



WISCONSIN CONNECTION

The newsletter of the Prader-Willi Syndrome Association of Wisconsin

Mission: The mission of the Prader-Willi Syndrome Association of Wisconsin, Inc. is to educate and assist families and professionals in dealing with individuals with Prader-Willi Syndrome.

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National Conference Highlights

The National PWSA conference was held July 20-22 in Seattle, WA. As usual the Wisconsin Chapter was well represented. Many of the other state and national association members comment on the excellent representation and commitment of people from Wisconsin. Below is a quick overview of what was presented.

THURSDAY

Vanderbilt University Grant:

Dr. Merlin Butler and Dr. Travis Thompson gave an overview of the five year project entitled "Prader-Willi Syndrome: Genetics and Behavior" which is being funded by a 2.3 million dollar grant.

Planning for the Future:

Mr. William L.E. Dussault, P.S. is one of the most knowledgeable attorneys on disability law in the nation. As a state consultant for six different states in U.S., and having direct contact with numerous families across the country with a PWS individual, he had a

tremendous amount of experience and knowledge to share.

Scientific Highlights:

So much has happened in the medical field during the last year pertaining to PWS. This was a chance to find out the latest advancements and get answers to all your questions. Subjects covered were: new diagnostic technique, methylation studies, growth hormone and much more.

Only Sessions:

This was a time for sharing and learning from each other. By breaking down into groups of Mothers only, Fathers only, etc., you're able to speak more freely about specific subjects important to your specific group.

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Notes from the President

Mike Larson

It seems inevitable that when anybody asks "What's New?", my brain goes blank and the automated response that comes dribbling out of my mouth, "Oh, not much." But this time I have to say there is a lot of things happening. On the home front, my son with PWS, Alex, is walking independently at 33 months; we have a new addition to the family, a golden retriever/lab puppy; and the Packers aren't doing half bad (unfortunately the other half isn't good). Also, our state organization is having a positive effect throughout the state. Our memberships have surpassed 60. PWSA of WI is becoming known and respected within Wisconsin's circle of professionals who are associated with developmental disabilities. We are reaching and educating people about PWS literally one person at a time! This is how PWSA of WI started and this is how we are growing. This growth is largely attributed to individual efforts of people like Pat LaBella and Barb Dorn. Pat and Barb are out there talking to small groups, talking to large groups, and talking to anyone who is willing to listen. They are spreading the word and educating.

Recently, the state office has obtained new letterhead, envelopes and business cards. This will enable our organization to present a more professional image and better first impression. In a lot of cases, this is the only side that people see of us. Thanks to Judy and Tom Scheidegger for their work on that project. We're looking good now!

The United Way campaign is under way now for many Wisconsin Businesses. The Prader-Willi Syndrome Association of Wisconsin is not a United Way agency. However, it is possible to designate your contributions to go to a non-United Way agency such as PWSA of WI. By designating PWSA of WI as the organization you wish to receive your donation, you can have a convenient way of utilizing payroll deduction to contribute to our organization. Also, many companies have matching fund programs. If employees make a contribution to a charitable organization, their company may match a portion or even double or triple it. If you have questions on how to designate PWSA of WI, see your United Way chairperson.

As a side note, PWSA of WI is entirely funded by memberships and donations by friends and families of our organization. This is one of the things that truly

makes us unique.

Other interesting notes. The annual National Conference in Seattle went off with out a hitch. It always amazes me the turnout from Wisconsin (it also amazes some of the other chapters). The weather and hotel were beautiful. This was my third conference. It seems each year we meet so many wonderful people. I enjoy hearing so many encouraging stories and new findings about this disability. It revitalizes me to be proactive and work to help others on this road of living with PWS. The highlights of the conference are in the lead article of this issue of the Wisconsin Connection. As it mentions in the section on the New Timers/Old Timers session, "We all have so much in common which makes us instant friends". That has to be one of best parts of going to the National Conference. To meet in a place where most every person has walked at least one mile in your shoes. The caring and understanding they all have for each other is unlike anything else I have experienced.

The last couple of months I have been consumed with working and learning how to get the National organization up and running on the Internet. Soon information about PWS will be instantly available to millions of people worldwide. There will be contact people, addresses, phone numbers, residential and service providers listings, Lists of available literature, order forms, Research highlights, and New breakthroughs concerning PWS. Down the road there may be a news group where anybody can post information or have ongoing conversations via E-mail. This promises to be an excellent source of information sharing. If anyone has ideas of information they would like to see available on-line, please send me any comments or ideas.

