



The *Gathered View*

January-February 2001
Volume 26, Number 1

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

Special Memories with Very Special People

By Barb Dorn, President, PWSA (USA)

When my son Tony (who has PWS) started high school last fall, he could not read a note of music or play a musical instrument. However, within the first few weeks of school he came home and proudly announced, "Mom, I'm going to play in the band." The band he was going to play in was the Very Special Arts Band.

Very Special Arts of Wisconsin is a statewide organization that reaches out to children and adults with disabilities, making it possible for them to be a part of the arts — music, dance, theatre and art. Their mission is to expand the capabilities, confidence and quality of life for children and adults with disabilities by providing many different arts programs.

At Verona High School, students with special educational needs are paired with "band buddies" — students who have volunteered to work with and teach students like Tony how to play a musical instrument. Tony had two buddies — Mia and Casey — who helped him learn to keep the beat on his instrument, the drum.

John Georgeson, the high school band director, provided the leadership. He has been involved in this program for more than 12 years. He was instrumental in getting members of the Very Special Arts bands from across Wisconsin to unite for a special performance.

Once a year, the band performs on Very Special Arts Saturday with the University of Wisconsin Marching Band at a Big Ten football game at Camp Randall Stadium in Madison.



At the Governor's Mansion, Tony Dorn (second from left) stands with Sue Ann Thompson and her husband, then Wisconsin Governor Tommy Thompson (now Secretary of Health & Human Services), John Georgeson and Mia Georgeson.

The University of Wisconsin Marching Band director and the members of his band open their hearts to these special musicians, and it is a win-win arrangement for everyone.

My husband and I were proud bystanders at the sidelines this year. Tears of joy fell down our cheeks as we watched Tony take the field, beating his drum with his band buddies at his side. Each band member wore a Very Special Arts sweatshirt and marched with head held high.

Later in the game, I met up with Tony as he was watching the game with other band members. As I waited, several University of Wisconsin band members

came by to talk and joke with these special young men and women. Later as we walked to our car, many fans stopped us and told Tony what a good job he had done. His sweatshirt was a symbol of pride and acceptance.

In early December, Tony and his band buddy Mia and her father, along with other staff from his high school were invited to the Governor's mansion. During a brief ceremony, Very Special Arts of Wisconsin honored the staff and students of Tony's high school as well as the U.W. Marching Band. Tony gave a short speech (about 6 words!), sharing his excitement and the fun he had

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The Prader-Willi Syndrome Association (USA)

5700 Midnight Pass Road, Suite 6
Sarasota, Florida 34242

1-800-926-4797

9 a.m. to 7 p.m. Eastern Time

Local: 941-312-0400

Fax 941-312-0142

e-mail: pwsausa@aol.com

www.pwsausa.org

Officers

President - Barb Dorn, Wis.

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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 at the address above.



Siobhan McGee given Pat Rupe Memorial Service Award

Pictured, L to R, are Executive Director Janalee Heinemann, office volunteer Siobhan McGee and Bill and Norma Rupe. The Rupes created the PWSA (USA) service award in honor of their daughter Pat, who died. It is given to the person who most exemplifies rising above adversity to serve others.

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Annual Report to the Membership for the Year 2000

By Janalee Heinemann

The Mission of the Prader-Willi Syndrome Association (USA) is to provide parents and professionals a national and international network of information, support services and research endeavors to expressly meet the needs of affected children and adults and their families.

In the year 2000, PWSA (USA) strengthened its position as the key resource and major provider of services for all who are impacted by Prader-Willi syndrome. Our efforts extend from coast to coast and nation to nation. Our voices are heard from young and old, rich and poor, and from all ethnic backgrounds.

A Network of People Helping People

The governing body, various boards and committees of PWSA (USA) and the volunteers and staff at the national office have spent many hours in meetings, phone calls and e-mails, working hard to improve the services of this organization. In addition, there have been many hard-working volunteers who have worked in communities across this nation, improving the lives of persons with Prader-Willi syndrome. Thanks go to all of you, including our 2000 Officers and Board Members.

PWSA (USA) continues to provide information and support services to all of those whose lives are touched by Prader-Willi Syndrome. This is accomplished in many ways.

Information and Support

During 2000, PWSA (USA) National Office responded to a new record number of phone calls and e-mails, providing information to hundreds of callers for

crisis intervention, educational and school advocacy, medical information, early intervention inquiries and student reports.

Awareness through Our Web Site

Traffic to our web site averages 10,000 hits a day. Many new features have been added, and we began hosting web sites for five chapters of PWSA (USA). The National office receives rave reviews about the information offered and its accessibility.

Our National Newsletter

The Gathered View continues to be one of our primary sources of information and sharing for our members. Approximately 2,270 copies of each newsletter edition were mailed.

Establishing and Expanding Programs Parent Mentoring Program:

Awareness of Prader-Willi syndrome is on the increase. We are receiving a significant increase in calls from parents with new infants who have been diagnosed with PWS. In response, we have begun a Parent Mentoring Program, coordinated by Carolyn Loker of Michigan. Early diagnosis, education and awareness are the keys to prevention of life-threatening obesity, and years of isolation and emotional trauma to the family of the child with Prader-Willi

syndrome. Early intervention can also save thousands of dollars in medical expenses and greatly reduce emotional turmoil on families.

Sponsoring Research

During 2000, PWSA (USA) provided financial support for the following research grants:

- Dr. Nathan Shapira, "Open Pilot Study of Topiramate in Adults with PWS"
- Dr. Susan Cell, an extension of "Neuroanatomical Correlates of Hunger Satiation in Subjects With PWS"
- Dr. Tracy Ballock, "Orthopaedic Manifestations of PWS"

Through the Young Parent Mentoring Program, eight volunteer parents with children who have Prader-Willi syndrome will be selected and trained to provide one-to-one mentoring and support services to parents of newly diagnosed children. These volunteer-mentoring parents will be trained and coordinated by Carolyn, who has recently completed the volunteer training manual.

