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
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. Bellman, MD
President

GRANT APPROVED

By board decision, during the conference, a grant of $5100. was awarded to a doctor at the University 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 surprising? 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 PWs". 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 Klin؜worth 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.
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.

A few more people you have read about, our Executive Director, Marge Wett and our President, Sam Beltran.
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 presenters and attendees. We are fortunate every year to have most of our presenters 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: not being too proud to frisk your kid at the checkout counter of the grocery store.
not having to worry about mice when you find little holes dug in the coffee cake.
frisking your kid after the halloween party.

sleeping with your wallet under your pillow.

finding teeth marks in the artificial fruit.
having a friend ask "did that cupcake you sent over have icing?"

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

having kids eager to empty the garbage.
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.

searching the bushes for the missing cereal box.

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

having the cleanest chicken bones in town.

buying bandaids in the large economy size.

listening to the same story over... listening patiently while your child reads you the grocery ads.

and over...and over...again.

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 GRATEFULNESS:

For Research donors, May, June:
Chausow, Hancock for Scalia, U.W. of Capital Area, Schramm, Trachtenburg,
U.W. of Ut, S NV U.W. and Andy Alterman.
Total of $584.33

For C.I.T., May, June:
Delta Kappa for Battersby, Lincoln,
Stege (Railton), Straight (Hornstein,
Blankenhurst, Evans), Wet (Schafer,
Nash, Schauer), Heinemann (Powers),
Noordzy (Lauglin), Boyd (2), Sojka
(Jones), Eggert (Kelly), Vermeulen
(Loezn), Dixon (2), Olson (2),
Labella (Van Tuyle, Frattinger),
Brewi (Sheron), PW CO, Castle(2),
Kroek (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), Ziffler,
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
generality 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 voca-
tional, 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.
Living With A Prader

by Laura Lynne Kwiatkowski

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

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

When Megan was born, she weighed 8½ 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 tiny hand and head would dangle through the day without waking up to be fed. This made having a child with PWS very demanding. Because she wouldn’t cry, I had to wake her up every 2 hours to feed her.”

Megan was found to have hyperactivity, four or more seizures of milk per feeding. But Megan didn’t have the strength to suck the bottle, so she took milk all at once and a half hour later she had a bowel movement.

Megan is a destructive desire.

The major problem with Prader-Willi Syndrome is that nobody really understands it. “It’s a real thin line to say mental retardation, that there is something wrong with your child and that’s not diagnosed,” comments Tina as she unconsciously tightens her arm around her child who is sitting on her lap. “Even if I had known it, I did not know about it, maybe she has a less tolerance level or is just a slow starter, and that maybe all of a sudden she’ll just grow, bring 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 somehow grow out of her “baby fat.”

But trying to get people to realize that 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 daughter that Megan can’t eat. "Megan will tell you that it’s "Mommy says no." Or Kelly will say "Megan say's no!"

Their father understands and understands his children with PWS very poorly. “When she goes to her grandmother’s house, she doesn’t believe she is in the syndrome. It’s a very good thing.”

Tina says in a whisper, "I’m not sure if I can go to her handle that.”

They think that, 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 isn’t hurting.

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

Increased public awareness and understanding would help to a great deal. One parent says, "It’s when we were at a restaurant, a woman even chastised me for moulding my daughter to keep her away" when we were outside. I was so angry and hurt. I wished I had a brochure to give to 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 all of the things we find unappealing, and become great connoisseurs 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 someone, she will see her face and call out. When Tina led the room in answering the phone, Megan grabbed the phone with all of her might and pulled hard on it. Of her other hand, hanging on the refrigerator handle with a pleading look for my cookie.

When ‘mommy’ returned though, Megan ceased her plea and mentioned another woman, Gloria, whose son Chris is a PWS child of 17 years.

Tina tells the story when a woman bought a sugar-candy and put it in her pocket. He was going to a party. The first time she did it, though, the police were called and brought his home. Gloria explained that Chris had a syndrome called Prader-Willi and that his response was that next time ‘they’ will have to arrest him.

Research Necessary

Gloria was not as fortunate as Chris in getting answers to questions about PWS. When Chris was about 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...
for Food

-Willi Child

be was already seriously affected by the syndrome. Chris weighed 32 lb.

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 barbecue and left six chickens cooking on the grill, unattended. Gloria's doorbell rang and it was the neighbors with their family left all six chickens. "How do you explain something like this to them? Is

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

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 of hours, or even a day.

Supervision Needed

Currently, Megan attends the Prader-Willi Support Group that Tina helped organize a year ago, and she is doing very well, rising at 6 a.m. to make a new开始 of the day. Megan has already had to reorganize her imagination, 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

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 of hours, or even a day.

Supervision Needed

Currently, Megan attends the Robert Warner Rehabilitation Center of Children's Hospital. There, special education teachers provide a highly structured school day 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 experience. In this unstructured preschool, Megan enjoys a sort of supervised freeplay. Tina explains, "The children 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 control over their child's 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 interested in the support group. Hopefully, by getting PWS on the telethon, people will realize that this support group is serious and continuing the research and giving the help necessary for PWS victims as well as their families.

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. Finally, doctors who can recognize the symptoms can diagnose the disorder.

Twentys-four-year-old woman with PWS before above, during above right, and after right loss of weight from 130 lbs. to 110 lbs. over a 1-month period. This was accomplished on a 700-calorie diet program modified fast. Her motivation was the desire to look good in a bathing suit.

Facial appearance of a female with PWS at six months, top, and at 6 years below.

Tina and her two daughters, Megan (left) and Kelly.
EXCERPTS FROM CONFERENCE, Peggy Brooks-Bertram, presenter

"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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PRADER-WILLI SYNDROME ASSOCIATION
5515 MALIBU DRIVE
EDINA, MINNESOTA 55436
U.S.A.