



# 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 Note from the President: Barb Dorn

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First of all, I would like to thank the membership of PWSA of WI, Inc. for allowing me to be your president and represent this organization. It is truly an honor and a privilege. I also want to thank Nancy and Steve Burlingame for all of their dedication and hard work as co-presidents for the past 4 years. I know they will continue to assist the organization as much as they are able. In addition, a special thanks to outgoing board members Kathy Bomber and Dan Beaver.

For those of you who do not know me – let me introduce myself and share a little bit about me. I am the mother of 2 young men – my oldest Tony is 20 years old (and has PWS); and my youngest Tyler is 18 years old. Tony is being supported by Prader-Willi Homes of Oconomowoc (PWHO) and lives in Anthony home in Oconomowoc. Tyler is a freshman at UW – Milwaukee. I am married to a wonderful, supportive husband – Don. I am a registered nurse and work part time in a geriatric clinic for University of WI Hospital and Clinics in Madison.

I am very committed to PWSA of WI, Inc and to PWS in general. I have been involved both locally and nationally – trying my best to make the world a better, more informed place for all who have or who are impacted by this disability. I was president of PWSA of WI, Inc. once before and I also served as the executive director/program director for several years. I have traveled to communities around the state as an educator and a consultant. My husband and I were one of the founding families of PWSA of WI, Inc and we have had many adventures and journeys with this organization. In the past I also served as president of PWSA (USA) and remain involved as much as time will allow me.

In 2006, PWSA of WI, Inc will be celebrating its 15<sup>th</sup> anniversary. It seems like yesterday when we had our 1<sup>st</sup> support meeting in the waiting area of a family practice clinic in McFarland where I was working. The room was filled with concerned parents who made the commitment to get this organization started. I am proud to say that PWSA of WI, Inc has been alive and strong for 15 years. We are so fortunate to have volunteers who make this possible. There are many states that do not have an organization like ours that serves as the voice of support, education and advocacy for all impacted by PWS.

In 2006-07, I feel a strong need for our organization to focus on helping to educate health care providers, parents, caregivers and persons with PWS about the health issues that often affect persons with this disability. Recently, we lost a young woman who may have suffered a severe stomach complication as a result of overeating. We grieve for her parents and all of her friends. We must do what we can to prevent others with PWS from dying prematurely. In February, Dr. Dan Beaver and I plan to do a presentation to physicians in the Oconomowoc area about acute health issues that may be seen in children and adults with PWS. Dr. Beaver is an emergency room physician at St. Claire Hospital in Baraboo. He is also the parent of 19-year-old Hana who resides in Oconomowoc. There are approximately 60 adults with PWS who reside in the Oconomowoc area so we felt that educating physicians in this area needed to be a priority. Over the next year we plan to feature at least one article on health in every newsletter. We also hope to host a health update seminar for parents and caregivers in the fall. We want to share written health information to health care providers. And we hope to provide educational sessions for persons with PWS. As you can see – we have our work cut out for us. If you would like to become involved with any of our upcoming activities, please contact Mary Lynn Larson at the state office on our toll free number or by email so we can all work together to make the world a healthier, safer place for persons with PWS. Take care!

Barb

## Titanium Rib Gives Hope

By Betsy Van Heesch  
Mother of Carley, 23 months with PWS

Our daughter Carley was diagnosed with Prader-Willi Syndrome (PWS) one month after birth. While struggling with many of the challenges parents face during that first year of life for a child with PWS, we also were faced with a rare form of scoliosis in Carley.

At seven months, we noticed some curvature in Carley's spine and consulted her pediatrician. At that time, the curve measured about 25 degrees. We kept a watchful eye, but quickly realized that the progression of the curve was very rapid. Despite multiple bracing efforts and body casting, Carley's curvature neared 80 degrees within one year.

**September 2005**  
**One last day at the beach**  
**for this year.**  
**Idiopathic scoliosis**  
**nearing an 80-degree**  
**curve**



Aside from the developmental implications from scoliosis, one of Carley's lungs was significantly compromised due to the condition. When she developed even the slightest cold symptoms, Carley would need to be hospitalized because of low oxygen levels. Over the period of one year, she had eight hospital stays.

Dr. Channing Tassone at Children's Hospital of Wisconsin is Carley's orthopedist who worked closely with us to discuss options, many of which we exhausted over the last year. Dr. Tassone suggested that Carley was a good candidate for the VEPTR (vertical expandable prosthetic titanium rib) procedure.

