



THE WISCONSIN CONNECTION

Newsletter of the Prader-Willi Syndrome Association of Wisconsin, Inc.

Vol. 4 No. 2

April 1998

Mission Statement:

The mission of the Prader-Willi Syndrome Association of WI is to Educate, Advocate and Support persons with Prader-Willi syndrome, their families and professionals in meeting the challenges of this disability.

State Officers:

President: Mike Larson
Vice President:: Jenny Lucas
Secretary: Pat LaBella
Treasurer: Tom Scheidegger
Executive Dir.: Barb Dorn

Office Address:

PWSA of WI, Inc.
305 Amanda Way
Verona, WI 53593
608-845-9597
Fax: 608-845-9638

PWSA of WI, Inc. is a chapter of
Prader-Willi Syndrome Association (USA)
2510 S. Brentwood Blvd.
Suite 220
St. Louis, MO 63144-2326
800-926-4797 or 314-962-7644

Table of Contents

Notes from the President.....	2
Elections.....	3
General Support Fund.....	3
1998 Members.....	4
Parents are Partners in Writing IEP.....	5
Encouraging Friendships.....	6
Where to Call for Help.....	7
Conference Updates.....	8

The Best and Worst of Times: Support Groups Help

from: ERIC Clearinghouse on Rural
and Small Schools. 1993.

Can you remember the feeling of becoming a parent for the first time? It's powerful, and fear is as much a part of it as love. How can any parent ever do what seems necessary? Somehow, most parents rise to the occasion. And as the new life unfolds, parents learn to take the bad with the good.

Part of taking the bad with the good may include dealing with what people now call "special needs." The term refers to children who are very different from most children. The difference might involve a handicap or disability, but it can also mean any out-of-the-ordinary condition (including special talents). The challenge, in fact, is to provide what the child needs as a result of being so different.

This is an important point. Meeting a special need means making things right for the child. The only questions are the usual ones: How? Who? Where? and When? The idea is to

overcome barriers, not to accept them. Not to give up. Not to accept "ifs" and "buts" and "no's" when you know you're right. Knowing when you are right is a matter of courage, knowledge, and the support of people you trust.

Parents of children with special needs can feel alone, stressed- out, and inadequate. They often feel guilty as a result. These emotions are natural. They come with the turf. Treating the child's need, however, requires that parents make solid connections with people they can trust.

These include other parents who face the same challenge. That's why "support groups" exist. Let's face it: The issues facing parents of special needs children scare other parents. That fear often prevents those whose children are not so different from helping. But parents who are actually facing the fear usually do want to help each other. These parents form support groups, often with the help of professionals.

Support groups exist for all kinds of special needs these days - victims of
(Continued on page 3)

Notes from the President

By Mike Larson

Here we are. Another year, another spring and another tax deadline! I hope everyone is faring well in all of these. I know I yet have the tax part to do.

There has been a lot of goings on in the world of PWS. Probably one of the items most in the media has been the Christina Corrigan case in California. Christina Corrigan was just 13 years old in November of 1996 when she died of heart failure due to obesity--she weighed 680 pounds. This past December, her mother, Marlene Corrigan, was put on trial in California for child endangerment. It was suspected that Christina had PWS. She was never tested nor was an autopsy performed after her death, but she exhibited many classic symptoms of the disability. Marlene was found guilty of misdemeanor child abuse in her daughter's death. Corrigan could have gotten six months in prison, but prosecutors did not ask for jail time. In addition to probation, Corrigan was fined \$100 and ordered to perform 240 hours of community service.

During the trial, Janalee Heinemann, PWSA(USA) Executive Director, testified as an expert witness about PWS. What does this say? As you pry into the details of the case, one glaring item that is said is that the system let the Corrigan's down. The school system, the social workers, and the health care system. Clearly, not having a diagnosis or having the knowledge of the disability made a difference in this particular case. That is why, we in Wisconsin, spend a lot of our time and efforts in educating everyone we can about PWS. We have training days, send out information about PWS to

hundreds of people every year, and diligently try to help improve the quality of life for all who are effected by this disability. We feel knowledge is power and a key weapon in fighting many of the devastating effects of this disability. Armed with the knowledge and being proactive in dealing with this disability can make the difference between life and death, as shown by this case. Sometimes we forget that this disability is a life threatening.

