



THE WISCONSIN CONNECTION

THE NEWSLETTER OF THE PRADER-WILLI SYNDROME ASSOCIATION OF WISCONSIN, INC.

Volume I, Number 2

January 1995

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.

State Officers:

President:

Mike Larson

Vice President:

Pat LaBella

Secretary:

Bonnie Jones

Barb Dorn

Treasurer:

Tom Scheidegger

Office Address:

P.W.S.A. of WI, Inc.
305 Amanda Way
Verona, WI 53593
608-845-9597
Fax 608-845-9638

PWSA of WI, Inc. is a chapter of the Prader-Willi Syndrome Association (USA)
2510 S. Brentwood Blvd.
Suite 220
St. Louis, MO 63144-2326
800-926-4797
or
314-962-7644
Fax 314-962-7869

Elections



Elections for 1994-1996 Board of Directors/Officers were held in November. The following are the results:

Michael Larson - President
Appleton, WI

Pat LaBella - Vice President
Madison, WI

Tom Scheidegger - Treasurer
Sun Prairie, WI

Barb Dorn - Co-Secretary
Verona, WI

Bonnie Jones - Co-Secretary
Janesville, WI

Grant Received

We have received, again this year, a grant from the Empty Stocking Club in the amount of \$350.00. This donation is intended for covering some of our expenditures for our spring dance and summer picnic.

1995 Calendar of Events

This is a tentative calendar of events for the upcoming year. More information on all events will be forthcoming in the Wisconsin Connection.

March 11 - 1:30 - 4:40 PM
PWSA of WI Meeting at Sun Prairie

April 1 -
Spring Dance

April 29 -
PWS Awareness Day

May 6 -
Estate Planning Seminar
(Tentatively in Stevens Point)

July 19-22
PWSA National Conference
(Seattle, WA)

August 26
PWSA of WI Picnic
Appleton, WI

October 19 & 20 -
Service Providers
Conference (Lincolnwood, IL)

November 4 -
PWSA of WI Meeting

Notes From The President...

Mike Larson

For those who don't know me, let me introduce myself. My name is Mike Larson, and I am a parent of a child with Prader-Willi Syndrome. I am stepping in as the new President of P.W.S.A. of Wisconsin. At this time I would like to commend Barb Dorn on her courage and commitment in undertaking the roll as the first president of this truly unique organization. This organization is unique because it was started by, organized by, and financially supported by friends and families of individuals with Prader-Willi. Those who have had the privilege of knowing and working with Barb will know her dedication and untiring drive to help others who, like herself, are traveling this rocky road of living with Prader-Willi Syndrome. For myself (and I'm sure many others), I have looked up to Barb for inspiration and encouragement as a parent of a child with Prader-Willi Syndrome. I know I can't replace Barb as President, but I hope to carry on where she has efficiently laid the ground work and perhaps expand in new areas where needs exist. I'm happy that Barb will continue to run the state office and assist as co-Secretary with Bonnie. From all of us THANK YOU Barb!

A little background on myself. I am 32 years old, have a degree in Mechanical Engineering and work for Valmet Paper Machinery. My wife, Mary Lynn, and I are both originally from the Upper Peninsula of Michigan and have been living in Appleton, WI for almost seven years. Mary Lynn is a Pediatric Speech Pathologist at St. Vincents Hospital in Green Bay. We have a two year old boy named Alex, who has PWS.

The first time I ever heard about Prader-Willi Syndrome was approximately a year and a half before Alex was born. Mary Lynn had seen a patient who they suspected had PWS. In Mary Lynn's usually thoroughness she started her own research on the topic and came home that night to tell me about this horrifying syndrome that she had read about. She felt so much for the family and what they must be going through. Little did she know how familiar she would become with this topic. I'm sure I don't have to tell many others how devastated we felt after receiving the diagnoses of PWS for our son Alex. Being a first time parent and having our dreams shattered before our eyes was a little too much at times. But after a while we started pulling together, reading more and more on PWS, and making new dreams of for our child and our selves. Occasionally we fall back a few steps, but keep trying to push forward. I find for myself that being proactive and working with PWSA of WI helps me keep a prospective of where we are and what we must do. One day Mary Lynn brought home the story about Going to Holland. I liked it very much and wanted to share it with you. It is included on page five of this issue of the Wisconsin Connection.

In the coming year there will be changes in the organization as we grow and reach more and more families and individuals with PW. We have tentatively set our activities for the upcoming

year. It seems that the year is too short to fit all the activities we would like to see.

