



# The *Gathered View*

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

## A Message from PWSA's New President, Barb Dorn of Wisconsin

**F**or all of you who were not in attendance at the PWSA (USA) conference in Ohio, I would like to introduce myself. I'm Barb Dorn ... your new president. I am looking forward to serving you over the next three years.

I am currently in a part-time, paid position as the Executive Director of PWSA of Wisconsin, Inc. I am a registered nurse, homemaker, wife, and mother of two boys — Tony and Tyler. Tony is 13 years old and has PWS. He loves mysteries, movies, and summer camp. Tyler is 11 years old and he is our little athlete. He loves baseball, football, and golf. I am married to a wonderful man named Don without whose support I would not have taken on this challenge.

Those of you who know me already know that I am a hard worker and very committed to this cause. I am one of those "PW Moms" who is very devoted (and driven at times).

I want to start off by thanking our Ohio chapter for the very successful national conference. We all left with lots of knowledge, support, and new and/or re-kindled friendships. We were delighted to see the premiere of our new video, "Searching for Solutions." Thanks to Don Goranson, Louise Greenswag, and all who contributed to its creation. It is truly a professional, moving, and informative piece of art. You will want to buy more than one to share with family, teachers, and anyone who may have contact with the person who has PWS.

The conference also enlightened many of us to the financial needs that our organization is facing. We learned about the possibility of scheduling our national conference on a biannual basis. Over the past few years, we have experienced significant financial losses with our conferences. State chapters have tried to secure extra funding to help cover the costs. The national organization has tried unsuccessfully to secure grants. The costs and expenses continue to grow, as does our attendance. We have wrestled with making the conference and services provided affordable while at the same time meeting our financial needs, and we have fallen short. The board of directors has committed to trying to continue with the conference on an annual basis, and we are waiting to see if we have a chapter willing to take on the challenge in the year 2000.

PWSA (USA) is definitely feeling "growing pains." We have experienced mixed blessings with the recent media attention. On one hand, we have been able to assist more families with getting a diagnosis and helping them connect to resources. On the other hand, our national office has been flooded with phone calls and other requests. With that comes the cost of the calls, support, and resources.

So what do we do? As members, we can encourage family members, friends, and professionals to support PWSA (USA) with a membership, donation, and/or the sharing of resources. The re-



PWSA President, Barb Dorn

sources we are talking about include the names of and contact persons for foundations and other funding sources that will donate to a national cause. Please share this information with our national office. A personal connection means a lot. It is not an easy process to secure grants, but we are all committed to pursuing this. We need and appreciate your help.

I have lots more I could say but I will close for now. Over the next months, I will continue to share our organization's peaks and valleys, trials and tribulations, and its hopes and dreams. I look forward to working for all of you.

If anyone wishes to share thoughts or ideas with me you can email me from our web site, [www.pwsausa.org](http://www.pwsausa.org) (click the e-mail button and type in [president@pwsa-usa.org](mailto:president@pwsa-usa.org)). You can also write to me at 305 Amanda Way, Verona, WI 53593.

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## PWSA Issues Health Care Guidelines for Individuals with Prader-Willi Syndrome

Suzanne Cassidy, M.D., chair of the PWSA-USA Scientific Advisory Board, reports that "In response to an identified need, Drs. Jeanne Hanchett and Louise Greenswag were selected by the PWSA Scientific Advisory Board to create an initial draft of a set of health care guidelines for people with PWS. They did so with the help of a small grant from the Research Fund this past winter. These guidelines were then reviewed by the members of the Scientific Advisory Board (SAB) and subsequently revised based on their input." The SAB approved the revised version, feeling "that this set of guidelines, if applied, would assure comprehensive care for the special issues raised by affected individuals and still allow for individual approaches."

The PWSA Board of Directors put the final stamp of approval on these guidelines at their July board meeting, and PWSA is happy to make them available now to our membership. They cover persons with PWS from birth through adulthood. In addition, a selected bibliography by topic (e.g., genetics, nutrition, developmental, medical, etc.) is included.

The *Health Care Guidelines for Individuals with Prader-Willi Syndrome* are now available on PWSA's Web site ([www.pwsausa.org](http://www.pwsausa.org)). They are also available in a spiral-bound booklet from the national PWSA office for \$6.50 to members, \$12.00 to nonmembers, including shipping and handling. (Overseas orders add \$6.00)

## Did you know? ...

Some United Way agencies will accept donations designated for PWSA (USA). It may be a way that you and your coworkers can help.

Check with your local United Way organization to find out how you can make PWSA your charity of choice for 1998.

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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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# For Those in Pain, Help is a Phone Call Away ...

*A divorced mother from North Carolina called our national office in distress over several issues regarding her high-functioning 15-year-old son with PWS. Through tears she remarked, "I see success stories in The Gathered View, and I wonder if anyone has the problems I have. I feel so alone."*

While the editors of the *GV* do indeed highlight the hope-giving "success stories" of many of our children and young people, we also sadly recognize that many others of our membership are struggling with a variety of difficult situations. Following is a sampling of the calls for help recently received in the national office from around the country, as noted in the office's telephone log.

- Michigan: Son, 4, weighs 95 pounds. In ICU on "death's doorstep." Upper airway restriction and enlarged heart.
- Virginia: Physician called about a 20-year-old girl just diagnosed with PWS. He knows mother, and she is angry it took so long to diagnose. She suspected it for a long time, but could get no one to diagnose.
- Connecticut: Daughter, 50, weighs over 350 pounds. Severe PWS-like symptoms, low IQ, obsessive-compulsive. Problems getting worse. Can't find help.
- Washington: Daughter, 18, moving to a group home two hours away. Mom feeling sad but thrilled daughter is placed. Called because she thought only another parent would understand her mixed feelings.
- Kentucky: Dietitian needs information on PWS. Knows little or nothing about it and will be seeing a 4-year-old weighing 104 pounds who has just been diagnosed.
- Arizona: Daughter, 32, diagnosed when she was about 5 years. Mother - "I let it go and let it go, and now her skin is almost bursting." 300 pounds and 5 ft. tall. Behavior problems, sleeps a lot, breathing difficulties and very depressed.
- South Carolina: Daughter, 24, weighs 215 pounds, 5 ft. Mother has known she had PWS since she was 13 but didn't know there was a PWS organization. Always thought her daughter's problems were because she was a bad parent. Needs information about diet, locks, picking.
- Kentucky: Teenage son arrested. Must go to court. Mother needs legal information.
- New York: Son, 18, 430 pounds. Social

## *How does the national PWSA office help?*

For parents, relatives, and professionals in crisis, Executive Director Janalee Heinemann and her staff are available Monday through Friday for phone consultation; Janalee personally handles the more complicated situations. Callers may be referred to appropriate professionals (e.g., a board member with expertise in the area of concern, a physician, a provider) or networked with state chapter presidents or parents of children of similar ages and in similar situations.

Depending on the need, crisis information packets to aid in supportive living placement, SSI appeals, or legal problems are prepared and sent, as are articles or booklets on the topic of issue (e.g., behavior management, management in the classroom, psychotropic medications). Financial assistance may be given in some crisis situations and to those who have the greatest need to attend the national conference but cannot afford to go.

There are many other types of calls handled by the national office besides those involving crises—for example:

- responding to general public inquiries

(often after a local article or TV show on the syndrome), parents who are wondering if their child has PWS or who have just received the diagnosis, relatives who want to know how to handle a child with PWS, teachers who have a student with PWS, college students doing research on the syndrome, new service providers in need of information, etc.;

- consulting with chapter presidents and other members interested in promoting awareness of PWS and enhancing services for families;
- assisting board members, officers, members of the Scientific Advisory Board, and committees;
- helping parents get the answer to many questions on many issues (growth hormone, insurance, genetic testing, inheritance, aging, skin picking, osteoporosis, dental problems, anesthesiology, diabetes, IEPs, etc.);
- and responding to our young people with PWS when they sometimes call because they are upset with their parents or have questions.

