



THE 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 PWS Awareness Day: Wisconsin Chapter

April 29, 1995 was the First Annual National Prader-Willi Syndrome Awareness Day. In cooperation with P.W.S.A. (USA) and other state P.W.S.A. chapters, events were held throughout the nation to create awareness of Prader-Willi Syndrome. Along with activities to create awareness of the syndrome, fundraising activities were also conducted. In Wisconsin, a mail-a-thon was held sending letters to friends and families of members. 400 letters were sent to persons whose names were submitted by members and from our mailing list.

In another attempt to create awareness of the syndrome, Wisconsin chapter officers targeted television and news media in select areas of the state to circulate information on Prader-Willi Syndrome and the mission of P.W.S.A. of WI. As the results of this contact with the media, newspaper articles were published in Appleton, Milwaukee, and Madison along with television news features in Madison and Green Bay.

Next year we hope to get more people involved and share information about

PWS to an even larger population throughout the state.

Legislative Update

Your letters and phone calls to your legislators **DID** make a difference. A major accomplishment was achieved recently when the Joint Finance committee voted not to cut SSI funding and not to cut funding for personal care workers. This victory will allow many disabled persons and elderly adults to continue the SSI funding and the Medicaid health care coverage even though they have (a very low) supplemental income. This legislative change will also allow disabled and

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Notes from the President

Mike Larson

Well, we're in the heat of summer and the days are long. I know things have been busy for Barb in the office after the Awareness Day activities and the many new memberships that have come in. I would like to extend a warm welcome to all of our new members. We appreciate your support by becoming a new member. If you are a parent I hope you find strength and support knowing that you are not alone and are able to use our pooled resources to your advantage. If you are a family member, your role is critical for families living with Prader-Willi Syndrome. You are the ones we call when we are having a bad day, to ask advice or just knowing you are there and care gives us comfort. If you are a professional, I hope you can empathize the day to day struggles that our families live day in and day out. And when we seem a tad bit off the deep end, we know we are but it is our way of coping. All the roles are important in living with this disability.

New memberships are imperative, but just as important are current members renewing their memberships. If you haven't renewed your memberships and wish to, there is a tear off section later in the newsletter you can fill out and send in to the office. If you can't remember if you've paid your 1995 dues we have enclosed a list of 1995 members with the tear off form. If your name is not on it, you haven't.

The National Prader-Willi Conference is slated for July 20th - 23rd in Seattle, WA. If you are intending on going and haven't registered yet, you had better hurry, time is running out. A note for next year, the National Office does offer grants for persons wishing to attend but need financial assistance. To apply all you need to do is write a short letter. Also, the state office occasionally runs into opportunities for help persons wishing to go (plane tickets and other grant sources). Keep this in mind next year.

I look forward to seeing all of you at the Summer Picnic August 26th in Appleton. For more information please look for details later in the newsletter.

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Holiday and Special Occasion Ideas.

Since the diagnosis of Prader-Willi Syndrome in our family I never realized how many of our social and family activities revolve around food. We have been trying to start new family traditions and customs for holidays and special occasions. Abandoning these traditions is difficult and heart breaking, especially since so many of my most treasured memories growing up are deeply rooted in these activities and I have always looked forward to sharing them with my family. Even though my son is still quite young we have begun to alter our ways. We felt if we begin now we can start new traditions while he is still young and he will never miss the old way of doing things.

I have heard other families going through many of the same changes and coming up with some very innovative and fun ideas to replace some of the traditional activities. A couple of things we have tried so far has been to eliminate the traditional birthday cake and replace it with a very decorative fruit pizza. On Easter this year we didn't want to start giving candy, but we made up an Easter basket with plastic eggs and stuffed small toys and prizes inside. There were some "treats" inside a couple, while others included raisins and low calorie cookies. Over the course of a week he opened one egg a day to find a surprise.

Our goal was not to have our new traditions to be so radically different than the "norm", but to twist them to conform to something fun that will not be detrimental to our routine and diet.

Holidays are difficult times for individuals with PW and their families. Here is your chance to help others. If you have something you have tried or an idea that you would be willing to share I would like to gather these and publish them in upcoming issues of the Wisconsin Connection. So please send your ideas, traditions, or your low cal recipes to the state office or Mike Larson. Look for more ideas in upcoming issues.

News From The State Office

by Barb Dorn

Things have been pretty busy around here. The mail-a-thon has kept me busy. This year all donations received a thank you response and all new members received a "Welcome letter". We really feel it is important to say thank you and welcome. This year our donations are down but our membership applications are up. As of June 1, 1995 our donation total is \$818.00 and our memberships are 47. I have included a list of our 1995 members. If you are not on it, please it's not too late to join.

