

The Gathered View

for the Younger Set

Newsletter of the Prader-Willi Syndrome Association

Prader-Willi Syndrome and the Crisis in Iraq

The Iraqi situation can change daily. We write this newsletter approximately one month before it arrives in your hands, so it is difficult to address a situation that may well be very changed by the time you read this. Yet, we felt that it was important to share this request with you, fully realizing the situation may be very changed by the time this issue arrives.

The Sharpan family has been involved with PWSA since 1982. Teresa is 19 years old and lives with her mother in Pacifica, CA. Her mother and father are divorced but this has never interfered with the way she feels about her father. Keith Sharpan is a communications systems engineer who has been a long-time employee of AT&T in the Middle East. He is one of the Americans reportedly being held as part of Hussein's "human shield" defense strategy. Teresa has not heard from her father since July. State department officials and AT&T officials have not given the family any information.

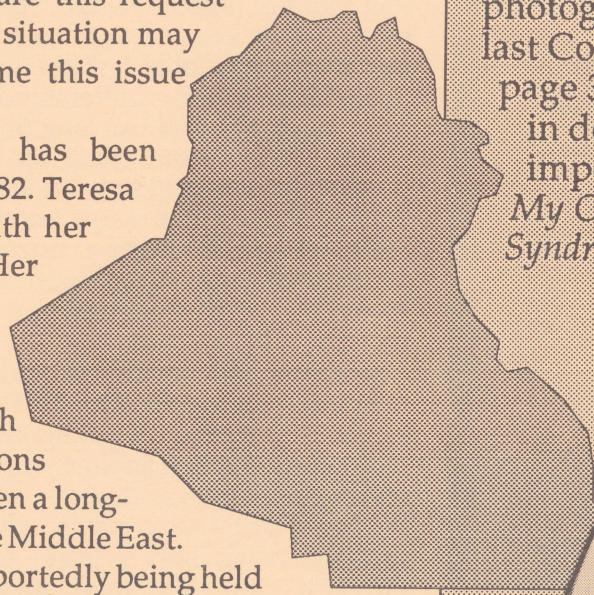
Teresa and her mother decided a letter campaign directed to President Hussein through the Iraqi embassy may influence the release of Keith. We were informed that Teresa's plea was aired for a few minutes on CNN news. Let's hope these efforts are fruitful.

Please write to: President Saddam Hussein, c/o Iraqi Embassy, 1801 P Street NW, Washington, DC 20013. Ask for the release of Keith Sharpan and all of the other hostages, as well as peace for our countries. If you would also like to give Teresa some encouragement, her address is: P.O. Box 222, Pacifica, CA 94044.

Volume V • Number 6
November-December 1990

In This Issue:

The highlights of this issue will be found in the "centerfold" (pages 6 & 7), where we treat you to a photographic view of our last Conference; and on page 3, where we describe in detail one of our important brochures — *My Child Has Prader-Willi Syndrome — Now What?*



Scott is certainly enjoying his lunch! Look on Pages 6 & 7 for other photographs taken at the Conference in Salt Lake City

Prader-Willi Syndrome Association

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President's (last) Message

by Delfin J. "Sam" Beltran, M.D.

Communication has been a major topic of discussion in my messages over the past ten years. Underlying communication is the existence of a language that conveys meaning from one person to another. The Scientific Committee under the guidance of Chairwoman and Mother Superior Dr. Vanja Holm is going to establish a current update to the definition for the term "Prader-Willi Syndrome." At a time when so many Prader-Willi Syndrome Association activities are expanding and fruitful academic research of the syndrome is increasing, it is essential that an improved definition be accomplished. With this, my last letter as president, I would like to discuss the topic of language and learning disability, which I feel is not clearly understood by many parents and professionals, but is critical not only to success in school, but forms the foundation for social interaction and failures due to behavior problems. When I inquire into the language status of a PW person, the usual response is "Oh, she had pullout speech class, but doesn't need it anymore." I immediately know that the school has pulled another fast one (another educational failure) and nobody concerned with that person's care really understands the depth of meaning in the term "language and learning deficit."

I'm far from being an expert in this field. The most positive facts that I know about language and learning deficits are that I have a lot to learn, and what Prader-Willi persons need ain't just speech therapy! Speech communication is only one form of expressive language that consists of modulating sounds to produce audible signals that carry meaning. Speech sounds must be further modulated by body language of movement, expression and contact as well as inflections, emphasis and unspoken words to become the full language that properly carries the intended meaning. Expressive language includes not only the modulated spoken word, but also the written language, visual symbols — and, yes — TV and movies and secret codes. Prader-Willi persons may reach maximum benefit from speech therapy somewhere around the teen years, but they never outgrow the language and learning deficit that has developmentally disabled their lives.

