



THE WISCONSIN CONNECTION

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

Mission:

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

State Officers:

President:

Pat LaBella

Vice President:

Jackie Stoner

Secretary:

Mary Mankowski

Treasurer:

Tom Scheidegger

Executive Director:

Barb Dorn

Office Address:

P.W.S.A. of WI, Inc.
305 Amanda Way
Verona, WI 53593
608-845-9597
Fax 608-845-9638
Email: pwsawi@itlis.com

PWSA of WI, Inc. is a chapter of the Prader-Willi Syndrome Association (USA)
5700 Midnight Pass Road,
Suite 6
Sarasota, FL 34242
800-926-4797 or
941-312-0400
Fax 941-312-0142
Email: pwsausa@aol.com
Website: www.pwsausa.org

A Message from the Executive Director

Barb Dorn

I want to extend a welcome to any new members or readers. Last week alone, I received three phone calls from parents of newly diagnosed (or almost diagnosed) children with PWS. The children's ages were 3, 5 and 8 years. It only seems like yesterday when we received the diagnosis. We've come a long way.

I have been busy working on the "Packet of Hope" project that we are working on for parents of children at the time of their diagnosis. I think it is good for all of us to reflect back and really see all the progress we are making. Our packet will include this handout as well as a flier on success stories from children and adults from around the State of Wisconsin. We have so many people who are doing well.

I have also been busy writing grants to help us fund our parent and professional education efforts for 1999. This is the hard part of my job – asking for money. What makes it a bit more challenging is asking for money that benefits people all over the state. Many foundations like to focus their efforts on a smaller geographically area. Educating others is a primary means of supporting persons with this disability. Without understanding PWS, people who support these individuals

are not given a chance of meeting the needs of these individuals in the best way possible.

We are looking forward to the upcoming dance as well. A lot of hard work goes into the planning and decorating. A big thanks is extended to the staff and residents of ODTG.

We would also like to extend a big thank you to Brian Fendt and Kristen Van Dusen who have offered to help us with the layout and publishing of this newsletter. It is so nice to widen our circle of volunteers.

Plans are underway for our parent group meeting to be held at Children's Hospital of Wisconsin, in Milwaukee. A group of parents have been working hard to secure a room, line up childcare volunteers as well arrange activities and a snack. The time is 1-4 pm on May 1st. Show your support and come. (Have you ever had a party where no one showed up? It's pretty disappointing).

Until next time, TAKE CARE!



Notes From The President

Pat LaBella

The mission of the Prader-Willi Syndrome Association of Wisconsin is to support, educate, and advocate for persons with PWS, their families and professionals in meeting the challenges of this disability."

On Sunday, Feb. 7, 1999 your officers met for an all day meeting to discuss our mission and to formulate our goals for 1999. Thanks to Jackie Stoner, our Vice-President and Oconomowoc Developmental Training Center for providing us with a free meeting room and a delicious lunch.



Here is a recap of our 1999 goals

In the area of supporting people with PWS, and those who care for them, we plan to:

- facilitate a parent support meeting in the Milwaukee area in May
- continue to sponsor two socials, the Spring Dance and the Fall Picnic. (These outings provide a safe environment in which all persons with PWS and their families can engage in a recreational and social opportunity with other persons who have PWS.)
- continue to provide 2 summer camp scholarships
- continue to provide financial support through our General Assistance Fund
- provide a scholarship to a family to help pay for attending the annual, national PWSA (USA) conference
- identify more people within our state who have PWS. According to population estimates from the 1996 Blue Book for the state of WI, we should have approximately 426 people with PWS in our state. So far, we have identified 112 people.

