

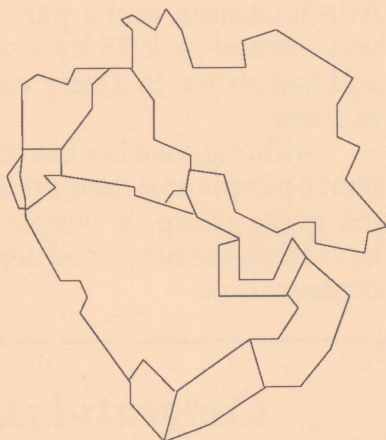
# *The Gathered View*

Newsletter of the  
Prader-Willi Syndrome Association

## *Starting the New Year with Good News!*

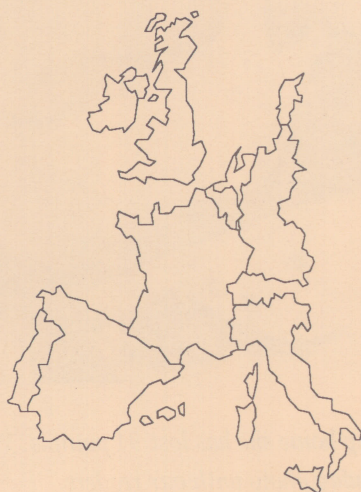
### **Good News from the Middle East**

Good News from the Sharpan Family! We are pleased to report that Teresa's father was released as a hostage from Kuwait, and was flown out on a plane arranged by the Senator from Texas. Teresa's letter to the Senator, according to her mother, directly resulted in the Senator's action. Actually, Teresa wrote over 400 letters in her attempts to get her father released, and received many responses and letters of support. We are truly happy to be able to start the new year by reporting such wonderful news to readers of *The Gathered View*.



### **... And Good News from Europe**

At a meeting held in December, it was decided to form the European Association for Prader-Willi Syndrome. One of the major reasons for starting this organization was to be able to apply for European Community funding for joint research projects. Henk P.W. Moezelaar of The Netherlands was elected to serve as president.



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**Prader-Willi Syndrome Association**

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## *This Would Have Been the President's Message!*

As you may recall, Dr. Delfin "Sam" Beltran submitted his resignation as President of PWSA effective the end of 1990. Suggestions and offers of volunteers was called for and will be submitted to the Board of Directors at their mid-year meeting in mid-January. A new President will be appointed at that time. Needless to say, these will be hard shoes to fill.

The PWSA is operated with a 12-person Board of Directors, officers in the form of President, Vice-President, Secretary and Treasurer, all of whom are volunteers. The actual office is operated by an Executive Director, Assistant Administrator, and a part time Secretarial person. PWSA was formed in 1975 by a small core of interested persons and has grown to a very viable organization, international in scope.

Although we lay the success of PWSA at the feet of the above people and their predecessors, a great deal is owed to the great group of people that we call our membership. Let's hope the new President will be a great addition to our organization.

## *Congratulations to Michele*



*Since Michele has been living in a group home she has lost 94 pounds. We are quite happy to share her birthday photo with our readers.*



## Our Supporters — Our Thanks

From mid October thru mid December, we acknowledge the following contributors:

**MEMORIALS:** *In memory of Mary Williams:* Solomon Bros., Elliott, Duncan, Dunne, Koun, Hotchkiss, Marchall, Ill, Flory, Townshend, Albuino, Dommerich, Fontaine, Hamilton, Cain, Farlow, Frog Rock Pony Club, Mulhall, Chandler, Allgauer, Mbehling, Wilson, Amidon, Stern & Gould. *Gilbert family donors:* Steriotis, Clidfetter, Diehl (2), Council Grove E1, Dammann, Daniels, Riffel, Madden, & Gilbert. Piefer family: Love, Kangas, Dellorto, Guercio, Berger, Bevacqua, Hughes, Luneburg, Black, Coffey, Mangan, Gorman, Caponi, Larsen, Broman etal, Schunk & Scarabi. *Lynch family:* Nannini, Bellavia, Battoglia, Zicari, Chastek, Freeman, Pesce (2), Ernst, Edwards, Megerle, VanHooser, Murphy, Armstrong, Edgecomb, Schroeder & Fernandez. *Other memorials:* DeGirolamo (Willinsky), Blumberg (Osherooff), McAndrew (Azinger), State Mutual & Berthel (Stone), Noon & Hinson (Hinson). These memorial donations added a contribution \$3649 to our funds.