**"I called the national PWSA office just a few hours after I received the diagnosis. I was fine while I was dialing, but as soon as I heard the "hello" I found I couldn't speak as I was crying too hard. The kind person on the other end was patient, reassuring and comforting. I will never forget his kindness, for understanding how much I love my son and for telling me that it wasn't so bad, that he knew many people with PWS and it wasn't so bad. He affirmed the correctness of my love for my child and the worth of my son as a human being. I felt stronger, and most of all, I knew I wasn't alone with this. Other people loved someone with PWS. My world of feelings expanded to include every person with PWS and every person who loved someone with PWS. I will never forget that phone call. It made a difference in my life."**

*—Carol Plotkey, Vancouver, B.C.*

services want to place him in a non-PWS home. Mother stated she would rather go to jail than have him where he will not be in a controlled facility. Social services say she is neglectful due to his weight and personal hygiene.

- North Carolina: Boy, 8, 192 pounds. His teacher called for information. Home condi-

tions very bad, low income. Reported to DFS due to so many school days missed.

*In August, according to the national office phone bill, there were 1,304 calls, averaging 62 calls on each of the 21 working days, at a cost of \$1,651.67. No, N.C. caller, you are not alone!!*



# Do We Really Need an Annual Conference?



by Janalee Heinemann

... and watched the "old timers" greeting each other with a hug and laughing, sharing, and getting "recharged" for another year.

... and watched our "kids" of all ages holding hands, exchanging phone numbers, and dancing the night away.

So, by Friday night, all practical thoughts went out the window. But, besides being caught up with the emotion of the moment, **I remembered some things about the outcome of the conference that are far less tangible:**

- The conference is where state chapter presidents get to connect and learn from each other.
- The conference is where the 20 percent that attend get what they need and go back to their states or countries and help the 80 percent that don't attend.
- The conference is where new members get the courage and concepts to go back to their states and do the impossible.
- The conference is the one time all of the PWSA (USA) committees meet face to face and plan the programs and publications that will help all dealing with PWS.

- The conference is where the scientists and providers learn from each other and where new research concepts are developed.

- The conference is where parents of young children make the decision that their child's life **will** be better than the lives of those who've gone before—and find the knowledge and resources to see that this dream comes true.

- The conference is the one time a year our young teens and adults with PWS don't have to feel different and can be in a safe, food-restricted environment that allows them a date, a dance, and many friends.

- The conference is often the first time a sibling realizes they are not alone with their thoughts and feelings.

- The conference is the one place our parents can go and get a nod and understanding smile if their child starts "losing it" and where each child has 700 mothers, fathers, and friends to keep an eye on them.

- The conference is the match that lit the fire for our family 17 years ago—and changed our lives forever.

**W**eeks before the national conference in Columbus, Ohio, I began to question myself and others on how practical it is to continue to have a yearly conference. It is getting more complicated and expensive to put on and takes a tremendous amount of time and energy from both the state host chapter and the national office. The expense typically is more than the revenue brought in from attendees due to our now paying for professional planning and supervision of the Youth and Adult Activity Program, the high cost of hotel food and break refreshments, partial payment of presenters' expenses, toll-free calls to the office, mailing costs, etc. So, the practical part of me began to compare the high cost ratio to the outcome—knowing that less than 20 percent of our membership actually attends the conference.

Our board and staff began to ask questions such as: Could we go to every other year and have a smaller conference on the off years for the birth-to-5 population, the scientists, and providers? Should we use the year 2000 as a test year, skipping the conference because of the effort the combination national/international conference will take in 2001?

**Then I went to Ohio ...**

... and saw the families talking eagerly to each other, learning, networking, and finding desperately needed support.



Janalee's son Matt, with Katie Wilson, at the banquet in Columbus.



## Organization News

### New Officials and Directors

At the PWSA national conference in July, members voted to retain **Jim Gardner** and **Wauneta Lehman** on the board of directors and elected two new members to the board—**Dr. Dan Driscoll** of Gainesville, Florida, and **Mike Larson** of Appleton, Wisconsin. Gail Thune, who had been a candidate for reelection, withdrew her name from consideration prior to the voting. Board terms are for three years, except that Wauneta will serve the two years remaining in the term she began in 1997, when a newly elected board member had to resign.

The board of directors chose **Barb Dorn** of Verona, Wisconsin, to serve as national PWSA president for a term of three years and reelected **Don Goranson** as vice president and **Jim Gardner** as treasurer. **Mary K. Ziccardi** was appointed secretary of the board, and **Jim Kane** was reelected board chair, each for a term of one year.

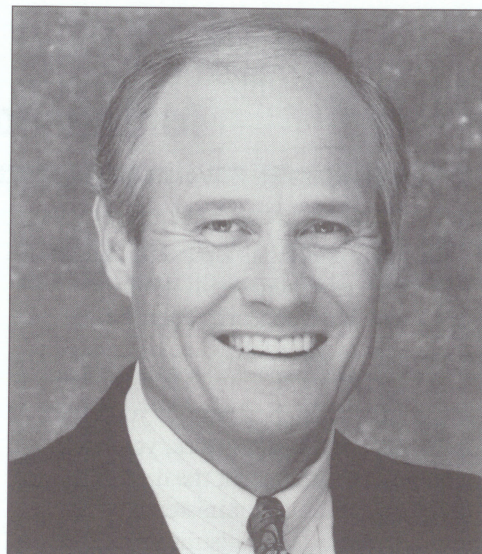
Dr. Suzanne Cassidy announced the addition of **Dr. William Zipf**, an endocrinologist from Ohio State University who co-chaired the 1998 scientific meeting, to the membership of the PWSA Scientific Advisory Board.

PWSA financial data reported to the membership in July are summarized below for the last full calendar year. Treasurer **Jim Gardner** explained that last year's significant deficit (\$30,753) was largely due to increased costs incurred for our 1997 conference in Orlando. (See also the President's Message, page 1, and Executive Director's View, page 4.)

## St. Louis TV Reporter Wins National Award for Series on PWS

Tom O'Neal of Fox 2 News, St. Louis, Missouri, received "The Art of Reporting" Award at the Alliance of Genetic Support Groups' 1998 conference for his series on Prader-Willi syndrome, "A Deadly Hunger." According to the Missouri PWSA chapter, this outstanding four-day news feature, which initially aired in 1991, was the impetus for approval of three supportive living homes for individuals with PWS in the St. Louis area. With Channel 2's permission, PWSA has been using a videotape version of the series on a national basis for education and advocacy.

Mark Floretta, president of the Missouri PWSA chapter, and Judy O'Leary, chairperson, nominated Tom O'Neal for the award, and PWSA Executive Director Janalee Heinemann wrote a letter of support. Janalee, who was involved with production of the original series, wrote: "Throughout the years of my working with this little-known genetic disorder and with children with cancer, I have found Tom O'Neal to have a sensitivity that exceeds all other reporters'. Unfortunately, his sensitivity did not come without a price. He lost his own teenage son to cancer. Tom has risen above his personal pain to help us all work towards the goal of sensitive awareness. We cannot thank him enough." Janalee, Mark, and Judy attended Tom's award ceremony September 12 in Arlington, Virginia.