In the area of educating people about PWS we plan to:

- train teachers & support staff throughout the state via 3, half-day training sessions in August
- train residential providers with an all -day training in October.
- facilitate a half-day parent training in Milwaukee in November.
- continue to educate with on-site requests, like the training we did for people at the state level who work with the state Bureau of Developmental Disabilities, Division of Community Services.
- continue to publish our state newsletter, The Wisconsin Connection, 4 times a year

In the area of advocating for people with PWS:

- our executive director, Barb Dorn, continues to work 40+ hours a week (even though we can only afford to pay her for 10 hours) by providing support and advocacy with phone, e-mail, faxes or written correspondence. Barb handles an average of 135 phone calls, etc. in the office every month. When possible (barring a crisis at home or bad weather) she also does on-site consultative services throughout the state.
- Thanks to a grant from the *March of Dimes*, Barb and Mike Larson are working hard to create a "Packet of Hope" to be distributed to the 12 genetics clinics in the state of WI so that families of a newly diagnosed person will have some positive & hopeful information to read.
- we hope to increase our paid memberships

Our most challenging goal is to maintain financial stability.

As PWSA of WI continues to strive to meet the many needs of people with PWS and those who support them, funding becomes more critical. As you can see from the above list, we need money to achieve many of our goals. For example a day-long state wide training costs us about \$1500. We have to pay for: speakers fees, conference room rental, food and beverages, audio visual rental, conference brochures, conference folders & handouts, copying, postage, envelopes, stamps, stationary. Funding is needed to pay Barb's salary and to cover the costs of running the state PWSA office. Barb has spent many hours in the Grant Library trying to find grants to fund our various goals and to pay her salary. She continues to work hard to keep our organization running on a shoe string but we need everyone's help. We plan to have a fundraiser this spring in association with National PWSA (USA) Awareness week. Watch for details in the mail. In the meantime, if anyone knows of a grant or a funding source please let us know.



General Assistance Fund

Purpose:

PWSA of WI, Inc. has money available to assist in increasing the quality of life for a child or an adult with Prader-Willi Syndrome.

Who is eligible to apply?

Any person with PWS who resides in the state of Wisconsin the caregiver or family member of an individual with PWS who resides in the state of WI may apply.

What can funds be used for?

This money can be used for purchasing of exercise equipment, transportation for medical treatment, assistance in modification of the living environment to increase the safety of a person with PWS, supplement respite care, etc.

*** In addition, this year we have allocated money for one \$500 scholarship to be used specifically for furthering the education of parents, by assisting them with expenses for attending the national PWSA (USA) annual conference. Deadline for application for conference scholarship is May 1, 1999.**

Method of publishing fund availability:

Fund availability will be published through the PWSA of WI state office and the *Wisconsin Connection*.

Method of applying:

Application can be made by using the application form or by writing directly to the state office of PWSA of WI, Inc. with eligibility requirements, along with any additional information which might be helpful. Application can be made once each calendar year.

Method of selection:

Applications for funds will be reviewed and issued on a first come first serve basis and solely at the discretion of the state Officers and the Board of Directors of PWSA of WI, Inc. based on the eligibility requirements as outlined below.

Eligibility requirements and information needed for application for funds:

- Person with PWS must reside in the state of Wisconsin
- Name and address of individual/family applying
- Name, address and age of person with PWS who will benefit from use of these funds
- Description of what funds will be used for
- Description of what the benefits will be for the individual with PWS
- Date when funds are needed by

Confidentiality

Names of applicants and recipients of funds will be kept confidential, except from those directly involved in the screening and selection process or officers responsible for issuing of checks.

Funding

The total amount that will be given will be determined annually and reflected in the annual budget as determined by the Officers and the Board of Directors of PWSA of WI, Inc. Unused funds from the General Support Fund will be rolled over into the next calendar year to be awarded along with the budgeted amount for that year.

Contributions to the General Assistance Fund can be sent to the state office of PWSA of WI, Inc. indicating the intention of the contribution.

Awarding of Funds

Applications should be received by the state office with a minimum of 6-8 weeks time to allow the officers to review and discuss the application prior to when the funds will be needed. Award notification will be made by letter to the recipient of the funds. Purchases made prior to funding approval may not be reimbursed.

After notification of the approval of the funds, a check will be issued to the recipient. After receiving a fund award, PWSA of WI, Inc. requests that copies of receipts or documentation of how funds were spent be forwarded to the state office.

