



# The *Gathered View*

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

## President's Message

By Barb Dorn

It's hard to believe it is already the holiday season. It can be a time of fun and excitement, especially for little ones. It can also be a time of upset schedules, extra food, and a little irritability for all of us. In our home, I try to keep Thanksgiving simple and reserve it for our immediate family—Don, Tony, Tyler and I. Both my family and my husband's family live out of town, so we travel for most holidays. Thanksgiving is our holiday to stay home.

This year, however, will be different. My father-in-law's health has been deteriorating, so this year we will be attending a big family Thanksgiving celebration. We will still be eating later in the day, which allows for only eating one big meal that day. (This is a strategy I've used for years.) We will need to discuss what "choices" Tony will have for food. He always wants some of everything. There is never a shortage for food. The stimulation of the large number of people in addition to all the food can often lead to an overly stimulating situation. I plan to arrive late and leave early, another strategy I have found to work.

At Christmas, we once again take to the road but we try to keep the day as structured as possible. Tony likes to obsess about what is in the packages so I've convinced family members to open presents first. It helps to keep us sane, and then it provides Tony with some things to do while the rest of us make the preparations to eat.

On behalf of all the officers, board of directors, and staff of PWSA (USA), I want to wish all of you a happy holiday season.

I would also like to thank all of you who have sent me your ideas to raise funds for PWSA (USA). Over the next few months, we will be evaluating your ideas as well as attempting to write some grants.

Another big way you can help our organization is to donate to our Angel Fund. This fund-raising event helps us to raise much of the funds used to keep our 800 number staffed and going. We also use these funds to cover many of our day-to-day expenses. Please remember our organization at this time of giving. My best friend and I no longer give each other a gift, but instead, we donate to our favorite charity. She donates to PWSA and I donate to PWSA. Our gifts go a long way to helping those near and dear to our hearts. Your gift, your generosity will be much appreciated.

I want to briefly update you on a few business items. This past summer at the conference in Ohio, our board shared their concerns about the future of having an annual national conference. These concerns were based on financial constraints as well as the reluctance of chapters to host it. The board met briefly after the conference and voted to support this as an annual event. This decision was made after hearing many of your requests to continue the conference in this way.

At this time, however, the conference for the year 2000 is not confirmed. We

may have a chapter bid, but the final decision has not been made. The Prader-Willi California Foundation continues to work very hard at making the final preparations for the 1999 conference. Minnesota is also moving forward for the International PWS Organisation conference in 2001. We want to thank everyone for the hard work and dedication. Until next time ... TAKE CARE!!



**Meet some of PWSA's  
very special Angels:**

**Our office volunteers**  
(pages 2 and 3)

**Family fund-raisers**  
(page 4)

**The creator of our new  
publicity poster on PWS**  
(page 12)

**Recent contributors**  
(pages 15 and 16)

**Won't YOU join our Angel Band?**



## *inside*

Book Review: *For the Love of Christie* —  
on "Acquired" PWS ..... 5  
1998 Scientific Highlights ..... 6  
Mending at the Broken Places ..... 8

1999 Awareness Week Plans ..... 9  
Sibling View: Humility and Strength ..... 10  
Jody's Success, E-mail Pen Pals ..... 11  
PWSA's New Poster ..... 13



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## Executive Director's View

# Our Angels of Mercy

## The Volunteers at PWSA (USA)

By Janalee Heinemann

I have always felt that a person is at their best and purest when they are doing volunteer work, and I was raised on Hillary's philosophy that, "It takes a village." So, it is not surprising that my career as a social worker began with volunteer work, or that I continue to do volunteer work. In spite of all of this being my norm, I continue to be delighted, touched, and amazed at the wonderful people who have walked into our lives at PWSA (USA). Let me describe just a few of our Sarasota/Siesta Key "angels of mercy."

**"Aunt Esther" Langolis** — a retired teacher originally from Cleveland, Ohio, is 90 years old but comes to the office every Thursday for the entire day to label brochures, stuff envelopes, etc. We have had thousands and thousands of brochures to re-label since the move, and we don't want any to go out with the wrong address. If we had kept count of how many she has done, Aunt Esther could probably go into the Guinness Book of World Records!

**Irving Nathanson** — 82 years old and also originally from Cleveland, Ohio. (A positive commentary on Midwestern ethics!) Irving's career was with the Cleveland Orchestra. He also volunteers every Thursday and does a variety of tasks.

**Ann Durell** — a recent retiree who volunteers on Tuesday or Thursday mornings. On those mornings, you might get Ann's cheerful voice on the phone. Ann also has been with us since the office opened here over a year ago. She is very committed to our cause and does a variety of jobs. Ann has a wonderful daughter, Edye, who is paraplegic due to an accident. Edye has done volunteer work for me in the past.

**Norma Rupe** — my dearest volunteer when I worked at St Louis Children's Hospital has followed me to Siesta Key. Her young grandson was one of my favorite oncology patients. Unfortunately, his mother—Norma's daughter—was killed in an auto accident. As with Ann, her own life circumstances are part of the reason Norma has such a heart for our families. Norma puts so many hours in at the office that sometimes we have to "kick her out" — for her own good! Norma is especially committed to our new Bereavement Follow-up Program.

**Jill Battaglia** — a bright young college student who is paraplegic from a gymnastic accident, volunteered half a day each week last summer for PWSA. Jill is a delight to be around, and we hope to get her back next summer.

(Continued on next page)

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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 directors of PWSA (USA). *The Gathered View* welcomes articles, letters, personal stories and photographs, and news of interest to those concerned with Prader-Willi syndrome.