Award winner Tom O'Neal of Fox 2 News in St. Louis

### Updated Video

Now a powerful supplement to the "Deadly Hunger" series has been added to the videotape available through PWSA (USA). Recently, Tom did a follow-up to the series. The original series went into the homes of several families and showed the desperate need for placement. The follow-up is a powerful testimony that appropriate placement does work. Showing young adults in their supportive living home, the latest report features Timmy O'Leary working on his paper route and volunteering at a nursing home and Jermaine Robinson riding a bike, over 200 pounds slimmer! The updated video, "A Deadly Hunger," is available to PWSA members for \$20 (\$30 for nonmembers), plus \$4 shipping and handling.

### PWSA (USA) CONDENSED BALANCE SHEET AS OF 12/31/97

<u>ASSETS</u>	
Cash	\$257,590
Investments	8,552
Inventory	16,503
Other	7,880
<b>TOTAL ASSETS</b>	<b>290,525</b>
<u>LIABILITIES</u>	
Payroll Taxes	\$ 4,858
<b>TOTAL LIABILITIES</b>	<b>4,858</b>
<u>FUND BALANCES</u>	
General Fund	\$220,834
Research Fund	64,833
<b>TOTAL FUND BALANCE</b>	<b>\$285,667</b>

### PWSA (USA) CONDENSED INCOME STATEMENT FOR THE YEAR ENDED 12/31/97

<u>INCOME</u>	
Earned Income	\$129,555
Public Support	135,626
<b>TOTAL INCOME</b>	<b>265,181</b>
<u>EXPENSE</u>	
Program Services	\$254,125
Management & General	29,958
Fundraising	6,651
Research	5,200
<b>TOTAL EXPENSE</b>	<b>295,934</b>
<b>SURPLUS (DEFICIT)</b>	<b>(\$ 30,753)</b>



# Eligibility for Social Security and SSI Benefits for Individuals with Prader-Willi Syndrome

by Barbara R. Silverstone, Staff Attorney, National Organization of Social Security Claimants' Representatives

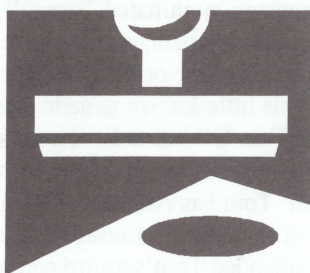
If your child has a chronic condition such as Prader-Willi syndrome, you may have concerns about being able to afford the care he currently needs and his well being when you are no longer able to support him. If your child is disabled and cannot work, you need more information about the disability benefits programs administered by the Social Security Administration (SSA).

If your child is unmarried and his disability has continued uninterrupted since before his 22nd birthday, and one of his parents is either retired, disabled, or has died after working enough quarters to qualify as insured, he may be eligible for Social Security disability benefits. These benefits, called Disabled Adult Children's benefits, are available to your child even if he or she has never worked, and can be used to support a disabled individual whose parents are no longer able to do so. If you think your child may be eligible for this benefit, you should contact the Social Security Administration for an application. Visit a local office or call 1-800-772-1213. For a referral to a private attorney who is familiar with these benefits, you can call the National Organization of Social Security Claimants' Representatives at 1-800-431-2804.

If your child has worked in jobs covered by Social Security, he may be eligible for Social Security disability benefits on his own record; Medicare coverage is available after two years of disability. Even if your child hasn't worked outside the home, and you have not yet retired, he may be eligible for *Supplemental Security Income (SSI)* disability benefits if your income and resources are very limited; Medicaid eligibility begins immediately for SSI recipients. Many people receive benefits under both programs. If your child is under 18 years old, SSA will consider your income and resources as well. If he is over 18, only his income and resources will be considered in determining financial eligibility for SSI benefits.

## Determining Eligibility

Social Security disability benefits are available to disabled workers who meet two conditions: (1) they are too disabled to work at any job, not just the jobs which they held in the past; and (2) through their employment, they have contributed enough FICA tax over the years to be covered. In general, workers who have worked at least five out of the 10 years just before the disability began are covered; the rules are different for workers under age 30. An individual's wage history determines the monthly benefit amount.



Remember, even an individual who has not worked, but whose disability began before age 22, may be eligible for Social Security disability benefits, as a Disabled Adult Child.

Supplemental Security Income (SSI) benefits are available to disabled individuals whose income and resources are very limited. Generally, to be eligible for SSI benefits, an individual may have no more than \$2,000 in resources (\$3,000 for a couple) and income of under \$500 per month (\$740 for a couple). The income levels change each year. Income and resources from a spouse or the parents of a minor child are deemed to be available to the claimant. The value of a home is not included. Your income will be deemed to your minor child even if he or she resides at a school if you have parental control over your child. Claimants who are eligible for Social Security disability benefits but whose payment amount is very low may also be eligible for SSI benefits.

## Who is "Disabled"?

Eligibility for disability benefits depends on the limitations your child has as a result of physical, mental, and behavioral impairments. SSA decides whether your child has been, or is expected to be, disabled for at least 12 months. SSA will first ask whether or not he is currently working. If he is not working, SSA will then compare your child's condition to its criteria in the "Listings of Impairments." There are several different listings under which an individual with Prader-Willi syndrome may be evaluated, but the most likely choice for children is "Multiple Body System." That listing is number 110.00. For adults, SSA will probably rely on the listing for "Obesity." That listing is 9.09.

SSA classifies as "multiple body systems" impairments those "life-threatening catastrophic congenital abnormalities and other serious hereditary, congenital, or acquired disorders that usually affect two or more body systems" and are expected to either produce long-term significant interference with age-appropriate major daily activities or result in early death. SSA will find a child disabled who suffers from multiple body dysfunction due to any confirmed hereditary, congenital, or acquired condition with: either persistent motor dysfunction; significant interference with communication due to speech, hearing, or visual impairments; or mental, growth, or cardiac impairments.

SSA will consider the **combined** effects of all impairments to determine if the child is disabled under this category.

SSA will rely on the results of medical tests to determine whether your child can be found disabled at this step of the evaluation, so it is important that he or she has been properly examined by a doctor. SSA wants to see that a doctor has done laboratory tests, including chromosomal analysis, where appropriate, and has diagnosed your child with Prader-Willi syndrome.



If your child's condition precisely meets any of these criteria, SSA will find that he is disabled. But meeting these criteria is not the only way to qualify for benefits. Even if your minor child does not have the exact test results required, SSA will continue to evaluate the claim by determining whether his or her impairments cause the same type of limitations as any of the listings (medically or functionally equal the listing).

SSA will find an individual disabled as an adult by relying on the obesity listing if his or her weight has reached a specified amount, which varies by height, and if he or she also suffers from a history of pain and limitation of motion in any weight-bearing joint or the lumbosacral spine associated with arthritis; hypertension with diastolic blood pressure persistently in excess of 100 mm. Hg; or a history of congestive heart failure, chronic venous insufficiency, or respiratory disease.

If your child is over 18 years old and does not have the exact test results required, SSA will continue to evaluate the claim by considering his vocational factors (age, educational background, and work history) along with his physical and mental residual functional capacities to decide whether he is disabled or whether there are jobs that he can do. *Keep in mind that your child's disability can be based on a combination of several impairments that may not be disabling when considered separately, but when evaluated together show that he cannot work.*

### **Applying for Benefits**

You can get the application forms for disability benefits from SSA by calling 1-800-772-1213. You can apply for Social Security and SSI benefits at any Social Security office. It is important to complete the form with as much information as possible. Give the full names and addresses of your child's doctors, and the dates of any hospitalizations. Make a list of the medications your child is taking or other treatments he has used and their side effects, and any medications and treatments he has tried but which no longer work for him. Describe your child's daily activities, and mention whether his behavior or weight prevent him from performing certain activities.

