



The *Gathered View*

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

Hard Work and "Hope" Bring Us an Inspirational Success Story

Clyde Mays and his mother, Hope, share with us Clyde's essay written in application for membership in the National Honor Society. Clyde was inducted into the NHS last October, and is, according to his mother, a remarkable young man. Hope Mays is executive director of the Georgia Chapter of PWSA and has been an advocate for people with disabilities for many years.

Why I Want to Join the National Honor Society

My name is Clyde Mays. I am 18 years old and a senior at Roswell High School. I have lived in Mountain Park since I was one year old. I have a unusual birth defect called Prader-Willi Syndrome which causes learning disabilities, an eating disorder and emotional problems. I have attended five Fulton County schools, and two private schools for Special Education programs. I have kept a 3.7 grade point average while attending RHS. This year I am beginning the Community Based Instruction Program. I will receive vocational training at various job sites and continue math, English and PE/health classes.

It is a great honor to be nominated to the National Honor Society. It makes me very proud of my accomplishments, and motivates me to keep up the good work. I hope my nomination will encourage other students with disabilities to also do their best. Here are some examples of service, leadership and character qualities that I have.

I have been a volunteer with the Mountain Park Fire Department for the last five years. I don't go on fire calls but I help keep the trucks and the fire department building clean. I also have volunteered with Mountain Park's Adopt-a-Stream program. I have helped test our creeks for pollution. Mainly I help keep the creek banks and culverts clean. At school I have volunteered to be a trainer for the football team. I have earned my varsity letter for three years of service. This year I have the official title of ballboy. It is an important position to keep the referees happy.

For the last two years I have been a volunteer cabin assistant at Camp Toccoa. Because of my special diet restrictions, I have to have supervision at camp myself. But the camp director has put me in charge of young campers and I have proved to her that I am responsible. At the end of this summer, I earned the title "Camp Toccoa Staff." I have helped my mom talk to legislators about my syndrome and what it's like to have it. I appreciate that my syndrome is under control. I am glad that we have been able to help people with Prader-Willi Syndrome who have it a lot worse than I do. I also have talked to my city, state and national representatives about things that are important to me like the environment and homelessness.

I believe I have the qualities of service, leadership and character that are required to be in the National Honor Society. I have learned in service work to help others. I have learned in leadership to set a good example. I have learned that having a good character means having a good attitude and self esteem, no matter what names people call me. I want to join the National Honor Society so that I can be a good example to students at RHS.

by Clyde Mays
submitted 9/11/98

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Do you work for either Brinker International or Land's End?

If so, we want to hear from you! PWSA (USA) is applying for grants offered by these organizations, and knowing an employee who has a connection with PWS can help.

Please call Janalee at 1-800-926-4797 or e-mail her at pwsausa@aol.com today!



Frank Moss (left) takes time out from San Diego conference planning to help the Pittsburgh conference planners make preliminary decisions for the Year 2000 PWSA conference. Next to Frank is Pennsylvania Chapter President Maria Silva, PWSA Executive Director Janalee Heinemann, and Pennsylvania Chapter Secretary Lota Mitchell.

Mark your Year 2000 calendars:

22nd Annual PWSA (USA) Conference Pittsburgh, Pennsylvania July 20-22, 2000

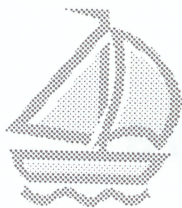
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Opinions expressed in *The Gathered View* are those of the authors or editors and do not necessarily reflect the views of the officers and board of directors of PWSA (USA). *The Gathered View* welcomes articles, letters, personal stories and photographs,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

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San Diego Highlights

By Frank Moss, 1999
Conference Co-chair

Planning for the 1999 PWSA (USA) 21st Annual National Conference in San Diego, California, has come a long way ... and we're still working to make it better than ever. Besides having a wonderful location for our conference, we have a number of innovative ideas for all parts of the conference.

First-Timers' Sessions — Immediately after the keynote address, there will be two concurrent sessions for first-time conference attendees: one for parents/care providers of children from birth to 8 years old, and one for parents of older children/adults. Our session moderators will address the concerns of first-time attendees at a national PWSA Conference ... first impressions, hopes and fears, and the potential for our children's success and happiness. We hope that through these first-timer sessions we can promote a hopeful outlook and an environment where parents of children of similar ages can get to know one another and possibly establish mutually supportive, long-term relationships.

Keynote Address — **Susanne Cassidy, M.D.**, Chair of the PWSA (USA) Scientific Advisory Board, will present a keynote address that focuses on: "Where we've been" — the progress we've made in the diagnosis, treatment, and management of Prader-Willi syndrome ... and "Where we're going" — the outlook for the future, and the hope for a "cure." This will be a presentation that emphasizes hope for the future ... a major theme for this year's conference.

General Sessions — Our three general sessions should be of interest to all conference attendees:

- **Behavior Management**

This session, led by **Elisabeth Dykens, Ph.D.**, will summarize the behavior research findings from the July 7 Scientific Conference, and will address approaches to managing the complex behaviors of persons with PWS.

- **Growth Hormone Therapy**

Phillip Lee, M.D., will summarize the results of the growth hormone research symposium portion of the Scientific Conference and will address therapeutic approaches to growth hormone deficiency.

- **Genetics Research and Medical Issues, and "Ask the Experts"**

Merlin Butler, M.D., Ph.D., will summarize the presentations on genetics research and medical issues presented during the Scientific Conference, and **Suzanne Cassidy, M.D.**, will lead a session entitled, "Ask the Experts." Written questions from the audience will be answered by a panel of recognized authorities in the diagnosis and treatment of PWS. This was an exciting feature of the 1998 International Prader-Willi Syndrome Organisation (IPWSO) conference in Italy, and we believe it will be a valuable opportunity for U.S. parents as well.

Breakout Session "Tracks" — We've designed breakout sessions on Thursday and Friday afternoons that will permit parents to follow a presentation and discussion "track" that relates to children in a particular age group:

- **Infant/Toddler/Preschool Track**

Designed for parents of children from birth through 5 years old, this track will be led by **Robert Wharton, M.D.**, and **Karen Levine, Ph.D.**, and will cover such topics as early childhood development, socialization and behavior issues, preschool education, speech therapy, physical therapy, occupational therapy, nutrition, diet, and exercise.

