



THE WISCONSIN CONNECTION

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*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: Mike Larson

Spring has sprung!! - and yet we have another 8 inches of snow here in Central Wisconsin...

It's hard to think about spring and summer when we still have snow. But if you plan on sending your kids to summer camp you need to be working on that now! Summer camp is a great opportunity for your kids to get away from you and for you to get away from them. In this newsletter, there is a variety of information on things to consider when sending your child/young adult to summer camp as well as information on many camps for persons with special needs in Wisconsin. The camps included here are ones that WI families have reported positive experiences when sending their person with PWS to these camps. For first time campers, it is much harder on parents than it is for the kids. But once your child attends camp, they have a ball and you get a short rest. If you have put off sending your kids to camp; do it and you will wonder why you didn't do it sooner. It's good for **both** of you. And remember PWSA of WI, Inc. has funds available to help send your child to camp. There is an application in this newsletter. Get the applications turned in by May 1, 2009.

Just a reminder...Hobby Day is coming up on April 18, 2009. This is our annual social event for persons with PWS. As usual it is being hosted by our most generous friends at Prader-Willi Homes of Oconomowoc. It promises to be a great time. This year there is a Hawaiian Theme, dig out your Hawaiian shirts and sunglasses. For the parents there will be a special speaker from Community Care - Connie Titter. Connie will be talking on Family Care, the new long term care program that is being rolled out across Wisconsin. If you haven't heard about Family Care, this would be a great way to learn. If your county is already involved in implementing Family Care, we would love to hear your perspective. You may have some important insights for those of us who are just starting the process.

Now that we are finished getting the boys IEPs set up, we are dealing with other day to day issues. The other day Mary Lynn and I were in the bedroom. We had forgotten to lock things up in the kitchen. We both stopped dead in our tracks when we heard foot steps running quickly down the hall and then Matthews's door slam shut. We immediately knew something was afoot. We went to Matthew's room, and found three hamburger buns on the back of his desk. Without saying anything we took them, and turned to walk out. While we were walking out of the room, Matthew blurted out, "How do you always know?" Lets hope he doesn't figure that out too soon!

Be Safe, Be Vigilant,
Mike

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 MAY 1, 2009.** 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 or may have already passed. **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

Email: respit1@wi-easterseals.org

Email: 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

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

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.

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 190th 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.



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



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 or call the office.



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).

Prader-Willi Syndrome
Association of Wisconsin,
Inc.
2701 N. Alexander St.
Appleton, WI 54911

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.

Office: 1-866-797-2947

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? _____

(Continued on page 5)

(Continued from page 4)

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.)

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: May 1, 2009

**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 under Services.)

(Continued on page 6)

Spring House Cleaning for the Person in Supported Care

By Barb Dorn

Every spring, many people begin the task of spring house cleaning. Windows are washed; walls may be painted and many items are refreshed or replaced. People who are in supported living situations also need this annual rite of spring passage performed; however, they require assistance and planning to prevent this from becoming a very stressful event.

In the world of residential supported care, there is a high turnover of staff. It is common to see a new set of faces supporting a person every spring. Agencies that provide care to these individuals would be doing their residents a great service in developing a plan to make sure that their environment and their personal belongings are cleaned and/or replaced every year.

“Spring house cleaning” is an overwhelming task for most of us. Many adults with PWS are hoarders and have great anxiety when they are asked to clean, sort and discard excessive items. It is important to break down this task into smaller, more manageable steps in order to encourage cooperation and minimize anxiety. Often times, there may be certain individuals in the person’s life who are better able to provide this assistance and support. (I know of one situation where the person with PWS was more willing to have a specific staff person help with sorting but would not do or allow other staff members to assist him.) A trusting relationship is often very important. Parents may also be allowed to assist but in many cases, parents are unavailable or unable to provide this assistance.

General Recommendations:

1. Break down the large task of cleaning into smaller tasks.
 - A. It may take 4—6 weeks to complete the task of house cleaning. It could take 5—6 “cleaning dates” to complete the full task of spring cleaning—especially the bedroom.
 - B. Limit cleaning jobs to 20—30 minutes, one to two times a week.
2. Provide a check list for the person to check off once the job is complete.
3. Provide an incentive once each step of the job is complete.



The bedroom is often the biggest and most challenging cleaning area and task to undertake. There are five areas in the bedroom noted in the table below. Consider having 5 separate “cleaning dates” for cleaning the bedroom. You will encounter failure if too much is undertaken at one time. Do this in small steps or you should expect emotional escalation.

