

THE GATHERED VIEW

Newsletter of PRADER-WILLI SYNDROME ASSOCIATION

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PRESIDENT'S MESSAGE

Almost five hundred people accepted the Texas challenge to make the annual PWSA Conference the biggest and best in our history. It was an impressive thing to see PW parents pool their talent and put on a first class, professional quality meeting that gets bigger and better every year. It is bigger because more PW persons discover the many benefits of attending the Annual Conference. The meetings are better because more of you benefit from the fellowship, experience and success sharing and all of the new information and maturing attitudes and techniques for problem solving.

To summarize, the exchanges that occurred at the conference would fill a book. I was able only to touch on some of the material and controversy in my discussion which lasted an hour on the last day. I think the individually most striking change has been the way reports of accomplishments have been seen, more often in deference to a preponderance of questions on, "How do you?". This can be exemplified by several chapters that reported the opening on new PW homes in just the last year. Some of these chapter projects have taken less than one year from start to finish. This is a mind boggling achievement when considering the morass of red tape that is usually involved.

Many of the chapters reported new members from the younger age group. When this organization was first formed the most common statement made regarded the prolonged time that it took to even find out a diagnosis. There is a considerable way to go toward educating the professions so that early diagnosis can be achieved in all cases, but your chapters are coming up with ways to accomplish this. The Texas Chapter sent out a mailing to all the physicians in the Texas Medical Society. That mailing resulted in at least one direct diagnosis of PWS and I had the pleasure of hearing the story from the mother to whom it happened.

Dr. Ledbetter deserves a round of applause for achieving the largest scientific meeting ever presented that was dedicated to the ongoing research in the field of interest to PW persons. There were twenty five papers presented at a day long meeting by prominent researchers from all over the U.S. All of this information will be published in a prestigious scientific journal as a special issue coming out next Fall. In a similar vein, Dr. Greenswag's book is nearing completion and your board of directors has given the go ahead for its publication with availability at our next conference in Kentucky in 1988.

At one point I referred to the organization incorrectly as a mature one, and was appropriately corrected to the fact that the PWSA is a maturing organization. This was well evidenced by the depth of the questions asked of the speakers during the

PRESIDENT'S MESSAGE (cont)

question periods following the formal presentations. It was also evidenced by the deep and continuing interest and talents expended at the local level to achieve the goal of becoming an active PWSA chapter.

One important topic that requires the efforts of all persons interested in PWS is the financial survival of this organization. Yes, there is a large sum of money set aside for the development of a crisis intervention center, and yes, there are funds sufficient to make grants for specific research in PWS, but these funds are not accessible to the daily operation of the organization. It was revealed that for the first time the finances face a deficit in the operating funds area. The other fact that each of you needs to know, is that the funds needed to support this organization come only from dues collected and the sale of the various materials. The net of that is we need new memberships of all the people who are interested in PWS.

Throughout the next year I plan to use some of the very interesting points brought out in the conference as the topic of future letters. Until then, think Louisville '88.

Delfin J. Beltran, MD

President

GRANT APPROVED

By board decision, during the conference, a grant of \$5100. was awarded to a doctor at the Universtiy of Chicago, Murray J. Favus, who is doing a bone disease study in PWS.

Your donations to the Research Fund have made this grant possible.

CONFERENCE LEFT-OVERS

PW Conference left-overs are not food, but clothing. Isn't that surprizing? We have a size small pink cover-up, a small gray tank top, and boys 7-8 blue tongs which were left pool-side. We also have a size 38 swimming suit and t-shirt that were left in the meeting room. Let us know where they belong and we'll drop them in the mail.

SEEKING CHAPTER MEMBERS

Some members are very interested in starting a chapter in the State of Louisiana. If you are interested, contact Denise Wolcott, 118 Doubloon Dr., Slidell 70461 or Dom Gulotta, 3504 Veronica Dr., Chalmette, 70043.

RAFFLE RESULTS

The big \$500. winner of the conference fund money raiser was Bob Jones of Wrentham, MA. The ticket was sold by the Sojkas'. The 2nd place, \$125. was won by Kerry Welch, daughter of Rita Welch of NY, who graciously returned to the podium and donated her prize "all of the PW's". Paul Alterman, another good supporter of our efforts, won the \$100. 3rd prize, donating half of it to PWSA and half to the new GA chapter. We thank these people for their support and generosity.

The second raffle, held at the conference, resulted with Barbara Underwood of Ft. Worth winning the beautiful donated quilt and Lois Klindworth of Lake City, MN winning the Continental airline ticket.

After the prize money, chapter rebates and expenses are subtracted, we have a little over \$2000. left which helps with conference costs. Twelve chapters took advantage of this means of helping the conference and their own chapter, with Kentucky earning a rebate of \$222.50 by their sales to be the best sales-people.

FUTURE CONFERENCES

Reserve June 23 - 25, 1988 for the 10th Annual Conference in Louisville, KY.

The board is also accepting bids now for the years 1989 and 1990. You need not be an official chapter to make a bid, but you do need at least 6 good workers to head the various committees for planning.