In November of 2005, Carley underwent the VEPTR procedure at Children's Hospital of Wisconsin. She was one of the first two children to have this surgery during Children's recent certification in the VEPTR procedure. Surgeons performed a bilateral implant of two VEPTR

devices on either side of Carley's spine, connected them to her ribs and pelvis on either side. The results are astounding!

Her pulmonary function improved immediately, and they were able to correct the curve in her thoracic spine by over 50%. The beauty of this procedure is that all of this is done without touching the spine itself, which is critical for a future spinal fusion. Carley will have surgery every four to six months, at which time Dr. Tassone will expand the VEPTRs incrementally to allow for her growth and continued correction.

We are absolutely amazed at the results of this procedure. It is a major surgery, yes, but our daughter now has greatly improved quality of life and hopefully will spend much less time in the hospital.

VEPTR has been performed on other children with PWS, and, according to surgeon Dr. John Smith, orthopedist and VEPTR specialist, has excellent results when combined with growth hormone therapy.

We are grateful to the orthopedic team at Children's Hospital and to Drs. Tassone and Smith, and want other parents of children with PWS and scoliosis to know about this excellent option.

Given our common ground as parents of children with PWS, we have the gift of learning from one another's experiences and sharing stories as we endure the beautiful journey with our children. There is hope! As parents and advocates for our children, we must never let go of that hope.



**December 2005**  
**Carley (23**  
**months) with**  
**brother Jack (6),**  
**sitting up straight**  
**and breathing**  
**easy!**

## 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 APRIL 1, 2006.** 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

Website: [www.wi-easterseals.org](http://www.wi-easterseals.org)

Email: [respite1@wi-easterseals.org](mailto:respite1@wi-easterseals.org)

Email: [wawbeek@wi-easterseals.org](mailto: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

### Wisconsin United Methodist Camps

Camping Office

P.O. Box 620

Sun Prairie, WI 53590

Phone: 608-837-3388 (ask for their 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 a positive report from one camper who attended this camp last summer.



### Lion's Camp

3834 County Rd. A

Rosholt, WI 54473

715-677-4761

Email: [info@wisconsinlionscamp.com](mailto: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 moderate to severe cognitively disabled. They have served children with PWS and their diet is managed by "portion control". **THERE IS NO COST FOR THIS CAMP.**

### 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.

**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 don't hesitate to get your application in soon.

**Camp Courageous of Iowa**

12007 190<sup>th</sup> 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.



**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](http://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.

**28<sup>th</sup> Annual Prader-Willi Syndrome Association (USA) and 16<sup>th</sup> Annual Prader-Willi Alliance of New York, Inc. Conference July 19 - 21, 2006**



**Wild about you!  
\*Save The Date\***

**\*REMINDER\***

**Membership Renewal**

Watch for a mailing in the next few weeks about PWSA of WI, Inc.'s membership renewal! Each year, we send a mailing to our membership and past members to remind them to renew their membership. Membership is \$25.00 per year and gets you our quarterly newsletter, discounts on trainings or conferences, the ability to apply for camp scholarships and financial assistance through our general assistance fund. We also offer associate memberships for grandparents, physicians, school personnel and others but associate memberships have no voting privileges. We want to make sure the important information is getting out to families and care providers as so often they are the ones educating medical personnel about the latest concerns and issues in dealing with clients with PWS. Remember, no one is ever denied a membership because of financial difficulty!

**Caring Is Sharing**

We would like to thank the following people for their generosity during our 2005 Caring Is Sharing campaign:

Al and Melodee Leuning  
John and Bonnie Kraft  
Walt and Jennifer Kryzak  
Roger and Alice Girdaukas  
John and Cathie Lehman  
Virginia Johnson  
Steve and Nancy Burlingame  
Tom and Agnes Hughes  
Joe and Jean Van Tuyle  
Gary and Marty Girdaukas  
Beatrice Sturm

Elsie Dorn  
Louise Guido  
Hazel B. Schuster  
Dan and Kate Beaver  
Larry and Lori Abler  
Don and Barb Dorn  
William Stege  
Jeanne Langlois  
Karen Czebotar  
Dr. Ken Herrmann  
Lorraine Beirl

Return yours today. Contact Mary Lynn at the state office if you need a new Caring Is Sharing packet!



Prader-Willi Syndrome  
Association of Wisconsin,  
Inc.

2701 N. Alexander  
Appleton, WI 54911

Office: 1-866-797-2947

Email:

Wisconsin@pwsausa.org

## APPLICATION FOR CAMP SCHOLARSHIP

### PURPOSE:

PWSA of WI, Inc. wishes to provide financial assistance so that a child or adult with PWS is able to attend summer camp.

