

THE GATHERED VIEW

for the younger set

Newsletter of the PRADER-WILLI SYNDROME ASSOCIATION

November - December, 1988

Vol. III, No.6

PRESIDENT'S MESSAGE

Tis the season! The season for thanksgiving, for reflection and for hope for the future. One can look back thirteen years and be thankful that the Prader-Willi Syndrome Association has lived to fulfill the dreams of that time. Although not a household word (most households that is) the name Prader-Willi is known to thousands of professionals and others through research reports, informational articles, magazine and TV spots as well as by word of mouth. There are legislators and other governmental persons who have been bombarded with our pleas and propaganda and will not have to ask, "What is Prader-Willi syndrome?" There is not only printed literature that describes the problem, but with the publication of Drs. Greenswag and Alexanders' book (have you ordered it yet?) there is now a clear path to tell you what to do about it.

This is also the time when your Board of Directors meets for its' winter session. Time, effort and expense is donated by them to ensure the life of the organization. This will be two solid days of headknocking to discern the problems and seek the answers. Applications for research grants are reviewed for acceptance or rejection. The crisis intervention center has taken a large effort, but government regulations have foiled the most promising solution. The money earned from funds donated to that goal will be used for crisis intervention through the intermediate plan developed by the board at its last meeting. (See information in this issue.) The biggest problem remains how to make and meet the budget. This year it could cost more to run the association than there is income to pay expenses. This means that reserves that are not from the research or crisis funds must be diminished for budget balancing. These are funds that are obtained from dues or sales of informational materials or from donations specified for expenses.

We are all concerned about balanced budgets and the unanimous response is to cut expenses, don't raise dues. For many, increased dues would not be a hardship, but we also know that many of our loyal members are not able to squeeze the nickel more than they have. From the number of persons that are local

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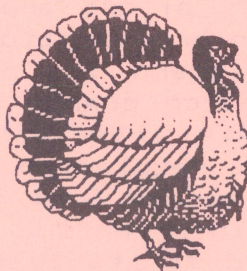
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chapter members but not members of the national, we know that this may also be a factor. Looking at expenses, we must realize that the labor factor is unrealistically low. As stated previously, the replacement of Marge Wett's voluntary efforts with a paid executive director could realistically exceed our annual budget in its entirety. Currently this leaves only two alternatives. The first was a topic of discussion by the annual committee meeting of chapter presidents. It is essential that the chapters endorse and implement a campaign to ensure that all persons with PW in their community be represented by an active member of the PWSA. It is also important that professionals in your community maintain and expand their knowledge of PWS. Circulars obtainable from the national as well as some of the individual chapter materials can assist in informing and enlisting the membership of educators, physicians, social workers, dieticians or other professionals that are helping persons with PW in your community.

Yes this is the season, and the reason I made the reference is that it is also the season for giving. More and more our membership is converting their giving programs to 100% PWSA. Now at the end of the year we must remember that one of the few things that remains a deduction on your income tax return is a donation to a charitable organization. The PWSA is your charitable organization and now is the season of giving.



Delfin J. Beltran, MD

President

OUR SPECIAL PEOPLE

A special thanks to the special people who remember PWSA with donations:

Research Donors

Hasker, U.W.-Capital Area (2), Nat'l. Area, Neason, Maas, Boyd (2), PW MO Chapter Memorials (2), HI Pac.Fed. (2), Maranon Memorials (2), Bintz (Miller), Lynch (Coke), Stephens, Moss (U.W.-LA), Gordon, Richarz, Sidlo, Lennhoff, CFC-SD, Robinson Memorials (2), Solinger, Tobin (Trask), Castle, Antin (Readers Dig.), Beltran, Ingalls (Spencer).

C.I.T. Donors

Kricheff, Goff, Olson (2), Beltran (2), Dixon, Sharp, Parent, Sidlo, Welch (Moylan), St. Dennis, Notbohm, Thompson (Adaptive Liv.), and C. Miller Memorials (22) (Nystrom, Mosley, LaBarge, Viala, Baum, Slobinski, Hahnefeld, Petipren, Brinkman, Blust, McManus, Ryan, McGinnis, Brewster, Tarchalski, K. Miller, Curnell, J. Reynolds, Hoff Eng., Feliksa, Throop, P. Miller)

Other donors (not named above) who contributed to operating through extra dues and donations:

Willinsky, Robinson (Deveau, Lux), Maurer, DiCosimo, Wett, Chausow, R. Miller, Hanchett, Voltz, Atwood, PW DE, Rieseman, Mitchell (Fraser).