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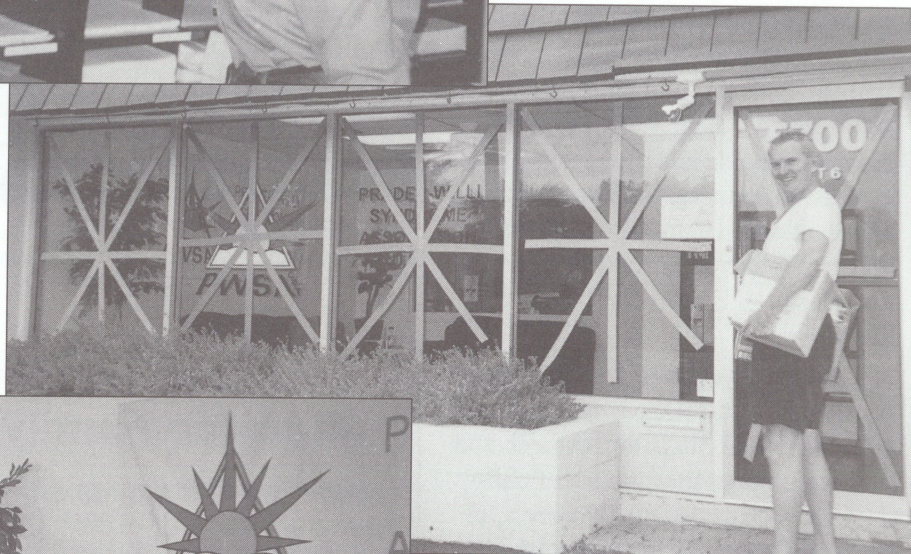
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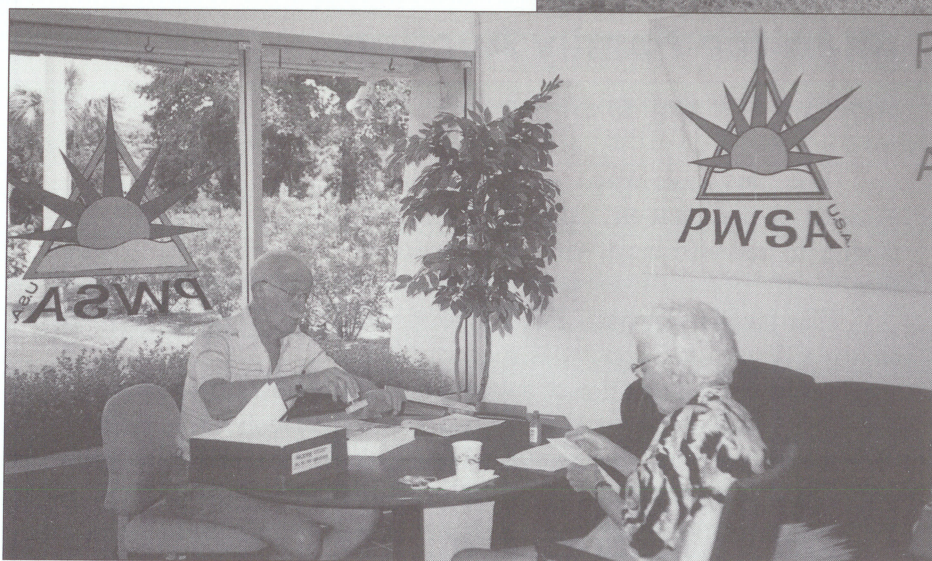




PWSA national office volunteers include Ann Durell and Norma Rupe (filling information requests, above), Bob Cumiskey (unpacking after Hurricane Georges, right), and Irving Nathanson and Esther Langolis (preparing a mailing, below).



ing where we would get the time and energy to get them all unpacked and reorganized before we hosted the Florida state chapter meeting the next weekend. Suddenly, we got a call from a stranger who said he heard we needed help. An hour later, a handsome young man walked in and, for the rest of the week, did everything from reorganizing boxes of files to changing our light bulbs and fixing the vacuum cleaner. As mysteriously as he had appeared, Joe disappeared — leaving us to always wonder who really sent him.



Although these are most of our regular volunteers (excluding my husband, Al), there have been many more who have been here for us when we needed them, and many parents from around the nation who have been on committees or done special projects for us in the last year. Each and every one is special and deserves our deepest thanks. What is even more special about most of those mentioned above is that they have no vested interest in Prader-Willi syndrome.

We don't have fancy volunteer dinners, and they get no community recognition. Our volunteers do what they do simply because they care.

I read somewhere that "Our character is what we do when we think no one is looking." It is a privilege to know so many people of such generous character.

## Angels of Mercy—Continued

**Mike Mancheno** — a local teenager who has PWS, has begun to come by the office at times to do volunteer work.

**Bob Cumiskey** — our Irish friend, began volunteering for us even before the office moved to Florida. Bob and his daughter, Carolyn, did pre-conference volunteer work for Orlando, and over the

last year he has played a variety of roles from working on fund development to envelope stuffing.

**Joe Ferguson** — our real-life "angel" who miraculously appeared the day we came back to the office after the hurricane evacuation. Brenda and I were sitting on the floor, staring at the dozens of boxes we had evacuated and wonder-



## NY Fundraiser Was the Start of Something Big

*New York Mother Will Head Up Next PWSA National Awareness Event*

Six years ago, Jessika Dickinson was born; and three years ago her parents, Tom and Jeannie Dickinson of Tonawanda, New York (a suburb of Buffalo), received the diagnosis: Jessika has Prader-Willi syndrome.

Jeannie says first came self pity, followed by pity for Jessika. Then a determination to do something for the cause replaced these feelings. She started speaking about PWS at high schools, colleges, and the University of Buffalo Medical School by contacting everyone she could think of—professors, principals, friends, etc. In a presentation lasting about an hour and a half, she talks about the syndrome, shows a video, and answers questions.

About a year ago the idea was born for a fund-raiser, a special event to raise needed funds for research and provide support for families of children with the syndrome. However, at that time Jeannie was pregnant with their second child, a healthy little girl named Fari who is now eight months old. So the project was postponed until this year.

On November 8, the Dickinsons' fund-raiser for PWSA (USA) was held at the Knights of Columbus in Tonawanda, drawing a crowd of 260 people, both adults and children. For a \$20 donation, participants enjoyed the antics of a clown, live music, three big-screen TVs for the Bills and Jets game, and a Chinese auction with a 50/50 split. Over 200 donated prizes were raffled off, and an open bar and catered food added to the festivities. After the bills were paid, a grand total of \$1,700 was donated to PWSA (USA).

Jeannie plans to make this an annual event and is already calculating how to make a greater profit next year. Not only did PWSA benefit financially from the November fund-raiser, but Jeannie has accepted an invitation to share her enthusiasm and serve as our national chairperson for the 1999 PWS Awareness Week! (See page 5.) We will be hearing lots more from Jeannie as she makes plans for this important PWSA event.

—Lota Mitchell



Jeannie Dickinson, PWSA's 1999 Awareness Week chairperson, with her daughter Jessika, age 6.

### All-in-the-Family Auction

*Here's a fun way to support PWSA ...*

"Roo" and Susie Wood of Easton, Maryland, e-mailed us to suggest an "easy way for all PWSA families to lend a financial hand to the organization."