YOUNGER SET GV

We did not publish a special edition this issue for the parents of children 10 and younger, as we have the past year and a half. The purpose of this special issue is to share information which is of more interest to parents of younger children. If we do not have information to share, these special pages are difficult to fill.

We know younger parents are very busy but if you want this to continue, we need more sharing to fill these pages.

PARENTS WRITE :

"Looking forward to the conference. It really has become a part of our life. ... PWS is getting to be known in our state! Today I attended a conference for nurses and PW was discussed in a genetic presentation."

"Personally, it's going well. The house and program (residence) is meeting her needs better than expected...Tonight she called, and has lost 61 pounds since last June. She is looking good, and has matured so much Never thought, but hoped, it possible."

* * * * *

"(My daughter) is graduating from high school this month. She has been on the honor roll in Special Education every semester. At her latest staffing, it was determined that she would go to (a technical institute) next to develop a marketable skill. We are very proud of her accomplishments"

ODTC PURCHASES NEW HOME FOR PW

The Oconomowoc Developmental Training Center has purchased a new home (located on a lake) with larger bedroom facilities and communal gathering areas. They have moved the residents from the previous Gatehouse on their grounds to the new facility.

* * * * *

The new Missouri group home is scheduled for opening in August. This home was specifically designed to meet the special needs of people with PWS and the parents who have worked long and hard to obtain this facility are looking forward to a great program.

* * * * *

Ruth Chausow, President of the Illinois PW Groups reports their state is very fortunate to have one group home serving 8 young adults and a monthly PW clinic with Dr. Walczak at the University of Chicago. She reports quality of life is vastly improved for the group of parents and offspring who are fortunate to be served by the group home.

Unfortunately, Illinois claims there will be no state funding available for the 87-88 fiscal years so another home cannot be opened even though it is badly needed.

NEW BOOK

After The Tears: Parents Talk about Raising a Child with a Disability by Robin Simons. Harvest paperback, \$4.95 or Hardcover, \$12.95.

After the Tears, is the story of parents who have struggled, learned, and grown in the years since their children were born. "Deeply sensitive book" "Helpful, hopeful"

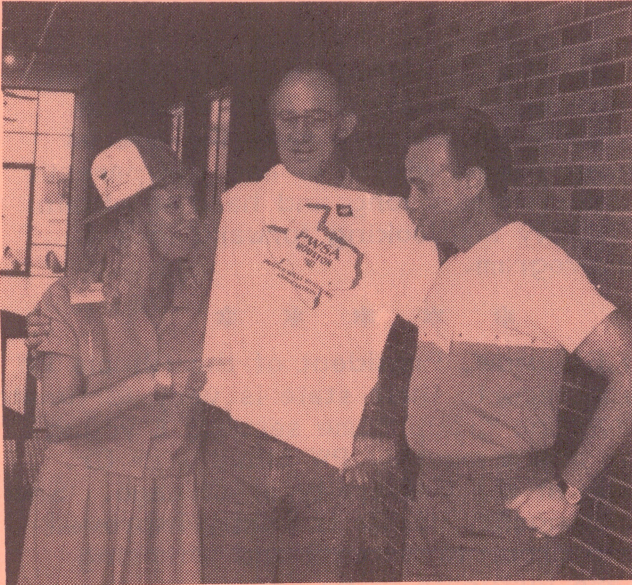
C.I.T. REPORT

We had hoped to go to the conference with the announcement that the last state approval had been obtained but unfortunately this hasn't happened yet. We are "on hold" at the moment waiting. Because of the number of young people in a crisis state, we are doing our best to move as fast as we can.

PHOTO CONFERENCE REPORT

In 1979 165 adults, 15 young people with PWS and 15 siblings attended the first PWSA conference. Over the years attendance has increased, programs have improved but one thing has not changed, attendees think its GREAT.

The 1987 conference planning started even before the 1986 conference had ended. Here is General Chair, Rayna Hicks and two committee members, Grady Hendrix and Bill Westbrook, sporting the hats and t-shirts offered at the conference:



It's impossible for people who attend the meeting to appreciate all of the planning and coordination necessary to make these meetings a success. The Texas committee deserves a great deal of thanks for all of their efforts.

For the second year, we had a pre-conference day which included a Scientific Presentations Day. Our many thanks to David Ledbetter for making this portion of the meeting successful. Here is David with his first "chromosome test" patient, Caroline.

David was able to obtain publication of abstracts or full papers from this day. The agenda was tremendously impressive with presentors from the Universities of Washington, S. Alabama, Arkansas, S. Florida, Oregon, W. Virginia, Iowa, Connecticut, Minnesota, St. Louis, Baylor (Texas), Nemours Childrens (Florida), Harvard (Mass.), Vanderbilt (Tenn.), Long Island Jewish (NY), Stanford (CA), and the Residential Rehab (PA).

Although translators are needed to help us understand what was presented, this day is a great step forward in professionals being aware of this syndrome.