Comments

Any questions regarding the funding process can be directed to the state office of PWSA of WI, Inc.



Prader-Willi Syndrome
Association of Wisconsin,
Inc.

305 Amanda Way
Verona, WI 53593

Office: 608-845-9597
Fax: 608-845-9638

APPLICATION FOR GENERAL ASSISTANCE FUND

Purpose:

PWSA of WI, Inc. has money available to assist in increasing the quality of life for a child or an adult with Prader-Willi syndrome (PWS).

Who is Eligible to apply?

Any person with PWS who resides in the state of Wisconsin or the caregiver or family member of an individual with PWS who resides in the state of Wisconsin.

What can the funds be used for?

This money can be used for purchasing of exercise equipment, transportation for medical treatment, assistance in modification of the living environment to increase the safety for a person with PWS, supplemental respite care, etc.

*** In addition, this year we have allocated money for one \$500 scholarship to be used specifically for furthering the education of parents, by assisting them with expenses for attending the national PWSA (USA) annual conference. Deadline for application for conference scholarship is May 1, 1999.**

Date of request _____

Applicant Name: _____ Phone (____) _____

Address _____ City _____ State _____ Zipcode _____

Name of person with PWS who will benefit from use of these funds: _____

Address _____ City _____ State _____ Zip code _____

Wisconsin Resident _____ Yes _____ No _____ Age _____

What will the funds be used for:

Amount Requested: _____

Date when the funds are needed by: _____

What will the benefits be for the individual with PWS?

Return this application to: PWSA OF WI, Inc.
305 Amanda Way
Verona, WI 53593

* *If additional space is needed, please attach additional pages to the back of this form.*

Welcome and Thank You to 1999 Members

On behalf of the PWSA of WI, Inc. we would like to thank you for your membership. This money is helping us to continue our efforts in providing you with this newsletter. It's not too late to send yours in. Membership runs on a calendar year, January 1st through December 31st. Don't forget to let us know if you want to continue on our mailing list even if you do not want to be members. I do however want to encourage you to become a member if at all possible. If you are unable to afford it please let us know and we will confidentially grant you a free one. A membership also gives you discounts for our workshops and publications. Please help us to continue our efforts in supporting persons who have PWS.

Membership total as of March 1st is 73. Help us reach our goal of 100!

Larry & Lori Abler
 Scott and Janice Adams
 Agape of Appleton
 Sue Allison
 ARC of Outagamie County
 Lorraine Beirl
 Brenda Bickelhaupt
 Bob and Kathy Bomber
 Kevin and Ann Bresnahan
 Community TIES Program- Paul White
 Karen Czebotar
 Dane County Human Service -Pam Hill &
 Julie Scheuer
 Carol Dern
 William and Gloria Doherty
 Don and Barb Dorn
 Jim and Judy Dorn
 Dreamweavers, Inc.- Heather Schaller
 Mr. and Mrs. Endres
 Family Support and Resource Center
 Miriam and Mike Farley
 Lori Fay
 Bob and Teresa Fischer
 Sheri Fritsch
 Robert and Jane Fritsche

Gary Girdauskas
 Mr. and Mrs. Joseph Grout
 Nancy and Dan Gulling
 Tim Hotek
 Agnes and Tom Hughes
 Eugene and Virginia Johnson
 Bonnie and Tom Jones
 Jean Kieffer
 Jean Marie Kieffer
 Bonnie and John Kraft
 Katie Kranjac
 Pam Krauss
 Pat and John LaBella
 Mike and Jean Langlois
 Joyce Lehmn
 Mike and Luci Liebe
 Rose Lopez
 Arlan and Dottie Lothe
 Jenny and Robin Lucas
 Lutheran Social Services - Madison
 Mary and Larry Mankowski
 Jan Marcou
 Cindy Mattison
 Pat Nelson