And on a sad note, I would like to offer my deepest sympathies to Russ Myler, the Executive Director of the National PWSA. Russ's mother passed away this past week.

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News From The State Office

by Barb Dorn

I just want to share with all of you that our organization continues to grow and become more acknowledged and utilized by parents and professionals. We are getting the word out about Prader-Willi Syndrome.

First of all, I would like to extend our entire organizations's GET WELL wishes to Pat LaBella our Vice-President who recently had major surgery and who is now recovering at home. We hope you're up and feeling strong soon!

Our picnic was a huge success. I think it was tops in attendance. We had close to 80 people attend this year's picnic that was held at Alicia Park in Appleton. We had a "Bubble Extravaganza", games, prizes, snack and entertainment by a magician named "The Amazing Davis". Thanks to Mike and Mary Lynn Larson for planning and pulling it all together.

Officers and representatives from our organization have been very busy over the past few months conducting training workshops and spreading the word about PWS. In July and August, two training workshops were conducted in Madison and 50

professionals (teachers, job coaches, residential providers and staff) attended a 1-day training about this disability. In early September, Mike Larson and Lisa Seis attended the State Special Olympics Conference where they exhibited our display and distributed pamphlets. We have also been asked to participate in a brochure display at the State Superintendent's Fall Leadership Conference in mid-October. PWS may also be one of the topics at the state Developmental Disabilities Network Training meetings that will be held in Madison on October 12. As you can see, we are working very hard at getting our message out.

In an effort to make sure that all residential providers who service persons with PWS are on our mailing list, I would like to ask parents, professionals and any other parties to send us the name and address of the provider who is assisting their loved one with PWS. You may use the form below. This also helps us know where persons with PWS are living and make sure we are best serving their needs. Please forward the following information to our office:

Mike Larson has been very busy assisting the National PWSA to become part of the computer Internet Network. He is quite the computer whiz.

Remember, if anyone has items that they would like put on the agenda for our next meeting, please submit them to our office. The last business meeting of the year is the time when any new official business can take place.

Residential Provider's Survey

Send to: P.W.S.A. of WI, Inc.
305 Amanda Way
Verona, WI 53593

Name of Provider: _____

Address of Provider: _____

City: _____ State: _____ Zip: _____

How many persons with PWS reside there? _____

Do people with other disabilities reside there? _____

Are the residents over age 18 or minors? _____

Mail-A-Thon Report

Our official total for the 1995 Mail-a-thon was \$1201, \$600 of which will be shared with the National PWSA.

We would gratefully like to thank the following persons for their contributions since our last newsletter:

Ray & Ethelreda Gustafson

Gerald & Alice Lales *

Joe & Elaine Gareau

Jane Majcherek

Paul & Joan Steinlage

Chuck & Diane Helman

** Other contributions we have received since the mail-a-thon include:

Modern Solutions c/o Renee Cardarella

United Way of Dane County

Beth & Milton Fuehrer *

Pam Hill

Sam's Club, Appleton location

Mike's Town & Country of Appleton

* Included matching funds from Philip Morris Company, Inc.

Memberships 1995 Update

After our last newsletter, many of you realized that you inadvertently forgot to send in your 1995 memberships. Thanks so much for the great response. Additional new memberships since our last newsletter include:

Karen Czebotar

Dave and Lori Fay

Bob & Teresa Fischer

Debbie Frisk

Mr. & Mrs. J. Grout

Louise Guido

Dan & Nancy Gulling

Yvonne Jones

Sarah Larkin

Pat & Rick Lapp

Robin & Jennifer Lucas

Jane Majcherek

Nick & Wanda Scheidegger

Mrs. Bea Sturm

Jeff & Laura Werner

** That Brings our 1995 membership total to 62!!!!!!

Conference (Cont. from page 1)

New Comers/Old Timers:

Meet new friends, say hello to old ones (figurative, not biological!) and have a good time. We all have something in common which makes us instant friends.

Tim Noah Concert:

Tim was the Grand Marshall of the 1995 Washington Special Olympics. His music was enjoyable for all ages. This was a fantastic special event sponsored by the Prader-Willi Northwest Association. People were dancing in the aisles.