To support their efforts, I have written grants to provide money to cover the following: training materials, phone cards (to eliminate phone expense for the volunteers) and specialized support packets ("Packets of Hope"). Carolyn and Jim Loker have donated the first set of phone cards for the volunteers.

Adding New Members

During the year 2000, 438 new members joined PWSA (USA), a 20 percent increase over the previous year. We now have 3,698 children with PWS in our database.

Report continued on pages 4 & 5

Providing Educational Materials about PWS

We now offer 14 educational brochures, 35 educational booklets, 14 educational videos, poster and wallet cards

New Products Available

- *Nutritional Care for Infants & Toddlers with PWS*, by J. Cox & D. Doorlag; edited by Linda Keder; consultants: Dr. Jim and Carolyn Loker
- *PWS Weight & Behavior Management*, Spanish edition
- *My Grandchild Has PWS, Now What?*, by Barbara McManus
- *Helping with Diet Management, Children With PWS at School*
- *Management of Prader-Willi Syndrome*, (soft-cover reprint) edited by Louise Greenswag and Randell Alexander
- Six educational videos from the San Diego Conference

Planned New Products

- The Publications Committee plans to reprint an extensive, 400-page Management Book in Spanish, edited by the Spain Association. Anticipated publication is June 2001
- Member parent Cheryl Couch has just written a great book titled *My Rag Doll*, a mother's journal of raising and loving a child with PWS - birth to age 6, to be offered with PWSA (USA) publication materials

Pharmacia has committed to funding new educational media products on Prader-Willi syndrome, to be made available through PWSA (USA):

- Slides & CD-ROM for grand rounds and other medical teaching
- DVD/video for health care professionals, especially physicians of newly diagnosed children with PWS
- DVD/video for non-medical people especially parents of children with PWS. At my request, there will be a special section for parents of the young child

Grandparent support program:

A grandparent booklet was published and a special session conducted at our Pittsburgh Conference. A free booklet and packet went to all grandparents on Grandparent Day. A board member has financed the cost of the grandparent booklet.

Crisis intervention:

Need for crisis management has also increased. We have provided crisis packets and counseling for more than 252 families at no cost to the family. Because of my extensive background as a medical social worker and counselor, I do the crisis management, along with the assistance of our volunteer crisis counselor, David Wyatt. David has a master's degree in counseling and more than 30 years of experience. We have received feedback that our crisis packets have been extremely helpful in crisis situations.

Legal advocacy team:

For the future, we are considering a Legal Advocacy Team so that we can provide more extensive support on crisis cases. It would include an attorney, social worker, physician, media person, someone who knows the judicial/government system, and someone who would facilitate and coordinate cases.

Bereavement Program:

Our volunteer bereavement coordinator, Norma Rupe, sends out three to four packets within the first year of a child's



death. Either Norma or I personally contact the family after a death. This year, Norma sent 146 holiday bereavement mailings. We do bereavement follow-up not only for situations where children with PWS die, but also if a sibling or parent dies.

Sponsorship of 25th Anniversary National Conference in Pittsburgh

In 2000, PWSA (USA), along with our PA host chapter, had nearly 1,100 participating in this national event, which is annually the largest gathering in the world of parents and professionals dealing with the syndrome. Parents and professionals have an opportunity to connect with others to update and share information and friendships. Two hundred twenty-six families were represented, and more than 300 participated in our Youth And Adult Program, which included 193 persons with PWS.

Financial Support for Those In Need

When a crisis or unforeseen situations take place, PWSA (USA) does its best to provide financial support to those in need. Once again, our organization was able to lessen the burden a little for those who carry so much. Last year PWSA (USA):

- Provided 24 families with conference grants
- Provided free memberships and newsletters for 78 families in hardship situations and to 43 adults with PWS
- Enabled our Executive Director to serve as an expert witness in New Mexico where a child, age 3, was being removed from her family

Major Grants Awarded

PWSA (USA) was awarded major grants from Pharmacia Corporation, Gerald J. and Dorothy R. Friedman Foundation, Ronald McDonald House Charities, The Children's Institute, The Maplewood Foundation, Edith Trees Foundation, and the Commonwealth of Pennsylvania Department of Community and Economic Development.

Strengthening Our Financial Security

PWSA (USA) strives to expand its financial security in order to keep up with the demands of operating and meeting the needs of our organization and its members. The Executive Director, with the support of the Board of Directors and Officers, continues to seek out new sources of funding as well as make sound decisions on current investments and revenues.

As we go forward in the Millennium of Hope, we are called upon to continue our efforts to improve the quality of life for children and adults with Prader-Willi syndrome. The Board of Directors and Officers of PWSA (USA) extend a special thanks to everyone assisting us as we continue to carry out our mission.

Total donations from all sources exceeded \$325,000. Of this amount, \$9,218 is restricted for research and \$114,578 is restricted for special projects. Last year's total donations were \$213,000. This is a substantial increase, which is due to the effort and generous donations of many people and organizations.

Thanks to the enormous fund raising efforts of the Pennsylvania state chapter, we were able to keep costs down for our national conference.

Expanded Volunteer Efforts

Almost all of the accomplishments by the Association throughout our 25 years have been from volunteer efforts of hundreds of parents and professionals like you. Volunteer efforts fall into six main categories:

- PWSA (USA) has a volunteer board of 12 members and four officers, 12 committees and several teams, also composed entirely of volunteers except for the Executive Director, who is an ad hoc member of each committee.

