



The *Gathered View*

March-April 2001
Volume 26, Number 2

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

Grandparenting our children with PWS

By Peggy Knopf

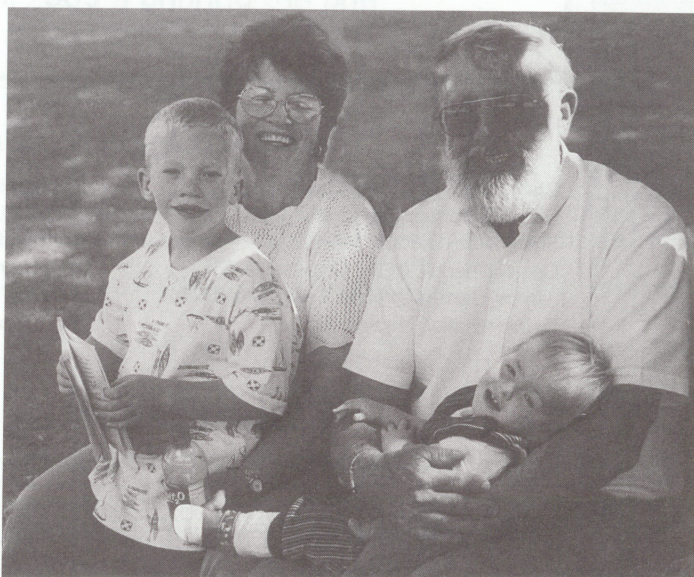
The day we became grandparents for the first time, my husband Dan and I were thrilled. We went to the hospital to meet our grandson, who was to be the beginning of one of the most wonderful parts of our lives.

The exhausted parents were happy and the baby was healthy and fine. Our family has grown since then. Our children now all have families. Our daughter and her husband have two beautiful daughters; our oldest son and his wife, after the tragedy of losing their daughter at birth to trisomy 13, now have a sweet, active little boy. Our other son and his wife are the parents of six boys, two of whom have Prader-Willi syndrome.

The day our grandson David was born, my husband met me at my car with a tight, grim look on his face. Our son had called to let us know we had a new grandson, but something was wrong.

An icy fear gripped my heart. We live in Addison, New York, 350 miles away and couldn't be there immediately. We made plans and left as soon as we could to be with my son and his family.

The awful uncertainty stayed with us during the next week while tests were done. When we met our grandson for the first time, he was 2 days old. He was absolutely beautiful, but because he had such poor muscle tone, he had trouble



Peggy and Don Knopf with two of their very special grandchildren, David Knopf, age 6 and Ben Knopf, age 18 months.

sucking and had to have his milk tubed into his tummy.

Our hearts went out to our son and daughter-in-law, who should have been rejoicing at his birth, but instead only looked worried and sad.

David was transported to Yale New Haven Hospital in New Haven, Connecticut after his birth for the best care possible. Eleven days later, we finally had a name for what was wrong: Prader-Willi syndrome. We had never heard of Prader-Willi syndrome before, but have learned much about it since then.

That was 6 years ago. One evening last year, our son called to tell us we would be grandparents again. But this

baby was already born. He had a diagnosis of Prader-Willi syndrome like David, and was in foster care needing an adoptive family.

Upon hearing this, most people might think, how can they? where do they find the time? or more often, are they crazy? But we were thrilled! Our children already had five boys and then Ben came home to complete the team. We have all gotten to know and love this handsome little guy.

When David was born, we questioned our capabilities of coping, but we learned as much as we could about PWS and knew that we would do everything we could to make

life easier for him. The love, trust and sweetness that is part of the personalities of children with PWS is special and felt by everyone who meets them, even complete strangers.

While David and Ben are both learning at their own pace, whatever they accomplish in spite of their limitations is worthy of high praise, because for them it takes so much more effort, and that makes us as grandparents prouder and tougher to face the challenges of the future.

When David was a baby, I prayed for a long time for a miracle to happen to change him to "normal," or for God to take away his disability so he could have

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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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Executive Director

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Newsletter

Editor - Jane Phelan

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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.

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for its generous grant. We were able to reprint our
Management of Prader-Willi Syndrome ~ 2nd Edition,
create and print additional brochures
and are printing a book in Spanish.

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Update on the Anamaria story

By Janalee Heinemann

Many parents have called and written in support of the parents of the three-year-old child in New Mexico, Anamaria Martinez-Regino, who was taken into state custody due to her life-threatening obesity. As most of you who are members are aware, I was called as an expert witness, but was under a gag order, so could not tell the details of the court case.

Many of you will be relieved to hear that Anamaria is now out of state custody and her parents have their full rights back. I have been in contact with her parents, Adela and Miguel, who report she is doing well.

Because so many media stories have been inaccurate, I would like to clarify some of the details as reported by Adela:

- **Weight** – Anamaria went into foster care at 112 pounds and came back to the parents weighing somewhere between 102 and 105 pounds. She lost approximately 10 pounds in the two months she was in care and now weighs about 98 pounds.

- **Diagnosis** – The family's main concern is that the medical community had not been aggressive in pursuing a diagnosis.

According to Adela, the attitude has been, "It isn't that important to get a diagnosis because whatever it is, she will have to stay on this strict diet regime in order to survive."

That is probably true about the diet, but as I wrote her new physician, "I feel it is important to pursue a diagnosis to assure the family gets the appropriate social service support they need. It will also help ensure that the educational system, friends and extended family members are attentive to her needs and enhance general understanding within her

community."

Since a DNA methylation test has not been done on Anamaria for Prader-Willi syndrome, that is one basic test that should be considered to definitively rule the syndrome in or out. I also sent a list of the many PSW-like syndromes. Fortunately, her new physician called and is



Anamaria with her parents Miguel and Adela

very interested in pursuing a diagnosis and an understanding of care issues.

- **Understanding** — Adela's story of the lack of understanding by the community and the media is not a new one. As I stated in the September–October edition of *The Gathered View*, "This is not the story about one child, but about the judgments we feel are made on our ability to parent that face all parents of children with PWS and PWS-like disorders."

Monitoring nutrition

The good news is that everyone now is taking Anamaria's need to be on a strict diet more seriously. The bad news is that everyone is scrutinizing every bite that goes into Anamaria's mouth. Adela even got a "report" that she was observed out in public feeding Anamaria an ice cream

cone. The reality is that at the time of the alleged incident, their attorney was with them and verifies that this was absolutely not true.

