

THE WISCONSIN CONNECTION

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PWSA of WI is a chapter of PWSA
(USA)

Website: www.pwsausa.org

*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.

Summertime School Prep

It is summer time and the last thing you need to worry about is school right?
WRONG!

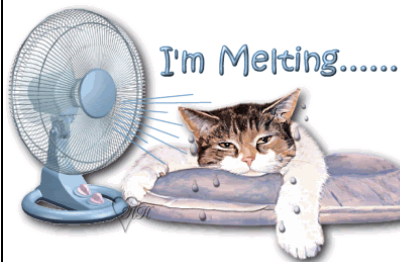
In order to ensure a great start to the next school year we wanted to furnish you with some tips to help your child transition into that next grade level, classroom, or even new school!

- ◆ Meet the teacher! Let your child have the opportunity to establish a relationship before the start of the school year.
- ◆ Take a tour of the new classroom. If the school is new to them, try to do this more than once. If you can find out where their locker will be, what bathroom they get to use, etc., even better!
- ◆ Try to get a schedule as early as possible so your child can become familiar with it.
- ◆ Share information about PWS with any new staff that will be working with your child.
- ◆ Connect staff with a PWSA representative (here in WI, that would be Josh!) who can provide them with additional info or training as needed. *You may need to sign a waiver allowing them to share information.*
- ◆ Be honest and upfront about both your child's strengths and weaknesses.
- ◆ Review your IEP. There may be changes that happen throughout the summer that need to be addressed in it. It is always better to make sure these things are addressed before the school year starts.
- ◆ Keep a positive attitude. This can be a trying process but it will go much smoother for you and your child if you keep those thoughts positive!
- ◆ Keep lines of communication open. One of the biggest causes of problems

PWSA of WI's phone has recently changed to a cell. Same number but now you can text us if you want!

IEP Pro-tip

Before signing it always give yourself at least a few days to look it over, reread, and make sure you are comfortable with it. You are not required to sign it the day it is given to you!



Tips For Surviving the Summer Heat With PWS

- Always travel with a frozen water bottle; metal bottles travel well. Keep one in your freezer and grab it whenever you go out, even for a short trip. It can serve as a drink and as a cold pack. Leave it on a car seat and let it defrost and cool the seat.
- Cold drinks or frozen drinks (Slurpees) can help reduce body temperature internally. In a crisis, don't worry about the sugar content of an ice-cold beverage. Avoid caffeine if possible. However, don't overuse frozen treats during hot weather, or your child may come to expect these. Zoku slush makers will allow you to make your slushy treats out of preferred liquids.
- Babies should sleep in an air-conditioned room with good air circulation. If you don't have central air conditioning, a window unit might be covered as a medical necessity – check with your insurance plan.
- Don't expect any person with PWS to do well in a hot car – let the car cool off. Park in the shade, open the windows and maximize the A/C before loading in your most precious cargo.
- Fans help cool the skin, which is a highly effective way to lower temperature rapidly. Invest in a small battery powered fan for travel, and a larger fan for at home. Wet skin plus moving air is a very effective treatment for the heat.
- Travel with a small insulated cooler filled with thin wet towels, a water bottle, and blue ice packs. The cooler can be fully packed and kept in the freezer between trips.
- Athletes use technology to keep cool, so check out the sporting goods aisles for the latest items – neck bandanas filled with gels that cool; Frogger towels, a shammy which stays cool when wet.
- Gauze blankets, commonly used for swaddling babies, are very thin cotton fabrics, perfect for draping over a stroller. Dip them in water first for an added cooling effect. Fold the blanket, dampen it, and store it frozen in a zip lock bag.
- Cooling gel pads are available – marketed for pet owners with hot furry pets– and are quite effective for short term use. These come in a variety of sizes. Most of these gel pads rely on pressure to active cooling, and some rely on water to be effective. There are also cooling gel pads made to fit into car seats.
- Duct tube devices can direct the front seat AC vents directly to the child in the back seat – such as The Noggle.
- Construction workers need to stay cool too so technology has been developed for the people who help get our roads repaired. Cooling vests can make extended time outdoors safer: polarproducts.com and ergodyne.com/cooling.html – available in child sizes.
- There are many small battery powered fans that include a spray water bottle, the ideal combination for cooling – air movement over damp skin.
- What child doesn't enjoy a wading pool or a sprinkler? Keeping your hose in the sun will “warm” the water so that the pool isn't too cold – just make sure the pool is in the shade before filling it up.

