



# 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*

**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 Program Director: Mary Lynn Larson

## HAPPY NEW YEAR!!!

I am sure we will be into January 2010 as this reaches many of you—so here are my wishes to you for a very Happy New Year!! As Program Director, the office manager, newsletter editor and wife to the outgoing President, I am taking the liberty of using the space for the Message from the President as we have a lot of information in this newsletter. I hope you find it informative and useful!

Things have been very busy both in the Larson household and the office lately. In October we had the election of new Officers and Board members for 2010—2012. We would like to thank our outgoing Officers/Board members for the hard work and dedication to our mission. Mike Larson completed his term as President and chose not to seek another term. Crystal Boser, a Board member and previous Vice President has been elected to the President position for a two year term. Melissa Sirovina was re-elected Secretary for a two year term. Al Luening, Jr and Candace Lipski were elected to Board positions. Al is completing his second term as a Board member while Candace is filling her first term. Candace has become involved in the organization through friends who have a child with PWS. Candace has assisted us as a volunteer at Hobby Day for several years. Candace will fill the one year term Board position that was vacated by Crystal. There was also a write-in candidate for a Board position: Katherine Girdaukas. Katherine will be a non-voting Board member. Katherine has a brother with PWS, Michael. Please join me in welcoming these new Board members.

### **Our upcoming Board of Directors for 2010 are:**

**President:** Crystal Boser

**Vice President:** Jackie Mallow

**Treasurer:** Tom Hughes

**Secretary:** Melissa Sirovina

**Board members:** Don Dorn, Al Luening, Candace Lipski & Katherine Girdaukas.

We ask that you take a moment and thank our outgoing Board members/Officers for their time and dedication the next time you see them.

January will be a crazy month for our family as Matthew will be having spinal fusion surgery on January 11th. We have been battling scoliosis for over 5 years and his S curve now measures at 54 degrees and 48 degrees. We will be spending a week or so in Madison at American Family Children's Hospital and then several weeks of recovery at home. At this point, we are uncertain what that will all entail—but will try to "take it as it comes". During this time, Melodee, our Assistant Program Director will be available via the toll free number with others willing to offer assist as needed. Any emails will be addressed as quickly as we are able.

Hoping the New Year brings you warmth, love, and good health!  
Mary Lynn

### **Board of Directors:**

**President:** Mike Larson

**Vice President:** Jackie Mallow

**Treasurer:** Tom Hughes

**Board members:** Melissa Sirovina, Crystal Boser, Al Luening and Don Dorn

**Program Director:** Mary Lynn Larson

**Assistant Program Dir:** Melodee Luening

### **Office Address:**

PWSA of WI, Inc.  
2701 N. Alexander St.  
Appleton, WI 54911-2312

**Toll free:** 1-866-797-2947

### **NEW Email:**

wisconsin@pwsaofwi.org

### **NEW Website:**

www.pwsaofwi.org

PWSA of WI, Inc. is a chapter of PWSA (USA)  
8588 Potter Park Drive,  
Suite 500  
Sarasota, FL 34238

**Toll free:** 800-926-4797 or  
941-312-0400

### **Email:**

info@pwsausa.org

### **Website:**

www.pwsausa.org

**Prader-Willi Syndrome Association of Wisconsin, Inc. – 2008 Financial Report**  
**SCHEDULE OF CASH RECEIPTS & DISBURSEMENTS – BUDGET VS. ACTUAL**  
**January 1 through December 31, 2008**