- Funds for PWSA (USA) are also raised through local and national volunteer efforts.

- The annual national conference is organized and staffed by PWSA (USA) volunteers from the host state under the guidance of the Executive Director and a volunteer conference committee. The presenters volunteer their time and most travel expenses. The YAAP program at the national conference is directed by paid consultants, but staffed entirely by volunteers.

- Publications are created and edited by volunteers, including our brochures and new softbound management book. Our poster on PWS was created and produced by a volunteer parent.

- Each state chapter is under the guidance of volunteer officers and boards. Only three state chapters have part-time paid executive directors. All parents are referred to state chapters by PWSA (USA)

for follow-up support and also to parents and professionals in their state who will provide support and consultation on a volunteer basis.

- Local Sarasota volunteers assist the office staff with the daily running of the national office. They route calls from the crisis hotline, log incoming mail and donations, assist with mailings, label brochures, assist with the bereavement follow-up program, assist with general organization of the office, copy and bind booklets and work on special projects.

The tenacity and resolve of the many families who have advocated through the years, combined with the undaunted energy of many new parents, resulted in the remarkable progress we've made this last year in understanding the syndrome.

It is encouraging to see and know that this new generation of parents, building on the foundation of the past, will be the driving force for the new decade. They will carry the torch and it will burn brightly.

Media Coverage

- PWS is featured in the February edition of the widely distributed Family Circle magazine, on the newsstands January 8, 2001. Our Lota Mitchell is featured in the section "Women Who Make A Difference."
- PWSA (USA) is working with CNN on a feature story about PWS. Watch our web site for an air date.
- Exceptional Parent had a section on PWS and the new FDA approval on growth hormone for PWS in their November 2000 edition.
- PWS received media exposure through the New Mexico case last August and September 2000.
- Several state chapters obtained media coverage during the year.
- PWSA (USA) Executive Director Janalee Heinemann was on two Sarasota TV stations that were programming information about the syndrome.

Awareness – An Ongoing Need, Ongoing Challenge

Many families and professionals continue to be faced with the challenge of persons in their communities not knowing about Prader-Willi syndrome and the unique needs of these individuals. PWSA (USA) with the support of many local chapters continues to strive for increased awareness and understanding.

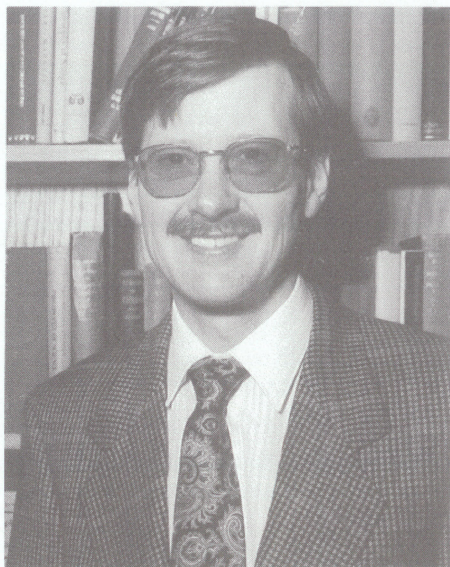
- Last year, we mailed free of charge more than 2,200 Awareness packets and 3,000 Educational packets. We create, publish and distribute more free literature about PWS than anyone in the world.

- Our Executive Director met with four state chapters and made presentations at their conferences, in addition to presenting in Monaco at the International Endocrinologist Meeting.

- PWSA (USA) co-sponsored Endo International in Canada.

Dr. Butler is Now Advisory Board Chairman

Merlin Butler, M.D., Ph.D., becomes the third chairman of PWSA's Scientific Advisory Board (SAB), following Suzanne Cassidy, M.D., who has served as chair for 6 years.



Merlin Butler, M.D., Ph.D.

The SAB is a panel of research-dedicated professionals whose chief responsibility is to review the merits of grant proposals that request research funds and recommend to the PWSA Board of Directors either approval or rejection.

Dr. Butler is currently chief of the Section of Medical Genetics and Molecular Medicine at Children's Mercy Hospital in Kansas City, Missouri, and holds the William R. Brown/Missouri Endowed Chair of Medical Genetics and Molecular Medicine and Professor of Pediatrics at the University of Missouri - Kansas City School of Medicine.

We Say Thanks

PWSA (USA) gratefully acknowledges grants from Ronald McDonald House Charities -- for production and distribution of PWS awareness and education packets and for assisting in reproduction of *The Gathered View*.

We also thank Pharmacia Corporation for an unrestricted grant used for educational purposes.

His background is an impressive one. He received his M.D. from the University of Nebraska Medical Center in 1978 and his Ph.D. in Medical Genetics from Indiana University in 1984. He became a Diplomate of the American Board of Medical Genetics in 1984 and is certified in both Clinical Genetics and Clinical Cytogenetics — one of approximately 550 cytogeneticists in the U.S., an increasingly important field as the Human Genome Project nears completion.

He became a founding fellow of the American College of Medical Genetics in 1993. He received the Osler Institute Teaching Award in 1989 and was elected to serve a six-year term as cytogeneticist to represent the American College of Medical Genetics on the American Pathology/American College of Medical

Genetics Cytogenetics Resource Committee in 1993.

A frequent speaker at PWSA national conferences and Honoree for 2000, Dr. Butler has contributed to the medical literature numerous articles on Prader-Willi and related syndromes, including the discovery of the paternal origin of chromosome 15 deletion in individuals with PWS. He has been active in the study of genetic characterizations of chromosome 15 and PWS.

PWSA(USA) is fortunate indeed to have a person of Dr. Butler's caliber and training heading the SAB. A warm welcome goes to him in his new position, as well as heartfelt appreciation to Dr. Cassidy for her work over the years.

