



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

It is only March and 2014 is already shaping up to be an exciting year for the Prader-Willi Syndrome Association of Wisconsin, Inc. First, I am thrilled to announce that PWSA-WI, Inc. has hired a new Program Director, Joshua Escher, who will begin full-time with the organization in June 2014. Joshua currently lives in Menasha with his wife Sara and their Great Dane, Harley. Joshua is a graduate from the University of Wisconsin-Oshkosh and has a background in teaching. During his teaching career, Joshua has had the pleasure of working with individuals with varying special needs. In addition, Joshua has personal experience with individuals with special needs as he has two nieces who were born with Joubert Syndrome. Joshua will be working closely our current Program Director, Mary Lynn Larson, throughout the rest of the year to ensure this transition goes smoothly. Joshua will be attending our 4th Annual *On The Move* walk-a-thon in May so everyone will have an opportunity to meet him.

Speaking of the 4th Annual *On The Move* event, we are excited to announce we are *On-the-Move* to a NEW location this year. In an effort to accommodate our growing crowd and get away from the cold wind coming off the lake, we are moving to the Lake Country Trail at Roosevelt Park across from the Imagination Station. As in years past, we will be having a delicious lunch immediately after the walk and our favorite DJ, Scott of Wileman Mobile DJ, will be back for some moving and shaking. We hope everyone will join us for this fun filled day; however, if you cannot, please consider visting our new online fundraising forum, Firstgiving, to sponsor an existing fundraiser or set up your own fundraising page. To visit our Firstgiving page go to <http://www.firstgiving.com/pwsausa/on-the-move-walk>. Remember, whether you walk the day of the event or you sponsor someone else to walk, your participation allows PWSA-WI, Inc. and PWSA (USA) to support individuals with PWS in a variety of ways. For example, the funds raised allow both organizations to educate and advocate on behalf of individuals with PWS and their families. In addition, the funds raised help send individuals to camp, families to conferences, and allow PWSA of WI, Inc. to hold fun social events, such as the Snowflake Ball. In essence, your support helps the organizations fulfill their missions of supporting, educating, and advocating for individuals with PWS and their families.

Before I close, I would also like to say **THANK YOU** to all of the amazing volunteers who came and helped out at our 3rd Annual Snowflake Ball. Without each and every one of you, this event would not have been the HUGE success it was. We are truly grateful for you all and appreciate your willingness to give up your valuable time to help us make the night memorable for all of our individuals with PWS and their loved ones. As many of us in this organization like to say, **YOU ROCK!!**

I hope to see you all at the upcoming On the Move event on May 10th and don't forget to mark your calendars for the 14th Annual Golf Benefit on August 23rd.

See you all soon!

Crystal L. Boser

Board of Directors:

President: Crystal Boser

Vice President: Don Dorn

Treasurer: Tom Hughes

Secretary: Candace Lipski

Board members: Melanie Ignatowski, Bobbi Pogrart, Jackie Mallow, Steve Steffen, Nancy Burlingame

Program Director: Mary Lynn Larson

Education & Training

Coordinator: Barb Dorn

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

Toll free: 1-866-797-2947

Email:

wisconsin@pwsaofwi.org

Website:

www.pwsaofwi.org

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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

* REMINDER: *

NEW PWSA of WI, Inc. membership requirements

Changes in Membership: In August of 2013, the membership voted to eliminate the fee for membership because, as an organization, we feel that everyone should have the most current information about Prader-Willi syndrome. We strive to keep our membership aware of the latest information about the syndrome through our newsletter and web site. This will require persons interested in membership to contact the office of PWSA of WI, Inc. annually to maintain their name on the membership list,. This allows them to be included in any mailings pertaining to upcoming events or pertinent medical updates. You can either send an email with your name and contact information to the office at: Wisconsin@pwsaofwi.org or call the toll free line.



Notes from the Office.....

By Mary Lynn Larson

Wow, I have to say a **BIG THANK YOU** to everyone who helped with the Snowflake Ball!! As you can see from the smiles in the photos posted later in the newsletter, it was a

huge success — a success that would not have happened without the help of SO many of our volunteers and families! I cannot say “thank you” enough to those of you who were so willing to pitch in!

Now we are getting things ready for our upcoming *On the Move* Walkathon on May 10th! This is a national and local fundraising and awareness event that we do in partnership with PWSA (USA) and other chapters across the United States. This year PWSA (USA) and PWSA of WI, Inc. are using an online forum

Follow  **FirstGiving**™ called Firstgiving to help streamline the donation process

and make it easier for people across the world to support a loved one or event. And we are hoping you will use Firstgiving to create your own fundraising page to help support our 4th annual OTM walk. In addition, Firstgiving allows you to track your personal fundraising efforts and see who the leading fundraisers for the Wisconsin event include. We will have instructions on how to set up a Firstgiving fundraising page in the upcoming mailing. If you have any questions, let us know.