Chapter Presidents also met this day and spent the whole day discussing the past year's achievements and future plans.



(Part of the group of 14 Presidents)

Another tremendously successful meeting found group home administrators and staff meeting and presenting. At least 25 different homes were represented with 57 people attending from 22 different states and two Canadian provinces.



PHOTOS (cont.)

The regular meeting started with the Executive Director doing a strip act--revealing a t-shirt "Going Bananas", which could be a new PW theme. Fortunately, the meeting improved from there.

In case you are curious, we thought we would share a look at your board members:



Because of all of the board meetings during the conference, many people have gotten the impression that Bobbie Miller and Bronnie Maurer are husband and wife (being a board widow and widower). To clarify that, we thought we would share a picture.

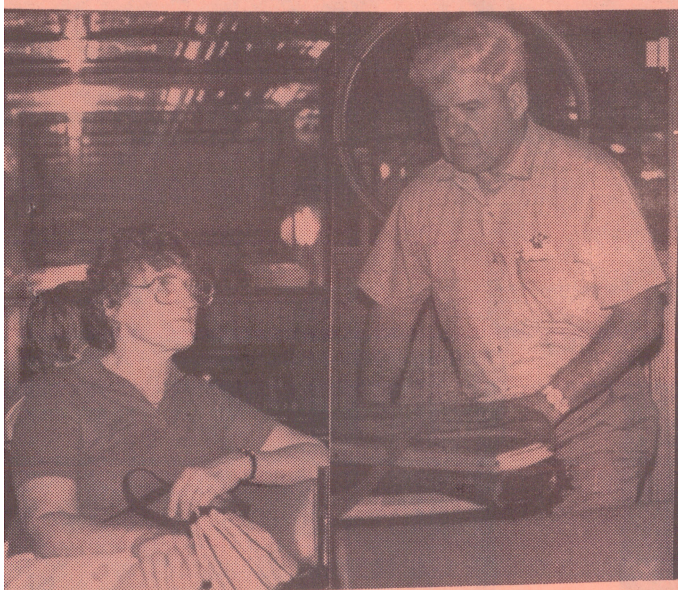


Leta Vanja Dick Suzie D.J. TED Fausta



STEW GENE Dorothy Tanalee Louise OFFICERS:
BUD SAM

A few more people you have read about, our Executive Director, Marge Wett and our President, Sam Beltran.



D.J. & Bobbie Miller



Dr. Cassidy is another name that is very familiar to all of us, and we are very happy to say she was re-elected to another board term.