The ethical, legal and emotional issues continue to churn in the minds of Anamaria's mother and father, Adela and

Miguel, as they try to piece their lives back together. These "shades of gray" that I mentioned in that fall article haunt every family dealing with PWS or like syndromes – and every professional working with them: How much do you have to deprive your child with PWS from a basic essence of life – food – in order to save his or her life? Why is it that some PWS and PWS-like families can keep their children's weight under control and some can't? Can you love your child to death? What is the emotional price the child and the entire family must pay to maintain weight? What is the financial price the state or federal government must pay? Who has the right to make these decisions?"

Although this is a new world of hope and progress with Prader-Willi syndrome, we cannot ignore the hundreds of calls we get yearly that reflect the trauma many of our families must still deal with – especially those who get a late diagnosis.

This month I received a call concerning a 9-year-old who was suspended from school for stealing a piece of pecan pie, and another where an 11-year-old was suspended for taking a piece of pizza.

We are having children with PWS of elementary school age not only suspended this year, but also arrested for assault if they hit teachers or aides. Our children are being included more into the mainstream of society – but at what price?

Anamaria continued on page 12

Calling All Conference Attendees

It's the 4th PWS International Conference

PWSA of Minnesota, Inc. invites everyone to attend this year's Prader-Willi Syndrome International Scientific Workshop and Conference in St. Paul, to be held June 27 to July 1 at the Radisson Riverfront Hotel.

The event is also the 24th National Prader-Willi Syndrome Association (USA) Conference.

"At our International Conference we have the possibility to talk more about our growing family of IPWSO, ready to face the new millennium with its challenges, and hear more scientific information to achieve a better future to improve life of all families involved the world over,"



Giorgio Fornasier, president of the International Prader-Willi Syndrome Organization wrote recently.

Special meetings include:

Scientific presentations June 27-29

Professional caregivers and providers June 28

International country delegate/state chapter presidents June 28

General Conference for parents and professionals June 29-July 1

For more information, consult our Internet web sites:

www.pwsausa.org or

www.ipwso.org; call (651) 762-7966

Don't forget to register

Deadline for registration is May 10. Due to the high volume of interest and complexity of organization of this conference, registration forms must be complete and received by this date to avoid late fees of \$75 per person.

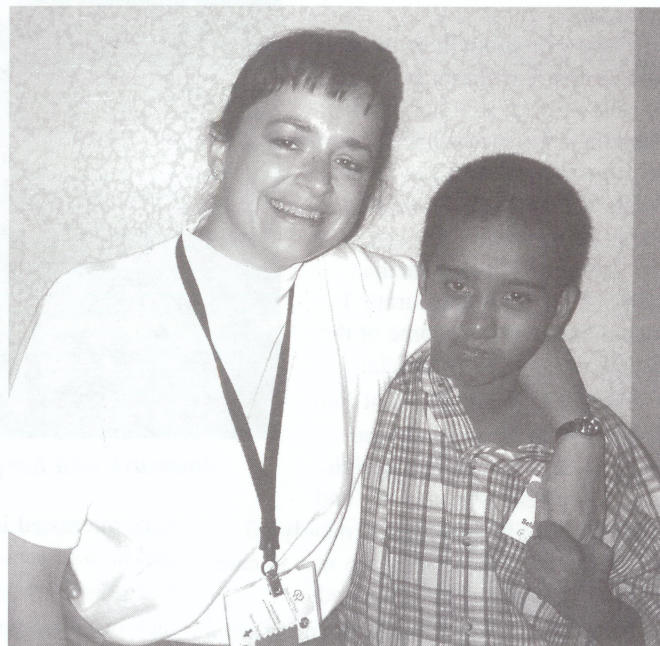
Absolute deadline for YAAP registration is June 1 ~ no exceptions will be made.

Book your hotel rooms early

When registering for the hotel, be sure to clarify it is the Radisson Riverfront Hotel, located at Kellogg and Wabasha St., St. Paul, Min. and tell them that you are attending this conference to get the \$97 per night room rate. We expect hotel rooms to sell out quickly; if necessary, you will be referred to our back-up hotel. Phone: (800) 333-3333 or (651) 292-1900.

To download registration forms and information from the Internet, go to: www.ipwso.org or www.pwsausa.org

For a hard copy of registration forms or if you have conference questions, call: 888-316-9869. For questions on registration after you register, call: 866-PWSAUSA — which is — 866-797-2872.



Mary Lynn Larson and friend

How to make conference grant requests

The following are criteria for obtaining a conference grant:

- The financial and emotional needs of your family should be detailed in a letter to PWSA (USA). Please state whether you have ever received a grant before.
- Because this is a combination national/international conference, we are making an exclusion this year regarding the requirement that all grant recipients must become members of PWSA (USA). International recipients will NOT be required to become members, but USA recipients will still be expected to do so.
- Due to the limited amount of financial resources, international flight expense, with the exclusion of Canada, will not be

considered. International grant requests for hotel and registration costs will be considered.

- Grants within the USA may possibly exclude flight fare to enable us to assist more families.
- Submission Deadline is April 23. You will receive a response from PWSA (USA) by May 11.

Grant requests should be mailed or faxed to:

Prader-Willi Syndrome Association
5700 Midnight Pass Rd.
Sarasota, FL 34242
Attention: Grant Committee
or Fax to (941) 312-0142

Grants continued on page 5

We're Expanding IPWSO's World

South America's first PWS and IPWSO meeting was held in Asuncion, Paraguay, last October. Here are reports from some of the participants.

Why Paraguay? Several times I have told the story: Our IPWSO President Giorgio Fornasier is an opera singer who often goes to South America and performs the music of the Italian baroque composer Zipoli, who lived in South America more than 200 years ago. Giorgio along with his artistic work has spread the voice of PWS and IPWSO and has many PWS contacts in South America.



Louise Greenswag and Giorgio Fornasier

We were met with such a warm hospitality that we shall never forget. We met many families and professionals from the countries in South America and the atmosphere at the conference was wonderful. Everybody was interested in sharing experiences and to help wherever possible. South America is a big continent, and it was impressive that so many families had travelled such long distances to get to the meeting in Asuncion.

Thank you to all....and only one thing more: looking forward to meeting you all again.

Susanne Blichfeldt, Denmark

Grants - continued from page 4

Other options for funding assistance

Each state's Developmental Disability (DD) Council provides federally funded grants for disability-related purposes. The grant may need to go through a sponsoring nonprofit organization, such as your local chapter of PWSA, The Arc, Parent-to-Parent, or other disability-related organization. Each state will be different, but the money is there (our tax dollars!) for us to use.

The purpose of your request should be expressed in terms of your DD Council's stated goals, such as "education and training," "family support," "community participation," "self-advocacy and empowerment," "caregiver training" for the parents, or "respite care" for the child with PWS. To locate your state's DD Council, call NICHCY at 1-800-695-0285 or go to their Web site: nichcy.org

Your local PWSA chapter may offer grants for this purpose; give them a call.