As we are hoping for spring, we, in the Larson household, are submitting applications for summer camp! Are you getting your paperwork together? If you are having financial constraints that might limit this, remember to consider submitting for those funds using our general assistance application! We do not have a copy in the newsletter like we usually do—due to space; but it is on our website! Look for the link on the next page!

We will continue encouraging you to check the web site as we are no longer sending paper copy of the newsletter. It is more cost efficient for us to communicate with the membership on important issues and events. It also is much more efficient for us to post something once on the web site versus sending out a mailing to hundreds of people. We try to keep it updated (although that is more of a challenge with only myself available these days). If you need something that you cannot find on the web; feel free to give me a call on the toll free number or shoot me an email.

We are currently working on some new publications that we will be adding to the web site so look for those in the near future. I will be posting something on SSI Disability Benefits that was shared with me recently also. Remember, as you go through your days and come across information that you find useful and think it might help others, feel free to share with me. We can then determine if this is something that we might want to share on the web site.

Thanks for all your help!

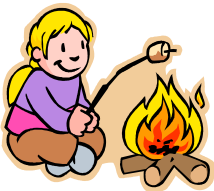
Mary Lynn

Start thinking summer!

I know, I know - with all the recent snow and cold, its hard to believe it—but summer is coming! It's time to start thinking about getting things ready for summer—and that means summer school, summer vacation and CAMP! Summer camp can be a fun-filled exciting time for both youth and adults with PWS. It can offer a week filled with activities, adventures and social opportunities. It can also provide families a break from the day to day monitoring and challenges we all face living with PWS. (Think RESPITE!!)



If you are thinking about sending your loved one with PWS to camp but are concerned about cost –consider applying for a general assistance scholarship . PWSA of WI, Inc. has the resources to provide financial assistance for families of persons with PWS to help meet the unique needs of these individuals and their families. We offer our General Assistance Scholarship. In order to apply for a general assistance scholarship, persons have to meet two requirements: 1) the person with PWS must reside in the state of WI and 2) the person with PWS or



their caregiver or family member of this person must be a member of the PWSA of WI, Inc. chapter. {See page 2 for NEW membership requirements.} You can apply for a general assistance scholarship online at:

http://pwsaofwi.org/general-assistance-fund/

Contact Mary Lynn at the office if you have any questions.

SAVE THE DATE!! August 23rd
PWSA of WI, Inc.'s
Annual Golf Benefit
at Windwood of
Watertown Golf
Course in Water-
town! Join us!!



PWSA of WI
Annual Golf Benefit
 SUPPORT • EDUCATE • ADVOCATE

We need your help...

Have you wanted to volunteer but never knew what you could do? We get many people who want to help but don't think they have the skills or talents. We have lots of opportunities for almost anyone to assist with... and you don't need a lot of special skills or talents! You might wonder "what can I do?" here are some of the ways you could assist:

1. Think about joining our Board of Directors; we will have several positions available during the fall elections. The terms of Vice President, Treasurer and 3 Board positions will be available.
2. Volunteer at one of our events; Each year we host the Snowflake Ball, the Walkathon and our annual Golf Benefit.
3. Do you have time to stuff and label envelopes? Can you assist with office mailings? We have several mailings that we do annually as well as information packets that we get ready for mailing when requests come in.
4. Has your loved one with PWS had a recent success that you would like to share with others? Think about writing it up for an upcoming newsletter! If you get it started, we can help with the rest!

If you are interested in learning more about any of these opportunities, contact Mary Lynn at the office by phone or email! If you have the time and energy to help, but aren't sure what you could do, call Mary Lynn and see what needs to be done....We always have things in the works; we just need extra hands! ...**WE NEED YOU!!**

Mark your calendars!!

May 10, 2014



On The Move

©2011 Prader-Willi Syndrome Association (USA)

On The Move

Walkathon

Do you have your team ready? Are you working on your pledges? The *On the Move* Walkathon is only about 10 weeks away!! This walk is a national and local fundraising and awareness event we hold each year.

*** NEW LOCATION ***

We are hosting it at **Roosevelt Park** this year, located at 100 E. Forest St, Oconomowoc, WI—across from the Imagination Station! We will have on-site registration from 9—10AM followed by a walk on the Lake Country Trail. We will return to the park for lunch and dancing! Pre-registration gets attendees lunch and a T-shirt (please indicate sizes when registering). Those

choosing to register the day of the event are **not** guaranteed to receive these as supplies on the day of the event will be limited.

We are also trying to make fundraising easier for our attendees! We are using Firstgiving; an online forum used to streamline the donation process making it easier for people across the world to support a loved one or event. It also allows you to track your personal fundraising efforts. To start, go to:

<http://www.firstgiving.com/pwsausa/on-the-move-walk>.