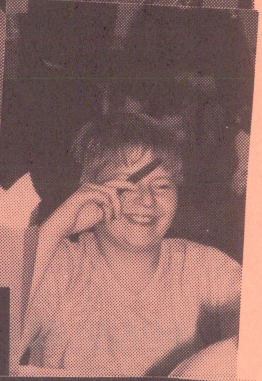
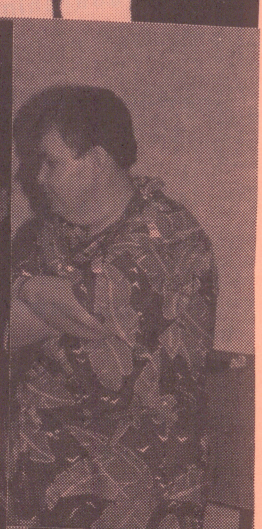
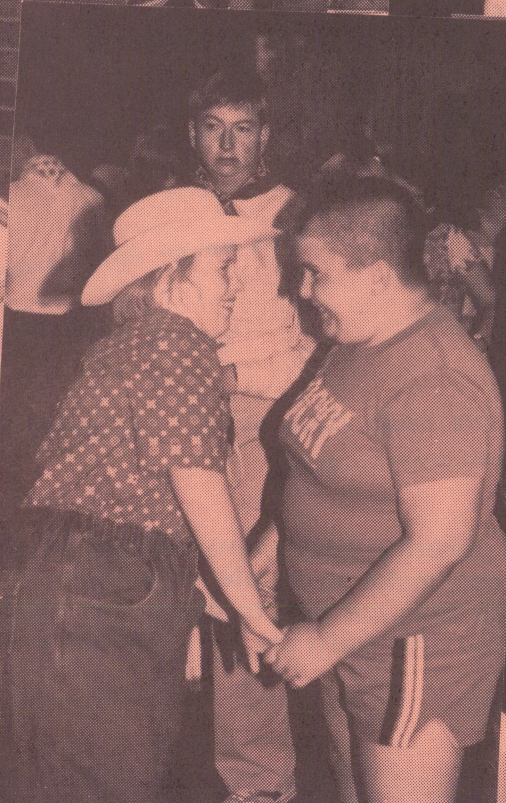
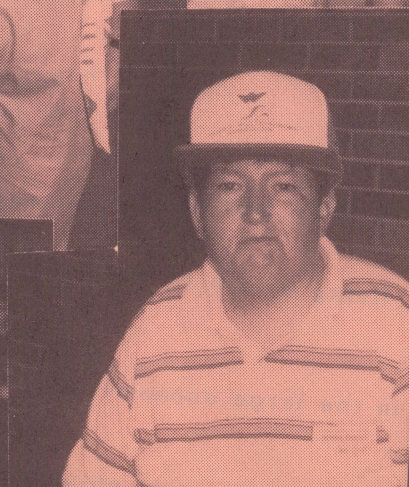
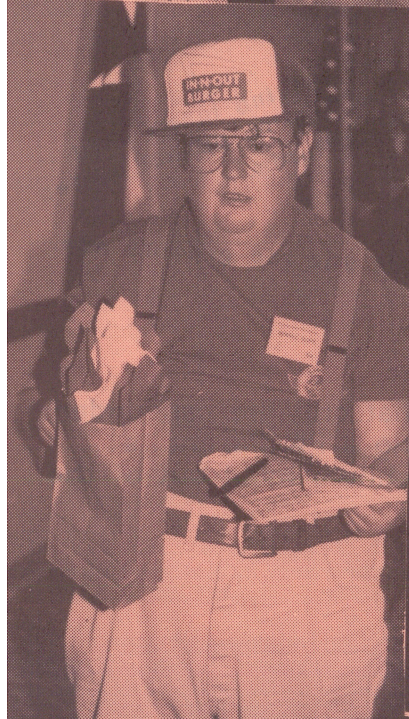
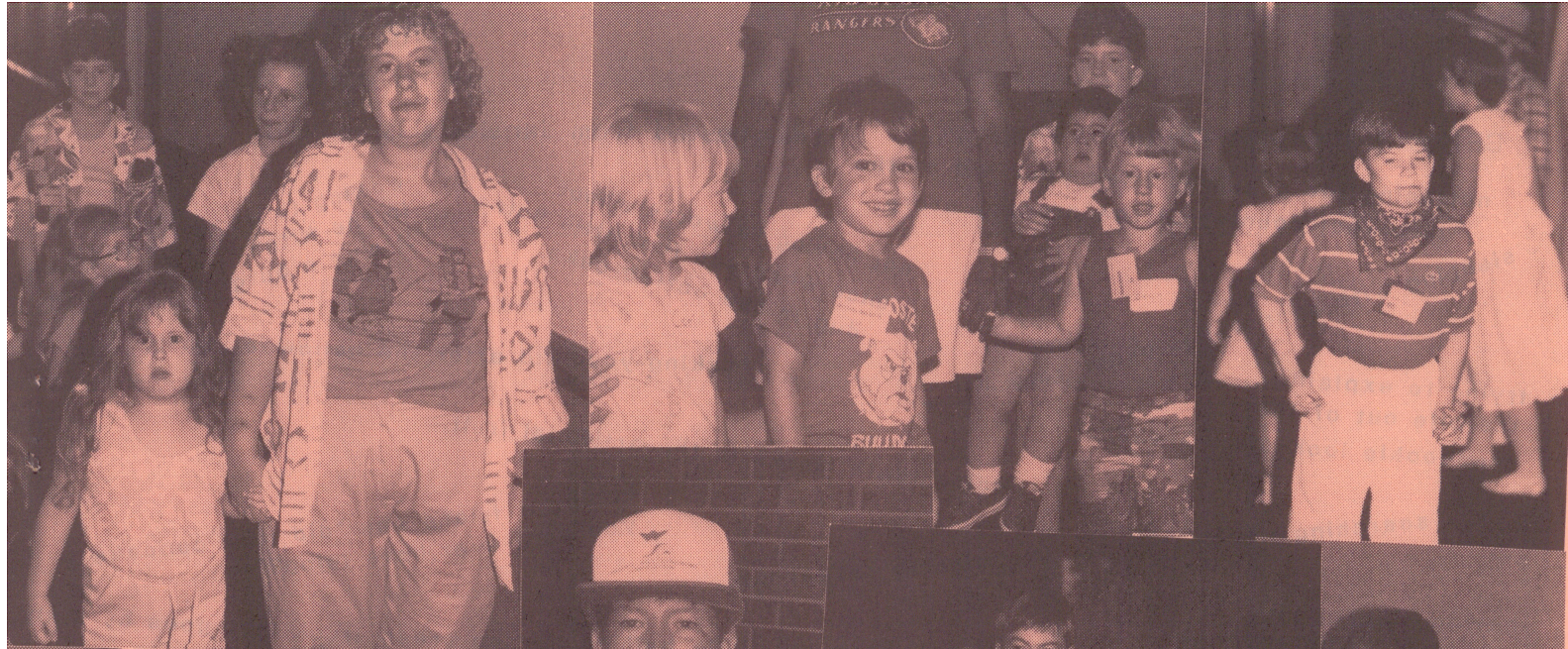
Marge was very surprised by some scheming and planning that took place during the year. It is our policy to honor someone at the banquet and she was informed the Texas group wanted to honor our President, Sam. Instead, she was honored and presented with a priceless scrapbook containing over 100 letters, photos, "PW is" quotes, etc., including a letter from Nancy Reagan and the Governor of Minnesota. (Many thanks to all who participated in this surprise, especially D.J. Miller and those who helped her.) This is a gift that will always be cherished. Roses, a serenade & other gifts were presented too. A conference cannot be successful without presentors and attendees. We are fortunate every year to have most of our presentors appearing without any reimbursement of expenses (which enables us to continue offering a low registration fee). We hope they know how much their contributions mean.

