



THE WISCONSIN CONNECTION

*The Newsletter of the Prader-Willi Syndrome Association of Wisconsin, Inc.
Supporting, Educating and Advocating for Persons with Prader-Willi Syndrome and All who
are Impacted by this Disorder*

Board of Directors:

President: Mike Larson

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Treasurer: Tom Hughes

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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.

A Message from the President: Mike Larson

Now that the National conference and the annual golf outing are over, I think that everybody who helped in these events is taking a collective sigh of relief. I can't tell you the amount of effort and dedication that these people have shown. I am very grateful and proud of all they have accomplished for this organization. We are still getting emails and phone calls with compliments of how well the National conference went. Thanks to all who helped.

After accomplishing so much, where do we, as a state chapter, go from here? Unfortunately even after all this is over, the phone doesn't stop ringing. Mary Lynn is still getting calls from individuals and families needing help. We will be having our next PWSA of WI, Inc. Board of Director/officers meeting soon to talk about where we are going. We have achieved some very lofty goals for our little organization, so it's time to talk about what do we want to do and where do want to go next? Goal setting time! As always, this is an organization of its members. So, as members we need to hear from you. What are your needs? What do you need help with? What are your dreams for our individuals with PWS? Call, write, or email. Let us know where we need to go and help us make a road map.

In fall we will be having elections. This is a chance to get involved and make the dream happen. We have officer positions and board member positions open. Please step forward and contribute. The work is not hard and the rewards are great! But we do need you!

The Larson household is in chaos. The anticipation of the start of school seems to bring out additional stress and anxiety for the pending school year. Every year it happens and every year we stress. It seems more intense this year with both boys anticipating, worrying and perseverating. But as parents, it is time to dust off the IEP's and start thinking of where we want the boys to go this year, what do we want to happen for them. Its time to make your goals and start fulfilling your dreams.

I'm sure Mom's across the state with be letting out their collective sigh of relief once school officially starts. Thank God for Mom's and their infinite patience.

Mike

PWSA (USA) and PWSA of WI, Inc host the 30th National Conference in Milwaukee, WI “Moo-ving Forward” What A Success! By Mary Lynn Larson

The 30th Annual PWSA (USA) National Conference, hosted by PWSA (USA) and PWSA of WI, Inc. was a HUGE SUCCESS!! I hope many of you were able to attend! There were over 400 individuals in attendance including parents, care providers scientists and researchers.

**Moo-ving
Forward**



As conference neared the end, many of the WI conference committee reported families would come up to them and express their gratitude. One mom stated, “You saved my life!” referring to the information and resources she gained to help her be a better parent and advocate for her child with PWS.

The first day of conference started with the Chapter President’s Meeting, Scientific Day, and Provider’s Day. This allows anyone in those roles (either researcher, MD, chapter leader or a provider) to meet, network and learn with and from others who are working with similar issues.

On Wednesday evening, the Welcome Reception allowed families to meet one another and involved the children in a variety of activities. The next two days were focused primarily on families and caregivers of persons with PWS. We had sessions on orthopedics, sensory integration, handling circumstances when law enforcement is involved with your child with PWS and so much more! Although I was unable to attend a full session on many of the topics because of the many issues working as a member of the Conference committee, the parts I did attend were very informative. The Gala event and Silent Auction were also a great success! We were able to raise over \$6000.00 with all the donations and generous bidders!

And we would like to extend our heartfelt **thanks** to everyone involved who helped with ideas; planning; volunteering time, treasure, or talent; offering funds; or whatever!! We could not have done this without you! I would like to especially thank those on the Wisconsin conference committee for the efforts they have put in for the last three years! Our WI conference committee was EXTREMELY well organized and prepared—and were able to pull things off with minimal glitches! **THANKS!!**

Notes from the office.... By Mary Lynn Larson

WOW.... It’s over! After being so busy and occupied with the Conference over the last 3 years... I am now trying to catch up on all the other things I missed while we were focusing on Conference—like sleep! Not that we are remaining idle!! We have been focused on the golf outing and upcoming Board meeting — just changing the priorities and timelines for different things in our lives!