Our office has also been busy doing one-on-one advocating for 3 persons with PWS. These include support meetings and many phone calls to determine what services are available at the present time. The bureaucracy and slow movement of many of these service systems is often frustrating. All I can say is to plan ahead and continue to keep your patience intact.

We do have some new publications available to our members and others. We have received the new edition of *A Handbook For Parents* (cost \$5.00) and *Management of PWS 2nd Edition* (cost \$43.00). Remember to make checks payable to P.W.S.A. of WI, Inc.

I would also like to thank all of the people from Wisconsin for all the cards and notes for Tony. He is doing well and has pretty much recovered. We will have to watch him extra carefully in the sun since this reaction has made him even more sensitive to sun burning. THANKS !■

UPDATE (Cont. From page 1)

elderly to secure personal care workers to assist with dressing, grooming and preparing meals when their disability or medical condition warrants support in these areas. This legislative change will also allow disabled and elderly to secure personal care workers to assist areas so that they can stay AT HOME, IN THEIR COMMUNITIES AND OUT OF NURSING HOMES AND INSTITUTIONS.

Another area where your correspondence was effective was in the area of Family Support. Governor Thompson had proposed that funding for this program be "lumped" into the Community Aids Program. This will not occur and the program will stay as is.

There are still many unresolved issues in the education area. Continue to communicate with your legislators. Encourage them not to cap funding for categorical aids (this is the

funding source for special education).

Once again - YOU CAN AND DID MAKE A DIFFERENCE! P.W.S.A. of WI., Inc. Is a part of the WI SSI Coalition which will help us keep updated on important issues in these areas. ■

MAIL-A-THON PROGRESS REPORT

PWSA of WI., Inc. in collaboration with our parent organization PWSA(USA) conducted its 2nd Annual Mail-a-thon Fund Raiser. This year our efforts were timed with the National PWS Awareness Day on April 29th. As of June 1, 1995 our donations totaled \$818.00. Fifty percent of this will be shared with our National PWSA organization. All donations received until June 30, 1995 will also be shared at a 50% rate.

We would gratefully like to thank the following persons for their contributions:

Duane Spice	Marcella Gross
Delbert & Mary Erdman	James Kemerling
Evelyn Reddin	Douglas Bergstrom
Joyce Otzelberger	Patricia Sullivan
Kristin Lay	John Scheidegger
Frank & Judy Marik	Don & Fran Becker
Heidi Kranz	Wauneta Lehman
Ray & Elsie Dorn	Joseph & Jean Van Tuyle
Joe & Elaine Gareau	Chuck & Diane Helman
Charles & Leva McLaughlin	
Dan & Roslinda Carolyn-Rahn	
William Jr. & Shirley Skinner	

*Many of the donations received this year were in the form of memberships. These will be acknowledged later in this newsletter. Other contributions received before the fundraiser started were:

William and Kathleen Appel
August Larson Memorial
Jeanette Becker Memorial
Mary Mankowski

Early Intervention Imperative to Child's Development

by Kimberly Allen, Editor of United Press

For all children, the first years of life are critical. Children learn and develop most rapidly from birth to three years of age. For children who have a developmental delay or a diagnosed condition, early detection and intervention is essential for the child to reach his/her fullest potential during the formative years.

"Quite a few studies show this (birth to three) is the most critical learning period, so we like to catch it when we can and foster any development we can," said Wendi Schreiter, Early Childhood Exceptional Education Needs Teacher (ECH-EEN) with Outagamie County Early Intervention Program.

The Outagamie County Early Intervention Program (EIP) is a home based program that is available to any child, birth to three, in Outagamie County who is demonstrating a developmental delay or has a diagnosed condition with a high potential for a developmental delay. Currently, there are 110 families in the program.

"Starting with families as early as possible just helps us give them the best possible start they can have. The earlier we can work with them, hopefully the more of a difference we can make," Connie Vanderboss, Speech Pathologist with the Outagamie County Early Intervention Program.

The Early Intervention Program provides services at no cost to the parents for any type of delay that effects their child's development. The professional staff consists of early childhood exceptional educational needs teachers, speech pathologists, physical therapists, occupational therapists, social workers, and pediatricians.

Referrals to the Early Intervention Program come from doctors, community agencies, parents or concerned relatives. Once a referral is received, by law, EIP has 45 days to assess the child and complete an IFSP (Individualized Family Service Plan). The IFSP involves gathering the birth history and assessing the family situation to determine the concerns. After screening tests are completed, the child is then referred on to the appropriate professionals. The therapists meet with

the parents to discuss all of the results and determine placement. It is a team decision, but the parents have the final say in anything that's done with the child. Therapy begins shortly after the team decisions are made.