- **Child/Adolescent Track: Education**

Covering grades K-12+, this track will address educational options, and Individual Education Plan (IEP) development and implementation.

- **Child/Adult Track: Weight and Behavior Management**

Weight management will be considered during two sessions on Thursday: Diet and Nutrition, and Exercise Options. On Friday, this track will focus on behavior management strategies.

- **Adolescent/Adult Track**

On Thursday, we will discuss residential and employment options, and on Friday

14th Scientific Conference

This year's PWSA (USA) Scientific Conference features two concurrent tracks on Wednesday, July 7:

- **Session I** will be an all-day symposium on **Growth Hormone (GH) Research**.

Our chair for this session, **Phillip D.K. Lee, M.D.**, has invited a number of national and international experts in the field of GH research.

- **Session IIA** will be a half-day program on **Behavior Research**, chaired by **Elisabeth Dykens, Ph.D.**

- **Session IIB**, also a half-day program, is devoted to **Genetic Research and Medical Issues**, co-chaired by **Merlin G. Butler, M.D., Ph.D.**, and **Paul Paolini, Ph.D.**

Parents may attend the Scientific Conference at no cost, but as observers only ... no participation or questions.

Residential and Community Service Providers Conference

The theme this year is "Facilitating Quality of Life for People with Prader-Willi Syndrome." Conference Chair, **Alan Gift**, plans papers and panel discussions on topics such as:

- What are the Quality-of-Life Indicators for people with PWS?
- Behavior management strategies that do and do not work.
- Parents and providers understanding each other and working together.
- Sexual activity in residential or vocational placements. What are the issues?

Parents are welcome to attend *most* of the provider sessions (some may be closed to parents) at no cost, and they may be invited to participate in some panel discussions.

two concurrent sessions will be offered: 1) Sexuality; and Guardianship/Conservatorship, Wills and Trusts; and 2) issues related to legal crises and response, featuring prominent attorney **Michael Cardoza**; obesity discrimination; and a session entitled, "When Your Child Does the Unspeakable," led by PWSA Executive Director **Janalee Heinemann**.

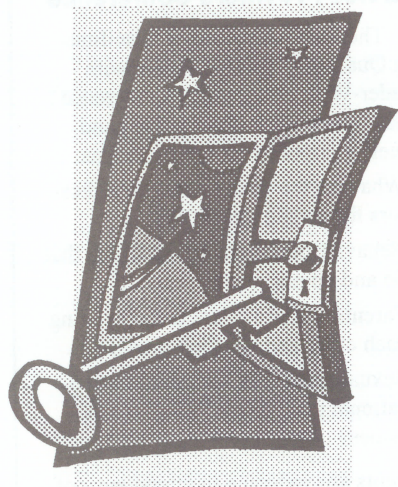
See page 16 for Youth Program and Social Highlights.

Preparing Our Children for Their Future

By Barb Dorn

I would like to focus a bit on one of the biggest jobs we have as parents — *preparing our children for their future*. This isn't a job that is unique for us as parents of children with PWS. It is a responsibility we have for *all* of our children. It doesn't start in high school. It should begin in our child's early years.

Taking on this task may be a bit more challenging for our child who has PWS than it is with our other children. It is, however, something that is achievable and necessary. We are not doing our children any favors by *not* teaching them life skills and responsibilities. These are the things that make a person feel worthwhile and needed. We *all* have this need.



I remember starting this venture when my son Tony was about 3 years old. It started with a sorting activity — sorting laundry. To this day, Tony has two wash baskets in his room — one for white clothes and one for colored clothes. This learning activity helped him to identify differences. It also helped me by saving time in laundry duty, and it gave Tony preliminary skills in the task of doing laundry.

As Tony grew bigger and stronger we added more responsibilities. He was expected to do the same number of chores as his brother. (The level of difficulty may not have been the same.) We made a

chart “to keep things fair.” Some of the responsibilities included:

- setting the table;
- bringing garbage containers from bedrooms to a central location; and
- returning garbage cans to the garage after they had been emptied.

As he grew older, we added more to this list:

- making his bed every morning;
- removing dirty sheets from his bed on designated days;
- brushing his teeth twice a day;
- taking a shower on designated days (This task took almost a year to complete. The steps needed to be clearly outlined and safety measures were addressed.); and
- using deodorant daily.

Tony is now almost 14 years old, and we are continuing to add even more responsibilities:

- putting clean sheets on the bed;
- doing the laundry;
- dusting his bedroom;
- vacuuming his bedroom; and
- putting *his* dirty dishes into the dishwasher. (You can hardly tell they are dirty!)

Teaching these skills has not always been easy. To be honest, in many cases it would have been lots easier to do these tasks myself.

Some strategies that have worked well for our family include:

1. **Talk it up!!** Get your child excited about learning to help. I know in my son's case, he loves to hear how grown up he is acting.

2. **Focus on *one* activity at a time...** and allow plenty of time to learn things.

3. **Start off slowly** and take baby steps. You may *both* begin with making a bed by pulling sheets up *together*.

4. **Make “reminder cards.”** In our house, we have these cards posted so they can help Mom and Dad remember the order in which a task is being taught. This really helps us be consistent in our

directions and acts as a visual reminder for Tony.

Being a parent is a challenging job. We have some of the same responsibilities in raising our child with PWS as we do with all our children. It is our job to prepare our children to become independent in as many areas as possible. Basic life skills is one of those areas. It is never too early to begin. This allows our children to be successful and productive. They need our help, guidance, and encouragement in preparing for their future.

Q: What chore can help teach reading, math, calendar use, sorting skills, and nutrition; promote fine motor skills; and save you money?

A: Coupon clipping!

When my daughter's occupational therapist suggested that I let Lesley (then about 5 years old) cut out my grocery coupons in order to improve her scissors skills, I thought it would be a short-term effort that *might* improve her corner-cutting and would at least keep her happily occupied for stretches of time. To my surprise, this small task turned into an incredible learning experience, as the study of coupons provided opportunities to talk about food choices, prices, and much more. At first, I outlined the coupons with green (GO) cut lines and red (STOP) dots at the corners, and Lesley cut and sorted them into envelopes labeled with pictures. Later she advanced to reading words and dates, sorting by word labels, and pulling expired coupons. Today, at 10 years old, she does the entire task with little supervision as one of her weekly chores. If we save a lot of money on a shopping trip, Lesley gets a “profit-sharing” reward.

