PWSA USA

The Gathered View

January-February 2002
Volume 27, Number 1

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

Report from the National Institutes of Health:
An Opportunity to Influence Research on PWS

By Janalee Heinemann, Executive Director

From November 29 to December 1, 2001, I was privileged to participate by invitation in a workshop, "Emotional and Behavioral Health in Persons with Mental Retardation/ Developmental Disabilities: Research Challenges and Opportunities."

The workshop was sponsored by the National Iinstitutes of Health Office of Rare Diseases, Joseph P. Kennedy Jr. Foundation, NINDS, NIMH and NICHD. The directors of each institute gave opening remarks, including Eunice Kennedy-Shriver, founder of the Kennedy Foundation.

Of the 90 participants, PWSA(USA) was one of only five disease-specific organizations invited to participate. The other attendees were primarily researchers renowned for their work with mental retardation/mental illness, or directors of major institutes who also have an impact on this population. I believe our invitation to participate in this conference was a defining moment in the history of PWSA (USA) and a big step in our involvement with research.

I was very moved at this conference for two reasons:
1) After all these years of dedication by so many parents and professionals, PWS is not just one of the 750 genetic syndromes lost in a maze of needs. PWS is *well known* among the world of researchers.
2) This workshop displayed how much passion and dedication there is among researchers for the cause of all of our children with a dual diagnosis.

Four speakers discussed PWS

Four different speakers discussed PWS in some form during that first morning. Three key speakers and two of the key organizers (Travis Thompson, Elisabeth Dykens and Mark Lewis) are all directly involved with PWS research.

Elisabeth Dykens, Ph.D., University of California at Los Angeles (and a member of the PWSA (USA) Scientific Advisory Board), reported a dramatic increase in the last 10 years in the number of articles published in medical journals on people with the dual diagnosis of mental retardation or developmental disability (MR/DD) and mental illness (MI). Of those articles, the second greatest number were about Prader-Willi syndrome.

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As parents, we often think that there is not nearly enough research going on with PWS, but I do know that proportionally, there is more research on PWS than most other syndromes.

Jim Harris, M.D., Director of Developmental Neuropsychiatry at Johns Hopkins University School of Medicine, discussed why people with a MR diagnosis have emotional and behavioral problems, including increased vulnerability, shared neurobio-logical basis, psycho-social etiology, and also as the result of an underlying psychiatric disorder.

Dr. Harris said epidemiology (the study of disease in a population) should be a means to an end – not just an end in itself. He stated that epidemiology should not be just "head counting" epidemiology, but that what we really need is more "experimental etiology (the cause of disease)."

Sir Michael Rutter, M.D., from the Institute of Psychiatry in London, England, discussed the "tyranny" of ICD-10 and DSM-IV (the diagnostic coding on which much of funding depends) and Internal Review Boards' (IRBs) diagnostic coding restraints. This topic was brought up many times in the 2½ days of the workshop. Clearly, participants believed that the solution involved more flexibility by the FDA and individual institutions in research design approvals, as well as use of criteria other than the DSM codes for diagnosis and reimbursement.

Elisabeth Dykens discussed the excitement of uncovering why there are variations within a syndrome, such as the

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$30 Individual
$35 Family
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For members outside the United States, dues are $40 Individual, $45 Family and $50 Agencies/Professionals (US Funds). We never deny parents membership for any reason.

Call for Papers

PWSA (USA) National Scientific and Provider Conference

"Angels Among Us"

July 11, 2002 — Salt Lake City, Utah

For an application to present at the Scientific Conference, go to:
www.pwsausa.org/conf_24/sciform.htm
Deadline: April 1, 2002

For an application to present at the Providers' Conference, go to:
www.pwsausa.org/conf_24/proform.htm
Deadline: February 28, 2002

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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) unless so stated. Medical information published in *The Gathered View* should not be considered a substitute for individualized care by a licensed medical professional.

The Gathered View welcomes articles, letters, personal stories and photographs and news of interest to those concerned with Prader-Willi syndrome.

Communications regarding *The Gathered View* or PWSA membership and services should be directed to the national office of PWSA (USA) in Sarasota, Florida.

There Are Angels Among Us...

Our thanks to a loving father who wants to help our PWS parents reach the ultimate goals for their children. Bill Vucci, who works with the U.S. Secret Service, is the father of Maria Christine, who has the UPD form of PWS. When he and his wife Anne attended the St. Paul Conference, he was deeply moved by our children and made an oath that he would do whatever he could to protect our "little angels" needs and rights.

Bill became an advocate for all of us in getting our message out to Federal government agencies and employees by getting the Secret Service to work toward placing PWSA (USA) into the Combined Federal Campaign (CFC). The CFC is the Federal Government's version of the United Way.

Bill saw the need for funding in our organization and found a way to bring attention to our cause and our needs. He brought awareness of the needs of PWS during a three-day CFC Drive by setting up an information table about PWSA(USA) in the main lobby of the Secret Service Headquarters in Washington, D.C.

Next year, when PWSA(USA) receives a Federal ID number, all government employees can contribute directly to our organization through their payment plan or by individual cash contributions. Tell us if you or anyone you know works for the federal government.



The Vucci girls: Maria and Angela

Bill is now focused on new goals within the federal system by helping us to obtain lobbying support to place PWS on the Social Security list of approved syndromes for funding.

In an e-mail to Carolyn Loker and me, Bill wrote, "I am doing this for all of our angels." At the very moment Carolyn was reading the e-mail, she looked up and her little Anna, who has PWS, was hanging an angel on their Christmas tree.

--Janalee Heinemann

November Issue of 'Exceptional Parent' Features PWS

Another big thanks goes to **Linda Thomas**, a parent member who wrote an article on PWS that was published in the November edition of *Exceptional Parent* magazine titled, "Living with Prader-Willi: The Starving Syndrome."

Exceptional Parent also included an "Organizational Spotlight" of PWSA (USA) and an article from Dr. Merlin Butler, our Scientific Advisory Board chair, titled, "Ask the Doctor." Linda and her family were also featured in the Tacoma, Washington newspaper in September.

Freedom Cards Are Still Available for Angel Fund Donations

Freedom means....

"not feeling hungry & having people watch over you all the time."
Matt, 28, MO

"having a fun, good, healthy life by having choices of what to do"
Yael, 14, NY

"to be allowed to carry my own money and to be able to get food."
Josh, 31, NY

"being able to watch BARNEY anytime I want to!"
Anna, 7, MI



...for children and adults with Prader-Willi Syndrome

PWSA USA

We apologize to those who received their annual angel fund-raising card folded inside out. We estimate that the mailhouse sent out approximately a third of the mailings folded incorrectly. The front of your card should look like the one on the left.

Remember, if you have friends or relatives to whom you want cards sent, just call us at 800-926-4797, or send us their names and addresses. It is an easy way to assist us with the main fund-raising that is so vital to keep PWSA (USA) operating.