FRIDAY

Needs & Resources:

This was for families with a young child with PWS, who need help in finding resources. This covered many aspects of need, not just medical.

Education & IEP's:

Froysne Mensendick is the Director of Special Education for the Seattle School district and along with Dr. Vanja Holm presented the ins and outs of dealing with educational needs for our PW children. This was a great help for those with school age children.

Employment for PW Adults:

For those with children with PW, who are, or soon will be, of employment age, this was the seminar for you. Pam Simonds, Sally Underwood and Mari Martonik, (all three are individuals with PWS), shared their experiences with employment. They brought their supervisors and support teams to detail how jobs can work with quality planning: how parents, teachers, vocational staff and the community can help people realize the dream of supporting themselves through dignified work.

Nutrition:

With over 30 years of experience between the two of them, Peggy Pipes and Betty Lucas helped you understand and deal with the nutritional aspects of PWS

Behavior Management:

Steve Sulzbacher, Ph.D., was a co-founder of one of the first Prader-Willi Syndrome Clinics and co-authored the first book on PWS. Mr. Sulzbacher is well versed in the neuropsychological and psychiatric effects of PWS and will explained ways to manage unwanted behavior in your child.

(Continued from page 4)

What about the Siblings?:

Many times we focus so much on our children with

special needs that their siblings can feel a bit left out. Louise Greenswag helped everyone understand the needs of siblings and how to deal with them. With a true insiders view, Shannon MacDonald, who is a sibling to an 18 year old male with PWS, shared her experiences about life as a sib.

Accessing Resources:

Finding resources can sometimes be an almost impossible task. This networking session tried to give you ways to find what you need both from a professional and non-professional standpoint.

Living Alternatives:

Thanks to Terry James from Canada and Douglas Cook from the U.S., who gave two different perspectives on living alternatives for adults with PWS. It was a very interesting discussion with insights from two different countries with two different health care systems.

SATURDAY

Awareness Week:

1995 was the first year for PWSA's National 'Awareness Week' which many chapters participated in. Don Goranson was the mastermind behind its creation and chronicled how successful it was and what will happen next year.

Residential Providers:

Louise Greenswag, Ph.D., RN presented an overview of highlights from Wednesdays Residential Providers Symposium which had over 80 people in attendance.

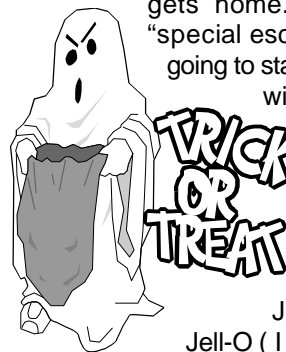
As usual, the conference was a huge success, with attendance numbers estimated to be 740. The Northwest chapter did a terrific job. If you have never attended a PWS national conference, it truly is a great experience. If you would like information on next years conference in St. Louis, the state office has travel and hotel information. Also, for those who would like to go, but cannot afford the costs of attending, the National PWSA offers grants for families and individuals wishing to go. Contact the National Office for more information.

Special Occasion Ideas

Halloween Ideas by B. Dorn

I always try to come up with new ideas for this holiday. In the early years, stickers were a big hit. We then moved to small treat bags filled with spider rings, pumpkins erasers or maybe Halloween tattoos. (Tony is 10 years old now and it gets more challenging to be "age appropriate").

We do allow Tony to go Trick or Treating. A predetermined route is discussed before leaving as well as how many pieces of candy he can eat when he gets home. Dad has always been his "special escort person". This year we are going to start foreshadowing that next year will be his last year.



I always try to volunteer to send snack for the Halloween party. I usually come up with a sugar-free Witches Brew or Pumpkin Jiggles made with sugar-free Jell-O (I even paint faces on the jiggles with h food coloring).

It's a tough time for all persons with PWS. We try to cut calories in any way we can. At the same time, we try to make Tony feel a part of things.

A Thanksgiving Note:

We always eat our Thanksgiving meal for supper. That way we end up eating only **ONE** big meal versus a lot of leftovers all in one day.

PWSA Goes On-Line

Soon Information about PWS will be accessible on the World Wide Web (WWW) through the Internet. Initially, basic information about PWS will be available along with information about state chapters, and the National and International organizations. Eventually the information on the WWW could include past articles from the Gathered View, the latest research news, surveys and a host of other information. Stay tuned for more information to come.