<u>INCOME</u>	<u>ACTUAL</u>	<u>BUDGET</u>
Membership Dues	1,775.00	1,700.00
Donations	2,829.58	2,500.00
Grants	1,663.42	5,000.00
Designated Donations – Conference	13,089.89	0
Access to Community Service	4,149.43	4,500.00
United Way (Donor Choice Program)	3,014.07	4,000.00
Conference Fees	1,430.00	2,300.00
Reimbursed Staff Travel	12.60	0
Fundraising	21,130.31	19,600.00
Rebates	100.00	0
Miscellaneous (Memorials/Honorariums)	1,040.00	200.00
Interest	<u>1,377.77</u>	<u>175.00</u>
<b>TOTAL INCOME</b>	<b>\$51,612.07</b>	<b>\$40,025.00</b>
<b><u>EXPENSE</u></b>		
Payroll Expenses	12,825.00	20,000.00
Employee Benefits	1,256.12	2,000.00
Accounting Fees	2,951.12	2,750.00
Office Supplies	444.55	1,400.00
Printing and Publications	319.10	200.00
Telephone and Email	1,021.63	800.00
Postage	466.25	700.00
Membership Dues/Fees	60.00	175.00
Liability Insurance	856.00	900.00
National PWSA (USA) Support	5,000.00	0
Gen. Assist/Camp Scholarship Fund	995.00	2,000.00
Fundraising Expense	6,514.59	6,800.00
Board/Membership Meetings	151.92	100.00
Staff/Board Training	70.00	0
Travel	200.47	575.00
Card Club	666.58	500.00
2008 National Conference Planning	10,009.24	13,850.00
2008 National Conference Scholarships	1,156.81	0
Hobby/Other Supplies	1,619.18	0
Educare	1,346.16	275.00
Food Expenses	<u>1,005.23</u>	<u>950.00</u>
<b>TOTAL EXPENSES</b>	<b>\$48,834.95</b>	<b>\$56,225.00</b>
<b>NET INCOME</b>	<b>\$ 2,777.12</b>	<b>\$16,200.00</b>

**Balance Information as of December 31, 2008**

<b><u>ASSETS</u></b>	
Checking/Savings	
Checking – Summit Credit Union	\$ 8,271.99
Savings – Summit Credit Union	\$ 397.97
Certificate of Deposit #1	\$ 7,015.57
Certificate of Deposit #4	\$ 11,165.82
Money Market – Summit Credit Union	<u>\$ 27,835.40</u>
<b>TOTAL ASSETS</b>	<b>\$ 54,686.75</b>
<b><u>LIABILITIES &amp; EQUITY</u></b>	
Equity – Opening Balance	\$ 23,119.78
Retained Earnings	\$ 28,789.85
Net Income	<u>\$ 2,777.12</u>
<b>TOTAL LIABILITIES &amp; EQUITY</b>	<b>\$ 54,686.75</b>

**PWSA of WI, Inc. Thanks Your Caring and Sharing Making It Possible For Us to Help Others.****Individual and Family Donors/Contributors**

Larry & Lori Ablor	Dan & Nancy Gulling	Rose Lopez	Tom & Judy Scheidegger
Frederick & Diane Adams	Louise Guido	Dorothy Lothe	Julie Scheuer
Susan Allison	John & Cory Hacker	Dr. Neal Lucchese	Tom & Debra Schmitz
Gerry Anderson	Florence Hambrick	Heidi Luebke	Ilene Schmitz
Rick & Barbara Ausick	Paul & Karla Hansen	Al & Kathleen Luening	Eric & Heidi Schoenberger
Dan & Kate Beaver	Dave & Cathy Hennig	Al & Melodee Luening, Jr.	Jessca Schroeder
Richard & Jayne Becker	Dr. Ken Herrmann	James Maciosek	Dennis & Sherry Schultz
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William & Gloria Doherty	Walt & Jennifer Kryzak family	Bob & Pat Nelson	Rosalie Tillman
Don & Barb Dorn	Kevin Konopacki	Keith Novotny	Nick & Christine Toman
Elsie Dorn	Jeanne Langlois	Wayne & Diane Nummerdor	Kim Tula
Jim & Judy Dorn	Carl LaBella	Jerry & Pam Offerdahl	Dave & Joan Unmacht
Chuck & Karen Dorn	Joe LaBella	Michelle Olson	Todd & Betsy VanHeesch
Mark Dorn	John, Pat & Chris LaBella	Cindy Organ	Ben Van Korn
Dennis & Cecile Engel	Rosalie LaBella	Michelle Pautsch	Cyndy Verhagen
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Charlotte Girdaukas	Jolene Lemerond	Dave Roemer	Judy Wolter
Gary & Marty Girdaukas	Melvin & Lois Lendt	James & Angela Romig	Rose Worden
Roger & Alice Girdaukas	Brett & DeeDee Lewis	Janine Rozina	Carol Young
Gary & Debbie Gostas	John & Candace Lipski	John & Marguerite Rupnow	
Laurie Grinnell	Jennifer Liska	Josh Rupnow	
Keith Gullicksen	Janet Logan	Steve & Liz Moser-Sadzewicz	

