



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: Crystal Boser

The Importance of Volunteers

Over the last several years I have had the pleasure of working with PWSA of WI, Inc. in one capacity or another. I began simply as a parent of an individual with PWS who wanted to get involved... I started by volunteering my time at the Spring Social and the Annual Golf benefit; however, I soon realized that there was much more to this organization than just hosting a few events. I then made a decision to get more involved by becoming a Board Member, the Vice President and now the President of this awesome organization. During the many years of my involvement with PWSA of WI, Inc., I have quickly come to realize that one of the reasons this state chapter is so successful is because of the wonderful people who donate their time, money and talents. I would like to take this opportunity to say **"Thank You"** to every person who has assisted this organization by volunteering at an event, donating money or by sharing his or her wonderful ideas....our organization wouldn't be where it is without you all!

I would also like to take this opportunity to answer a question that I get asked quite often by parents, siblings, teachers and friends...."What can I do to help?" The mission statement of our organization is "to support, educate and advocate for persons with Prader-Willi syndrome, their families and professionals in meeting the challenges of this disability"; therefore, interested individuals can help us achieve this goal by volunteering at the Spring Social, the Annual Golf Benefit or at the various conferences and trainings held throughout the year. In addition, interested individuals can assist with various mailings or with the Card Club program that is sponsored by the organization. Interested individuals can also become parent mentors or become involved with fundraising. If people cannot donate their time but would still like to get involved they can make a monetary donation to the organization to help cover camp scholarships or general assistance to families in need. As you can see, there are many different ways that you can help the organization so if you want to get involved or share a new idea on how we can achieve our goals and mission please contact the main office or one of our dedicated Board Members. I promise we will welcome your assistance.

I hope to see many of you at the Spring Social on April 24th and other events that are going to be held throughout the rest of the year.

Happy Spring!

Crystal

Board of Directors:

President: Crystal Boser

Vice President: Jackie Mallow

Treasurer: Tom Hughes

Secretary: Melissa Sirovina

Board members: Don Dorn, Al Luening, Candace Lipski and Katherine Girdaukas

Program Director: Mary Lynn Larson

Assistant Program Dir: Melodee Luening

Office Address:

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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)

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Suite 500

Sarasota, FL 34238

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

Email:

info@pwsausa.org

Website:

www.pwsausa.org

Did ‘Ya Know?

Do you have any information, situations, products that you would like to share with others on our membership list? If yes, please feel free to send it to Mary Lynn Larson at the office at her email: wisconsin@pwsaofwi.org so she can share it with everyone.

WI HOMESTEAD CREDIT

Submitted by Barb Dorn

Is the person with PWS that you support eligible for Wisconsin’s Homestead Credit? Consult your tax advisor or go to the website at www.revenue.wi.gov/faqs/ise/home.html to view information and frequently asked questions on this program. The person must be paying rent to a landlord who is a for-profit entity. There are also income limitations which most people with PWS will qualify for. It may be a profitable opportunity that you will want to check out.

SSI – SOCIAL SECURITY

Submitted by Barb Dorn

If you are your son or daughter’s representative payee, did you know that only one person can be listed to access and/or change information with the social security administration? We learned this the hard way. We recently had to change some information for our son and we learned that only one of us had the ability to do this. After attempting unsuccessfully to make a change on the phone, we were advised to come to their office. Both my husband and I gathered our information including our guardianship papers and our son’s social security card and statements and traveled to the Social Security Administration office. That is where we learned that only one of us could have the responsibility for being the contact person or representative payee who can access information and communicate any changes on our son’s behalf. If you are not your child’s

representative payee (and the county is), any changes must go through your county case manager or county representative.

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Notes from the Office.....

By Mary Lynn Larson

Strangely, things are settling down here in our household since Matthew’s spinal surgery in January. (Although you know I have just jinxed us by saying that!) Matthew has recovered amazingly well and is doing phenomenally with his therapies to regain strength, flexibility and endurance! Thank you for all the prayers and well wishes during his recovery!

The office is busy with working on the upcoming Carnival, the Golf Benefit and our October Behavior training. Melodee has all sorts of games and activities and a Great Magic Show for the Carnival on April 24th! There will be a lot to do, so please get your registration form in early! We are also happy to have family members volunteer to help! Don’t hesitate to call the state office if you have any questions.