Legislative Initiatives of the Wisconsin Council on Developmental Disabilities

Citizenship in Wisconsin has traditionally suggested independence, self-sufficiency, choice, responsibility, and accountability. The goal of full citizenship for people with disabilities has been a focal point for activities of the Wisconsin Council on Developmental Disabilities since 1987. The Council believes that all persons have the same basic rights and responsibilities associated with the status of citizenship.

Everyone, including people with disabilities, can contribute to society and exercise their citizenship with the appropriate supports. The 1995-97 Legislative Initiatives enhance the citizenship of people with developmental disabilities by encouraging the development of independence and self-sufficiency. People with disabilities of all ages and their families should have the option to make essential decisions as where to live, with whom to live, and how and where to spend their time. The Initiatives support the desire for independence by building upon the foundation of community services built over the past decades. These are legislative initiatives supported by the WCDD.

SUPPORTING SOCIAL SERVICES

Community Aids

The council supports increasing Community Aids by the rate of inflation for each year of the 1995-97 biennium.

PROMOTING HEALTHY PREGNANCIES AND CHILDREN

Medical Assistance Prenatal Care Coordination

The Council supports increasing funding for Prenatal Care coordination to expand the program's availability for 25% to 100% of all eligible women.

SUPPORTING FAMILIES AND CHILDREN WITH DISABILITIES

Birth to Three Program

The Council supports fully funding the Birth to Three Program. The Council supports increasing the allocation for the program by \$2.9 million in each year of the biennium.

Family Support Program

The Council supports increasing funding an amount sufficient to serve an additional 500 families.

ENABLING EVERY CHILD TO ACHIEVE

Education of Children with Exceptional Education Needs

The Council supports maintaining Categorical Aids for Handicapped Education as a segregated fund. They also support increasing funding of Handicapped Education to reimburse special education costs of school districts to the same percent as regular education.

SUPPORTING PEOPLE IN THE COMMUNITY OVER THE LIFESPAN

Community Integration Program

The Council supports eliminating the multi-tiered funding approach to CIP 1A and CIP 1B rates. The Council supports the increased rates proposed by Governor Thompson for CIP 1A, however, full funding should be available at the maximum rate allowed by the federal government for all placements.

Community Options Program

The Council supports increasing the Community Options Program by an amount sufficient to serve an additional 600 individuals over the 1995-97 biennium. The Council also supports retaining the language of 1993 Wisconsin Act 469.

Medical Assistance Case Management

The Council supports the proposal of the Department of Health and Social Services to expand case management services to families with children at risk of serious physical, mental, or emotional dysfunction.

Medical Assistance Personal Care

The Council supports continuing Personal Care as a covered benefit of Medical Assistance. The Council also supports increasing the funding to allow cost of living increases for providers.

SUSTAINING PEOPLE FINANCIALLY***Supplemental Security Income***

The Council opposes further cuts in SSI to recipients.

GETTING THERE FROM HERE: THE CORNERSTONE OF INDEPENDENCE***Transportation***

The Council supports the Legislative Council recommendation to increase funding of the 85.21 Program by \$16 million over the biennium.

The WCDD works to make Wisconsin a better place for people with developmental disabilities to live, work, learn, and participate as members of the community. If you would like more information on the Legislative Initiatives of the Wisconsin Council on Developmental Disabilities call 608-266-7826 or write to WCDD at 722 Williamson St., 2nd floor, P.O. Box 7851, Madison, WI 53707-7851.

Upcoming Conferences

Health and Sexuality for People with Developmental Disabilities

An Educational Telecommunications Network discussion will be offered on the following Tuesdays from 12:00pm - 12:50pm. Dates and topics include:

September 12, 1995 - *Psychopharmacology*

October 10, 1995 - *Promoting and Supporting Self Care*

November 14, 1995 - *Recreation and Socialization*

December 12, 1995 - *Mystery Topic: Your Choice*

January 9, 1996 - *AIDS, STDs, and Reproductive Health*

February 13, 1996 - *Attitudes, Values and Beliefs: Ourselves and the Community*

March 12, 1996 - *Sexuality Education and People with Developmental Disabilities*

April 9, 1996 - *Working with Parents and Guardians*

May 14, 1996 - *Tough Issues: Sexual Orientation, Consent, Challenging Sexual Behaviors*

For Program Information contact Health Promotion Project (608) - 265 - 4079. For Registration Information contact Diane Poppa (608) - 262 - 0810. This ETN conference is sponsored by the Health

Promotion Project - Health and Human Issues, Division of Continuing Studies, University of Wisconsin - Madison.