**Memorials / Honorariums****In Honor of Andy Mankowski:** Lillian Peronto**In Honor of Olivia Leuning:** Jessica Mitchell, Mike and Marsha Jahn**In Memory of Patricia Lalor:** Patrick & Debbie Newlin, Robert & Diane Klaas, Gilbert & Karen Ellis, Frederick & Diane Adams**In Honor of Beth LaBella:** Rosalie LaBella**Business and Corporate Donors**

University Hill Farms Association	Paragon Candles	BACZ Arts & Crafts LLC	Fabco-CAT	Avon
UW – Waisman Center Genetics	Goebel Woodwork, Inc.	Thunder Bay Grille	Fireworks City	
Access to Community Services	Unicus Promotions	Creative Care Options	PWSA (USA)	
United Way of the Fox Cities	Suzy's Cream Cakes	WKLH Radio	CSI Testing	
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United Way of Brown County	Regent Mental Health	PWSA of WI, Inc.	Xpressions by Peggy	
Virchow, Krause & Co, LLP	WTMJ Radio	RD Image	Milwaukee Heart Scan, LLP	
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GE Water & Process Technologies	Wigwam Mills	Hughes Dental Clinic	Colleen's Angels	
Oconomowoc Developmental Programs	Agape of Appleton	Panera Bread	Balistreri's Blue Mound Inn	
Prader-Willi Homes of Oconomowoc	Alliance Capital	Jim's Marina	Tosa Pediatrics	
Bodoh Home Improvements	Kraft Foods	PromHagen	Comedy Café	
Machine Shed Restaurant	Milwaukee Brewers	Oconomowoc Developmental Training Center	M and I	
SSM Health Care, St. Clare Hospital	Sedgwick-Claims Mgmt Services, Inc.			

## It's That Time of Year Again ... Information on Summer Camps Compiled by Barb Dorn

Summer camp can be a fun-filled, exciting time for both youth and adults with PWS. Knowing what camp and at what age is best for your child is a decision that each parent/care provider needs to make.

Over the years, PWSA of WI, Inc. has compiled a list of some of the camps that parents of children and adults who have PWS have attended. You can call the state office Toll Free at 1-866-797-2947 if you have questions or contact the camp directly with your questions or concerns. Everyone has different opinions and views. **You** need to make the final decision...but don't delay.

If your decision to attend camp is based on finances (or lack of), don't hesitate to apply for PWSA of WI, Inc.'s Camp Scholarship. This year, we have once again set aside funds to help a child or adult attend camp. Any person with PWS, living in Wisconsin, young or old, is eligible. You must be a member of our organization to be a recipient. Membership scholarships are also available. **DEADLINE IS APRIL 30, 2010.** A copy of the application form is included in this newsletter.

Camp can offer a week filled with activities, adventures, and social opportunities. It can also be a week where families (especially siblings) get a break from the monitoring and challenges that we all face.