The New England Chapter (MA) shared a map with circles representing Residential Facilities designed for PW only and a diamond for mixed facilities. Members appreciated their efforts in this study they have just completed and sharing this information.



And last but not least, is the Youth Activity Program. A program that is far more work than the adult one. We are happy to share a few photos of some of the attendees, from the younger to the older--all having a terrific time.





BEING A PRADER-WILLI PARENT IS: (Requested from Janalee's collection)

not being too proud to frisk your kid at the checkout counter of the grocery store.

sleeping with your wallet under your pillow.

trying to explain the bite out of the oreocookie look-alike eraser.

searching the bushes for the missing cereal box.

having kids eager to empty the garbage.

trying to figure out how to lock up an apple tree.

having the cleanest chicken bones in town.

listening to the same story over... and over...and over...again.

not having to worry about mice when you find little holes dug in the coffee cake.

waking to someone roaming in the kitchen and wishing it was a burglar.

frisking your kid after the halloween party.

finding teeth marks in the artificial fruit.

having a friend ask "did that cupcake you sent over have icing?"

wanting to smash the little bell on the ice cream truck that goes by daily.

living with a pack rat.

not serving lunch until the missing peanut butter jar returns.

buying bandaids in the large economy size.

Prader-Willi parents have many things in common, especially humor that only we can understand. We can make a couple of additions from the conference: Being a PW Parent Is: warning Room Service not to make any deliveries, and holding your child's hand out of the dining room so the waitress tips remain on the tables.

BOARD ELECTION RESULTS

Our congratulations to Dr. Suzie Cassidy and Dr. Dick Wett in their re-election as board members and to new board member, W.Rhett Eleazer of South Carolina. The next highest vote getter, Tim Inwood, of Connecticut, will be an alternate in case of a mid-term need.

Due to the resignation of Roy Smith, Harvey "Bud" Bush was appointed as the new treasurer. Bud is from California. Stewart Maurer of Georgia, was appointed to fill his former spot of Vice President.

DIRECTORY

The updated Directory is now available (listed under New Materials in this issue) but can be continually updated. It has been placed on the computer and additions can easily be made. If you feel you have an experienced professional to add to this listing, or you are a professional who would like to be listed, please let us know at any time.

Finding someone either in the medical or educational field that is acquainted with PWS is very important for those first seeking information.

IN GRATITUDE:

For Research donors, May, June:
Chausow, Hancock for Scalia, U.W. of
Capital Area, Schramm, Trachtenburg,
U.W. of Ut, S.N.V U.W. and Andy
Alterman.

Total of \$584.33

For C.I.T., May, June:
Delta Kappa for Battersby, Lincoln,
Stege (Railton), Straight (Hornstein,
Blankenship, Evans), Wett (Schaefer,
Nash, Schauer), Heinemann (Powers),
Noordzy (Lauglin), Boyd (2), Sojka
(Jones), Eggers (Kelly), Vermeulen
(Loenz), Dixon (2), Olson (2),
LaBella (Van Tuyle, Frattinger),
Brewi (Sheron), PW CO., Castle (2),
Krocka (Balko), Breneisen (Yost),
Beltran (2), Neason, Hanna, Maranon
(Brewer), Nanzig (Nanzig 2),
Schneider (Schneider (3), Clark,
Lynch (Coke 2), Weisel, Hall (U.W.),
Regester (PW KY), Clubb (Clubb),
Sharp (2), Mitchell (Echols), Ziifle,
Scalia (Hunt-Liles, Rutkauskas, Ding-
ley, Gaffney, Brown, Johnson),
Arnold, Dam (Digital Eqmt.), Town-
send (Furr), Ingalls (Lamplighters),
Foley, Antin (Readers Digest Fd.),
Moritti, Cicairos, Hadsall (Hadsall),
Umbaugh (Wagner), Bintz, Miller
(Fleming).

Total \$4729.68

NEW MATERIAL

The Clinic Service Directory has been updated and now contains listings for services, the camping list, government offices, PWSA chapters and listings of facilities. The new DIRECTORY sells for \$3.00 (U.S.).

Dr. Vanja Holm has updated our annotated bibliography. This complete listing of all medical papers published sells for \$8.50. (U.S.)

For a complete listing of all materials available from PWSA, please ask for our order form.

We also have a full membership listing available in alphabetical order or by zip codes. These sets sell for \$3.00 (U.S.).

PUBLICITY

The value of professional public relations assistance and publicity was discussed at the conference and during the board meetings as it has many times before. The board is continuing to seek ways (that are affordable and will be successful) to obtain the much needed attention to this syndrome.

