



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

Since I last wrote, I had the pleasure of attending the 31st PWS National Conference in Orlando FL. For those of you who have never attended a conference, it is a time to greet old friends and meet new ones. A time where parents, providers and experts can share new information about PWS and past experiences.

During my first day at conference, I had the pleasure of spending the day w/ representatives from PWSA (USA) and chapter leaders from around the United States. Some leaders have been involved with their state chapter for years and others were just beginning the journey of establishing a chapter and solidifying their presence in the state. This meeting was a wonderful opportunity for everyone to share their experiences with the group and a time where everyone could brainstorm new ideas to help educate and spread awareness about PWS. As I sat there listening I was reminded about how important the membership is to the success of the chapter. Although many of the states hosted an annual *On the Move* event, several of the states also had members who held local grassroots fundraiser events. These ranged from spaghetti dinners to car washes to baseball tournaments and each time an event was held, more people became aware about what PWS is. That being said, I would like to thank those of you within our membership who have supported the organization by making donations, holding grassroots fundraising events or simply showing up to one of our chapter sponsored events to show your support. We are appreciative and welcome ideas about how we can all continue to educate and spread awareness.

During the second and third days, I had the pleasure of working side by side with the extraordinary staff of Prader-Willi Homes of Oconomowoc and volunteers from the Florida area in the Youth and Adult Program (YAP). This year, YAP was themed Survivor Orlando and 60 individuals with PWS joined one of the following five tribes: Monkeys, Octopus, Toucans, Sharks, and Chameleons. While their parents, guardians and caregivers went off to attend general conference topics, the YAP participants engaged in a variety of activities that included: arts and crafts, an obstacle course, jamming out to Rock Band and learning a dance. Participants enjoyed snack and lunch during both days and were able to participate in a special YAP gala that consisted of a sit down dinner and DJ on Saturday night. As usual, Conference concluded with a closing ceremony and during this event the tribes performed a special dance to Lady Gaga's *Born This Way*. It was a truly amazing sight to see 60 individuals with PWS embrace their uniqueness and show their loved ones how proud they were to have been **BORN THIS WAY!!**

While I was at conference I heard someone say, "we are all part of a family we never wanted to be part of", which is true; however, as this year comes to a close, I am thankful to be a part of the PWS family. Together we have spread awareness, educated people, and continued to improve the lives of individuals with PWS. I hope you all enjoy this holiday season and embrace your unique family.

Happy Holidays!! Crystal

Board of Directors:

President: Crystal Boser

Vice President: Jackie Mallow

Treasurer: Tom Hughes

Board members: Melissa Sirovina, Al Luening, Don Dorn, Candace Lipski

Program Director: Mary Lynn Larson

Assistant Program Dir: Melodee Luening

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Snowflake Ball

*Mark your calendars for
January 28, 2012*

On Saturday, January 28, 2012, PWSA of WI, Inc will be hosting a “special evening of elegance” for persons with Prader-Willi syndrome and their families. We are having our Snowflake Ball in Oconomowoc at the Prader-Willi Homes of Oconomowoc Gymnasium. Through the hard work and efforts of many, the gymnasium will be transformed into an elegant venue for an evening of fine dining and dancing. We want this to be a very special event, so dress attire is encouraged. Registration begins at 4 pm, with dinner being served at 5 pm with the dance following the dinner. Cost is \$10.00 per person. There are scholarships available for anyone experiencing financial difficulties. If you need more information, please visit our web site at www.pwsaofwi.org. Don't hesitate getting your registration in - our deadline is January 2, 2012. If you have questions or concerns, please call the toll free number at 1-866-797-2947 or send Melodee an email at programassist@pwsaofwi.org. Please join us!



Notes from the Office.....

By Mary Lynn Larson

Wow, the holidays are upon us! I can't believe how fast time is flying! Things are crazy busy trying to get everything ready for the Snowflake Ball which is coming up January 28, 2012! We all know how much fun it is to get all dressed up, go out and spend time with friends! We are encouraging **ALL** of our Board members to attend as we hope to have them serving the dinners if possible. Its also a great time for everyone to see old friends and meet new ones. This night is sure to be a lot of fun! We hope to see all of you there! Please contact us and let us know if you have questions!

We are also starting to think and make plans for our annual Walkathon which is happening in Oconomowoc on May 12, 2012! And while the snow might just be starting to fall, we are already working to make our 2nd Annual Walkathon as successful as last year! But we will need your help... start thinking of getting family and friends to donate and encourage them to join us in the walk! Remember, not only is this a fundraiser, it is an opportunity to spread awareness about Prader-Willi syndrome! We will have more information available on our web site in January! Look for it soon or give me a call if you have questions or ideas.

