the camel's back. I sucked in my gut, threw my shoulders back, stuck my chin out and



**Marie Meshok with her son, Joshua, and his sister, Leslie.**

put my foot down! I took him home, after informing the school and I.U. that he would not return until an appropriate placement was found. And I held that stance for two years, while the school and the state ran around in circles trying to appease me. You wouldn't believe what we were offered and how many times I refused to sign on the line. I said, "An appropriate placement!" Where I got the strength, God only knows, because during those two years Josh was home 24 hours a day with me and his younger sister. Not only did our finances hit rock bottom, but our spirits were following the same downhill slide fast. The residential

schools and institutions we visited did nothing to help matters.

Then I found Camphill, Beaver Run. It was there the whole time. Only an hour-and-fifteen-minute drive from home, and I knew it was the perfect place for my Josh. The state, however, was pushing for an out-of-state, federally funded placement. I knew it was time to get real tough (Besides, what did we have to lose? Our minds were already gone!). I wrote a letter to Barbara Bush—short and sweet and to the point—asking her aid in helping us get back to some sort of normalcy. I soon received a phone call from the Department of Education in Washington, an investigation took place, and in a few short months my Josh was accepted into the community of Beaver Run, Camphill.

This is his fourth year as a resident of what I call a fairyland, where dreams do come true. The changes and improvements and all the good qualities that were there all along have emerged. He has won ribbons in horse shows and an award in an art contest. Most remarkable of all, Josh now likes himself and loves the world and almost everybody in it. How normal can you get?

At 5' 6", Josh maintains an approximate weight of 150 pounds. At Camphill, children are never left alone, and meals are served at a scheduled time daily, family style, with strict table manners and consideration for all (different faiths, vegetarians, etc.). Emphasis is taken off the event, task, meal, whatever, and always placed on the importance of the individuals living in community.

Everyone is important to their community no matter what their race, religion, or disability. In a very spiritual, holistic, uplifting atmosphere people work, learn, play, and pray together for the good of all. Just like everyone else, some are good at this, some are good at that, and in the end it all works out fine, everyone with his own specialty.

Camphill Special School teaches "curative education." And talk about hands on learning. When Josh was study-

*Continued on next page*



## Camphill—continued from page 9

ing about Guttenberg, they built a printing press. When they studied about Columbus, a ship with sails and all appeared in his classroom. There is weaving, woodwork-ing, all forms of art, especially music. They are even put to sleep and awakened with a flute or lyre. There is responsibility for chores, inside and out, and the animals and stable for the equestrian program (Josh's favorite). There are outings to mu-seums, symphonies, movies, shopping, games, swimming and fishing (another of Josh's favorites).

At 18, he has grown into a fine young man anyone would be proud of. All be-cause of a little community called Camp-hill Beaver Run.

With only one more year until Josh graduates, I guess it's time for Mom to oil and shine her armor. I am currently seek-ing residence for him within another Camphill community for young adults. The waiting lists are long, and the needs

are great. Josh expresses a desire to live where he does have freedom of choice, where options are pleasurable and not a form of punishment, and where people of different disabilities come together to help each other. Being with other persons with PWS offers him no help with his problem as they must deal with the same one. But being with people who have different problems allows him to understand he is not isolated, takes his mind off himself, and gives him the opportunity to be help-ful and build self esteem.

Perhaps the staff of our group homes for PW could make their jobs easier and more beneficial for all if they could adopt the ideals of Camphill. Here government regulations are met, but the focus of the community is on the people, individually and as a part of a loving family that ex-tends to the whole community, depending on each other and working with and for each other. If only our world could get back to this simple basic—that is the spiri-tual need of us all.▲

## About Camphill

Camphill, Beaver Run, is part of the much larger Camphill Movement, which was started in 1939 by an Austrian doctor living on an estate named Camphill in Aberdeen, Scotland. According to a feature article in *Parade* magazine last year, Dr. Karl Konig believed that "many chil-dren labeled 'retarded' could in fact develop significant abilities."

