



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

PWSA of Wisconsin, Inc. Hires New Program Director

As I mentioned in our previous newsletter, PWSA-WI, Inc. has hired a new full time Program Director, Joshua Escher, who will begin full time in June. In an effort to get to know Joshua better, I conducted the following interview with him earlier this month.

Q. Where do you currently live and are you single or married? I currently live in Menasha with my wife Sara and our Harlequin Great Dane, Harley. My wife is a personal trainer and we have been married for just under a year. We got married by Elvis in Las Vegas last July and our wedding is on YouTube for us to watch whenever we want.

Q. Do you have any children? I have a stepson named Alex. He is 19 and an amazing guy!

Q. Where did you graduate from college and where are you currently employed? I am a graduate from the University of Wisconsin-Oshkosh and currently teach 6th, 7th, and 8th grade students at a private school.

Q. What made you want to join our organization? I wanted to be able to help families and kids in a more direct manner. Some of my most rewarding experiences in teaching have come through working with kids with disabilities.

Q. Can you expand on what experience you have with individuals with disabilities? Both of my nieces were born with Joubert Syndrome. They are both teenagers so I have had a large amount of experience working with them and have had the opportunity to watch them grow and develop despite their disability. I have also had the opportunity to work in a special education classroom for numerous months helping students of varying age levels and diagnoses be successful in school.

Q. What do you do in your spare time? The number one thing I do right now is coach for the Fox Cityz Foxz roller derby league. My wife has been a part of the league since it started and when I met her I got involved. I run two to three practices a week and spend numerous weekends traveling to coach our All Star travel team against teams from other cities in the Midwest. We also try to attend as many roller derby games as we can when our schedules allow so we often travel to Madison and Milwaukee to see their leagues play. Outside of that, I play softball during the summer and go to the gym pretty regularly. (My wife is a trainer after all!) I also play bass and occasionally play with a band I have been in for a number of years now.

Over the next few months Joshua will be working with our current program director, Mary Lynn Larson, and you will get to learn even more about him. We are all very excited for Joshua to join our amazing organization and can't wait for you to get to meet him in person at some of our upcoming events, such as the 14th Annual Golf Benefit on August 23rd. Don't forget to mark your calendars.

Happy Spring.

Crystal L. Boser
President

Board of Directors:

President: Crystal Boser

Vice President: Don Dorn

Treasurer: Tom Hughes

Secretary: Candace Lipski

Board members: Bobbi Pogrnt, Jackie Mallow, Steve Steffen, Nancy Burlingame,

Melanie Ignatowski,

Program Directors: Mary Lynn Larson & Joshua Escher

Education & Training

Coordinator: Barb Dorn

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CALL FOR NOMINATIONS PWSA of WI, Inc. OFFICERS AND BOARD MEMBERS

PWSA of WI, Inc. is once again looking for some dedicated individuals to serve in the following roles for a two year term of office: **Vice-President; Treasurer; and three Board member positions.** A brief description of each of the positions follows. If you have questions regarding these roles or responsibilities, feel free to contact the PWSA of WI, Inc. office or any current officer or board member.

The VICE-PRESIDENT may be delegated by the President to perform his/her duties in the event of the President's temporary disability or absence from meetings, and shall have other such duties as the president may assign. The Vice President receives the monthly time sheets and notifies the payroll data service of hours the employees have worked for the month.

The TREASURER shall be responsible for the financial integrity of the organization. The treasurer will work closely with the volunteer accountant keeping an account of all moneys received and expended for the use of the organization and shall report to the National office and the membership on the financial status of the organization. He/she will establish the necessary controls and checks for the handling and accounting of all financial transactions for the organization.

BOARD MEMBERS serve as advisors in providing governance to the organization. He/she assists in projects, committees and other capacities as needed.

What to Do ... When?

Please obtain and complete a candidate form. You can download it from our website www.pwsaofwi.org or receive one by contacting our office toll free 1-866-797-2947. Submit the completed form to the state office by email or US mail **no later than September 15, 2014.** A ballot will be mailed to all primary members of PWSA of WI, Inc. by October 1, 2014. Return of all ballots are needed by October 15, 2014.

