



# 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 President: Barb Dorn

Summer is almost over. Each year, the time seems to go faster. It has been a very busy one for me personally as well as for PWSA of WI. As we continue our adventure in planning the national PWSA (USA) conference next year, I am amazed at the dedication and commitment of the volunteers sharing their time and their talents. Wisconsin members – you are the best!! I am confident that this next year will bring us closer as we unite to bring national and international experts in the field of PWS to our state. Over the next few months, we will be recruiting, asking and begging for you to help us in any way you possibly can. We will be sending out notices asking for your help – please continue to do the fantastic job you are doing at offering your assistance.

**“To Punish or Not to Punish ... That is the Question.”** I wanted to touch upon a topic that comes up quite frequently to those caring for adults and children with PWS. That topic or question is – Should the person with PWS be punished when they steal food? Over the past two years, I have been doing more writing and training on the topic of health for the person with PWS. Preventing and managing food seeking behavior is an integral part of health and wellness in the life of a person with PWS. I was surprised to hear so many people say – “yes”.

I am going to be frank in saying that I firmly believe that we should NOT punish our children/adults for this behavior. Food seeking is a major part of PWS and it will not stop with punishing or negative reinforcements. We must do everything we can to create a “food safe” environment. If and when food seeking takes place, we need to encourage our children and adults to share and tell – especially if a large quantity of food has been ingested. This can be a life threatening situation and we can only help them if we know it has happened. Teaching and encouraging the person with PWS to tell may be a life long job we have as their care givers. Yelling and/or punishing are not going to make this happen. When they share it has occurred, we must compliment the person for sharing this important health situation. We then must closely monitor the person to make sure there is no abdominal distention, vomiting or ill feeling. We must also evaluate how it happened and take steps to prevent this from happening again. We love our children and adults and we want them to be safe and healthy.

I ask people who feel they should be punished – “Would you punish a person with a seizure disorder for having a seizure?” Food seeking is as much a part of the disability of PWS as a seizure is for a person with epilepsy.

If we approach the situation with an attitude of helping, most persons with PWS will cooperate. If they consume an excessive number of calories in a binge eating event, I often suggest an alternate meal be provided. I do not feel that their meal should be eliminated since that serves as a negative reinforcement. A substitution of a very low calorie meal can and should be provided. (An example might be broth, diet Jell-O, ½ cup cooked vegetable, ½ sandwich made with light bread, lettuce and 1 slice of thinly sliced luncheon meat, light string cheese and non-caloric beverage (coffee, tea, SF Koolaide...)). This meal substitution totals less than 200 calories and provides the person with a number of healthy food items that will not further tax his/her gastrointestinal system. There are people who feel that a substitution meal should not be done and many do not change the food plan or food consumption for that day. Providing empathy, support and health education will help them understand why we do what we do.

I hope everyone enters this fall season with good health, good times and good memories. Take care, Barb

### **Board of Directors:**

**President:** Barb Dorn

**Vice President:** Crystal Boser

**Treasurer:** Tom Hughes

**Board members:** Melissa Sirovina, Jackie Mallow, Betsy VanHeesch and Al Luening

**Program Director:** Mary Lynn Larson

### **Office Address:**

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

### **Email:**

wisconsin@pwsausa.org

### **Website:**

www.pwsausa.org/WI

PWSA of WI, Inc. is a chapter of PWSA (USA)  
5700 Midnight Pass Rd,

Suite 6

Sarasota, FL 34242

**Toll free:** 800-926-4797 or  
941-312-0142

### **Email:**

national@pwsausa.org

### **Website:**

www.pwsausa.org

## An A+ for Awareness

Over the past few months, PWSA of WI, Inc has participated in many awareness opportunities. Thanks to your willingness to share and donate your time, we continue to educate more and more about this disability.

### Friday May 4<sup>th</sup> PWS Featured on Milwaukee Television Show, The Morning Blend



Thanks to the efforts of Melissa Sirovina and daughter Kayla w/ PWS, age 12, we were able to participate in a brief interview on this morning television show. Barb Dorn, president and consultant for PWSA of WI, Inc helped to provide a brief explanation of PWS and the progress we are making.

### July- Oshkosh Northwestern features "Girl with Rare Disease Donates Hair for Locks of Love"

Three year-old MacKenzie Hacker of Neenah was featured as she donated her long hair at her recent hair cut to the Locks of Love Foundation. The article highlighted when and how MacKenzie was diagnosed as well as information about PWS and PWSA of WI, Inc. We are grateful to the Hackers for sharing their story.