**CIT:** Beltran (2) and Olson (2). **RESEARCH:** Levine, Uzendowski, Riesenman, VanZomeran (2), Spencer Monday Club, Tirabasso, Fleming, Lockwood, Boyd (3), Weiner (2), PWSA Kentucky, Reedy, Kellerman & Hinson. **OPERATING:** Immekus

And a special thanks to our new **ANGELS:**

**CHERUBS:** Sidlo, Noordzy, Mitchell, Jones, Krocka, Olson, Belsher, Hinds, Burke, Eager, Antine, Weger, Hebel, Bitzer, Maas, Sherard, Laws, Houpis, Dern, Wangberg, Gomez, Gemar, Fankhauser, Neiger, Hannuksela, Werner, Gall, Anderson, Lorschach, Vektor, Schneider, Renner, Watson, Hill, Gottschalk, Kircheff, Macho, Deisroth, Dodds, Busalacchi, Koch, Smith, Alexander, Gordon, Kropf, Snyder, Verziroglu, Kania, Curtan, Jordan, Hiatt, Simon, Rangitsch, Straszewski, Ranck, Steinmann, Turney, Dade, Gastelum, Stone, Small, Howe, Moloney, Hill, Cardona, Mitchell, Weinberg, Krauss, Stinogel, Midthus, Heidel, Gordon, Beck, Jensen, Clift, Becker, Needel, Press, Bowles, Rudolph, Aydelotte, Kuhne, Smith, Eggers, Cortellini, Grout, LaBella, St. John, D'elia, Sheeran, Cornejo, Newman, McEttrick, Herchick, Cardin, Klausen, Stoffel, Schramm, Bryant, Hausner, Prettyman, Huitbregtse, Trask, Ridling, Gruneberg, Engstrom, Saacks, McGun-inness, Johnson, Glaser, Henningsen, Vermeulen, Mans, Reedy, Macdonald, Dunn, Cooley, Browne, Belgum, Morlock, Victoria, Henry, Korte, Abell, Harper, Richards, Mahar, Heinrichy, Noll, Dauenheimer, Martin, Gerdes, Seiler, Clark, Botich, Clark, Peterson, Giles, Culp, Ponti, Madden, Sundell, Lacroix, Maurer, Schoepe, Herbst, Cooper, Hanrahan, Stamp, Wyka, Hontos, Lockwood, Beechner, Sidlo, Langenbucher, Allan, Newman, Vuz, Schramm, Rattray, Chase & Karlsson.

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**HEAVENLY ANGELS:** Notbohm, Tyler, Mitts, Trentacosta, Rose, Muirhead, Foley, Brock, Cheng, Beltran, Anonymous, Hilgenberg, Linonis, Lavalliere & Barkeley.

Additional support of \$1255 came from Contributing dues: Toby, Schenk, Korte, Milana, Kumm, Rooney, Willott, Bush, Blumberg, Letcher, Shoemaker, Janes, Hadsall, Singer, Childers, Persanis, Kane, Evans, Ledoux, Pike, Kellerman, Gardner, & Mitts. Patron dues: Miller, Johnson, Willinsky, Townsend, Groenboom & Keenan.

We added \$3079 to our funds with CIT, Research and Operating Donations. An additional \$14,257 was contributed through our annual Angel fund raiser. *DUE TO THIS GENEROUS SUPPORT, EVEN THOUGH WE PASSED A DEFICIT BUDGET, PWSA WILL COME OUT IN THE BLACK AGAIN THIS YEAR.* We do hope that people will continue to support this annual effort though so we can surpass our last year's total of over \$30,000.