Awhile back I referred to research into the learning process and the first necessary step scientifically determined was a person alerted to receiving information. Prader-Willi persons unfortunately have a genetically determined overriding drive to seek food, lack the appropriate alerting mechanisms, and tend to lapse into drowsiness. These are severe inhibitors to the learning process when we realize that in order to learn we must first be paying attention. Years ago while observing teachers interacting with students at a school for the deaf, I repeatedly observed the teacher cradling the students' chins in her hand and direct their gaze at herself in order to alert them to the learning situation.

Since my daughter has been attending a language-based school for the multi-handicapped, and I have had the opportunity to see her program, I have come to realize the multiplicity of things that I assumed she knew, but in fact had not learned and

(Continued on Page 5)

My Child Has Prader-Willi Syndrome — Now What?

"You've learned that your child has this strange sounding 'syndrome,' a word that just means a group of signs and symptoms which together identify a condition, and you have so many questions:

What is Prader-Willi syndrome?

PWS is a birth defect of unknown cause. Infants, because of weak limb muscles (hypotonia), usually nurse or suck poorly and often must be fed with special nipples or tubes. They sit up, crawl and walk later than the average child. Around two to four, most children develop an insatiable appetite which can result in life-threatening obesity if not carefully controlled. This appetite, accompanied by easy weight gain, and behavior problems such as stubbornness and temper tantrums are the major problems associated with PWS. Small hands and feet, short adult stature, poor balance and coordination, and lack of puberty are characteristics, too. Not every child has every characteristic, and there are degrees of severity. Keep in mind that this list does not include all the positive qualities that children with PWS also have!

Will my child be retarded?

IQs are usually in the 70s but vary in PWS from as low as 40 to as high as 100 (above 90 is normal). Normal IQs, even in the 90-100 range, are accompanied by learning disabilities. Almost all children require some form of special education.

Can't PWS be outgrown?

No, it is a lifelong condition. But most children with PWS learn to feed themselves, are toilet trained, walk, talk, swim, play, work and enjoy many pleasures of life. Take pride in his accomplishments and his own special developing personality. ENJOY TODAY.

Then why do I feel so bad?

In a very real sense, you lost the beautiful normal baby you dreamed about for nine months. And you've lost the hope that the problem was temporary or curable. You're going through a grieving process, mourning the loss.

My husband/wife doesn't seem to feel about it as I do.

Often the father may withdraw into his work, respond with anger, refuse to talk about it, or act practical with comments like 'We have to accept it since we can't change it,' while the mother may be tearful and emotional and see him as unfeeling. Sometimes these roles are reversed. It is vital that each understand that both are grieving but men and women as individuals do it at different rates and in different ways. Seek help if it starts to undermine your relationship.

What can I do to help my child?

First of all, take care of yourself and your marriage. Don't let this child take over your every minute; allow relatives and friends to help. Keep balance with other children, friends and extended family. *Find a doctor who knows PWS* or is willing to learn. Don't be afraid to ask questions — and insist on answers, even if it is 'I don't know.' *Seek early intervention services.* Physical therapy helps strengthen weak muscles; many need speech therapy. *Keep a careful, detailed baby book.* It has proven to be invaluable for obtaining services later. *Set limits.* Don't do for him what he can do for himself or treat him as if he is handicapped or helpless. *When eating begins to improve, don't reinforce it with food or praise.* Start food security when child becomes mobile, e.g., clear the table immediately after a meal, keep food off counters, no more candy dishes on the coffee table. Locking up food when child gets older can lower stress on all. *Learn all you can about nutrition. Incorporate exercise in your growing child's daily life.*

You can prevent your child from being obese by learning to say 'NO,' even when your child gets upset and begs for more food. The younger you start appropriate food management (and exercise), the easier it will be.

Where can I find support? No one seems to understand.

Generally a young child with PWS who is not obese looks normal, so family and friends often do not understand either the need for food security or the parents' grieving. The best source of support is other parents going through similar circumstances. Confidentiality rules bar professionals from giving you names, but you can give them permission to give out your name. The Prader-Willi Syndrome Association (PWSA) can put you in contact with others in your area.

We hope you will let us help you along the way in raising your child. PWSA's theme is 'Caring and Sharing.' Our bi-monthly newsletter, *The Gathered View for the Younger Set*, is our best means of carrying out that theme. Our many readers are also available to help in any way."