Our golf outing is not far away and our chairpersons are hard at work as always! We can use your help with finding golfers, prizes and hole sponsors—so if you have any ideas and have not yet been approached, give the office a call! I am always available to answer questions!

We are very excited about our upcoming Behavior training featuring our guest speaker, Dr. Linda Gourash. Many of you may have heard Dr. Gourash speak at previous National Conferences but if you haven’t—she is a dynamic speaker who has over 30 years of experience working with persons with PWS and shares the humor we, as parents often need to find in our children’s exploits. We are very excited she will be here to share her insights into dealing with some of the challenges of PWS. Our conference will be at the Country Springs Hotel and Water Park in Waukesha, WI. We, as an organization, are not offering child/adult care at the conference but many of us involved with the planning have made arrangements to include our kids/loved one with PWS so we can spend some “fun” time with them outside of the conference. We are hoping this will be an opportunity for you to spend some “fun” time and learning time with your loved one with PWS.

Enjoy! Mary Lynn

PWSA of WI, Inc's. Carnival will be on April 24, 2010



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Prizes, Games and FUN!! And a Magic Show!!

Have you signed up to attend our Spring Carnival yet? On Saturday, April 24th, 2010 PWSA of WI, Inc. will be holding a carnival at the Oconomowoc Residential Programs Gym in Oconomowoc. We will have all sorts of games, prizes, face painting and a **Magic Show** featuring Magicians Andrew & Lynette Baerlocher. Registration starts at 9am with the games starting at 9:30am. Lunch will be provided and in the afternoon we will have the **Magic Show!** It is sure to be a GREAT

time and we look forward to seeing you. Cost is \$10.00 per person to cover lunch but there are scholarships available. If you have not received paperwork on this yet, you can find it located

on the PWSA of WI, Inc. website at: www.pwsaofwi.org or call Mary Lynn at the office at 1-866-797-2947. In order to make this event a success for everyone, **WE NEED VOLUNTEERS!!!** If you are interested or able to volunteer for this event, contact Melodee via phone at 262-375-2181 or email her at: programassist@pwsaofwi.org. It is sure to be loads of fun! Please join us!!



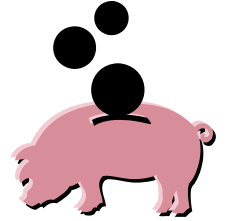
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PWSA of WI, Inc. Pick 'n Save WE CARE PROGRAM

Do you shop at Pick 'n Save? Did you know that PWSA of WI, Inc. can benefit from your shopping purchases? Designate our organization on your Pick 'n Save Advantage Card.

**PWSA of WI, Inc's number is
622600**



Q: What to do if I don't have an Advantage card:

A: Just go to the service desk and apply for one. There is no fee. It will offer you all kinds of savings plus a certain percentage will be donated to our organization. Please designate our organization as one of your WE CARE organizations. **Remember # 622600.**

Q: How do I add/change what I have designated?

A: Just go to the service desk and ask for a change form. Add our organization to your list.

Please share this information with family and friends. Help us raise funds that will benefit all who have Prader-Willi Syndrome!

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Request for Email Addresses or Updates

Would you be willing to receive your newsletter by email? This could be a great cost savings for our organization. Are you receiving all of our last minute updates and information? Often times, our office receives information that we pass on to our membership via email. This is also a cost-savings way to keep you informed. Please drop us a note to let us know your email or inform of us of any changes. We strive to keep you updated on issues of concern.

CONTACT: wisconsin@pwsaofwi.org



**PWSA of WI, Inc and Prader-Willi Syndrome Assoc. IL Chapter
Are Proud to Host**

Special *Tricks* on *Treating* Prader-Willi Syndrome: A Behavioral Approach

**Featuring Guest Speaker Dr. Linda Gourash, MD, a Developmental
Pediatrician and National & International Expert on
Prader-Willi Syndrome.**

**Friday October 15, 2010
Country Springs Hotel Water Park & Conference Center,
Waukesha WI**

Dr. Linda Gourash, MD, is a board certified Developmental and Behavioral Pediatrician. She has over 30 years of experience in working with children and adults with developmental disabilities who have behavior and medical disorders. She is a past Medical Director of the Prader-Willi Syndrome (PWS) and Behavior Disorders unit at the Children’s Institute in Pittsburgh, PA. Dr. Gourash is co-founder of her current practice in the Pittsburgh Partnership. She has authored many articles and publications on practical management of challenges faced by individuals with PWS. She serves on boards for both PWSA (USA) and the International Prader-Willi Syndrome Organization (IPWSO). Dr. Gourash is a dynamic speaker and has years of experience as a consultant in helping those who support persons with PWS.