We especially thank the Reynolds family in designation PWSA for memorials for C. Miller's sister who died recently. Memorials for the death of Kermit Robinson and Joseph Maranon.

RESEARCH

It was very encouraging at the last conference when one of the researchers mentioned the possibility of gene therapy in FWS. He said this was not coming in the next year or two but certainly a possibility in the next ten years.

A recent article stated Dr. James Wyngaarden, the director of the National Institutes of Health, said he was delaying final approval of the first government-endorsed experiments to transplant genes into human patients because of "unresolved questions". The experiments would genetically alter patients' blood cells in an effort to gauge the effectiveness of a cancer treatment, but would not attempt to treat a genetic disease, which is the goal of gene therapy.

Let us hope these "unresolved questions" are resolved and this research continues to move forward.

SUCCESSFUL JOB IN WI

Scott, 18, had a summer job through JTPA (Job Training Partnership Act) at minimum wage for up to 20 hrs/wk. at a nearby branch of the public library. He helped record information from children involved in the summer reading program and helped file books back on the shelves. The librarians were very helpful in making sure no extra food was available during this working hours. He loved his job and his pay.

RECEPTION FOR EDITORS

Dorothy Thompson and Marge Wett were able to attend the reception held for Louise Greenswag and Randy Alexander at the University of Iowa in honor of their publication of the management book on FWS.

They were also able to tour the facilities that are offered in their developmental center and meet a number of the staff. We were pleased to hear of the parent's efforts to obtain a group home in their state.

ANIMAL RIGHTS RESEARCH

The Animal Rights Controversy is still alive and there is a great need for more people to make their feelings known. Many charges are made that are very inaccurate - photos of tortured animals in labs, stories that pets are stolen for use, animals are used unnecessarily by cosmetic companies, etc.

Animal biomedical research could be extremely important for FWS. The Pet Theft Act (s.2353) will be used as the first step on the road to a complete halt of animal research. Take the time to let your legislators know how you feel about the necessity of continuation of animal research for all syndromes. (This bill may or may not have been voted upon but your opinions are still important for future considerations.)

WELCOME NEW CHAPTERS

A belated welcome to the PWS Delaware Association for becoming an official chapter of PWSA on the 10th of May. Karen Swanson, a sibling, is serving as

President of this group with Diane Rosetta, Vice Pres., Becky Trump, Secretary, and Laurie Lamberson, Treas.

Chapter #24, PWSA of North Carolina joined the ranks in early September with Glenda Abbe, President, Robert Townsend, V.P., and Carol Conway, Sec./Treas.

Chapter #25 is welcomed as the PWSA of Kansas, joining in late September with President Kenn Ashcraft, V.P. Bob Redmond, and Sec./Treas. Jeane Redmond.

Chapter members appreciate how much support can be obtained from an active support group in their area. We are happy to welcome these three new groups.

GROUP HOMES

Recently representatives from Iowa, Texas, Louisiana and South Carolina attended a "learning session" conducted at the Oakwood Residence in Minnesota. The South Carolina home has already been opened; the Texas facility is serving several young people with PWS in their mixed facilities and hope to expand service to PWS; Iowa and Louisiana groups hope to open facilities in the near future. Progress is being made.

A CA MOTHER WRITES

When our daughter was young, we, like many parents of young PW children were determined to somehow "change the course" for our child. We spent much time, energy and money on lessons in ballet, gymnastics, swimming, three years of Brownies, church choir, children's drama productions, alternative recreation (a program for DD) etc etc. We became very involved in her school program, always making certain she received every opportunity the special education program offered, speech therapy, sensory integration, adaptive P.E., special aids, etc. We spent many hours teaching her to roller skate, ride a bike, practice her reading. We gave her numerous camping and travel opportunities to broaden her world. At age fourteen she chose to live in a group home (fortunately we had this option available). During the past three years we have never doubted that she was happy with her choice. But we have often wondered if anything we had done had really counted for anything!