## **Research Participants Still Needed**

**The University of Illinois at Chicago behavior study** on children ages 6 to 18 was announced in the March-April newsletter and was also distributed by researchers at the PWSA national conference in Ohio. If you picked up a questionnaire packet at the conference, the researchers ask that you please consider completing the survey and returning it as soon as possible. If you wish to participate and need a questionnaire packet, contact: Nicolay C. Walz by phone at 312-914-3632 or by e-mail at ncwalz@uic.edu.

**The Vanderbilt University comprehensive study of PWS**, described in our last newsletter, is in particular need of individuals with PWS due to maternal disomy 15 (both chromosome 15s from the child's mother) and those with other genetic characteristics than the typical paternal deletion. Dr. Merlin Butler explains that it is necessary to study a higher percentage of those with less common genetic findings in order to draw reliable conclusions about differences in the groups. Participants in this study undergo a series of medical and other tests at Vanderbilt (Tennessee), with most expenses being covered. Note that individuals on growth hormone therapy must be excluded from the study. For more information, please contact Elizabeth Roof at 615-322-8982.

Tell your child's doctors that he is applying for disability benefits, and they should expect to receive a request for more information from SSA.

### **The Application and Appeals Process**

If your application is initially denied, there are several steps in the appeal process. Only about 30 percent of disability applications will be approved at the first step of the process. Many claimants who receive denials file appeals. Over half of the claimants who request a hearing before an Administrative Law Judge will receive favorable decisions awarding benefits. For those who are turned down again, the next steps of the appeals process are the SSA Appeals Council, and, if necessary, Federal Court. The amount of time and effort it takes to pursue an appeal is definitely daunting. Perseverance and persistence are crucially important.

### **How Long Will the Application Process Take?**

It is not uncommon for a claimant to wait six to 12 months for a decision on an application for disability benefits. Claims which must be appealed administratively (to an Administrative Law Judge and the Appeals Council) or to Federal Court will take much longer. (To give you some perspective on the program, consider that almost three million

applications for disability benefits were filed last year.) When a case is finally approved, benefits will be paid to cover the months during which you were waiting for a decision.

### **Once Approved, Can I Work and Continue to Receive Social Security/SSI Benefits?**

SSA has many work incentive programs which allow recipients to work for a limited amount of time, or under special circumstances, without losing their benefits. Recipients who are considering trying to work should contact SSA at 1-800-772-1213 or consult an attorney who is familiar with Social Security programs for specific guidance.

### **How Can I Get Help or Additional Information?**

Additional information can be obtained from SSA by calling 1-800-772-1213. Most people apply for benefits on their own, but often want assistance in pursuing an appeal. If you need legal representation to assist you in obtaining Social Security disability or SSI benefits, contact your local legal services program or your local bar association referral office. Or, you can get a referral from the National Organization of Social Security Claimants' Representatives by calling 1-800-431-2804.



# Prader-Willi Syndrome and Obsessive-Compulsive Disorder

by Lota Mitchell, M.S.W.

*Anna asks questions over and over and over again, repeating them until her parents are beside themselves with frustration. ... Kevin collects and hoards cassette tapes. It is difficult to get into his room because of the piles of tapes stacked everywhere, but he still wants more. ... Alicia picks at sores on her skin, often keeping a sore from healing for months at a time. ...*

The child with Prader-Willi syndrome (PWS) typically begins early in life to display preoccupation with food — eating it with delight, seeking it, hoarding it. Many other repetitive thoughts and behaviors appear as well that are not related to food, such as persistent skin picking; hoarding of non-food items; ordering and arranging; concerns with symmetry and exactness; need for sameness in daily routine; the need to tell, show or ask; re-writing; excessive grooming; and repetitive and incessant talking.

Families and caregivers of individuals with PWS are likely to quickly recognize some or all of these behaviors. Elisabeth Dykens, James Leckman, and Suzanne Cassidy, in their article "Obsessions and Compulsions in Prader-Willi Syndrome" (*Journal of Child Psychology and Psychiatry*, Vol. 37, No. 8, pp. 995-1002, 1996), observe that the non-food-related behaviors "are often more difficult to manage than food-seeking." Many families would heartily agree.

Researchers are beginning to examine the obsessive-compulsive behaviors of the syndrome and to consider their relationship to the psychiatric disorder known as *obsessive-compulsive disorder* (OCD), which occurs in the "normal" population. Measuring such behaviors in special populations, including those with PWS, has been difficult because of their inability

to answer self-report measures, and much more work is needed before the full picture can be seen and understood.

## What is Obsessive-Compulsive Disorder?

The American Psychiatric Association's *Diagnostic and Statistical Manual of Mental Disorder* (4th edition) provides current criteria for all mental disorders. Obsessive-compulsive disorder (pages 417-419) is classified as an anxiety disorder. The *DSM-IV*, as the manual is popularly known, defines *obsessions* as "persistent ideas, thoughts, impulses, or images ... that cause marked anxiety or distress" and *compulsions* as "repetitive, intentional, purposeful behaviors, the goal of which is to prevent or reduce anxiety or distress, not to provide pleasure or gratification."

"The obsessions or compulsions must cause marked distress, be time consuming (i.e., take more than one hour a day) or significantly interfere with the individual's normal routine, occupational functioning, or usual social activities or relationships with others. Obsessions and compulsions can displace useful and satisfying behavior and can be highly disruptive to overall functioning."

The distraction of obsessions can greatly diminish the ability to concentrate. Most adults with OCD at some point recognize to a greater or lesser degree that the obsessions or compulsions are excessive or unreasonable, but this requirement for diagnosis does not apply to children (nor likely to persons with PWS) because "they may lack sufficient cognitive awareness to make this judgment." The disorder is found equally in males and females.

## OCD in PWS

### Research by Dykens et al.

The above-mentioned study by Dykens, Leckman, and Cassidy first

looked at the range and severity of non-food obsessive-compulsive symptoms in 91 children and adults with PWS aged 5 to 47 years. This group included 41 males and 50 females, with an average age of 19 and IQs ranging from 50 to 89. Several types of questionnaires were administered to parents and to the 91 persons with PWS.

### Range of Behaviors

Almost all (98 percent) of the participants showed skin picking. Over half of the group had the symptoms of hoarding (various types of objects) and the need to know, tell, or ask. More than one-third (35 to 38 percent) had ideas of symmetry and exactness and the need to rewrite, order, and arrange things according to certain "rules." About a quarter showed excessive showering, toileting and grooming. The 23 percent of participants who were on psychotropic medication at the time of the study did not differ in obsessive-compulsive symptoms from those not on medication.

### Severity of Symptoms

Sixty-four percent of the group showed at least a moderate level of severity in compulsions, and 40 to 54 percent showed moderate to severe obsessive symptoms.

As age increased, it appeared that the total number of symptoms increased, but not the severity. There was little difference between males and females in the number of obsessive and compulsive symptoms; males, however, had significantly higher total symptom severity scores. The study did not find any significant relationships between the number or severity of the symptoms and either family socio-economic status or parental obsessive-compulsive symptoms. However, heightened familial stress was associated both with increased numbers of symptoms and severity of compulsive behaviors.

When the symptoms were compared with clinical criteria for OCD, fully 60



percent of the children and adult participants met the criteria, and another 25 percent showed key symptoms but did not fully meet diagnostic criteria. These findings suggest increased risk of OCD in PWS.