"Our families, as most, gather together for the holidays. A few years ago it was suggested that we, as a family, begin a tradition of supporting a charity or organization. As a result the annual "Holiday Auction" was born. The premise is simple and has provided our family with hours of entertainment. Every family member is asked to bring an "auction item" to the event. Ours takes place every Thanksgiving. The items can be anything from garage sale treasures to home-made crafts, collectibles, etc.—Imagination is the key.

"We have one particular piece that makes a comeback every year. We are still not quite sure what it is, but we always find a buyer. Choose an auctioneer—there is one in every family—and let the games begin. Whether you raise \$20, \$100, \$200 or more, one thing is certain, your gift will be appreciated. Our family has chosen PWSA-USA as our recipient this year, and hopefully for many years to come.

"Good luck with *your* auction!"

*Editor's Note: Roo and Susie are the parents of a 10-month-old son with PWS, "Peter."*





# For the Love of Christie:

## A Mother's Story About "Acquired" Prader-Willi Syndrome

A book review and comment by Janalee Heinemann

Having been the mother of a child with Prader-Willi syndrome at the same time I was an oncology social worker, I have been aware of "acquired PWS" for some time. I had a couple of patients who became very "PWS-like" after their hypothalamus was damaged due to surgery to remove a brain tumor. In my current position as executive director of PWSA, I

have heard from many parents who are now struggling with the main problems related to PWS due to their child having a brain tumor or other damage to the hypothalamic portion of the brain. Reading *For the Love of Christie*, though, is the first time I have been in the home and heart of a family dealing with "acquired PWS."

Christie's mother, Loraine Zarr, has written a very beautiful and poignant book about their struggles, their strength, and their love. I was touched by and fascinated with their story. Christie could not have been more PWS-like if she were born with the syndrome—and yet Loraine was told by several doctors that, "There is no such thing as PWS-like or acquired PWS." I strongly disagree, and so would most of the doctors who have had a significant amount of experience with PWS. One of my goals is to encourage more research on this issue and for PWSA (USA) to provide more of a support system for these families. If they can't turn to us, where can they turn?

Loraine has agreed to allow us to advertise and sell her book through the association. I know that any family that is dealing with acquired PWS, or which has a teen or adult with PWS, would appreciate this book. Also, any parent who has lost a child to PWS would relate to this family's struggle.

Loraine is now interested in getting involved with PWSA. I have often found that some of the most compassionate and courageous families I have dealt with are bereaved parents. I once asked the father who founded Parents of Murdered Children in St. Louis how the death of his son changed him. He said, "Before my son's death, I did all I could to avoid suffering and pain. Now I walk with open arms toward those who are suffering." We want to thank Loraine for giving us this very personal glimpse into her family's life, and I want her and all families dealing with acquired PWS to know that our arms are open to them.

### To order the book

*For the Love of Christie* is now available exclusively through PWSA (USA). An order form for this and other new PWSA products appears on page 14. The price is \$12.00 plus \$4.00 shipping and handling to U.S. and Canada. (See the order form for international rates.)

## Grandparents Needed

Grandparents of children with Prader-Willi syndrome often play a very important role in their lives, but they also often go unsupported and their interest and talents are underutilized. I would like to see us work towards the following in the next year:

- 1) Grandparents writing articles for *The Gathered View* on what it is like to be the grandparent of a child with PWS and explaining their issues.
- 2) Create a team of grandparents who agree to follow the conference year-to-year and work the on-site registration. This would relieve the state host committee members and allow them to attend some of the sessions they've worked so hard to plan.
- 3) Provide a special reception for grandparents at each conference and include a special sharing session or panel that deals with issues and feelings of grandparents.
- 4) Initiate a special committee of grandparents to assist us with awareness and fundraising.
- 5) Initiate a grandparents support network.

Please call or write me if you have ideas, time, or talent to share.

— Janalee

You are the grandparents who keep an empty cookie jar out of love  
And wish you could ease the pain for your child and grandchild.

Some things you cannot change,  
But you can make a difference.

Put your hand in ours,  
And together we can provide the strength and resources

To create a brighter future  
For all grandchildren  
Who cannot have that cookie

...Out of love.



# 1998 Science Highlights from IPWSO

Reprinted from *Wavelength*, the newsletter of the International Prader-Willi Syndrome Organisation (IPWSO)

## Endocrinology

### Growth Hormone

The news on growth hormone treatment in PWS received great attention [at the IPWSO conference in Italy]. Reports from Lindgren et al (Stockholm, Sweden), Whitman and Myers et al (St. Louis, Missouri), and Grugni et al (Milan, Italy) all suggested that growth hormone deficiency is a common finding in patients with PWS. Furthermore, two studies, by Lindgren et al and Whitman and Myers, reported on the effects of growth hormone on linear growth and body composition. Both demonstrated a remarkable increase in growth velocity during the first year of treatment, even greater than that generally seen during treatment of children with isolated growth hormone deficiency. There was a dramatic change in body composition, with a decrease of the body fat from about 40 percent to 30 percent during the first year of treatment. The American group could also show that after one year of treatment the children increased their running speed and the number of sit-ups performed, suggesting that muscle strength was also improved. This was corroborated by an increase in muscle volume, shown in the Scandinavian trial. A more surprising finding was that Lindgren et al could demonstrate that growth hormone treatment markedly increased ventilation and central inspiratory drive in PWS children.

In the poster session, Sippillä et al reported the Finnish experience with growth hormone treatment in PWS. They also found that growth hormone secretion during baseline conditions was low, with a poor response to provocation tests. Similar to the other studies, height increased by 1.2 SD [standard deviations] scores during the first year of treatment, while body fat decreased from 45 percent to 36 percent.

Ringrose et al studied possible behavioral changes of 28 children who were treated with growth hormone. Special

attention was paid to the possible increase in temper tantrums. This was not the case. Thus, the general impression from the reports on growth hormone in PWS was that it markedly increases growth rate, reduces body fat, and increases muscle strength/volume and function. However, it should be stressed that these reports generally cover only one or two years of treatment. Possible adverse events during continued treatment should be looked for, and therefore it was suggested that growth hormone treatment should continue to be done within the frames of clinical studies, to make long-term follow-up possible.

### Diabetes

In a retrospective study, Becciara et al studied the prevalence of diabetes and impaired glucose tolerance in a total of 72 patients with PWS. They noted non-insulin dependent diabetes mellitus (NIDDM) in approximately 10 percent of the patients, while another 14 percent had impaired glucose tolerance. The age of the patients did not influence the risk of NIDDM or impaired glucose tolerance. However, there was a significant correlation between body mass index and occurrence of impaired glucose metabolism: the more obese the patients were, the higher the risk for diabetes or impaired glucose tolerance.