Overview of PWSA of WI, Inc. Activities and 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. Exact dates, times and locations are determined at the previous meeting. Every attempt is made to work around Bd 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 Awareness Event—***On the Move* Walkathon. This event is a PWSA(USA) and PWSA of WI, Inc. sponsored fundraising and awareness event. We host a 2 mile walk around Roosevelt Park in Oconomowoc and also offer lunch and entertainment after participants complete the walk. We encourage all walkers to get as many pledges for their efforts as possible. This is a RAIN or SHINE event—so come prepared! We always need assistance with set up and tear down the day of the event. We ask board members to assist with recruitment of sponsors, walkers and pledges.
- **Annual Charity Golf Benefit**—This event typically occurs in late summer. It is held at Windwood of Watertown golf course. The date is dependent upon availability. Jackie Mallow has been the chair and works with a committee of volunteers. All board members are asked to obtain 2-3 hole sponsors, seek out door prizes, 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**—We try to sponsor some sort of training workshop or educational project on a regular basis. The topic, speaker and location vary. In the past, some board members have been speakers, .

- worked 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 the project.
- **Social Media -**
 1. **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 work on the printing and distribution. Board members are encouraged to submit an article or help with any aspect of this.
 2. **PWSA of WI, Inc. on Facebook**— We have a Facebook page that is administered by a small group of 3—4 Board members and staff.
 3. **PWSA of WI, Inc's web site**— We currently have a web site that is maintained and updated by staff and board members.
- **Card Club**—This is managed by the Program Director and a Board members with several dedicated volunteers who address and mail the cards to persons with PWS each month.
- **Packet of Hope Program**—All genetics clinics in the State of Wisconsin have been given our Packets of Hope, a packet of positive information developed to be shared with families receiving a new diagnosis. Annually we contact each of them and replenish their supplies. 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.
- **Annual Mail Fund Raiser**—Once a year, we conduct a mail fundraiser, typically in late fall of the year. Currently the program director creates the letter and prepares 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.

As you can see, there is a wide variety of activities to become involved with. We need everyone's help to help our organization continue its high level of service for persons with PWS as well as those who support them. By becoming involved, you will meet and become friends with others who truly can be an inspiration and support for you.

Changes in membership...

Are you a member of PWSA of WI, Inc.? In August, 2013 the membership voted to eliminate the fee for membership because we feel that everyone should have the most current information about Prader-Willi syndrome. We want to keep the membership aware of the latest information using our newsletter and web site. This requires persons interested in membership to contact the office of PWSA of WI, Inc. annually to maintain their name on our membership list! You can either call the toll free line at 866-797-2947 or send an email with your name and contact information to the office at Wisconsin@pwsaofwi.org. This allows you to be included in any mailings pertinent to upcoming events or medical updates. Our current membership list for 2014 is considerably smaller than last year... are you included?

PWSA-WI 14th Annual GOLF BENEFIT



PWSA of WI
Annual Golf Benefit
SUPPORT • EDUCATE • ADVOCATE

August 23, 2014
Windwood of Watertown
Golf Course

Notes from the Office..

By Mary Lynn Larson

Wow, things are changing here in the office! We are working on getting things ready for Joshua to start and trying to figure out who does what, how might this work with transitioning things over, and just figuring out how and why we do things the way we do! I have come to realize that just because it might make sense to me, does not mean it makes sense to someone else! And I have to try to put it in writing so it does make sense to someone else! This process is also making us take a look at why we do things, as well as asking, is there a better way to be doing this? Please bear with us during this time... I do have to take a moment and give a big THANK YOU to Barb Dorn and several others for helping me with this process! You have been invaluable in this process!