ODTC – Mark Hohenwald
 ODTC - Jackie Stoner
 ODTC - Liz Moser
 ODTC - Nona Miller
 ODTC - Brian Fendt
 Outagamie County – DDSLL
 Florian and Catherine Plon
 Karen Plosczynski
 RFDF – Karen Berg
 Phil and Ellen Roe
 Judy and Tom Scheidegger
 Hazel Schuster
 Betty Schutz
 Judy Schutz
 Duane and Emma Spice
 Richard Stark
 Bill Stege
 Russ and Dawn Stuczynski
 Beatrice Sturm
 U. W. Waisman Center - Sandy Van
 Calcar
 Joe and Jean VanTuyle
 Lillian Weigand
 Robert Weigand
 Gary Ziegelbauer

Fall Picnic



Is there a family/ families who would be interested in hosting the fall picnic in your area? In the past we have gone to a Children's museum, to the park, swimming, bowling... We have offered a morning activity (like swimming), then stopped for lunch on our own and then offered an afternoon activity (like going to the Children's museum). We have traveled to Appleton and Madison. We are open to any help and/or ideas. If you'd like to host the picnic in your city please call the state office at 608-845-9597. We can provide you with funding, ideas and lots of enthusiasm.

On the Lighter Side

A teacher in Madison asked her eighth grade students about their thoughts on lying. Here are some of their responses.

Q: Is lying always wrong? If not, when is it permissible to tell a lie?

A: "It is OK to lie when your mother is pregnant and if she asks you how she looks, it is OK to tell her she looks great, even if she does not!"

Q: How does lying differ from "misleading" or "distorting" the truth?

A: "It's OK to mislead sometimes. For example, if you like a boy, you can mislead him."

Q: What is the worst lie you ever heard?

A: "The worst lie I ever heard was when my sister said she doesn't lie."

A: "The worst lie I ever heard was when my brother ate a whole cake and he said he was sleep walking and ate it in his sleep!" (Is there a child with PWS at that house?)

PWSA of WI, INC. Accomplishments in 1998

We are very proud to highlight **some** of our accomplishments in 1998.

In the area of Education, we:

- Published and distributed four issues of the "Wisconsin Connection" the PWSA of WI, Inc. newsletter.
- Sponsored a statewide training, "Supporting the Person with PWS" targeting professionals who work with persons who have PWS. 50 professionals attended.
- Held our first training which specifically targeted parents. Our training "Strategies and Support for Parents of Children with PWS" proved to be a big success. 30 parents, grandparents and siblings attended.
- Conducted five on-site training sessions in 3 schools, 1 vocational agency, and 1-residential agency.

In the area of Advocacy, we:

- Traveled to a community in southeastern Wisconsin for four meetings to help families and human service workers initiate a plan to open a supported living environment for 4 adults with PWS.
- Assisted in 4 team meetings, 2 court hearings as well as numerous calls to assist several young teens in crisis.

In the area of Support, we:

- Continued to provide support through one-on-one contact, phone consultations, email, education trainings, our Internet site and chat rooms and through support meetings. In 1998, our average number of monthly "telecommunications" was 133.
- Held a parent meeting at Milwaukee Children's Hospital Genetics clinic. Our goal has been to increase contact to families in the Milwaukee area and assist in connecting parents with each other.

In the area of Social, we:

- Sponsored a dance and social with the help of the staff and residents at the group homes from Oconomowoc Developmental Training Center. Approximately 80 people attended. There were games, prizes, music and a DJ. A low calorie snack as well as diet soda was provided. It was an afternoon of fun, reunions and friendships for persons with Prader-Willi Syndrome as well as siblings and parents.
- Held our annual summer picnic and outing. Eighty-five persons participated in an afternoon of swimming at the Appleton YMCA and took a trip to the Appleton Children's Museum.