President's Message



From The Lows Grow Steel Magnolias

By Lota Mitchell

Everyone who becomes a parent signs on for life, but when the child has PWS, it means permanent active duty.

As I write this, the New Year, 2002, lies dead ahead, and 2001 is gasping its last. What a year it was, filled with highs like the birth of a new grandchild, becoming PWSA(USA) president, and being featured in *Family Circle* magazine in the section "Women Who Make a Difference."

Then there were the lows. The horror of 9/11. And the low that comes when your child is having problems.

This message has a warning label on it: You may want to skip to another part of *The Gathered View.*

For my daughter Julie, who is now 32, the year 2001 was a rough one.

I shared my distress at the December meeting of our Pennsylvania Chapter. Our members, with children from age 2 up, were wonderfully supportive and understanding.

When I asked if I should write a condensed version in my next president's message, they said definitely. They wanted reality, they wanted to know what could lay ahead. And I felt I would be impersonal and inauthentic if I did not. Your officers, board and staff are real people struggling with their own real problems.

Julie has always had a severe skin picking problem. Last January the doctor tried a medication which instead of helping, set her on that "edge" with which many of us are all too familiar: it erased her smiles and spontaneity, and as her house manager commented, even after it was discontinued, many weeks passed until Julie "got her personality back."

In June Julie developed cellulitis on her face, probably from bacteria transmitted via the skin picking, and was in the hospital for a week on intravenous antibiotics, followed by a long course of oral antibiotics. She didn't get to go to conference or to camp. Of course, she picked at the healing sores on her face.

In early August she had a psychotic episode and was put on an anti-psychotic medication, which she is still taking.

I have believed that much of the "zoned-out" behavior and lack of animation I'm seeing now (similar to what I saw with the medication she was on earlier, only without the "edge") is due to the anti-psychotic drug and her extreme sensitivity to anything the least bit sedating. But on the other hand, I have to concede that it may instead be the result of the mental illness. There is really no way of knowing.

In response to my plea to reduce or eliminate that medication, her doctors warned that she might then relapse into a worse episode from which she might never completely recover.

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This is the dilemma, I suspect, of many parents when they and the doctor(s) disagree. One of our chapter members shared her story about her 8-year-old son having abdominal pain, which his doctor had concluded was "in his head." Finally, she took him to the hospital, where they found a strangulated hernia. Knowing our own children as we do, we are often right—but sometimes we might be wrong.

From all this I draw several conclusions:

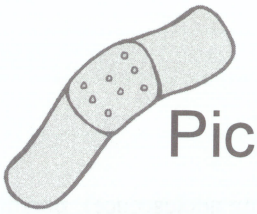
First, we know everyone who becomes a parent signs on for life, but when the child has PWS, it means permanent active duty.

Second, difficult decisions may face us for which adequate information may not be available or even exist.

Third, we are so fortunate to have our chapters and other parents who understand and offer support in the low times.

Fourth, I am delighted that the research world shows interest in the dual diagnosis of mental retardation and mental illness (read Janalee's front-page article). We know that people who are mentally retarded are 3 or 4 times more likely to have psychiatric problems, and we know that people with PWS are at greater risk in their adult lives than the rest of the population. We need all the help we can get.

And last but not least, we PWS parents get up from the lows, dust ourselves off, tighten our belts, and go right back to being steel magnolias.



Picky, Picky, Picky: A Parent's Perspective

By Theresa Kellerman

Our kids are not picky eaters, but they sure are picky pickers. Skin picking is common in many children and most adults with PWS (about 80 percent).

Although infection should always be considered a risk, most parents report that their children who pick seldom get an infection. Nevertheless, this is disturbing behavior and not conducive to being accepted by peers and others in the home or community. The technical medical term for compulsive skin picking is "psychogenic excoriation."

The skin picking most likely starts as a result of inadequate messages from the skin to the CNS (central nervous system) and a decreased sensitivity to pain. Skin picking is more likely to occur during periods of boredom or stress, and occurs most often at bedtime, in the bathroom, in class, and in the car. Sensory stimulation can be provided to help reduce the incidence of the picking. An occupational therapist trained in sensory integration can do an assessment and make recommendations for activities that increase sensory stimulation, such as skin brushing and play activities that are fun as well as effective in reducing the need to pick.

My daughter began picking her skin around age 2. At first it was just insect bites, but eventually she would pick at her skin on her hands or arms relentlessly. At one time she had 20 sores in various stages of healing (or non healing). Some sores were picked at for two years before they were allowed to heal completely. She picked her skin regularly until age 13, when my use of back rubs at bed time totally stopped the picking for two years.

After she entered a group home, the picking started again and increased in seriousness over the years. At one point she was able to control it and stop as a result of a contract, but the motivation offered to make this effective must be something she really, really wants. The picking eventually started again after the staff person who initiated the contract was no longer present.

I believe my daughter has become addicted to the picking. When tissue damage occurs, natural chemicals are released in the brain that produce a good feeling. After a long period of time, it becomes extremely difficult for the person to stop picking, they are so dependent on the effects.

But there is a medication that blocks the release of the brain's endorphins and thus eliminates the "high" from the picking, and is quite successful in causing the picking to cease in persons with PWS.

The medication is ReVia* (naltrexone). A dose is prescribed for once a day might not be often enough for a person with PWS, as it is out of the body's system in 16 hours. Twice a day may be necessary for it to be really effective. My daughter tried the ReVia for a short period when it worked well, but she has since refused to take it, probably because she prefers the neurological effects of the picking. But she knows that if the picking reaches a serious level again, she will go back on the ReVia.

Skin picking is more likely to occur during periods of boredom or stress, and occurs most often at bedtime, in the bathroom, in class, and in the car.

I've been told that Duoderm, a burn dressing sold by the box, can also be helpful. Duoderm is not always easy to find, so ask your health care provider or pharmacist about it.

PWSA(USA) is currently sponsoring a grant on a new drug, Topiramate, that seems to have some potentially good results for dealing with skin picking. A report about Topiramate will be published in the next issue of *The Gathered View*.

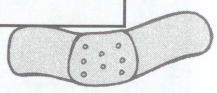
What does not work? Punishment, lectures, nagging, consequences, undue fussing, blaming and shaming, and all the responses we persist in even when we know they are not working.



What works?

Some remedies that might be effective:

- Bandages and Ace wraps
- Lotions and skin creams
- Redirection
- Back rubs
- Sensory Integration therapy
- Short term rewards (pickles)
- Contract with reinforcements
- Benadryl
- Understanding the organic origin
- Duoderm (a burn dressing)
- ReVia (naltrexone)



* Naltrexone and fluoxetine in Prader-Willi syndrome. *J Am Acad Child Adolesc Psychiatry*. 1993 Jul;32(4):870-3.

Editor's Note: PWSA(USA) strongly urges you to consult your health care professional on any medical advice.