—Linda Keder

Planning Your Child's Educational Goals?

These spring months for many of us involve making plans for our child's goals and objectives for the 1999-2000 school year. A part of that plan can include discussion of how to educate new staff about your child and PWS. Parents are encouraged to have school personnel purchase educational items that will help them gain a better understanding of this disability. Items that might be considered include the following. (Prices shown are PWSA member rates, followed by nonmember prices, and do not include shipping and handling charges.)

- ▶ **Management of Prader-Willi Syndrome.** This textbook is a valuable resource for many of the people who support your child in the school setting. This book helps to educate the team members using a multidisciplinary (many different professionals) approach. (\$39.95/\$45.00)
- ▶ **Supporting the Student With PWS Across Their Life Span.** This new audiotope for teachers addresses a number of different issues that affect the student with PWS from birth through 22 years of age. The accompanying handout also serves as an excellent resource. (\$5.00/\$7.50)
- ▶ **Transition From School to Adult Services in Prader-Willi Syndrome: What Parents Need to Know.** This booklet is targeted for those who have children with PWS entering high school. It helps parents understand the issues and areas that should be addressed during the high school years in order to best prepare their son or daughter for life after high school. It can be a valuable tool in guiding parents as to what areas need to be addressed in their child's educational plan. Includes state contacts and a glossary. (\$10.00/\$15.00)
- ▶ **Children With Prader-Willi Syndrome: Information for School Staff.** This booklet will assist teachers and other school personnel who have a child with PWS in their class or school. (\$5.00/\$7.50)
- ▶ **The Child With Prader-Willi Syndrome: Birth to Three.** This booklet is a valuable tool for parents of young children to share with their early intervention teacher and school personnel. It provides a comprehensive overview of the early years to help staff become more knowledgeable. (\$5.00/\$7.50)
- ▶ **Physical Therapy Intervention for Individuals with PWS.** A good resource to share with therapists working with your child. (\$4.00/\$6.50)
- ▶ **Exercise and Crafts & Activities for the Individual with Prader-Willi Syndrome.** The articles in this collection would be valuable for a child's physical and occupational therapists, as well as the regular teacher and the physical education teacher. (\$6.00/\$8.50)
- ▶ A few brochures that are also recommended:
 - **What Educators Should Know about PWS**
 - **Speech and Language and PWS**
 - **Management of PWS in the Work Setting: A Guide for Employers and Supervisors**

All of these resources are available through PWSA (USA). Take advantage of school meeting time to ask that school staff obtain the information they need to make your child's next school year a successful one.

U.S. Shipping Charges:

Total orders up to \$7.99—add \$1.50; orders of \$8.00 to \$38.99—add \$4.00; orders of \$39.00 to \$99.99—add \$6.00; and orders of \$100 or more—add \$10.50.

For a complete list of PWSA products and ordering information, please call 1-800-926-4797 or visit PWSA's Web site: www.pwsausa.org



PWSA President Barb Dorn (right) presents an appreciation award to Mary Peterson for her work in the creation of PWSA's new audiotope for educators. Mary is a radio professional whose voice is heard on commercials throughout Wisconsin. She donated her voice to the project and helped get the recording studio to donate their work as well. A big thanks from all of us, Mary!

NEW Staff Training Video About PWS!

"Understanding Prader-Willi Syndrome," an 18-minute video designed to train service provider staff on the needs of individuals with PWS, has just been completed by PWSA's Minnesota Chapter. Thanks to the chapter and to Joan Gardner, PWSA now has 250 copies of the training video available to sell. The price is \$20 (plus \$4 S&H) for PWSA (USA) members and \$40 (plus \$6 S&H) for nonmembers.

It is a professionally produced video with good practical advice for individuals who work with persons who have Prader-Willi syndrome. Participants in the video project included four agencies, nine providers and staff, three parents and more than a dozen persons who have Prader-Willi syndrome. Orders can be mailed or phoned to: PWSA (USA), 5700 Midnight Pass Rd., Suite 6, Sarasota, FL 34242; Tel.: 800-926-4797.



Using Medications as a Management Strategy for Persons With Prader-Willi Syndrome

Barbara Y. Whitman, Ph.D., Professor of Pediatrics
St. Louis University School of Medicine

Often, one of the first questions of parents who have learned that their child has Prader-Willi syndrome (PWS) is, "What medications may s/he need?" This simple question requires a very complex answer. As with many genetic syndromes, there is no "cure" for PWS. Medications and other medical interventions are employed to correct specific impacts of the disorder, or for "symptom management" of aspects of the disorder. For example, heart surgery may completely correct a heart defect in a child with Down syndrome but does not change the character of the syndrome itself.

PWS presents unique management issues on many dimensions. Besides managing the hyperphagia (excessive appetite) and its consequences, cognition, learning and behavior are additional challenges presented by the person with PWS. Indeed, as the young person with PWS matures, managing behavior difficulties is frequently more problematic than managing food-related issues. Additionally, these evolving behavior challenges are frequently accompanied by intense emotional disturbances that further complicate management. And all of these issues are further complicated by a little-understood refractivity (unresponsiveness) or, conversely, a toxic reaction to medications effectively used for these "symptoms" in persons without PWS.

Let us briefly review some of these areas.

Hyperphagia and Obesity

A number of medications have long been employed to suppress appetite. Foremost among these are the "amphetamines" such as Dexedrine and Benzedrine. While quite effective, the side effects of long term use of these medications has led to the search for alterna-

tives. In the past two decades, a number of newer compounds have been introduced with variable effectiveness. In addition, other compounds that work to block fat absorption or to "dissolve" fat tissue are in development. Without exception, these medications have been ineffective in addressing the brain signals that drive the person with PWS to seek food and overeat. Until such a medication is discovered, good management depends on environmental protection against overeating, as well as an understanding caregiver who recognizes that a constant feeling of being hungry is a natural stimulus for being irritable and occasionally hard to get along with.