During our last business meeting an overwhelming concern over estate planning was discussed. Since then we have been able to schedule a seminar on estate planning for people with disabilities. This will tentatively take place on May 6th. Exact location has not been determined yet but more information will be outlined later. Another highlighted event this year will be The First Annual National PWS Awareness Day. During this period we are planning to run our second fund raising letter campaign. More details of how you can help are outlined in the article on fund raising. I feel there is a good balance of events this year in providing educational opportunities, promoting the awareness of Prader-Willi Syndrome, sharing and having fun and fellowship with the others we have grown to know well over the years and our new friends that we will meet in 1995. This schedule is outlined in this issue of the newsletter.

As you can see we have adopted a new logo for our state chapter. We have taken on the look of the National Organization to show that we are a chapter of the National Organization. We also can take advantage of the National brochures. With the logos being similar, we have a uniform and professional look. We are in the process of developing letter head and business cards for the state office in order to present a more professional image and that we take our mission seriously.

Before I close I would like to say that this is your newsletter, and we are very interested in having as many persons contribute to it's content as possible. So this is where I will give my pitch for you to please send us your thoughts or ideas on topics you would like to see. If you've read an interesting article, just jot down a few sentences on what it was about. It doesn't need to be lengthy. Do you have any questions you would like answered, favorite low calorie recipe you want to share, or just a story or inspiring poem. Please feel free to call or drop us a line. I can be reached at the following:

Mike Larson
2701 N. Alexander St.
Appleton, WI 54911
Phone: 414-749-1174
Fax: 414-749-0906 or 414-738-8539
Internet: Mike.Larson@vpi-app.ccmil.valmet.com

Conference Announcements!

Service Providers Conference - Oct 19 & 20, 1995

Prader-Willi 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.

More information about the conference will be passed on as it develops. So far, the two key speakers will be Dr. Merlin G. Butler of Vanderbilt University and Dr. Elisabeth Dykens of the Yale University Child Study Center.

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 or on the Internet at visink@delphi.com.

Brothers & Sisters of Children with Special Health Care Needs - March 3, 1995

This conference is dedicated to the siblings of children who have disabilities. The relationships of these siblings are distinctive and unique. The brothers and sisters of children with special health care needs require special attention, understanding and support. Through joining together to discuss their concerns, needs and experiences, we will be better able to help them cope with the ongoing challenges of their family relationships. Pat LaBella will be participating on a panel discussing the emotional and behavioral aspects of having a sibling with a disability.

This conference will be held at the Holiday Inn-Southeast, 3521 Evan Acres Road, Madison on March 3, 1995 from 8:30 AM to 4:30 PM. For more information contact LeaRae Galarowicz, outreach program coordinator, Continuing Education in Nursing.

2nd Prader-Willi Syndrome International Scientific Workshop and Conference - Oslo, Norway-July 15-18

This conference sponsored by the International Prader-Willi Syndrome Organization will be held at the Sormarka Conference Centre, 1404 Siggerud, Norway. All inquiries and material should be sent to: 2nd PWS-Conference, Frambu, N-1404 Siggerud, Norway. Attn: Christen Aashamar Tif: 47 64 865460 Fax 47 64 865860. For more information on conference registration and agenda contact the PWSA of WI office or Mike Larson.

Fund Raising Mail-a-thon

In 1995 during the National PWS Awareness week/day we will

again conduct the Mail-a-thon to friends and family. Our campaign last year was very successful. A total of 193 letters were sent out and over \$2000.00 was raised. This year our goal is to send out 400 letters and raise \$4000.00. With this years campaign being tied with the First Annual PWS awareness Day, it has been decided to split the contributions 50/50 with national. In order to reach our goal we need to have each and every person fill out the enclosed form of names and address of persons we can send the fund raising letter to. The letter will briefly explain what PWS is and tell about our organization and our mission. Please take time and fill out the enclosed form. If additional space is needed please use another sheet of paper to complete your list. Please return these lists to the State office by March 1st. If you have any questions please feel free to call the state office or any of the officers.