Teresa Kellerman is president of Prader-Willi Syndrome Arizona Association and the mother of Karie, 26, who has PWS. Her article was first published for the Prader-Willi Syndrome Arizona Association in the Fall 2001 issue of Prader-Willi-Nilli News, *Volume VI, Issue 2.*

Understanding Osteoporosis

By Merlin G. Butler, M.D., Ph.D. FACMG

Osteoporosis (brittle bones) is usually an asymptomatic condition until or unless complications occur, such as fractures.

Osteoporosis is reported to occur in 60-90 percent of patients with Prader-Willi syndrome (PWS), and affects an estimated 25 million people in the United States. Osteoporosis can be recognized by direct measurement of bone mass from the spine or total body using dual energy X-ray absorptiometry (DEXA) even before there are any fractures or problems associated with osteoporosis.

To determine the bone density status in Prader-Willi syndrome, we analyzed 21 subjects with PWS between the ages of 10 to 44 years and 9 subjects with obesity of unknown cause. We obtained bone density data by DEXA, physical measurements and markers of bone turnover, and reported our results in the *American Journal of Medical Genetics* (103: 216-222, 2001).

N-telopeptide levels from urine samples were obtained in all subjects. N-telopeptides are the protein fragments of type I collagen, the major bone connective tissue material. During periods of active bone degradation or high bone turnover, high levels of N-telopeptides are excreted in the urine.

Although N-telopeptide levels were higher in the subjects studied, the levels were not significantly different compared with obese subjects without PWS.

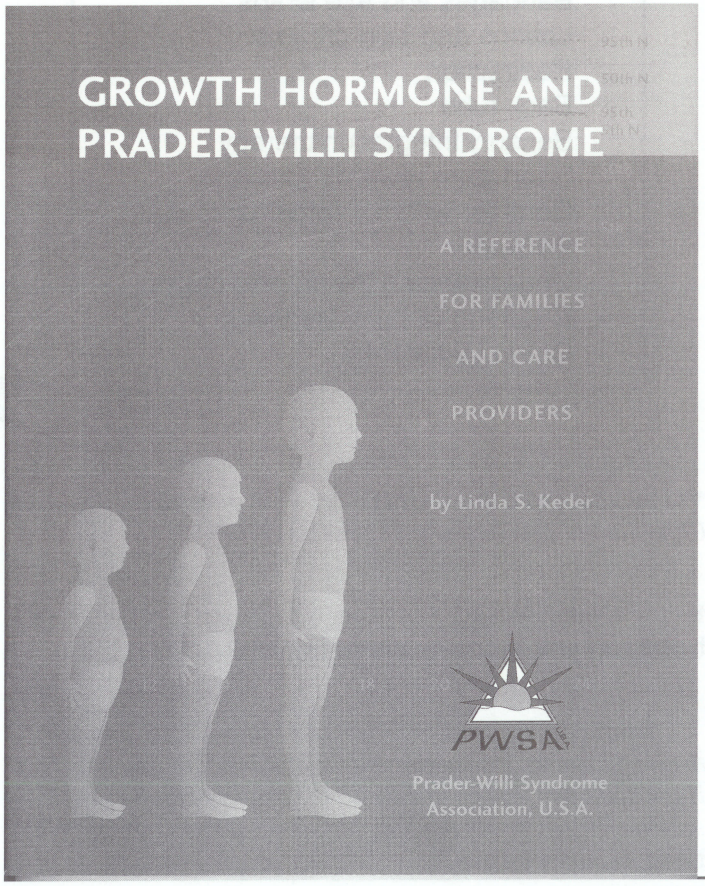
The subjects with PWS had significantly decreased total bone and spine mineral density and total bone mineral content for their age. There were no apparent differences in bone density or markers of bone turnover between those PWS subjects with the chromosome 15 deletion or those with maternal disomy 15 (both 15's from the mother).

The decreased bone mineral density in subjects with PWS may relate to the lack of depositing bone mineral during growth when bones are becoming more dense (e.g., during adolescence), possibly because of decreased production of sex growth hormones and/or long-standing hypotonia.

Our study further supports the importance of early diagnosis of PWS and the use of DEXA measurements in early childhood to determine the bone density status of these subjects. Possible hormone replacement (sex, growth, and/or thyroid) may be needed if studies show hormone deficiency, and calcium supplements may be helpful in the diet.

Hopefully, the decreased bone density in subjects with PWS may be alleviated and risks lowered for possible fractures in this subject population.

Dr. Butler chairs the PWSA (USA) Scientific Advisory Board and is chief of the Section of Medical Genetics and Molecular Medicine at Children's Mercy Hospital in Kansas City, Missouri, and Professor of Pediatrics at the University of Missouri-Kansas City School of Medicine.



New Resource Book is Now Available

The book, *Growth Hormone and Prader-Willi Syndrome: A Reference for Families and Care Providers*, has just been published.

A huge thank you to our parent members, Linda Keder, the book's editor, and Don Goranson, coordinator of graphics, layout, production and printing. They did an outstanding job!

The Growth Hormone book is now available through PWSA (USA) thanks to an unrestricted educational grant from Pharmacia Inc.

It is a comprehensive must read for all parents considering or using growth hormone, as well as their medical providers.

Thanks to the grant, PWSA(USA) has been able to send free copies of the book to nearly 3,000 physicians around the nation. We are also able to provide the book at a cost of $10.00–but can waive that fee when appropriate.

Call the PWSA(USA) office today to order your copy and one for your physician.

Meet Our Chapter Presidents — Part 2

By Lota Mitchell, PWSA(USA) President

Let me introduce a few more of our hard-working chapter presidents. They are truly special people and deserve recognition.

NEW JERSEY — **Doug Taylor** is a school music teacher (grades 4-8), involved with band competitions and church. His only child, Heather, now 21, lived with her mother until she was 10. Then Doug cared for Heather as a single parent for several years until his remarriage.

IOWA — A hairdresser with her own business, **Tammy Davis** is in her fourth year as president. She has three children, 9, 13, and 15. Nine-year-old Eric was diagnosed clinically only at 12 days with PWS. Insurance won't pay for further testing. If any research trials are going on that he could get into to further determine his diagnosis, she'd like to know about them.

CONNECTICUT — **Vicky Knopf and husband Dave** have David, 6½, with PWS. In addition, they have adopted Ben, 2½, and Caroline, 6 months, who also have PWS. They also have four other children, all boys, the oldest of whom is 12. Somehow Vicki manages to work in parent mentoring for PWSA(USA) as well as Parent-to-Parent.

OREGON — Transplanted from Idaho to Oregon 12 years ago to get better special education for two of her three children, **Lennae Elkington** has a son, 24, with autism, Megan, 18, who has PWS, as well as a daughter, 23, in college. She says she spent 5 years in Idaho educating legislators, educators and others, finally gave up and moved to Oregon. She comments also that she "kind of lost her self" in all the efforts.