## *Independence*

Our daughter moved into her own government subsidized apartment, which is designed for senior and handicapped persons needing limited "In-home supportive services." An aide comes in for up to 2-hours a day to supervise food preparation, she has a locked refrigerator but a second small one that contains the one day supply of food. We take care of her needs on weekends.

She loves living on her own, we talk daily and we only live a short distance away. Being close we can work on small problems before they become big ones. She works 2-3 full days a week. She has her two birds and a cat with her and they help occupy her time. She is truly a very good housekeeper. She makes her own grocery list and shops with little help. Two signatures are required on her checks so we always have the final say on all of her spending. Her transportation is either by bus or the family.

She has her screaming and yelling sprees when things don't go her way and that concerns me when it happens in her apartment since everyone lives so close. But over all, it is working out wonderfully.

How would you compare the above situation with this one?: My daughter lives in a group home that the state considers too large but because of the number of residents there, the home is able to afford a great staff. She doesn't have to be concerned with shopping or arranging meals -- all of this is done for her. She is served great meals that give her the very most she can have on her limited calories. Arrangements are made for her for transportation to work so we never have to worry about being available or concerned with her vulnerability on public transportation. She goes to work every day, but still has time left to take advantage of the many social activities that are planned by her residence. There is always a few people going to the movies, taking in a play, off to a sport's activity, etc. There are always people around to play games with, staff to discuss problems and we can make arrangements for her to visit whenever it is convenient for us. We can rest assured that if anything happened to us tomorrow our daughter is in good hands.

Alternative living situations is certain a subject that needs discussing, researching, and generally "worked on". PWSA conducted an open discussion on this subject at the last conference and will continue to research in this area. Hopefully alternatives will be available that will enable our people to have a workable situation that not only meets their needs but satisfies their desires for independence too.

## *Look for the Lucky 13th!*

Never has the number 13 been so lucky! We're talking about the 13th Annual Prader-Willi Syndrome Association Conference, which takes place this summer at the Hyatt Lincolnwood in Chicago. July 24th is the Pre-Conference Day, and the regular Conference takes place from July 25th through the 27th.

By the way, if you've received our new 1991 PWSA Calendar, why not make the Conference your first entry! If you're planning your summer vacation, remember to include the Conference in your plans. More on the "Lucky 13th" later!

## *New Clinic in Boston*

We are happy to share the announcement of the opening of a PWS clinic at the Spaulding Rehabilitation Hospital in Boston. The clinic will provide individualized comprehensive assessment leading to educational, therapeutic and medical strategies to optimize development and personal and family well being.

Robert Wharton, M.D., associated with this clinic, has been working with this syndrome for many years. If you would like further information, he can be reached at (617)720-6816.

## *Medication Suggested*

As some parents well know, skin picking can be a problem in the very young child up through the adults. Treatments have been recommended in the past but we have never come up with a good answer to this problem. Some of the past suggestions have been a product, new skin, to cover the wound, derma patches, water-based lotions, bandaids as well as keeping the child's hands occupied, nails cut short, etc. One parent reported the use of Prozac was helping. The latest suggestion that we have had is "Bactroban," which enables the sores to heal 2-3 times faster.



## *Ah, the Great Outdoors!*

As much of the country shivers, we can derive some "inner warmth" by reminiscing over some of our friends' and members' recent outdoor activities. Our black-and-white versions of these photographs does little justice to the colors of the scenery!



Thanks to Margaret and Geoff Willott for sharing a photo taken on their annual camp-out weekend. The young people with PW pictured also allowed their parents and siblings to come along too and a perfect weekend (weather, occupations, and behavior) was shared. The scene is the William Watson Lodge, Kananaskis, Alberta, Canada.



A fun time was had by all at the first family picnic held by the PW West PA Association in September. Marge Wett was also happy she was able to share with this group at their early November meeting.