At this time PWSA of WI is at a crossroads where the demand for information and services are growing beyond our capacity as an all-volunteer organization. At the last meeting of the state Officers, it was agreed that, if we are to continue to grow and serve people at our current level and beyond, we need to create a paid position to manage the daily business of the organization. Finding the funds for this position will be one of our challenges this year. The plan is to start this as a part time position and continue to expand the job description as the needs of the organization grow. With this addition, it will allow us to better serve the needs of all people with PWS in Wisconsin. With this big change we have an even larger demand for people to get involved in the organization.

HOW CAN YOU HELP?

Glad you asked...

There are election of officers this year. All positions are up for anyone to run for.

Officer positions include:

President, Vice-President, Secretary, and Treasurer. These people are the driving force of the organization and will be a HUGE force in the upcoming years of guiding the

organization, business, the upcoming changes in staffing the office, and possible ways that funding from government programs will work. This will affect every person with PWS in WI. (There are some very important changes in the way The State of Wisconsin will distribute funding for the disabled. Don't just sit back and let it happen... you have the opportunity to influence your future.)

Please forward any and all nominations to the State office. It is certainly OK to nominate yourself, if you are interested in being involved.

We also need a fundraising chairperson to lead a committee for looking after the financial health of the organization and the challenge of funding a paid position.

We need a social chairperson to help plan the two outings we support each year.

We need help for our training days that are sponsored by PWSA of WI. Could you help in finding facilities, speakers and making all the arrangements for a conference.

Are you interested in writing an article for the newsletter? Or helping with the mailings.

There are so many things that need to be done but we do not have the people to help. So if you feel this is a worthwhile cause, you need to help or it may not always be there to help when you might need it most.

Elections

PWSA of WI will hold election of Officers in November of this year. The offices of President, Vice President, Secretary and

Treasurer will be chosen. Interested candidates must notify the State office by September 1, 1998 to be put on the ballot.

This is a great way to be an informed person about PWS, upcoming events and to help shape the future of persons with PWS. Please feel free to nominate yourself if you are interested in running. For more information or to nominate yourself or someone else, call the state office at 608-845-9597.

General Support Fund

PWSA of WI is starting a General Support Fund. We have budgeted \$500 to be given away in 1998. The money can be used by individuals and families for anything that will improve the quality of life for a person with PWS.

Typical examples of uses for this fund could be:

- if a group home or family needs financial assistance for exercise equipment
- if a family needs help to install locks in a kitchen
- to help attend the national conference
- Travel for emergency medical treatment

Guidelines and application procedures are being drafted and will be approved by the officers in the upcoming months. When complete they will be published in the Wisconsin connection. If you have any comments, suggestions or would just like to know more, please call the state office at 608-845-9597

The Best and Worst of Times: Support Groups Help

(continued from page 1)

abuse and neglect, people with AIDS, people who have lost a loved one, parents of disabled children. Groups that meet face-to-face on a regular basis are ideal. But even if you live in an isolated rural area, you can get help and information by contacting state or national organizations. And - chances are - you can make contact with someone in similar circumstances with whom you can talk by phone when needed.

To learn more about support groups for children with special needs - or virtually any topic related to education and raising children, call the ERIC Clearinghouse on Rural Education and Small Schools (ERIC/CRESS) toll-free at 1-800/624-9120. They can send you a free packet of six brief reports about special needs students and put you in touch with organizations that can help. To find out more about the ERIC system and its services, call ACCESS ERIC at 1-800/LET-ERIC.

Editors note: I've been told that lots of parents don't like the idea of a "support group", they feel that has some negative connotation and that they are weak if they need a "support group". Well, nonsense, I say! That term has been used often to cover people with emotional difficulties but, if a parent of a child or young adult feels they do not have emotional difficulties, then I would really

worry about them! Our organization is not here to be a twelve-step program, we have no psychologists on staff or on the Board. We are simply a group of parents who has been or is going through very similar experiences as the rest of you. We're here to provide a connection to resources, share our experiences and possibly some suggestions, and be a shoulder to cry on if you need it.

I urge you to get involved with the Prader-Willi Syndrome Association (USA) and the PWSA of Wisconsin. If anyone can understand your circumstances and empathize with you, it's parents just like you who have "been there".

If you haven't already done so, please renew your membership today and make a commitment to be more active in the association this year. We need you as much as (we think) you need us.