Children and adults with Prader-Willi syndrome often face behavior challenges at home, school, work and in their community. This conference will provide those who support these individuals with information, tools and networking that will help them gain a better understanding of how and what they can do to prevent and/or minimize these challenges.

Other Speakers Include:

Gus Ludwig OTR: Occupational Therapist from Oconomowoc Developmental Training Center who has training and experience in Sensory Integration Sensory Regulation.

Barb Dorn, RN, BSN: Volunteer Consultant on Prader-Willi Syndrome and parent of 25 year old son with PWS.

Peggy Burns, RD: Staff dietician for Prader-Willi Homes of Oconomowoc who provides nutritional services for over 70 persons with PWS.

NO CHILD/ADULT CARE SERVICES WILL BE PROVIDED

LODGING: Country Springs Hotel in Waukesha has provided PWSA organizations with very reasonable hotel room rates. Visit their website www.countryspringhotel.com. Make sure to mention “PWSA” when registering or you will not receive these reduced rates. Hotel Contact: Toll free: 1-800-247-6640 or locally 1-262-547-0201

ROOM	SINGLE/DOUBLE RATE – WITHOUT WATERPARK	SINGLE/DOUBLE RATE – WITH WATERPARK *Includes 4 passes to 45,000 water park
Standard	\$95	\$115
Executive Suite	\$155	\$175
Governors Suite	\$216	\$235

COST: **\$35** (for members of PWSA of WI, Inc or PWSA – IL)
 \$45 (for non-members)
 Scholarships are available for members

***Certificates of Attendance will be awarded to social workers, educators and other professionals.**



The Camper with Prader-Willi Syndrome

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 Prader-Willi syndrome.

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 and Experience with Campers who Have Prader-Willi Syndrome: 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 our toll-free number 1-866-797-2947.

Prader-Willi syndrome in the media recently:

Discovery Health Channel's: Mystery Diagnosis:

On March 22, 2010 Mystery Diagnosis featured Conor Heybach, a young man with PWS and his parents Sue and John. Conor is on PWSA (USA)'s Adults with PWS Advisory Board, while John is co-chair of the PWSA governing board. The program was filmed over several months and the producers were very pleased with the overall results. It focused on the search for a diagnosis of what the family was dealing with over the course of Conor's early years into early adolescence. It lacks some depth in the specifics of Prader-Willi syndrome but the whole premise of this series is the search for a diagnosis.

Another positive that came out of this show is the producers want to do another show (not certain yet if it will be on Mystery Diagnosis though) focusing on the specifics of Prader-Willi syndrome and they sent out a request for looking for families dealing with specific issues of PWS. They hope to get things in production and we will share the details of that show when we know more. Look for more details about it, likely on our web site coming once we know!

Extreme Makeover: Home Edition

If you are not going to be home on Sunday, May 2nd, 8pm Eastern time, set your DVRs to record an upcoming episode of ABC's Extreme Makeover. This episode features a family with a child with PWS!! The Starkweather family is getting a new home courtesy of thousands of volunteers and ABC's Extreme Makeover: Home Edition. Amy and Toen Starkweather and their three sons, Jared, Ryan and Ethan (who has PWS) recently found out they were chosen for the show. Learn more about Extreme Makeover: Home Edition at <http://abc.go.com/shows/extreme-makeover-home-edition>.

Check out these web sites!!

By Mary Lynn Larson

Have you checked out the PWSA of WI, Inc. web site recently?

PWSA of WI, Inc. at www.pwsaofwi.org

There are some changes going on! I sometimes forget to check out our own web site on a regular basis—even though I seem to regularly be sending things onto Jennifer K., our web master to post there. Then when I have a minute to actually look at it, she has all these new pictures or links that I had never seen before! It certainly allows me to catch up on how big some of 'your' kids are growing as well as how well they are doing! Keep sharing your photos—it tugs the heart strings and makes us smile!