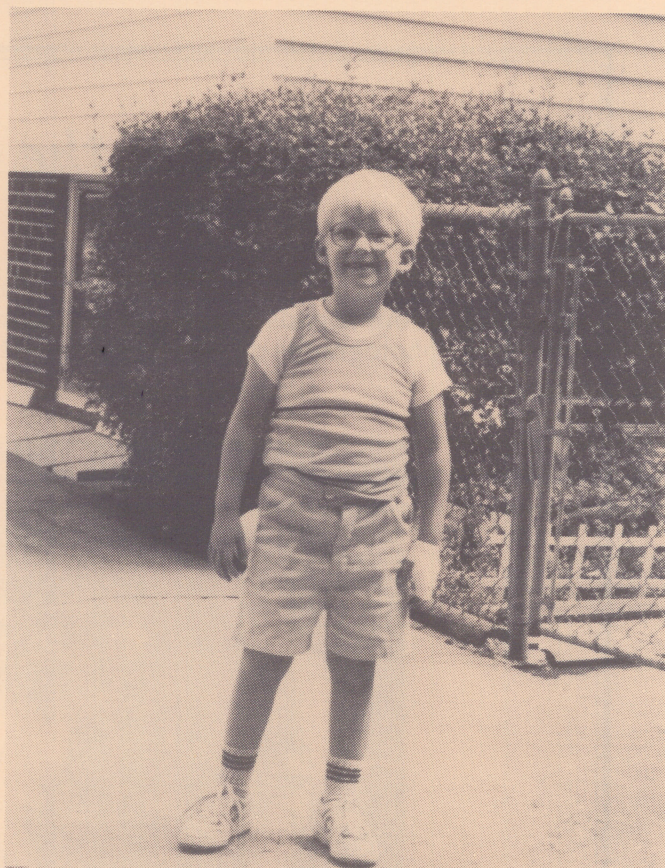


## Abilities Vary

We can never stress enough that people with PWS are individuals. A woman called the office one day and said her child was diagnosed with a mild case of PWS. The first thought was being diagnosed with a mild case of pregnancy. PWS and pregnancies exist, they are there, but when taking a look at pregnancies they are individual too. With both, you can get a wide variety of symptoms or very few.

You can see by the photo (top right) just how well Francis is doing. His mother writes he just turned six, is able to have 1200-1500 calories a day depending on exercise. Keeping up fairly well in kindergarten. He has some temper problems but as long as things are kept fairly routine he keeps calm.

And then we have Brian, at age 16, who attends a TMR class and is classified as severely retarded. Brian has very little speech but does do some signing. His behavior has been very difficult to deal with. Fortunately, a greater percentage of our children do fall in the mildly retarded range, and are not severely handicapped. When contacting a new family, PWSA writes something similar to this statement: "When a diagnosis is first received, it is difficult for parents to read all of the symptoms related to PWS. We feel it is important for parents to acquaint themselves with all of the possible symptoms but it is also equally important for you to remember each child is an individual. They do not develop all of the symptoms and there certainly are degrees of involvement. The other point is that so much progress is being made, particularly in the field of medical genetics, that we just do not know what the future will hold for our children."



## A Parent Responds

The article calling Angelman syndrome a "sister" syndrome really stuck with one of our families. Paul's sister's syndrome is Angelman. His adoptive family has Paul, who is 3, an older adopted sister, Kelsey, with Angelmans, and older siblings as well. We're happy to be able to share this lovely picture (bottom right) with our readers.



## Thanks, (Dear) Abby!

A recent "Dear Abby" column shared this poem by Joy Whitman, which we're certain you will all benefit from reading:

*Comes the Dawn*

*After a while you learn the subtle difference between holding a hand and sharing a life.*

*And you learn that love doesn't mean possession, and company doesn't mean security and loneliness is universal.*

*And you learn that kisses aren't contracts and presents aren't promises.*

*And you begin to accept your defeats with your head up and your eyes open, with the grace of a woman not the grief of a child.*

*And you learn to build your hope on today, as the future has a way of falling apart in mid-flight, because tomorrow's ground can be too uncertain for plans.*

*Yet each step taken in a new direction creates a path toward the promise of a brighter dawn.*

*And you learn that even sunshine burns if you get too much.*

*So you plant your own garden and nourish your own soul, instead of waiting for someone to bring you flowers.*

*And you learn that love, true love, always has joys and sorrows, seems ever present, yet is never quite the same, becoming more than love and less than love, so difficult to define.*