P.W.S.A. of WI., Inc.
1998 Memberships
As of 3-28-98

Lorraine Ablor

Scott & Janice Adams

Susan Allison

Laverne Becker

Lorraine Beirl

Robert & Kathleen Bomber

Kevin & Anne Bresnahan

Jon Cardarella

CHILDREN'S HOSPITAL OF WI
GENETICS CENTER

COMP SYSTEMS – NEW HAMPTON
GROUP HOME

CREATIVE COMMUNITY LIVING
SUPPORT
KRISTI ANDERSON

COMMUNITY TIES PROGRAM
PAUL WHITE

DANE CTY HUMAN
SERVICES/ADULT COMM.
SERVICES
JULIE SCHEIER

Lisa Danelski

Carol Dern

William & Gloria

Don & Barb Dorn

James & Judy Dorn

DREAMWEAVERS, INC.

Mr. & Mrs. Orville Endres

FAMILY SUPPORT & RESOURCE
CNTR

Miriam Farley

Lori Fay

Robert & Teresa Fischer

Gary Girdaukas (PARENT)

Chris Gursky

Tom & Agnes Hughes

HUMBOLT WORKSHOP INC.

BRUCE JENSEN

Yvonne Jones

Madonna Kieffer

Bonnie & John Kraft

Richard & Victoria Kral

Katie Kranjac

John & Pat LaBella

Lee & Shirley Larson

Mike & Mary Lynn Larson

LAURA BAKER SERVICES ASSOC.

John & Cathie Lehman

Mike & Luci Liebe

Rose Lopez

Robin & Jenny Lucas

Helen Lynch

Diane Lytton, PhD

Jan Marcou

Cindy Mattison

Donald Morgan

Robert & Pat Nelson

Marshall & Sylvia Nickelson

ODTC
MARK HOHENWALD

Cindy Organ

OUTAGAMIE COUNTY – DD UNIT

Karen & James Plosczynski

Sue Polasik

RESPONSIVE EMPLOYMENT
SERVICES

RFDF COMMUNITY LIVING

Nick & Wanda Scheidegger

Tom & Judy Scheidegger

Hazel Schuster

Laura Ellen Schutz

Raymond and Yvonne Seeley

Mr. & Mrs. Duane Spice

Richard Stark

William Stege

Russell Stuczynski

Beatrice Sturm

Rosalie Tillmann

Gladys & Tom Yuenkel

Gary Ziegelbauer

NOTICE:

This will be your last newsletter unless you call or return a response card that was mailed to you in January. We are purging the mailing list of people who no longer wish to receive mailings . If you have any questions, call the state office at 806-845-9597.

**PARENTS are PARTNERS
in WRITING the IEP**

by Pat LaBella

The newly revised federal special education law, **IDEA 97**, considers parents as partners in the entire educational process: **M-team** evaluation, **IEP** development and **placement**.

IDEA 97 has many changes to the IEP itself, but they do not take affect until July 1, 1998. However, there are many things you can do now to get ready for your child's upcoming IEP meeting.

1. According to the law, the IEP meeting must be held at a mutually convenient time/date for the school and the parents. Prior to the IEP meeting notice being sent out, let your child's teacher know what dates and times would be convenient for you to meet. You can also share your ideas as to who you would like to participate in the IEP meeting: regular education teachers, special. education teachers, support teachers like OT, PT, Speech/ Language therapists.
2. Prior to your IEP meeting, review the school records you already have. Remember to make a list of your child's strengths as well as his weaknesses. "M-Team" evaluations are done at least every three years. You can request a copy of your child's "M-Team" report. Put your request in writing, date it, and keep a copy of the letter.
3. Parents are partners in writing the IEP. It's okay to have an informal draft from the school that outlines needs, currents levels of performance, goals and objectives. You should create a draft too. However, it is illegal for the school to pre-write the IEP without your input. The school cannot hand you a finished document and tell you it's the IEP. IEP's are developed in a process of discussion and decision

making that must include the parent.