The following are the names, addresses and phone numbers of camps our office has heard of (If you know of more...let us know). Some do not have staffing and support for special needs children but others do. We may be able to help, BUT don't delay. Many deadlines for camp registrations are approaching soon **Please note some internet links and email addresses have changed.**

### Easter Seal Camp

(Camp Wawbeek and Pioneer Camp)

Camp Wawbeek – for persons with physical disabilities/  
Respite camp for persons with cognitive disabilities  
Business address:

101 Nob Hill Rd., Suite 301, Madison, WI 53713

608-277-8288 or toll free: 800-422-2324

Website: [www.wi-easterseals.org](http://www.wi-easterseals.org)

Email: [respit1@wi-easterseals.org](mailto:respit1@wi-easterseals.org)

Email: [wawbeek@wi-easterseals.org](mailto:wawbeek@wi-easterseals.org)

Easter Seals Wisconsin has a respite program as well as various summer camp sessions. The camp is located on a wooded 400-acre site near Wisconsin Dells. This camp provides a variety of experiences for children and adults with disabilities. They do have experience in serving persons with PWS. They also offer respite weeks and weekends. They have a low counselor to camper ratio so they are able to handle some higher need campers. Their rates are on the high side

### Lion's Camp

3834 County Rd. A., Rosholt, WI 54473

715-677-4761 Email: [info@wisconsinlionscamp.com](mailto:info@wisconsinlionscamp.com)

Website: <http://www.wisconsinlionscamp.com/>

Lion's Camp is located in central Wisconsin, 2 miles east of Rosholt, and 16 miles northeast of Stevens Point. \*This camp serves the needs of mild/borderline cognitively disabled youth, and young adults. They have designated weeks for youth (ages 9 –17). They do not feel comfortable handling persons with moderate to severe (behavior) problems or those who are moderately to severely cognitively disabled. They have served children with PWS and their diet is managed by "portion control". **THERE IS NO COST FOR THIS CAMP.**

### Wisconsin Badger Camp

P.O. Box 240

Platteville, WI 53818-0240

608-348-9689 Website: <http://www.badgercamp.org/>

\*Wisconsin Badger Camp is located 10 miles south of Prairie du Chien, Wisconsin. It serves developmentally challenged individuals regardless of severity. They have a well-trained staff and medical personnel. They have certain weeks devoted to different ages. They have served many young adults and adults with PWS. They fill up very fast so get your application in soon.

### Archdiocese of Milwaukee - Adult and Family Ministry

3501 S. Lake Dr.

P.O. Box 070912

Milwaukee, WI 53207-0912

Phone: 414-769-3439 or 1-800-769-3973

Website: [www.archmil.org](http://www.archmil.org)

You must be a resident of Milwaukee County to attend. We have received positive reports from one camper who has been attending this camp for several years. It has a low counselor to camper ratio.

### Wisconsin United Methodist Camps

Camping Office

P.O. Box 620

Sun Prairie, WI 53590

Phone: 608-837-3388 (ask for Special Needs Camps)

Toll Free- 1-877-947-2267

Website: <http://www.wisconsinumc.org/camps/>

Wisconsin United Methodist Camp has 3 locations. Byron Center is located southwest of Fond du Lac on County F near Brownsville, WI. Pine Lake is located northwest of Westfield near Hwy 51 between Portage and Stevens Point. Whispering Pines is located in the northwest part of the state about 75 miles from the Twin Cities near Frederic, WI. All three have weeks that serve three age level programs. Their Children's Program serves children ages 8-14; their Youth Program serves youth 15-21; and their Adult Program serves adults 22 and up. All campers must be able to care for their own basic daily needs and have a diagnosis of mild to moderate mental retardation.



They do not serve individuals with severe mental retardation or mental illness. We have received positive reports from 1 camper who attended this camp in previous years.