### July 14<sup>th</sup> PWS Awareness Night at Milwaukee Brewer game – Guest Visitor at Tailgate – Clint Hurdle, Manager of Colorado Rockies team



The afternoon began with a tailgate party in the parking lot of Miller Stadium. Families and friends gathered to share the excitement of having PWS featured in many areas of this Brewer-Rockies baseball game. Clint Hurdle, manager of the Colorado Rockies and parent of five year-old Madison who has PWS, stopped by and shared an inspirational message of hope for all in attendance. He took time to sign autographs; shake hands; take photos and talk with parents and

friends. Later, inside Miller Park, a public service announcement featuring Clint was aired on the large score board. In addition, volunteers spent time distributing bracelets, fliers and other informational materials next to a large display board. The Milwaukee Brewer organization also provided PWSA of WI, Inc with some discounted tickets in very nice seats, allowing PWSA of WI to raise funds in support of awareness opportunities.



### August 1-3<sup>rd</sup>, PWSA of WI Begins Marketing Efforts for the 2008 Conference in Milwaukee

PWSA of WI, Inc had eight committee chairpersons attend the 2007 national PWSA (USA) conference in Dallas, Texas in preparation for hosting the 2008 conference in Milwaukee. With the theme, "Moo-ving Forward", efforts were made to take the Dairyland theme and make it a fun, memorable marketing strategy encouraging this years' attendees to begin planning for this annual event in 2008. Thanks to Bobbi Pogrart and Independent Printing Company for donating their printing services including conference brochures, bookmarks and cards for magnets. Bobbi's daughter, Addison is featured (in a cow costume). We also want to acknowledge and thank Ed Talbott of the Wisconsin Milk Marketing Board for the donation of the inflatable cow and other dairy products.

### Saturday August 25<sup>th</sup>, PWSA of WI, hosts their 7th Annual Golf Benefit in Watertown



People do not always realize how fund raising and events like a golf benefit help to increase awareness and understanding of PWS. Donors, golfers as well as the staff at the golf course often have little or no knowledge of PWS. PWSA of WI parents, friends and other volunteers recruit and educate others about this disability as they gather support for this worthwhile event.

## **ADDRESS CHANGE!!**

**Effective September 1, 2007,  
PWSA(USA) will have a new**

**address:**

**PWSA(USA)  
8588 Potter Park Drive  
Suite 500**

**Sarasota, FL 34238**

**1-800-926-4797**

**Local: 941-312-0400**

**Fax: 941-312-0142**

\*\*\*Please note the zip code printed  
in the Gathered View was incorrect!  
Phone numbers remain the same.

### **Back to School Tips:**

- Take advantage of resources to help educate school staff about your child and PWS.
- Purchase new DVD: Understanding the Student with PWS: Strategies for Success (Available through PWSA (USA) 1-800-926-4797)
- Obtain an education packet filled with handouts and a book for educators. (Contact our state office 1-866-797-2947)
- Create a 1-page informational handout and share with ALL staff about your child and how to assist him/her with the challenges of PWS.
- Check out PWSA (USA) and PWSA of WI websites for information that you can download to assist you in educating educators about PWS and areas that may impact learning.
- Set up a time to meet with educators and do a short training. If you need help or guidance – contact our state office.

## **RESEARCH OPPORTUNITY:**

### **Learning Profiles of Children with Prader-Willi Syndrome**

Researchers at the Clinical Center for Development and Learning (CDL) at the University of North Carolina at Chapel Hill are conducting a study on learning profiles of children with Prader-Willi Syndrome (PWS). The results of this study will be used to develop a tool for developing learning plans specific for children with PWS.

We are seeking 100 families of children ages 3-17 with PWS to participate in a questionnaire study. This study will involve parents and teachers completing a questionnaire designed to explore the educational and cognitive strengths and needs of children with PWS. Parents will also be asked to complete three additional short questionnaires about their child's behavior and food preferences. Participation in this portion of the study will take approximately 30 minutes for teachers and 1 hour for parents. Parents will receive a letter outlining their child's strengths and needs, with recommendations based on their child's profile.

In addition, we are seeking 50 families to complete the above study; in addition their child would participate in an assessment of neuropsychological and educational abilities. The assessment at the CDL will take approximately 3 hours. Families will receive a thank you gift and a full report of their child's neuropsychological and educational strengths and needs, with recommendations based on their child's profile.