NEW YORK — A CPA, **Henry Singer** lives in Brooklyn. His office building is right next to Building 5 of the World Trade Center. He needed police escort to get to it for weeks. Having served 8 years total with 2 years off, Henry cannot succeed himself, and he is concerned about who will be the next president. Active in his temple, he has a daughter, 27, who lives in Jerusalem, and son Josh, 31, with PWS, who is in a residential placement.

OHIO — A physical therapy assistant who also has a business degree, **Johanna Costello** works 10-24 hours a week. She and her attorney husband have a daughter, 18, a son Anthony, 6, with PWS, and a son aged 2. Although Johanna is American born, her family is in Holland.

NEW ENGLAND — **Margaret Bell** has been president for a year, was treasurer for 4 years before that. Her past includes being an orthodontic assistant and in sales, but she hopes to go a different direction in a part-time job soon. Son Ryan, 26, diagnosed with PWS at age 5, is her only child. He has been at Cardinal Cushing Center for the past 6 years.

FLORIDA — Husband and wife team **Keith and Debbie Peaton** share the presidency of this chapter. Keith is a sergeant with the St. Petersburg police department, and Debbie works out of their home, managing property. They have two sons, Shay, almost 17, and Rory, 19, with PWS. Their travel agency sent them to St. Louis instead of St. Paul for the 2001 conference, and the Peatons did not realize they were in the wrong city until they were at their hotel. They rented a car, drove 8 hours to St. Paul, attended the conference, and drove the 8 hours back to St. Louis to fly home!

Nominees for PWSA(USA) Board of Directors wanted

Who can be a Board Member?

A member of PWSA (USA), which includes parents, caregivers, adult relatives, grandparents and professionals.

Who is qualified to be on the Board of Directors?

Anyone willing to volunteer time, talents and expertise to to support the mission of PWSA (USA).

What are the expectations for Board Members?

Board Members are required to attend two board meetings a year, one at the annual PWSA (USA) conference and one in January at the national office in Sarasota, Florida.

Are there any other responsibilities?

Conference calls and mail votes are required throughout the year. Each Board Member must serve on at least one committee. Current committees are Leadership Development, Publications, National Conference, Crisis/ Intervention and Training, Finance, Funding and Grant Development, Board Advisory and Executive.

What is the term of office?

The Board Member serves a 3-year term and can run for three terms consecutively.

How to Apply

Names of members interested in or recommended for a seat on the PWSA(USA) Board of Directors should be submitted no later than April 1, 2002.

Recommendations should include a brief description of the member's qualifications to serve on the Board.

Please send recommendations by mail, fax or e-mail to:

PWSA(USA)
Attn: Ken Smith, Chair, Board of Directors
5700 Midnight Pass Road, Suite 6
Sarasota, FL 34242

E-mail: *pwsausa@aol.com*
Fax: 941-312-0142

Questions and Answers About Research

By Elisabeth Dykens, Ph.D.

Our progress in unraveling the many complexities of PWS depends on a critically important partnership—one between families and researchers. Both groups have vested interests in ensuring that this partnership stays viable and healthy. Families have questions about PWS that researchers can help answer, and researchers need families to participate in their projects and to sharpen their research questions. We need the expertise of both families and researchers, working and learning together, to solve the many pieces of the PWS puzzle.

Beyond these lofty goals, what are the nuts and bolts of actually doing a study? This article outlines some of the many questions that families often have about research in general, and about research in PWS in particular. Now more than ever, PWS is the focus of genetic, medical, and behavioral research, and thus the time is ripe for an article that overviews questions from families and practitioners alike.

Why aren't more researchers studying PWS?

The answer to this depends on whether you think the glass is half empty or half full. There are now more than 750 known genetic causes of intellectual disabilities, and PWS actually enjoys more research than many of these other syndromes. This is due, in part, to the revolutionary effects that the genetics of PWS have had on the larger field of molecular genetics.

Thus the genetics of PWS and its related sister condition, Angelman syndrome, remain hot research topics. Indeed, these two syndromes have made molecular genetic history as the first, known human disorders associated with genomic imprinting.

But other research, particularly behavioral research, has lagged behind. This is because most behavioral researchers study people who have mixed causes for their delay. Instead of singling out PWS, these researchers might study groups comprised of people with mild mental retardation caused by Down syndrome, autism, seizure disorders, cerebral palsy or even unknown factors.

While the use of these mixed etiologic groups is now being questioned, these groups still predominate in behavioral mental retardation research. Thus for many behavioral issues we know a lot more about people with mental retardation in general than we do about PWS *per se*.

That's the bad news. The good news is that things are changing. Though some colleagues continue to de-emphasize etiology, more and more researchers, students, and federal granting agencies appreciate the scientific value of studying behavior within specific conditions such as PWS.

What is the process of doing a study, what are the steps involved?

Studies are initially based on ideas about what might be happening, or hypotheses. Researchers get their hypotheses from reading professional journals, listening to and talking with colleagues, and by talking with and listening to families and individuals with PWS themselves.

The hypothesis could be genetic, medical or behavioral, but before they start out, all researchers need to have a well-developed sense of what they might find and why.



Elizabeth Dykens, Ph.D.

Armed with their hypotheses, researchers must then climb up a rather daunting set of stairs to test their ideas and put them into action.

First, they must go through an ethics committee and get permission from their university to actually conduct the study. This permission is needed no matter what type of study is being proposed—working with mouse models of PWS, analyzing blood samples drawn from individuals with PWS or interviewing people with PWS and their families.

All research universities have an Institutional Review Board, or IRB, which reviews applications from researchers seeking permission to conduct projects. The IRBs are mandated to follow federal guidelines that safeguard the health, rights and well being of both human and animal research participants.

A focal point of the IRB is the informed consent process. This process ensures that prospective research participants are fully aware of the goals and expectations of the study, confidentiality of data, and any risks or benefits for them. Depending on the university, researchers may spend many months going through the IRB process.

IRB approval in hand, researchers then need grant funding to actually conduct their studies. The amount of funding may vary, but most universities expect researchers to pay for their projects. They need to pay for everything from phone calls, photocopying and lab equipment to the salaries of research assistants, and often, salaries of the researchers themselves. Many researchers, especially junior faculty or those based in medical schools, are on so-called "soft money," and their salaries depend on grant support or earnings from their clinical or other activities.

Obtaining funding, then, is the next big hurdle. But before researchers can apply for a large grant, they need some evidence that their ideas make sense, and that the project is likely to succeed. They need to gather and analyze "pilot data," and then use these preliminary findings to justify asking for bigger dollars.

Some universities have small amounts of start-up pilot monies that junior faculty can apply for. The PWSA also funds pilot studies that help promising researchers obtain larger grants devoted to PWS.

At some point in their careers, most researchers apply to the federal government for a grant, typically from the National Institutes of Health (e.g., NIMH, NICHD, etc.). These applications are extremely competitive. Once submitted, a

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PWSA (USA)'s Research Fund

PWSA(USA) maintains a Research Fund especially designated for research and nothing else. Since its inception in 1983, it has funded over 20 studies in amounts up to $25,000.