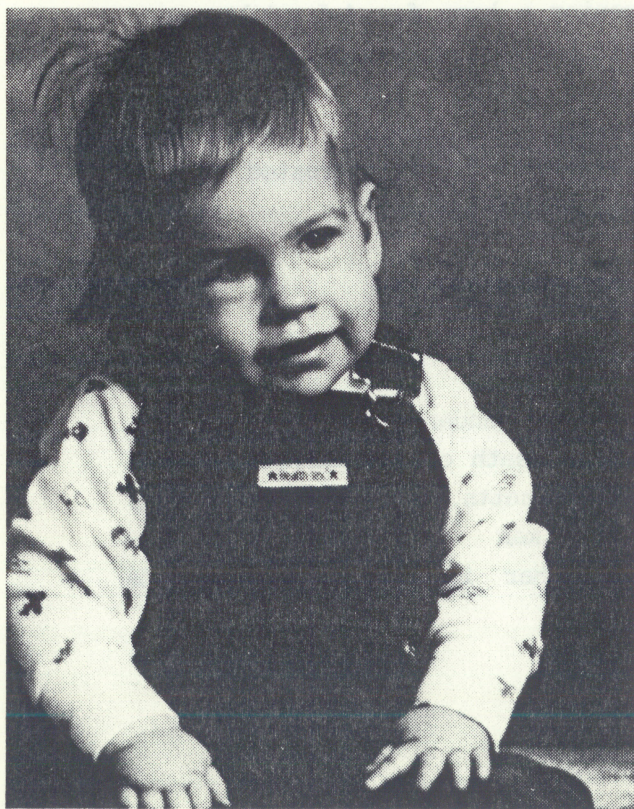
This past labor day weekend she was home when the son of some dear friends committed suicide. She became involved in this with us. While driving her back to her group home we had a long discussion about suicide which she ended by saying, 'I would never commit suicide, I have a very happy life.'

If we are the sum total of all we have experienced then everything we did with or for her was worth it. To have a 'very happy life' was our goal."

A WASH. PARENT SHARES

Our Ian is now 16 mos. old. He pulls himself to standing along furniture, beginning to take steps, uses a spoon to eat and a cup to drink.

I would like to share the information that you can nurse if you really want to. Ian was bottle/gavage fed from 0-3 months (at which time I expressed breast milk) and then successfully breastfed from 3-12 mos. Though he nursed weakly, and I had to continue to express milk, he eventually got better at it. Much prodding (rocking, patting, etc.) was required to keep him awake while nursing but I feel breastfeeding was too rewarding for words. An electric breast pump helped me keep up with the pace. Don't let the doctor tell you not to do it if you want to.



A MN PARENT WRITES

My son is doing well at the Laura Baker School (LBS), which is a larger school containing a PW program. He does have some characteristics that vary from descriptions usually published about people with PW. He is very affected by unpleasant behavior around him. He becomes upset when a peer is upset or exhibits aggressive behavior, although this co-dependency may come from his previous home environment. He is self-centered but he does become genuinely attached to friends and has a hard time adjusting if a friend moves. He also picks up bad habits from others but he knows he does this and behaviors are easily controlled. Because of these differences, we feel his residence, with many types of people, is a more desirable place for him. We are especially pleased with the staff at LBS.

(Our organization is frequently accused of recommending group homes specifically for PW only as the only option for a residence. We certainly have found from our experience that programs developed for our children/adults specific needs are the ones that work but this does not have to be found in PW homes only. If a home is willing to make the necessary adjustments, it can work. LBS, is a good example of a larger facility that has developed a program that obviously does work.)

A FRIEND IN ISRAEL

Each time I get your bimonthly message I decide to write some words but my ability in expressing myself in English falls far away behind my feelings of gratitude to you. It is amazing how similar are the symptoms you, and the other families, relate to, and the things that we've got to face with our child. What a strange feeling, that from so far away we share the same experiences, share the very same human fate which conquers all difference in religion, nation, and geographic distance. Isn't that exciting!

Doron is seven, adorable and beloved, and we are happy to share



his picture with you.

We are happy to share this letter and photo as it certainly reflects the opportunity we have to share worldwide.

SUPPLEMENTAL FOOD

Women, Infants, and Children (WIC) was established by congress in 1972, a grant program funded through the Food and Nutritional Services of the U.S. Dept. of Agriculture (USDA) and administered by state departments of health or public health. Its purpose is to provide supplemental foods, health care referrals, and nutrition education to young children up to five years of age, that are at "nutritional risk". Programs are available in Alaska, Ariz., Ill., Ind., Mass., Mich., Minn., NJ, NY, Penn., RI, Texas and Wash. It is possible additional states also have funded this service for those in need.