## Metabolism

The resting metabolic rate has been reported to be lower in PWS than in normal or obese controls. Brains et al demonstrated clearly that the reduction in metabolic rate seen in PWS can be explained by the altered ratio between fat and lean body mass. If the metabolic rate was calculated relative to lean body mass, it was actually higher in PWS than in the obese controls. The same group (Golds et al) discovered that in PWS, there was a selective reduction in visceral fat rather than subcutaneous fat. This is in contrast to what would be expected, considering the probable growth hormone deficiency, the hypogonadism, and the reduced physical activity (that would favor disposition of visceral fat). The authors suggest that there may be CNS [central nervous system] control of regional fat deposition.

Finally, several authors reported that leptin concentrations in blood are increased rather than decreased in PWS patients and no different than what are found in other obese subjects.

Professor Martin Ritzén  
Paediatric Endocrinology  
Karolinska Hospital  
Stockholm, Sweden

(Continued on next page)

## Unusual Symptoms

There was an open "bulletin board" session at the IPWSO conference to discuss unusual symptoms in PWS. Some parents raised issues regarding temperature regulation and reaction to warm weather; several others reported their children's interest in or fear of particular noises. Louise Greenswag (University of Iowa) reported on a case of psychotic symptoms that appeared to be related to excessive water drinking, and other similar cases were mentioned, leading to a proposed study of how much people with PWS drink. Three cases of urinary reflux were reported, and because of the potential damage to the kidneys, it was recommended that urinary infections should be considered as a possibility when a child has abdominal pain or fever for otherwise unknown reason.

Dr. Susanne Blichfeldt of Denmark, scientific advisor to IPWSO and co-editor of *Wavelength*, urges people to write to *Wavelength* about unusual symptoms in PWS: "There might be symptoms that are more common than we know of. What YOU report could happen to be of great importance to our knowledge of PWS to the benefit of children and adults with the syndrome." Dr. Blichfeldt can be reached by e-mail at sblichfeldt@dadlnet.dk or by fax at +45 5826 4220 or +45 4637 3203.



## Clinical, Medical Findings

One study of the clinical findings in 58 patients with PWS confirmed by molecular testing indicated that fully half of all patients either lacked one or more of the major criteria or had some extra findings. Some patients were tall, some had normal intelligence, normal puberty, or lack of hypotonia in infancy. Others had large or small head size or unexpected malformations or medical problems. Patients who were black were more likely than white patients to have tall stature and normal size hands and feet, and to lack the typical facial appearance.

Another study done in the four Scandinavian studies showed only small differences in medical problems and management among the different countries. A few studies mentioned small differences between patients with deletion and uniparental disomy as causes of PWS, most of which suggested that disomy was harder to diagnose and the patients were less likely to have lethargy.

Recent observation suggests that there may be an increased incidence of death from acute illness in very young children with PWS, and a collaborative study was organized.

There was also information about medical problems in adults with PWS, which includes gastrointestinal problems including perforation of the stomach, hypertension, and osteoporosis, as well as significant skin and extremity problems such as edema, cellulitis, and phlebitis.

Finally, health care guidelines for people of all ages with PWS developed by the Scientific Advisory Board of PWSA (USA) were presented.

*Suzanne B. Cassidy, M.D.*  
Professor of Genetics and Pediatrics  
Case Western Reserve University  
Chair, PWSA (USA) Scientific Advisory Board

*Editor's Note: The International Prader-Willi Syndrome Organisation (IPWSO) publishes its newsletter, Wavelength, twice a year. The editors are Cindy Adams-Vining of New Zealand and Susanne Blichfeldt, M.D., of Denmark. The September issue included notes and photos from the May IPWSO conference and introductions of IPWSO officers and delegates. A photocopy of the 19-page IPWSO newsletter can be obtained from PWSA's national office for \$4.00, including mailing.*

## First Announcement

The 14th Annual Scientific Conference  
of the  
Prader-Willi Syndrome Association (USA)  
will be held

**Wednesday, July 7, 1999**

followed by PWSA's National Conference, July 8-10

**San Diego, California**

The 1999 PWSA Scientific Conference will feature concurrent sessions with emphasis on the following research areas:

Growth Hormone  
Medical and Genetics  
Behavior

**Watch PWSA's Web Site ([www.pwsausa.org](http://www.pwsausa.org)) for more details.**

Families are advised to alert their children's care providers to the dates of this year's conference. Please notify PWSA of any researchers who may wish to be added to our mailing list for the Scientific Day Call for Papers. Telephone 1-800-926-4797; FAX 941-312-0142; or E-mail [pwsausa@aol.com](mailto:pwsausa@aol.com).

## 1998 Ohio Conference Notes

### *PWSA's 13th Annual Scientific Conference*

Eighteen scientific papers were presented of the most recent research in this field. The meeting was well attended with both guests and speakers from many states and multiple countries.

The meeting was highlighted by the presentations of Martin E. Ritzén, M.D. Dr. Ritzén is director of Pediatric Endocrinology at the Karolinski Institute in Stockholm, Sweden, and has been one of the principal world investigators of the growth problems of children with PWS and the possible role of growth hormone in treating this condition. Dr. Ritzén presented summaries of his and his laboratories' past and current research, and he chaired the scientific session on growth hormone use in PWS.

Other presentations included reviews and updates on the most recent genetic and molecular studies of the genetic abnormalities being studied in both PWS and Angelman syndrome, data on the biochemistry and physiology of the appetite abnormalities of the PWS, recent research results on the behavior abnormalities and both presentations and observations of the use of various medications being used to assist with the behavior abnormalities of the PWS.

The meeting resulted in improving the opportunity for those scientists involved in the PWS to network and to share ideas on current therapies and the design of future research studies. For the first time, the meeting was granted the authority to give Continuing Medical Education Credits to the participants toward the AMA Physician Recognition Award.

*William Zipf, M.D.*  
1998 Scientific Day Co-chair  
Member, PWSA (USA) Scientific Advisory Board

*Editor's Note: This summary appeared in the Prader-Willi Voice, the newsletter of PWSA's Ohio chapter. Abstracts of the scientific presentations from the 1998 PWSA meeting are available on PWSA's Web site ([www.pwsausa.org](http://www.pwsausa.org)) or in booklet form from the national PWSA office (\$6 members/\$8 nonmembers).*



# Mending at the Broken Places

By Paul Robinson, Ph.D.