One previous suggestion to parents has been having a personal report in your local paper. The next two pages contain a Buffalo, NY article that was extremely well done. (Unfortunately, parents do not have control over what is printed, so this can not be said for every article that appears.)

Gay Harrington, President of the New England Chapter, made a suggestion during the Chapter President's meeting, that a united effort be made by all members to be on one of the network shows. She also commented on the importance of having a plan, a script, and knowledgeable people involved. One parent or even PWSA requesting a show can be easily ignored but if we really made an united effort we might have a chance. We hope to present this idea in the next GV issue. If anyone has any suggestions, please forward them to PWSA in the next few weeks.

NEW DEVELOPMENTS

Grady & Lou Beth Hendrix attended a seminar in Houston as representatives of PWSA. U.S. Surgeon General C. Everett Koop called on nationwide effort to establish networking in treating children with special medical problems, such as chronic illness or disabilities. Unfortunately the meeting never got beyond generalities but at least efforts are being made.

It was disappointing to read a lovely 47-page booklet prepared by the Governor's Planning Council on Developmental Disabilities entitled, "A New Way of Thinking". As always, PWS will again fit "into the cracks" in their renewed efforts to lump all D.D. problems into one bag. People with mental retardation and other disabilities need a choice of options for vocational, developmental and residential services. The push for smaller, more "home-like" residences and employment "in the community" may meet the needs of some young people with PWS but certainly not the majority.

Special Report:**A Destructive Desire****Information and Support Groups:****Objectives:**

- ✓ Open Discussions
- ✓ Family Involvement
- ✓ Sibling Support Group
- ✓ Professional/Public Awareness
- ✓ Knowledge of our Childrens Rights

International Association:

The Prader-Willi Syndrome Association
5515 Malibu Drive
Edina, Minnesota 55436
(612) 933-0113

State Association:**P.W. New York Association**

Rita Welch, President
612 160th Street
Beechurst, New York 11357
(718) 767-6077

Local Support Group:**Meetings:**

Bi-Monthly
Professional Guest Speakers

Contact:

Tina Caudill - (716) 873-0593
Rose Oragovic - (716) 826-9480
Sharon Spinx - (716) 823-3095

A team approach of doctor, nutritionist, psychologist and endocrinologist is recommended for treatment

Infant Characteristics:

- ✓ Lack of fetal activity
- ✓ Hypertonia (poor musculature), lack of control to head and limbs
- ✓ Weak cry
- ✓ Poor sucking reflex
- ✓ Poor appetite
- ✓ Ability to control head and sit up occurs late in the first year
- ✓ Walking at about 2½ years
- ✓ Talking in short sentences at about 3½ years

Adult Characteristics:

- ✓ Short stature
- ✓ Small tapering puffy hands and feet
- ✓ Wandering or crossed eyes
- ✓ Stubbornness or temper tantrums
- ✓ Diminished sense of pain
- ✓ Poor ability to fight infection

Living With A Prader

by Laura Lynne Kwiatkowski

Megan Caudill is a 3½ year old girl who possesses a life-threatening desire for food.

Megan is the daughter of Tina Caudill, a student at ECC North. Tina invited us to her house to learn more about this rare birth defect called Prader-Willi Syndrome.

When Megan was born, she weighed 5lbs. 3 ounces, which is about average for newborns. What was unusual was that Megan lacked muscle tone, size, and strength.

Tina explains, "You could hold her in the palm of your hands and her limbs and head would dangle down from your hands." This is not at all uncommon for a child with PWS. They will rarely cry, and some would sleep straight through the day without waking up to be fed. This makes having a child with PWS very demanding.

"Because she wouldn't cry, I had to wake her up every four hours to feed her," Tina goes on. "Usually a baby will consume four or more ounces of milk per feeding. But Megan didn't have the strength to suck a bottle, so it took me an hour and a half to feed her one ounce."

Public Misunderstanding

The major problem with Prader-Willi Syndrome is that nobody really understands it. "It's a real thin line to say openly that there is something wrong with your child, and that it's not diagnosed," comments Tina as she unconsciously tightens her arms around Megan who is sitting on her lap. "Even I had denied it for a long time, that, well, maybe she has a low tolerance level or is just a slow starter, and that maybe all of a sudden she'll just grow... being my first child I didn't know."

Some parents of PWS children, even after realizing that something is wrong, will say they don't need help and that they can handle it themselves, but they can't. Having not known Megan was a child with PWS, one would think she was a "very healthy" little girl who would soon grow out of her "baby-fat."

But trying to get people to realize that it isn't "baby-fat" is a difficult task. These children gain weight easily with fewer calories than a normal person would need. Tina has explained to her daughters that Megan can't eat. "Megan will tell her daddy, 'Mommy says no.' Or Kelly will say 'Megan can't have'."

Their father understands now, but Megan's grandparents do not. "When she goes to her grand father's house, he doesn't believe in the syndrome... it's a real problem," Tina says in a whisper. "I'm not sure how I'm going to handle that." Tina then laughs. "They think I underfed her, and that's why she's always hungry. They just come up with these bizarre excuses for this syndrome. And, of course, the 'one bite won't hurt'."