Participation is completely voluntary and you may choose not to participate in any portion of the study or withdraw from the study at any time.

For more information contact Dr. Anne Wheeler at 919-966-3566 or 919-966-5171 or via email at [anne.wheeler@cdl.unc.edu](mailto:anne.wheeler@cdl.unc.edu).

***This research is funded by the Foundation  
for Prader-Willi Research***

**Prader-Willi Syndrome Association of Wisconsin, Inc. – 2005 Financial Report**  
**SCHEDULE OF CASH RECEIPTS & DISBURSEMENTS – BUDGET VS. ACTUAL**  
**January 1 through December 31, 2005**

| <u>INCOME</u>                         | <u>ACTUAL</u>       | <u>BUDGET</u>       |
|---------------------------------------|---------------------|---------------------|
| Membership Dues                       | \$ 1,440.00         | \$ 2,000.00         |
| Donations                             | \$ 6,083.80         | \$ 5,000.00         |
| Grants                                | \$ 974.50           | \$ 1,500.00         |
| Access to Community Service           | \$ 4,005.91         | \$ 4,000.00         |
| United Way (Donor Choice Program)     | \$ 6,480.03         | \$ 4,000.00         |
| Conference Fees                       | \$ 870.00           | \$ 700.00           |
| Fundraising                           | \$ 14,984.93        | \$16,025.00         |
| Designated Donations                  | \$ 0                | \$ 50.00            |
| Miscellaneous (Memorials/Honorariums) | \$ 1,220.00         | \$ 610.00           |
| Reimbursed Expenses                   | \$ 114.80           | \$ 100.00           |
| Interest                              | <u>\$ 381.52</u>    | <u>\$ 175.00</u>    |
| <b>TOTAL INCOME</b>                   | <b>\$ 36,555.49</b> | <b>\$ 34,110.00</b> |
| <br><b>EXPENSE</b>                    |                     |                     |
| Payroll Expenses                      | \$ 9,078.00         | \$ 12,240.00        |
| Employee Benefits                     | \$ 883.64           | \$ 1,200.00         |
| Accounting Fees                       | \$ 4,319.83         | \$ 2,350.00         |
| Office Supplies                       | \$ 812.80           | \$ 250.00           |
| Printing and Publications             | \$ 0                | \$ 250.00           |
| Telephone and Email                   | \$ 410.65           | \$ 700.00           |
| Postage                               | \$ 851.82           | \$ 700.00           |
| Membership Dues/Fees                  | \$ 50.00            | \$ 175.00           |
| Liability Insurance                   | \$ 0                | \$ 1,400.00         |
| National PWSA (USA) Support           | \$ 2,000.00         | \$ 2,000.00         |
| Gen. Assist/Camp Scholarship Fund     | \$ 2,143.91         | \$ 3,000.00         |
| Fundraising Expense                   | \$ 5,508.89         | \$ 7,213.00         |
| Board/Membership Meetings             | \$ 92.35            | \$ 100.00           |
| Travel                                | \$ 852.60           | \$ 1,250.00         |
| Hobby/Other Supplies                  | \$ 506.54           | \$ 1,500.00         |
| Entertainment for Social              | \$ 0                | \$ 275.00           |
| Food Expenses                         | \$ 909.13           | \$ 600.00           |
| <b>TOTAL EXPENSES</b>                 | <b>\$ 28,420.16</b> | <b>\$ 35,203.00</b> |
| <b>NET INCOME</b>                     | <b>\$ 8,135.33</b>  |                     |

**Balance Information as of December 31, 2005**

**ASSETS**

|                                |                    |
|--------------------------------|--------------------|
| Checking/Savings               |                    |
| Checking – Summit Credit Union | 5,672.97           |
| Savings – Summit Credit Union  | 6,309.13           |
| Certificate of Deposit #1      | 6,005.11           |
| Certificate of Deposit #2      | <u>5,471.41</u>    |
| <b>TOTAL ASSETS</b>            | <b>\$23,458.62</b> |

**LIABILITIES & EQUITY**

|                                       |                  |
|---------------------------------------|------------------|
| Equity – Opening Balance              | 23,119.78        |
| Retained Earnings                     | -4,990.22        |
| Net Income                            | <u>5,329.06</u>  |
| <b>TOTAL LIABILITIES &amp; EQUITY</b> | <b>23,458.62</b> |