I'd like to take a moment to say “Thank you” to our two retiring Board members: Al Luening, Jr. and Melissa Sirovina. The amount of time our Board members, their families and extended families spend doing “behind the scenes” work for so many of our events is astounding!! They have spent a lot of time and energy working to spread awareness and support the mission of PWSA of WI, Inc. Thanks so much. If you happen to run into them, be sure to let them know how much we appreciate all they have done.

I'd also like to take a moment and remind everyone to be vigilant over the holidays watching to make sure your loved one with PWS is safe... We often hear of individuals bingeing during the holidays and many times tragic events occurring because it was not discovered until too late. It is important to have a plan in place prior to attending events with large amounts of food and many unseen opportunities to snack.

May you all have a Blessed and Joyous Christmas! Wishing all your dreams come true.

Mary Lynn



...the results are in!

The results of our fall election are in! Our new officers and Board members are:

President: Crystal Boser;

Board members: Bobbi Pogrnt and
Melanie Ignatowski.

The new Board members start their term in January of 2012. Bobbi is parent to 5 year old Addison with PWS and Melanie is currently the Admissions Coordinator for Prader-Willi Homes of Oconomowoc (PWHO) and has recently agreed to take on the role of volunteer accountant for our organization. Prior to the election, one of our current Board members, Candace Lipski agreed to take on the role of Secretary for retiring Board member Melissa Sirovina.

We would like to extend our heartfelt thanks to both retiring Board members, Melissa Sirovina and Al Luening, Jr. The assistance you both have provided on so many of our projects and activities has been invaluable!

THANK YOU!!

Tips for the Holidays...

As the holidays approach with parties and "get togethers" with family and friends... — and the focus is on food and treats for many... families with a loved one with PWS are dreading the inevitable, "can I have some of that?" All of us, PWS or not, struggle to find the balance between enjoying the season without always worrying about calories. One of the strategies families dealing with PWS quickly learn is to celebrate in ways that keep the emphasis off of food. It is often dependent upon fo-

cusing on the traditions and memories you make by focusing on activities. Here are some ideas:

- Plan activities like caroling or tree trimming with individuals who might need some assist with this.
- Plan activities like skating, skiing or sledding.
- Have a gift wrapping party—where the focus is on wrapping the gifts vs. food.
- Do a holiday jigsaw puzzle as a family.
- Volunteer to help prepare and send holiday cards.
- Exercise before attending the holiday event.

When the scheduled event will involve food—think about these ideas:

- Bring fresh out of season fruit like a pineapple to gatherings.
- Offer to bring a vegetable tray and fat-free dip.
- On party day, eat lightly at all other meals.
- Discuss food choices before attending the party.
- Allow second servings of vegetables and no calorie drink options only.
- Choose one favorite food and have a regular serving of this food to count as the "special treat" for the holiday.
- Chew a piece of sugar-free gum after the meal is over.
- Have a friend or parent fill your plate with low-calorie hor d'oeuvres.
- Avoid alcohol which is an appetite stimulant. Ask for a "Virgin Mary" - (spiced tomato juice minus the vodka).

Get thru one party at a time. And remember, if you binge, extra exercise won't hurt!

Taking Control During the Holidays

by Olivia Luening
(age 8, with PWS)
(Dad helped...a little)

Next to my birthday, this is my favorite time of year. Starting with Thanksgiving and ending with my birthday on January 2, there is so much excitement. Party central! I like seeing all of my family and friends, staying up later and taking a break from school. There is so much to do to keep me busy and moving from place to place, but it is also a very hard time. At every party, there's so much food around and it's very important and also very difficult for me to take control. There are so many good things to eat but I have to make healthy choices and decisions. Normally, I get to sample small portions of everything that's out. Sometimes, this is not possible though, because there is just too much to sample and I should only have a very small amount. For example, my great aunt had Thanksgiving this year. Now, in the past there have been a lot of tasty things to eat. However, this year there were only a few items out. My great aunt really is very considerate of me and knows how hard it is for me to maintain control. Also, there was a smaller gathering at her house, so she didn't need to put a lot out. Earlier in the day we were at a bigger gathering with some work friends of my dad. There were over 50 people there and a lot of really good stuff out. I had small portions of a few things and worked out a plan with my dad, that if I felt bothered by the food, he and I would take a walk outside to get away and get my mind off of eating. We took two walks around the block, even when the Packer game was boring. It was a little cold, but if felt nice to be outside.



up yet and we are talking about some of the things that I can do to stay in control.

At some of these holiday parties there will be cousins and kids my age to play games and read books and be social with. I am going to try to focus on being more social and taking an interest in what aunts and uncles have been doing since the last time I saw them. My mom and dad say this would be great. Some of the parties will be bigger with a much bigger spread of food. I'm going to do my best and try to take control but if it starts to bother me, my family and I have a plan and that makes me feel better about it.