### ELIGIBILITY:

**Eligibility is based on financial need of the person with PWS. Financial need being equal, the second consideration would be given to those who could benefit most from attendance (respite intervention or personal/behavioral issues that need to be addressed).**

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 the PWSA of WI, Inc.

Date of request \_\_\_\_\_

Camper's Name: \_\_\_\_\_ Sex \_\_\_\_\_ Birth date \_\_\_\_\_

Address \_\_\_\_\_ City \_\_\_\_\_ State \_\_\_\_\_ Zipcode \_\_\_\_\_

Phone (\_\_\_\_\_) \_\_\_\_\_ Does camper reside in WI? \_\_\_\_ Yes \_\_\_\_ No

Contact person \_\_\_\_\_ Phone (\_\_\_\_\_) \_\_\_\_\_

Name and address of camp you plan to attend: \_\_\_\_\_

Dates of camp: \_\_\_\_\_

Amount Requested: \_\_\_\_\_

Who is a member of PWSA of WI, Inc.? \_\_\_\_ Person with PWS \_\_\_\_ Family Member \_\_\_\_ Care Giver

Why would this scholarship be helpful to you? (Financial need, need for respite, etc.) Use reverse side or attach additional paper if needed.

Return this application by: April 1, 2006

Send to: PWSA of WI, Inc.  
2701 N Alexander  
Appleton, WI 54911-2312  
1-866-797-2947

You will be notified by mail if you are awarded the grant. PWSA of WI will send the grant money directly to the camp.

**Gastroparesis, Gastric Dilatation/  
Necrosis and PWS -  
What Do We Know?  
By Barb Dorn, RN, BSN**

PWSA (USA) receives calls from around the country about people with PWS who are experiencing gastrointestinal problems. More persons with PWS are being diagnosed with a problem called **GASTROPARESIS** (weakness of the stomach). This condition occurs when there is a delay or slowing in the contraction of the stomach. Because of this delay, stomach contents build up and distention can occur. The stomach is a muscle that contracts very much like our heart muscle. Unlike the heart, instead of pushing blood, the stomach pushes food out of its cavity into our intestine for further digestion. It is not surprising to learn that persons with PWS who already have generalized low muscle tone may have poor muscle tone in internal muscles of their body.

Feeling full is our body’s mechanism for regulating the amount of food that the stomach can accommodate. When a person eats, the stomach stretches. It may become “over stretched” or distended when one overeats. We know that persons with PWS do not have the normal mechanism of registering fullness as they eat. They are at a very high risk of over distending their stomachs.

It is believed that if persons with PWS over distend their stomach, it can stretch to the point that it cuts off its blood supply causing necrosis (the stomach tissue dies). This can then result in rupturing of the stomach with highly acidic gastric juices leaking into the chest and abdominal cavity. This is a life threatening situation if it is not quickly diagnosed and treated. Over the past few years, we have seen more persons binge eat and develop this condition - especially during the holiday season. Many people with PWS have developed **GASTRIC DILATATION WITH GASTRIC NECROSIS and STOMACH PERFORATION**. Unfortunately, most of these cases have resulted in death and been diagnosed in a postmortem examination. Persons with PWS may be at higher risk for gastroparesis. Many parents and

caregivers report that some children and/or adults with PWS experience rumination (the regurgitation of undigested food from the stomach back up to the mouth). It was believed to be a behavioral issue. Is this problem caused by gastroparesis? We may need to change its management approach.

**Some of the risk factors seen in both conditions are summarized below.**

<b>Risk factors for Gastroparesis</b>
Diabetes - most common cause
Adrenal and thyroid gland problems
Certain drugs weaken the stomach - many antidepressants and heart medications
Neurological or brain disorders such as Parkinson’s, stroke and brain injury

<b>Risk Factors Seen in Persons with PWS</b>
Diabetes - many persons with PWS have diabetes.
Many persons with PWS have been found to have low functioning of their thyroid gland.
Many persons with PWS take antidepressant medications as part of behavior management and some may be taking heart medications.
We continue to learn the effects of PWS on brain functioning.

It has been found that people with PWS who have suffered from gastric dilatation with gastric necrosis, have had a recent binge episode. It is also more common in those whose weight is under control. The usual symptoms seen in gastroparesis include abdominal distention or bloating, abdominal pain, heartburn, vomiting and regurgitation of stomach fluid into the mouth. These symptoms can be very difficult to detect in persons with PWS. Any signs of acute abdominal illness should be evaluated by a health care professional.