School in our house is only 1 week away as I write this!! I am working on getting my boys ready for the new school year as well as getting calls from other families who are preparing for similar transitions, needing information for their child’s school personnel and wanting to know how they can help the teacher understand just how important it is to have structure and routine in their child’s life or to know how to help a child with PWS transition from music class to math class without a meltdown! If you ever need help or assistance in this area, **do not** hesitate to call the office! If I am not available, I can usually put the word out and other families who have worked with their own school are often willing to step up and help out other families having difficulties in this area.

We are looking for potential Board members and Officers as Fall signals election time in the organization. If you are interested in what positions are open and the responsibilities of a Board member—please see the next page! Fall is also the time we hold our “Young Parents meeting”. This is not a meeting specifically for *parents* who are younger in age but for those who are parenting a child with PWS who is younger—usually under the age of 10 years. We will be holding this meeting (technically referred to as the “Meeting for Young Parents of Children with PWS”) in the Milwaukee area again this year on the same date we are having our annual membership meeting. We do arrange for child care for the children so that parents are able to network without having to focus on keeping their children busy. Location to be determined.

I hope many of you are able to attend. It is always great to meet new families and members during the Meeting for Young Parents of Children with PWS. Hope to see you there,

Hugs, Mary Lynn

UPCOMING HEALTH TRAININGs

Health Education for Persons with PWS

Wednesday October 1st and 8th, 2008 from 6-7 pm

Location: UW-Waisman Center Outreach: Madison

Registration Fee: NONE

Register: On line - <http://www.cow.waisman.wisc.edu/traincon.html> or call 608-265-9440 Ext 440

People with Prader-Willi syndrome (PWS) have health issues that are unique and often confusing to those who care for them as well as to themselves. This 2-part class will provide teens and adults with this disability a basic understanding of these health issues as well as simple strategies of how to prevent and care for these issues. It will also attempt to give them some tools that will assist them to become health advocates for them selves as they interact with health care professionals. The class is designed to share information in a variety of formats followed by time for "Good Health" BINGO which reinforces concepts presented. Prizes will be awarded at the end of each class.

Barb Dorn, RN BSN is an advocate, educator, consultant, and parent of a young man with PWS. She is Registered Nurse at the University of Wisconsin Hospital and Clinics and has extensive knowledge in the health and well being of persons with PWS.

Behavior Management Strategies for Supporting Teens and Adults with Prader-Willi SyndromeDate:

Wednesday November 5th, 2008 Time: 12-2 pm

Location: UW Waisman Outreach Office in Madison

Register: On line - <http://www.cow.waisman.wisc.edu/traincon.html> or call 608-265-9440 Ext 440.

FREE Health Information Packets

As part of our ongoing efforts to educate parents, caregivers and professionals about health issues that may be faced by a child or adult with PWS, PWSA of WI, Inc has free health information packets available. There are two components – a packet that provides information for the health care professional who cares for the person with PWS and a packet that provides information and resources to the health advocate – the parent, caregiver and person with PWS. To receive your free packet, contact PWSA of WI, Inc office by phone Toll free: 1-866-797-2947 or by email – Wisconsin@pwsausa.org



FREE Packets to Educate Educators

It is back to school time again and time for parents to share information with educators so that the student with PWS can have a happy, successful school year. PWSA of WI, Inc. has packets of information that include handouts, brochures and other resources for parents to share with educators. It is strongly advised to create a "cheat sheet" for all members of the students' education team. Include items that you know will help to prevent errors or situations that may result in failure or turmoil for the student with PWS. What are his/her interests? What motivates him/her – what upsets him/her? When sharing this information - don't forget to include ALL educators including physical education teachers, art teachers and others who may not have easy access to the student's IEP. Contact PWSA of WI, Inc office for your packet.

Work Place Giving –

Remember PWSA of WI

It is that time of year again, when many employers offer employees the opportunity to sign up for payroll deductions that will benefit the charity of their choice. Please make PWSA of WI one of those charities. If you work for the State of Wisconsin, City of Madison, Madison Metropolitan School District, Madison Teachers Inc., Dane County, Monona School District, or Madison Area Technical College you can easily make this donation through the Combined Campaign or Partners in Giving Program. PWSA of WI, Inc is a member of the umbrella, Access to Community Services and we are listed as a recipient organization (#511). If you do not work for one of these organizations, you may still be able to list our organization in the "donor choice" area. In most cases, all you need to do is to list PWSA of WI, Inc along with our address – 2701 N Alexander, Appleton, WI 54911. Thanks to the generosity of our members and their family and friends, PWSA of WI, Inc has been able to receive donations from many work place campaigns. If you have any questions, please feel free to contact our office. Your generosity counts in helping us to continue our support, education and advocacy efforts.