Happy Holidays and healthy eating to you all.



On The Move

ARE YOU READY?

PWSA of WI, Inc.'s Second Annual *On the Move* Walk-athon and Awareness Event is scheduled for May 12, 2012 at Fowler Park in Oconomowoc, WI! We want you to start getting your teams ready, 'cuz - we want to see you there! More information will be available in January on our web site at www.pwsaofwi.org

Sharing the JOY...

This is another of our "Sharing the Joy" series where we ask parents to tell us the success stories their child is having. Too often we focus on the challenges and negative aspects of life that they are dealing with. We wanted to take a minute to remind each other—and ourselves that they have those wonderful moments of success too! Let's remember to celebrate those!

Success on the Field

By Mike Larson

One day last spring, Alex came home and said he was going to be on the football team! Mary Lynn and I were a little taken aback. (NOTE: Alex had just gone through a spinal fusion surgery last year.) Alex is 18 years old and had not expressed a lot of interest in sports before, but then he explained that his friend, David was the student assistant for the Appleton North Football Team and David had asked Alex to help. His main



duties would be to keep the water bottles full and to get them to the guys when they needed them. He and David were also responsible for hauling equipment to and from the field.

David had been the Student Assistant the year before and had gotten to be friends with Alex over the years. The summer started out with David coming over in the afternoons to get Alex out for bike rides to get

into shape for the football season because he told Alex there was a lot of running up and down the field during practices and games—and they needed to be able to keep up. They also helped with several football camps for younger aged elementary school kids during the summer.

When the regular season started he had many long days at practice, coming home hot and sweaty. I remember when I played

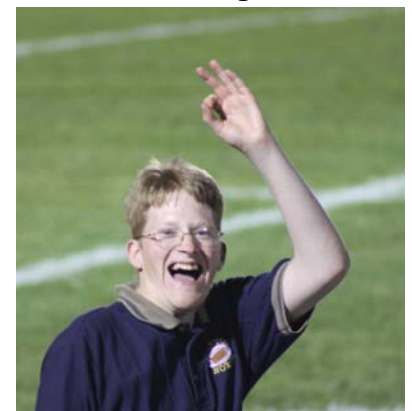


high school football there were many late dinners and early morning

practices. It was no different for Alex, but he really enjoyed the camaraderie of the guys on the team and never complained about his disrupted meal schedules. One night, Alex came home and casually mentioned that he had accidentally run over Coach with the golf cart that day. They use a golf cart to haul equipment to and from the field. Coach was good about the incident, telling Alex that it wasn't the first time he was run over by the cart.

Alex received a team shirt to wear for each game (the same as the coaching staff)

and he was so proud to be a part of the team. When I went to the first game, he and David ran out onto the field leading the team. (cont on pg 6.)



I was impressed at how hard he worked through the entire game. During timeouts, he would run out on the field with his water bottles and help the guys when they came to the sidelines. He also would help to pump up the



fans in the stands when the team needed a boost. At the end of the game, he was right out on the field

with the team congratulating the opposing team. The team had a very successful year going 8-1 for the season and into the second round in the playoffs.

This was probably one of the best social experiences Alex has had in his high school career. He was well accepted by his teammates and truly a full member of the team. There were a couple of bumps during the season with a few misunderstandings on his part but all in all, it was an extremely successful experience. He is looking forward to next year, when he is the Head Student Assistant.



Start thinking about the golf benefit.... We are always looking for donations, hole sponsors and volunteers to assist with our upcoming Golf Benefit which is August 25th this year!

Donations and Contributions

Thank you for your continued support! We have been remiss and neglected to report donations received in **2010**.

Please note these donations were received at PWSA of WI, Inc. from 01/01/2010 through 12/31/2010.

We try to be accurate in recognizing contributors and apologize for any errors or omissions. If you note an error, please do not hesitate to contact us so we might correct it.

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Honoring Andy Mankowski:

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Honoring Beth LaBella:

James & Angela Romig;

The Ausick Family

Honoring Beatrice Ford:

Joseph & Mary Elaine Gareau

THANK YOU!!

PWSA of WI, Inc.'s Event Calendar

January 28, 2012	PWSA of WI, Inc.'s Snowflake Ball	PWHO Gym Oconomowoc, WI
May 12, 2012	PWSA of WI, Inc.'s 2nd <i>Annual On the Move</i> Walkathon	Fowler Park, Oconomowoc, WI
August 25, 2012	PWSA of WI, Inc.'s 12th Annual Golf Benefit	Windwood of Watertown Golf Course

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