Behaviors and Emotions

When the behavior/emotional aspects become unduly disruptive to daily functioning and resistant to other forms of management, behavior change medication is often sought to supplement other management strategies. As is the case with appetite suppressing medications, many first-line behavior change medications commonly used in other circumstances are ineffective for persons with PWS. Additionally, many have been noted to worsen the behaviors being targeted by the medication or to create unac-

ceptable side effects such as further increasing appetite. In an effort to develop a systematic database, Dr. Louise Green-swag and I initiated a study of effective behavior change medications for persons with PWS. Our initial study was conducted in 1988 and 1989. In order to maintain as current a database as possible, we have since repeated the study three additional times. A brief description of how the data were obtained is necessary before discussing the results.

All studies have used essentially the same method. Volunteer parents or caregivers respond to a telephone administered interview that systematically inquires about recent (the past year) and prior (ever in lifetime) use of medications to suppress appetite, facilitate sleep, alter mood (depression, anxiety), alter behavior, modify feelings (e.g., anger), and the like. Fifteen separate questions regarding various thoughts, feelings, and behavior are systematically addressed. Several additional questions inquire about the use of counseling or psychotherapy or other forms of behavior therapy. To fully cover the scope of possible medications, one final question that lists many common behavior change medications is asked. Often this question jogs a memory of a medication briefly tried that was forgotten in responding to the other questions. Finally, when parents who are willing return signed release of information forms for doctors who may have prescribed such medications, the medical records are then requested. Thus we try to obtain the best quality information by building in a number of pathways to reliability and validity of the data.

The results of the initial study were startling in a number of aspects. We found that almost every behavior change medication "known to man" had been tried both singly and in multiple combinations in an effort to help alter severe

behavior problems in persons with PWS. What was startling was the ineffectiveness to absolute toxicity of most of those medications. At the time of that initial report, we were able to document real effectiveness only for Haldol, Mellaril, and a then-new medication—Prozac.

As we have repeated the study several times over, we have been encouraged by the addition of many more medications that have been successfully used for persons with PWS. Many of these are the newer generation of the prototype SSRI (selective serotonin reuptake inhibitor) medication, Prozac. Several medications that have been successfully used for other conditions such as seizures have in some instances proven helpful in altering difficult behavior in PWS. So today, there is a larger medication armamentarium that can be employed to help difficult behavior in persons with PWS.

Considerations and Cautions

Despite the larger number of medications that may be helpful, there are a number of cautions that must be raised and issues considered before initiating any medication for a person with PWS.

- First is the **issue of necessity**. Many persons with PWS who are exhibiting frequent and very difficult behaviors are able to completely turn around when a number of environmental changes are instituted. While requiring a lot of thought and hard work to restructure an environment, this solution is always preferable due to the uncertainty of medication effects in any one person.
- Second, **no single medicine is universally effective**. While many persons with PWS have responded dramatically to Prozac, others (just as in the general population) have had severe negative reactions, both behaviorally and medically, so that any medication must be carefully thought through and conservatively approached.
- Third, we have learned from many difficult situations that **persons with PWS are unique in their dosage needs**—many responding to one-fourth to one-half the dose normally prescribed, but becoming toxic with worsened behavior at what would be considered “normal” dosage levels for someone without PWS. Thus, unless an extremely cautious approach to dosages is employed, there is

Low dosages, conservative increases, and monumental patience are needed to select and regulate medication for persons with PWS.

risk of making the situation worse. Low dosages, conservative increases, and monumental patience are needed to select and regulate medication for persons with PWS.

- Fourth is **what can be addressed with these medications**. For instance, many medications have been initiated to alter the frequency of skin-picking. While an occasional parent has reported some positive response on this dimension, most do not. Other medications are given to alter or eliminate “bizarre” thoughts. In the event that a person with PWS is hearing voices or seeing things that aren’t there (auditory or visual hallucinations), then these medications may be quite effective. Most parents and caregivers, however, report “bizarre” thoughts that are not hallucinations—such as concern that someone has tampered with or stolen their “stuff.” In this instance, medication may or may not be helpful.
- Finally, the **question of when to start medication** is often raised. For many, this question is based on an assumption of the inevitability of medication use, with the age of starting medication the only uncertainty. There is no evidence to support an assumption that medication use is inevitable. Many never need medication. Many may require medication to get through a difficult time, but with appropriate environmental supports can discontinue its use. Thus, the “when to use” is answered with “when the behavior is so out of control that all other forms of intervention have failed.” This may be sooner for some persons, if it is not possible to adjust their environment effectively, and much later for others.

Both Dr. Greenswag and I are always available to work with you and your doctor as you seek to think through some of these difficult issues. (Call PWSA for contact information: 1-800-926-4797.)

Skin Picking Solutions?

Since medication doesn’t generally stop skin-picking — a common habit that one mother recently described as the “most disabling” part of Prader-Willi syndrome — what can families and care providers do about this vexing problem? Here’s an approach that was recently reported by two visitors to PWSA’s Website message board:

“I work one-on-one with an 11-year-old girl. She was a severe picker. Over the course of about five months we set up a behavior intervention plan. On a dry-erase board she got a happy face next to every half an hour that she didn’t pick. When she earned so many, she got a toy or stickers of her choice. This worked so well her legs are fully clear and she is even proud of how beautiful they are.”

“This is the same thing that we did with our daughter. (She was 6 when we put this into effect.) We started out on short time intervals of giving a sticker, pencil, eraser, (you get the picture) if she did not pick. If she did pick, we really talked about how disappointed we were that we didn’t get to give the prize. (We didn’t discuss our disappointment in her, just the missed prize.) At other times general discussions were had about how bad picking is. As she got better, we lengthened the time. We got to where two or three days could pass. Now, she hardly ever picks. It is extremely rare. One of the times that we really rewarded was when she first got up in the morning as this seemed to be a bad time for us. We just really praised her to the ceiling if she didn’t pick and it finally paid off.”

Other approaches *some* people have tried with *some* success:

- Keeping sores bandaged
- Keeping hands busy—provide small objects or toys to handle (something that can be kept in a pocket or worn)
- Brushing skin—a sensory integration (SI) treatment approach; requires special brush and instruction from a trained occupational therapist
- Swedish massage

Got a solution to share? Please write, or e-mail us at pwsausa@aol.com.

Life With PWS: Another View

by Avalon Bruce, M.P.H.