Our 4th Annual *On the Move* Awareness — Walkathon was a HUGE SUCCESS!!! We hosted it May 10, 2014 at Roosevelt Park in Oconomowoc this year. We had a gorgeous day with the weather cooperating and the new venue was perfect for our needs! Many thanks go to our supporters, donors, corporate sponsors, walkers, volunteers, families and friends! We could not have the successes we do without each and everyone of you!! Thank you so very much!! You can read more about it and see some pictures here in our newsletter, but we have more on our web site and on Facebook! Check it out: www.pwsaofwi.org and www.Facebook.com/PWSAofWI

Our next big event will be the Annual Golf Benefit which is scheduled for August 23, 2014 at Windwood Golf Course in Watertown. Save the date and join us!! A mailing on the specifics of this event will be sent out shortly. This year we need your help! We always want more golfers, more hole sponsors and more silent auction items, but this year we noted we have been depleting our stash of prizes that we use for those who attend each year—so we need your donations! We rely on donated items such as coolers, lawn chairs, lawn games, gift certificates of any kind, grilling supplies and obvious-

ly golf items. This is **NOT** an all inclusive list so if you come up with some other creative ideas, just let us know!

Another thing we need help with is new persons running for our Board of Directors and Officer positions. When we talk about persons becoming members of the Board of Directors, we encourage anyone—whether they are a parent, relative, support provider, professional or even family friend! We are looking for someone who has a relationship with a person with PWS and wants to do what they can to support them. If you know of someone who fits into this description, please encourage them to consider running for a position. Many of our current Board members and officers have been part of the Board for quite some time... and while they will tell you it is very rewarding—they would welcome new persons and new ideas! **{And it is NOT like we want to get rid of our current Board members because, trust me, if there is something we might need them to do once they might not be on the Board anymore, we will NOT hesitate to contact them!}** We are just looking for more involvement from the membership, or perhaps ideas and suggestions on what the membership wants or needs for their loved one with PWS! If you have any questions or concerns regarding a Board position, feel free to contact one of the current Board members or call me in the office.

Mary Lynn



May is National Prader-Willi Syndrome Awareness Month. Help spread the word.

DONORS/CONTRIBUTORS:

The following donors have made contributions to PWSA of WI, Inc. between 12/01/2013—03/31/2014. We want to thank you for your support. We try to be accurate in recognizing our contributors and apologize for any errors or omissions. If you note an error, please contact us so we might correct it.

Robert Thielke and Julie Mitchell

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In Honorarium

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In Memoriam

Prader-Willi Homes of Oconomowoc:

In memory of Tom Reinhold

In memory of Vincent Lasee

JOY

A reminder from Melodee...

A few years ago, when Melodee was the Program Assistant—she wanted to initiate a specific project. She wanted a story or article in the newsletter each time it was published. She wrote this in the September 2011 *Wisconsin Connection*:

It's time to share our JOY

Everyone has trying times. We've all felt the terror of a behavioral meltdown or the frustration of answering the same questions: "When do I get to eat?" "When is snack time?" However, when our kids shine, they remind us that inside of our flawed selves we are all deeply human. Regardless of condition, ability or drive, every person is an emotional and sometimes irrational being. That being said, it is this divine human spirit that can defy odds and overcome obstacles. Stories like these put the lump in our throats and cause us to smile, cheer and rejoice in the beautiful glow that is LIFE. Hard times pass leaving us with a renewed sense of what's really important. That's what we wish to share here.

Joy. Pass it on.

I would LOVE to hear about the joys in your life about your loved one with PWS! Please share!

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On The Move Walkathon Roosevelt Park

May 10, 2014



Wow, I had SOOOO much fun at our 2014 Walkathon-Awareness event!! I hope you did too! The weather was absolutely FABULOUS—especially after the crazy wind you might remember from last year!! This year, we had over 300 attendees—both walkers and volunteers! And the new venue at Roosevelt Park worked GREAT! After registration, we mingled a bit with new and old friends. Once the walk started, we walked 2.0 miles on the Lake Country Trail and returned to the park for lunch, followed by music and dancing with our friends!!

This event is both a fundraiser and an awareness event for our organizations. And when we were going around Oconomowoc putting up posters to make the community aware of the upcoming event, many people had heard of PWS or remembered the walk from previous years! We often remember the times we would talk to people about Prader-Willi syndrome, and they would say, “Prader-what?” This means—we are doing it!! We are raising awareness!! **Thank you for helping us to make a difference!**

Thank you to our corporate sponsors!!



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. 13th Annual Golf Benefit	Windwood of Watertown Watertown, WI
January, 2015	PWSA of WI, Inc. Winter Ball	

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