Call for Candidates – 2008

Are you looking for a way to get involved and help all with PWS? PWSA of WI, Inc. has 3 Board positions open for election this fall and serving a two-year term. If you or someone you know is interested in serving our organization, please contact our office for filing papers. You can and will make a difference in the lives of persons with PWS. A ballot is sent to all members in mid-September. Our annual membership meeting will be held on October 11, 2008 in Milwaukee. (See below for more details). The following is a brief outline of some of the major events and activities that PWSA of WI, Inc. attempts to sponsor on an annual basis. We have outlined these activities to help potential board members and officers learn their responsibilities as well as help them to decide what areas they would like to become more involved.

VICE PRESIDENT: may be delegated by the president to perform his/her duties in event of the president's temporary disability or absence from meetings, and shall have such other duties as the president may assign.

TREASURER: shall be responsible for the financial integrity of the organization. He/she shall keep an account of all moneys received and expended for the use of the organization and shall report to the National office and the membership on the financial status of the organization. The treasurer shall establish the necessary controls and checks for the handling and accounting of all financial transactions for the organization.

BOARD MEMBER: Serves as advisor in providing governance to the organization. Assists in projects, committees and other capacities as needed.

OVERVIEW OF BOARD MEMBER RESPONSIBILITY:
The following is a brief outline of major events and activities PWSA of WI, Inc. sponsors annually.

BOARD MEETINGS: The board of directors meets three times a year. The meetings are typically in February, early June and October. The exact dates, times and locations are determined at the previous meeting. We typically meet from 11 am to 3 pm. Every attempt is made to work around board members' preferences and location. We try to meet at a central location if possible. We have tried many approaches and currently schedule it on the same day as our fall training workshop prior to the annual membership meeting.

BOARD MEMBER INVOLVEMENT: We encourage Board members to become involved in **at least one activity or project** per year. The following is a list of our current activities and projects. Dates and types of events are discussed and determined at our Board Meetings.

Annual Social-Training Day This event typically occurs in the spring of the year. We have tried various approaches, activities and locations for this event. The primary focus has been hobby activities in the morning with a dance - social activity for children and adults

with PWS in the afternoon. We also provide either a training or support opportunity for parents and/or professionals. The event is one day, however the planning and preparation goes on year-round.

Annual Charity Golf Benefit – This event typically occurs in the late summer or early fall. It has recently occurred at Windwood Golf Course in Watertown. The date is dependent upon availability. Jackie Malloy is the chairperson and she works with a committee of volunteers. All board members are asked to obtain 2-3 hole sponsors, seek out door prizes and disseminate fliers and recruit golfers for the event. They are also expected to attend/assist at the event if able.

Annual Training Workshop or Education Project

PWSA of WI, Inc tries to sponsor some sort of training workshop or educational project on an annual basis. The topic, speakers and location vary. In the past, some board members have been speakers, worked at the registration table or assisted in other ways. As an alternative, we may chose to do an education and/or awareness project. A board member may be willing to offer their expertise in some aspect of a project.

PWSA of WI, Inc. Newsletter – The Wisconsin Connection The newsletter is published and distributed 4 times a year. Currently the program director solicits articles, prepares layout and has it printed. We have a volunteer fold, secure, apply mailing labels and stamps and mail them out. Board members are encouraged to submit an article or help with any aspect of this.

Packet of Hope Program All genetics clinics in Wisconsin are given 5 copies of our Packet of Hope each year. We contact each of them and replenish their supplies annually. Packets need to be compiled and mailed. Help is needed in replenishing and distributing these packets.

PWSA of WI, Inc.'s Annual Mail Fund Raiser Once a year, we conduct a mail fund raiser typically in the fall of the year. Currently the program director creates the letter and prepares it for mailing. Any board member (or volunteer) who is interested in any aspect of the creation of this annual mail fund raising letter is graciously appreciated. The program director assists with the production of labels and any other supplies that may be needed. (We are always looking for creative people!)