UNBELIEVEABLE BUT TRUE

A Maryland parent has been working with an organization interested in opening a home for 4-5 adults now. Additional interested people are needed to fill the beds. Please contact Martin Teichman (301)649-5993, if interested.

OUR SYMPATHY

We were saddened to hear of the sudden death of Dr. Samuel Latt of Massachusetts. Dr. Latt was a very nice man and an interested researcher in PWS. He will be missed.

BOSTON MORNING SHOW

A PW show was done by "People Are Talking" in Boston with a panel of Nancy Hollingsworth of Human Options; Rob Whorton, M.D. of Spaulding Rehab.; Thelma and Gunther Lennhoff of NY (parents who had lost a daughter); Mary Tsoules, a young lady with PWS; and Marge Wett.

The show was a bit of a disappointment because (as usual) the focus was on eating only but Mary was the star of the show. Mary is a very articulate young lady of 32, who has her weight under control, and did a beautiful job of responding to questions on the syndrome.

We continue to work toward getting on one of the national TV shows. One of our siblings from Delaware recently applied to the Oprah Winfrey Show and at least got a response (more than we have accomplished). Maybe if Oprah receives many letter (like our Good Housekeeping efforts) it would help them to decide to do a show. Write to her at ABC, 7 W. 66th St., NY, NY 10023.

HAWAIIAN PROGRESS

We are happy to hear the Hawaiian parent group, working with the Easter Seal Society of Hawaii, is meeting monthly and conducting

recreational activities for the children during the meeting.

The PWSA group home was scheduled to have opened by now and we hope this was accomplished. The home is one of five units on a property with the other units including other DD children/adults, a respite home and a private unit. The PW unit is located on the upper floor in one of the double-story buildings, will serve 4 adults (3 in long-term placement and 1 respite), and will be staffed by 7 workers on rotating shifts.

The Director writes that the most pressing need is appropriate medical services for PWS. "Our biggest frustration has been that few physicians and medical professionals have heard of PWS; those who have are quite limited in their knowledge." This group is working to eliminate this situation and we certainly wish them luck in their endeavors.



CALL FOR PAPERS

A national conference is being held next August in Michigan for concerns and needs of sibling of DD.

A call for papers is being used for 60-90 minutes presentations, to be submitted no later than the end of the year. Please contact PWSA for further information if interested.

We thank the 24 people who responded to our request for information in the last GV. Two people felt they did detect a scalp odor but felt it more of a sweet odor rather than acid-type smell. Ten people responded they did not detect any odor.

Four women responded that they would be interested in a "single parent" pen pal circle. There is one other person who we know is interested -- that is the person who requested we seek others and we don't remember who it was. Would you please let us know so we can start the circle?

The majority of people responding (from this request and previous conversations) voted that the conference be held each year the 2nd week of July. The board will be discussing this in December so it is not too late to offer your opinion.

The many other comments and suggestions will be carefully considered in the future for PWSA and the newsletter. We thank you again for responding and your help.



CANADIAN PARENT WRITES

This is a long overdue letter to let you know how much my daughter and I appreciated and benefitted from the last conference.

Our daughter has the 15th chromosome deletion but is not a "typical" PWS child. Both my husband and I are coming to terms with how much stress has gone unrecognized, and we have

not compensated for, in having a PWS child. The conference helped us deal with that.

Today I received the new management book -- took it immediately to our

family doctor, who asked to borrow it. I know her teachers need it desperately (and us as well) so it will be well-read. The workshops at

Many parents wrote that there should be more sharing in the GV. That's up to all of the members, we can only share what we have. One parent wrote, "my daughter has come a long way since birth, has given us a lot of joy and love along with the tears, and I don't mind sharing that with anyone."

The consenses seemed to be sharing too many success stories without waiting for a reasonable trial of the accomplishment would give false hope to parents, but they would like to hear more what other people are doing and accomplishing -- as one mother wrote, "even hearing of a good camping experience is encouraging". Another mother wrote, "The success or limited success of each story is reality. I feel it is far healthier for the families with PWS children to hear about what other families are going through and what may or may not work. We do not need to be shielded from real stories." "Share failures too, false hope will produce decisions based on unrealistic expectations -- disastrous for our PW's -- they don't need more bad advice."

the conference taught us of the essential need for educating EVERYONE on the syndrome.

Many things will happen in our life because of this conference -- how can we thank you.