Money provided by PWSA(USA)'s Research Fund may fund an entire study, or serve as "seed money" to help the researcher(s) get a larger grant, say, from the federal government.

Health-related nonprofits, no matter their size, do not undertake the research, but help to provide funding. PWSA(USA) has a system in place for researchers applying for funds:

- The researchers send a detailed proposal including IRB approval with a dollar request to PWSA(USA).
- This is reviewed by members of the Scientific Advisory Board (SAB), a panel of researchers themselves, which then makes recommendation to the Board of Directors to accept or reject the proposal.
- The Board of Directors reviews the research proposal and SAB recommendation and generally follows that recommendation to give final approval or reject the proposal.

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committee of researchers evaluates the scientific merit of the application—a process that takes from 4 to 5 months.

After the applicant has the committee's score and the written critiques of the proposal, the applicant can revise and resubmit the grant application up to three times. Once funded, often more than a year or two after the initial submission, the applicant can finally begin the study.

Finally, that adage about academics —"publish or perish" — is absolutely true. Researchers need to publish their findings in peer-reviewed journals, as their livelihood and careers depend on their scholarly productivity. Researchers also need to share their findings with their research participants. Some researchers offer individualized feedback to participants in a letter or feedback session, while findings based on the entire group can be shared at conferences or in newsletters such as *The Gathered View*.

Why do researchers need to compare people with PWS to others? We already know that they are different.

Comparison groups are needed to identify those features that are unique to PWS, and those features that are shared with others with or without developmental disabilities. These comparison groups might consist of others with similar ages, behavioral problems, cognitive delays or degree of obesity as the group with PWS. Comparison groups are chosen on the basis of the questions being asked by the researchers, and are an important aspect of research.

My child/adult doesn't have certain features of PWS, or they have them more or less compared to others. Should we still participate in studies?

By all means, yes. One of the goals of many PWS research programs is to understand the huge amount of individual variation that we see in this syndrome. Some researchers are focused exclusively on unusual cases of PWS, while others are interested in why we see such wide variation in features such as hyperphagia, compulsivity or even visual-spatial skills. We need to assess the entire range of people with PWS to answer these questions.

Further, by studying a variety of persons with PWS, we also get a better handle on factors that contribute not just to problems, but to health, competency and well-being.

Why does research take so long?

Even though researchers are interested in individual differences, they still need to identify what is happening for the group as a whole. This means collecting information from a large group of individuals, which can be very labor intensive and time consuming.

Sometimes, based on their preliminary analyses, researchers might need to recruit a more selective group: for example, children aged 3 to 5 years, or adult females in group homes, or cases with maternal UPD living at home, etc. This type of specificity also slows things down.

Once the data are collected, they are typically coded (to protect confidentiality of participants), scored, entered into a computer and analyzed, which is also time consuming. After the data have been interpreted, they need to be written up for possible publication in peer-reviewed journals. Much like the lag of a year or two for obtaining a grant, it may take a year or more for a paper to finally appear in a journal.

If you participate in a study, be sure to ask the researchers when you are likely to hear back from them, either with individual feedback about your child, or with summary findings from the entire group. Also, recall that researchers are typically funded from many sources, and often have clinical, teaching and administrative obligations that take away from their research activities. Most researchers guard those precious few hours each week that they can devote exclusively to their research!

We have a very hectic work and family schedule—why should we take the time to participate in a study if the researchers tell me that my child won't benefit?

The pat answer is that by participating you can feel good about contributing to science and furthering knowledge about PWS, both for your family and for the next generation of babies born with PWS. Although true, this answer is a bit simplistic.

Recently, my husband and I were asked to fill out a lengthy survey on the personality of our 3-year-old son for a graduate student study here at UCLA. As I dutifully trudged through the 120-item survey, several thoughts came to mind: first, it's hard to place our wonderfully complex son on a 5-point scale; second, how many more of these are left; and third, why am I doing this again?

Technically, the consent form that we signed said that we would receive no direct medical or therapeutic benefits. But at about item 23, I realized that we were definitely deriving other benefits. We are usually so busy caring for Alexander that we don't often pause and ask ourselves to rate his budding

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expression of some of the behavioral symptoms.

She said an average of 4 different non-food compulsions are now classified in PWS, and that the number and severity of compulsions in PWS is about the same as classic cases of Obsessive Compulsive Disorders (OCD). There is a dramatic difference (higher percent) in those with PWS who have OCD and other mixed MR/MI groups. This all leads to the question: Is chromosome 15 directly related to causing OCD in all populations?

David Braddock, Ph.D., Executive Director and the Associate Vice President for Research at the Coleman Institute for Cognitive Disabilities at the University of Colorado, said that the cost of those with a dual diagnosis living in public institutes is $3.7 billion a year. This cost includes 200 percent of typical staffing cost, and totals 70 percent of cost of care for all. In the past, more than 50 percent of those with a dual diagnosis were in large residential settings. Now 61 percent of those in residential settings are in homes of 6 or fewer people. Nine states now do not operate any state institutions.

Have we improved the quality of life?

One of my own questions is whether we have really improved the quality of life. More studies need to be done on which supportive care models have the best success ratio with PWS in diet management, behavior management, client satisfaction (family relationships, friendships, functioning ability, health, etc.), parent satisfaction and longevity of staff.

Sixty one percent of those with MR/MI are with aging caregivers. What happens to them when parents can no longer provide their care? For all with a dual diagnosis, we need to study which programs are most effective.

Informed decisions versus risk

Regarding research, there was much discussion throughout the conference as to what constitutes "minimal risk" and what constitutes an "informed decision."

Research that participants believe should be priority includes:

- *Psychotropic drugs – how they react on diagnosis-specific groups and how they interact with each other.*
- Mental health problems of people with developmental disabilities.
- Combining biological treatments with behavioral and psychosocial interventions.
- The effect of intensive early intervention through an interdisciplinary team approach in the community. (Travis Thompson said that the extensive research that was done in autism in this area could build a bridge for other disorders.)
- *Families should be included early on in the design of research if feasible.*
- Researchers should look at the cultural dimensions of treatment acceptability.
- Advances in neuro-imaging should be used to examine the mechanics of how treatment does and/or doesn't work.

(Italicized above are components I lobbied for – and I had a great deal of support.)

Impediments and solutions

Impediment: Getting beyond parallel structures of primary and secondary diagnosis, and the parallel structures of research entities.
Solution: We need a coalition of service providers and research disciplines. Multi-site, multi-collaborator designs need to become the norm. We need more cross-discipline collaboration, and also a coalition of disease specific national organizations (such as ours) for research collaboration. I talked with Dr. Robert Fletcher, the Executive Director of the National Association for the Dually Diagnosed (NADD), who agreed to coordinate a future conference.