4. Make a list of the issues, concerns and ideas you have for your child's education. Chances are you can't have everything you want. Decide which issues you can compromise on and which ones you can't. It's O.K. to stand firm on some issues. You are your child's advocate. However, if the school sees that you are willing to make some compromises, you will be perceived as a team player rather than an adversary.
5. You have the right to have someone attend the meeting with you. Ask a friend, relative or another parent to go to the meeting with you. This person can take notes for you. This allows you to concentrate on what is being said rather than worrying about trying to get everything down on paper. Ask for clarification if someone uses a term that you don't understand.
6. Consider tape recording the meeting. Inform the school, in writing, that you plan to tape record the meeting and that you will be happy to give them a copy of the tape. It may be difficult for both parents to attend the meeting. IEP meetings can be very stressful so a tape recording can be a helpful way to review the meeting.
7. Include your child in the IEP process by talking with your child and incorporating his/her ideas into your list so that they are addressed. Your child has the right to attend the IEP meeting. In fact it's recommended for teens and young adults. They often have the best insights as to what will work for them.
8. The IEP does not have to be finished within one meeting. If you and/or the team need more time, you have the right to adjourn the

meeting and continue it at a later, mutually acceptable date. A good IEP takes a lot of team planning. It is rarely completed in 15-30 minutes, even if that's what the school wants.

* Contact the Department of Public Instruction (DPI) for a copy of EEN Triangle of Support. It describes the process of special education planning in "regular" language. To get a free copy call Sharon Stark at 1-800-441-4563 or 608-266-1781.

If your child with PWS will be turning 18 soon, he/she may be eligible for Supplemental Social Security Income (SSI). You can apply for SSI by contacting your Social Security office. They will consider your application during the first month after the child turns 18. EX. If your child turns 18 on February 21, they will not accept your application during February because the child was not 18 as of the first of the month. The Social Security office will accept your application on March 1 or after because your child was 18 as of the first of March.

#####

How To: Encourage Friendships for Children With Disabilities

Research shows that friendships give people with disabilities social, emotional, and practical supports and integrate them into community life. People with disabilities also bring their own gifts, such as acceptance, spontaneity, trust, simple enjoyment of life's pleasures, honesty, and several

other contributions to their friends.

To facilitate friendships, you must be open to friendship development, flexible, and persevering. Orient toward the child's strengths and allow the child to make his or her own choices, because the ability to make respected choices develops independence.

With younger children, you might have to teach the child how to interact with his or her peers in play. You will also need to educate peers. Start by discussing the child's disability with playmates. Ask for questions. This encourages tolerance and understanding of individual differences. If the child has a communication disability, tell playmates ways to communicate with the child with a disability.

Studies indicate that group size influences social play of children with disabilities. Two or three children play better with a child with a disability than larger groups. Another tip is to vary the children in the group. More sophisticated children will be role models and have better communication skills. Less sophisticated children allow the child with a disability to exhibit more leadership and problem solving.

Play activity also factors in connections. Some toys (balls or board games) promote play with other children. Toys (such as books or crayons) encourage solitary play. Organize materials to promote interaction and have them in a defined area with sufficient space to play.

Barbara Wolfe, University of Wisconsin-Eau Claire, who gives workshops on fostering young children's friendships, suggests games that allow children with disabilities to

help children interact. For instance, Shoe Mix-Up, where children take off one shoe and close their eyes, while an adult hides the shoes and then tells children to search for the missing shoe, is one such game. If the child with a disability is unable to physically get his or her shoe, a peer will gladly help look for the missing shoe.

With older children, research shows that peer tutoring, cooperative learning, disability-awareness training help children with and without disabilities to socialize, play, and just hang out. Successful strategies are:

1. One-to-one matching. Here, in a formal volunteer program (such as Best Buddies, Natural Ties), a similar-aged peer, often as an academic course requirement, is matched with a similar-aged peer who has a disability. Many long-lasting friendships emerge from these matches.

2. Existing or formal networks. In the McGill Action Planning System (MAPS), the child and family are asked to look closely at their environment and plan for a better life by examining the child's current relationships and coming up with ways to expand and improve those connections. A related method is Group Action Planning, which brings together family, friends, and community members to regularly problem solve for and with the child with a disability. For those who have few or no relationships, Circle of Friends is a method where peers are invited to make a commitment to a child with a disability. Often, this is done in the school setting and can be part of an existing or new club. Promoted to students as an extracurricular activity, this "friendship club" should allow members to choose the relationship they want to develop and

make sure the child with a disability is regarded as a peer at all times.

3. Community activities. Many places in the community actively encourage people with disabilities to participate in their programs. These include the Young Men's Christian Association (YMCA), Boy and Girl Scouts of America, 4-H (which offers more than just agricultural offerings), park and recreation programs, community theater groups, and volunteer organizations.

4. Consciousness raising advocacy. This approach, where one person or a group goes into the community to discuss disability issues, often leads to friendships.

Winning Strategies

Find opportunities to bring children together. A key trait of friendship is close proximity and frequent opportunities to socialize.