The View From Our Chapters

California

The chapter published a listing of residential homes in California that serve adults with PWS.

Georgia

In October, the chapter held its annual retreat for families of young children with PWS.

Indiana

The chapter published a web site address for the Governor's Planning Council for People with Disabilities, to encourage parents to follow disability issues in Indiana government, reminding parents that they need to build relationships with their elected representatives.

Iowa

Through generous local contributors, the chapter was able to offer full and partial Camp Scholarships for people with PWS to enjoy respite weekends or week-long camps at facilities in Iowa.

Md/Va/DC

Get Ready for a New School Year offered tips and resources for parents to assist with a successful school experience for children with PWS. The chapter has also developed a resource directory of doctors, therapists and other professionals.

Michigan

In conjunction with Hope Network, the chapter organized a PWS Awareness Walk Around Reeds Lake in Grand Rapids, with proceeds benefitting PWSA of Michigan.

New England

The Association hosted a winter Parent Discussion Group, a spring Family Swim Day and a fall New England Conference.

Pennsylvania

After a successful national conference in July, the Chapter relaxed and celebrated with a family picnic in August, graciously hosted by Keystone Community Resources, a large Pennsylvania residential provider.

PWSA (USA) Board of Directors Seeks Nominations

Board of Directors

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?

Someone who is willing to volunteer his or her time, talents and expertise to work together to support the mission of PWSA (USA).

What are the expectations of a Board Member?

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

Are there any other responsibilities?

Conference calls and mail votes are required throughout the year. Each Board Member is expected to be on at least one committee. Currently the 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.

IPWSO Parent Delegate

The International Prader-Willi Syndrome Organization (IPWSO) provides support to member associations in their efforts to improve the quality of life for all people with Prader-Willi syndrome and their families.

The Parent Delegate represents PWSA (USA) to IPWSO, acts as a liaison between IPWSO and PWSA, attends IPWSO International Conference/ Meetings and submits activity reports two times per year among other duties.

This position will become vacant after June 30, 2001.

We are looking for a member of PWSA(USA) who preferably has some knowledge of international cultures. The Parent Delegate will meet and network with parents and professionals from 26 countries. The delegate will act as a contact for people visiting the U.S. from other countries and will plan the itinerary

when the IPWSO President visits the U.S. or when requested.

Proficiency with the Internet and handling e-mail is an essential requirement for this position.

How to Apply

The Leadership Development Committee requests that names of members interested in, or recommended for, a seat on the PWSA (USA) Board of Directors or the Parent Delegate for IPWSO be submitted to the committee no later than April 1, 2001.

Recommendations should include a brief description of the member's qualifi-

cations to serve on the Board or as the Parent Delegate for IPWSO.

Who to contact

Please send recommendations by mail, fax or email to:

PWSA(USA)

Attention: Leadership Development Committee Chair

5700 Midnight Pass Rd., Suite 6
Sarasota, FL 34242

Email: pwsausa@aol.com

Fax: (941) 312-0142

If you have any questions, please feel free to contact Carolyn Loker, Leadership Development Committee Chair

Email: carolynloker@yahoo.com

Families Needed for Siblings Study

By Erica Burner

I am a graduate student receiving my master's degree in genetic counseling at Case Western Reserve University. I first became interested in Prader-Willi syndrome through my involvement in a project led by Dr. Suzanne Cassidy, and my contact with her patients diagnosed with Prader-Willi syndrome.

I have developed a project to look at how the diagnosis of Prader-Willi syndrome affects the entire family. I am especially interested in how this diagnosis in one sibling impacts the brothers and sisters.

The specific goal of this project is to identify siblings' feelings concerning having a brother or sister with PWS, as well as the relevant factors that contribute to these attitudes and feelings.

I hope that by completing this project, more effective support resources will eventually be developed that successfully meet the educational and psychosocial needs of these siblings.

Additionally, this study will present opportunity for future research to define possible coping strategies siblings can use in dealing with the daily stresses of living with their affected brother or sister.

Conclusions drawn from the study may also lead to advances in genetic

counseling strategies that use a more family-centered approach in dealing with PWS and incorporate the siblings' needs into the coping strategies of the entire family.

Your help is needed in accomplishing the goals of this project! If you have children ages 10 and older, and would be willing to participate in this study, please contact me with the following information: your name, address and telephone number, name and age of child with PWS, names and ages of other children. Please indicate the best day and time to contact you and your children.

My mailing address is: Erica Burner, Genetic Counseling Student, Case Western Reserve University, Biomedical Research Building, Department of Genetics, Room 620, 2145 Adelbert Road, Cleveland, OH 44106.

If you prefer, you can send this information to me via email at: elb8@po.cwru.edu or telephone me at (216) 368-1891. Please also feel free to contact me by any of these means if you have any questions regarding this project.

You will be contacted by telephone at a later date to participate. Thank you so much for your interest.

Characterizing and Managing Behavior in Prader-Willi Syndrome

By Kevin Jackson, Ph.D., CBA
ARC of Alachua County

This is the second of a three-part series of articles based on my training as a behavior analyst and my 13 years of working with children and adults with PWS in family settings, schools and as director of behavioral services for a large residential treatment program specializing in PWS. The concepts discussed have been very effective in addressing the behavior of those with Prader-Willi syndrome.

Part II. Improving Behavior

Parents can learn to deal more effectively with the behavior of their child with PWS while learning and practicing parenting skills that are relevant to all of their children. The same basic parenting practices that are most effective with ordinary children are also most effective with PWS.

Unfortunately, parenting practices which are ineffective or counter-productive with ordinary children are especially harmful and counter-productive with PWS. For this reason, I believe it is critical for parents of a child with PWS to learn how to parent more effectively. By practicing effective parenting techniques such as those described below, parents can significantly decrease the overall amount of time and energy they spend dealing with problem behaviors.