A second part of the Dykens study compared the symptoms of 43 adults with PWS with a group of 43 nonretarded adults diagnosed with OCD. The levels of symptom severity were similar; however, the PWS group was more likely to hoard, and the OCD group was more likely to have religious obsessions and checking compulsions.

The researchers suggest that since OCD often involves a disturbance in the neurotransmitter serotonin, "people with PWS may similarly show reduced brain serotonin function ... Open trial case studies in people with PWS find that serotonin reuptake inhibitors (SRIs) reduce emotional lability and, sometimes, repetitive behaviors such as skin-picking." Although no controlled studies have yet been reported, this does hold promising implications for pharmacotherapy.

### ***Research from Vanderbilt***

Two studies were conducted at Vanderbilt University to identify the onset and characteristics of OCD behaviors in children and adults with PWS. (Research by E. Roof, A. Dimitropoulos, T. Thompson, M. Butler and W. Stone, reported at the 1997 PWSA Scientific Conference)

The first study looked at compulsive behaviors, eating problems, and tantrum behaviors of preschoolers with and without PWS. Participants were 83 children with PWS and 50 typically developing children between the ages of 2 and 6 years. The young children with PWS showed significantly more compulsive behaviors than the comparison group. For example, 51 percent of the children with PWS engaged in skin picking, compared with only 4 percent of the comparison group. In addition, the number of different types of compulsive behaviors increased with age in children with PWS and decreased in the children who were developing typically. Tantrum behavior appeared to have its onset at the time of the onset of increased appetite.

The second study compared the prevalence of specific psychiatric symptoms in a group of 22 subjects with PWS

and a comparison group of 15 matched for age, IQ, and weight. The group with PWS had significantly more compulsive behaviors than the comparison group. For example, skin picking occurred in 71 percent and hoarding of small useless objects in 37 percent of the subjects with PWS, compared with 23 percent (skin picking) and 6 percent (hoarding) in the comparison group.

Knowledge today about obsessive-compulsive behaviors and PWS is imperfect and far from complete. Medication can help in many cases, but it does not cure. But there is hope—hope that research about behavior and research in pharmacology will combine to provide a better life in the future for our children with PWS. ▲

## ***Research + Real Life: A Parent's Report***

Judy O'Leary of St. Louis, Missouri, mother of Timmy, 27, who has PWS, decided to tackle the subject of OCD for a college paper in 1997. She obtained information on seven adults with PWS who were in local group residences—their diagnoses, medications, obsessive-compulsive behaviors, and the effect of the medications on each behavior—without identifying the individuals by name.

All seven had the diagnosis of PWS, but the psychiatrists who saw them gave them quite a variety of additional diagnoses. The number of obsessive-compulsive behaviors in each individual ranged from eight to 15. All the various medications that were prescribed were ones used for obsessive-compulsive disorder, although only one person had actually been given this diagnosis. Many of the behaviors improved to a greater or lesser degree with medication, but none disappeared. The behaviors most improved were thinking about and eating food, scratching and picking, protection of their living quarters and belongings, talking and chattering, and shoplifting.

Judy's report states that, "In the obsessive-compulsive behavior, there are numerous ideas, thoughts, and impulses that are senseless," and gives an example of this in her son: Timmy "has had thoughts and ideas about the trash man since the age of 4. He cannot sleep [because of] waiting and listening for the truck to come and take the neighborhood trash. He continues this same behavior today. He sneaks to the phone to call the trash company if the truck is late, and he continually talks and mumbles to himself about the whole situation. One moment he wants to fire the company; the next moment he wants to hire them back; then he switches and suddenly wants the trash men's autograph."

She also describes her son's difficulty with change: If he is getting ready to go to a dance, "he drives himself and everyone else crazy with every detail—sweating, worrying, continuously talking, thinking and chattering to himself about the situation. He is afraid he is going to be late, afraid he will get lost, or afraid he will not make the dance at all. One minute he says he is going; the next minute he changes his mind. This lasts until he either does not go or eventually leaves for the dance in total exhaustion."

For Timmy, medication has been a godsend, Judy reports: "My son, age 27, has been on medication for three years now. The change in him has been incredible, and every area of his behavior improved. I wish I had obtained help for him sooner. He is not as obsessive as he once was, and he is able to deal with life in a more relaxed and calm manner. He can actually take criticism without becoming agitated, and we can hold a normal conversation. In other words, I can reach him in a way that I never could before. The medication has also made it possible to apply behavior management with overwhelmingly wonderful results. Even the trash man is not as important as he once was."

She goes on to say: "As a parent, had I known when my son was younger that these were indeed obsessive-compulsive behaviors, it could have helped me to understand better his actions. And it could have provided me with more opportunities of finding help for him by informing or asking doctors about the possible use of a medication for these behaviors."



# Exercise Essentials

by Jennifer C. Deau, M.S.

*(The questions and answers on this page are excerpts from a new PWSA publication. See box on page 11 for more information.)*

## Why is it so important that people with PWS exercise?

A person's basal metabolic rate is the minimum quantity of energy used by any resting organism to sustain life and is measured in calories, or the amount of heat given off by a person

at rest. Caloric balance generally exists when a person burns whatever calories they take in, i.e., 2,500 calories in and 2,500 calories burned through daily activity/exercise. As we age, our bodies' ability to burn calories efficiently decreases.

A person with PWS is not as fortunate. Their basal metabolic rate is lower than the general population. If they follow the same 2,000-calorie diet their siblings do, they will "wear" an excess of 800-1,000 extra calories/day, as they need far fewer calories/day. That excess

amount of calories adds up very fast and contributes to the morbid obesity which is prevalent in PWS. To compound matters, the PWS population doesn't burn calories as efficiently during exercise either, thus making it even more frustrating to lose weight. However, the more vigorously they exercise, the more heat they lose and the more calories are burned.

Cardiopulmonary status is very low in this population—their capacities when compared to their peers/gender usually finds them way off the charts. They have high respiration rates, fatigue easily, have very low self esteem and low muscle tone, with developmental delays that preclude them from playing with their peer groups in aerobic sports. As they get older, their behaviors interfere and they have great difficulty finding friends to play with. Obviously, finding age-appropriate activities that stress the heart and lungs can be difficult at best—but it

is essential that every possibility be pursued.

Exercise is helpful in preventing/treating depression and offers an avenue of control. The positive aspect of "I can manage my weight" is a forward incentive to keep exercising and stay in the same clothing size. Praise and acknowledgment of their efforts to maintain good health is a powerful ploy in maintaining caloric balance. A good workout releases endorphins in the body and has its own kind of "high." Treating an exercise session as something "cool" to do helps maintain a normal image of what people generally do who want to look and feel good.

Exercise increases bone density and builds muscle tone. The population with PWS struggles with osteoporosis and hypotonia. Vigorous exercise can offset these deficits.

## Can a person with PWS lose weight without exercising?

Yes. However, it is a very poor choice. The person will lose muscle mass if he or she diets but doesn't exercise.

The population with PWS does not have a surplus of muscle mass to pass as protein in their urine—they will do themselves a favor if they incorporate some exercise as well. That combination will net all positive results.