A direct request for help to airlines, motels, and other trip-related companies has won some creative families donations and discounts to help with their expenses.

Mary K. Ziccardi, Conference Committee Chair

I want herewith to thank IPWSO and all other friends who made this conference possible. It started as a dream to have a conference that other families from our area could share and take part in.

Until one year ago we were the only national association in South America, with 64 families that shared experiences.... We now have friends in Chile, Uruguay, Venezuela, Paraguay and Brazil with PWS in their families.

All this is very important in countries like ours where people are worried about hunger in this third world and cannot

think that someone that eats too much can have problems.

But due to the (conference), all newspapers, medical articles and even the radio talked about the syndrome and how to detect it. This is very important for us.

Parents felt cared for, we do not feel alone anymore. Thank you all.

Elli Korth, Argentina (Mother of Mariela (18 years PW), Sofia, 15, Juan, 12 and wife of Alex

We will treasure the recollections of the warm welcome given to us by everyone. All who participated in the program seemed eager to acquire additional understanding that might help them make informed decisions. Our visit certainly attests to the expanding presence of IPWSO. We are truly becoming a global community.

Several of IPWSO's South American parents and professionals will be attending the International Conference June 27 to July 1 in St. Paul, Minnesota. I join with members of PWSA(USA) in welcoming them to our country to to IPWSO's international family.

Louise R. Greenswag, U.S.A.

With the help of Pharmacia and our friends in South America, we organized a very successful first Latino American conference about PWS in Asuncion, Paraguay.

We cannot ignore that more than three quarters of the world know nothing about PWS, and families keep struggling, feeling alone and lonely, not knowing what's going on! If our aims and objectives are those written in our statutes and brochure, we must look at PWS as one world, without any classification or given numbers just to establish cultural and social differences.

The Paraguay experience taught us a lot as we met wonderful people to whom we brought important information and sharing and got a much bigger and richer return we will never forget.

Giorgio Fornasier, Italy, IPWSO president

Clip and Use the PWS Medical Alert Form

By Janalee Heinemann, Executive Director

As Executive Director of the national Prader-Willi Syndrome Association (USA), I am concerned about the medical complications and sudden deaths that can occur due to a lack of knowledge of the syndrome.

Prader-Willi syndrome (PWS) presents some unique medical characteris-

tics, of which we want the emergency room staff to be aware.

Call our office at 800-926-4797 for a Medical Alert brochure and other medical alert articles that contain detailed, pertinent information. The Medical Alert brochure should be in the front of every chart of a child/person with PWS admitted to the hospital.

We appreciate your cooperation in educating all staff treating patients with PWS.

I have written a guide on shown on page 7 that addresses the most life-threatening aspects of the syndrome. We suggest that you use this sheet to alert medical personnel who may treat someone with PWS.

The Family Trust: A Resource for Individuals With Disabilities and Their Families

By Timothy Pawol

This is the first of a two-part series on planning considerations for individuals with disabilities and their families.

Who will oversee the wellbeing of my disabled family member when I'm gone? How do I provide future financial support without jeopardizing my family member's eligibility for public benefits? These are the questions faced by families with disabled loved ones, and The Family Trust has answers.

The Family Trust, a member of the ARC Allegheny family of corporations, offers both estate planning and a professionally managed trust program for families with mentally and physically disabled individuals.

Here are the key factors to consider when developing sound financial plans for the disabled.

Financial

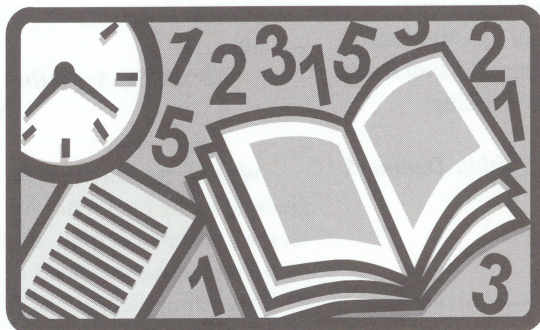
- What supports will be available from the government?
- What supports will be available for the family to supplement government services?
- How much funding is necessary to continue this supplemental support in the future?

Decision Making

- Is assistance with decision making

necessary or desirable?

- Which of these options for decision making assistance is most suitable —



representative payee, power of attorney, advance medical directives, executor, trustee or guardian?

Asset Allocation

- How will funds for my family member be held and distributed?

Without expert counsel, many families leave money in their wills to a third party, often a sibling, with the unwritten promise to use the funds for disabled family members.

Unfortunately, death, divorce or bankruptcy make this a risky option. Also, direct transfer of assets to disabled individuals renders them ineligible for most government benefits until assets are spent down to \$2,000.

The Family Trust offers guidance on three types of trusts that prevent inelig-

bility for government funds (a special needs trust and payback and pooled trusts).

The Trust also provides expertise on financial planning and decision making models, as well as a free Personal Planning Guide to record information for the future care of disabled loved ones.

The Family Trust is a non-profit organization which was incorporated in 1998 by a group of parents who are members of ARC Allegheny.

The Trust was originally designed to offer pooled trust services to legally shelter assets, prevent spend-down and maintain eligibility. The mission was expanded to assist individuals with disabilities and their families to make and implement plans for the future.

Currently, the Trust has 44 funded accounts totaling approximately \$3.7 million. These funds will be used to supplement the governmental supports the individuals with disabilities will receive throughout their lives. The Family Trust is available for any person with a disability throughout the Commonwealth of Pennsylvania and is willing to assist families or organizations in other areas to establish their own trusts. The Family Trust may be reached at 412-995-5000 ext. 405 or 434 or at 711 Bingham St. Pittsburgh, PA 15203 or via e-mail at www.arcallegheeny.org.

MEDICAL ALERT ON PRADER-WILLI SYNDROME FOR EMERGENCY ROOM STAFF

INFANT-SPECIFIC ISSUES:

Although avoiding life-threatening obesity is one of the major issues of an older child/adult with PWS, failure to thrive is the major problem of the infant with PWS. The weak muscle tone makes sucking difficult. (PWSA (USA) has a detailed booklet on infant feeding available.)

If an infant has respiratory problems, he/she should be closely monitored because the weak muscle tone makes clearing secretions more difficult. An infant on an NG tube may also have more difficulty due to reflux and aspiration.

ALL AGES WITH PWS:

Due to a lack of typical pain signals to the brain, poor body temperature regulations and lack of vomiting, a person with PWS can have serious medical problems which remain undetected. (This is caused by the hypothalamic dysfunction in the brain.) The following should be carefully noted:

Temperature - An individual with PWS may not register a fever even when seriously ill and may run dramatically below-normal temperatures at times. Even slight temperature elevations should be considered a warning sign.