"We've really learned a lot from the families we work with. We never try to act like we have all the answers. We really do try to work as a team and try to figure things out together. Hopefully with our education we can guide people in the right direction. I hope we have as much to offer families as they have to offer us and together we can really make a difference. That's our goal," said Vanderboss.

The age at which a child enters the program depends on the developmental delay.

"If it is something you would see at birth, such as Down Syndrome, then the child would enter the program pretty young. If it is something such as Cerebral Palsy that is not always apparent until the child starts missing some of the milestones - doesn't roll over, walk to crawl on time - it can be later. If it is speech language, the child may be 16 to 18 months old," said Vanderboss.

"A lot of the times, the tests we do when they're just infants don't show a lot because we don't expect a lot. But

as they grow older and as the tasks we expect get harder, the delay becomes more evident. So if we waited, the child could be 2 1/2 and we would only have six months to work with them. We can enter children into the program if they have a diagnosed condition with a high probability and we know it's coming down the road. This way, we get to work with them a little bit earlier," said Vanderboss.

Professionals in the Early Intervention Program help parents and the entire family help themselves by showing them how to work with the child early on and helping them understand what is going to aid their child's development at home. After age three, the public schools are mandated to provide services to children with exceptional needs. The Early Intervention Program

refers children who have continuing needs to the schools through a transition program. This program makes the transition easier by telling parents what to expect, and teaches parents to be advocates for their child.

"The families go through the school process on their own. We help them by telling them what's going to happen, and try to help every parent realize that they are their child's advocate and the only advocate their child has," said Schreiter.

The Early Intervention Program seeks to empower parents to utilize the resources, such as support groups, that are available to them in the community. Also, many friendships

"Kids really start gaining their self-attitudes and self-esteem during the first years, and if they start out real young knowing they can't talk or walk like the other kids and you don't act on that and say, 'but you can do this and this,' it can be real detrimental to their development. So if we start early building them up and giving them those successes, it's better for them," noted Schreiter, ECH-EEN

have developed and an informal network has evolved from parents meeting other parents at EIP's group programs.

"I enjoy helping the families get over their hurdles and knowing I made a difference - knowing I can help them and at least lead them in the right direction," noted Schreiter.

The state recently began mandating that every county have an Early Intervention Program. The Outagamie County Early Intervention Program has been in place for many years and is already in compliance with most state regulations.■

"We were referred to the Early Intervention Program by our pediatrician. Our son was born two months early, and was in the intensive care unit for seven weeks before we were able to bring him home with a monitor and oxygen. It was a scary time, and I don't know how we would have done it without the support of Early Intervention. It was like they knew how we felt. We were shown exercises to help him support his head and strengthen his muscles. I also learned his best position for feeding. I looked forward to going to Explorers Group where I could talk to other moms. We worked together with therapists who provided lots of neat experiences for the children. He's still a little wobbly. He loves songs, and I sing them to him at home. He can hold up his fingers for "Two Little Monkeys." I hate to think what it would have been like without the Early Intervention Program."

Anonymous, Early Intervention Parent

Conference Updates

Sexuality Education for Youth with Developmental Disabilities

Friday July 14, 1995, 8:00am - 4:00pm 8th Floor at the Waisman Center, University of Wisconsin Madison. In this workshop, the presenter will discuss issues, present material and facilitate group discussions regarding sexuality education for youth with a wide range of developmental disabilities. She will use the guidebook, Skills Training for Assertiveness, Relationship-building and Sexual Awareness (Stars 2), to identify specific techniques and educational resources for teaching positive sexuality and the prevention of sexual abuse to children with developmental disabilities. For information contact Lynn Levin @ 608-263-5815.

SIBS CAMP

The Family Support Program is sponsoring a camp for siblings of children with disabilities. The camp is open to boys and girls ages (8-16) and will be held the weekend of

June 24 through June 26, 1995, at Camp Bird in Marinette County. SIBS Camp hopes to provide a weekend of fun and sharing between individuals who may share some of the same everyday experiences. For more information call Jacki Walske @ 608-834-7011 or 608-834-7000.

Developmental Disabilities Network Training

July 13, 1995 - This Developmental Disabilities Network Training will focus on what we have been learning in Wisconsin from the Community Supported Living Arrangements Program, and from a variety of other county efforts to enable the people we are serving to choose how they want to be supported and who they want to provide that support. In addition, we will hear from Tom Nerney and Rick Crowley from the New Hampshire Self Determination Project, a Robert Wood Johnson Foundation grant which has enabled funding for persons with developmental disabilities to be put into a single simplified funding stream and used as if it belonged to the person receiving support.

