

INDIANA

PRADER-WILLI SYNDROME ASSOCIATION

Still hungry for a cure.

PWSA of Indiana – Annual Meeting Minutes October 1, 2011

The Prader-Willi Syndrome Association of Indiana (PWSA - IN) met on October 1, 2011 at the Ruth Lilly Learning Center at Riley Children's Outpatient Center in Indianapolis, Indiana. Our meeting convened at approximately 10:30 AM.

The following were in attendance: Jim and Rita Koerber, Mike and Amy Pfeiffer, Darla Legan, Barbara Barnett, Patrick and Lisa Phernetton, Janice Agarwal, Deb Romoser and son, Joseph, Jacque McGuire and son Hunter with friend Bobby, Danielle, Ryan and Katie Warmuth.

Jim Koerber, President of PWSA - IN, welcomed everyone and we began meeting with introductions.

Jim provided an update on PWSA-USA. The national conference will take place November 11-13, 2011. Indiana will have approximately 12 families attending. Evan Farrar, Executive Director has decided to retire from his position to pursue a career in counseling. PWSA (USA) has made the decision to not recruit a replacement until after the national conference in November, 2011. David Crump is currently serving as the interim manager Director.

PWSA-IN Chapter activities (Amy Pfeiffer):

There are currently 54 PWS families in Indiana.

Our spring fundraiser, the Prader-Willi syndrome “On the Move” 5K walk/run and silent auction, took place on May 21, 2011 in Indianapolis. The weather was cooperative and we had approximately 200 participants. We raised \$20,900 net.

The second annual fundraiser will take place on May 19, 2012. The fundraising committee will be having their first conference call soon to begin planning. Indiana members who would like to participate and help organize next year's event can contact Amy Pfeiffer or Danielle Warmuth.

PWSA-IN Board Elections:

Dr. Laurie Ziliak of Haubstadt, Indiana was nominated to serve on the PWSA-IN board. Her biography is as follows:

Dr. Laurie Ziliak lives in Haubstadt, Indiana with her husband, Jon and their children Ethan, Aubrie, and Garrett. She taught special education serving students with mild and severe disabilities for seven years and more recently taught undergraduate and graduate courses in special education for Oakland City University's, School of Education. In the spring of 2011, Dr. Ziliak was given approval by Oakland City University to research inpatient weight gain of people with Prader-Willi syndrome. Additionally, she is collaborating with peers to open a group home for individuals with Prader-Willi syndrome in the Evansville area and is looking forward to other opportunities to continue to serve people with disabilities.

Our agenda also included the election of board members whose terms end on December 31, 2011:

- Patrick Phernetton – Board Member
- Jacque McGuire – Board Member
- Rita Koerber – Board Member

Elections of Board Members

By unanimous vote of attending membership, the following persons were elected to serve on the PWSA-IN Board:

- Dr. Laurie Ziliak was voted to the board
- Rita Koerber, Patrick Phernetton and Jacque McGuire were reelected to the board

Their three-year term will begin on January 1, 2012.

Future elections:

Board member's term ends on December 31, 2012

Darla Legan – Board Member

Janice Agarwal - Board Member,

Mike Pfeiffer – Board Member

Board member's term ends on December 31, 2013

Jim Koerber – Board Member and Chairperson

Bret Johnson – Board Member

Danielle Warmuth – Board Member

The Board elected the following officers to serve one year terms in 2012.

Jim Koerber – President

Darla Legan – Vice President

Mike Pfeiffer – Treasurer

Danielle Warmuth - Secretary

In summary, the PWSA - IN board members, officers and executive director for 2012 are:

- Janice Agarwal – Board Member
- Bret Johnson – Board Member
- Jim Koerber – Board Chairperson and President
- Rita Koerber – Board Member
- Darla Legan – Board Member and Vice President
- Jacque McGuire – Board Member
- Amy Pfeiffer – Executive Director
- Mike Pfeiffer – Board Member and Treasurer
- Patrick Phernetton – Board Member
- Danielle Warmuth – Board Member and Secretary
- Dr. Laurie Ziliak – Board Member

Update on 911 Gives Hope fundraisers and Jacob's Village group home project. (Patrick Phernetton)

The next Guns and Hoses event is April 21, 2012. It will take place at the new stadium in Evansville. Patrick would like electronic photos of our PWS children for the brochure cover. The photos can be emailed directly to Patrick at: atcepd@sit-co.net.

The Guns and Hoses fundraiser has dedicated approximately \$58,000 to the group home project in Evansville, Indiana. The money for the group home project is currently valued at \$100,000 and is kept in a structured CD. The idea is to save and plan for good quality group homes.