Impediment: Lack of new researchers in the field of MR/DD and MI (dual diagnosis). Research training opportunities can come too late to set the direction of clinical training.
Solution: PWSA (USA) has already been looking at solutions in this area by considering as part of our 5-year strategic plan to fund a 2-year Fellowship for PWS. The cost would be $35,000 to $50,000 a year. Medical doctors may also need a stipend to offset reimbursed/managed care clinical work their research may bring.
Larger solution: Create extra training centers of excellence.

Impediment: Often those with MR are automatically excluded from research. Also, research (and disability funding) often excludes those who have MR/MI that does not exhibit itself until after the age of 18 (an example is a young adult who has acquired PWS (hypothalamic obesity due to a brain tumor or head injury).
Solution: Broaden those included in research with added safety protections.

Ethical issues unique to PWS

I was able to tell of the unique ethical issues of Prader-Willi syndrome, and how it defies the current mainstream of "least restrictive environment." Intrigued by my comments, the editor of the *Journal of Child Neurology* asked me to write an article on this topic for the journal.

As I have stated before, our impact on research can be far-reaching if we do it wisely. Although we are not in a position to hand out millions of dollars, I believe we can dramatically impact research on PWS by:

- Careful assessment of what research would be the most effective to support – such as a fellowship.
- Being the organization to network and link researchers, families and new concepts.

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Report from NIH - *continued from page 10*

• Networking with other organizations that deal with like problems and needs — to learn from each other and provide a coalition that will impact on researchers and legislators. This conference was a tremendous "kick start" in this area.
• Learning from researchers the realities of their world and helping them be grounded in the reality of our world and needs.

If we all used Eunice Kennedy-Shriver as our role model, we would realize we *can* make a difference. None of us may have the Kennedy name, money and power – but we can all have the Kennedy passion and compassion and tenacity when it comes to the cause of our children with special needs.

Robert Kennedy once said, "We must admit the vanity of our false distinctions among men and learn to find our own advancement in the search for the advancement of others.... But we can perhaps remember, if only for a time, that those who live with us are our brothers; that they share with us the same short moment of life; that they seek, as do we, nothing but the chance to live out their lives in purpose and happiness, winning what satisfaction and fulfillment they can."

Comments by Eunice Kennedy-Shriver

"Our work at this conference can set the course of action for the future."

"Seventy percent of those with mental retardation (MR) have a psychiatric disorder (3 to 4 times as much as the general population)."

"Pay special attention to teachers' training."
(I discussed personally with Ms. Kennedy-Shriver the issue of our children with PWS being integrated/mainstreamed into schools with teachers who are not trained or willing to meet their special needs. Combine that with the new zero tolerance attitude, and many of our children are getting suspended, expelled and even arrested. -- JH)

"We must do what we can to stop states from eliminating services."

"We need research, but do not forget that these people [(MR/MI diagnosed] need services."

Eunice Kennedy-Shriver and her Kennedy siblings, Joseph, John, Kathleen, Patricia, Robert, Jean and Ted, have a sister, Rosemary, who is mentally retarded and

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- *continued from page 9*

personality. Is he really "wary"? Well, okay then, in what situations? How come my answers didn't always agree with my husband's?

By completing the survey, we took a step back from our emotional roles as parents and viewed Alexander through a different set of lenses. And we most certainly learned something new in the process.

Research projects differ in the extent to which they offer medical or other therapeutic benefits. Before participating, it is important that families understand exactly what they will and will not gain from their involvement in a study. But even in studies with no direct benefits, families shouldn't be surprised if they still learn something new about themselves, their children and PWS.

How can families specifically be of help?

Ask to be on the research list of the PWSA, so that you can be informed of research opportunities. Before researchers can invite families on the research list to be in studies, they need to have their goals, IRB approval and consent letter reviewed by the Scientific Advisory Board of the PWSA.

Larn about the projects that are ongoing, and consider the pros and cons of participating. Be a critical consumer. If you learn about a project and don't like it, let the researcher know why you are declining to participate.

Talk to researchers at conferences and ask them questions. Let the PWSA know what you think would be important research questions for them to fund as pilot projects. Be patient, especially with graduate students or new researchers who are just starting out. They need to learn about PWS, and you have a wealth of knowledge to share with them.

Finally, bear in mind that students and more seasoned researchers come to PWS with great intellectual excitement about a topic that is near and dear to your hearts. Even though researchers wear their scientific hats, they have invested considerable time and energy in PWS, and join with families and the PWSA in working hard to improve the quality of life for people with PWS of all ages.

Dr. Dykens is a professor at the University of California Los Angeles Neuropsychiatric Institute Child and Adolescent Psychiatry Neurobehavioral Genetics Center.

Growth Hormone Advisory

Aren't there natural GH supplements my child could take instead of getting shots?

Although many nonprescription supplements and pills are being promoted today as growth enhancers or GH releasers, they are not oral forms of growth hormone, nor are they effective for the needs of children with PWS. Since these supplements are not regulated by the Food and Drug Administration, there is also no way of knowing their actual content, effects, or safety.

Some GH manufacturers are trying to develop alternative ways to deliver GH to the body, and we may eventually see forms of synthetic growth hormone that can be taken orally or through the nostrils. If these products do come to market, they will be prescription drugs regulated by the FDA.

From the Home Front

Life With a Fun Little Boy

By Lou Bladel

We are writing this article to describe our experience as parents of a child with Prader-Willi syndrome. Our son Sam was born 5 weeks premature on July 6, 2000, by an emergency C-section after my wife's doctor was concerned by the lack of his *in utero* movement.

At birth Sam weighed 5½ lbs. and scored a 9 on the Apgar. Initially we thought everything was fine, but the doctors noticed a few irregularities and Sam started having problems breathing. He had a high, arched palate, undescended testes, and was very "floppy." A few hours after his birth he was in the Neonatal Critical Care Unit on oxygen and an IV. He stayed there for 6 weeks. He could not take a bottle or breathe on his own. The next 11 days were a parent's worst nightmare as the doctors tried to figure out what was wrong.

After Sam passed a litany of tests, including a chromosome screening, a neurologist suggested looking for PWS in a more specific chromosome test before conducting a muscle biopsy. Sure enough, we had our diagnosis, which was heart wrenching. How could this happen? My wife and I have always had perfect health, we are in our early 30's, and are not part of any risk group.



Sam Bladel is a friendly little boy

Sam left the hospital with a G-tube and oxygen. We expected the worst. As the days turned into weeks, Sam slowly improved. He was taken off oxygen within a month, and the G-tube was removed by 6 months. Sam continued to make progress, smiling at 6 weeks, eating orally by 4 months, rolling over at 7 months, and sitting with help at 11 months. He laughs, plays, and vocalizes like any baby.

Sam is hitting his cognitive milestones at age appropriate times; however, his physical limitations have been more of a challenge. He recently developed scoliosis and has very small hands and feet, but continues to grow without interruption. Sam is a real joy and very social, smiling and laughing, especially at new faces. He claps, waves, bangs on toys, and puts everything in his mouth. Our nightmare turned into a life with a fun little boy.

