

THE GATHERED VIEW

Newsletter of PRADER-WILLI SYNDROME ASSOCIATION

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PRESIDENT'S MESSAGE

Has anyone recently seen , or heard, news that didn't tell us about a new way to become ill? Were you among those who wrote to the FDA asking for a stay on the proposed ban of saccharin? The witches of Salem are still with us. Fear seems to be the most important news product available; fear of crime, fear of nuclear war, fear of cancer, fear of poverty. It is difficult to go through the day without encountering at least one news episode expounding on the danger of existing as a human being on the planet Earth. If you think it is bad today, wait until tomorrow's broadcast. In freshman English at the University of Wisconsin, back in '46, we were required to read "The Autobiography of Lincoln Steffins." Mr. Steffins was a reporter in New York City around the turn of the century. One chapter in his book was entitled, "How I Started a Crime Wave." As a cub reporter, he was assigned to cover the police blotter at the local precinct station. After a few days of utter boredom and a sense of failure to develop any news, he changed his tactics. Looking at each blotter as a reportable crime, he soon had many news items to report. Since copy editors were always looking for fillers, his short reports were ideal and he soon found that he was commanding more than his share of the ink. The response of the public was not unexpected. Each day more and more crime was being reported. Soon there was a crime wave in New York City.

It would seem that our news media is at it again. With competition for the consumer's time—spread thinly through the plethora of television, radio, newspapers and magazines, that spread the "truth"—it is necessary to capture interest in the micro-second that is focused on their product. The net result is that every human fear is exploited in hopes of capturing an audience. One nationally acclaimed "anchor" was recently asked why no good news was reported. He responded that people don't turn on to good news. But good news can also be turned into bad news even if it isn't the truth. Artificial sweeteners have become a way of life for Prader-Willi families. The entire topic of food flavoring and preservation has been the victim of every whim and fancy of the news media. A popular book, years ago, was "20 Million Guinea Pigs" and the sequel "Ten Million Guinea Pig Children" described the horrors of the food and drug industry after WWI. Later, when aluminum cookware became available, fadists touted the poisonous effects of using it. Today, it would seem that unless it is grown by Mother Goodness in solar-sterilized earth and placed in your mouth by hands cleansed in new fallen rain, it is certainly going to cause your glands to rise up and consume your soul in painful agony that will spread like the plague throughout all your seed. WOW!!

Cyclamate was banned by the FDA several years ago on the basis of research that has since been discredited. Documents from the FDA indicate that the substance is not only safe, but its ban was based on political fears. This was reported in an editorial in Barrons this year. At the time that Stanford University President Kennedy went to the FDA, there was a raging war that saccharin should be banned because it was causing bladder cancer in rats. I questioned a senior urologist at Stanford's medical school about this and his response was interesting.

LEUKEMIA

In the past few months, two residents of Oakwood Residence, Inc. have been diagnosed as having leukemia. The residence houses 15 people with PWS. The two young women with leukemia are age 21 and 29. One has a diagnosis of acute myeloid leukemia. The other woman has been found to have chronic myeloid leukemia. Even though these diagnoses are similar in name, the two diseases are very different in their severity and treatment. A diagnosis of two cases of leukemia in a resident population of 15 is a higher incidence than would be expected in the general population. The information that is available in medical literature does not lead us to think that leukemia is any more prevalent in the Prader-Willi population than in any other population.

We mention these facts so that everyone who works with, or cares for, people with PWS will be aware that there MAY be a greater incidence of leukemia in people with this syndrome. We should keep these facts in mind when a person with PWS has an illness. People with Down Syndrome are known to have a higher incidence of malignancy than the average population. This same type of incidence may be present in people with PWS. However, there is NO evidence to support this type of finding.

We have included this report in the GV in order to share any information that the national office has. Information gathering and sharing is one of the main functions of the national association. Even though these two people with PWS have the same residence, there is no proof that the same living environment has any relationship to the disease of leukemia. Currently, the true cause of leukemia is unknown. We do not see any cause for alarm, but forewarned is forearmed. Most parents and families are more aware of the problems that people with PWS have than most medical people. As a result, sometimes they are required to assist in educating the medical caregivers.

Richard J. Wett, M.D.

ANOTHER LETTER

One parent wrote that the family is very excited about the upcoming conference. Her daughter, Debbie, is especially excited because she made a special friend at the Kansas conference two years ago. Debbie carries a purse which contains two pictures of "HER" friend. Her mother also wrote that Debbie is doing well in school, she is mainstreamed and continues with speech therapy. She is in a combination 1st and 2nd grade room and she spends part of her day in a resource room. Debbie's name was recently added to the pen pal list. She is getting a lot of mail. Having pen pals is encouraging her verbalization. Before she can write her letters, she must tell her mother what she wants to say. Her mother then prints the letters and Debbie copies them. Each day, Debbie asks for the mail and tells the rest of the family about her letters. It is also helping her with spelling and penmanship. Debbie's mother wrote that having pen pals has put a "bright spot" in her daughter's life.