The above copy is beautifully illustrated in a lovely brochure that was developed by PWSA recently. We are very happy to supply in limited quantities to our members without cost.

Chapter News

- The New England chapter reported a very successful summer meeting which included speakers on the topics of early intervention, research and physical therapy. The younger parents from this group have also formed a support group.

- The PWSA of South Carolina was happy to hear the report from Brookwood, a designated PW home. A majority of their residents had reached their ideal body weight and many were able to increase their daily calories. They also reported a number of the residents were on medications when they moved into the facility but almost all medications have been stopped. This is certainly a report we all want to hear. The members of this chapter have also been busy spreading the word of PWS with brochure mailings.

- Kentucky is happy to report they "outlasted HUD" and were now proceeding with their designated home. The ground breaking should have taken place by now. We certainly wish them the best of luck with the home, it has been a long struggle.

- Penny Townsend, President PWSA of North Carolina shared this information via their newsletter, "The five hour flight time returning from the national PWSA meeting in Salt Lake City gave me time to come to grips with what I had just experienced. The national conference this year was excellent. I have never been to any type of conference that I did not feel something was a waste of time or energy...until this year's PWSA conference. It was four days of intense learning and sharing — There were sessions on everything from legal rights to stress management for PWS families. The speakers were terrific and the people attending were outstanding. We had sessions just to rap amongst parents in our own child's age bracket. Talking to other PWS families means so much and there are great 'suggestions' you can learn from each other. I made friends at the conference that I'll never forget. The last night, five of us stayed up until 3:15 AM talking! Start a Chicago fund right now — you will not regret it."

- We are happy to welcome the "PW Alliance of New York, Inc." as our 27th chapter and congratulate Harry Persanis elected to serve as their first President.

- Congratulations also to Janet Wallis, newly elected President of the PWS Missouri Association.

A Paper Reports . . .

"Sweetener wars. While we're on the subject of sweets, the Food Channel newsletter notes that the sweetener wars will be heating up as the patent on aspartame (NutraSweet) expires in 1992. (Time flies while you're losing weight.) Among the possible combatants: acesulfame-K (Sunette), crystalline maltitol, D-Xylose and other things that sound positively transuranic. Meanwhile, Searle is seeking FDA approval for microencapsulated NutraSweet for use in cookies and muffins — encapsulated so the NutraSweet doesn't break down when it is heated."

Identities Sought

Our handbook for younger parents is nearing completion. We may use some photos and would like to identify the children by their first names. We would like to identify some of the younger children in the group pictures in this issue of *The Gathered View*. If the photo is not identified, would the parents please drop us a line and let us know the names of their child?

Help!

Do you have a child with PWS that is more retarded than the average person with PWS? Do you have some helpful hints for working with this child at school? If so, please drop us a line. We have a parent who is in need of any helpful suggestions. Her child has been diagnosed as severely mentally impaired. Behavior problems at school are the major difficulty. The mother feels understanding is not the problem, but that the child just isn't cooperating. We would appreciate any suggestions that could be shared with this parent and also with our other families.

Book Written by CP Kids

"The Discovery Book: A Helpful Guide for the World," sounds interesting in exploring social and psychological aspects of childhood disability. Brief autobiographies by the children reveal a variety of personalities and disabling conditions. If interested, this book may be ordered from United Cerebral Palsy, 959 Transport Way, A-1, Petaluma, CA 94952. Book cost \$7.95, postage \$1.50.

A Member Shares

As an experienced user, I highly recommend the X-Cel Chinese Wok for low calorie cooking. I pop corn with no oil, I brown and drain meat and poultry and then add additional ingredients for one dish meals. Because of the silverstone lining, frying does not require oil, the capacity is great and the domed lid makes it especially unique over other silverstone pans.

Our Supporters . . . Our Thanks!

From mid August thru the first week in October, we acknowledge the following contributors:

Stone Memorials (Ingalls family): Am Gro, Tedford, Tucker, Duggan, Beer, Bouvier, Ingalls, Lamoreux, State Mutual, Charbonneau, Lapierre, & Snow.

Honorariums for Leonard Levine's 90th birthday (Weiner & Willinsky families): Weiner, Levy, Gordon, Levine, Cherkas, Smith (2), Lutzky, Zarinsky, Kandall, Hershman, Hirsh, Cohen, Siegel, Poorvu, Finkle, Needel, Reinherz, Sugarman, Prensky, Gitkind, & Bass. (Over \$750 in donations)

Other memorials & honorariums: Vahey for Stuckenschneider (MO Chapter), Sojka (Supczak & Ryzewski), VanZomeran, Pinerman (Singer), Fargo (Santeler) & Levine (Smith).