## How much should they exercise?

A good rule of thumb is an hour a day. Realistically, five days a week would be great. Four is essential. Exercise

should be continuous and as vigorous as possible. Initially, frequent rest may be necessary—decrease the rests as their breathing tolerance allows. I generally

only encourage short standing rests at corners. "Sitting rests" should be avoided if possible—once they sit down it can be difficult to get them up. Remember my favorite adage: "Inch by inch it's a cinch; yard by yard it's hard." Exercise programs should show a progression of increased activity (faster walking, longer distances, improved tolerance for exercise). If this is not happening, scrutinize

## What are good exercise activities?

Anything is good that helps them move continuously. Aerobic exercise enhances both heart and lung

function as well as strengthens the mus-

culoskeletal system. Exercise should be CONTINUOUS AND AS VIGOROUS AS POSSIBLE. Tailor a program to your child—basketball, swimming, softball, volleyball with a beach ball—whatever works! Walking in the woods is great—it really helps with balance. Avoid hand

holding. Encourage your child to "do curbs." Do use arms while walking. Try jump roping. See if karate is a viable team sport. Participating in team sports helps them with interpersonal skills and the concepts of winning/losing as well as taking turns.





## New Exercise Publication Available from PWSA (USA)

The exercise questions and answers on page 10 were written by Jennifer C. Deau, M.S., exercise physiologist, The Children's Institute, Pittsburgh, Pennsylvania (formerly The Rehabilitation Institute of Pittsburgh), for an article entitled "(Just About) Everything You Ever Wanted To Know About Prader-Willi Syndrome and Exercise." This article is the introductory piece in PWSA's new collection called *Exercise and Crafts & Activities for the individual with Prader-Willi syndrome*.

Among other questions addressed in Ms. Deau's article are:

- Can exercise overcome hypotonia?
- What exercises can we do in the winter?
- Why should they alternate feet on steps?
- Where do I get shoes to fit?
- What about rewards?
- What about when they say "I can't"?
- Whom should I hire to exercise with my child?
- Can we really have fun exercising?

Besides the general article on exercise, this new collection includes: "Upper Extremity Strengthening in People with Prader-Willi Syndrome," a program developed by Ms. Deau and others at the Pittsburgh PWS program and presented at the 1997 PWSA conference; and a number of articles previously published in *The Gathered View*—"Toys and Equipment to Help Young Muscles," "An Exercise Program for the Child with Prader-Willi Syndrome," "Commonly Asked Questions About Infants and Children with Low Muscle Tone," and articles from parents on exercise, sports, and other activities for skill and fun.

*Exercise and Crafts & Activities for the Individual with Prader-Willi syndrome* is available for \$10.00 per copy to PWSA members (\$12.50 each for non-members), including shipping and handling. (Overseas orders add \$6.00)

Send request with payment to: PWSA (USA), 5700 Midnight Pass Rd., Suite 6, Sarasota, FL 34242; or call 1-800-926-4797 for charge orders.

## A Dad's View

### She Could Have Been A Supermodel!

By Timothy McMahon

What is it like to be the parent of a child with PWS? We all already know the answer to that question, and I can't imagine that anyone who isn't is particularly interested in hearing much about it. No, it's a unique experience that like most of life's unplanned experiences can, on any given day, be pretty good ... or then again maybe not so hot. It's all a matter of timing and perspective.

My mother was wrong. I was 6 years old in 1956 when I saw my first child with a "disability" (keeping in mind that we didn't have such nice words as "disability" back then). My mother said that these were "God's Little Angels" and that He sent them only to very Special Parents. I thought that was nice ... a little strange, but nice. I've found that the "God's Little Angel" part sounds good just about until we're in the middle of a temper tantrum. As for us being "special," well I don't even want to go there.

Not only are we not especially "special," I'm beginning to think that we're not even particularly unusual. After Betsy was born, my personal coping mechanism was making myself tell people that I had a handicapped child. I didn't turn it into a cru-

Native Americans valued their  
Hunters because they could  
always find food.  
On the plains my daughter  
would have been a God!

sade, but if someone would ask me if I had children, when I came to Betsy I'd mention that she was disabled. That's when I learned about "The Big Secret." If you don't already know, "The Big Secret" is that everybody has a child (son, daughter, niece, nephew, cousin, brother, sister ...) with some kind of disability and they just can't wait to talk about it! (I have since changed my policy. I never tell anyone when I'm on a three-hour airplane flight.)

I've often said, as has everyone else, that the trick is learning to enjoy the gifts your child does bring. Just because they're different than you expected doesn't mean they're not as good. That's true although it sometimes requires some redefining of exactly what a "gift" is. My grandmother used to say a hearty appetite was a gift. Scratch that one. Native Americans valued their Hunters because they could always find food. On the plains my daughter would have been a God! I sometimes remind myself that during the Renaissance, when "plumper the better" was the definition of beauty, my daughter's figure would have made her a supermodel! Like I said, it's all a matter of timing and perspective.

Betsy is lovable, and that's a real gift. You don't find many children (or adults for that matter) as honestly and completely true in the love and affection they give. Maybe for that reason, there's no one as rewarding to give love to as Betsy. When I think about it this way, all the rest of it doesn't seem to really matter very much. Besides, I'm the father of a supermodel. (Michelangelo, Rubens, Titian, where were you when we needed you?)

*Betsy McMahon is a 15-year-old with PWS and the youngest of four children. The McMahons live in New Hampshire. Her father, Tim, is an author and syndicated columnist and her mother is a teaching assistant.*



## From the Home Front

*In response to our request for parent wisdom on locks and alarms, one family e-mailed us the following great ideas for the kitchen and for that "trickiest" of holidays—Halloween.*

### A Menagerie of Alarms ...

Our son, Dustin, will be 17 in a couple of weeks so we feel fairly experienced in this subject. We have only had one padlock in our entire kitchen and that is on the pantry. We keep no food on the counters. We have a pig in the refrigerator that squeals whenever the light comes on, which means the door is open. We have a dog that barks and a frog that "ribbits" whenever anyone walks by them. We place them strategically so that Dustin cannot get to any food without a loud noise. It is amazing how well we can hear these at night. We have ordered all of these animals out of cheap catalogs for less than \$10 each and they have been well worth the investment. It has worked very well for us and helped to keep a little sense of humor in our own "zoo."

### ... and Some Halloween Tricks!

Every year from the time our son was old enough to trick or treat until 6th grade, which is when we cut it off for all of our children, Dustin has really enjoyed Halloween. We went out every year on the day before Halloween and handed out mints, gum, and fat-free treats for Dustin to all the houses we planned to trick or treat. Then as we came to each house the next night, each person would announce that they had something "special" for him. This seemed to turn this into a special time for him and made it something he could successfully do. Hope that you will share this with other parents because it sure made Halloween fun for us.

—Ross and Naomi Rhodes

### Tips on Toilet Training

When my son was little, we made a big deal about underwear with characters on them. We overly excitedly told him how special they were but that he couldn't mess on them because Winnie the Pooh would not like that.

As far as nighttime training, we had to do the alarm clock scene. My husband woke up each night and woke our son and made sure he got up and went. It was very hard work on our part, but it finally paid off. We felt it was more of a laziness issue than lack of control. We praised him a lot and rewarded him for dry nights.

—a mom, via e-mail

Both our pediatrician and our geneticist had been recommending a nighttime urine alarm for my daughter because of her bedwetting. This past summer, we finally gave it a try because she was approaching age 10 and really wanted to be out of Pull-Ups. I ordered a product called "SleepDry," and within one week my daughter had learned to respond to her body's signals and wake up to use the toilet. The alarm is a simple device that snaps onto the pajamas near the neck and has a split wire that extends down the front of the body and attaches to an outer pair of underpants, worn specifically for this purpose. Wetness on the pants completes the connection of the wires and makes the alarm buzz. It's harmless, and for my daughter it was unbelievably effective. Unfortunately, it hasn't been as successful for another family who tried it with a daughter about the same age.

For anyone interested in trying this approach, there are various alarm products on the market. For information on SleepDry, call 1-800-346-7283. I'm told Fisher Price also makes one, and I've seen similar alarms advertised in *Exceptional Parent* magazine.