The Bedroom:

1. The Bed

- Mattress
 - Check its condition & age (average life span for a mattress is 8—10 yrs).
 - Flip & rotate—If it is a pillow top, just rotate.
- Mattress cover
 - Check condition—wash, replace if needed.
- Sheets & Blankets
 - Check condition—wash, replace if needed.
- Pillow & pillow cover
 - Check condition—wash, replace if needed. (Recommend replacement annually).
 - People often neglect washing the pillow cover on a regular basis.

2. The Closet

- Remove & review clothing items in closet—are any items too small or worn?
 - May suggest donating items to local charity. This approach is often successful in utilizing the person’s willingness to help others.
 - Launder any clothing items that may need this. Often winter coats, hats & mittens may need to be washed at the end of the season.
- Remove & review other items in closet. Determine if any items need to be tossed.
 - If this is difficult, suggest items be donated & discard items out of sight of the person with PWS.
- Dust & vacuum floor & shelves.

3. The Dresser

- Remove & review clothing items in the dresser—are any items too small or worn?
 - Once again, suggest donating items to a local charity. This approach is often successful in utilizing his/her willingness to help others.

4. Window and Window Coverings

- Wash windows & window coverings. Dust blinds.
- Clean window sill & surrounding area.

5. Rugs

- Vacuum &/or wash floor coverings & throw rugs.
- Suggest rearranging the furniture. This will allow you to vacuum all areas—especially under beds & behind large furniture.

House cleaning, whether weekly, monthly or annually is a necessary evil that we must all undertake. By planning and providing support and encouragement, the individual with PWS can be successful in completing this difficult task. For those who are in supported care, it is important to make sure that this task is completed annually using careful planning.

The following is a checklist that may be used or adapted in helping the person with PWS with the task of cleaning.

The Bathroom:

1. **Shower Curtain and Liner (Shower Door)**
 - Should be washed at least 3—6 months
 - Replace liner at least annually
 - Wash shower door with bleach solution every 2 to 4 weeks.
2. **Windows / window coverings**
 - Wash windows & window coverings.
 - Dust blinds.
 - Clean window sills & surrounding area.
3. **Floor coverings / Throw rugs**
 - If throw rug surrounds toilet—wash weekly & replace annually. Strongly suggest not using a rug in this location due to high colonization of germs.
4. **Toilet lid covering**
 - Wash weekly & replace annually.
 - Best not to use at all.

The Kitchen:

****It is best if the job of cleaning the kitchen is left for staff. This would be a very challenging task for most adults with PWS. **Best if done when person is not at home.**

1. **Refrigerator**
 - Clean all shelves & drawers.
 - Look at expiration dates on all bottled items—discard if needed.
2. **Stove / Oven**
 - Clean stove & oven per manufacturer's guidelines.
3. **Windows/window coverings**
 - Wash windows & window coverings.
 - Dust blinds.
 - Clean window sills & surrounding areas.
4. **Floor coverings/Throw rugs**
 - Move refrigerator & stove.
 - Wash all floors.

If other areas of the person's home must also be cleaned, it is often helpful to solicit help from the residential staff. Sharing of responsibilities assures that the individual's

home remains clutter-free (or at least minimally clutter-free) and clean. Staff resident cooperation is often needed. Each individual situation should be considered.

The Living Room:

1. **Windows/window coverings**
 - Wash windows & window coverings.
 - Dust blinds.
 - Clean window sills & surrounding areas
2. **Floor coverings/Throw rugs**
 - Move all furniture & vacuum
 - Wash or replace throw rugs.

NOTE: Make sure to wipe off exercise equipment with antibacterial wipes and/or cleaner. If used by a number of different individuals—this should be done between each use.

PWSA of WI, Inc.'s

9th Annual

GOLF BENEFIT

Saturday August 22, 2009



Being held at

Windwood of Watertown

Golf Course

Prizes, Food, Silent Auction &

Most of All Fun!

For more information, check out our web site
or contact the office toll free:

1-866-797-2947

PWSA of WI, Inc.'s Event Calendar

April 18, 2009	Luau Party	Oconomowoc, WI
May 1, 2009	Deadline for Camp Scholarship applications	
June 4 – 5, 2009	First International Conference on Hyper- phagia	Baltimore, MD
August 22, 2009	PWSA of WI, Inc.'s 9th Annual Golf Benefit	Windwood of Watertown

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