Editor's note: Many, if not most, of our personal stories in the GV are "success" stories. We look for these stories because we all need hope and inspiration to push ahead in advocating for your children. But life with PWS can be difficult at times for anyone, and especially so if you're a single parent. Here is a mother who, after reading one too many "success stories" wanted a chance to "tell it like it is"—or at least the way it felt on a bad day. She welcomes contact from other parents. Call her at 915-536-2415; or write to: Avalon Bruce, P.O. Box 98, Imperial, TX 79743; e-mail: avalonb@nwol.net.

After being told for 17 years I was sterile as a brick, the pregnancy test was positive in March of 1982. I was 38, single, shocked and freshly committed to AA (1/26/82) and sobriety, and this news was a page out of Dickens—the best ... and the worst of all possible worlds. Hard choices faced me: to abort or not, to adopt or not, to drink again or not. I put my head down, dug in my heels, and have literally kept them there for the past 17 years, having made the "right" choices for me—to keep my child, rear her alone, and stay sober regardless!

My daughter, Eryn "Brittany" (as she likes to be called) Bruce, was born two and a half weeks late in November of '82. She had never moved in utero, other than to hiccup. After the emergency C-section, a tiny, quiet, flaccid bundle was laid in my arms. She'd flunked her Apgars, refused to nurse, and spent the next week in neonatal ICU, reluctantly taking expressed breast milk via a preemie bottle and nipple.

When I took her home, alone, since I had never been around infants before, I just assumed I had a very "good" baby—nothing to compare her with. A home-based physical therapy was begun when she was four months old, and my only complaint was that the baby never smiled or seemed happy, but she WAS easy to care for and love.

We continued on with years of physical, speech and occupational therapies, an early childhood program as pre-kindergarten, and then some home schooling in the first, second, and fourth grade, when she finally went into Special Ed and has remained there ever since.

We KNEW there was something "wrong" with this child, even suspecting atonic C.P. (cerebral palsy), but had no

idea what until early summer of 1993, when she spent two and a half weeks at the Elks Diagnostic Hospital, and a pediatrician there suspected Prader-Willi. The high resolution chromosome scan was negative, but Brit still presented with ALL the signs and symptoms of PWS. That summer we attended the PWS annual conference in Arizona. I learned a lot and cried even more.



Avalon and Brittany

I began learning all I could about this syndrome and managed my child as IF she had tested positive—we got her weight down 15 pounds and kept it under control that summer on an 850-1,000 calorie/day diet—lots of sauerkraut, raw fruits and veggies, and nutritional supplementation.

Her temper didn't really become Vesuvius-like until the end of the sixth grade. Then, to quell the nasties, GABA-Calm (a sublingual amino acid product from Source Naturals) was used very suc-

cessfully until about 18 months ago. Being a vegetarian, I put a small fortune down this kid's throat—B-vitamins for her nerves, chelated minerals, herbs (she's had only four head colds in her whole life, thanks to Echinacea in the winter) and free-form amino acids for protein needs. She grew well, gaining 5 inches in two and a half years without growth hormone or an inappropriate

weight gain. Today, at 4'10" she's right around 120 pounds. I found that massage on her back (she has scoliosis) using aromatherapy oils (Thyme, Peppermint, Birch, et al) CAN result in a height gain over an inch—but the relaxation is short-lived. Still, better than implantation of Herrington rods and a 6-9 month recuperative period.

I'd like to say this is another one of those "wonder bread" stories that I am both pleased and revulsed by when I read them in the PWSA newsletter. We HAVE made the best of a bad deal—but there's more to it than that. There's MY frustration in trying to get anyone's attention when I claim this child HAS PWS—most have never heard of it; many disbelieve that food can be deadly and think I'm a mean parent when I limit Brit's food at church potlucks or Christmas parties. NO ONE, other than another parent in the same situation, understands the strain on me, physically, mentally, spiritually, and emotionally, not to mention financially—my "career" went south when I became a single parent to a handicapped child. The stress of having to contend with the flesh of my flesh when she is being physically aggressive, incredibly self-absorbed and indifferent to any needs or concerns other than her own, or into a full-blown, argumentative rage and asking the same question over and over and OVER is above and beyond the call of "normal" parenting!

Conference Benefits: Help & Understanding for Tough Behaviors

Kim Nicholas writes from Calgary, Alberta (Canada) about how the 1998 PWSA conference benefited her—and enabled her to educate police and transit workers in her community.

Thank you for your generous support that allowed me to attend the 1998 PWSA (USA) conference in Columbus, Ohio, this past summer.

My son Dallyn was diagnosed with Prader-Willi syndrome when he was 3½

years old. He is now 9, and while his weight is proportionally average for his height, it is a constant concern, especially as he is a runner and a hoarder. He started running off when he was 7, and in the past year has taken off in excess of 25 times from home, school, neighbors, day camp as well as while we are out on what was supposed to be a pleasurable outing. His favorite get-away method is to hop on the public transit.

Before the conference I was thought of as a negligent mother who laid around on the couch all day in a drunken stupor. On several occasions I was given suspicious looks from transit officials who were bringing Dallyn home. One policeman even had the nerve to say to me that my son would be better off going home with him! Since the conference I have

had the opportunity to help both members of the transit and the police department gain a clearer understanding of the syndrome.

The result has been positive. One of the transit supervisors has taken it upon himself to circulate Dallyn's picture and our phone number to the other supervisors and has even brought Dallyn home himself several times. I no longer receive comments like, "When we find him, shall we take him to Child Welfare?" And when I call the police, they say, "Oh, is this the boy with the eating disorder?" Both the police and transit employees are genuinely pleased when they hear that Dallyn has been returned safely. What a dramatic difference this has made in reducing my stress level!

The information I gained at conference has been very beneficial, and the "orange textbook" has offered further insight. What I found most valuable, however, was the opportunity to meet with other parents who have many of the same challenges that I have every day. It was amazing to know that I am not the only one on the planet with a kid who runs off, steals food, and throws fits over what to most other people are the smallest things. Wow! I'm not alone! We may not be able to live in a colony situation, as one father expressed, but just being around others who could relate to what your life is like was amazing!

I've started saving pop bottle money towards San Diego. This time I hope to bring Dallyn and his younger brother, Ashton, so they, too, can meet others like them.