*Editor's Note: Dr. Robinson was the keynote speaker at the 1998 PWSA national conference in Columbus, Ohio. He speaks widely on living with mental retardation and developmental disabilities and managing associated family stresses.*

Ernest Hemingway wrote: "Life breaks us all. The strong mend at the broken places."

One of the greatest tragedies we can experience in life is when something bad happens to one of our children. Whether it be the death of a child, life-threatening illness, a chronic disorder (mental or physical), or the birth of a child with a disability, we are "broken." We hurt and we grieve. Emily Dickinson observes: "There is a pain so utter, it swallows being up." Healing at the broken place from "a pain so utter" is very difficult work. It takes a lifetime, and then perhaps only part of our hurt and sorrow are resolved. I know. I have been/am there. Like you, the reader, I, too, have known the sorrow and fear of having something awful happen to one of my children. My son survived cancer, and another is recovering from an addiction. Me? I *am* becoming stronger at the broken places.

When our oldest child was diagnosed with cancer at age 15, my "healing at the broken places" work began. It continues to this day because life constantly sends us experiences that break us or, at the least, cause us to bend. Each and every day I work on facing life's challenges and accepting life "as is." Frankly, some days are easier than others; but I find that if I do my healing work, my day goes much better.

That healing work involves fine-tuning my mind and heart, i.e., doing the necessary psychological and spiritual work. I hope what I will share with you will assist you in your healing work.

**Absolutely essential to mending or recovering is finding the courage to face what is.** It is a mistake to run from

the reality that your child is not the normal, healthy baby that you wanted. But to run is natural, too. It was a very sad day in your life when you learned that your child had PWS; but face it you must. Then, and only then, can we begin our mending work.

It is very hard at times to accept life "as is" or as it is. Each of us has our expectations about how life should be. One of the more basic "shoulds" is that our children should be born and grow up "healthy and normal," get married, be successful, and give us grandchildren.



**As difficult as it is, we must learn to surrender all expectations of life.** Resisting life as it is only compounds our problems and delays our recovery. We must accept that life is neither fair nor unfair. Life just is. Some will have normal, healthy children. Some will not. That is the way life is.

Just as we cannot expect life to be fair, we cannot expect God to change how life is for us. We need to develop a faith "big enough for life," a faith that can embrace life as is without demanding it be otherwise or expecting God to change what is.

Yet, at the same time, we must also accept those persistent and disturbing thoughts and emotions that occur when something tragic happens to our child. It is quite natural and normal, too, I must

add, to feel cheated, angry—even angry at God—depressed, frustrated, resentful, and the like.

Moreover, it is natural and normal to have thoughts that are disturbing. The "death wish," for example, is perhaps more common than many realize. The "escape wish," i.e., to run away from all your problems, is quite common as well. Common also is to think that what has happened to your child and you is not fair.

The point is: **mending requires that we accept our thoughts and feelings or mood states for what they are.** To view them as normal, even healthy, reactions to tragedies is healing in itself. To have such thoughts and feelings can be disturbing enough. When we feel guilty or abnormal when we think or feel the way we do, we compound our problems.

**Essential to mending is also the absolute necessity of sharing our thoughts and feelings with someone else.** To keep persistent and disturbing thoughts and feelings to ourselves is to become "emotionally constipated." Emotional constipation hurts just like physical constipation does. Not only does it hurt, but it prevents mending. To recover, we must release those strong emotions laid down at the time we first became aware of the tragic event.

It hurts to expose ourselves to them, but not to do so and not to release them causes the "pain so utter" to persist and remain intense the rest of our lives. They must be visited and they must be shared if we are to mend.

We must find someone we feel absolutely safe with. To share such private thoughts and to experience pain so deep demands someone who will listen non-judgmentally and who will listen with a compassionate heart. It is imperative that we feel safe, free from condemnation and advice. Otherwise, we will keep it all bottled up, which takes a serious toll on us.

**To that end, we must give ourselves permission to grieve. We must grieve in**



(Continued from page 8)

**our own way and time.** There is no set pattern or time that is right for everyone. Grieving is as individualistic as fingerprints. Do not let anyone tell you how you should grieve or for how long. Find what works for you and do it. You may have to experiment to find the best way for you. What is important is that you develop your own prescription for grieving. Borrow from others only if it works for you.

**Use your support system for all the practical things you need help doing as well as for emotional and spiritual support.** Life is a lot easier and tragedies are easier to bear if we allow others to help and support us. Surround yourself with folks who understand, care, and are willing to put their caring and love into action. Interdependence is not the same as dependency or co-dependency.

**Nurture yourself and your marriage.** You will need all the strength you can muster and a loving, supportive spouse can make the difference in whether you find the strength to meet another day. Too often, sometimes by necessity, the affected child consumes all our time and energy. We neglect, again sometimes by necessity, others and, of course, ourselves.

It is a delicate and difficult balancing act taking care of others while we struggle to take care of ourselves. We can become too centered on the affected child. None of us are superheroes. **We cannot expect that we always give our best to our child. No one else always gets our best.** Neither can your child. If caring for your child leaves you absolutely exhausted at day's end, please, for your sake and the sake of others, let others help you.

Sure, it is important to do the best you can for your child. They do have special needs and require special attention. But you do not owe that child your life. You are not required to sacrifice yourself or your marriage or even the well-being of your other children for that child. Some sacrifice will be required, to be sure, but do not make it a 24-hour, seven-day-a-week, whole lifetime piece of work. That is too high a price to pay.

In conclusion, I want to say that you have been dealt a difficult hand. It will be very hard to accept it, at least initially.

## PWS Awareness Week Goes International in 1999

The first-ever International Prader-Willi Syndrome Awareness Week is planned for **April 24th through May 2, 1999**. Officials from PWSA-United Kingdom (UK) and PWSA (USA) agreed to coordinate national awareness events this spring and are encouraging other countries to plan public relations events during the same week.

This year's theme will be "Keeping a Balance," which demonstrates what managing PWS is all about:

- ◆ Keeping weight in balance
- ◆ Keeping coordination in balance
- ◆ Keeping emotions in balance
- ◆ Keeping family needs in balance
- ◆ Keeping interpersonal skills in balance.

*The 1999 Awareness Week has three main goals:*

1. To make people more aware of PWS and the fact that it is not just an eating disorder
2. To provide a focus for fundraising events
3. To make PWSA known as a caring, active, supportive organization

We are very fortunate to have Jeannie Dickinson of New York as chairperson for this year's U.S. activities. (See story, page 4.)