*And you learn that, through it all, you really can endure, that you really are strong and that you do have value.*

*And you learn and grow with every goodbye.*

*You learn.*

## Personalized Children's Books Available Through PWSA

PWSA has been approached by a publisher who has five books available that can be personalized for your child. The titles currently available are, *This is My Birthday*, *I Like Me*, *One Wish*, *I Can Fly* and *My Special Christmas Eve*. Please note that these are not special books developed for the disabled, just regular stories for any child. The books are in color, hard bound with a plastic coating or available as a coloring book. The cost is \$15.00 per book. You order by supplying personal information, and the book is then printed for you. If you order through PWSA, the publisher will commission us \$1.00 for each book ordered. If you are interested in a brochure and order form, please let us know. We are just offering this in case some of you may be interested.

## No Response . . . But . . .

In the last *Gathered View*, we asked if parents of the younger children pictured would identify their children. Surprisingly, not one proud parent wrote us to identify their child. We did get one letter though from another parent who feels she has found her child's twin. Her daughter, Melisa is now almost 10 but she feels her twin was in one of the photos shared. Do you agree?



Melisa's parents would like to share experiences with her "twin" if the parents would drop us a note and identify themselves. Finding a "twin" is not uncommon in this syndrome. Even though our children do not have specific identifying appearances, we are amazed at the conferences how many children look like they are related.



## Principles for PW Parents

You have often read in this newsletter a better functioning family is one who looks after themselves so they can look after the children. Here are some ideas to work with: If you have a serious problem to overcome, tell yourself you are starting over again. Be a firm believer you can start over by putting the past behind you and infusing your mind and thoughts with new energy and resolve. Believing in your power to change is the first step. Don't let that sense of enthusiasm and determination wane, keep it going, keep feeding positive attitudes in your efforts. *Think creatively and positively* — re-examine your mental attitudes, your motivation. Establish a goal — know what you want. What really is your biggest problem? Is it the attitude that you have to be a policeman 24 hours a day? Is it that you are continually battling for control and never winning? With the right positive attitude, you will start with the biggest problem first. If it's policing, what can you do to give yourself respite. Some people are shocked when they are told cupboards are locked, wouldn't that be better than continually guarding the food? If it's battling, think about the importance of you winning. Does it really matter if he insists Chicago is 250 miles from New York? Choose your battles carefully.

*Find yourself.* Are you hiding behind the feeling that the problems are your fault? Do you resent having a handicapped child? Don't be crushed by your difficult environment, do something about it by getting your feelings out in the open.

*Motivation.* You need a sense of purpose. Certainly a better relationship with your child could be that purpose. The prayer by Norma Halverson included, "Tell me I'm beautiful or handsome." We're always saying a little praise goes a long ways.

*Do your best.* Sometimes the pressure makes us press too hard. Don't try to be super Mom or super Dad. Your family has a "special" child, there has to be differences.

*Open your mind.* No situation can change if you can not see through the problem. Awareness of the situation is essential.

*Discipline yourself.* Hold your temper, keep your good spirits, maintain your imperturbability.

*Forget, Forgive, Live.* It is difficult to not build on the past and when building the stack becomes high and unbearable. The old adage, "One day at a time" applies here too. Forget yesterday was a "bad" day, don't carry over the frustrations. Forgive yourself and your child for yesterday, today is a new day. Pull down your mental curtain just as the daylight ends and becomes the dark of night, wake up fresh and live the new day. Brooding about yesterday and worrying about tomorrow spoils today. Live today.

## A Parent Writes . . .

"We have a small problem, our daughter is doing well in her group home but she collects stickers and books. She has done so since she was three years old. She likes to take a bag of books (10 or more) even though she knows they won't all get done. The group home thinks she should be doing older things. But this is her thing. It causes more problems for them in the long run. My husband and I would like your thoughts on this matter."