Pain - Individuals with the syndrome frequently demonstrate decreased pain sensitivity. Therefore known injuries must be carefully assessed for more serious problems, and signs of unreported pain should be observed. In the absence of a verbal complaint of pain, other symptoms of specific injuries should be evaluated. Reports of undetected, severe gallbladder disease and infections are common.

Vomiting - Individuals with PWS do not commonly exhibit a vomiting reflex. All identified and reported episodes should be thoroughly investigated. If a person with PWS suddenly reports pain, is vomiting and has abdominal distention or bloating, it may be a sign of a life-threatening gastric inflammation or necrosis, and emergency surgery may be needed. (See the Medical Alert brochure for more details.) It also may be a warning that the person has ingested a large amount of food. In either case, death can occur in hours. These abdominal conditions are more prevalent in a teen or adult with PWS.

Bone fractures - Due to the high pain threshold, it is not unusual for a person with the syndrome to have an undetected broken bone. Following a fall or other injury, a person with PWS should be closely monitored for a change in walking or arm movement. Observe for deformities, swelling or bruising.

Anesthesia - A person with the syndrome may respond excessively to anesthesia. Anesthesia should be carefully monitored. Pulmonary hypertension is also a concern with the child or adult who is severely overweight.

THE CHILD/ADULT WITH PWS:

Obesity-related problems: High blood pressure, diabetes, congestive heart failure and pulmonary compromise are the most common problems for the older child/adult with the syndrome who are significantly overweight. This weight gain is because of their constant sense of hunger and potential for gaining weight on very few calories.

Food foraging - If left unsupervised, an individual with PWS can consume life-threatening amounts of food. A dramatic weight increase within a day—especially if coupled with reports of stomach distress or vomiting—may be a sign that the person is in an immediate crisis situation. Stomach rupturing is possible. Diarrhea, significant fluid retention or discharge are all reasons for concern.

Obstructive sleep apnea - Excessive weight in addition to the weak muscle tone of PWS creates both potential and probability of serious respiratory problems. Sleep apnea is a common disorder in this situation. It is associated with decreased oxygen saturation, an irregular breathing pattern, snoring, and short periods of not breathing when sleeping.

Skin lesions - Because of chronic skin picking behaviors, another characteristic of the syndrome, a person with the syndrome should be carefully monitored for open, raw sores and infection. If there are open sores, staff should be alert for signs of acute infection including warmth at the site of the sore, redness, streaking, bleeding or pus.

*Janalee Heinemann, MSW, Executive Director
Prader-Willi Syndrome Association (USA)*

This alert has been reviewed and approved by medical professionals working with the syndrome. PWSA (USA) has contact information if consultation is needed. Call 1-800-926-4797 e-mail us at pwsausa@aol.com or visit our web site at www.pwsausa.org

New Book Focuses on Young Child with PWS

One of our parents from Alabama, Cheryl Couch, has written the first extensive book from a parent of a young child's perspective. It is titled *My Rag Doll: A Mother's Journal of Raising and Loving a Child with PWS ~ Birth to Age Six*.

Cheryl draws her readers into the emotional roller coaster world of Prader-Willi syndrome. Written from a Christian perspective, Cheryl shares her heart as she experiences the depths of despair and the height of joyous pleasure in her angel, Elana.

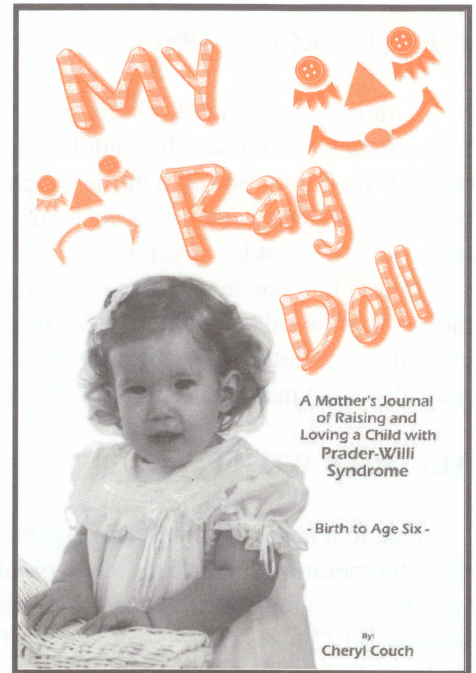
Using her journal, she gives us a picture of her struggle to assimilate the rational information being spoken by the physicians into a picture where Elana is

more than a medical statistic. Her story flowed so easily, I found it hard to put down.

She expresses poignantly the pain all parents go through when they first get this devastating diagnosis. Cheryl also shares with us how education gave her strength, faith gave her hope and Elana gave her a new perspective of how sorrow and joy go hand in hand."

We now have this 229-page book for sale through PWSA (USA) for a cost of \$15.95 plus shipping. The only note of caution is that it may be difficult for very new parents to read due to her stories about food control issues as Elana ages.

Janalee Heinemann



Another New Parent's Story

By Elizabeth Greskovics

Aside from all the difficulties that parents go through when learning that their child has Prader Willi syndrome, one of the tougher periods was our daughter's sudden, unexpected choking bouts.

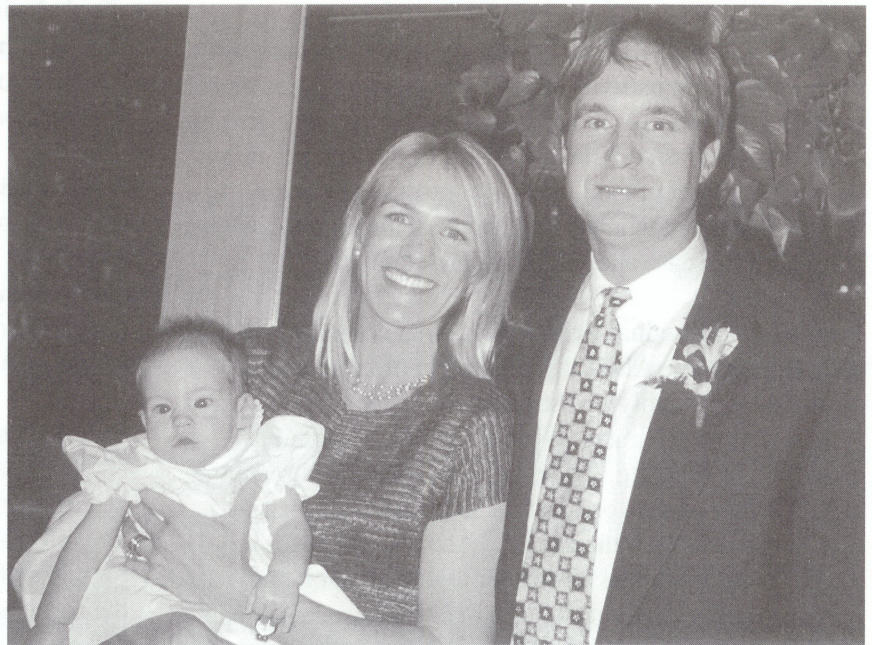
Approximately two months after we brought GiGi home from the hospital, she began to choke. This would happen when she was feeding, or more often, 2-3 hours after.