We've put together a work group to help coordinate and facilitate support to chapters and are in the process of pulling together needed materials and ideas to promote awareness. Information and promotion packets, including press releases and fund-raising ideas, will be sent to PWSA chapters in the months ahead.

***Let's make this year's Awareness Week the most successful yet!***

—Barb Dorn  
President, PWSA (USA)



You will feel a "pain so utter" that it consumes you. You will mend, however.

You will find a way to do what you questioned you could do. You will need the love and support of others. Don't be afraid to ask for that.

You will need to be kind to yourself, too. It will even be healthy at times to let yourself feel sorry for yourself. Grieve in your own way and time.

Believe in yourself. See the good in life, too. Take care, and may God bless.



## The Sibling View

*Cherie Sakschewski, from Paradise, California, writes: "I thought it would be a blessing to you to read an English assignment my 17-year-old daughter wrote about her 14-year-old brother with PWS ... I, of course, am very proud and cried when I read it." (Thank you, Cherie and Lynae, for sharing this essay with us.)*

# Humility and Strength

by Lynae Sakschewski

I get to school early, hoping to get some studying done before first period. On my way to the library, I hear my brother's voice coming from the special education classroom. I decide to listen to what is going on, since he recently started high school, and I am trying to look out for him.

"I'm not allowed to eat that. I'm on a diet," he says with determination. "C'mon, Lance. It's only one. What's your problem?" another voice chimes in. "Yeah dude, I know you love candy bars. Don't you want it?" says another boy. I begin to get very angry. Why are these boys doing this to him? They know he can't have candy bars. I hate the way they pretend to be his friends.

"No! I'm on a diet! You're my friends. Don't you know about my diet?" my brother says in desperation. I am proud of his will power. They continue to press him and tease him. "I can't!" he says again. I listen a little bit longer, and I begin to feel sick. I think of ways to rescue Lance without embarrassing him. Everything I think of seems wrong. Finally I run to the soda machine and buy a diet soda. Just as I am returning, I see Lance take the candy and begin to open it. I am not angry with him because I know he can't help it. These boys are using Lance's vulnerability to entertain themselves.

"Hey buddy! Sissy bought you a diet soda! You know that candy is not part of your diet. Give it back, okay?" He jerks his head toward me, startled and ashamed. I give him a reassuring smile, and this time his eyes fill with love as he gives the candy back. I place my arm in his and lead him away from the crowd. Although I am still angry, I am quite satisfied with the way the situa-

tion turned out. I know that Lance is happy, and I know that those freshman boys are embarrassed that I caught them being immature. Still, what is going to happen next time, when I'm not there to protect him?

This is the kind of predicament that I find myself in almost daily, when dealing with Lance's syndrome. He was born with Prader-Willi syndrome, and it affects his behavior, his capability of learning, and his diet. In order for him to be healthy, he has to eat low fat and low calorie foods, but he constantly wants to eat more. His brain doesn't function the same as a normal person's brain does. He talks funny, and he doesn't understand a lot of things. Sometimes it takes a great deal of energy and patience to be kind to him.

But with Lance's inabilities comes a humble and refined spirit. In the 14 years Lance has been my brother, I have come to realize that there is much to be learned from the weak. Lance has had to struggle with his syndrome his whole life, and these struggles have produced in him a kind of humble strength which would not be there had



Lynae and her brother Lance Sakschewski—in the early years (left) and on a recent winter outing (below).



"There is something very special in this sibling relationship that is beyond earthly description," says their mom, Cherie.

he been born normal. Instead of becoming a bitter person, Lance has learned how to forgive and forget quickly. I envy that! When I compare myself to him, I don't see a fortunate normal girl and an unfortunate retarded boy. I see his strong character and my weak one. I see his perseverance and my lack of discipline. I see a refined spirit and a lax spirit.

With his limited understanding comes an innocence that protects his heart. How many times have I wished that I didn't understand a dirty joke, or a person's rude comment about me? No matter how difficult or inconvenient it may be to love Lance, I will always continue to do my best to do so, because love is all he needs to be content. He doesn't ask for much in return for a genuine friendship. Besides, I still have a lot to learn from him!



# Thoughts on Being a Person with Prader-Willi Syndrome

By Jody Starr Zacher

When I was 5 or 6 years old I learned that I had something called Prader-Willi syndrome. When I got a bit older I wanted to find out about this and what it meant for me. I frequently got food when no one was looking. I gained lots of weight and although I lost some from time to time, it always came back.

Getting any nice things to wear has been a very frustrating experience. Having this syndrome has made me feel both angry and frustrated at the same time. Learning to manage myself is a full-time thing and it often doesn't go well. There are many days when I do very well at this management thing.

When I was almost out of my teen years my parents enrolled me at the Pittsburgh [Rehabilitation] Institute where I learned about diet, exercise, and how to lose some weight. I was there more than once!

Early in 1994 my parents enrolled me at Martha Lloyd Community Services, a residential facility where I am today. During this time I have lost almost 35 pounds. I don't mind saying that I am currently at 128 pounds! My goal is to reach 125 pounds, hopefully in the near future.



Jody before her weight loss (top), and 35 pounds lighter (right).

*(Editor's Note: Marlene von Voigtlander, program specialist at Martha Lloyd Community Services in Troy, Pennsylvania, assisted Jody in writing this essay earlier in the year. She later informed us that Jody not only reached her goal weight goal but continued to lose another 10 pounds. She is now a slim 115 pounds!!—Way to go, Jody!)*

## Wanted: E-mail PEN PALS



*(To get on our next list, send e-mail to PWSAUSA@aol.com)*

### Alex, 15—

ckroth@communityonline.net  
I live in California and go to high school. I love animals and art. I would really like to have a pen pal about my own age that also has Prader-Willi.

### Andraea, 22—

andraea@onslowonline.net  
I live in North Carolina at home. I work two days a week with severely handicapped children. I like to play Super Nintendo, love to dance, listen to CDs, write letters, and playing on the computer. I really would love to have some pen pals that had PWS.

### Christine, 21

christinedicosimo@netscape.net  
I love working with children, and I am going to ballet class. I want to be your pen pal and look forward to hearing from you! What is your name? Where do you live? How old are you? Do you have pets? I have a dog and a fish.

### Lisa, 22—

Lisalawrnc@aol.com  
I have blond hair and blue eyes. I love animals so I have 5 cats and 2 dogs + 3 horses. Plus I love to do crafts.