You can personalize an event page for family and friends to donate online and see who the leading fundraisers are for the Wisconsin OTM event.. More information will be included on our website, on our Facebook page and in the registration mailing.

We also have sponsorship footprints and corporate sponsorship opportunities available. Contact Mary Lynn at the office at 1-866-797-2947 or visit www.pwsaofwi.org for more information.



Enamel Erosion and Severe Tooth Wear in Children and Adults with Prader-Willi Syndrome

By Barbara Dorn RN and Dr. Kimberly Wachter, DDS

For years, it has been noted that individuals with Prader-Willi syndrome (PWS) have problems with saliva production resulting in dental caries/cavities, loss of enamel and severe tooth wear. Recent studies on “Salivary Flow and Oral Abnormalities in Prader-Willi Syndrome” as well as the study on “Severe Tooth Wear in Prader-Willi Syndrome: A Case-control Study” done by Saeves, Nordgarden, Espelid and Storhaug (2010 and 2012) from Oslo, Norway continue to support and validate these findings. The challenge now facing those with PWS is what to do to prevent and/or manage these problems. The following resource provides an overview of these dental problems along with some possible approaches.

ENAMEL EROSION is the wearing down of the protective coating (enamel) of the teeth. When enamel wears down, microscopic channels in the tooth open up and become exposed. Most people with this problem complain of discomfort & pain. However, since persons with PWS have an altered pain response they may not experience this sensation.

Common Causes:
 Abnormal salivation
 Diet high in sugars and acid
EXAMPLES OF FOODS AND BEVERAGES WITH HIGH ACIDITY: Soft drinks, sport drinks, fruit juices, lemonade, coffee, tomatoes, strawberries. (Citric acid, phosphoric acid, and ascorbic acid are a few ingredients to watch for in foods.)
 Grinding of the surfaces of teeth
 Health conditions including gastric reflux
 Medications (aspirin, antihistamines and some vitamins)

Signs:
 Translucency of the enamel
 Darkening or discoloration of the teeth
 Pain or cold sensitivity (may not always be reported in persons with PWS)

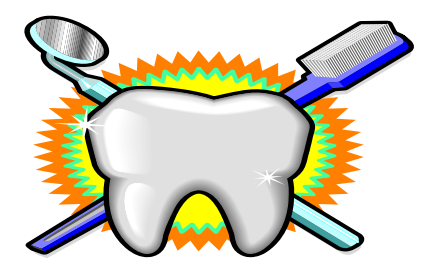
Prevention:
 Drink water. Limit soft drinks, sport drinks, juices and coffee in moderation. Dilute juices with water.
 Swish mouth out with water or brush teeth after drinking or eating items high in acid
 Don't sip on beverages for extended periods of time.
 Do not drink or eat high acid beverages/food in the evening after supper.
 Use a straw to keep acids away from teeth.
 Brush with fluoride toothpaste. Minimize swallowing. (Too much fluoride can cause problems like enamel fluorosis. This condition can occur in children and causes defects in the enamel of the teeth. Ingesting large amounts of fluoride can be toxic and cause nausea, stomach pain and/or vomiting. It may not be quickly detected in persons with PWS).
 Get regular dental checkups and cleanings – at least every 6 months.
 Talk to a dentist about daily fluoride mouthwash if there is a history of cavities (Use as a rinse; do not swallow). If needed – apply with Q-tip.
 Ask the dentist if sealants may be helpful in preventing enamel erosion and tooth decay.

Treatment:
 Once lost, enamel cannot be replaced. Treatment of tooth enamel loss depends on the underlying problem.
 If a person with PWS is found to have a sudden loss of tooth enamel, testing should be done to determine if a medical condition is present. (May require special diet and medication intervention).

SEVERE TOOTH WEAR / GRINDING (also called bruxism) occurs most commonly at night. When teeth grinding occurs on a regular basis, teeth can be damaged and other oral complications can arise. Often seen in both children and adults with PWS.

Causes:
 Exact cause is unknown.
 Often contributed to stress and/or abnormal bite

Treatment:
 Mouth bite guard – best if individually fitted by a dentist. Used most commonly while the person sleeps. May require incentive program for compliance.
 Avoid or cut back on foods and drinks that contain caffeine, such as colas, chocolate, and coffee.
 Avoid alcohol. Grinding tends to intensify after alcohol consumption.
 Discourage chewing on pencils or pens or anything that is not food. Minimize chewing gum. It allows jaw muscles to get used to clenching and makes it more likely to grind teeth.
 Work with person with PWS to learn not to clench or grind his/her teeth. Have him/her practice relaxing jaw muscles.
 Try holding a warm washcloth against the cheek in front of the earlobe.
 Include plenty of water. Dehydration has been linked to teeth grinding.