1. Focus on positive interactions

Interactions between people may be categorized as positive or negative:

Positive interactions include smiles, greetings, compliments, eye contact, supportive gestures, small talk, expressions of care and concern, enthusiasm and friendly, non-threatening and non-judgmental advice.

Negative interactions include criticism, frowns, arguing, screaming, threatening words and actions, talking down to or lecturing in the traditional parental way, showing disapproval, scolding and bossy or demanding talk.

A social environment of predominately negative interactions directly contributes to problem behaviors. Conversely, a predominately positive social environment can reduce or eliminate many problem behaviors. In a healthy social environment, positive interactions outnumber negative interactions by a ratio of at least eight to one. That is, there should be at least eight times as many positive interactions as negative interactions.

We know that people are happier, healthier, more cooperative, more productive and less likely to exhibit problem behaviors when their social environment is a positive one.

If you think that a ratio of eight to one is not attainable, I can assure you that it is. Consider infants in their first year of life. They are typically smothered with love and affection (i.e., positive interactions) probably at a ratio of 100 to one or greater.

Recently, I watched in amazement as my daughter's track coach ran an entire meet, with about 25 girls participating, while remaining focused on positive interactions. In fact, he had a kind word for each and every participant in every single event. Let me tell you, those girls were motivated, well behaved and they had a great time!

Studies with children in family settings show that when positive interactions sufficiently outnumber negative interactions, the children are more likely to be successful in school and to be emotionally, intellectually and socially advantaged.

Some people, and some families, naturally focus on positive interactions. However, most of us have room for improvement in this area. I recommend taking your own data as a method of enhancing your own interaction ratio. Use a sheet of paper or 3x5 card with two columns labeled for positive interactions and negative interactions. You will find that the more positive interactions you

engage in, the fewer problem behaviors your child will exhibit.

One key to creating a positive social environment is to eliminate coercion. Coercion means using criticism, sarcasm, threats, arguing, questioning, and/or physical or verbal force to control behavior. Eliminating coercion does not mean abandoning discipline or letting your child get away with murder. It means replacing primitive disciplinary practices with practices that actually lead to long-term beneficial behavior change.

Coercion may appear to work because sometimes a coercive interaction can stop an ongoing problem behavior. However, this short-term effect is misleading. In actuality, the overall probability of the child engaging in problem behaviors can be expected to increase with the continued use of coercion. This is true in part because coercion motivates the individual being coerced to retaliate and get even with the people and social situations providing or associated with the coercion. Non-compliance, resistance, tantrums, theft and aggression often occur in response to coercion by others.

In addition, coercive practices contribute to problem behaviors by directly demonstrating inappropriate behavior to the child. The coercive emotional outburst of an angry parent serves as a model of unacceptable behavior. This behavior is readily imitated when at a later time the child is angered by some event. When intervening with problem behaviors, it is best if the parent is in control, and the consequences are administered calmly and confidently.

Coercion may be particularly harmful for children with PWS. As described in Part I of this series, the behavior of children with PWS often appears to be directly reinforced by the emotional coercive responses of others. Coercion may also be more likely to trigger an emotional tantrum in a child with PWS.

Behavior continued on page 9

You will find that by staying focused on positive interactions, and by learning the other interventions I describe, you can comfortably and more effectively control your child's behavior without resorting to the use of negative or coercive interactions.

2. Ignore systematically

There is a natural tendency for people to ignore appropriate behavior and to attend to inappropriate behavior. However, studies of social practices in education, business and family settings show that attending to appropriate behavior while ignoring inappropriate behavior is a more effective option.

Ignoring means refraining from social interaction (e.g., eye contact, talk, gestures, facial expressions) when a problem behavior occurs. It means pretending you never saw or heard the behavior and are going on as if it didn't occur, or as if you completely don't care.

A. Ignore harmless annoying behavior

Ignore behaviors that do not threaten the basic quality of life, limb and property. Annoying noises, talk and silly or mildly disruptive activities all fit in this category. Pick your battles. Do not waste time and energy on minor behavior issues that are inconsequential.

Instead, focus on your child's appropriate behaviors by attending to them with praise and positive interactions.

Learn to tolerate and ignore the harmless behavior of your child with PWS. This includes age typical behaviors characteristic of all children, minor PWS typical behaviors (e.g., skin-picking), as well as other peculiar behaviors that may annoy you but are actually harmless.

For example, brief episodes of yelling or mildly aggressive play should be ignored. Unusual noises or verbalizations, which may be fun for your child but annoying to you, should be ignored.

Minor instances of non-compliance, when immediate compliance is not essential, should be ignored.

With non-compliance, a good strategy is to wait patiently for compli-

ance and then reinforce compliant behavior, when it occurs, with a positive interaction.

If a problem behavior is so annoying that you cannot stay and ignore, leave the area. You can go outside, go to another room or walk away and do something else.

If you absolutely cannot ignore the behavior, try redirecting the child to another area or activity with a friendly, nonthreatening prompt. In either case, wait for your child to do a more appropriate behavior and attend to this behavior instead.

B. Ignore arguing

Individuals with PWS are often predisposed to argue. Therefore, it is especially important to address arguing as a problem behavior.

First, you can prevent some arguments by not saying no to your child's requests unless you are sure that you mean it and there is a good reason to say no.

Sometimes parents say no to a request initially (perhaps because it is not a convenient time or the request requires some effort on the part of the parent) and then after further argument and consideration give in and say yes. This practice may inadvertently reinforce arguing. The next time the parent says no, the child will be more likely to argue the point.

In general, you should honor your children's requests unless there is a good reason not to. If you say no to a request, then stick to it. If saying no results in an argument, ignore it.