LENDING LIBRARY

PWSA does offer to loan the hardback books, "Prader-Willi Syndrome" by Dr. Holm et al and "A Difference in the Family" Life with a Disabled Child by Helen Featherstone, to any of our members that cannot afford to buy them at this time. Let us know if you would be interested in reading either of these books.

Fast Calories

ARBY'S

Beef and cheese sandwich	450
Club sandwich	560
Ham'n cheese sandwich	380
Roast beef sandwich	350

ARTHUR TREACHER'S

Chicken	271
Fish	241
Shrimp	331

BURGER CHEF

Cheeseburger	290
Regular french fries	250
Fish fillet	547
Hamburger	244
Salad	18

BURGER KING

Chicken sandwich	620
Fish sandwich	646
Hamburger	290
Beef sandwich	644

HARDEE'S

Big cheese	495
Big deluxe	546
Ham and cheese	376
Roast beef sandwich	376

JACK IN THE BOX

Breakfast jack sandwich	301
Bonus jack hamburger	461
Double cheese omelette	414
Jack burrito	448
Jack steak sandwich	428
Moby jack sandwich	455

High Fiber Menu

1 c. cooked old-fashioned oatmeal with 1 t. br. sugar	167
$\frac{1}{2}$ c. skim milk	44
1 c. tomato juice	50
	<hr/> 261

1c. beef bouillon	10
Sandwich: 2 oz. sardines 2 med. carrots, grated on 2 slices whole wheat	276
$\frac{1}{2}$ c. ambrosia (orange grapefruit and cococnut)	86
	<hr/> 372

$\frac{1}{2}$ baked chicken breast	155
$\frac{1}{2}$ c. sesame noodles with 1 pat butter	100
1 c. broccoli with lemon wedge	40
Marinated mushrooms	25
Melon rings with fresh strawberries (4)	55
1 c. skim milk	88
	<hr/> 463

Snack: 1 c. plain popcorn	54
	<hr/> 1150

APPLE-MUSHROOM SALAD 52 calories a serving

1 apple, small; washed, cored and
sliced with skin
 $\frac{1}{2}$ lb. fresh mushrooms, sliced
2T. fresh lemon juice
2T. sesame seed or safflower oil
2T. fresh parsley, chopped
 $\frac{1}{4}$ t. vegetable seasoning
Watercress or alfalfa sprouts

GATHERING THE VIEW

Melissa's mother is asking other members to offer suggestions for low calorie treats. She said diet pop is no longer a treat and she has used sugarless lollipops. We will be happy to share any ideas that are sent to us.

Two helpful hints that recently appeared in the paper are:

1) "Tofutti", a frozen tofu dessert, contains no cholesterol, no milk, no butterfat and only 32 calories an ounce. The product, being sold in gourmet shops, health food stores and department stores across the nation, come in six flavors.

2) Cook rhubarb in low-calorie black cherry pop to lower calories.



* * * * *

A Michigan parent wrote that her son, Donnie, has lost 65 pounds since last June. Keep up the good work.

* * * * *

A mother wrote that her daughter has gone from 360 pounds in August 1982 to her current weight of 164 pounds. She is aiming for an ideal weight of 150 pounds. This mother would like to know if any doctors or parents will share information with her about having a "tummy tuck" done when her daughter reaches her ideal weight.

Any information on this will be greatly shared with the rest of the membership.

* * * * *

A parent, who also teaches, shared this information with us:

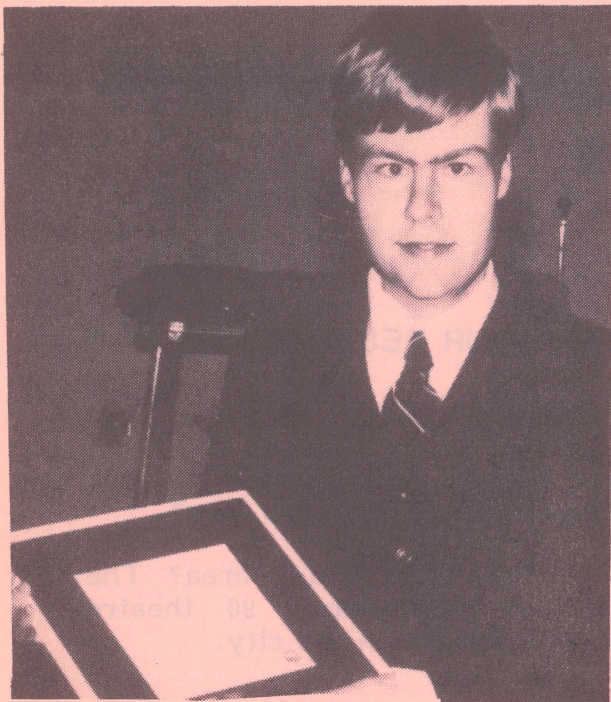
"Because I teach full-time, I can't be a guest speaker anymore. The local high school has listed me as a source of information on PWS. The students come and I share information and loan them my booklets from PWSA."