**PWSA of WI, Inc. Thanks YOU!! Your Caring and Sharing Makes It Possible For Us to Help Others.**

|                          |                            |                             |                             |
|--------------------------|----------------------------|-----------------------------|-----------------------------|
| Larry & Lori Abler       | John & Cory Hacker         | Bob Lindauer                | Vance Rayburn               |
| Kay Adams                | Karla Hansen               | Richard Lofthouse, Sr., DDS | Atty Lois Rentmeester       |
| Sam & Sue Allison        | Larry Haas                 | Chris Lomascola             | Dave Roemer                 |
| Rick & Barbara Ausick    | Lee Haas                   | Rose Lopez                  | Josh Rupnow                 |
| Brian Balestrieri        | Norb Haas                  | Dottie Lothe                | Marquerite Rupnow           |
| Dan & Kate Beaver        | Ed Hastreiter              | Keelyn Lyon                 | Steve & Liz Moser-Sadzewicz |
| Richard & Jayne Becker   | Charles & Diane Helman     | Heidi Luebke                | Laurie Salzman              |
| Karen Berg               | Pamela Hill                | Richard MacNally            | Tom & Judy Scheidegger      |
| Brenda Bickelhaupt       | Frank Hilscher             | Jane Majcherek              | Julie Scheuer               |
| Rick Block               | Mark Hohenwald             | Gloria Marich               | Kurt Schoenfelder           |
| Dale & Julie Bollig      | Dr. Jean Holder            | Erik Martin                 | Tom & Debra Schmitz         |
| Robert & Kathy Bomber    | Dr. Thomas & Agnes Hughes  | Jeremy McPherson            | Dennis & Sherry Schultz     |
| Clint & Crystal Boser    | Mike Inkmann               | Doug Meek                   | Louis & Judy Schutz         |
| Gary Boser               | Nancy Jansen               | Gregory & Mary Beth Meller  | Betty Schutz                |
| Todd & Jerilyn Bramson   | Mr. & Mrs. Eugene Johnson  | Bob & Joann Millard         | Carl & Alice Schwartz       |
| Kevin & Anne Bresnahan   | Al Johnson                 | Robert & Marge Miller       | Lynn Ann Seeger             |
| Steve & Nancy Burlingame | Karen Johnson              | Tom Miller                  | Rayelle Simonsen            |
| Evelyn Burnridge         | Penny Johnson              | Laurel Mills                | Willie & Gudrun Sindermann  |
| Jeff & Nikki Buske       | Andy Jones                 | Virginia Mitchell           | Chad & Melissa Sirovina     |
| Ginny Cardarella         | Tom & Bonnie Jones         | Terese Moore                | Paul & Mary Smith           |
| John Christensen         | Madonna Kieffer            | Don & Hazel Morgan          | Constantine Stamatelakys    |
| Eric Chrtsen             | Marilyn Klingele           | Larry Morris                | Richard Stark               |
| Henry Clement            | Gerald Koerner             | Dr. Marta Muller            | William Stege               |
| Bruce Crass              | John Kozarek               | Mary Mulligan               | Jackie Stoner-Mallow        |
| Steven Dobbs             | Robert Kozarek             | Wm & Margaret Nagle         | Russ & Dawn Stuczynski      |
| William & Gloria Doherty | John & Bonnie Kraft        | Mike & Jean Naumann         | Beatrice Sturm              |
| Don & Barb Dorn          | Richard Kral               | Bob & Pat Nelson            | Judith Sweet                |
| Elsie Dorn               | Katie Kranjac              | Keith Novotny               | Gail Sylvan                 |
| Jim & Judy Dorn          | Walt & Jennifer Kryzak     | Wayne & Diane Nummerdor     | Ed & Daun Talbott           |
| Mark Dorn                | Brad Kuenn                 | Richard Nutter              | Brian Tworek                |
| Gerard & Helma Drag      | Tom & Pat Lahey            | Howard O'Dell               | Todd & Betsy Van Heesch     |
| Cathy Eareckson          | Jeanne Langlois            | Michelle Olson              | Ben Van Korn                |
| Dreamweavers, Inc.       | Carl LaBella               | Cindy Organ                 | Sandra Van Korn             |
| Dr. Anne Felden          | Joe LaBella                | Paul Ostopowicz             | Joseph & Jean VanTuytle     |
| Joseph & Mary Gareau     | John, Pat & Chris LaBella  | Outagamie Co. DDSU          | Greg Wagner                 |
| John Gawin               | Mike & Mary Lynn Larson    | Jolene Paiser               | Deb Wald                    |
| Charlotte Gir daukas     | John & Cathie Lehman       | Jim & Karen Ploszcynski     | Sean Wegner                 |
| Gary & Marty Gir daukas  | Al & Kathleen Luening, Sr. | Lori Porte                  | Paul & Ellen White          |
| Robert Grant             | Al & Melodee Luening, Jr.  | Carol Potts                 | K. Wisniewski               |
| Laurie Grinnell          | Matt Luening               | Patricia Raffel             | Rose Worden                 |
| Louise Guido             | Wade Liljegren             | Don & Rosalind Rahn         |                             |