Response: "Age appropriateness" is certainly not a new subject associated with developmental disabilities. A swing set was removed from a facility because all of the residents were adults even though several of the people tremendously enjoyed a swing now and then. Surveyors go through homes and make notes that the residents have stuffed animals on their beds and should be encouraged to discontinue this practice. (Have they ever visited college dorms?) Look at it this way, it's good exercise to lug this bag of books around. People are allowed to watch TV — does that have more value? As long as the habit is not interfering with the home, I feel she should be allowed to continue this activity. There is certainly nothing wrong with efforts being made to steer people to more age appropriate activities but there is nothing wrong with the caregivers understanding the compulsiveness of this syndrome and allowing the person to do her own thing.

## This Little Piggy . . .

A Radio Shack ad listed the "Snack Alert" Piggy for \$12.95. The piggy "oinks" a friendly reminder when the refrigerator door light comes on. If the oinking isn't loud enough for an alarm, maybe it will be of help to us parents who are in need of that reminder too!



## Congratulations, Maureen!

Maureen, 25, weighed 425 pounds last year. She could hardly move, breathing was labored. Through the tremendous efforts of the Rehabilitation Institute of Pittsburgh, she lost 75 pounds in the 90 days there. She continued to lose at home (at 800 calories/day) another 103 pounds through the efforts of her family, the workshop and some state people. Maureen's mother writes, "The Rehab. staff have given my daughter a new lease on life." She also writes, "The workshop has really come through for her, the entire staff is helping Maureen keep off the weight by watching so she doesn't get into any food, by constantly encouraging her and commenting about what an improvement her weight loss has made not only in her appearance, but in her personality and work production." The state has also been a Godsend by giving her an aide to help with her exercise and conducting her weigh-in and setting goals. Keep it up, Maureen.

## Congratulations to Toya, Too!



Toya in her cap and gown for her June 1990 graduation

## The Human Genome Project

The Human Genome Project is an international research effort with the goal of producing a variety of biological maps of human chromosomes and determining the complete chemical sequence of human DNA, the substance that makes up genes. Scientists refer to all the genetic material in the cells of a particular organism as its genome. The Human Genome Project will spawn new research tools — chromosome maps, DNA sequence information, lab technology, and computer databases — that are expected to become the foundation of biomedical science in the 21st century. Knowledge gained from this project will one day help scientists understand and eventually treat many of the more than 4000 genetic diseases that afflict human beings.

Several independent scientific committees have recommended that the level of this project be \$200 million years, bringing \$3 billion. This sumes that reported in the of the project prove the effimosome map-sequencing about tenfold. man genome at U.S. univer-funded and be added in 1991. The plan to map and sequence the entire human genome rests on the belief that humankind will benefit from spin-off advances in medicine, biological research, and biotechnology. We certainly hope PWS will be a recipient of this "spin-off" knowledge.



*Mapping Our Genes: The Genome Project and the Future of Medicine*, E.P. Dutton, 8-31-90, at \$19.95. The mystery of our genetic heritage and its consequences are explored in this book. It is not a dry medical text; rather, it takes on the politics and personalities of the scientists who are racing each other to immortality through identification of chromosome markers and genes. Competition amongst these scientists is awesome, and the behind the scenes disputes are as interesting as any cops and robbers novel. This book provides an eye witness account of science in progress. The hunt for genes that cause syndromes and illnesses are detailed in a manner that makes you wonder about personalities, motivations, the possessiveness of research institutions, ferreting out of large kindreds with genetic diseases, and the "publish or perish" phenomena. The book reads like fiction, but indeed is fact.



## Member Questions Behavior

Paul started to have "spells" of semi-consciousness, a trance-like state lasting anywhere from 5 to 90 minutes in May of 1990. The first one occurred at school and he eventually ended up in the hospital, where he was released in a couple of hours with no answers. When Paul has the spell he is very unresponsive, in a trance-like state, very limp, pale and not aware of what is going on around him. He was kept home for a few days, doing fine and then had another spell within 30 minutes of being returned to school. He was admitted to a more knowledgeable hospital, and released after a variety of non-conclusive tests. Spells continued into June but not as severe or as frequent. Mid-July they ended for the rest of vacation.

When he returned to school in September, it only took a few days for them to start again. Another session followed and then he was fine for an entire month. Two more occurred in October, then in November (when we last heard from the parent). Paul's parents would appreciate hearing if any other parent has encountered a similar circumstance or if any of our professionals would have any suggestions. Please contact the PWSA office if you can help.