The Snowflake Ball was a success!

As you may have guessed, our Snowflake Ball this year was once again a huge success!! On January 25, 2014, the Oconomowoc Gym was magically transformed to a winter wonderland! The place was filled with snowflakes—just like it was outside, despite the bitter cold! But the friendships and camaraderie of everyone attending soon warmed the place up—unlike the weather outside!!



We had over 185 persons with PWS and/or their families attend with over 30 individuals assisting with a range of things! We had families attending from Wisconsin, Michigan, Illinois and - even the East Coast!!



We need to say, "Thank you!!" to everyone who helped in some way!! This event could not have happened without everyone pitching in and helping, believe me!! Everyone came dressed up and ready to have some fun. Each attendee got to have their picture taken by our professional photographer, Tom and was able to take a photo home! (Some of them



are shared here—but if you want to see more, go to Facebook at <https://www.facebook.com/PWSAofWI>. We had time to renew old



friendships and catch up with folks we may not have seen for a bit! We had several new families attend and luckily, we got to know them better! We are so glad each of you decided to join us! After a nice dinner, which was served by some of our staff and Board



members, there was an opportunity for everyone to dance! A great time was had by all who were on the dance floor! Unfortunately for too many of us, the night ended too soon. But, don't worry, we **will** be back next year!



FREE Tax Preparation Help for Persons with Prader-Willi Syndrome in WISCONSIN

Are you looking for FREE help in preparing the tax form for a person with PWS? In many cases, the income of a person with PWS is low and he/she does not have to file a tax form. However, many individuals are able to take advantage of the Wisconsin Homestead Credit program so it may be worthwhile to file. There are also individuals with PWS who have a higher income or may have other situations that require them to file. The following is a brief overview of the Wisconsin Homestead Credit program as well as information in how to locate a FREE program in your community to help you prepare the tax form for a person with PWS.

1. What is the homestead credit program?

The homestead credit program is designed to soften the impact of property taxes and rent on persons with lower incomes. The benefit available may take the form of an income tax credit or a direct refund. The credit is based on the relationship of your household income to the amount of your allowable property taxes and/or rent for the calendar year. Most people with PWS qualify for this credit if their income is low and they are paying rent to a landlord/organization that is not a tax-exempt organization.

2. How do I learn more about this program?

To view or download information about this program, go to:
<http://www.revenue.wi.gov/taxpro/fact/hc.pdf>

3. What Free Tax Prep Resources Are There?

There is a program called the Volunteer Income Tax Assistance program that provides free basic income tax preparation. More information is provided below:

What is the Volunteer Income Tax Assistance (VITA) program?

The VITA program is a cooperative effort by the Internal Revenue Service (IRS) and many individual states, including Wisconsin. Volunteers trained by the IRS and the Wisconsin Department of Revenue (DOR) prepare basic income tax returns for free. Most VITA sites offer free electronic filing.

Who can get help at a VITA site?

VITA income tax assistance is available for:

1. Low-to-moderate income individuals
2. **Individuals with disabilities**
3. Non-English speaking taxpayers
4. Military personnel
5. Elderly individuals
6. Individuals who qualify for the homestead credit or the earned income credit

Where are Locations for These Services in Wisconsin?

VITA sites: (site locator becomes available in February)

- Call 1-800-906-9887
- Visit irs.gov, keyword VITA
- www.irs.gov/Individuals/Find-a-Location-for-Free-Tax-Prep
- Call "211" for a site near you

4. What should I bring to the VITA site?

You must bring the following:

- Photo identification
- Social security cards for you, your spouse and your dependents
- All wage and tax statements, including Forms W-2, W-2G, 1099-R
- Interest and dividend statements
- Any other tax documents you received

If you are claiming homestead credit, you must also bring:

- ◇ Copy of 2012 property tax bill or rent certificate signed by your landlord (you can ask for this from the landlord or agency providing residential support if you pay them rent).
- ◇ Record of any Wisconsin Works payments you received in 2012

Note: If you are filing a joint return, both you and your spouse must be present.

FOR MORE INFORMATION PLEASE CONTACT:

WISCONSIN DEPARTMENT OF REVENUE
Customer Service Bureau
P.O. Box 8949
Madison, WI 53708-8949
Phone: (608) 266-2772
Fax: (608) 267-1030

PWSA of WI, Inc.'s Event Calendar

May 10, 2014	PWSA of WI, Inc. 3rd Annual <i>On the Move</i> Walkathon	Roosevelt Park Oconomowoc, WI
August 23, 2014	PWSA of WI, Inc. 14th Annual Golf Benefit	Windwood of Watertown, Watertown, WI
January 2015	PWSA of WI, Inc. Winter Ball	

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