There are also links to a wide variety of topics including health related topics, trainings, and other resources. One of the new items I noted was the link to the National Sibling Support Project or Sibshops, a non-profit group that is dedicated to the interests of brothers and sisters of people with special needs and long-term illnesses. This is a phenomenal organization that allows siblings the opportunity to share all the "good and bad" of having a sibling with special needs or long-term illness. My experience with it over the years has been it is a very positive experience for siblings and I encourage all families to investigate it to see if it would be beneficial for your circumstances. Feel free to share your own experiences with us.

Over the past year, we have had a feature on the WI web site called **Persons with Success** detailing the many successes—large and small that our family members with PWS experience. We have currently hit a 'dry spell' and we think families have forgotten about this feature. We continue to look for more of these because, as we know, it is so important to celebrate the positives in all of our lives! If your family member with PWS has had a successful opportunity or event that you would like to share—send us a note! We would also love to include a photo of them!! It could be anything as simple as learning to tie their shoes to passing an exam in one of their school classes! Let them have their moment to shine in front of everyone!!

New email group specific to PWS in Wisconsin

PWSA (USA) and PWSA of WI, Inc. are pleased to announce a new online support group for Wisconsin families. This group is for family members, friends and professionals involved in the life of someone with Prader-Willi syndrome, to share information about Medical and Professional Resources in Wisconsin, Individual Educational Plan issues, openings for supportive living arrangements, eligibility for state services as well as creating and staying in touch with 'focus' group meetings around the state. If this is something you are interested in being a part of, sign up for this group. Send an email to

pwsa-wi-subscribe@yahoogroups.com or visit
<http://health.groups.yahoo.com/group/pwsa-wi/>

PWSA of WI, Inc's 10th Annual Golf Benefit

Keep August 28, 2010 open to attend PWSA of WI, Inc.'s 10th Annual Golf Benefit to be held at Windwood of Watertown! This is our big fundraiser of the year and we need your help and participation!! We are looking for golfers, prizes, volunteers to help out and hole sponsors! For more information, contact Mary Lynn at the PWSA of WI, Inc office at 1-866-797-2947 or visit the web site:

wisconsin@pwsaofwi.org



How to help at the golf benefit...

Looking for an idea on how to help the golf benefit, but you don't golf? A suggestion we had from another family was to make a plea to their family and friends to



"Honor your Friend, Family Member with PWS" by sponsoring a hole in their name! If people wanted to do a family hole sponsorship with parents, grandparents, siblings, etc. join together to sponsor their loved one with PWS. A group of friends might be willing to do the same. This is a great idea for family and friends who are not golfers but want to show their support! I have on file a sample letter this family used in contacting their own friends and family... send me a note and I can easily share it with you. Including a picture of your loved one with PWS can really tug on their heart strings even more. The money we get from our hole sponsors—especially NEW hole sponsors is very profitable for our organization! Last year, we were successful in having 40 Hole sponsors—we are hoping to get more this year; but we need your help!

In order to make the golf outing a success, we need prizes for our golfers and silent auction! Some great ideas for prizes include: coolers, lawn chairs, lawn games, gift certificates of any kind, grilling supplies, and golf items. Remember, this is NOT an all inclusive list so if you have other ideas either for golf prizes or silent auction items, let us know!

Another way to support the golf outing is to encourage family and friends who are golfers to join us! If you only have 2 or 3 people and not a full team, we can always find others who would be willing to join to make their team complete. While many of us who work the golf benefit are NOT golfers, we can personally attest to the fact that everyone seems to enjoy themselves!! Personally, I love getting to meet the names of family or friends of our members whose names I recognize from the mailing list! If you are looking for more information to sign up golfers, check out the web site or call the office!

PWSA of WI, Inc.'s Event Calendar

April 24 2010	PWSA of WI, Inc.'s Spring Carnival	Oconomowoc Resi- dential Programs Gym Oconomowoc, WI
August 28, 2010	PWSA of WI, Inc.'s 10th Annual Golf Benefit	Windwood of Watertown
October 15, 2010	'Special Tricks on Treating PWS: A Behavioral Approach'	Country Springs Hotel & Conference Center, Waukesha, WI

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