**Memorials/Honorariums:****In Honor of Andy Mankowski:** Lillian & Leroy Peronto**In Honor of Alexander Linck:** Don and Barb Dorn**In Honor of Beth LaBella:** Rosalie LaBella, Willi & Gundrun Sindermann**Business and Corporate Donors:**

|                                       |                                    |  |
|---------------------------------------|------------------------------------|--|
| University Hill Farms Association     | ParTee Pub and Grill               | Hughes Dental Clinic                     |
| Metso Paper USA, Inc.                 | United Way of Brown Co,            | Capital Alliance                         |
| Paragon Industries                    | Milwaukee Admirals                 | Principal Financial Group                |
| Blockbuster Co Stars                  | John Hawks Pub                     | Hollywood Video                          |
| Fabco-CAT                             | Xpressions by Peggy                | FM 106                                   |
| Employees' Mutual Benefit Association | Virchow, Krause & Co, LLP          | Prader-Willi Homes of Oconomowoc         |
| Camilee's Trattoria                   | WTMJ TV                            | Oconomowoc Residential Programs          |
| PWSA (USA)                            | Milwaukee Electric Tool            | Nashotah Clubhouse                       |
| Thunder Bay Grille                    | Milwaukee Heart Scan, LLP          | Menards                                  |
| WTMJ-Radio                            | EWB Small Business Accounting, S.C | Bodoh Home Improvements                  |
| Milwaukee Bucks                       | Paganica Golf Course               | Pick N Save WE CARE Program              |
| Access to Community Services          | Six Flags Great America            | Kraft Foods                              |
| Altria Employee Involvement Program   | First Associated Insurance         | Oconomowoc Developmental Training Center |
| Suzy's Cheesecakes                    | Family Land Water Park, WI Dells   |  |
| WKLH Radio                            | Gray Jewelers                      |  |
| CSI Testing, Inc.                     | Anchor Moving                      |  |
| United Way of Greater. Milwaukee      | Medinet                            |  |
| Green Bay Packers                     | Glen Erin Golf Club                |  |
| Milwaukee Waves                       | Wigwam Mills                       |  |

## CALL FOR NOMINATIONS – 2007 OFFICERS AND BOARD MEMBER - PWSA of Wisconsin, Inc.

PWSA of WI, Inc is once again looking for dedicated individuals to serve in the following roles for a 2 year term of office. If you have any questions regarding these roles or responsibilities, feel free to contact the PWSA of WI, Inc office or any current officer or board member.

**The PRESIDENT** is the principal officer of the organization and presides at meetings of the organization's membership. This officer communicates to the association such matters and makes such suggestions that may in his/her opinion tend to promote the welfare and increase the usefulness of the association, and shall perform such other duties as are necessary incident to the office of president. The president serves as a member of the Chapter Advisory Board for the National Prader-Willi Syndrome Association.

**The SECRETARY** has the responsibility to give notices, to keep a record of proceedings (minutes), to attest documents and perform such other duties as are usual for such an official as may be duly assigned.

**The BOARD MEMBER** serves as advisor in providing governance to the organization. He/she will assist in projects, committees and other capacities as needed.

### What to Do ... When?

Please obtain and complete a candidate form. You can download this from our website:

[www.pwsausa.org/WI](http://www.pwsausa.org/WI) or call our office at toll free 1-866-797-2947.

Submit completed form to the state office by email or US mail **no later than September 15<sup>th</sup>, 2007**.

A ballot will be mailed to all primary members of PWSA of WI, Inc by October 1, 2007.

Return of all ballots are needed by October 15<sup>th</sup>, 2007.

Ballots will also be available at our annual membership meeting which will be held on October 6<sup>th</sup>, 2007 in Milwaukee. (exact time and location being determined).