If a person with PWS is experiencing gastrointestinal symptoms, he/she may be referred to a gastroenterologist (a doctor who specializes in disorders of the stomach and intestine). Optimally, gastroparesis is diagnosed through a gastric or stomach emptying test. Food that has been “marked” is given to the

patient. A scanner then tracks the time it takes for food to leave the stomach. Another test that may be performed is an electrogastrogram (EGG). This is a test similar to the EKG of the heart. The EGG measures the electrical waves that normally sweep over the stomach with each contraction. In gastroparesis, these electrical waves are slower than normal.

If caught early, gastroparesis can be treated. Any underlying medical condition should be treated. Diet and nutrition is adjusted. Since fats delay stomach emptying, foods high in fats are avoided. Because high fiber food stays in the stomach for a long time; they may be restricted. Liquids leave the stomach faster so they are not limited. Eating frequent small feedings 4-6 times a day may be helpful. In many cases, medications may be used to stimulate the stomach to contract and empty more normally. It is important to follow the recommendations of your health care professional and/or dietician.

### Hobby Day Reminder...

Don't forget to keep **April 1, 2006** open to attend our annual Hobby Day in Oconomowoc. This is a day where individuals with PWS and their siblings get a chance to work on learning skills for different hobbies. They are provided with all of the supplies and direction so that they can learn the skills needed as well as take home a completed project! This is one of our most well attended events of the year. We provide morning and afternoon snacks (100 calories), lunch, and an afternoon of **FUN** and learning. There is an opportunity for parents and family to listen to a speaker and network with one another while everyone else is enjoying a social with a DJ!! More information will be coming soon!

### CHECK IT OUT...

#### The web sites, that is

Check out both the PWSA(USA) [www.pwsausa.org](http://www.pwsausa.org) and PWSA of WI, Inc.'s web site at [www.pwsausa.org/WI](http://www.pwsausa.org/WI) We have added new information and a variety of links to all sorts of other services. There are ideas to raise funds through PWSA(USA)'s Lose-a-Thon and for research through the Valentine research campaign. There are also opportunities to participate in new ongoing research on psychotropic medications with PWS.

### Notes from the Office...

By Mary Lynn Larson

I hope this newsletter finds you and yours all well after the holidays! At the Larson house, we have had much of the classic cycle of a) anticipation for upcoming events, b) meltdowns because of the anticipation for the upcoming events, c) "the event", d) meltdown occurring during "the event", e) anticipation for returning to structure and routine, and f) meltdown because of the return to structure and routine... Prior to this holiday season, we had run into circumstances where we needed to "lock" food access from one or both of our boys intermittently whereas, after the holiday, we recognize that we need to be more consistent with locking rather than intermittent. As we have been looking for locks to fit our needs, we have been corresponding with another family experiencing the same thing. I am including some things both families have found helpful during this time:

We discovered gun locks are pretty effective for most cabinets. Most gun locks have a vinyl covered cable that has one side of the cable permanently attached into a keyed lock set. I believe the cables come in a variety of lengths. We discovered that many police departments, sheriff departments and other community service agencies actually give these locks away free through their Project Childsafe programs. To see if there are agencies in your area that may have these programs; contact your local police agency or check online at: <http://www.projectchildsafe.org/>

Another interesting resource I discovered recently was shoes made to fit toddlers and children wearing AFOs. Now, most parents who have gone through the experience of searching for shoes that will accommodate the extra height and width their child's foot has when wearing Ankle-Foot Orthotics (AFOs) will know that most insoles are not easily removed to accommodate these devices. And finding one that is wide enough for your child's foot is another challenge if your children have these flat wide feet like my two boys. There are some online resources that sell shoes to accommodate both the height and width requirements!! The web sites for these companies; Hatchback footwear and Keeping Pace footwear can be found online at:

<http://www.hatchbacksfootwear.com/> and <http://www.keepingpace.com>

The shoes start at about \$45/pair plus shipping. My boys are finally to a point where they can find shoes in a regular shoe department to accommodate their AFOs without difficulty but this was not the case when they were toddlers! I hope this is helpful – and if you have discovered any resources that you use that others may find helpful, please give me a call or drop me a note and we will include them on our web site!!

Take care, Mary Lynn

**PWSA of WI, Inc. 2006 Calendar**

<b>February 4, 2006</b>	PWSA of WI, Inc Board of Director's meeting	Madison, WI
<b>April 1, 2006</b>	Hobby Day	Oconomowoc, WI
<b>April 30 - May 6 2006</b>	PWSA(USA) Awareness Week	Nationwide
<b>July 19 - 21, 2006</b>	PWSA (USA) conference	Grand Island, NY
<b>August 26, 2006</b>	6 <sup>th</sup> Annual PWSA of WI, Inc. Golf Benefit	Oconomowoc, WI

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