There also is a distinction between calmly asserting one's position about an issue and aggressively arguing. If your child is calmly discussing an issue with you, it is fine to listen and consider his or her perspective. If your child engages in loud, aggressive or persistent arguing, ignore it.

C. Ignore inappropriate behavior that occurs in the context of appropriate behavior

This is the most sophisticated form of ignoring. It usually involves ignoring

inappropriate talk while attending to other appropriate behavior.

The following scenario, which takes place prior to leaving for a shopping trip, illustrates the technique:

Mom: "Oh Tommy, that shirt doesn't fit. How about going back to your room and putting on another one that fits better."

Tommy: Slowly walking back to his room, "But it does fit, Mom.... Who cares anyhow, it's my shirt, not yours, I am sick of this, it is not fair!"

Mom says nothing and walks away to do other activities, completely ignoring Tommy's inappropriate talk. Tommy is doing exactly what his mother asked. His argument is harmless behavior that should be completely ignored.

Five minutes later, Tommy returns with another shirt.

Mom: Noticing Tommy's shirt, approaches Tommy and gives him a hug, "Thank you Tommy, that shirt really looks much better. Now we can go to the store."

Here, Mom initiates a positive interaction based on Tommy returning with an appropriate shirt. She is reinforcing his compliant behavior, while ignoring his minor inappropriate arguing.

An additional reinforcer in this scenario is the opportunity to go to the store, which was withheld by the mother until Tommy complied with her request by changing his shirt.

If the mother consistently uses this technique, Tommy's arguing will virtually disappear. Mom has removed the payoff for arguing.

The interventions described here are based on good science and research. I use these techniques myself, and I have seen them work time and again.

This does not mean that implementing these methods is easy. Learning to do things differently requires considerable effort, commitment and a plan.

To help, a parenting book I recommend is *The Power of Positive Parenting* by Dr. Glenn Latham. This book may be ordered at 1-800-748-4850 or from the web site, parentingprescriptions.com, where related materials are also available.

Water Intoxication Alert

Due to a medical crisis where a young person with PWS ended up in intensive care with a possible diagnosis of water intoxication, I e-mailed our medical boards about the situation. The following responses are from physicians with experience regarding PWS and water toxicity. We're sharing their thoughts here to make the PWS community aware of this potential medical condition ~ Janalee Heinemann, Executive Director

Water intoxication is well known to occur in children and adults with eating disorders regardless of mental abilities, and also in individuals who are severely retarded. This is not a new phenomenon. I am frankly surprised that it doesn't occur more often in PWS.

We have seen this type of situation several times. In my opinion, anyone who drinks 72 oz. (9 x 8 oz.) is drinking too much water, unless he or she is in a situation such as intense exercise and/or in a hot climate where there is a high rate of water loss. We have been trying to restrict intake to 1- 1/2 quarts per day. I would think that even some "normal" people who drink that much water daily would be at risk for hyponatremia.

We have had several of our patients with PWS worked up by adult endocrinologists with no specific findings, except

one who might be mildly deficient in antidiuretic hormone (ADH), and most of the time, he does not take his DDAVP and keeps a normal sodium with a restricted fluid intake. I think that this case is probably water intoxication, such as happens in many major cities, usually in babies who have parents who do not know better than to feed water to an infant.

The problem of water intoxication is a difficult one and may be related to two different physiological mechanisms: some of the patients we have seen have compulsive water drinking and often need to be restricted and/or monitored in order to keep their electrolytes in balance; this seems to be a problem related to the PWS itself.

On the other hand there is a syndrome called SIADH which is related to a problem the kidney has in filtering out the excretions, and in this case the kidney absorbs too much water. This problem may be related to medications, may occur with other psychiatric maladies and may occur unrelated to all of these. The latter situation is much more likely to throw the electrolytes out of order, as the body usually seems designed to handle fluids without throwing electrolytes off. However, for the person with PWS this may be more complicated because of right heart failure, and decidedly needs to be reviewed and handled by a pediatrician/internist.

This person needs to be fluid restricted, but much more importantly, this person needs to be evaluated by a good endocrinologist (and perhaps a neurologist as well). It may be SIADH, but several tests are needed before a diagnosis and treatment plan are made. Water toxicity can be very dangerous.

I would be skeptical about water intoxication. What you haven't said is what medications the individual was on or if there were other medical issues. It is possible that this may be a case of SIADH that can have a host of causes. In SIADH, there is an inappropriate release of antidiuretic hormone that causes water retention and can cause this severe of hyponatremia. Also when you said the kidneys were normal, what studies were used? Without more information, this is all speculation, but the amount of water we are told was consumed should be adequately handled by normally functioning kidneys as long as there is not an underlying problem like SIADH.

There are two issues: first, identifying individuals at risk and situations in which risk is increased for all individuals; second, protection and treatment.

Individuals at risk are those who consume large amounts of fluids daily where the majority of fluid consumed is water. Specific high-risk situations occur when fluids such as sweat, diarrhea, etc. — that is, fluids containing salt — are lost and then replaced with water, which obviously contains no salt. Certain medications and medical conditions also have a likelihood of causing SIADH that others have referred to.

For those few individuals at risk, prevention is first the identification, to ensure that they don't have unlimited access to water; individuals who sweat a lot in the summer, etc., need to properly replace lost fluid with fluids such as Gatorade. Providers and families also need to understand the potential seriousness of the problem.

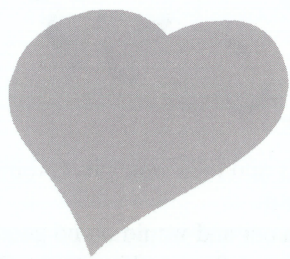
Infants/Toddlers Wanted for Growth Hormone Study

University of Wisconsin Children's Hospital is recruiting infants with PWS (age 4-36 months) to participate in a research study using daily injections of growth hormone.