—Linda Keder



### For the Love of Christie

is a mother's book about her daughter, who, because of a brain tumor that required surgery, radiation, and chemotherapy developed what is called "acquired Prader-Willi syndrome."

(Although PWS is typically present from birth, damage to the hypothalamus portion of the brain can cause similar symptoms in an otherwise normal person.)

Christie's tumor was diagnosed when she was 11. After her treatments, she developed the intense food-seeking behaviors typically associated with PWS and eventually weighed 385 pounds; she died at age 23 of obesity-related causes.

Christie's story is told not only in the book but also on a new Web page: <http://praderwilli.com>

The book is available directly from the author for \$12, including postage: Loraine Zarr, 117 24th St. S.W., Minot, ND 58707.

### Looking for an e-mail pen pal? ...

A dad writes that he "would love" for his daughter to develop e-mail pen pals with others who have PWS.

Any takers out there?

In our next newsletter issue we'll feature an "E-mail Pen Pals Corner." If you'd like to be listed, send an e-mail to: [pwsausa@aol.com](mailto:pwsausa@aol.com)

In the subject line, type PEN PALS. In the message area, please type:

- your first name
- your age
- something about yourself, such as interests or hobbies

"I wanted to take a minute to tell you how much we enjoyed the conference! Without the grant we wouldn't have gotten to go and would have missed out on a lot. We learned a lot, got to meet lots of wonderful people and had a great time! [Our daughter] had a great time and didn't want to leave! I pray that one day we'll be able to repay what you have given us for another family to get the same blessing!" —a note to PWSA from a 1998 conference grant recipient



# Ian's Story

by Sandy Phillips  
Newport News, Virginia

Our first child, Ian, was born in Bremerton, Washington, in May, 1987. After a week, he was transferred to Children's Hospital in Seattle, where we met Dr. Vanja Holm and Nutritionist Peggy Pipes. We remained there for a week while I was taught to gavage-feed and do range-of-motion [exercises] with him. Within two days of his release, he began receiving multiple services including physical therapy and my regular meetings with a dietitian. Because of the early intervention and being followed regularly at [the clinic] in Seattle for the first two years of his life, I believe he is doing remarkably well.

At birth Ian had no ability to suck; by the time he was three months old he was nursing. When he was 2, his sister Page was born. He adored her from the first and was always challenged to do what she did.

[After a move to Virginia], we enrolled Ian immediately in the Program for Educating Exceptional Preschoolers (PEEP), and he enjoyed the wonderful support of many talented individuals on the PEEP staff.

When Ian was 5 and ready to exit this program for the challenge of mainstreaming, our third

child, Cory, was born. We opted for an LD (learning disabilities) class with mornings spent in kindergarten. The teacher and school staff did not follow the IEP, and failure to communicate caused many problems which could not be resolved. We removed him from the school in favor of full-time mainstreaming into a T-1 (transition to first grade) placement. Ian skipped kindergarten and enjoyed a successful year in T-1 at our local school with the help of a very sensitive teacher. His IEP included physical therapy and speech therapy. He is only a year behind where he should be in school but is successfully achieving at this time.

Ian is in a regular 4th grade classroom. He does well in school except for the treatment he receives from some

adults and peers who think he is "normal" and treat him as though he were any other kid. His reactions to negative behaviors of the children in his class are what seem to cause most of the problems. He follows the rules—and expects others to do so. Mainstreaming was and is the best possible placement for Ian, but now we feel that some changes are necessary. We are currently planning to rewrite his IEP beyond his academic needs to include some things that will help to make his life more pleasant at school. He is given no benefit at all when it comes to his grades, and he maintains Cs in all of his subjects except for math. In math, Ian receives As!

He is the classroom alarm clock, reminding everyone when it is time to get ready for art class, library, or lunch. He enjoys class meetings, when he has an opportunity to tell his peers what they have done that upsets him and try to find solutions together. The guidance counselor has offered several group sessions that he has benefited from. One very helpful one called "Anger Management" concentrated on reactions.

Ian has never been overweight. We have always been extremely careful to watch his portions and eat lots of fruit and veggies. We watch the calorie count on the packages of everything

we buy. We serve small portions so seconds are almost always possible. Ian isn't permitted to cook or get his own food, which helps avoid food-related problems. His lunch is packed each morning, and we discuss and agree on what is to be included. He is permitted to buy his lunch once every week or so. Fortunately, our school district serves good choices. We look over the monthly menu and make selections.

Changes in routine or planned events can be a big problem for Ian. Lots of notice and discussions about where we are planning to go and what we'll do there can avoid these problems. He is not very conscious of cold or heat, so guidance is required regarding clothing, coats, etc.

He is a packrat by nature. It is difficult for him to part with even a scrap of paper he has scribbled on.

Ian has no cavities so far, but sometimes must brush his teeth three or four times to pass the "clean teeth" inspection at night. Skin picking is a problem. Keeping a fresh bandaid on the problem area is usually a satisfactory solution. At one time he bit his two thumb nails down to nothing. I had to apply an antibiotic

ointment and bandaids two to three times daily for a few weeks.

When we have problems with Ian at home, there are usually several contributing factors.

Often Ian is tired and wants to do something that we have said no to. He becomes upset and tries loudly to dissuade us. This results in his being sent to his room, where he can be really loud and bang on the walls. I often begin listing privileges that will be removed if his behavior continues. This usually brings a satisfactory end to his behavior because he knows we will follow through with taking the privileges away. Keeping careful restrictions on TV viewing, video game playing, and computer time has always been a part of our children's lives.

Ian was given a new bicycle for Christmas this year and managed to keep control of it for about 80 feet the second time he rode it. Jumping rope was an extremely difficult challenge, but he has learned how. He swims most summer days and enjoys it tremendously. Ian is successful in Cub Scouting with our encouragement. He has attained the level of first year WEBELOS and just completed the requirements for his WEBELOS badge. He took part in the district Klondike Derby, walking over seven miles in one day.

We feel that we've been very successful meeting the challenges that parenting a special child like Ian entails. If anything, the long discussions we have over issues that concern Ian and our family have made us closer than ever. The optimism with which we face each day encourages us to do our best for Ian, to ensure that his dignity and spirit remain intact.

**"... the long discussions we have over issues that concern Ian and our family have made us closer than ever."**

**"... by the time he was three months old, he was nursing."**



## 1998 Conference Abstracts and Videos Available

For those who want to keep up on the latest in PWS research, the national PWSA office has for sale the collected abstracts from our own Scientific Conference, held July 22 in Columbus, Ohio, and the complete package of abstracts from the International PWS Scientific Workshop and Conference that took place May 21-24 in Italy.

The PWSA conference abstracts are one-page descriptions of 18 presentations, including four on growth hormone and six on various aspects of behavior and behavioral interventions.

The international conference packet features 96 abstracts from presentations and posters, covering a full range of issues related to PWS.

In addition to the packet of abstracts from Italy, PWSA is able to offer, through the foresight and generosity of Kumiko Egawa of Japan, a two-video set covering parts of the international conference. Ms. Egawa is a research student and the mother of three, including 7-year-old Hiro-taka, who has PWS (see photos, below).

Ms. Egawa's videos include presentations by Drs. Cassidy, Ledbetter, Greenswag, and Hanchett, and Janalee and Al Heinemann from the United States, as well as a number of presenters from other countries. While they are amateur videos, these films provide conference coverage that would otherwise not be available in any form.