Even strangers will come up and offer the girls a piece of candy or a cookie. Tina just says, "Thank you, but she has an allergic reaction to sugar."

Increased public awareness and understanding would help a great deal. One parent says, "when we were at a restaurant, a woman even chastised me for scolding my daughter to keep her from overeating. I was so angry and hurt. I wished I had a brochure to give her. There are so many people so ignorant."

Other parents say that since PWS children don't look mentally disabled, strangers have come up to them in restaurants and have

made nasty remarks about the child's eagerness to eat. "These people think they have a right to lecture us on our child's weight problem."

Children, and adults with PWS will eat a lot of things we find unappetizing, and become great connivers at a very early age to get any kind of food. They will hide, sneak, and even go as far as to steal.

When Megan meets a stranger, she will see how far she can go. When Tina left the room to answer the phone, Megan grabbed my hand with one of hers and, with her other hand, hung on the refrigerator handle with a pleading look for my consent. When "mommy" returned, though, Megan ceased her plea.

Tina mentions another woman Gloria, whose son Chris is a PWS child of 19 years.

Tina tells the story "when Chris was caught in a supermarket putting food in his pocket, he was let go with a warning. The next time he did it, though, the police were called and brought him home. Gloria explained that Chris had a syndrome called Prader-Willi, but their response was that the next time they'll have to arrest him."

Research Necessary

Gloria was not as fortunate as Tina in realizing her child had PWS. When Chris was about 10 or 11 years old, Gloria knew something was wrong. But since Prader-Willi hasn't attracted much publicity, parents often don't know what's wrong, and doctors may be slow to make a diagnosis.

After extensive travel, Chris was finally diagnosed by a PWS expert in Pittsburgh, but by this time, Chris was 17 years old and

Prader-Willi Syndrome

by Judith Peterson

Prader-Willi syndrome is a birth defect of unknown origin. A dysfunction of the central nervous system, the syndrome results in short stature, mental retardation, incomplete sexual development, and lack of muscle tone. The primary characteristics are the uncontrollable need for food, and the resulting emotional outbursts, when denied. Because this syndrome leads to extreme obesity, Prader-Willi is life-threatening. The individual must remain in a controlled environment for life.

Most families of people with Prader-Willi, did not learn about the syndrome from doctors, but rather from articles in

magazines, newspapers, and journals or, more often, word of mouth. This shows a need for increased awareness on the part of the professionals. Early diagnosis is essential for parents to be prepared to exert necessary controls on the child's food-related behavior.

Infants diagnosed with Prader-Willi are generally low birth weight babies, who display poor sucking reflex, poor appetite, and weak muscle tone. Development is delayed. Between the ages of one and four, the change occurs. The child who originally would not eat, is now always hungry and unselective about what he or she will eat - even going so far as to

The primary characteristic: uncontrollable need for resulting emotional outbursts, when denied.

eat pet food, spoiled food or food from garbage cans. The family must now begin the lifelong vigilance necessary to keep the child from obtaining food. Family mealtimes can become a trial and social outings almost nonexistent.

The person with Prader-Willi needs fewer calories than a normal person and, therefore, gains

for Food

-Willi Child

he was already seriously affected by the syndrome. Chris weighed 220 lbs.

Family Difficulties

Prader-Willi does not limit its effect to the victim; it is very difficult for the family as well. They also experience the pain and suffering, the hurt, anger, and even humiliation.

Once Gloria's neighbors were having a barbeque and left six chickens cooking on the grill - unattended. Gloria's doorbell rang and it was the neighbors with Chris. Chris had eaten all six chickens. "How do you explain something like this to them. Ex-

plain it so they understand?"

PWS can create many awkward situations since there is no way to control the amount of food a child can "find" to eat.

While we talked in the kitchen, Megan played quietly on the floor. Or so it seemed. But I soon noticed that she had found a dirty cracker under the stove. Not being accustomed to PWS children, I thought little of it - until I realized Megan would eat that dirty cracker. When I reached for the cracker, Megan lunged for it. Even after I had it, Megan had to be forcefully restrained from retrieving it.

Prader-Willi does not limit its effect to the victim; it is very difficult for the family as well.



Tina Caudill with her two daughters, Megan (left) and Kelly

Emotional outbursts are normal for people with PWS when food is denied them, whether it be quiet, physical, or extremely loud. The outbursts may be spontaneous, which according to Tina is Megan's way, or they may delayed a couple hours, or even a day.

Supervision Needed

Presently, there is no known PWS person living on their own. They need constant supervision in a controlled environment. Since Megan can now climb, Tina has already had to rearrange her cupboards, keeping only canned goods on the bottom shelf. What happens when Megan learns how to use a can opener? Tina answers: "...by that time I'm sure everything will be locked up."