In the area of Finance:

- Our organization received grants from the following foundations and organizations:
 - Wisconsin State Journal Empty Stocking Club Grant — assisted with our socials
 - Bureau of Developmental Disabilities, Division of Supported Living, Department of Health and Family Services — assisted with our education conferences
 - U.W. — Health Promotion Project - assisted with our education conferences
 - Prader-Willi Foundation — assisted with our education conferences
- We had 90 paid memberships with 2 additional memberships granted to those unable to afford this service.
- Our organization took a big step by creating its first paid part time staff position.
- We awarded two camp scholarships to two youth in order that they might attend summer camp.
- Our organization provided financial assistance to two individuals in need through our General Assistance Fund

A Brief Financial Report

1998

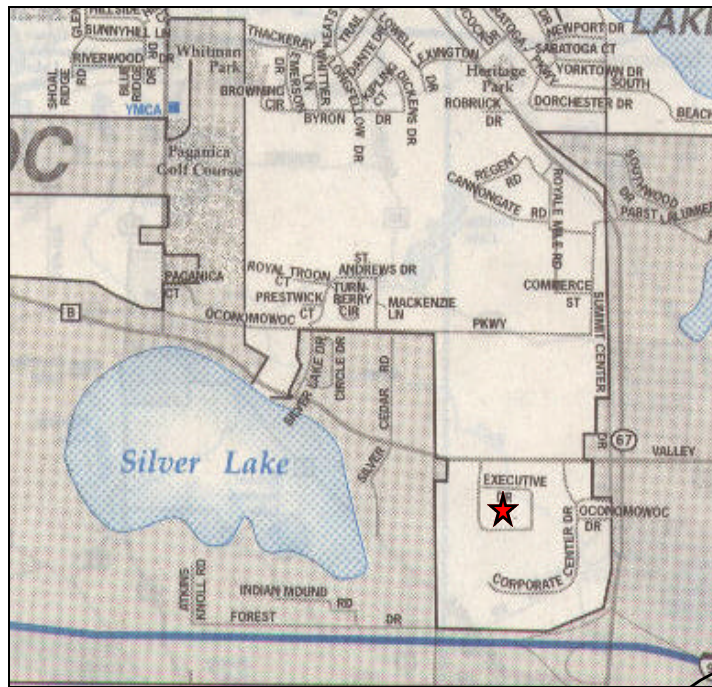
**Starting
Balance** \$19,584

**Ending
Balance** \$15,716

1999 PWSA-WI Spring Dance Oconomowoc Developmental

April 24

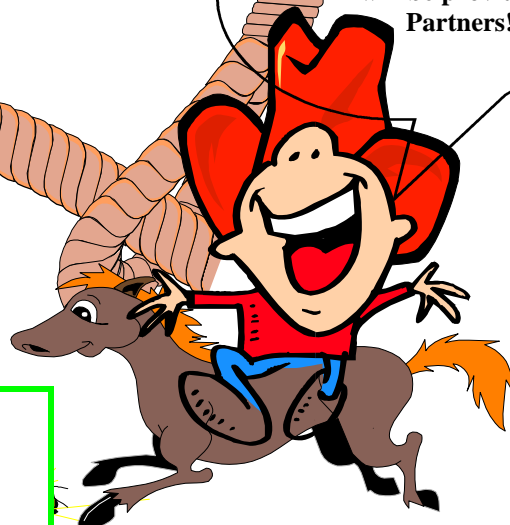
1-4pm



Soda and snack
will be provided
Partners!!!!

Directions to the Coral

HWY 94, exit HWY 67, Oconomowoc
 HWY 67 North to the first stop light
 Left on Valley Road (by Target Distribution Center)
 2nd Left on Executive Drive
 ODT Corporate Center is on the right side of the road



Progress and Hope for Persons With Prader-Willi Syndrome

Over the past 43 years, we have made several advances in our understanding of Prader-Willi syndrome (PWS). We are seeing progress being made in the areas of genetics, diet management, growth hormone therapy as well as other areas. We **have** a better today than yesterday with hope for an even better tomorrow.