### Loretta, 30—

lorettanoll@enter.net  
I have a variety of hobbies: I enjoy counted cross stitch, crafts, horseback riding, swimming, my computer, audio books, I like going on trips to different places, I love animals and going to the movies etc. I would like to find out more about you and sure would love to be your pen pal. Please write to me and tell me about yourself as well and then we can keep in touch.

### Michael, 21—

Tippypm@aol.com  
I am in Special Olympics. I just appeared on the Sally Jesse Raphael show on Prader-Willi. I like going out places like to mall and movies, camping, fishing, dating girls with Prader-Willi and without. My hobbies are hot wheel school busses and bells.

### Michael Paul, 14—

raskew@rcs.rome.ga.us  
I love fishing, drawing, scouting and camping out, music and dancing, oh, yea, school!

### Phillip, 28—

philkeen@mail.swbell.net  
I am greatly interested in computers and church. I someday want to own my own computer business and ministry. My website is <http://home.swbell.net/philkeen/> There you will find out a ton of information about myself. I frequently attend and am very active at Lakewood Church.

### Rebecca, 18—

SanGin2@aol.com  
Likes fishing, hunting, puzzle books, computer games, reading and swimming.



# Tales of a Poster Child ... and a Poster

*PWSA's brand-new publicity poster, reproduced on page 13 in black and white, comes with quite a story. Its designer, Bob Hartnett, is the parent of a toddler with PWS and a graphic artist by trade. As he explains below, there were a number of adventures involved in making this project a reality. Through his dedication to the cause, PWSA now has a dramatic visual tool for spreading the word about Prader-Willi syndrome—all at virtually no cost to the association. (See page 14 to order copies of the full-size poster.)*

By Bob Hartnett

**O**n February 17th of 1997, our second son, Callaghan McAuley Hartnett, came into this world by emergency C-section. Despite the fact that he was six weeks early, he was a fighter. The NICU nurses couldn't get over his full head of blonde hair. Within five days, Callaghan had started speech and occupational therapies, and at just nine days, our geneticist came into the NICU nursery and told us that our precious little 4 lb. 2 oz. baby boy had PWS ... and thus the journey began.

There were endless hours of feeding, therapists and nurses parading in and out of our house, and of course all of the waiting in doctors' offices; sometimes not sure exactly why we were there, since often we knew more about PWS than they did. (Does any of this sound familiar?) It was at this time that we realized that awareness of PWS is critical, and we made a vow to help with this awareness in any way that we could.

In May of 1998, Callaghan was a poster child for the Springfield and Central Illinois area Children's Miracle Network Telethon. This was just the beginning, and yes, it officially confirmed what we had been saying all along, that he was our little "Miracle Child." He even received a hat proclaiming him to be a "Miracle Kid"; now it was official!

In July of 1998, my wife, Regina, went to our first national PWSA (USA) conference in Columbus, Ohio. At the conference, they asked if there was anyone who could help with graphics and desktop publishing. Remembering our vow to help with awareness in any way that we could, my wife graciously volunteered my services, since that is what I do for a living. I am a graphic designer for Bunn-O-Matic Corporation in Springfield, Illinois. Shortly after the confer-

ence, I was contacted by Lota Mitchell, the chair of the Publications Committee and asked to help with some projects, one of them being a new awareness poster. Janalee then also contacted me, and the three of us put our heads together and formulated a plan of attack. It all went off without a hitch ... almost!

I received pictures from Janalee at the national headquarters, and from various parents around the country. I chose a sampling as best as I could to show the "Many Faces of PWS." We wanted to show both boys and girls, different races, different ages, etc. The poster was just about finalized, but I needed one more little girl to make the poster complete. Our answer came when Doctor and Caroline Loker (Michigan chapter presidents) agreed to e-mail us a picture of their beautiful little daughter, Anna. After several attempts, the file attachment finally came across, and after about three hours of trying, I was successful in unscrambling the picture. I now had what I considered to be a completed poster.

A friend of mine who was just starting a new business in large format color output named Pixel Perfect agreed to loan me the equipment to do the poster at home, since I do not have one, and he agreed to do full-size proofs for us at cost. My employer, which has a sister company in the wholesale grocery and paper industry, agreed to donate the paper for 5,000 posters, and a print vendor for my company, Bloomington Offset Process, Inc. (BOPI), agreed to donate the printing. Everything was falling into place. As I wrote all of the finished files to a CD, however, the entire computer crashed. It seems that the software for the CD writer that I was using from my work was no longer compatible with the up-

graded system software from my friend's computer. I had already mailed the pictures back to parents across the country and I had lost everything. Through a lot of prayer and effort, however, I was able to recover all of the photo files, and the logos, and all that I had to do was reset the type and re-lay out the poster. Not too bad a recovery from a total disaster, I thought. God was definitely on my side, as he has been from the beginning.

The posters are now done and are at the national headquarters in Sarasota.

As you can see in this issue, they are available for order. They have already been used in fund-raisers in New York (see page 4) and here in Springfield. They are being posted in doctors' offices and hospitals as fast as we can get them out, and I am confident that they will be a vital tool in fighting for the

awareness that we have been looking for.

As for Callaghan, of course he is in the poster ... the "Little Irish Prince." He is now on growth hormone and doing tremendously. He has come leaps and bounds in his short 22 months on this earth and has consistently broken all of the goals that the doctors, nurses, and therapists have set for him. Our church threw a fund-raiser recently to purchase us a computer at his therapists' request, and he is due shortly to begin using this to increase his communications skills. It is all just utterly amazing to us. This small child has brought friends and family together from all over the country. The amount of support that we have had, and the prayers that have been said from the beginning are just astronomical. Truly, God works his miracles through special little children, and he has given to us our greatest personal miracle thus far. He is smiling upon us, and we are eternally grateful!