After a few good scares, we took GiGi to the hospital for a swallow study and 24-hour pH study to test for reflux.

The studies showed poor swallowing but were otherwise inconclusive. GiGi had many doctors, who all had their different spin on what should be done. As parents, it was difficult to sort through the different tests and information to determine what was best for our daughter.

One educational resource that proved invaluable to use was the "Nutritional Care for Infants and Toddlers" handbook. We were better informed and able to work with GiGi's doctors to make the best decisions for her. We are thankful to Janalee for making us aware of this handbook and for sending it to us.

We believe GiGi's choking was due to her prematurity (2 months) and poor swallow (a



Andrew and Elizabeth Greskovics of Manhattan Beach, Calif. with GiGi.

result of her poor muscle tone). Now that she is 8 months and stronger, she has outgrown the choking. We would urge parents to seek and utilize the informative booklets that PWSA (USA) offers. This knowledge enabled us to make informed choices concerning our daughter's health care.



Winding Down -- A Slow Farewell

By Barb Dorn

It is hard to believe, but over the next few months I will be winding down as president of PWSA (USA). It has been a memorable three years, and I will never forget all the great people I have gotten to meet and know. It has truly been a great experience. Many have asked why I am not seeking another term. I have a son turning 16 years old — Tony, who has PWS. I have a lot on my plate with him these days and a lot more in the days ahead. I am very devoted to PWSA and to helping all who have PWS, so I will never be very far away.

Mary Lynn Larson is also ending her term as vice-president. I can't say enough about Mary Lynn. She has been my right hand person. I couldn't have done it without her. We have made a lot of changes — good ones, I believe. I want to thank her for all her hard work and her willingness to help whenever I needed her.

New Officers with New Priorities

Because of the many changes, I felt it was important to take a close look at the job descriptions for both the president and the vice president.

During the January board meeting, two new job descriptions were presented and voted into practice. In addition, the board appointed three new "officers-elect" for the positions of president and co-vice president.

Until they take office at the 2001 conference, Lota Mitchell will serve as president-elect, and Carolyn Loker and Regina Hartnett as co-vice presidents-elect. We are all beginning the process of transitioning into new roles.

Lota Mitchell is not new to the leadership team of PWSA (USA). She is a past board member as well as a past board chairperson. She has been very active as chairperson and co-chairperson of the

PWSA (USA) Publications Committee.

Carolyn Loker is a current board member as well as president of the Michigan Chapter. She will be taking on the primary role of chapter communication and support. She and Lota will work together in making sure chapter needs and issues remain a priority.

Regina Hartnett is new to a PWSA (USA) leadership role. Her husband Bob is currently a board member. Her primary responsibility will be awareness. She will serve as chairperson for the Awareness Day committee and also will work with Lota at increasing our efforts in making awareness an important area.

I am very excited about the new leadership team and I want you to join me in welcoming them.

Highlights from the PWSA (USA) Board Meeting - January 2001

It only rains in Sarasota when the PWSA (USA) board members come to town. Even though the warm weather is always a motivating factor in bringing us to Sarasota in January, we don't find much time to enjoy it because of the many hours we spend in meetings. Here are some highlights from those meetings:

- The board accepted a bid for 2002 conference from the PW Utah Association. The people from Utah are busy making plans for our first condensed PWSA (USA) conference.
- Plans continue to be finalized for the 2001 PWS World Conference in St. Paul in June of this year. Jim and Joan Gardner have been doing an outstanding job.
- The board agreed that PWSA (USA) will host the 2003 conference in Orlando, Florida. Our site selection committee is working on negotiations.
- PWSA (USA) conference committee and the executive director are developing a job description for a future conference planner. The goal is to work toward funding this position.
- Plans are under way to begin a strategic planning process for PWSA (USA). A team of members will be gathering information and ideas over the next months. A retreat is anticipated for the fall of 2001.
- The 2001 budget was approved.
- The board, after review, is moving forward with the formation of the Prader-Willi Family Foundation, part of our planned giving program. More information will become available later.
- The board approved a temporary position for a half-time crisis counselor in the national office. (See the executive director's report regarding this position.)
- Several policies and procedures for our board manual were revised. This manual is now available on disc for all board members and is posted on our board website. Two hard copies will be at all meetings.
- PWSA (USA) is in the process of becoming registered as a nonprofit organization in all states that require this. As of January 20th, we had been approved in 24 states; 16 are pending.
- Our insurance company informed us that they are not able to "umbrella" chapters under our liability insurance. We are investigating other insurance companies who can possibly provide this coverage.
- Jim Kane, a parent and former board member, has offered to investigate the concept of developing a clearinghouse of research for PWS and related topics. (See the executive director's report.)

Dorn continued on page 14

Characterizing and Managing Behavior in Prader-Willi Syndrome

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

This is the last 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 III. Improving Behavior

3. Reinforce Appropriate Behavior

The positive reinforcement approach to getting your child to behave in ways that are pleasing to you is often a more effective alternative to conventional parenting practices.

Positive reinforcement is also less likely to produce emotional outbursts, resistance or retaliation. Rather than trying to make your child behave, you can arrange things so your child will want to do the same things that you want him or her to do.

The benefits of positive reinforcement are seen in many areas. Politicians have learned to use positive reinforcement to get citizens to voluntarily give money to the state. State lottery programs generate financial revenues by arranging positive reinforcement in the form of winning tickets. Lotteries are an effective alternative to simply raising taxes, which is coercive in nature ("give us more money or else!") and is likely to anger citizens and generate retaliatory voting or political resistance. Similarly, as a parent you can learn to use positive reinforcement to generate substantial revenues of good behavior from your child without the emotional by-products of more coercive parenting techniques.

All children with Prader-Willi Syndrome regularly engage in completely appropriate behaviors that are worth reinforcing. In fact, even individuals with the most volatile behavioral characteristics go through periods of time when their behavior may be characterized as "good as

gold." As a parent, your goal should be to increase the frequency and duration of this good behavior, and positive reinforcement is an essential mechanism for doing so.

The most basic and often easiest way to reinforce good behavior is to initiate a positive interaction immediately after the behavior occurs.