Maybe more of us can do the same to help spread information.

* * * * *

A teacher for a home-bound, 12-year-old, student with PWS wants information from other teachers. Specifically, current home programs, parent programs, outside services for assistance (other than local school), procedures for a public school educational plan. We will appreciate having other teachers, currently working with this type of plan, contact the national office. We will either share this information with others, or put the teachers in contact with each other.

* * * * *



On February 18th, the VITAL SERVICE AWARD was presented to Andy Maurer by the ARC-Atlanta.

Andy has been a fulltime volunteer at the North Fulton Training Ctr. for the past 2½ years. Some of the many things he is responsible for are: making personal birthday cards for each staff member, holiday decorations, daily attendance sheets, daily lunch count, bus assignments, classroom assignments, etc. He also assists the instructors with the small children on field trips. The center has been amazed at Andy's interaction with the small children.

We are sure he justly deserves this award. Congratulations Andy from all of PWSA.

NEW PUBLICATION NOW AVAILABLE

PWSA was pleased to hear about the publication of an overview of the syndrome written by Suzanne B. Cassidy, M.D. of the University of Connecticut Health Center. The January, 1984 publication of "Current Problems in Pediatrics" devoted the entire 55 pages to PWS. It was, hopefully, seen by many pediatric professionals.

Dr. Cassidy's article started with an excellent 15-point self-assessment questionnaire. After completing it, doctors may better realize how much they know (or don't know) about the syndrome. The rest of the overview is very well done and informative. We appreciate that Dr. Cassidy mentioned our association as a source for more information on the syndrome. We have ordered a supply from the publishers to add to our resource materials. We can offer this at a discounted price of \$6.00 per copy. We still recommend our own overview for our general membership, but offer this for professionals or for parents that would like to give a copy to their doctors. (Canadian funds/overseas mailing, add \$1.50 to \$6.00 cost).

LETTER FROM MS

Barbara White of Jackson, MS wrote that a group named "The Mustard Seed, Inc." is working to develop a home and workshop in Central Mississippi. They hope to have a cottage or wing for persons with PWS (or at least dietary needs). If anyone is interested in joining to push for this, she would appreciate hearing from you.

She also wrote that her daughter, Laura, is a member of this group's handbell choir. It will appear at the World's Fair in New Orleans the last Saturday in September. Laura also sings a solo with this group. The "Bells of Faith" have performed in many churches and have made major trips. Our congratulations Laura.

6th ANNUAL PWS NATIONAL CONFERENCE

JUNE 21, 22, 23

IT'S APPROACHING FAST!!!

HELP THE PLANNING COMMITTEE, GET YOUR RESERVATION IN NOW

CME credits will be available for health fields (not including M.D.s)

For further information, contact PWSA national office. Fees stated on the pre-registration form are U.S. currency (sorry this was omitted from the form).

Why not spend a few more days vacationing in the Twin Cities area? The Metroland offers 936 lakes, 3,523 restaurants, 124 nightclubs, 90 theatre companies, 16,000 retail shops, 77 art galleries, and that is only in the city.

City Attractions, | City Events

AMERICAN SWEDISH INSTITUTE. A historic 33-room mansion filled with fine exhibits depicting Minnesota's Swedish heritage. Open all year.

THE CHILDREN'S MUSEUM. Exhibits on everything from building houses to running a car. All specially set up on a "touch and explore" basis for kids. Open Tuesday through Sunday.

FORT SNELLING. From May through October see costumed guides make history come alive in this picturesque restored fort from an era of Indian uprisings.

GUTHRIE THEATRE. World famous repertory theater built by Sir Tyrone Guthrie offers outstanding productions from June through March.

IDS Center Fifty-seven story home of Investors Diversified Services. Breathtaking atrium.

MINNEAPOLIS INSTITUTE OF ARTS. A monumental museum filled with over 65,000 famous paintings, sculptures and objects 'd art.

MINNEHAHA PARK. One of the city's most scenic spots, this 144 acre woodland is the site of the 53-foot Minnehaha Falls immortalized by Longfellow in his poem "Song of Hiawatha".

MINNESOTA ZOO & ZOOLOGICAL GARDENS. See animals from around the world in a natural environment at this unique 425 acre setting. Open year round and only minutes from downtown, special features include a tropical garden and Minnesota animals on exhibit.

VALLEY FAIR FAMILY AMUSEMENT PARK. Over 50 acres of thrilling rides, shows and family fun. Open May through August and weekends in September.