# PRADER-WILLI SYNDROME

## Major Characteristics Include:

- Infantile Hypotonia (low muscle-tone)
- Infantile Failure-to-thrive (poor sucking ability)
- Insatiable Appetite
- Obesity (unless externally controlled)
- Developmental Delays
- Learning Disabilities
- Speech Delay / Poor Articulation
- Behavioral Problems
- Skin Picking
- Small Genitals / Incomplete Puberty
- Small Hands and Feet
- Short Stature (Improved using growth hormone)

Prader-Willi syndrome is a genetic abnormality caused by a deletion or disomy of the 15<sup>th</sup> chromosome or by parental imprinting. The characteristics listed above appear in varying severity in persons with Prader-Willi syndrome. This disorder occurs in all races with incidence estimated at 1:12,000 to 1:15,000 individuals. Now, genetic testing for early diagnosis is nearly 100% accurate and allows for the introduction of a continuous weight management program which helps to avoid life-threatening obesity. Studies with growth hormone have shown such results as increased stature and muscle

tone. Several of the Prader-Willi persons pictured here are involved with such programs and/or studies and have reached near-normal weight and stature. Appropriate educational planning is also benefited by early diagnosis. Awareness of Prader-Willi syndrome is critical, and both state and regional chapters as well as local parental support groups have been formed in many areas and are of great help to all involved. **Prader-Willi syndrome is lifelong and life-threatening, but it CAN be controlled.**

The Address of Our National Organization is:  
Prader-Willi Syndrome Association, USA

5700 Midnight Pass Road • Suite 6  
Sarasota • Florida • 34242  
Phone: (800) 926-4797 or (941) 312-0400 • Fax: (941) 312-0142  
www.pwsa-usa.org • E-mail: pwsa-usa@aol.com

For further information contact your nearest state or regional chapter, or your local representative at the address listed below.



Posters designed by Robert J.B. "Bob" Horvath, father of Catherine MacAulay Horvath - born 2/1/77 - diagnosed 2/26/87. 1996 © 1998 PWSA, USA

Poster printing donated by Washington Offset Process, Inc.

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# Order Form for New PWSA Publications and Products

Quantity:

## **The Early Years**

A collection of articles from *The Gathered View* of particular interest to parents with younger children. Includes stories and photos sent in by individual families, as well as articles on feeding, development, and medical issues in the early years of PWS.

**Price: \$5.00 Members/\$7.50 Nonmembers**

*Add shipping and handling from chart below.*

## **Audiotape and Guide for Teachers**

New, professionally produced audiotape about PWS specifically designed for teachers. The tape runs 27 minutes and comes with a chart of PWS-related issues and interventions for school staff.

**Price: \$5.00 Members/\$7.50 Nonmembers**

*Add shipping and handling from chart below.*

## **For the Love of Christie**

Book by Lorain Zarr about her daughter, Christie, who had "acquired" Prader-Willi syndrome. Christie was treated for a brain tumor and subsequently developed the classic symptoms of PWS. Moving story about the family's struggle with this outcome, leading up to Christie's death of obesity-related causes. 114 pages.

**Price: \$12.00**

*Add shipping and handling from chart below.*

## **PWSA Publicity Poster**

2' x 3' full-color poster, featuring photos of children and adults with PWS and listing major characteristics of the syndrome. Great tool for Awareness Week events!

**Price: \$5.00 each for 1-4 posters; \$4.00 each for 5-9; \$3.50 each for 10-24; \$2.50 each for 25 or more**

(Shipping and handling are included in poster prices.)

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Editor's Note: Due to lack of space, other recent donations, including contributing and patron membership renewals, will be listed in the next issue of *The Gathered View*.



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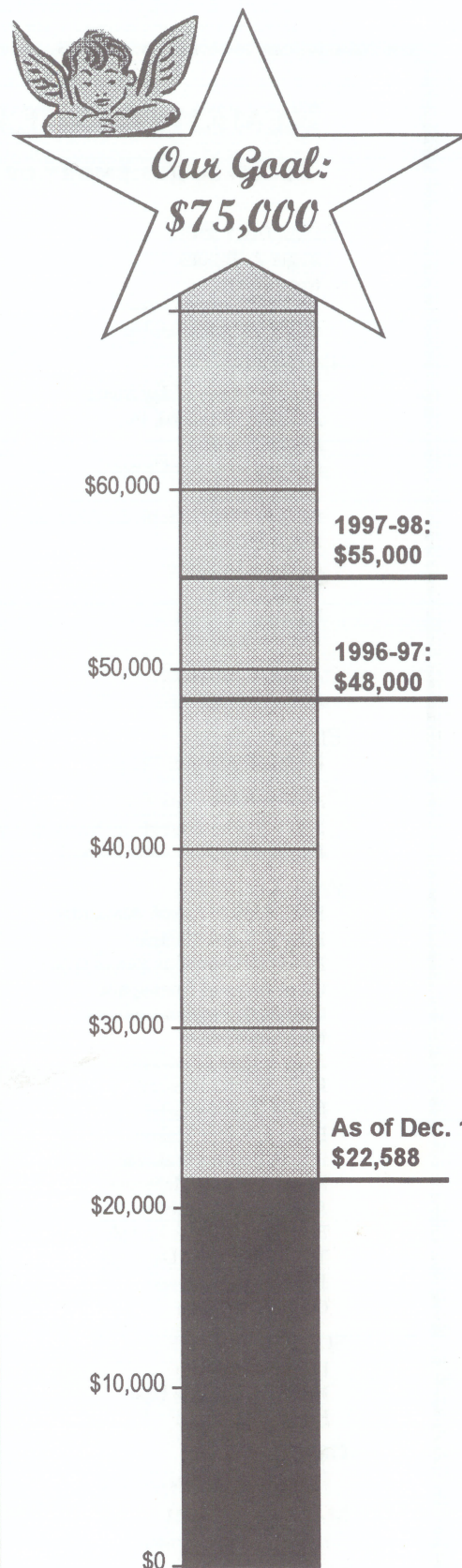
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Ralph & Margaret Reimer  
Ross R. Robbins  
James & Willie Ola Robinson  
Janet M. Schuman  
Shirley Small  
Millard & Leona Smith  
Beatrice Sturm  
Nancy Talbot  
Guy Tomasicchio  
Karen Trucios  
Linda Tull  
Arlene B. Turbes  
Powell & Joane Underwood  
Jay & Donna Kelly Vadl  
Kenny Vertor (*for his daughter, Larita*)  
Bengi Vezir oglu  
Lenora R. Watson  
Marilou Wett  
Wayne & Kathryn Whyte  
Peter & Kathleen Wyka  
John J. Yoncha



**Prader-Willi syndrome (PWS)** is a birth defect first identified in 1956 by Swiss doctors A. Prader, H. Willi, and A. Labhart. There are no known reasons for the genetic accident that causes this lifelong condition which affects appetite, growth, metabolism, cognitive functioning, and behavior. The Prader-Willi Syndrome Association (USA) was organized in 1975 to provide a resource for education and information about PWS and support for families and caregivers. PWSA (USA) is supported solely by memberships and tax-deductible contributions.