This strategy is sometimes called the "praise and ignore" technique. This technique involves praising appropriate behavior while ignoring minor inappropriate behavior. In applying this technique, the expression, "catch 'em being good," can be a useful prompt or reminder to pay attention to, and reinforce, appropriate behavior (i.e., being good).

For example, when you notice your child is independently cleaning up after him or herself, you should initiate a positive interaction, "Wow! I am so glad to see you cleaning up like that, I am very proud of you."

This simple response will have a greater impact in increasing the overall probability of your child independently cleaning up than any amount of scolding, lecturing or threatening that might otherwise occur for an incident in which your child fails to clean up. Notice when your child is behaving appropriately or engaged in some particular behavior you would like to see more of, and immediately initiate a positive interaction. Catch 'em being good whenever you can. The positive results may amaze you.

Another useful positive reinforcement involves access to reinforcing activities or items. These can be activities that are logically related to the behavior being reinforced or artificially related.

For example, shopping may be a form of positive reinforcement for a child with PWS. If this same child has been playing outdoors prior to a shopping trip and needs to wash or change before going, the opportunity to go shopping can be used as a logical reinforcing consequence of washing. This is a logical consequence because in our culture people are expected to clean up before going out in public.

Making the shopping trip dependent on the behavior of cleaning up is consistent with this social norm. If the child is prompted to wash and refuses, review the rule relating washing to being able to go shopping and patiently wait for the child to comply. If your child is not used to this strategy, you may have a longer wait the first or second time you try this. However, if you stick with it, and if shopping is a positive reinforcer, compliance will increase.

Your child will become more generally compliant as you regularly practice making reinforcing activities dependent on completion of appropriate and responsible behavior, while remaining calm when noncompliance occurs.

Activities can also be artificially set up as reinforcers for particular behaviors you would like to strengthen. For example, if daily showering is a behavior that needs to be strengthened and your child spends a lot of time watching TV, that access can be made dependent on showering first. There is no logical relationship between showering and watching television; it is an artificial relationship you can set up to increase the probability that your child will bathe regularly.

Access to particular toys or other activities your child prefers can often be used to reinforce appropriate behavior.

Finally, special drinks (e.g., diet sodas) or other low-cal edibles can be used as reinforcers for particularly important behavior you may wish to strengthen.

Positive reinforcement can be a very effective way to address problem behaviors. Instead of treating problem behaviors as an opportunity for coercion or punishment, treat problem behaviors as a prompt for you to teach your child some appropriate behavior using positive reinforcement.

For example, rather than punishing noncompliance, pick the most troublesome noncompliance problem your child may have and set up a reinforcement plan

Behavior continued on page 11

for strengthening compliance in that particular area.

The showering example given above illustrates this approach to the problem of noncompliance with routine bathing. Other noncompliance problems can also be addressed by developing a program to intentionally reinforce compliance.

Another problem behavior common in individuals with PWS involves handling transitions or changes from one activity to another.

Suppose a child with PWS is regularly missing the school bus because of difficulty handling the transition from morning breakfast and television time to being outside on time to catch the bus. A parent could easily become frustrated and angry with this problem behavior, increasing the chances of resorting to some form of coercion.

However, such a situation can be corrected with positive reinforcement. A special reinforcer can be set up as a consequence of being outside and ready for the bus on time. If the item you selected is a reinforcer, then the behavior of being on time for the bus will be strengthened. With a strong enough reinforcer and consistency on your part, you can expect your child to almost never miss the bus again!

A good general strategy for using positive reinforcement is to decide what behavior you want your child to do. Review that behavior with the child and have the child repeat back what the behavior expectancy is and what reinforcer will be used.

If possible, model, practice or role-play the behavior, and during this practice time reinforce the child's behavior that is consistent with what you expect. Finally, reinforce the desired behavior in the real situation in which it occurs.

Individuals with Prader-Willi syndrome do better when there is a set routine and sequence to doing things. It is a good idea to make important behaviors part of a regular routine.

The probability that your child will regularly and cooperatively perform routine tasks such as bathing, brushing teeth, homework and chores will be increased when these tasks are scheduled according to a regular routine.

In scheduling a routine, it is useful to arrange more reinforcing activities to follow less likely tasks. Some examples are illustrated below:

get weighed → eat breakfast
clean up toys → eat dinner
take a shower → watch t.v.
do homework → play video games

Routines can be drawn out or written and scheduled on a wall chart as a prompt to your child and to you as to how routines are supposed to go.

Especially when the routine is new, you will need to follow it closely to ensure compliance with the routine. While doing so, remain focused on positive interactions, review components of the routine in advance and praise your child for correctly describing the routine and for complying with it.

When important behaviors become part of a regular routine arranged in this way, those behaviors become virtually automatic and your child becomes that much more responsible.

4. Use a kitchen timer

In conjunction with positive reinforcement, a standard mechanical kitchen timer can be a very useful tool in managing behavior in individuals with Prader-Willi syndrome.

A. Compliance With Routine Tasks

If a reinforcer has been arranged for a particular activity or task such as cleaning a bedroom, a kitchen timer can improve the effectiveness of the reinforcer arrangement.

Set the timer for a reasonable time frame (one that you are certain your child can easily meet), and inform your child that he will earn a reinforcer if the room gets cleaned before the timer goes off. Individuals with PWS and other children seem to be motivated by the challenge of beating the clock.

B. Speed Up Behavior

Suppose your child is cleaning up her bedroom and earning a special treat for doing so. However, this task takes her a particularly long time to complete. When you prompt her to go faster, she gets angry and seems to work even slower.

The kitchen timer provides a mechanism for speeding up bedroom cleaning behavior while minimizing resistance and emotional reactions.

First, time how long it takes your child to clean the bedroom when there is no time requirement. It would be best to record this time on at least two occasions.

Next, select a time value that the child already meets on most or at least half of occasions (for example, 1 hour). Share this information with the child and review the new rule about being required to clean the bedroom before the timer goes off to earn the reinforcer.

The next time the room is scheduled to be cleaned, set the timer for the selected value. Once she is consistently beating the timer, systematically decrease the timer setting based on how fast she actually is getting the job completed. Her speed will increase until she is regularly getting the room cleaned in a more reasonable amount of time (maybe 20 minutes), at which point the timer setting can remain constant at this value.

C. Eliminate Problem Behaviors

A kitchen timer can also be used to help eliminate behavior problems.

For example, we worked with someone with PWS in our program who engages in rectal digging while in the bathroom at her day program.

Initially, her bathroom visits averaged over 30 minutes, and when checked while in the bathroom, she was usually found to be engaged in rectal digging. On occasion, she would complete a bathroom trip in 15 minutes or less.