Another holiday-coming note comes from the folks who make the artificial sweetener Sweet 'n Low. If someone at your holiday table is on a diabetic diet, you might want to call Sweet 'n Low's toll-free hotline, staffed by nutritionists, for advice on making traditional recipes suitable for the diabetic diet. The number is (800) 231-1123. Here are some tips: use evaporated skim milk for evaporated whole milk in desserts. And (surprise): replace half the sugar in cookie recipes with Sweet 'n Low.

MUSCLE TONE IMPROVING

We have a boy, who is 8½ years , diagnosed at 1 year. We have been able to do real well on his weight. He's never required locking things but is watched and food is very important to him. He always asks what we're going to eat next.

His muscle tone continues to improve each year and we feel his three years of gymnastics have helped. He is doing very well in 1st grade.

PRECOCIOUS PUBERTY

Puberty is defined as precocious when it appears before age 8 in females and 9 in males. The gonads are stimulated to release estradiol or testosterone, which causes puberty hair, underarm hair and beginning of breast development.

Precocious puberty has been reported in some children with PWS, but they have not followed through with normal puberty in their teens. We also have reports of more normal teen development in some children (some who have been treated with estrogens or testosterone, and some who have not). Some of the young people do have true breast development and regular menses; some are "typical PWS" and some are "atypical" cases.

GRANTS AVAILABLE

Do you have a financial need because of a crisis-type problem relating to your child/adult with PW? PWSA is now using interest available from the CIT Fund to help its members. Usual grants will go up to \$3000.

Send or call the national office and your request will be considered by the Crisis Committee.

NEW MANAGEMENT BOOK

Many times people ask, what can we do to help? Unfortunately, most of the time things must be done in the national office BUT right now we have an opportunity to let everyone help. "Spreading the word" can be very important to PWS. How can you do this? One page of this newsletter is an order form for our new management book. Many compliments have already been received from those that have seen the new book. Take this order form to your local insti-printer and share a copy with your local library, medical school if one is nearby, and any other schools and colleges. Your chapter could even do a mailing to local doctors, clinics and schools. Having this book available in these locations will increase the knowledge of PWS and will be of benefit to all of us.

CONTINUE SHARING

Parents frequently send us clippings from newspapers and ask about information. We hope you will continue to share, we do appreciate getting all of these articles, but one way to tell the difference of a true news article and an advertisement is just that word -- if the article looks like this and has the caption "Advertisement" it is just that.

— Advertisement —

Accidental Discovery May End Obesity

WASHINGTON — Obesity may be controlled naturally with a new type of pill.

The heading and dateline are made to look just like a news item so you will be led to believe it is. When you see the word, advertisement, forget it, it isn't even worth reading.

GROWTH HORMONE THERAPY

Determining who will respond favorably to GH treatment is still limited, and possible longer-term effects of therapy are still imperfect.

With a normal short-statured child, the decision is generally based on the psychological status but with PW extra height can be helpful in weight control. As some people have been known to say, "I am not overweight, I am underheight."

GH therapy is estimated at \$22,000/year, which can (in some instances) be covered by insurance.

A PARENT SHARES

Our son, Lawton, is a very active 3-yr. old who was diagnosed at 2, but we had known from birth that he had PW symptoms.

Lawton has been only a joy. He loves people, makes friends easily since he had already learned the practice of sharing. He has not yet thrown any "food" tantrums, but has just recently started putting on weight. A dietician has put him on the food exchange plan used for diabetics. We hope that starting our whole family on this plan will teach Lawton good habits for the future.

Thanks for the help you have been through the GV.

LACK OF PHYSICAL ACTIVITY NEEDS ATTENTION

According to a study by a researcher, the lack of sufficient physical activity in the child's early years may hinder their intellectual growth. There has been controversy, in the past, about the importance of early physical experiences. Dr. Jeffrey Rothman stated his study shows children do learn from their environment and deprivation of physical stimulation from the time of birth may seriously affect their ability to learn as they grow. He was quick to point out though that parents should not rush out to buy "super baby" toys and equipment but instead the parents should remember the basics of playing with their children - allowing them to move about, rolling a ball toward them, have them grasp objects and encouraging any other explorative activity.

Working parents should carefully evaluate the program of day-care centers and choose those that offer their children a balance of physical activities along with passive ones.

The doctor also encourages the strong need for early physical therapy intervention when needed.