This 2-year study will include tests of muscle strength and motor development, as well as body composition, and limited blood work. Costs for growth hormone and medical evaluations will be covered. Annual visits to Madison, Wisconsin will be required.

Enrollment is limited, and interested families should contact Heidi Luebke or Dr. Aaron Carrel at 608-263-2459.

PWSA (USA) Begins Parent Mentoring Program



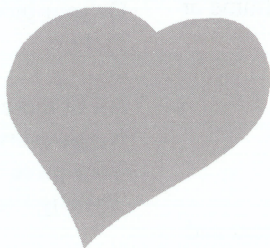
TO

Early diagnosis, education and awareness are the keys to prevention of life-threatening obesity and years of isolation and emotional trauma to the family of the child with Prader-Willi syndrome. Early intervention can also save thousands of dollars in medical expenses and greatly reduce emotional turmoil on families.

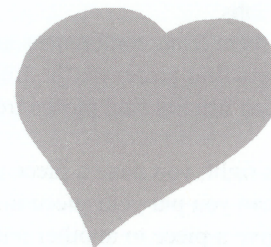
Through the (PWSA (USA) Young Parent Mentoring Program, which has just been initiated, eight volunteer parents with children who have Prader-Willi syndrome will be selected and trained to provide one-to-one mentoring and support services to parents of newly diagnosed

children. These volunteer mentoring parents will be trained and coordinated by another volunteer parent from Michigan, Carolyn Loker.

To support their efforts, mentors will be provided with specific resources, including information and referrals provided by the national office, training materials and phone cards (to eliminate phone expense for the volunteers). If we receive additional funding, we ultimately plan to also include specialized support packets — “Packets of Hope.”



TO



A Little Story That Will Lighten Your Heart

By Carolyn Loker

Last fall, David Wyatt, a volunteer at the PWSA (USA) office called me to mentor a parent from California who had given David permission to share her phone number with me.

Her baby girl was born September 19, diagnosed with PWS on Oct 4. Mom called the office three days later after diagnosis.

David's message to me was that this mom could not hold her baby and did not know if she would be able to keep her child. She has two other children, 18 months old and almost 3 years old.

I called the mom the very same day, and she had lots of questions. Will my child look disabled? Am I a bad mom because I cannot hold and bond with my baby? She feels that she hates her. Will my child be retarded? Is it true that they will eat dog food? How is my own child (Anna) doing?

Some of the questions were very hard to answer, some I answered as we shared tears. But we both got through it, spending an hour on the phone. She was very appreciative that I called.

I asked her if I could call her back, and she welcomed that. I called David back to tell him I had been in contact with

her, and to please include the nutrition booklet (even if I paid for it) with her new parent information packet.

On my return call to her, she was doing much better. We started talking about feedings. Her doctor had her feeding her child 2 ounces every 2 hours! This poor mom was not getting any sleep.

Jim and I were able to decrease the amount of feedings for her by diluting the formula. So this mom and baby will only have to get up one time a night now.

A call from Lisa

It was during this time that I received a call from Lisa Graziano wanting information on CoQ10. Lisa is a California PWS parent with a 2-year-old just 40 minutes away from the mom I had spoken with. During my conversation with Lisa I realized how far along she is with her son on Growth Hormone, seeing Dr. Lee and wanting information from Dr. Judy about CoQ10. She is a very positive person. She has also been at the last two national conferences.

We talked about supporting other parents and she is so willing and gave me all the right reasons how the Parent Mentoring Program can be beneficial for

new parents and also for her.

With permission, I gave Lisa the mom's phone number, and Lisa called her the same day. Lisa's report just warms my heart, and gives me the reason to keep on with this.

Lisa's Report to Carolyn

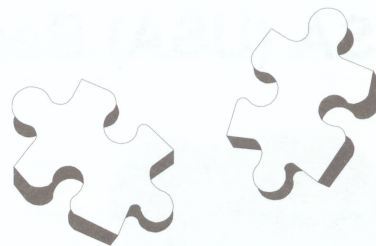
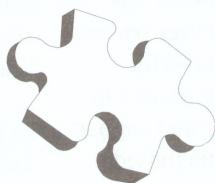
I wanted to let you know I had a nice long conversation with the new mom the other day. I really tried to assure her that PWS isn't a "horrible sickness," as she calls it, and that with the help of her family and support therapies, her daughter should lead a full and rewarding life.

She sounded relieved and more hopeful when I told her how well Cameron is doing and how many medical research studies are under way to help our kids. She has an appointment to see the same endocrinologist that our son has — Phillip Lee, M.D. — so I know she's in very good hands.

I will check in with her in a week or so — she has my number — to see if she's better able to hold and cuddle her baby. Also, now that I know of three other women in the Southern California area, I will arrange a chapter meeting with Fran Moss!

Putting the Pieces Together

We all have a piece of the puzzle,
But it is up to you to use it.
To use it how, you might ask?
To place it in the Big Picture.



The Big Picture needs a lot of work,
It needs your piece.
The Big Picture may need you to put your piece in the frame or
in the middle of other pieces.
Or your piece may only fit with one other piece for
the time being, but nevertheless it needs your piece.

The Big Picture needs you to obtain pieces too.
Where to get the pieces it so desperately needs?
Some get them from doctors and therapists, or researchers and
chemistry labs.
Some get them from conferences and chapter meetings,
While others find pieces on the Internet and in libraries.
And you can usually find pieces from other parents.

Yes, that's right, you have a piece to give away too.
Not only can you put your piece in the Big Picture,
You can give a piece to another parent or doctor
To help them on their journey to put their pieces in
the Big Picture.