The Jacob's Village group home complex is looking to add senior housing. This would add diversity and possible employment for the residents.

Guest speaker: Evansville Police Officer, Patrick Phernetton
Topic: Working with your local police

If an officer is called into a situation involving a PWS person or a person with disabilities, the officer's duty is to take charge of the situation and to quickly make decisions to diffuse the matter at hand.

Crisis Intervention Trained police officers (CIT) are trained to handle situations involving people with disabilities. If your community has a police department, they have CIT officers. The purpose of this program develops an effective, compassionate, and safer approach to interacting with people who suffer with a mental illness or developmental disability crisis.

In the past, the absence of collaboration between mental health systems and law enforcement systems created situations where people with disabilities were locked up immediately. Now with trained CIT officers, they can be held for 72 hours at a hospital for evaluation as oppose to immediate lock-up. .

Officer Phernetton told us a story of an Evansville PWS person who broke into a home because she was seeking food and another time she wouldn't leave a bar because she wanted a diet coke. Both times the homeowner and business owner just wanted the person removed from their property and consequently each time this person went to jail.

If you find yourself having to deal with the police your best plan of action is to 'not become confrontational'. Remain calm and communicate. Explain the situation. Present an ID and have literature about PWS.

Your best reaction would be to say, "Officer can I explain how _____ happened?" Ask to take responsibility for the PWS person and if you may remove them from the situation.

It is also important to make sure that the officer knows that PWS persons are 'genetically wired' differently and often do not make good choices as well as the fact that they do not harbor 'ill intentions'.

If you find that the situation has escalated and in the event that the PWS person is headed to jail, take the following steps:

- Communicate and explain PWS to the officer.
- Explain the IQ and food seeking behaviors.
- Explain that they will be taken advantage of and will need to be separated from the general population.
- Call an attorney.
- Communicate to the county prosecutor. (Make sure both sides understand PWS)

You can help your law enforcement officers and child by allowing the local news and media to do stories about your kids. While this type of media coverage does exploit the negative aspects of PWS, in the long run it helps our PWS people in crisis situations.

Educate by communicating with your local CIT officers, law enforcement, crime prevention officers, training officers, school liaison officer and neighborhood patrols. Share information about PWS. Hand out brochures and information.

You want these officers to know your children!

If you live in a rural area, call or visit the sheriff's office. Ask to train their staff on PWS. Give them literature. Offer your phone number as a resource if there are problems.

It is equally imperative that our children are not afraid of police officers. They must understand that cooperating with the police is important because an officer's job is to take charge and make immediate decisions.

Make sure school officials also know your children and understand Prader-Willi syndrome. Indiana law states that there are 'no' second chances in schools. Incidences, such as pulling a fire alarm, result in immediate jail time.

The more you communicate the better!

Flying with PWS persons:

Danielle Warmuth, flight attendant reiterated the fact that, like the police, the on-board crew will take charge and will make immediate decisions regarding events that occur in air.

To start a trip on a positive note, the PWS family should communicate with the airline as soon as the reservation is made. Make sure that the words "Prader-Willi syndrome" are entered into the reservation. This will give the flight crew a heads-up that your family might need special assistance and will most assuredly explain why some behaviors might occur during the flight.

Communicate with the gate agent upon check-in that one of your family members has PWS and that you want to make sure that it is listed within the reservation and at that time, check to make sure a wheelchair or other needed assistance is ordered for your entire itinerary.

Once you board the aircraft, speak to the flight attendant at the door. Have literature available for the crew. Explain Prader-Willi syndrome and all the behaviors that go with it. Assure the crew that you realize the aircraft *is not a food free environment* but that sometimes food, transitioning from one phase of flight to another (such as having to turning off electronic equipment), or other factors might cause behavioral issues. Dependent upon the PWS person and their specific behaviors, it might be beneficial to have business cards explaining PWS to hand to other passengers in the area – especially those within the same row!

Informing and educating your crew will create a peaceful flight for all involved!

Questions and Answers

We spent the last part of our meeting sharing information. Some of the topics discussed were:

- Changes in medication dosages can affect the behaviors of PWS children and adults.
- The difficulty of finding the perfect medication balance for young adults.
- The importance of journaling and charting behaviors to create a history that one can use in determining behavioral changes.
- Learning negative behaviors from other classmates.
- Sensory integration
- Certificates vs. high school diplomas
- IEPs
- Group homes
- Allowing our children to plot their life courses as opposed to 'our' ideal plans for them.

As always, sharing experiences and problems within our group was helpful and informative to all in attendance.

Meeting adjourned at 12:45 PM.

Respectfully submitted,

Danielle Warmuth, Secretary
Prader-Willi Syndrome Association of Indiana