At first it was a matter of just sharing life and work in a community environment. Then education was added, and some of the mentally disabled residents—called "villagers"—learned to read, write, and express themselves. Arts, crafts, and music were also part of their curriculum. Most learned rudimentary work skills. Today 68 communities exist world-wide, with seven in North America—both schools and villages. Nonprofit, their finances come from disability payments; growing much of their own food; selling such items as bread, cookies, and crafts made by residents; and other fund-raising activities.

The adult "co-workers"—nondisabled community residents—receive no salary but are provided food, clothing, and shelter. Many come intending to stay months and end up stay-ing years. (The average for those staying more than one year is 17 years!) Most marry and raise their children with the villagers. Training courses help prepare them to live and work with one another. According to the Fall 1995 newsletter, the *Camphill Clarion*, "People of all ages with real interest or experience in community building and/or work in human ser-vices/education and who are looking for positive lifestyle changes, extended internships, and/or life and work experience during or after the college years are welcome to apply."

Josh's Camphill Special School in Glenmoore, Pa., serves children from age 5 to 21, as well as offering an International Camphill Seminar in Curative Education. Other communi-ties are Camphill Soltane, Glenmoore, Pa.; Triform Camphill Community, Hudson, N.Y.; Cam-phill Village Copake, Copake, N.Y.; Camphill Village Kimberton Hills, Kimberton, Pa., Camphill Village Minnesota, Sauk Center, Minn., and Camphill Village Ontario, Angus, Ontario.

To learn more, contact Camphill Association of North America, 224 Nantmeal Road, Glenmoore, PA 19343.

## Publications

*"Parent's Guide to Alternative Living Arrangements"* is a new PWSA publi-cation designed to help parents select an appropriate residential placement for their son or daughter with PWS. Written by Mildred Lacy, the mother of a young adult with PWS, this 14-page booklet covers types of placements and what to look for in the administration, staffing, environment, and program-ming of a residential facility. Includes a checklist and many tips for parents. Price: \$4.00 for PWSA members, \$6.50 for nonmembers, plus \$1.50 shipping charge. (See order form enclosed with this issue of *The Gathered View*.)



*PWSA brochures now available in Spanish:* "Medical Alert," "Weight and Behavior Management," and "What Educators Should Know About Prader-Willi Syndrome." A **French** version of "My Child Has PWS—Now What?" also is available. These are photocopies of the originals as trans-lated by the Spanish and French PWSA organizations, now available from PWSA (USA) at our standard brochure prices.



*Literature on PWS is available in many languages* from PWS organiza-tions around the world. The latest issue of *Wavelength*, the newsletter for par-ent representatives to the International Prader-Willi Syndrome Organisation, lists publications in Danish, Dutch, German, English, Hebrew, Italian, Norwegian, Polish, and Swedish. If you need to find information in other lan-guages or contact PW families in an-other country, call PWSA (USA) for assistance: 1-800-926-4797.



*Dictionary of Developmental Disabili-ties Terminology* (1996), a new book co-edited by PWSA board member and scientific advisor Barbara Whitman, Ph.D., with Pasquale Accardo, M.D., provides easy-to-understand definitions of more than 3,000 terms in the dis-abilities field. A handy reference tool for professionals and parents. 368 pages. Price: \$35 paperback, \$55 hard-back. Available from Paul H. Brookes Publishing Co., 1-800-638-3775.



*The poem at right was written by Joyce Banks shortly after confirmation of her daughter Ebonee's diagnosis of PWS at age 16. Her reading of the poem to those present at the "Mothers Only" session at the St. Louis PWSA national conference drew a standing ovation from a most understanding audience. Joyce is president of the Arkansas chapter of PWSA and is working hard to spread the word about PWS so that other families may be spared the years of uncertainty she suffered.*

## Parents Seeking C.O.N.N.E.C.T.I.O.N.S

☐ *The mother of an 18-month-old* would like to connect with other parents of babies or young children with PWS. She writes: "I am finding very little information on dealing with the first stage [of PWS] and the frustration and stress it brings the families of these children. Just as overeating is a problem in the older kids, undereating and failure to thrive is equally a problem with the babies. A lot of parents of adult PWS people didn't know about the syndrome when their children were babies, so they weren't faced with the added stress that even though you are begging this child to eat now, just don't get him used to it because in another couple of years you won't be able to stop him! David only weighs 18 lbs. and barely eats enough to sustain himself. Another thing I wish was discussed more is how to handle some of the behaviors of the syndrome as they emerge. ... I'd really like to know what some other parents have done to try to head off things like temper tantrums and food related issues before they become problems." Parents who would like to respond should write to Vicki Knopf, P.O. Box 2044, Salem, CT 06420, or E-mail Vicki at: My5Boyz@aol.com.