- * Highlight the child's strengths and gifts.
- * Have the physical environment accessible to the child with a disability.
- * Encourage independence. Follow the child's lead.
- * Collaborate with general education teachers.
- * Present information on disabilities to others to promote understanding.
- * Teach social skills. Talk to your child about how to make and keep friends.
- * Expect people to accept the child.
- * Have the child attend the neighborhood school.
- * While planning the child's school goals, include community activities and developing relationships.
- * Give the child time to spend with

friends.

- * Invite community members to participate in your family's life.
- * Prepare the child to answer questions that others typically ask, such as "Why do you use a hearing aid?"
- * Consider how the child can make the best possible first impression in terms of clothes, hair style, or greetings.
- * If the child has communication difficulties, offer meaningful comments to emphasize his or her similarities to other children.
- * Be open to different types of relationships.
- * Encourage the child to make friends with others who have empathy -- who can "stand in the shoes" of another.
- * Get information on Circle of Friends, Group Action Planning, or other person-centered future planning approaches.
- * Realize that true friendship needs some basis for exchange (reciprocity).

If you have more questions about friendship and disabilities, contact the Beach Center on Families and Disability at 3111 Haworth, University of Kansas, Lawrence, KS 66045 (913-864-7600) for more information. For additional information, see *Making School and Community Recreation Fun For Everyone: Places and Ways to Integrate* by M. Sherril Moon published by Paul H. Brookes Publishing Company.

Another excellent book by Brookes is *Friendships and Community Connections Between People With and Without Developmental Disabilities* edited by Angela Novak Amado. See, also, *A Guide to Thoughtful Friendship Facilitation for Education and Families* by C. Beth Schaffner and Barbara Buswell.

It is available from the PEAK Parent Center, 6055 Lehman Drive, #101, Colorado Springs, CO 80918.)

This article reprinted with the permission of The Beach Center on Families and Disability

Meeting:

"Circle of Friends"
Sponsored by the ARC of Outagamie Co. and PWSA of WI

When: April 16, 1998

Where: Goodwill Industries
Appleton, Wisconsin

Time: 6:30 p.m.

Topic: "Circle of Friends", How to help your handicapped child build friendships.

Where to Call for Help -

A Statewide Directory of United Way Information and Referral Services

Here is a listing of the locations and telephone numbers of services that provide help to people in need: United Way-supported information and referral services in communities statewide. Whether these services are called Helpline, Information and Referral, or First Call for Help®, each one helps by:

Providing information about community services that help people in need.

Explaining how to get help from those services.

Talking with people who need help,

to refer them to the most appropriate agencies or services.

Acting as advocates for people who need help, when they are unable to represent themselves.

If you yourself would like to volunteer to help others in your community, your local information and referral service will link you with the appropriate agencies that can utilize your unique abilities.

Fort Atkinson(414) 563-9555
Janesville(608) 752-3100
Kenosha(414) 657-7188
La Crosse(608) 782-8010
Lake Delton(608) 254-8353
Madison(608) 246-4357
Manitowoc(414) 684-7070
Marshfield(715) 384-5565
Menasha(414) 954-7200
Milwaukee(414) 272-5600
New Richmond(715) 425-6751
Pewaukee(414) 547-3388
Wausau(715) 848-2255

PWSA OF WISCONSIN PRESENTS TWO TRAINING DAYS THIS FALL!

"Supporting the Person Who Has Prader-Willi Syndrome"
September 17, 1998, Ramada Inn-I90, Madison, WI

8 – 8:45 am REGISTRATION
8:45 – 9 am WELCOME – Mike Larson, President PWSA OF WI, Inc
9 – 10 am Barb Dorn RN, BSN, Executive Director PWSA of WI., Inc.
Topic: OVERVIEW OF PWS

10 – 10:15 am BREAK

10:15 – 11:15 am KEYNOTE: Dr. Barbara Whitman Ph..D Behavior Specialist, University of Missouri, Serves on Board of Directors PWSA(USA)
Topic: To be determined
11:15 – 12:15 pm Dennis Harkins –

Developmental Disabilities
Consultant on Self Determination,
former Director of Bureau of
Developmental Disabilities for State
of WI

Topic: Self-Determination

12:15 – 1 pm LUNCH

1 –2 pm Diane Lytton, Ph.D.
Topic: Stress Management for
Those Who Support the Person who
Has PWS

2-2:15 pm BREAK

2:12 – 3:15 pm Breakaways

1. Supporting the Student who has PWS
2. Addressing the Nutritional Needs of Persons with PWS
3. Behavior Management Strategies for the Person with PWS

3:15 – 3:45 pm Panel of Persons
Who Have PWS

3:45 – 4:00 pm Closing Remarks
and Evaluations

“PARENT TRAINING DAY”

Place: RFDF Community Living
2875 Fish Hatchery Rd
Madison, WI 53713
608-274-4353

Date: Saturday November 7, 1998

Time: 9:30 am- 3:00 p.m.