- 45 YEARS AGO ... Prader-Willi syndrome had no name. Doctors did not know how to help these people. Most died in their teen years of problems resulting from obesity.
- TODAY ... This is no longer true. In 1956 Drs. Prader, Willi and Labhart identified and named this disability. We have learned that with proper diet management and behavior strategies, these people are now living happier, healthier lives. We have more children and adults who are **not** obese. We are seeing some celebrate birthdays in their 40's.
- 30 YEARS AGO ... Parents were given little hope. They were often advised to put their young child with PWS into an institution.
- TODAY ... Children with this disability are successfully growing up at home with loving parents and family members. They are attending their neighborhood schools. Adults are living in supported homes and working in their own communities.
- 25 YEARS AGO ... We did not have any organization in the United States that helped parents or professionals learn about PWS and how to manage all that these children and adults needed.
- TODAY... The national Prader-Willi Syndrome Association (USA) has been in existence for 24 years and has a membership of over 2,000. It is the only national membership organization for victims of Prader-Willi syndrome and their families in the United States. **Its mission is to provide parents and professionals a national and international network of information, support services and research endeavors to expressly meet the needs of affected children and adults and their families.**
- 10 YEARS AGO ... Children and adults with PWS were given no hope of any medications helping them control their behavior or their out of control feelings.
- TODAY ... Many children and adults are being helped with new medicines that are helping them control their feelings. It has not cured their disability but it is helping them live happier, more successful lives.
- 9 YEARS AGO ... We only had one blood test available to diagnose PWS. This test identified one problem on the 15th chromosome. We knew that PWS resulted from problems on this chromosome but we did not know much else. We were only able to diagnose 60% of people who had PWS using a blood test.

TODAY ... We have better ways of testing for PWS. Doctors have learned more about problems with the 15th chromosome. They have discovered that there are three different ways that the 15th chromosome could have been changed to cause PWS. We are now able to diagnosis 95-98% of persons who have this disability with a simple blood test.

8 YEARS AGO ... The State of Wisconsin did not have any organization, which helped to educate, support and advocate for persons with PWS and their families.

TODAY ... The Prader-Willi Syndrome Association of Wisconsin, Inc. is an active organization that helps persons with PWS across the entire state. It connects parents with other parents. It helps parents and professionals learn about new ways to help persons who have this disability and keep them healthy.

7 YEARS AGO ... Doctors did not have a clear understanding that people with PWS had a growth hormone deficiency. They did not know how low levels of this hormone were affecting their lives.

TODAY ... Doctors are now doing research right here in Wisconsin that is helping us learn more about how growth hormone therapy can help children with this disability. We hope that tomorrow they will learn how to help some of our adults who have problems as a result of low levels of this hormone.

We must never lose hope. Hope keeps us looking forward to tomorrow. Hope keeps us looking for answers to questions we don't understand. We ARE finding answers to many of these questions. We ARE making progress.



The Prader-Willi
Syndrome Association
of WI, Inc. and the
March of Dimes,
Working Together to
Help Children.



March
of Dimes
Saving babies, together

This is a copy of the Hopeful Handout that will be included in our Packet of Hope that will be given to parents at the time of diagnosis. In our packet, it is printed on colorful paper with a rainbow on it. We hope to make this time a more supportive, hopeful time.

WISCONSIN

Nov. 6	Parent Training: 1-4 PM, Milwaukee (Tentative date-pending funding)
Oct. 12	Residential Training: Fond du Lac 8:30 AM-3:30 PM
September	Officer's business meeting: Time and place to be determined
August 28	Fall picnic: Time and place to be determined
August 16, 17, 18	8:00 AM - 12:30 PM (Tentative dates - pending funding) Education Trainings: Madison, Appleton, Milwaukee, National PWSA (USA) Conference, San Diego CA
July 8, 9, 10	Milwaukee Parent meeting: 1:00 - 4:00 PM, Children's Hospital of WI
May 1	National Prader-Willi Syndrome Awareness Week
April 24 - May 2	(ODTC) 1:00 - 3:00 PM, <i>Western theme</i>
April 24	Spring Dance: Oconomowoc Developmental Training Center
Feb. 7	Officer's business meeting: ODTC, 11:00 - 4:00 PM

1999 Calendar

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