☐ *The mother of a 7-year-old who has tested negative* for PWS on all available tests yet exhibits many characteristics of the syndrome would like to hear from other parents of children with negative or inconclusive tests who appear to have PWS. Her daughter has seizures, sleep disorder, and significant cognitive impairment. To respond, write Jennifer Rittelmeyer, 1507 Burwick Rd., Cary, NC 27511, or E-mail to: jrittel@nando.net.

## My Ragdoll Girl

by Joyce M. Banks

Floppy, low suck – no cry ... ragdoll girl  
That's how my child began in this world;  
So sweet, so quiet – would sleep all night!  
Though Heaven sent ... something just wasn't right.

Hospitalization to get her to eat  
Touch and go ... doctors thought MOM mistreated  
Back and forth many doctors to see  
Finally came the answer ... ragdoll girl has C.P. (cerebral palsy).

On to braces, special care ... 4 kinds of therapy ...  
Please Dear Lord have mercy on my child and me:  
Seizures came – then went away  
But the ragdoll's eating habit was here to stay.

Thin – then chubby – in a few months called ... FAT!  
Used to be choicy ... Now wanting too much of that ...  
FOOD!! FOOD!! FOOD!!!! INEDIBLES too !!!!!  
Tears are now falling — What must I do????

Years passed, more tantrums came  
More and more food was the name of the game  
BAD TEETH, POOR SIGHT, SLEEP APNEA, CRIPPLED  
STRIDE ...  
Caused ragdoll girl to be mean – yet pleasant and mild.

Then came the word. DIABETES has set in  
She may die ... won't respond to insulin.  
I prayed and cried Lord is this a dream  
A most cruel joke on us it seems.

Doctor, dietician, dentist, teacher ...  
We need an answer – ragdoll is like a food seeking creature;  
Would you believe I found out on my own!  
PRADER-WILLI SYNDROME has invaded our home.

Perplexed, Distressed, Weary I get so tired  
Overeats Oversleeps Harsh words she cries!!!  
But then like an ANGEL ... we can't help but love  
Our ragdoll babies that come from above.

No one's created for whom God won't provide  
Dear Lord touch hearts and lead us in the right strides;  
Grant us peace Wipe tears from our eyes  
We need a cure Please help us one to find.

Lord hear my prayer  
Give us a HOME ... more RESPITE ... Personal Care  
Food is a forbidden fruit for our children so rare  
Only you know the burdens that our family must bear.

DEDICATED WITH LOVE TO MY RAGDOLL GIRL ...  
Ebenee Cherie Rudley. 1995





## Calling All Cooks ...

The PWSA board of directors is publishing a cookbook of favorite low-calorie recipes for people with PWS.

If you have a dish that's a hit with your favorite person on a Prader-Willi diet, please send it to us for consideration for the cookbook.

You can send more than one recipe, and you can send recipes from published cookbooks—just note the name and author of the cookbook. Recipes will be tested and analyzed for nutritional content by members of the board. Submissions should be mailed, with your name, address and phone number to: **Pauline Parent, 159 Walnut St., Manchester, NH 03104.**

## Worth Noting ...

**Sept. 27-29—National Organization for Rare Disorders (NORD) Annual Patient Family Conference.** Marriott Quorum, Dallas, TX. Information sessions for families and support group leaders. Reg. fee: \$85 NORD members/\$110 non-members/\$70 additional registrants. Contact: Jean Campbell, 1-800-999-6673, ext. 210.

## Our Sincere Thanks

*for contributions received May 18 through August 29*

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Jacques & Pauline Parent  
(correction from June issue)

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### 1996 AWARENESS WEEK

Georgia Association for Prader Willi  
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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.