Continued from page 10

Rearing "normal" children is hard on single mothers. When the child has PWS, it can be a living hell when there is no family or support. I hounded MH/MR in this state for almost a year, asking JUST for two or three weekends of respite per year—taking it to my state senator and representative—to no avail. It was not until Brit spent nine days at a private mental health hospital that I got any "respite." She was placed on appropriate meds (Depacote for the rage and aggression, and Prozac), which have helped greatly. She's 16, going on age 6—she still likes to color, play with kids half her age, and assert her violent, argumentative and sometimes hostile "orders" and dictates.

She finally tested positive [for PWS] in January 1998, via a DNA-methylation test.

Sure, it does no good to dwell on the missing components of our children's personalities and abilities, due to the missing chromosome material—it does no good to blame or ask "why" or harangue the heavens. But to retreat into denial is to minimize and do disservice to the almost super-human responsibilities ALL single parents and most couples shoulder in rearing a child with this syndrome. There IS justified grief over the child that will never be ... the loss of a future,

and the loss of a relationship one longed for with a person they could relate to on ALL levels. We DO have justified anger at the insensitive individual we HAVE to care for, whether we like them or not, whether they appreciate us or not, whether our own careers and social lives are satisfying or not.

H___ no, these are NOT "god's little angels"—but their challenges can foster US into becoming more than perhaps we ever imagined—more patient, stronger, more compassionate. And, no, we aren't "special" to have been singled out as parents of "special" children. We are far more put upon than most parents ever imagine; we usually have fewer resources and less support than other parent with handicapped offspring.

We become "special" in that we are forced to draw upon an inner strength that is usually reserved for prisoners of war or victims of massive natural disasters. We become survivors because we have to. Many—some—of us walk on eggshells until our toes are numb, dodge incoming mortar fire on a daily basis, and turn grey-headed VERY early. But in the end, when we rise to the challenge of our children's challenges, we must take great pride and satisfaction in our OWN intrepid strength.

Don't Go to Camp ... without PWSA's updated Medical Alert brochure!

Make sure your child's care providers have the *latest* information for both routine and emergency health care by giving them our completely revised "red" brochure. Available on the Web (www.pwsausa.org) under "Basic Facts" and "Medical Alert" or in brochure format (\$0.25 each for 2-20; \$0.20 each for 21-100) from PWSA:

1-800-926-4797.

The Right Sport for Luke

Glenna Kanish of Kittanning, Pennsylvania, proudly relates the tale of her son's sports accomplishment.

Having an athletically inclined older brother may be somewhat difficult for a male sibling with Prader-Willi syndrome. That was the situation in which our son, Luke, born January 19, 1988, found himself. After he made numerous requests to play football and baseball in the competitive atmosphere of our small town and stated time after time, "I know I can!", it became clear to me that it was imperative to seek a sport for Luke.

During the summer of 1997, when he was 9, Luke felt like part of a sports team by sitting in the dugout during the games with his brother, Zach, and Zach's Little League team. Luke would bring his own score book and keep tabs of balls and strikes in his own way. At the end of the season, Luke proudly received a "Coach of the Year" trophy, awarded from Zach's team.

The need to be a team player was still there. Reading in the local newspaper one day, I noticed there were sign-ups for youth bowling at one of the local bowling lanes. Could this be the sports opportunity for Luke? While registering Luke for bowling, I was relieved to find out that the scores are individual and based on the bowler's handicap. Luke was his own competitor.

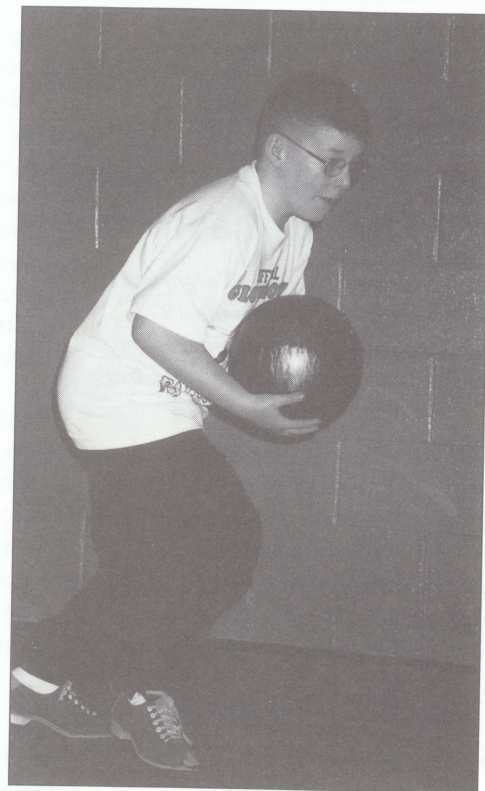
The first several weeks Luke's game scores averaged in the 20s and 30s. Luke was content, though. There were a few tears shed following consecutive gutter balls along with "high fives" slapped after spares and strikes.

In January of 1998, we learned that Luke qualified for a district Coke tournament in Butler, Pennsylvania. As luck would have it, a week prior to the tournament, Luke fell and broke the little finger on his left hand, requiring a cast. This could have prevented Luke from taking part in the tournament, but Luke uses both hands when he bowls.

On March 8, 1998, we traveled to Butler, where Luke bowled a 90, 100, and a 134 game. The score of 134 was his highest score ever, and he received a 710 score for the series with his handi-

cap. Luke received a \$200 scholarship as the result of his second place finish out of 63 bowlers in the under-11 age group, along with a certificate and medal.

You see, bowling is certainly the sport for Luke. A sport where his "handicap" pays off—bowling handicap, that is!! And he's going back for this year's tournament in March 1999 to try his luck again.



Luke Kanish, 10, goes for the strike.