Cost: Free to members / \$15 to
nonmembers but will include 1 yr
membership

Registration deadline: Friday October
23, 1998

Childcare will be provided at no cost.
Morning and afternoon snack will be
provided.

AGENDA

9:30 – 10:00 AM Registration

10:00 – 10:15 AM Welcome –

Mike Larson – President P.W.S.A.
of WI., Inc.

10:15 – 11:00 AM Behavior
Management – Where Do We
Begin?

FACILITATOR: Paul White,
Behavior Specialist – U.W.

Waisman Center

Parent panel: Barb Dorn & Pat
LaBella

11:00 – 11:15 AM BREAK

11:15 – 12:00 NOON Legal
Advice for Parents of Children with
PWS

SPEAKER: Lois Rentmeister,
Attorney & Grandparent of girl with
PWS

12:00 – 1:00 PM LUNCH ON

OWN – BROWN BAG IT OR
THERE ARE SEVERAL FAST
FOOD

RESTAURANTS IN AREA

(***Reunite with children)

1:00 – 2:00 PM The Residential
System – How Does It Work In
WI?

SPEAKER: Ginny Cardarella,
Director RFDF Community Living,
Parent of Son
who has PWS

2:00 – 3:00 PM Parent
Networking – sharing resources &
getting to talk to
others

**ELECTION OF 1998-2000

PWSA of WI., INC OFFICERS
WILL BE DONE THROUGHOUT
DAY

3:00 PM PICK UP CHILDREN

OTHER CONFERENCES:

Developmental Disabilities Network
1998 Calendar:

June 11 & 12, 1998

UW-Madison Memorial Union
800 Langdon
Madison, Wisconsin

DD Network & Health Promotion
Project Summer Institute: **Sexuality
and people with developmental
disabilities**

Presented by: David Hingsberger

Registration deadline: June 4

Fee: \$59/one day; \$99/two days

October 8, 1998

Monona Terrace
1 John Nolen Drive
Madison, Wisconsin

The Spirit of Our Work

Presented by Dennis Harkins

Registration deadline: Sept. 27

Fee: \$35.00

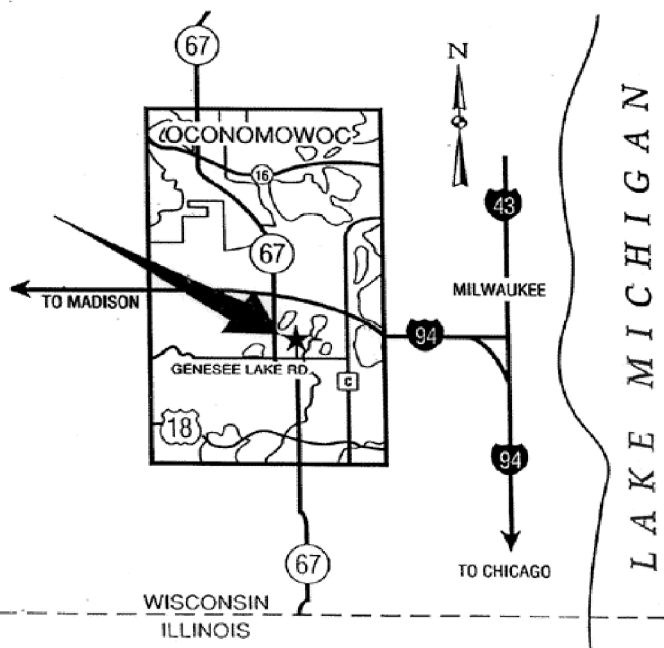
For more information please call
Howard Mandeville at
(608)266-9538

PWSA Spring Dance Sat. April 25th



1:00 to 3:00 p.m.
More details inside!

Dance on in to...
ODTC
36100 Genesee Lake



Road
Oconomowoc, Wisconsin

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