Thanks to the following Contributors:

Sam and Sue Allison
Richard and Karen Larson
Carl and Susan LaBella
Valmet Paper Machinery
Matching funds from Philip Morris Company

1995 Membership Drive

In 1995 we are still striving to increase our membership. Our Mission is to: "educate and assist families and professionals in dealing with individuals with Prader-Willi Syndrome." Membership dues are \$12 per calendar year. If you are not able to afford the yearly dues and want to be a member please contact the PWSA of WI office and sponsored membership can be arranged. As our organization grows we can do more and support to an even greater extent more individuals and families effected by Prader-Willi Syndrome. Please encourage friends and families of everyone you know of that is effected by Prader-Willi Syndrome to become a member. A reminder for current members: Your 1995 members ship dues are payable any time in January.

New Fax for PWSA of WI

A fax machine has been donated to the Prader-Willi Syndrome Association of WI by Joes Communication of Escanaba, MI. A separate number has been set up for this fax to receive documents. This new number is 608-845-9638. With this fax machine we should be able to communicate with people much more efficiently.

**** **BOOK REVIEW******

NEW BOOK PROVIDES PARENTS WITH A CHILD WHO HAS A DISABILITY WITH VITAL INFORMATION ON LIFE AND ESTATE PLANNING

Planning For The Future is a highly acclaimed new book providing a comprehensive guide to parents of children with disabilities. The 400 page book contains all the information parents must consider as they plan for their child's life after their own deaths. Easy to read and understand, the book describes in step-by step detail what the authors term "comprehensive estate planning," which comprises all the elements - personal care, financial, and legal - that parents must consider to secure a happy and fulfilling life for their child. To order your copy of **Planning For The Future** call (800) 247-6553 (credit card only, please) or send your check for \$24.95 plus \$3.50 shipping and handling to American Publishing Company, P.O. Box 988, Evanston, IL 60204-0988 (be sure to include your address).

The book begins with an extensive discussion of the life planning process, describing in careful detail all the various options available to those with disabilities in terms of social activity, residential care, and employment and educational opportunity. Parents are shown how to convey crucial information to others, so their hopes and aspirations for their child will be realized. Examples of several life plans illustrate the process. The book then guides readers through the complicated maze of financial planning, providing useful information on government benefits in an easy-to-understand way. Also included is an extensive discussion of funding sources to assure parents that their children will have access to resources sufficient to enable them to meet their financial needs.

The book ends with a discussion of the more traditional planning documents - wills and trusts. Parents are introduced to the concept of the special needs trust, which can be used by parents to leave money for a child with a disability without affecting the child's eligibility for badly needed government benefits or subjecting the child's inheritance to a seizure by the government for cost-of-care claims. Other topics include probate avoidance, and estate and income tax planning, which can potentially save families many thousands of dollars. Another important chapter explains how the reader can avoid the devastating costs of old age.

Planning For The Future contains twelve chapters and three appendices designed to give readers all the information they need to ensure a happy and meaningful life for their children after they die. The book draws on the authors' extensive personal experience in planning for families with children who have disabilities, providing a number of case histories and specific examples to enable readers to understand the

planning process with greater ease.

Planning For The Future is a vital new resource for parents of children with disabilities. It is a must read for parents who are concerned about their children's future well-being.

Note: *There are 2 copies of this book available for 30 day loan from PWSA of WI state office. Please call if interested in checking out.*

Life Planning Approach

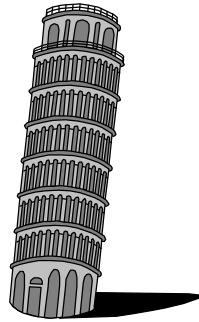
There are few guarantees in life. Yet, unless the family does Life Planning, there may be no guarantees at all. If a family wants to "guarantee" that their child or relative with a disability will always live in a comfortable environment, have adequate funds, competent people to look after him or her and, generally, have a meaningful lifestyle, Life Planning is essential. In many instances, proper planning can also protect government benefit programs, but even if the government changed the rules tomorrow, the Life Plan will still take care of the person. Naturally, the person with the disability should be a full member of the planning team where possible. It is something that needs to be done now whether the person is one month old or 50 years old. Life Planning is important to all persons with mild to profound disabilities. Good planning can help protect the person's future and the family's estate.

On May 6th Randall Gomoll, a Certified Financial Planner from Estate Planning for Persons with Disabilities (EPPD) will give a informational seminar on comprehensive life planning. EPPD serves as a national clearinghouse for parents and professionals on this highly specialized topic. EPPD presents free two hour educational seminars to inform families about Life and Estate Planning. With this information and motivation, families are ready to begin the process.

More information will be published in the next issue of the Wisconsin Connection. If you are interested in attending this seminar, please contact the state office or Mike Larson for more information.