#### **Camp Albrecht Acres of the Midwest**

14775 Sherrill Rd., Sherrill, IA 52073

319-552-1771

Camp Albrecht Acres is located 8 miles north of Dubuque on the Sherrill blacktop road. This camp may be accessible for those living in southwestern Wisconsin. It is designed for all who are disabled. They have a 24 hour nursing staff. They have some experience in working with children and young adults with PWS. It is "family style" eating but staff will monitor for portion control

#### **Camp Wil-O-Way**

Easter Seals Kindcare Southeastern WI, Inc

Contact: Susan Klawien

1016 Milwaukee Avenue

South Milwaukee WI 53172

414-571-5566

#### **Camp Courageous of Iowa**

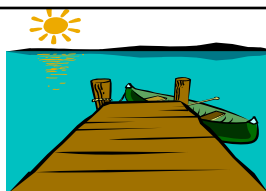
12007 190<sup>th</sup> St. P.O. Box 418

Monticello, IA 52310-0418

Phone: 319-465-5919

Website: <http://www.campcourageous.org/>

Camp Courageous of Iowa is located about 5 miles south of Monticello, Iowa. It serves all people regardless of ability level. They have both a summer camp as well as a respite program. They have served persons with PWS.



### **The Camper with PWS: Questions to Ask**

For many parents and caregivers, sending a child with Prader-Willi syndrome away to camp can be filled with mixed emotions. There may be excitement that their son, daughter or resident will be able to participate in an activity that allows them some fun and friendship opportunities. There may be some fears – will they be safe; will their medical needs be met? And there may be worries – will they be successful and not have any major behavior challenges; will their dietary and food seeking needs be met? Most want to know if this is the right camp for their child or adult with PWS.

There are many camps across the State of Wisconsin that serve children and adults with disabilities. There are camps that operate day or week programs. Some offer a variety of different experiences and others may be more specialized. Some have experience in working with persons with Prader-Willi syndrome – others do not. For some, they will readily make accommodations for diet and behavior – others will not. Often times, parents begin the search in the early months of the year. Some camps have a limited number of

slots or have special weeks for certain ages or disabilities. It is never too early to begin the research.

The staff at PWSA of WI, Inc. relies on parents and caregivers to share camp resources. When we do not have resources, we do our best to locate some special needs camps in your area that the parent or caregiver can contact. Each year, there may be new counselors and/or new leadership at a camp that may affect the campers' experience. One camp may be a wonderful experience for one person with Prader-Willi syndrome and a not-so-nice experience for another camper. **In all cases, it is up to the parents and caregivers to research and determine if the camp we may suggest is the right match for your son, daughter or resident. The staff at PWSA of WI, Inc are not responsible for any actions that do or do not take place at a camp.**

We would like to suggest asking questions or taking note on some areas when researching a camp:

#### **Knowledge & Experience with campers with PWS:**

Have they served campers with PWS? Do they understand or are they willing to learn more about PWS? Are you willing to teach and assist in this learning?

**Health Services** – Do they have a nurse on duty? Who is responsible for administering medications? If a person becomes ill, what is done? Are they willing to learn about the unique health issues that may face persons with Prader-Willi syndrome?

**Diet and Meal-Serving Style** – Do they accommodate special diets? How are meals served? Do campers serve themselves or are portions served to them and monitored? Do they have a camp store or food opportunities that the person with PWS could access food? How much is food a part of their camp experience?

**Behavior Management** – Some have very strict rules about taking campers with behavior problems – you will want to know this in advance. Do counselors receive special training on behavior management? What sort of approaches or consequences do they use?

Make sure to share information about Prader-Willi syndrome and the camper with PWS with camp staff. Include suggestions on how to avoid food and behavior issues; make sure to list any strategies that you know will help the camper. Include the form- ***Health Concerns and the Camper with Prader-Willi Syndrome Information for Camp Staff*** and don't forget to include a health brochure so they will be sure to be aware and understand some of the unique health issues that can face this camper.

We all want the camper with Prader-Willi syndrome to have a positive, healthy experience. If you have had successful camp experiences, please share this with us. Please email us at [Wisconsin@pwsaofwi.org](mailto:Wisconsin@pwsaofwi.org) or call the office.