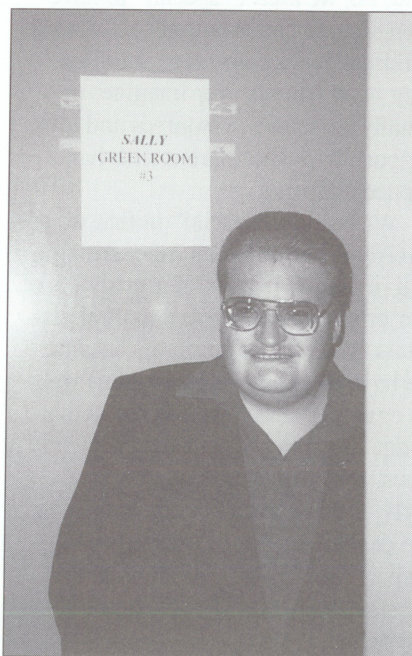
My Turn on the Sally Jessy Show

Janalee called me on November 2, 1998. She invited me to be on the Sally Jessy Raphael Show. Grandma and me had to leave on Nov. 3 because the show was taped on Nov. 4, 1998. We had to hurry. I almost lost my job. The assistant manager didn't give my message to my supervisor.

The show was called, "Don't Stare—We Are Still Human." [Editor's note: It aired Nov. 27, the day after Thanksgiving.] There were six people on the panel. We had rare disabilities or disorders. The people that run the show was really nice to me. I was kind of nervous. It was exciting. We even

rode in a limousine. Sally ask us how we felt about our disorders. Sally ask us what we did when people stare or say things that hurt our feelings. Most of us said we try to ignore or walk away. In Orlando I wrote a card about my feelings. Sally read my card and showed it on the screen. My card said I do not feel human. I feel like an alien because I can't have children. Sally made me feel good because she said I look good. Thank you, Janalee, for letting me go.

—Michael Parker



And thanks to you, Michael, for boosting awareness of PWS!

E-Mail Pen Pals Wanted

Mfg4050@aol.com

Hi. My name is Kerry. I have Prader-Willi and I am interested in meeting others with Prader-Willi. Please write back.

JOSEPHWEND@aol.com

I work with two twin boys who have Prader-Willi. They are in their 20s and are looking for a pen pal who also has Prader-Willi. If anyone is interested, please e-mail me.

URGRNDED@aol.com

My son Darrel is looking for a pen pal.

moo-moospice@msn.com

My daughter would like to become an "e-mail pal."

Dallas0813@aol.com

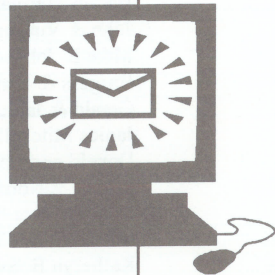
I live in Ohio and am in the 7th grade. I enjoy riding my bike, horseback riding, listening to CDs and fishing. I am also involved with the youth group at my church. I have one dog and a cat. I like writing to pen pals, so please write to me soon. Brian, 13

sassy2_16@yahoo.com

I live in Pennsylvania. I'm in 9th grade. I like cats and have one as a pet. I like to listen to music and sing. I like to make things from plastic canvas. I like doing things with Special Olympics. I would like a pen pal around my age. Kelley, 16

Dinasnight@aol.com

My name is Dina. I'm 17 years old and I have PWS. I live in Pasadena, Maryland. I go to high school and work in an enclave at J.C. Penney's. I like reading books everyday. I am in Special Olympics. We are doing basketball now. I have a little dog named Bear. I would love to have some pen pals with PWS also. Please write back as soon as possible. This is my first time doing this. I will check my mail everyday!



How About a Pen Pal in England?

I am 35 years of age and I have Prader-Willi syndrome. I am a member of the PWSA—UK (United Kingdom). I am writing to find out if there are any boys and girls living in the States who would like a pen friend from England. They must be around age 15 upwards and have the same interests as myself.

I am very keen on writing letters and I have a computer of my own which I've had for 2 years as my Christmas present from my eldest sister in London. I love receiving letters and I have not had a pen friend from the States for years and years. ... I like computers, discos, parties, socializing, visit to the cinema, ten pin bowling, going to keep fit at the sports centre in Liverpool. ...



Yours faithfully,

Wayne John Cummings
5 Rawlins Street
Liverpool L70JE
England (UK)

Parent Connections

With the arrival of the Internet, there are so many ways for parents to connect that no one with a computer and a modem needs to feel isolated.

The hottest place to talk about Prader-Willi syndrome these days is on two discussion lists available through a Web site call Onelist (www.onelist.com). Last September, two mothers launched the **Prader-Willi Onelist**, which now has more than 100 subscribers. Another mom started a second list in January, called the **PWSissues Onelist**, geared to parents of teens and adults

Some parents use the lists in a very personal way to share laughs and tears, as well as information. Some are still trying to get their children diagnosed and understand genetic issues. Many are dealing with issues related to development, diet, growth hormone, behavior, education, finding good medical services, balancing family needs, and so forth. Some parents write almost every day; many just listen in and comment occasionally. New subscribers always get a warm welcome and some introductions. Parents on the Prader-Willi Onelist are even conducting a survey on members' children. (To get a copy, e-mail Katie McKay in Australia at this address: ktmckay@ozemail.com.au) Yes, the list has become an international meeting place!

Here's how the Onelist service works:

- Subscriptions to a list are free, and only subscribers can send e-mails to the list. To subscribe, you need only an e-mail address and a password.
 - When any subscriber sends e-mail to the list, it is sent to every subscriber on the list. A regular subscription gets you every e-mail individually (and any attachments the subscribers send). Switching your subscription to "digest form" compiles a number of individual e-mails into one long e-mail (with no attachments). You also have an option of stopping your list mail for a period of time, such as when you go on vacation.
 - Anyone can read the "Archives" of messages (in digest form) compiled since that particular list began—a good way to decide if you want to subscribe. (They're on the Onelist Web site.)

So what are you waiting for? Go to www.onelist.com and look up Prader-Willi and PWSissues to see what you've been missing ...

"Provide a Legacy"

is a new awareness initiative of PWSA (USA) to encourage planned giving through wills or estate plans. This is the first of a series to inform members and friends of PWSA of a unique opportunity to support the association.