WALKER ART CENTER. One of the finest art galleries, the Walker houses a large collection of 20th century art and an impressive collection of contemporary sculpture.

Gibbs Farm Museum, Cleveland & Larpenteur Ave., St. Paul, 19th Century

Planetarium, 300 Nicollet Mall, downtown Mpls. in the library

Little Six Bingo Palace, Shakopee, 10 miles west of hotel area.

Carleton Celebrity Room, 8350 24th Ave. Bloomington, top entertainment

Shop the Dales, closest to hotel, Southdale, W.66th & France Ave. S., large indoor shopping center

Butler Square, 100 N. 6th St., downtown renovated warehouse shopping

Town Square, Cedar & 7th st., St. Paul, new shopping complex

City Center, 33 S. 5th St., downtown Mpls. complex with 75 shops

Chanhassen Dinner Theatre, Chanhassen, four theatre stage productions

Minneapolis



For FURTHER INFORMATION:
The Minneapolis Convention
& Visitor Commission
15 South Fifth Street,
Minneapolis, MN 55402
Telephone: (612) 348-4313

APPEAL TO MEMBERS:

Many of you are aware of the need of proper living facilities for our young adults. Several deaths have occurred this year because of this need. Parent groups have been responsible for opening several homes but there is a critical need for more. Many of these young people have no hope of ever being served in the state they now live. States, where one home has been opened, have no hopes of opening another funded home, and have long waiting lists for openings that do not come.

Members in Minnesota decided an effort should be made to open a National residence. A committee, comprised of PWSA members representing chapters and parent groups, needs to be formed.

Another very important factor is the need for national office space. This national home could also serve as a national office and incorporate some paid staff in conjunction with the secretarial staff of the home. An incorporation of these two facilities could ensure the continuation of PWSA.

After much discussion, it was agreed that the only way that we could develop a home that would meet the needs, and be available to all, would be to open a private non-profit home. Many sources of funding have been discussed. We have no doubt that the money is there if we can only reach the right people. We need to hear what sources are available to you, and what contacts you have with foundations, corporations, grant sources, etc.

We also feel a National home would not only fill a great need but would mean a great deal in our efforts to make this syndrome a known syndrome. This home can have repercussions in other areas of need also. PWSA has received many letters from parents and social workers seeking placement but a list has not been compiled. We need numbers -- if you are seeking a placement now, please complete the form below.

A tremendous amount of funding and effort will have to be put forth by all of us in order to realize this desperately needed facility. ARE OUR CHILDREN WORTH IT? ARE YOU WILLING TO COMMIT YOURSELF TO THIS PROJECT? Other groups have dreamed the impossible dream and attained the impossible goal. ARE WE A GROUP WILLING TO SACRIFICE TO DO WHAT WE KNOW SHOULD BE DONE? LET US HEAR FROM YOU NOW.

I would like to serve on the planning committee _____

I have immediate need of this facility for _____

Name	Age
------	-----






Suggested sources of funding (include your contacts) _____

Name _____

Address _____

Please return before June 8th.

SOME MATERIAL AVAILABLE FROM PWSA

-  ■ ■ ■ HANDBOOK "Prader-Willi Syndrome - A Handbook for Parents" by S. Neason.
\$2.50 U.S. members; \$3.50 Overseas/non-members.
-  ■ ■ ■ OVERVIEW "An Overview of the Prader-Willi Syndrome" by L. Mitchell, MSW.
Recommended for parents and professionals.
\$2.50 U.S. members; \$3.50 Overseas/non-members.
-  ■ ■ ■ PWS BOOK "Prader-Willi Syndrome" edited by Holms, Sulzbacher and Pipes.
Text book collection of medical conference papers. Recommended
for parents and professionals. \$26.50 U.S.; \$33.50 Others.
-  ■ ■ ■ SIBLING CHILDREN'S BOOK "Sometimes I'm Mad, Sometimes I'm Glad...on
being a Prader-Willi Family" by Janalee. Written to promote
discussions on dealing with brother/sister with PWS. \$2.50/copy
-  ■ ■ ■ PWS CHILDREN'S BOOK "Prader-Willi and You" by Duno, During & Jeffers.
For persons with PWS; deals with feelings, diet & activities.
Includes controlled calorie plans with food exchange coupons.
\$5.50 U.S.; \$6.50 Canadian funds; \$10.50 Overseas.

THE GATHERED VIEW is the official newsletter of the PRADER-WILLI SYNDROME ASSOCIATION and is sent to all members. Duplication of this newsletter for distribution is prohibited. Quotations may be used if credit is given to PWSA. Membership dues are \$15.00 per year for U.S. members; \$20.00 per year for Canada and Overseas members. Send dues and change of address notices to: PWSA, 5515 Malibu Drive, Edina, MN 55436.

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