PWSA of WI, Inc. Website We continue to look for help in upgrading our website exposure.

Annual Meeting for Parents of Young Children In the past few years, we have sponsored an annual meeting specifically for parents of young children. Two parents of young children have made all the arrangements for this event.

(Continued on page 5)

Prader-Willi Syndrome Association of Wisconsin, Inc.— 2007 Financial Report
SCHEDULE OF CASH RECEIPTS & DISBURSEMENTS—BUDGET VS. ACTUAL
January 1 through December 31, 2007

<u>INCOME</u>	<u>ACTUAL</u>	<u>BUDGET</u>
Membership Dues	\$ 1,640.00	\$1,800.00
Donations	\$ 2,725.00	\$3,000.00
Grants	\$956.32	\$800.00
Access to Community Service	\$4,946.47	\$3,000.00
United Way (Donor Choice Program)	\$5,498.76	\$4,000.00
Conference Fees	\$900.00	\$1,000.00
Fundraising	\$25,885.59	\$17,450.00
Designated Donations	\$20.00	\$50.00
Miscellaneous (Memorials/Honorariums)	\$350.52	\$150.00
Reimbursed Expenses	\$110.52	\$100.00
Interest	<u>\$1,644.24</u>	<u>\$175.00</u>
TOTAL INCOME	\$44,677.26	\$ 33,025.00
<u>EXPENSE</u>		
Payroll Expenses	\$12,191.50	\$16,000.00
Employee Benefits	\$1,205.64	\$1,486.00
Accounting Fees	\$2,611.96	\$2,550.00
Office Supplies	\$1,551.63	\$500.00
Printing and Publications	\$318.50	\$1,150.00
Telephone and Email	\$912.75	\$500.00
Postage	\$590.19	\$700.00
Membership Dues/Fees	\$185.00	\$175.00
Liability Insurance	\$1,712.00	\$1,200.00
National PWSA (USA) Support	\$0	\$0
Gen. Assist/Camp Scholarship Fund	\$2,444.88	\$2,500.00
Fundraising Expense	\$8,010.36	\$7,275.00
Board/Membership Meetings	\$24.33	\$100.00
Travel	\$0	\$3,000.00
Hobby/Other Supplies	\$718.81	\$1,300.00
Entertainment for Social	\$0	\$275.00
Food Expenses	\$943.50	\$700.00
Miscellaneous Expenses	\$2.19	\$200.00
Educare	\$184.42	\$700.00
Card Club	\$596.36	\$705.00
National Conference		\$900.00
TOTAL EXPENSES	\$38,794.17	\$41,916.00
NET INCOME	\$5,883.09	\$(8,891.00)
<u>Balance Information as of December 31, 2007</u>	<u>ASSETS</u>	
	Checking/Savings	
	Checking – Summit Credit Union	\$12,872.64
	Savings – Summit Credit Union	\$ 395.58
	Certificate of Deposit #1	\$ 6,773.96
	Certificate of Deposit #4	\$ 10,675.80
	Money Market – Summit Credit Union	<u>\$ 21,191.65</u>
	TOTAL ASSETS	\$51,909.63
	<u>LIABILITIES & EQUITY</u>	
	Equity – Opening Balance	\$44,316
	Retained Earnings	\$1,710.54
	Net Income	<u>\$5,883.09</u>
	TOTAL LIABILITIES & EQUITY	\$51,909.63

PWSA of WI, Inc. Thanks For Your Caring and Sharing—Making It Possible For Us to Help Others.
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In Honor of Beth LaBella: Rosalie LaBella; **In Honor of Louis & Alice Golembewski:** Joseph & Mary Elaine Gareau;

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PWSA of WI, Inc.'s Event Calendar

October 3, 2008 & October 8, 2008	Health Education Class for Persons with PWS	Waisman Center Madison, WI
October 11, 2008	Board meeting Parents of young children w/ PWS meeting Membership meeting	Exact location to be determined, Milwaukee
November 5, 2008	Behavior Management Strategies for Supporting Teens and Adults with Prader-Willi Syndrome	Waisman Center Madison, WI

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