WELCOME TO HOLLAND

I am often asked to describe the experience of raising a child with a disability - to try to help people who have not shared that unique experience to understand it, to imagine how it would feel. It's like this...



When you're planning a fabulous vacation trip - to Italy. You buy a bunch of guidebooks and make your wonderful plans. The Coliseum, the Michelangelo David, the gondolas in Venice. You learn some handy phrases in Italian. It's all very exciting.

After months of eager anticipation, the day final arrives. You pack your bags and off you go. Several hours later, the plane lands. The stewardess comes in and says, 'Welcome to Holland.'

'Holland?!?' you say. 'What do you mean, Holland? I signed up for Italy! I'm supposed to be in Italy. All my life I've dreamed of going to Italy.'

But there's been a change in the flight plan. They've landed in Holland and there you must stay.

The important thing is that they haven't taken you to a horrible, disgusting, filthy

place, full of pestilence, famine and disease. It's just a different place.

So you go out and buy new guidebooks. And you must learn a whole new language. And you will meet a whole new group of people you would never have met.

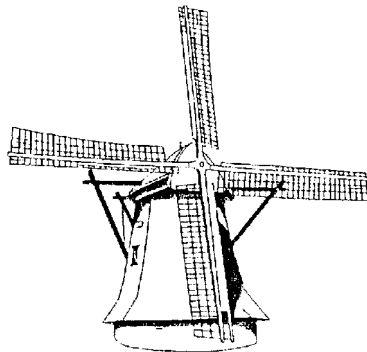
It's just a different place. It's slower-paced than Italy, less flashy than Italy. But after you've been there for a while and you catch your breath, you look around, and you begin to notice that Holland has windmills, tulips, and Rembrandts.

But everyone you know is busy coming and going from Italy, and they're all bragging about what a wonderful time they had there. And for the rest of your life, you will say, 'Yes, that's where I was supposed to go. That's what I had planned.'

The pain of that will never, ever, ever go away, because the loss of that dream is a very significant loss.

But if you spend your life mourning the fact that you didn't get to Italy, you may never be free to enjoy things about Holland.

Author: Emily Pearl Kingsley



OUR NEXT MEETING

WHEN: Saturday March 11, 1995

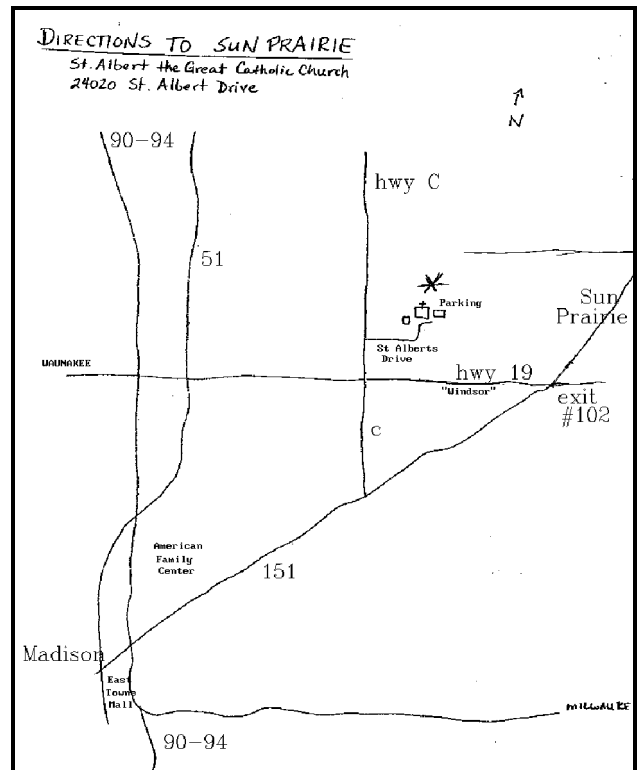
TIME: 1:30 - 4:00 P.M.

PLACE: St. Albert the Great Catholic Church
2420 St. Alberts Dr. SUN PRAIRIE
(MAP ENCLOSED)

TENTATIVE AGENDA: Discuss more plans for 1995, discuss PW Awareness day, Spring Dance plans, SHARE!!

***CHILDCARE WILL BE PROVIDED but we are asking for a small donation so we can provide our child care providers with a small thank you gift.

We are looking for volunteers to provide low calorie snacks for the children and persons attending the meeting. Please call the state office to volunteer.



Prader-Willi Syndrome Association of Wisconsin, Inc.

305 Amanda Way
Verona, WI 53593