CIT: Gemini (Wett) & Beltran.

Research: Dooley, Boyd(2), Xerox (Rivers), Power Technologies, Honor Foods (Kricheff), Venneman, Nanzig, Olson, & United Way (Vermeulen).

Operating: Sheeran & Kresbach.

Our special thanks go out to the Weiner & Willinsky families for arranging the birthday donations, to the Vermeulens for their continued generosity, as well as all of you who continue to support your organization. This time period we were able to add over \$3300 to our funds.

Additional support of \$1850 came from the following: **Contributing dues:** Rosetta, Conry, McGuinness, Drummond, Mayer, Ruzicka, Shacklett, Anderson, Nijhawan, Ceppos, Plymel, Wicks & Lehman. **Patron dues:** Atwood, McManus, Hruska, Gulling, Wissmann, Maurer, Kricheff, Griggs, Hanchett, Mleczewski, & Dicosimo.

President's (last) Message

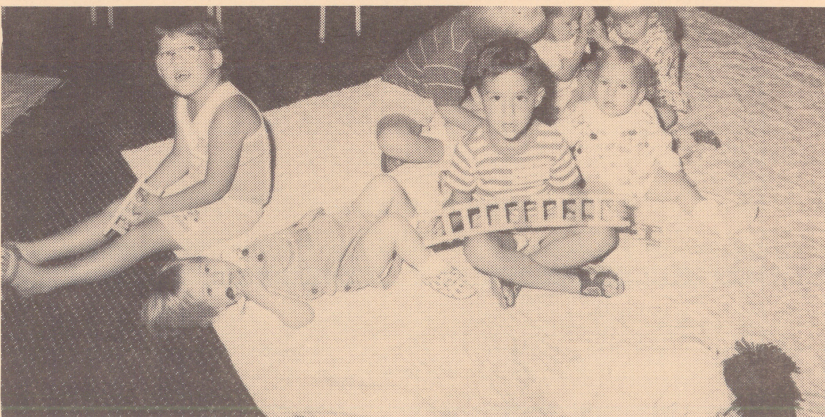
(Continued from Page 2)

made a part of her knowledge and behavior structure. She has not had the opportunity to learn how to be a child with normal communication skills that would permit her to know how to be the social being that she is expected to be. I used to say that she is unable to modulate or alter her behavior or mind-set so that it would fit in with the social situation that existed. It confused me that she would come home from school with a good grade on an addition worksheet, but when confronted with the same type of problems, on the same type of worksheet to be done as homework, she had no idea of what the task was or how to begin, until she was given a series of visual and auditory clues — "What do we call it when we want to add two numbers together?" "Are these problems on your homework sheet like the problems your teacher gave you on this sheet?" On the other hand, she could pop remembrances of distant events as if by magic. Then the next minute if I asked what she did while I was at work, she would ask her mother for clues that would help her remember that they went to the shopping center.

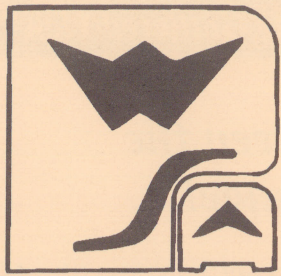
This whole field of knowledge acquisition and information transference grew out of attempts to teach the "deaf and dumb" to communicate, to teach the cerebral palsied to develop understandable speech, and to aid the code-breakers of the U.S. Signal Corps during World War II to develop methods of keeping secret messages out of enemy hands. This is certainly not a new field, but rather was the area of concern that became the field of special education. Somewhere over the years since the days of PL94-142 legislation, it seems that regulation and budgets have been determined to eliminate students with these disabilities rather than to identify and support their needs. Only through knowledgeable parents and not uncommonly private evaluations will our Prader-Willi language and learning disabled children receive the education and social integration that they need to survive and reduce behavior problems that block their progress through a world that they seldom understand and that certainly doesn't understand them.

The Conference in Pictures

Thanks to photographer Gary Collins (and a couple of photos courtesy of a parent) we are happy to share some of the memories of the past Conference. As you can tell, a good time was had by all. If you have what you feel are outstanding photos taken at the Conference, why not send them to us — we might just publish them!