It is crucial to stand back from the Big Picture and examine it.
You might see an area that is missing,
Or you might find pieces slammed into the wrong place.
You may even find pieces that don't belong to the Big
Picture!

You did not have a choice about possessing a piece of the Big
Picture,
But you have a choice as to whether you are going to make the
journey to the Big Picture to put your piece in place.

You may think that no one cares and hide your piece, thinking
The Big Picture will never miss it.
Or that your piece old and worn out and would do no good.
Or your piece is new and could not offer anything to the Big
Picture.

All of these reasons are misguided, because the Big Picture
Needs every one of its pieces.
Your piece is unique and CANNOT be duplicated.
The Big Picture needs all of its pieces to be complete.

Your journey to place your piece may be rough and seem
fruitless,
But you do not walk alone.
Other people are carrying pieces too.
They will help you on your way and maybe even carry your piece
from time to time.

But in the end, it is YOUR responsibility
To put your piece in the Big Picture.
And when you do, you will look at the Big Picture and smile,
Knowing that you are going to find another piece, and yet another
Until the Big Picture is complete!

If you are asking yourself what the Big Picture is,
It is a happy, healthy, full life for our children and
Other children with PWS.

*I dedicate Putting the Pieces Together to my sons,
Callaghan and Reilly, who have given me my pieces and
empower me every day to put the pieces in the Big Picture.*

Regina Hartnett

The Chuckle Corner



Scotty Brady, 46, loves to help with cooking and decorating when he comes home from his group home, but he's rather nonchalant where clothes are concerned. Whether they are appropriate for the occasion or whether they fit right just isn't important to him. No matter how nice the clothes are that his parents buy and send back with him, somehow different ones—of varying sizes and condition—always seem to come home with him.

Last year during one of his visits home, his parents were expecting company. Scotty retired to his bedroom to get ready, but when he came out, he was wearing pants that were up above his ankles. His dismayed mother protested, asking him why he had on those pants, and he answered, "Because they are comfortable."

"But they are 'way too short," she objected.

"Well," he said, "they're only too short at the bottom."

Submitted by Regina Brady, Honesdale, PA

Do you have a joke or funny story to share with readers? Send it to the PWSA office. Be sure to include your name, phone number and address in case we have any questions. We're waiting to hear from you!

PWSA (USA) Office Receives Canadian Ambassador

To express thanks for all the information and support she received from the PWSA (USA) office, Sheila Symons and Janice Pitchelli of Ontario, Canada sent a teddy bear, bedecked with all 12 provincial logo pins and one for the Minister of Health/Canada.

"Please accept "Johnny Bear" as a wee thank you offering. I just cannot thank you enough for your wonderful help," Sheila Symons wrote.



Executive Director Janalee Heinemann holds "Johnny Bear."

Not Everyone Can Cope With Sexual Issues

I read the article in the September/October 2000 issue of *The Gathered View*, "From the Kitchen to the Bedroom."

Please let me tell you how I feel about this.

I am a parent of a 27-year-old girl with Prader-Willi syndrome. She has been living in a wonderful group home for PWS only an hour away from us.

She has always talked about getting married, having kids and living on her own. I am her legal guardian, as she needs one.

Many of the kids with PWS are retarded, some more than others. My daughter's mentality is that of ages 5-7 in most things. I can't imagine she could be ready for sex in any way, other than perhaps hugging, kissing and showing of affection.

Since I am her mother, I say it will never happen to her — what 7-year-old could handle sex? She didn't start her period until she was around 20 years old.

My daughter has her rights — she has been told many times. But she could never handle mentally sex and all the responsibilities that go with it, especially maybe having to have a baby — which I would not let her have. A person who cannot and never will be able to take care of herself should not be able to make that kind of decision for herself. That is like her being able to vote. She doesn't even understand that or drinking and what it could do to her.

Maybe there are some PWS adults who aren't retarded and could stand the stress of sex, but I don't think very many.

Having boy or girl friends and a loving friendship is OK, but not the sex. My daughter knows about sex, but if she didn't need a lot of guidance and constant watching, she wouldn't be in a group home.

*Sara Beechner
Naples, NY*

American Pen Pal Wanted

My name is Wayne John Cummings I am almost 36 years old and I have Prader Willi syndrome. I would like another American penfriend... I like discos keep fit going to the gym and have a good work out computers learning to speak French with my French support worker....I also like having loads of friends for perminate friendship plus cinemas ten pin bowling.... If I was a millionaire I would love to visit the states even the Big Apple in New York and visit my aunts and cousins in Brooklyn who I haven't seen for the rest of my life. I would also love to visit my Prader Willi friends....or I would love to meet Michael Jackson and all those American stars in Hollywood and get their autographs as well I am a Will Smith fan because everyone thinks I look like him with the amount of weight I've lost and even with my shades on me as well.

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

Tony - continued from page 1

experienced. He was honored to have his picture taken with Governor Tommy Thompson and his wife Sue Ann and others.

Most recently, Gov. Thompson was appointed by President George W. Bush to serve as the Secretary of Health and Family Services. Gov. Thompson is the person who signed the legislation that added PWS to our state statutes. I am confident that our new Secretary of Health and Human Services is aware of Prader-Willi syndrome. Tony and I have met with him personally over the years. I think, however, that the Very Special Arts event was Tony's most memorable meeting.

Tony still cannot read a note of music, but he can keep a beat, and he is now a member of a very special band that



PWSA (USA) President Barb Dorn and her son Tony

has brought him some very special memories.

PWSA of MN, Inc.

invites you to attend



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We misspelled the name of Anneliese Agarwal in *The Gathered View* and we sincerely regret the error.

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.