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## Overview of Board Member Responsibilities:

The following is a brief outline of some of the major events and activities that PWSA of WI, Inc. sponsors on an annual basis. We have outlined these

activities so that board members and officers learn what activities they might choose from in their involvement with our organization.

**BOARD MEETINGS:** The board of directors meets 2-3 times a year. The meetings are typically in February, (early June as needed) 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.

**BOARD MEMBER INVOLVEMENT:** We encourage all board members to become involved in some way in at least one activity or project per year. The following is a list of our typical activities and projects. The dates and types of events are discussed and determined annually.

- **Annual Hobby Day, 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. It recently moved to Windwood of Watertown golf course in Watertown. The date has been dependent upon availability. Jackie Mallow has been 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/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 choose 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 is hosting the annual PWSA (USA) national conference in 2008. This event will serve as our educational event. It is really 3 conferences or meetings in 1 event. There is a 1-day Scientific meeting where researchers gather and share their findings. There

is also a 1-day training event for Residential Providers; and a 2 day conference for parents, care givers and others who support children and adults with PWS.

- **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 the State of Wisconsin have been given at least 5 copies of our Packets of Hope. On an annual basis, we make contact with each of them and replenish their supplies if needed. Packets need to be compiled and mailed. Any board member who may be interested in assisting with this can work with the program director to do so.
- **PWSA of WI, Inc.'s Annual Mail Fund Raiser:** Once a year, we conduct a mail fund raiser. This is typically in the late fall of the year. Currently the program director has created the letter and prepared them 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!)
- **Annual Meeting for Parents of Young Children:** Over the past few years, PWSA of WI, Inc has sponsored an annual meeting specifically for parents of young children. Any board members or parents of young children who are interested can help in the planning and arrangements for this event.

## Message from the Office...

### By Mary Lynn Larson

Things remain hectic in the office — **and** the Larson household as we transition from summer back to school! We are all looking forward to the return to structure, routine and consistency that is not set up or being arranged by Mom! Things seemed much more hectic during the summer as I tried to focus on either keeping the boys busy and structured or just trying to enjoy the laid-back days of summer! We have had a crazy summer with my youngest

brother getting married and all five of my siblings returning home with their families for a 7—10 day period! With five different sets of structure, routine and rules — it really threw my boys for a loop! Now we are **so** ready for the school year to begin! Matthew begins 2nd grade and Alex is starting high school! Alex is very anxious to start high school and appears to have none of the common anxieties that most of us experienced! He just has faith that everything will be great!

I am hoping for some of that same 'faith' as we are looking at only 10 months until the 2008 National Conference that we (PWSA of Wisconsin, Inc.) are hosting in Milwaukee in July!! There is so much to do — and so little time! The National PWSA (USA) conference is truly 3 separate conferences all held at the same time; the Scientific conference, the Residential Providers conference and the Family/General conference! The conference committee is beginning to really start working on the specifics of who, what, when, where and how of it all! We are hoping that many of our families in Wisconsin will help us out and step forward to assist! We will meet again on Saturday, September 16, 2007 at the Four Points Sheraton in Milwaukee — the site where we will be hosting the conference. I will be working on determining some conference topics and potential speakers — so if you have some ideas; please let me know!! If you are interested in volunteering but want to know what all is involved with certain things or want to help out in ANY way, feel free to give me a call on the toll free line or drop me an email at: [Wisconsin@pwsausa.org](mailto:Wisconsin@pwsausa.org) Looking forward to the return of school and wishing us all a smooth transition back to the school year,

Mary Lynn

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

|                                    |  |                                     |
|------------------------------------|--|-------------------------------------|
| September 16, 2007                 | 2008 Conference Planning Committee Meeting                   | Four Points Sheraton, Milwaukee     |
| September 26th and October 3, 2007 | Health Education Class for Persons with PWS                  | Waisman Center Madison, WI          |
| October 17th and October 24, 2007  | Health Education Class for Persons with PWS                  | Oconomowoc, WI<br>Classes are full  |
| October 6, 2007                    | PWSA of WI Board Mtg<br>Parents of young children w/ PWS mtg | Milw. Heart Scan<br>Milwaukee, WI   |
| July 2-4, 2008                     | 30th PWSA (USA) Conference<br>"Moo-ving" Forward             | Four Points Sheraton, Milwaukee, WI |

Prader-Willi Syndrome Association of WI, Inc.

2701 N. Alexander St.

Appleton, WI 54911-2312

1-866-797-2947

Email: [Wisconsin@pwsausa.org](mailto:Wisconsin@pwsausa.org)