If providing a legacy is of interest to you, take the next step and contact your attorney, or call or write the Prader-Willi Syndrome Association (USA), 5700 Midnight Pass Rd., Suite 6, Sarasota, FL 34242. Telephone: 1-800-926-4797

Prepared by Robert Comiskey, Certified Financial Planner and PWSA-USA volunteer

8 Things You Can Do To Provide a Legacy:

1. Prepare a will. Fewer than 40 percent of people who pass away have one.
2. Leave a gift in your will for PWSA (USA). Less than 6 percent of people include nonprofits in their estate plans. Recently, a physician from Texas left 2 percent of his estate in his will to PWSA (USA) — the gift amounted to approximately \$10,000. Imagine the impact on the growth of our association and the progress in research if everyone made a small donation in their will!
3. Leave a specific dollar amount or a percentage of the assets in your will.
4. Consider various assets for your charitable gift, such as: IRAs, savings bonds, stocks, bonds, CDs, real estate, etc. Such gifts may even provide a tax savings.
5. Name PWSA (USA) as the beneficiary of an existing life insurance or annuity contract.
6. Remember to let loved ones know that upon your death you want memorial gifts to go to PWSA (USA).
7. Encourage family and friends to leave deferred gifts to PWSA (USA) in their wills. Ask your financial advisor to include charitable giving as part of counsel to other clients.
8. Consider establishing a life income gift that will provide current income to you and your loved ones. It will also provide significant tax benefits. (This strategy will be covered extensively in a future *Gathered View*.)

DONATIONS RECEIVED IN MEMORY OF LOVED ONES

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R. B. Gilpatrick
S. S. Werlinich Jr.

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(AND IN HONOR OF JEFF BOND)

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Special Thanks to Our Recent Donors

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(\$1,000 or more)

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Kit & Buddy Welch (*for research*)

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Arch Angel

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Lionel Lamoureux
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Curt & Marion Shacklett

Angel

(\$100-\$249)

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Paul & Pam Alterman (Epson color printer for office)
Prader-Willi Syndrome Association of Michigan (strategic planning project)

Operating Fund

United Way/Capital Area
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Operating Fund—continued

Bernard & Joan Bena
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New England Power Service
(*matching contribution from Robert Snow*)
Louise Robinson (*in honor of the birthday of Shirley Burnett*)
Dr. Terrance Wardinsky
Eugene and Nancy Woo

In honor of Jessika Dickinson:

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Judges and Police Exec. Of Niagara County
Robert Sawyer

In honor of the birthday of Shirley Lehman:

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Jerome Goldstein
Della Grossman
Alex and Nettie Insdorf
Irving Lamm
Hania Annie Neuer
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Stanley Perlman
Morrey L. Rotenberg

In honor of Lota Mitchell on her birthday:

Sandra Caffo
Mary Lou Clark
Elaine Dively
Sandra Faulkner
Nan Koerner

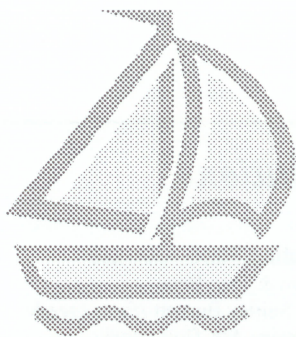
In honor of Jackson D. Lowe:

Parker L. Kidder
Jean & Douglas Lowe



We're only a few thousand dollars away from meeting our Angel Fund goal, thanks to our generous supporters!

It's not too late to contribute ...
Please help us reach our star!



1999 PWSA Conference Special Events

If you need a conference registration packet, call PWSA (USA) today —

1-800-926-4797

— or visit our Web site for complete registration forms and conference information:

www.pwsausa.org

**Conference registration
deadline:**

*** JUNE 1st ***

Youth and Adult Program Highlights

Thursday, July 8, we plan on a celebration in the hotel that will offer interesting entertainment and learning opportunities. We will have a magician, a storyteller, "Amazing Reptiles and Animals," a carnival under the "Big Top" tent, and lots of prizes. There will also be video games.

We'll also have a sibling workshop on Thursday for the brothers and sisters of our children and adults with PWS. This will be a wonderful opportunity for siblings to share their experiences with their peers, and to have some private time.

Friday, July 9, we will take our children/adults with Prader-Willi syndrome, their siblings, and volunteers on an exciting and educational field trip. We'll board state-of-the-art buses that "kneel" for easy entry and have multiple video monitors for entertainment while waiting and riding.

- Our first stop will be the Stephen Birch Aquarium and Museum, a part of the Scripps Institute of Oceanography, located on the campus of the University of California, San Diego. We'll tour the aquarium's living displays of Pacific Coast fishes and marine life, from the arctic to the tropics. We'll also visit the museum, which contains many items of interest in the study of marine life and oceanography (including a display on sharks) and the outdoor living tide pool display.
- Then we travel to Balboa Park for a picnic lunch under the trees, right next to the Reuben H. Fleet Space Theater and Science Center.
- After lunch, the group will attend a private showing of the current feature at the OMNIMAX theater in the Reuben H. Fleet (now showing "Everest"). After the film, YAAP participants will be transported back to the hotel for afternoon refreshments.

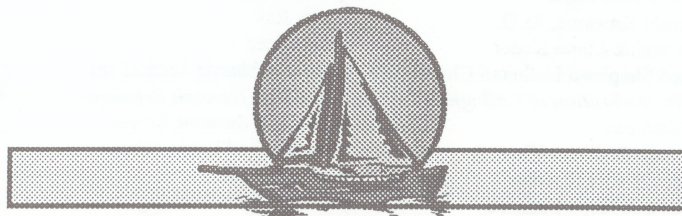
The Dinner-Dance — Friday evening the participants in the youth/adult program will enjoy the popular annual dinner-dance. **This year the Dinner-Dance is FREE!** Because of the generosity of our donors, all YAAP participants will be able to join in the Dinner-Dance festivities at no cost to their parents/guardians/service providers. We will have a well-prepared and well-presented low-calorie banquet meal, contests and prizes, and a special deejay who will play music for your dancing pleasure.

We are offering an optional family event ... a sunset cruise of San Diego Harbor on Thursday night, July 8, 1999. The response to the flyer mailed with the conference registration forms has been good, but there are more openings if you have not yet signed up.

The harbor cruise will board at about 6:30 p.m., depart at about 7:00 p.m., and return at about 9:00 p.m. Complimentary diet soft drinks, coffee and tea will be served aboard the ship. A no-host bar will also be available. The fares will be \$20 for adolescents and adults (13 years and older) and \$15 for children 6-12 years old. Children under age 6 are free.

If you want to go, but haven't yet signed up, call Fran Moss at the Prader-Willi California Foundation, (805) 389-3484.

SUNSET HARBOR CRUISE



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.