Like other parents, we pray every night that Sam will be OK. We try to keep abreast of all the treatment options and feel like we have a good plan. With the help of Dr. Morris Angulo (Prader-Willi specialist) and the many early intervention therapists (physical, occupational and speech therapy, and special education), we think Sam is on his way to having a better than average chance to achieve and be a happy member of society.

Currently, with the exception of family and a handful of close friends, we do not go into detail about Sam's condition. He has shown delays in gross motor development; however, everything else has been pretty typical since he turned 6 months old. Most people attribute his problems to being premature, which is fine with us.

We are not ashamed of the fact that Sam has Prader-Willi, but we don't want him to be labeled at such a young age before it is apparent what his particular challenges will be. We know he has special needs, but we don't want anyone to expect less of him just because he has more to overcome. When he does his therapy he tries so hard. It is really motivating to those of us who are close to Sam and are able to witness the effort he puts into every task that comes so easily to others.

For all the new PWS parents out there, enjoy these sweet-spirited kids, and don't let the diagnosis crush your expectations.

Sam now has a baby brother, Joseph, born on September 6, 2001. He is only be 14 months younger, and we are a little scared to say the least, but so far, all of us are doing well.

We only know what it is like to have a child with PWS. All the tests on the new baby have been normal, no PWS or any other major problems have been found. We just hope Sam will have a caring little brother to experience life with, believing that it will be beneficial to have other siblings close in age to Sam. Having another child so quickly was not our original plan, but we could not be more excited and happy with our choice. Focusing on an obscure birth defect is not how we want to deal with Sam's specific challenges. We believe that surrounding him with a loving family can only have a positive result for all of us.

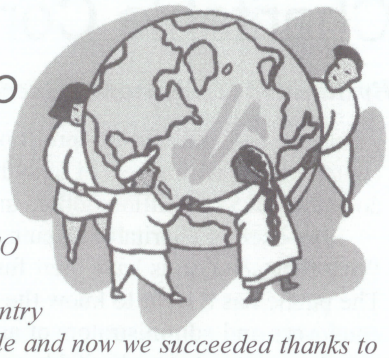
For all the new PWS parents out there, enjoy these sweet-spirited kids, and don't let the diagnosis crush your expectations. We've talked to many parents whose kids lead great lives, albeit lives that may be a little different from the lives we envisioned before any of us ever heard of PWS.

We try to stay upbeat, because for every medical textbook horror we read about, there is an uplifting, real-life story. As new PWS parents we realize that we have a long road ahead. We take one day at a time and believe that in a weird way we are fortunate that we will be able to control many aspects of the syndrome with medical treatment and behavior modification. So far Sam has exceeded our expectations and we are optimistic about his future. With the help of Gonadotropin, early intervention, Coenzyme Q10, and eventually growth hormone, we hope and pray that Sam may have a fun and rewarding life.

Lou and Mary Bladel live with sons Sam and Joe in New York, N.Y.

PWS Families Around the World:

Letter from Pam Eisen, PWSA(USA) Parent Delegate to IPWSO



When I first heard of IPWSO, I imagined a world consisting of parents, families and professionals reaching across continents, linked arm in arm, united in purpose, and cooperating in the sharing of information, experiences, emotion, and support.

Today, this vision is a reality with the potential for an international collaboration of research and with the opportunity for nations to share the most up-to-date medical treatments and behavioral strategies for PWS.

With still more than half the world not yet represented, there are many challenges ahead. However, we know that our mission has no barriers—only possibilities.

IPWSO was founded in 1991. When an international conference was held in Jeslo, Italy in May of 1999, there were 20 member nations, 90 percent of them from European countries. Now, less than 3 years later, we have 44 member nations representing all seven continents!

In the very short time that I have served as the PWSA(USA) delegate to IPWSO, I have witnessed the genesis of new national organizations in Greece, Paraguay and Chile.

We can be proud that PWSA(USA) has played an invaluable role in supporting the growth of IPWSO through disseminating information and lending support to families throughout the world.

When an international e-mail comes to our national office in Sarasota, it is shared with IPWSO. Jessica Mancheno sends a welcoming packet of information to the requesting party, including publications on PWS along with other relevant material. All of these responses and resources must be carefully communicated in the native languages of those involved. Janalee and David, our crisis counselor, in cooperation with the President of IPWSO, personally respond to many of the requests for information, support or crisis intervention.

An exuberant man of never-ending energy, Giorgio Fornasier, the President of IPWSO, has traveled far and wide, sharing his passion for building an international network of communication between parents and professionals.

He has worked diligently on behalf of all of us in a quest to improve the quality of life for all people with PWS and their families. Recent contacts include Taiwan, the Dominican Republic, India, Portugal and Egypt.

Through e-mail, Giorgio has shared many exciting and historic events that will make a tremendous difference to families worldwide in dealing with the day-to-day challenges of PWS. Giorgio's heartfelt and often poignant messages are a constant reminder of the need and urgency to expand and share research so that people with PWS in poor countries where resources are sparse—as well as in rich countries—may benefit. A joyful e-mail, received just this morning, is representative:

Dear friends,

I am very pleased to announce that on January 3, 2002 we founded the National PWS Association in Brazil. I visited Sao Paulo purposely on my way back to Italy, after a holiday I spent in Paraguay, together with my wife Maurizia and my son Daniele (with PWS). It has been a very touching and emotional day.

Since many years IPWSO was trying to establish an association in this huge country with over 150 millions people and now we succeeded thanks to contacts we had by email with the right persons: President of the Association and Parent Delegate is Maria Helena Portugal: helenaportugal@uol.com.br; Professional Delegate (endocrinologist) is Dr. Jack Yunk Kuo: jackyk@bol.com.br

I dedicate this success to Elli and Alex Korth from Argentina, who are our Angels in South America and helped me a lot in my contacts. Muchas gracias.

I'd appreciate if you all send Helena and Jack a warm welcoming message in our international family, offering cooperation and information material this important association in South America can translate and use.

Helena is a fantastic mother of a 15 year-old girl, whose name is Fernandinha, who has serious problems of weight and behavior. In spite of that, Helena's mission is to help all PWS cases spread all over Brazil and one day have her dream come true: she is holding a clinic together with her mother where they presently follow old people. They would like this structure to become one day a home for abandoned PWS people.

All member associations having group homes services are invited to send Helena information, advice, pictures publications or whatever you think useful to help her in planning her project better. We're sure it will come true one day!

Jack is a young endocrinologist in Sao Paulo, very sensible to PWS cases and he is alone fighting against colleagues who do not care about. I invite our scientific advisors and professional delegates to offer him their encouragement, support and co-operation.

They both speak English and will come to our meeting in Italy in April 2002.