Using this information, we would set timer for 15 minutes prior to her entering the bathroom. If she finished using the bathroom before the timer went off, and refrained from engaging in rectal digging, she would receive a calorie-free breath savers mint.

Despite the fact that she previously and regularly engaged in bathroom visits lasting 30 minutes or more, she beat the timer the very first time we used it. Gradually, we were able to decrease the timer from 15-minute intervals to 10- and 5-minute intervals, and she continues to beat the timer consistently without evidence of rectal digging.

Thoughts on Finding God's Perfection

Editor's Note: The following is a response to a story called "Finding God's Perfection" that was published in the November-December 2000 edition of The Gathered View.

At first when I read the story I was touched by the essential wisdom of the message: Pay attention to how you respond to others who are less fortunate than you....let their need of your kindness open up your heart and move you to act generously.

But I have second thoughts. Perhaps the sentimentality of this story is not grounded in a deeper understanding of what people who are disabled, like my daughter Ann who has PWS, really need.

One of the most difficult issues for Ann is that she cannot live independently like other people. Yet I believe it is not independence *per se* she really wants, but to *belong* — just like people who are not mentally disabled. I believe she would be able to let go of this craving to be and live as a non-disabled person, to be someone she is not, if she could be accepted and belong as who she is — a person with some very serious physical, mental and emotional limitations.

In her life, we have already, inadvertently, given her "tastes" of things that she cannot, with her own innate ability and skills, sustain on her own. She has had some opportunities, like the little boy in the story, to "play ball" with folks above her skill level (her very real limitations denied) because for a short time, others were willing to sacrifice their game — a game that they had the skill to fully play.

But the boy in the story was not being cheered for a skill he really has: it was a very short lived, "let's pretend I am not disabled and I am just like you — and you will cheer me for being skilled just like you." And the little boy is not very likely going to get to play ball again the way he did for that one magical game. Tomorrow is going to be pretty dull and sad as he sits home alone while those who are not disabled are out enjoying the privilege of stretching their skills with each other.

Having a taste of folks bending their game to let her win only made Ann want

more of the same. But what she and others like her really need is folks who will spend time with her on activities at her skill level that help her stretch her potential in a realistic way. A great

Yes, pay attention to how you respond to others who are less fortunate than you...let their need of your kindness open up your heart and move you to act generously...help them develop their



A Special Olympian

This picture of Ann Keating was taken when she was part of the California team that competed in the 1975 International Special Olympics Games in Mt. Pleasant, Michigan.

Ann won a silver medal in swimming the backstroke.

Now 37, Ann lives in a small group home for PWS in Conoga Park, California. The California Foundation for PWS was instrumental, along with the help of parents, especially Ann's father, Bob Keating, in making Ann's home a reality. Ann and the other residents of her home are signed up for Special Olympics this year.

example of this is the Special Olympics. It takes the ongoing commitment of time and money of a lot of volunteers for this project.

Ann's participation in swimming in the Special Olympics was a thrilling experience for her. She was proud of her ability to perform at her own level of skill and win medals for doing so. Another example, in Ann's case, would be having someone who will just spend time with her putting together jigsaw puzzles or playing the simple board or card games that she enjoys and is capable of playing.

With some children with disabilities, the activities have to be even more simple. For all, it requires someone with patience who will listen, speak and teach them at their level so they feel understood and part of the human family.

Doing something this simple with someone who is mentally disabled is not as dramatic a good deed as the ballgame story, but it will sure teach us the art of careful and kind attention, a skill we can use with everyone in our lives!

I know I am on a soapbox here, but I want, heart and soul, to advocate for Ann and folks like her. We really don't have to ask fully abled kids to sacrifice their skills for the less abled. We want them to grow to their full potential, too.

unique potential in whatever way you can. And send in a contribution to the Special Olympics!

*Kathleen Keating Schloessinger
Ladysmith, B.C., Canada*

Anamaria -

continued from page 3

Where do we go from here?

How do we help all of our "Anamarias" who do not catch the attention of the press? How do we save our children's lives, yet save the sanity of their families? Is their right to food greater than their right to life?

PWSA (USA) is taking a two-phased approach: Thanks to the Sam Alterman Foundation (and to Sam's son, past board member, Paul Alterman), we just received a 5-year commitment to fund a part-time counselor who will assist me in providing support to our families in crisis.

Thanks to yet another past board member, Jim Kane, we have initial funding to work on creating a clearinghouse for all PWS and related research. The board approved Jim's spearheading this project. Jim's goal is every member's goal — to find a cure for the constant sense of hunger that is so disabling and life-threatening to our children.

From the Home Front

2000 PWSA Walk/Run for Nicholas a success

The second annual PWSA 5K Walk/Run for Nicholas, held last fall, was a great success. There were activities for kids of all ages, including a kids' race, with all receiving prizes for participating. The event also featured face painting, a clown, refreshments and many prizes.

Laurie and Loten Baskin of West Bloomfield, Michigan organized the event again to help aid research concerning constant hunger, which they feel is the greatest need for children with PWS. Their 3-year-old son Nicholas is the driving force behind helping these kids today. The race netted more than \$11,000 to be used for a grant in appetite research.

"I now feel I know why God blessed me with Nicholas. Through this fund-raiser I'm helping to make a change in the future of kids with PWS," said Laurie.

Laurie would love additional help for next year's race, currently scheduled for September 22, 2001 at Marshbank Park in West Bloomfield, Michigan. If you can help, please call (248) 363-3433.

Little Nicholas and legendary NBA player Big Bill Laimbeer



The Chuckle Corner

My daughter Jill was a patient in a nursing home for two years following an accident in which her left leg was broken.

On several occasions during that time, complications arose, necessitating an ambulance trip to the emergency room.

On one occasion I was out of town, so my attorney son-in-law Tim and one of my other daughters accompanied Jill to the hospital. They waited for about two hours for their turn in the ER.

Finally, a doctor came over to Jill and said, "Hello, Jill, who is this you have with you?"

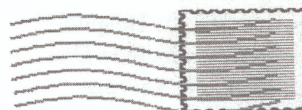
Jill perked up immediately and replied, "Well, this is my sister, Cindy, and this is my lawyer, Tim."

The doctor's facial expression dropped, and Jill received very prompt attention.