Prader-Willi Syndrome  
 Association of Wisconsin,  
 Inc.  
 2701 N. Alexander St.  
 Appleton, WI 54911  
 Office: 1-866-797-2947

### APPLICATION FOR GENERAL ASSISTANCE SCHOLARSHIP

**PURPOSE:**

PWSA of WI, Inc. wishes to provide financial assistance in order for families of a person with PWS to help meet the unique needs of these individuals and their families.

**ELIGIBILITY:**

Eligibility is based on financial need. Financial need being equal, the second consideration would be given to those who could benefit most from funds (respite intervention or personal/behavioral issues that need to be addressed).

1. Any person with PWS who resides in the state of WI.
2. The person with PWS or the caregiver or a family member of the person with PWS must be a member of the state chapter of PWSA of WI, Inc.

Date of request \_\_\_\_\_

Name of person w/ PWS: \_\_\_\_\_ Sex \_\_\_\_\_ DOB: \_\_\_\_\_

Address \_\_\_\_\_ City \_\_\_\_\_ State \_\_\_\_\_ Zipcode \_\_\_\_\_

Is individual, family member or caregiver a member of PWSA of WI, Inc? \_\_\_\_\_ Yes \_\_\_\_\_ No

Does individual reside in WI? \_\_\_\_\_ Yes \_\_\_\_\_ No Parent/guardian: \_\_\_\_\_

Home Phone \_\_\_\_\_ Work phone: \_\_\_\_\_ Cell phone: \_\_\_\_\_

Parent/guardian's or Person w/ PWS's employer if not residing at home : \_\_\_\_\_

Current position \_\_\_\_\_

Employer's address: \_\_\_\_\_

Dates at present job: \_\_\_\_\_

Gross annual income: (select one) \_\_\_\_\_ < \$15,000; \_\_\_\_\_ \$15,000 - \$29, 000; \_\_\_\_\_ \$30,000 - \$41,000; \_\_\_\_\_ \$42,000 - \$59,000; \_\_\_\_\_ \$60,000 - \$119,000; \_\_\_\_\_ over \$120,000

Average monthly amounts of other income: (Please specify sources, ie. SSI, SSDI, MA, CIP) \_\_\_\_\_

Specific dates funds are needed by: \_\_\_\_\_ Amount requested: \_\_\_\_\_

What will funds be used for? \_\_\_\_\_

Why would this scholarship be helpful to you? \_\_\_\_\_

How will funds improve the quality of life for the individual with PWS? (Financial need, need for respite, etc.)

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I certify that all of the information given above is true and correct. I understand that any false or incomplete statements in this application may make this application ineligible for funding. I authorize verification of any of the above information.

Signature: \_\_\_\_\_

**Return this application by: April 30, 2010**

**Send to: PWSA of WI, Inc.  
2701 N. Alexander St.  
Appleton, WI 54911-2312  
Toll free: 1-866-797-2947**

(Note: I apologize this is not a one sheet application. If it is easier, a General Assistance application is available on the web site at [www.pwsaofwi.org](http://www.pwsaofwi.org) under Services. )

## PWSA of WI, Inc.'s Event Calendar

<b>April 24, 2010</b>	<b>Spring social</b>	<b>Oconomowoc, WI</b>
<b>August 2010</b>	<b>PWSA of WI, Inc.'s 10th Annual Golf Benefit</b>	<b>Windwood of Watertown</b>
<b>October 15, 2010</b>	<b>PWSA of WI, Inc.'s Behavior Training</b>	

Prader-Willi Syndrome Association of WI, Inc.  
 2701 N. Alexander St.  
 Appleton, WI 54911-2312  
 Toll free: 1-866-797-2947  
 NEW Email: [Wisconsin@pwsaofwi.org](mailto:Wisconsin@pwsaofwi.org)  
 NEW Web site: [www.pwsaofwi.org](http://www.pwsaofwi.org)