Parenting Children With Special Needs: Planning for Children Growing Up

October 17, 1995 Envisioning and planning the futures of children with disabilities and special needs can challenge families. What to do and how to plan for the future will be addressed at this parents' forum to discuss issues of transitioning children to adulthood and dependence to independence to the fullest extent possible. Offered at Saint Joseph's Hospital Back Quadrant of the Four Seasons Cafeteria in Marshfield WI from 6:00pm to 9:00pm. For more information, contact (715) - 387 - 5228. This forum is sponsored by the Down Syndrome Support Group in cooperation with Marshfield Children's-a service of Saint Joseph's Hospital and Marshfield Clinic, Children's Miracle Network and North Central Wisconsin United Cerebral Palsy.

Developing and Implementing Recreation and Socialization

October 13, 1995 Gateway Technical College in Racine, WI

November 1, 1995 Ranch Community Services in Menomonee Falls, WI Program is from 9:00am to 3:30pm.

Looking for community recreation service projects that involve and reward everyone concerned? Together, we'll build a list of ideas and contacts that you can use to motivate and inspire others to action. Follow - up after the workshop to share further solutions, innovative practices and resources. For program information contact the Health Promotion Project, (608) - 265 - 4079. To register call (608) - 262 - 7942. Presented by the Health Promotion Project - Health and Human Issues, Division of Continuing Studies, University of Wisconsin - Madison with support from the Arc - Wisconsin.

Understanding the IEP

November 9, 1995 A partnership between parents and educators. Panel of parents, educators, and Jon Nelson, the ARC-WI Executive Director will discuss a variety of issues relating to the IEP process. At St. Pius X Church in Appleton from 7:00pm to 8:30pm. Sponsored by the Arc of Outagamie County.

Our NEXT MEETING

When: November 4, 1995
Time: 1:30 - 4:00 pm
Place: St. Albert the Great Catholic Church
Sun Prairie, WI

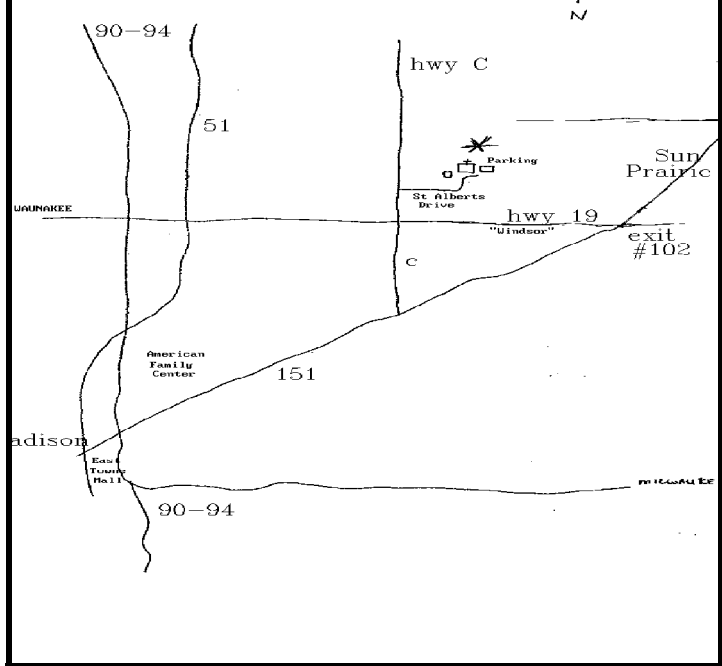
Agenda: Next years calender of events, 1996
Goals, Board of Director proposal,
sharing.

CHILDCARE WILL BE PROVIDED

A 100 calorie snack will be provided for the children. A small donation for childcare will be collected.

DIRECTIONS TO SUN PRAIRIE

St. Albert the Great Catholic Church
24020 St. Albert Drive



Prader-Willi Syndrome Association of Wisconsin
305 Amanda Way
Verona, WI 53593