Prices for these materials are as follows:

### PWSA Scientific Abstracts—

\$6.00 members/\$8.00 nonmembers

**International PWS Conference Abstracts—**\$10 members/\$15 nonmembers

### International Conference 2-Video

**Set—**\$30 members/\$40 nonmembers

Packaging and shipping to U.S. and Canadian addresses are included in these prices. Please add \$6.00 for shipping to all other countries.

To order, call or write to the national PWSA office (see page 2).

## CALL FOR SPEAKERS & PANELISTS

### 1999 PWSA (USA) National Conference

July 7-10, 1999

San Diego, California

For the first time the host chapter for a PWSA (USA) national conference is issuing a "Call for Presenters and Panelists" for the Parents and Professionals Conference in San Diego, July 1999.

In issuing this call, we are seeking to broaden the number of participants, including parents, in our national conference. We invite all professionals involved in research, management, or treatment of PWS to provide a synopsis of papers they may wish to present in a conference session. (Note that there will be a separate submission process for abstracts for the 1999 Scientific Conference.) In addition to the wonderful contributions by the professionals who provide such valuable information to our members every year, we want to encourage families to get involved.

Our preliminary vision for the 1999 conference is to structure a number of "tracks" — a series of presentations, panel discussions, and question & answer sessions that will thoroughly cover a subject area. Each of these "tracks" would be structured to address issues for separate age groups. To get the full benefit of the knowledge of **all** of the experts, we want parents, guardians, and families to participate with the professionals by talking about their experiences, either in a separate session or as part of a panel.

Some of the tracks being considered are:

- Early Childhood Development & Pre-school (0-5 years)
- Educational Issues (K-12)
- Obtaining Services
- Transition Issues (Guardianship, Residential Options, Employment)
- Behavior Management
- Weight Management (Diet & Exercise)

Please consider how you could contribute to discussion of one or more of these topics, either as a speaker (you could team up with a parent, professional, or service provider) or as a panelist.

If you want to help, please call Fran Moss at the Prader-Willi California Foundation (PWCF), (805) 389-3484 or e-mail her at [pwcf@msn.com](mailto:pwcf@msn.com)

**WE WANT YOU!!! BE A PART OF THE 1999 CONFERENCE.**



Kumiko Egawa with her family, right. Above: Hiro-taka, 7, "grew corn and eggplant and cucumbers from seed" in front of their house; he "studied planting in his special education class" and "is a good little farmer."





## The Sibling View

*Siblings at the national conference in Columbus were asked their thoughts and wisdom about living with Prader-Willi syndrome. Some of their replies, which Gary Mann shared with those attending the Friday night banquet, are reprinted here for all to savor and ponder.*

### What's PWS and what does it mean to you?

"It's some kind of syndrome."

"Something is just wrong."

"Missing part of my Dad's body."

"I'm not sure but I'm jealous ... they get all the attention."

"You have to know how to count calories."

"It's a chromosome thing."

### What do you like best about your brother/sister with PWS?

"He never meets a stranger, but that worries me, too."

"He loves me and I like being around him."

"She always makes sure I get a snack."

"She makes stuff for me."

"He's kind."

"We enjoy swimming together."

"We understand each other."

"He's nice and understanding."

### You're the expert — What advice would you give to a family of someone with PWS?

"Make sure they brush their teeth."

"They are sometimes hard to understand, so let them show you so they don't get frustrated."

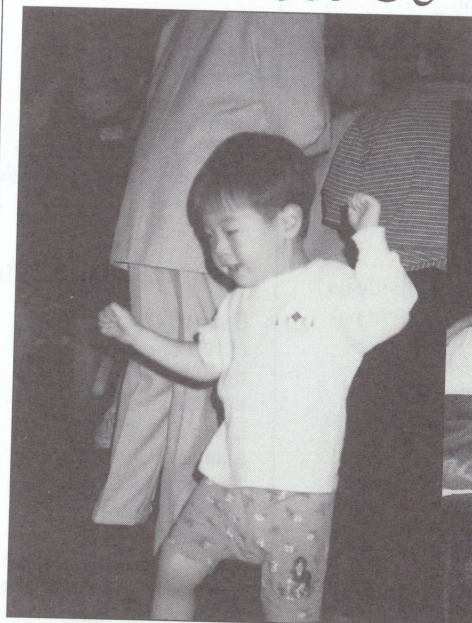
"Don't argue with them ... you won't win."

"Don't let them sit on you."

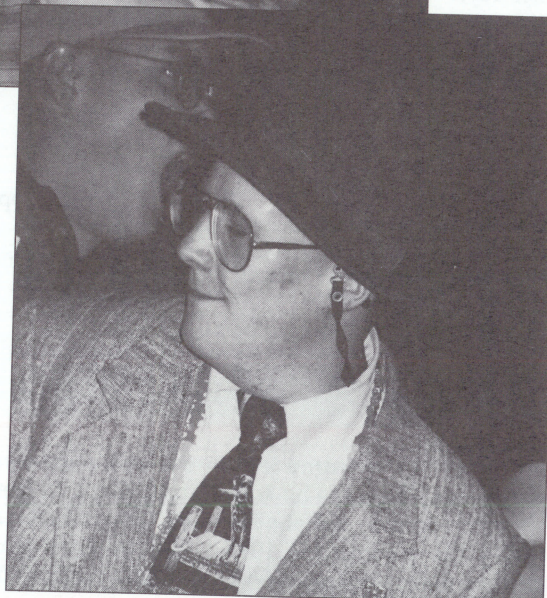
"Treat them like everyone else."

## Conference Scenes

Brennan Yim of Virginia solos on the dance floor (left); Carol Jamieson of Ohio (below) poses in her Finnish folk-dancing costume with Linda Ryan of California, director of the 1999 PWSA conference youth program.



Joyce Abell of Kentucky enjoys a reunion with Chris Guenther of Florida (above), while Curtis Deterling (right) of Minnesota demonstrates some dance floor style.







# A Heartfelt Thank You

by Pat Shiley,  
Ohio Conference Co-chair

The Ohio chapter would like to say a heartfelt thank you to everyone who joined us in Columbus for the 20th annual PWSA-USA conference.

To all the parents, siblings, and individual volunteers who worked so hard to plan the conference and to those who worked the YAAP program, a *heartly* thank you. We also thank the staff of the Adam's Mark Hotel who worked very closely with the Ohio chapter.

We would like to recognize some of the many individuals and organizations who contributed to the success of 1998 national conference.

## Members of the Ohio Conference Committee:

Drs. Jim & Ivy Boyle, Dr. Suzanne Cassidy, Tony & Johanna Costello, Sandy & Tom Giusti, Margit & Carole Jamieson, Max Litke, Patty & Gary Mann, Carl Miller, Nancy Richards, Nancy Roberts, Jack & Pat Shiley, Ken Smith, Cis Speer, Norma Wilson, Mary K. Ziccardi, and Dr. Bill Zipf

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Delaware County Board of Mental Retardation & Developmental Disabilities—staff and transportation for conference preparation, conference facilitators  
REM Consulting, Inc.—Service Providers' Program breakfast  
Pharmacia & Upjohn Co., Eli Lilly, Genentech, and Endocrine Sciences—Dr. Martin Ritzen's travel expenses from Sweden  
Mt. Carmel Hospital Systems—300 lunches for the Friday Youth Program  
Ohio Association of County Boards of MR/DD—300 admissions to COSI museum for the Friday Youth Program  
Ikon—photocopy machine  
Gary & Patty Mann—office supplies for conference committee  
Dottie Lee—nursery school program for the preschoolers  
BlockBuster Video—evening video program and prizes for the Youth Program carnival  
Eileen Doyle—meeting room signs  
Melissa Storer—graphics for conference folders and logo

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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.