*Marion Goodman
St. Petersburg, FL*

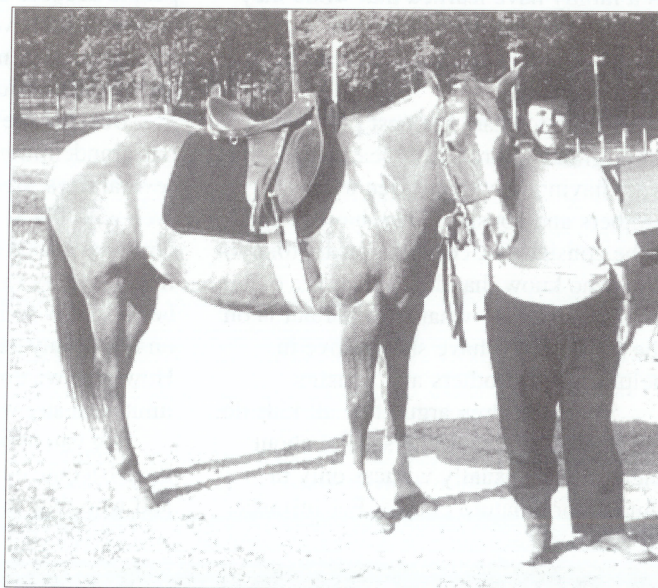
PW POST OFFICE For people with PWS



I am a member of a Therapeutic/Recreational Equestrian Program called the Dream Riders in Lexington, South Carolina. My Dream and Goal is to go to the 2003 International Special Olympics in Ireland. I hope I make it but if I don't it will be all right.

There is a weight limited to ride so I am working on keeping my weight down and lose a little more.

When I first started horseback riding I had to have a leader and a sidewalker, but now I ride independantly. At first I walked the



Andy and his horse are ready to ride

horse around the ring and did exercises on the horse. Then when I got a little better I started to learn to trot and control the speed of the trot. Also I go through varies obstacles and back the horse. I ride in and out of cones and go over poles and stop in a box and make a 360 degree turn and go through an L shape maze. Pretty soon I am going to be ready to learn how to canter.

We learn how to groom and tack our horses to ride. We also have to wear safety helmets when we are riding horses and working around them.

I have ridden in Horse Shows and won several ribbons. I am also on the Dream Riders Board of Directors as the Athlete Member in behalf of the other Athlete Riders in the Program. We meet about once a month. I love Horseback Riding a lot and my instructor, Jennifer, is great.

*Andy Maurer
Batesburg-Leesville, SC*

The View From Our Chapters

California

PWCF is planning its first annual Walk-Along to promote awareness of PWS on April 29 in Encino.

Under its long range plan, PWCF will address achieving "Qualifying Disability" status for PWS in California. The group is also beginning a Quality of Life Advocacy Program to address long-term advocacy for persons with PWS after their parents or guardians are deceased.

PWCF is also learning more about Self Determination, a movement with three pilot projects in California. Purpose of the projects is to try new ways of assisting people with disabilities, with help from their families and friends, to have more control over decisions and resources in order to determine their futures.

Florida

PWFA celebrates its 10-year anniversary with a Spring Conference in Gainesville on April 27-28. Held at the Holiday Inn West, the event includes tours of group homes and Shands Hospital Brain Institute. Speakers include Dan Driscoll, Ph.D., M.D., N. Andrew Shapira, M.D., Ph.D. and Educational Specialist Lisa Schiavoni.

New England

The Chapter held a Parent Discussion Group this month at the home of Tim & Margaret Bells in Milford, who also provided dinner. April 28 is the Chapter's Swim Day at Massachusetts Hospital School in Canton.

North Carolina

The March Spring Meeting in Albemarle focuses on residential alternatives for those with PWS and CAP funding. CAP (Community Alternatives Program for Persons with Mental Retardation and Other Developmental Disabilities), is a special Medicaid program begun in 1983.

A new clinic/ study group program for people with PWS is under way at the University of North Carolina Chapel Hill. Its goal is a multi-disciplinary approach to assessing and treating PWS.

Wisconsin

Learning and Laughing...Together was the theme of the Chapter's March PWS training session held at the Holiday Inn, Stevens Point. It was a day-long event for those with PWS, parents and residential providers.

The Chapter will assist at least one PWS family or person with PWS to attend the upcoming PWS World Conference in St. Paul, Minn.

Over the years, the Chapter has compiled a list of summer camps that children with PWS have attended. The Chapter plans to award a scholarship to attend summer camp this year to a PWS of Wisconsin member.

Dorn -

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- The board has approved a new and faster mail delivery method for *The Gathered View* for a trial period of 6 months..
- The process of revising The Management of PWS textbook is under way. A Growth Hormone booklet as well as other educational products are also under production.

The board continues to work very hard to improve the services to persons with PWS as well as those who support them. I am truly inspired by the devoted work of our national office staff as well as our board and officers. Geographic hurdles have not kept progress and work at a standstill. Thanks again to all who make the world a better place for persons with PWS. Take care.

Grandparents - continued from page 1

the future that his brothers all have. But God in His infinite wisdom has shown me that David is going to be OK.

Now we have Ben, who is a year and a half old. He like his brother had to have a feeding tube, which has just been taken out for good. While Ben and David both have PWS, their challenges differ, and we as a family have learned that while they have to work harder to meet life's challenges, we have to be there to help and understand.

I have to share the best part. Our other grandchildren have learned so much from having David and Ben as their brothers and cousins. They have learned to be considerate, compassionate, tolerant kids who know that differences are only on the outside — what is important is on the inside. They have shown love in helping their brothers and cousins.

These children argue like all kids do, but they have something special about them that we usually witness only in much more mature people. For instance,

if David can't run as fast as the other kids, then one of the children will encourage him or give him a helping hand. I have seen the children beg to hold Ben and help him when they could be doing something else.

I'm not saying they are perfect, but I do think these children are much better people because they have brothers and cousins who have a need for help. They are nurtured as much as David and Ben are by their actions.

Because they live so far away, when our grandchildren visit, it is usually for several days. Because we have grandchildren with PWS, we make sure that we don't have food out where it can be eaten freely. We try to have more healthy snacks because it is so important to keep an eye on how many calories are consumed. However, we don't find that our lives are limited in any way because of PWS.

We can honestly say that our lives have become enriched by David and Ben and who they are.

We encourage grandparents of children with PWS to attend the upcoming 2001 IPWSO Conference in Minnesota June 27 to July 1.

Gabriel
(\$1,000 or more)

Jim and Joan Gardner
Torbert Produce, Inc.
Sam P. Alterman Family
Foundations, Inc
Nook Industries, Inc.
R. B. Galloway

Heavenly Angel
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A. J. Welch, Jr.

Arch Angel
(\$250-\$499)

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Tony & Laura Abbott
Deborah and Paul Carroll
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Linda & Mark Ryan
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Nancy Belleman

Cherub
(Up to \$99)

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Darlene & Dwain Buer
Ellen & Patrick Burke
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Bill and Judy Castle
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