## 1991 PWSA Calendars

PWSA did develop a calendar — some of you have already seen the end product, as we mailed a complimentary copy to all members who had paid Contributing or Patron dues, and to all persons who had contributed \$25 or more to the Angel Fund Raiser (our annual giving campaign). We will continue this practice as dues and donations are received. We also filled the orders that were received from the last newsletter. This calendar is not the expensive, glossy paper, product as some but it was developed with the thought in mind that our families would like a copy and it could be shared as an educational tool to friends and relatives. It could also be used by chapters and resold as an effort to increase "pocket money" a bit for the expenses of running a chapter. If interest continues, we could work on producing a better one next year. You can order your 1991 PWSA Calendar from PWSA at \$4.00 each. Just send your check, made payable to PWSA, along with your name and address to: Prader-Willi Syndrome Association, 6490 Excelsior Boulevard, E-102, St. Louis Park, MN 55426. Why not order several? They not only make great gifts, but they offer some good information about Prader-Willi Syndrome!

## Growing Up with PWS — Thoughts and Feelings

I think having PWS took a big part on my life because some of the things I end up doing that are wrong and I know it is wrong. I go ahead and do it anyway like for instance taking batteries from the VCR and one time I stole some ciggarets from a good friend of my foster fathers. The thing that really made me mad after I got caught was he made me apologize in his face which took me three days to finally get enough courage to do it.

Having PWS is not easy to deal with because of the fact that the people that does have it end up doing things that they will regret doing that are bad for the rest of their life like shoplifting, setting fires, etc. PWS if you have it like I do makes you pick sores until they bleed and until that sore gets real big and gets infected real bad. Another thing that when someone leaves their money laying around where I can see it after I see the money laying around I get the earge to take the money so I can buy candy bars, cookies, doughnuts, gum or breath savers, etc.

I wish I was a normal young man like everyone else and not have PWS because of the fact that having PWS makes you do things that are wrong and you know it's wrong to do but you do it anyway. We have a hard time loosing weight because they have now matablitzum so it is a lot harder for us. We have to watch what we eat and we don't get enough so we steal food which just gets us into trouble. Having PWS makes you lie, steal, cheat, pick sores. We lie so we don't get into trouble. We have low muscle tone and that makes it easy to tear ligaments in knees, easy to get hernia's and getting sick. Doctors tell mothers that we can't build muscles but I found out that we PW's really can keep our weight under control and that we can build our muscles up even if we do have low muscle tone. When we

get caught in a lie we get punished for the wrong thing we lied about and also for the lie. Sometimes other people talk us into doing things that we really don't like to do like writing nasty letters to the gardians or foster care providers along with their mother or to whoever the person wants us PW's to write those nasty letters.

The people that have PWS wants to smoke ciggarets all the time when PW's have heart murmmers, but we PW's don't really care because of the fact that they think smoking is cool and because of the fact that all of their friends smoke.

(Editor's note: Sorry Mark, but I had to shorten your 7-page letter for the newsletter, but we appreciate you sharing your feelings with us. Mark is a new member of PWSA, is 20 years old and would like us to share his name and address also as he is seeking some new pen pals. Mark Eugene Berry, 10944 Old U.S. 31, Box 188, Carp Lake, Michigan 49718.

## Arkansas Group Home Prospects

Mountain Home, a resort community located in North Central Arkansas, has been chosen as the site for a facility designated as a PW home. If you are a resident of this state or know you would be able to fund a placement in this home, please contact: Gerald Hammon, H.C. 62, Box 25, Flippin, AR 72634. Daytime phone (314) 822-6955, Nights 227-5087 or weekends, (501) 453-8164.