Clockwise from top left: Artists at work • Just some of the gang • Resting at the zoo • Fun in the nursery • Going to the dance



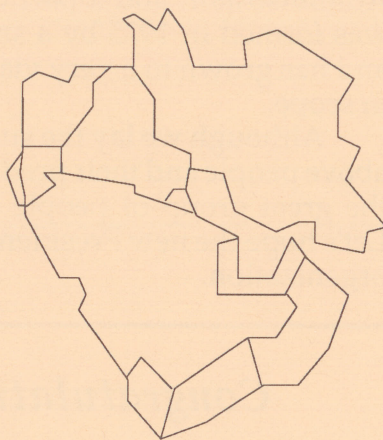
The Gathered View

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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January-February 1991

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 University of Iowa

Barbara Y. Whitman, Ph.D.,
 St. Louis University

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, Albunio, Dommerich, Fontaine, Hamilton, Cain, Farlow, Frog Rock Pony Club, Mulhall, Chandler, Allgauer, Moehling, Wilson, Amidon, Stern & Gould. *Gilbert family donors:* Steriotis, Clidfetter, Diehl (2), Council Grove E1, Dammann, Daniels, Riffel, Madden, & Gilbert. *Pieffer 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 (Osheroff), 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, Lorsbach, Vektor, Schneider, Renner, Watson, Hill, Gottschalk, Kirchhoff, 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, McGunness, Johnson, Glaser, Henningsen, Vermeulen, Mans, Reedy, Macdonald, Dunn, Cooley, Browne, Belgum, Morlock, Victoria, Henry, Korte, Abell, Harper, Richards, Mahar, Heinrich, Noll, Dauenhimer, 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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ARCH ANGELS: McAndrew, Thompson, Underwood, Masterton, Olson, Buhai, Krauss, Talbot, Breneisen, Nash, Furr, Hoffrichter, Suppes, Ziifle, Holm, Nanzig, Fick, Gardner, Moore, Faherty, Ranberg, & Lennhoff.

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.



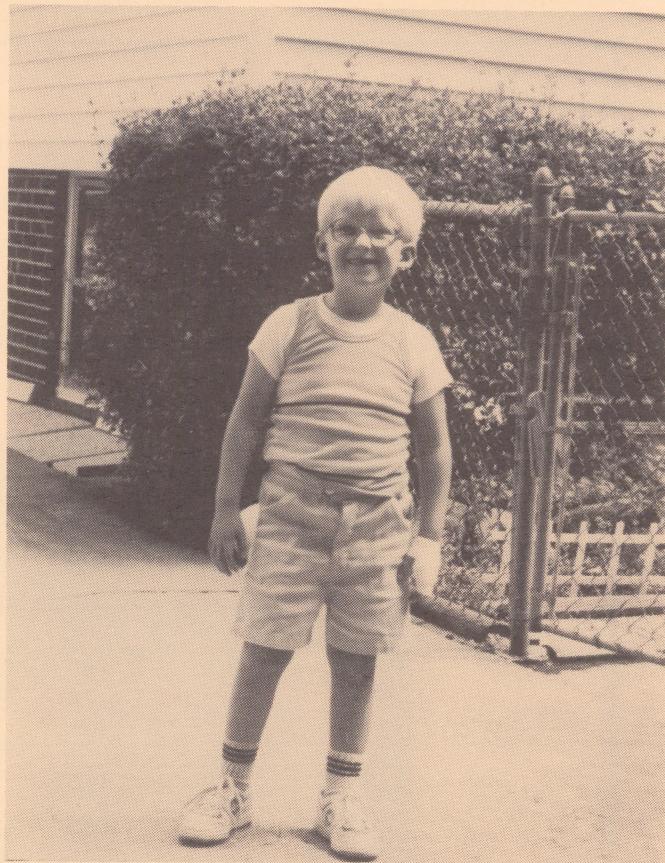
A fun time was had by all at the first family picnic held by the PW West PA Association in September. Marge Wett was also happy she was able to share with this group at their early November meeting.

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.

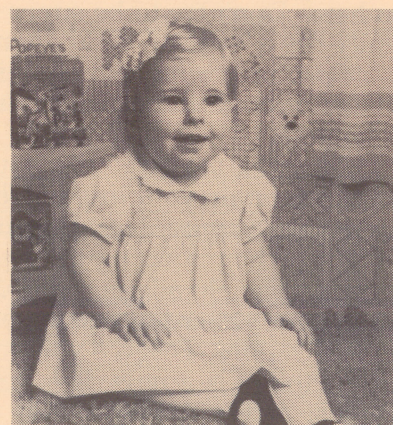
You learn.

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 U.S. support for approximately \$200 million per year for 15 years, bringing the total cost to estimate as \$3 billion. This sum is expected to 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 matablizzum 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.

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