A practical and relevant handbook...

Management of Prader-Willi Syndrome

Edited by
Louise R. Greenswag and Randell C. Alexander,
The University of Iowa, Iowa City, IA

This comprehensive sourcebook on Prader-Willi Syndrome discusses the characteristics, etiology and diagnosis of the syndrome and offers practical, common sense guidelines for management. Its chapters are written by professionals in many different health and allied specialties, who provide an interdisciplinary perspective on clinical, social, familial, and community issues relating to care.

Health and education specialists in academic, clinical, and community settings will find **Management of Prader-Willi Syndrome** an indispensable source for information about the syndrome and for pragmatic management strategies.

From the foreword by Hans Zellweger: "The book gives useful directions to all of those involved in the care of children and adults with PWS; not least to the parents. It may not only help to provide a sophisticated treatment program for PWS, it may also help to get the specialists closer together in a collaborative effort to help PWS individuals and their families carry their lot."

Contents:

Preface, D.J. Beltran. Foreword, H. Zellweger. Introduction, L.R. Greenswag, R.C. Alexander.

Physiologic and Genetic Considerations

Prader-Willi Syndrome: An Overview, R.C. Alexander, J.C. Hanson. Differential Diagnosis, H. Zellweger. Hypogonadism and Osteoporosis, K. Rubin, S.B. Cassidy. Genetic Counseling Issues, E.R. Thomson.

A Case Presentation

A Chronology of Hope, J. Sherman, G. Ente

The Interdisciplinary Process

A Team Approach to Case Management, L.R. Greenswag, R.C. Alexander. Medical and Nursing Interventions, R.C. Alexander, L.R. Greenswag. Dental Manifestations and Treatment, A.J. Nowak. Nutritional Management, D.E. Downing. Psychological and Behavioral Issues, S.B. Sulzabacher. Educational Concerns,

M.H. Lupi. Speech and Language Development, J.H. Munson-Davis. Physical Therapy and Occupational Therapy, M.D. Minor, T. Carr. Vocational Concepts, J.T. Inwood. The Role of the Social Worker, J.F. Porter.

The Socialization Process

Social Skills Training, W.B. Mitchell. Understanding Psychosexuality, L.R. Greenswag. A Parent's Point of View, J. Tomaseski-Heinemann.

Delivery of Services

Advocacy Services, R. Newbert. Residential Planning, D.G. Thompson, L.R. Greenswag, R. Eleazer. Parent Support: The Prader-Willi Syndrome Association. Glossary of Terms. Suggested Bibliography. Appendices. Index.

1988/approx. 312 pp., 35 figs./cloth

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_____ \$27.50 for members of the Prader-Willi Syndrome Association + \$10.00 for Canadian Exchange and Overseas book air rate.
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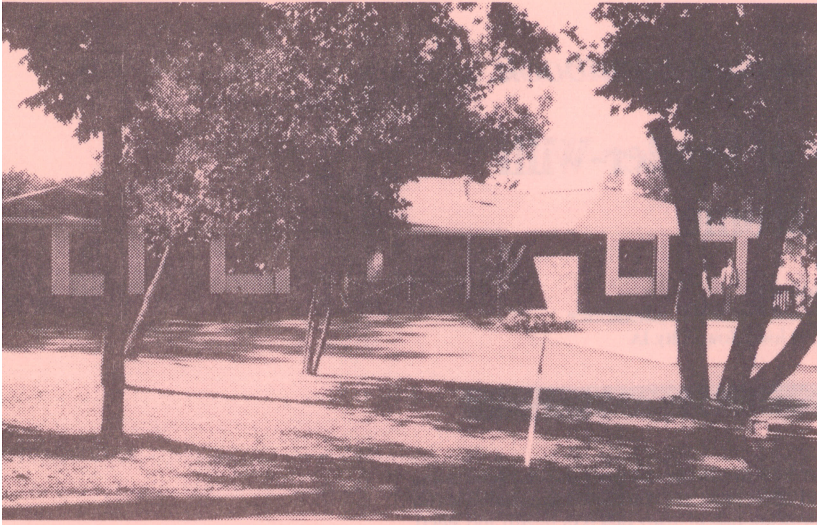
Address _____

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Return to: **Prader-Willi Syndrome Assoc**

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Elmhurst, 2nd group home in Michigan

Dedicated to Clarissa Miller - moving force in developing homes from MI chapter.



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