The day will be an opportunity to share information on some of the best and most interesting supports being provided for people with developmental disabilities in Wisconsin. For more information call Tom Swant @ 608-266-3717.

Service Providers Conference

Oct 19 & 20, 1995 - Prader-Will Syndrome Professional Associates, The Prader-Willi Syndrome Information Forum, & *Prader-Willi Perspectives* will be jointly hosting **The First Annual Prader-Willi Syndrome Service Providers Conference**, a two-day gathering of professionals in all fields - and parents- designed to bring everyone involved with Prader-Willi Syndrome closer together in a dialogue of mutual understanding, respect, and concern for our Prader-Willi children.

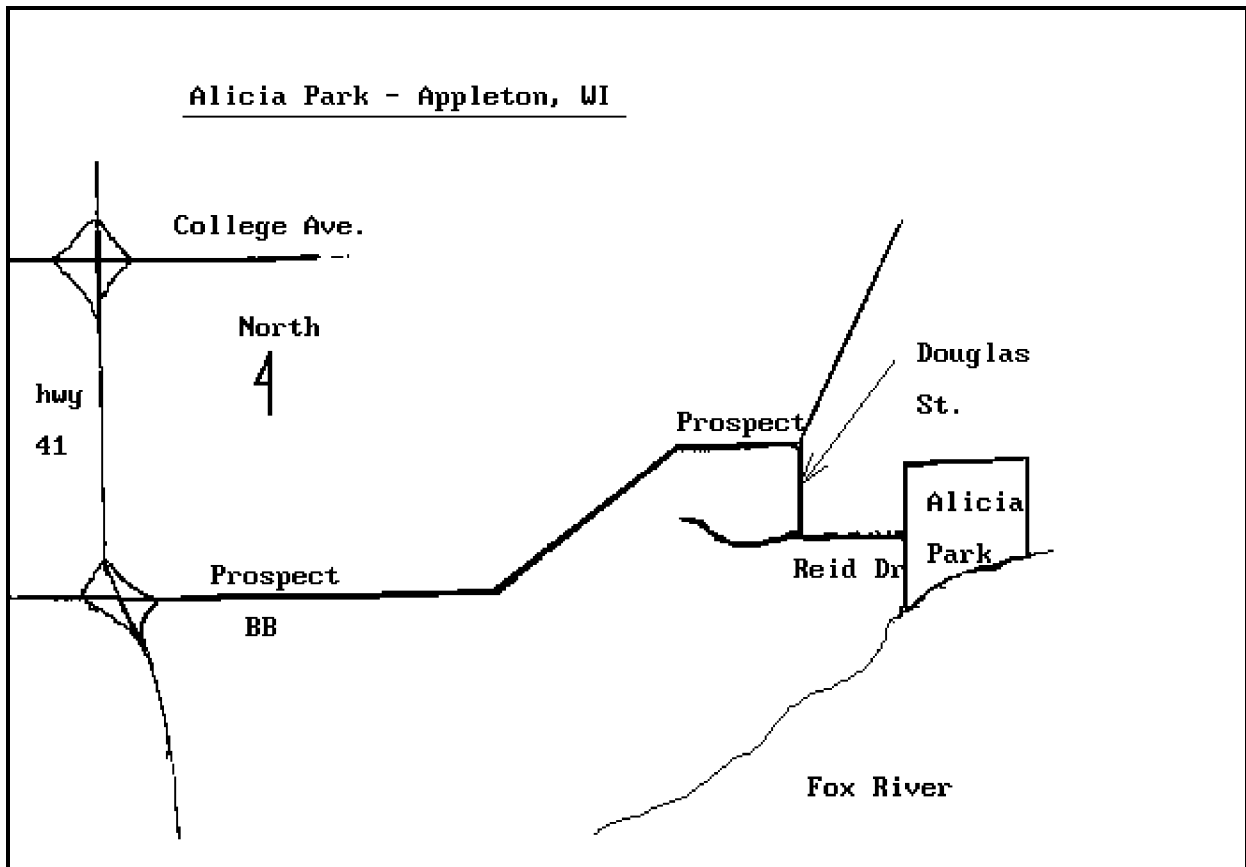
The conference will be held on Thursday & Friday, October 19 & 20, 1995 at the Radisson Hotel Lincolnwood • Lincolnwood, IL (Near Chicago). For more information call The Forum at 1-800-358-0682 • Fax 1-516-484-7154.