God bless you all and many thanks,

Giorgio

It is my sincere hope that you will join me in greeting these new members of our PWS family. They are to be applauded for their courage and given necessary support in their dedication to spreading information and understanding of PWS.

In April of this year, a very special Exceptional Meeting of all delegates, associated members, and new country contacts will be held at the Baschirotto Institute for Rare Diseases (BIRD) near Vicenza, Italy, where the IPWSO office is located.

Through Giorgio's miraculous efforts, an Italian company has volunteered to pay travel expenses for delegates from countries, which cannot afford the costs. This will be an exciting and rare opportunity for the exchange of recent scientific findings and many other topics relevant to PWS.

When I return, I look forward to sharing my experiences from this thrilling event in the world of PWS.

Charitable Contributions: Give, But Give Wisely

By Janalee Heinemann, Executive Director

Close to 1 million non-profit organizations are in the United States, with assets of $389 billion dollars. They receive donations of $125 billion dollars annually.

Tax-exempt charitable organizations can make money. What they *can't* do is have their funds benefit private persons. The public has a right to know the names and salaries of the employees and administrators of any non-profit.

Remember that a charitable organization can be *legal* but not *ethical.* Prior to making a contribution, consider the following:

- Who are the organization's officers and who is on the board? If the board is only a few people, proceed with great caution. A good charitable organization has a full governing board. Typically the board is a minimum of 12 people and has a broad representation of the community it serves.
- Why was the organization created? (An example is that parents who had children with PWS founded PWSA, which is an understandable motive.)
- How long has the organization been in operation?
- What percent of the money goes to marketing and administrative cost? Request information in writing. Better Business Bureau standards are:

At least 50 percent of total income should be spent on programs and activities directly related to the organization's purposes.

Fund raising costs are not to exceed 35 percent of related contributions.

Total fund raising and administrative costs should not exceed 50 percent of total income (there are some exceptions).

- *Never* give to an organization you don't know based on a phone call appeal, or on an appeal you receive by mail without checking on the legitimacy of the group. I always tell telemarketers that I never commit to giving money unless I see something in writing and can first check out the organization. This gets them off the phone quick!
- Watch out for look-alike names (i.e. similar to the American Cancer Society) and groups that use prevailing fears of the elderly (i.e. Medicare cuts) or unrealistic hope for a cure. Is what they are promising to do realistic?
- Know not only what the money is going to, but also how the decisions are made for funding. For example, when PWSA (USA) awards a scientific grant, it must be reviewed and approved by the Scientific Advisory Board and receive final approval from the governing board. This review also gives both a professional and community-served perspective. Funding guidelines should be in writing.
- Check out the agency's local/state registration status. Organizations must be registered in every state where they solicit funds.
- Keep envelopes in which questionable materials have been mailed. This is evidence that the material was sent by mail, which could be helpful for prosecution purposes.

If in doubt about any fund-raising effort, contact the National Center of Non-Profit Boards at 202-452-6262.

Shop the PWSA(USA) Web Mall

Shoppers can from from 140 top Internet merchants who pay "Your Organization" commissions on all purchases. Shoppers pay the same prices for their purchases, and PWSA(USA) gets a commission up to 14 percent on every sale.

Participating merchants include Amazon, CDNOW, Borders.com, Disney, ESPN, L.L. Bean, Lands End, CVS.com, Hallmark, and FTD. This is a great way for PWSA (USA) supporters who shop on-line to help even more.

Find the mall at www.pwsausa.org. All shopping is fully secured, and the mall respects and offers full privacy protection. The mall is simple to use and navigate.

A Prader-Willi Prayer

Please do not give me food that I am not allowed,
Or leave food where I can sneak it.
It sets me up for failure, and I do not handle this well.

Please be firm with me, it gives me security.
Love me even if I am not kind to you.
Try to be honest with me,
Even if I am not always honest.

I am a very demanding person at times;
Handle my demands with respect,
But don't give in unless it is appropriate.
Praise me for a job well done.

Food is my main thought,
Give me an appropriate time to discuss it.
If you make a mistake, please admit it.
It's nice to know I'm not alone.

Tell me I'm beautiful or handsome,
I don't hear that very often.
Don't make promises you can't keep.

Please don't use the words "no" or "can't,"
They are too final.
Give me choices instead.

I am argumentative. Do not argue with me;
It just prolongs the time to calm me down.
Try to understand and be my friend.

When days are good,
I can be witty, loving and appreciative.
Let me live one day at a time,
So the next day will be fresh.
Thank you for trying, and I will try my best.

By Norma Halverson

Contributions In Memory Of

Kenneth Ayotte
Community Bridges
Toyota Motor Manufacturing (Ronald & Eileen Ayotte)
Andover Ladies Golf Association
Andover Golf & Country Club, Inc.
Toyota Motor Manufacturing, Kentucky,Inc
Joseph & Beverly Angelari
Richard D. Baldwin
Wallace & Marilyn Barnes
Barbara W. Beard
Irving & Joyce Bell
Rita Jordan Beverly Angelari
Robert & Paula Coney
Irene & John Corbett
John & Janet Cruickshank
Armand & Ruth Cubelli
Hugh W. Emerson, Jr.
Melissa A. Galloway
Deloris A. Gifford
Everett & Anna Gifford, Jr.
Roger & Linda Harvey
Roger & Anne Hebert
William & Elizabeth Kamuf
Donald Lebrun
S. Donald & Susan A. McCullough
Gene & Gloria Mosley
Jacques & Pauline Parent
Janet G. Robertson
John Sullivan

Denise Capitani
Black & Decker Corp
Mike Phillips

William A. Capraro, Sr.
John & Patricia Martin

Isabel B. Flowers
Arney & Brunhilde Thomson

Sarah McCamman
PWSA of Missouri

Laurine Mundy
(Anna Loker's Great Aunt)
Chuck Akers
Alonzo & Barbara Burdine
Bob Francis
James & Carolyn Loker
Bob Mundy
Edna L. Rice

Howard Merritt Christman
Lee W. & Thelma L. Berridge
Teresa & Stephen Boyd
William & Estella Cole
Mary J. Eaton
Norman & Barbara Hardenburg
John J. & Janet J. Loughray
Carolyn Lovejoy
Robert Nordin
Wilma J. Palmer
Florence & Jerry Root
Gloria Schmaltz
Jack H. Sloan
Ruth E. Springgay
Drs. Walker, Gilin, Pank & Kursik
Theresa & Patrick Boensch
David & Judith Bouchard
Jean Christman
Mark & Linda Christman
Sharon & Dennis Christman
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A New Look for Our Web Site

Thanks to our secretary/grandparent, **Barb McManus**, we have a new look to our web site. **Mike Larson** is grateful to get her assistance, and Barb plans to keep the web site varied, so check it out at *www.pwsausa.org*.

One of the new additions is Giorgio Fornasier, our IPWSO president, singing one of the songs he did at this summer's International Conference.

Acknowledgements

Our Sincere Thanks for Contributions Received in October & November 2001

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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.