Education and the Future

Currently, Megan attends the Robert Warner Rehabilitation Center of Children's Hospital. There, special education teachers provide a highly structured school/play environment which Tina believes has been very beneficial for her daughter, allowing Megan to interact with other children while she receives supervision tailored to her special needs.

Megan also attends Head Start where she receives a much different but just as successful experience. In this unstructured preschool, Megan enjoys a sort of "supervised freeplay." Tina explains, a healthy social environment where she receives special supervision. Even there, though, Tina had to conference with the school's teachers, the aides, the nurse, and the nutritionist to make them aware of Megan's unique needs. "They've been super, though," Tina concludes.

Soon Megan will be of school age, however, which presents a new set of problems for Tina and other parents of PWS children. Most schools would not be capable of providing the supervised environment that Megan needs. "PWS children cannot be safely mainstreamed," Tina explained. "There would be no way of knowing if Megan was being properly supervised nutritionally."

BOCES works with many sorts of handicapped children, but Tina doubts that even they are adequately equipped to supervise PWS children and keep them away from food.

As a result, when Megan reaches school age, Tina plans to seek legal guidance to help obtain adequate educational services. Perhaps by that time, the Prader-Willi Parents' Support Group that Tina helped organize a year ago, will be strong enough to make real changes and put pressures on schools.

Tina hopes her group can increase public awareness of PWS. "Usually children/adults are diagnosed through word of mouth, or by reading it somewhere." PWS is something that has to be recognized very early so parents will be prepared to exert the appropriate controls of their food intake.

Presently, Tina is working towards getting the Prader-Willi Syndrome on the Children's Hospital Telethon, for a couple of reasons. The first, to get people aware of such a syndrome, and the second, to get parents involved with the support group.

Hopefully, by getting PWS on the telethon, people will realize that this support group is serious on continuing the research and giving the help necessary for PWS victims as well as their families.



The major problem with PWS is that nobody really understands.



Megan cooks in her "little kitchen."



Tina tries to fulfill the needs of both her children.

me

characteristics are the need for food, and the emotional outbursts, when

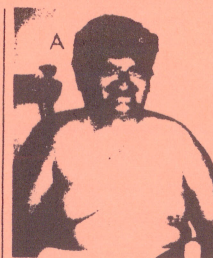
uncontrolled weight. The accompanying retardation is relatively mild, but learning ability may be impaired by the obsession with eating, and associated emotional outbursts.

Public and professional awareness is extremely important. The causes of Prader-Willi are unknown, but with public support, research will continue. Friends and relatives with an understanding of the syndrome, will comply with the restrictions. Professional awareness will bring about more of the needed support services to help families cope. Finally, doctors who can recognize the symptoms can diagnose the disorder.

weight easily. Along with the uncontrolled obesity, other life-threatening complications of Prader-Willi include: diabetes, heart disease, kidney failure, hypertension, and respiratory failure. If diagnosed early and diet is controlled, the individual's life expectancy can be the same as a normal person's. Those with a controlled weight gain, function at a higher level than those with



Facial appearance of a female with PWS at age 6 months (top), and at 6 years (above).



Twenty-four year old man with PWS before (above), during (above right), and after (right) loss of weight from 195 lbs. to 130 lbs. over a 10 month period. This was accomplished on a 900-kcal/day protein-sparing modified fast. His motivation was the desire to look good in a bathing suit.

EXCERPTS FROM CONFERENCE, Peggy Brooks-Bertram, presentor

"The reason why this association and the local chapters have been able to move forward as they have been is because parents have assumed a large professional role. The activities we are engaged in today are professional activities, they are organized with the purpose of effecting political and social change. Let me just say what is happening on the horizon (in terms of service) after 10 years with this organization, many of you have made an impact on educating the public, the professionals, and the press. Your primary goal has been advocating for your individual with the syndrome, and your secondary activity is playing a key role (and an unprecedented role) in providing and assisting researchers in further study of this syndrome.

In bio-medical research, the activity of the National PWSA and the state chapters has to go down in history as being a major force, allowing professionals and researchers, in an organized frame work to gather an enormous amount of data on a syndrome that no one would have known anything about otherwise. It is because you are willing to participate in studies (I can't imagine that you have contributed to any less than 50 questionnaires in the last 5 years), all to the benefit of educating not just yourselves but allowing professionals and researchers the opportunity to use your knowledge as growth and professional development for them. What I want to see is a marriage between the researchers and service needs so the dotted line between the two becomes a dark line."

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 THE GATHERED VIEW is the official newsletter of the PRADER-WILLI SYNDROME ASSOCIATION and is sent to all members. The opinions expressed in THE GATHERED VIEW represent those of the authors of the articles published, and do not necessarily reflect the opinion or position of the officers and Board of Directors of the PWSA. Duplication of this newsletter for distribution is prohibited. Quotations may be used if credit is given to PWSA. Membership dues are \$20./year Individual, \$25./year Family, and \$30./year for Agencies/Professionals. (U.S.Funds) Send dues and change of address to: PWSA, 5515 Malibu Dr., Edina, MN 55436.
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