## Let's Share Our Information!

*The phone rings, a parent asks, "My 22 yr.-old daughter just had her first menstrual period and it was a heavy flow for 19 days, then after a 6 day pause she started to flow again. My doctor said in researching information he could not locate anything regarding this being usual or unusual for a person with Prader-Willi."*

Where does research information like this come from? It comes from the parents who are willing to share information regarding their children. PWSA ran a 7-part questionnaire study a few years ago and a tremendous amount of information was garnered. When this occurs, we can share information with parents when they do call, such as a response to the above question. When researchers want to do a project, we share the names of people in the age group, right sex, or whatever category, they are researching. The names that we share are parents who have given us permission to share their child's name for seeking information. This is called our consent list. This list was established, for most part, when members first joined PWSA (on the membership application). PWSA is a national clearinghouse for information on this syndrome. Many of our members have not given us this permission. We want to be as effective as we can possible be in assisting with research and support. As we feel this is a very important area, we are asking you to take a few moments and fill in the form below.

### Consent Form

*In order to obtain a true update we need permission to list all persons with Prader-Willi Syndrome. We sincerely thank you for your cooperation.*

As parent(s), guardian(s), of a person with Prader-Willi syndrome, I(we) give permission to the Prader-Willi Syndrome Association to share the name and birth date of this person for research, statistic purposes, or in connection with the attempts for establishing a support group, opening a home, or any other legitimate reason that we feel would be of benefit to people with this syndrome.

Name: \_\_\_\_\_

Birth Date: \_\_\_\_\_

\_\_\_\_\_  
Signature(s)

## Sleep Patterns

"I have just received your November-December 1990 issue of *The Gathered View*," a mother writes. "The article on sleep patterns hits very close to home. I have always wondered about Andrew's sleep patterns, and have considered a sleep clinic 'one day'. I have never read or heard anything about this in other kids with PWS."

Andrew is seven years old and relatively high functioning. I sometimes hear him going to the bathroom every hour from about 2:00 a.m. A couple of years ago, I would catch him going back to bed at 4 a.m. We now prohibit him to leave his room before 6 a.m. Sometimes he's out at 5 or 5:30 but usually he leaves his room at exactly 6 a.m. Always the same moment. I wonder how he does this.

He must be awake for ages, waiting for the right time. He has never left his room later than 6:01. We have been told by friends to put him to bed later and he'll get up later. Please — don't you think we've tried everything? Actually the later we put him to bed, the earlier he gets up.

He will also always pass out in a moving car. He wakes up talking, as if he never slept. He also wakes up just moments before we reach our destination."

This story represents just another one of the many puzzlements about this syndrome. The letter points out the importance of reading all of the materials about the syndrome that you possibly can. It is important when treatment is recommended for various problems to know whether they are associated with the syndrome or not and if others have had experience with this area. Over the past few years much more interest is being expressed in this aspect of the syndrome.



## Plans Progress for International Conference

An organizing committee composed of PWSA members (from the U.S. and other countries) has accomplished a tremendous job of putting together an outstanding conference to be held May 2-5, in Noordwijkerhout, The Netherlands. PWSA has the necessary information and registration forms (in limited quantities) for anyone who feels they will be attending the meeting. Unfortunately with the exchange rate of a guilder being approximately 1.64 (U.S.), we estimate the cost of registration, room and food would be in the neighborhood of US\$600 per person. (This does not include any transportation.)

Since this is the first time that scientists, professionals and parents from all over the world have been invited to come together, there may be great interest. May is one of the most attractive times to visit The Netherlands too, so hotels get booked early. Please help the committee and yourselves, by registering as early as possible.

*The Gathered View* is the official newsletter of the PRADER-WILLI SYNDROME ASSOCIATION and is sent to all members. The opinions expressed in *The Gathered View* represent those of the authors of the articles published, and do not necessarily reflect the opinion or position of the officers and Board of Directors of the PWSA. Duplication of this newsletter for distribution is prohibited. Quotations may be used if credit is given to PWSA. Membership dues are \$20.00 per year Individual; \$25.00 per year Family; and \$30.00 per year for Agencies/Professionals (U.S. Funds). Send dues and change of address to: PWSA, 6490 Excelsior Boulevard, E-102, St. Louis Park, MN 55426. Any questions? Call us at (612) 926-1947.

**PRADER-WILLI SYNDROME ASSOCIATION**  
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*First Class Mail*