Come One, Come to the P.W.S.A. of WI Annual Picnic

FUN! GAMES! PRIZES!

WHERE: Alicia Park
Appleton, WI (see map)
When: August 26, 1995
Time: 11:00 to 3:00 pm

REMEMBER TO BRING YOUR OWN LUNCH.
A SNACK (100 calorie) AND DIET SODA WILL BE PROVIDED



MEMBERSHIPS 1995

In response to our Mail-a-thon, we received many new membership applications. This is another way for persons to show their support. Once again, THANKS!!!

***If you have not paid your 1995 dues, it's not too late. Your dues help us to make this newsletter possible as well as other supports and communications. If you are unable to afford our membership, your correspondence and ability to receive help will never be denied. We are here to offer help to all who assist, support and have PWS.

1995 PWSA of WI, Inc. Members

Lorraine Ablor
 Mike and Brenda Ablor
 Scott and Janice Adams
 LaVerne Becker
 Ruby Becker
 Lorraine Beirl
 Ruth Brost
 Ellen Burke
 Randy Cardarella
 Carol Dern
 Gloria and Bill Doherty
 Don and Barb Dorn
 Jim and Judy Dorn
 Mr. and Mrs. Orville Endres
 John Gustafson
 Leslie Hall

Mark Hohenwald
 Bruce Jensen
 Stanley Jeselun
 Tom and Bonnie Jones
 John and Bonnie Kraft
 John and Pat LaBella
 William and Pat Lalor
 Mrs. Walter Langer
 Jeanne Langlois
 Norman Larkin
 Lee and Shirley Larson
 Mike and Mary Lynn Larson
 Kristen Lay
 Bette Lemkul
 Mike Liebe
 Dorothy Lothe

Joyce McNamar
 Don and Hazel Morgan
 Rachel Nissen
 Greg Patek
 Larry and Barb Preston
 Tom and Judy Scheidegger
 Hazel Schuster
 Ray and Yvonne Seeley
 Lisa Seis
 Kaaren Skaer
 Duane Spice
 Richard Stark
 Sunset Ridge Care Home
 Rosalie Tillmann
 Ed and Joan Wittlin

MEMBERSHIP REGISTRATION

Name: _____

Address: _____

Name and Birthdate of Individual with PWS (optional)

1 Year Membership (\$12.00)

I am financially unable to afford the \$12.00 but would like to be a member.

Make checks payable to and mail to: P.W.S.A. of Wisconsin
 305 Amanda Way
 Verona, WI 53593

Our NEXT MEETING

When: November 4, 1995

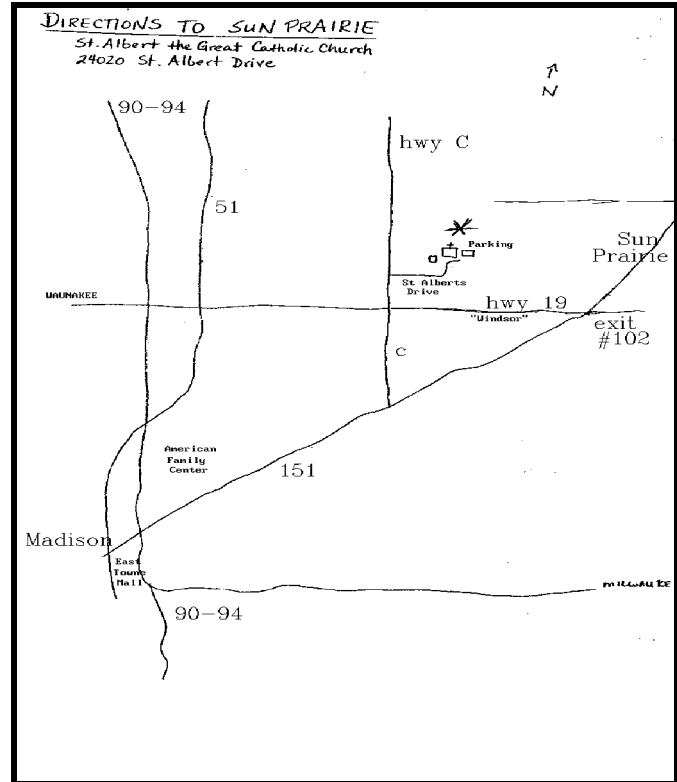
Time: 1:30 - 4 pm

Place: St. Albert the Great Catholic Church
Sun Prairie, WI

Agenda: Yet to be determined

CHILDCARE WILL BE PROVIDED

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



Prader-Willi Syndrome Association of Wisconsin

305 Amanda Way

Verona, WI 53593