Tips taken from the PWSA (USA) article entitled “Too Darn Hot” written by Kathy Clark



is Proud to Welcome

Tammie Penta



Retired Sergeant Tammie Penta worked for the Tucson Police Department where she was a police officer for over 27 years, with the last 20 as a sergeant. Tammie was a detective sergeant for the Elder Abuse Task Force, which included investigations of vulnerable adults, the Child Abuse/Homicide Unit, Special Investigations and Aggravated Assault Unit. Additionally she was the training supervisor responsible for new officers coming into law enforcement and completed her career as the administrative supervisor for the largest division in the city.

Sgt. Penta worked for many years as one of the instructors for the Crisis Intervention Training of officers in Southern Arizona. This training gave officers the tools needed to interact with our developmentally disabled population and also introduced them to Prader-Willi Syndrome. Over the last 20 years, Tammie has provided training to state group homes and families as it relates to law enforcement interaction as well as advocating for families who have had law enforcement involvement in the schools or where arrests have been made on PWS Staff or people with PWS.

Sgt. Penta has been on the Prader-Willi Syndrome Arizona Association board since 1996 and has been on the Prader-Willi National Board since 2014. She is the proud mother of Victor who is 22 with PWS.

OH NO FIVE-O!

A guide to prevention and education with Law Enforcement

This course will provide introductory information on how to best prepare for an incident dealing with a family member, client or staff and law enforcement. Preparation before a crisis situation is critical for both law enforcement and the provider or caretaker in order to provide the person with PWS the best service and positive outcome possible. This class will teach parents and professionals various ways to accomplish this and how to best work with law enforcement so that officers have a knowledge base about your child or the group home and their clients. Information will be provided on how to contact law enforcement and what information should be provided and when. Additional topics will include social media pitfalls; what to do when family or a staff member is accused of a crime that results in an investigation or arrest; what to do when the person with PWS is arrested or being investigated for a crime and understanding law enforcement's responsibilities and expectations. Finally, the class will learn about civil remedies that may allow for an alternative to criminal charges.

***Date:* Saturday, June 23, 2018**

***Time:* Session for Law Enforcement Personnel
9:00 – 10:00 am**

**Session for Parents, Family Members,
and Caregivers (child care will be provided)
10:30 am – 12:00 pm**

***Location:* Aurora Medical Center-Summit
36500 Aurora Drive
Oconomowoc, WI 53066**

***Rooms:* Draper and Valentine Conference Rooms**

***Cost:* No Charge for Session for Law Enforcement**

**\$10 parents and family members
\$15 professionals**

**(Scholarships are available if needed).
Contact Josh Escher at PWSA of WI, Inc.
for further information and assistance.
Phone: 1-920-733-3077**

To register head to our website to print off the registration form. All questions can be directed to Josh at the office. 920-733-3077



Many donations were made over the last quarter in loving memory of loved ones who have been lost. PWSA of WI sends our deepest condolences to the families of Elaine Gareau, Ronald Rogahn, Karen Elsa, and Wiley Utterback. Their memories live on in all of you.



PWSA Board of Directors Positions Up For Election This Year

In October of 2017 we will be holding elections for board positions.

Each position, when elected, holds a 2 year term.

Board members participate in quarterly meetings, help organize events, make decisions that steer the organization, as well as other responsibilities.

Please consider joining our family! Board elections are held in October.

If you are interested in running for one of these positions or have questions about being a part of the PWSA of WI Board contact our program director. 920-733-3077 or Progdir@pwsaofwi.org

Hoodies, t-shirts, and coozies can be purchased from our webstore by visiting <http://tiny.cc/PWSAWIstore>



One of the best ways to avoid skin picking is prevention. In the summer time this is especially true.

Sunburn

Sunburn can lead to things like blisters and peeling skin. Both of these things can lead to an increase in picking and sores that will be difficult to heal.

*Use lots of sunscreen and make sure you apply at least every 2 hours, preferably more often, especially if you go in the water!

*Buy a high quality sunscreen between 15 and 50 SPF

*Covering up is always more effective than sunscreen.

*Long sleeves and pants and hats with brims are your #1 most trusted ally against the sun.



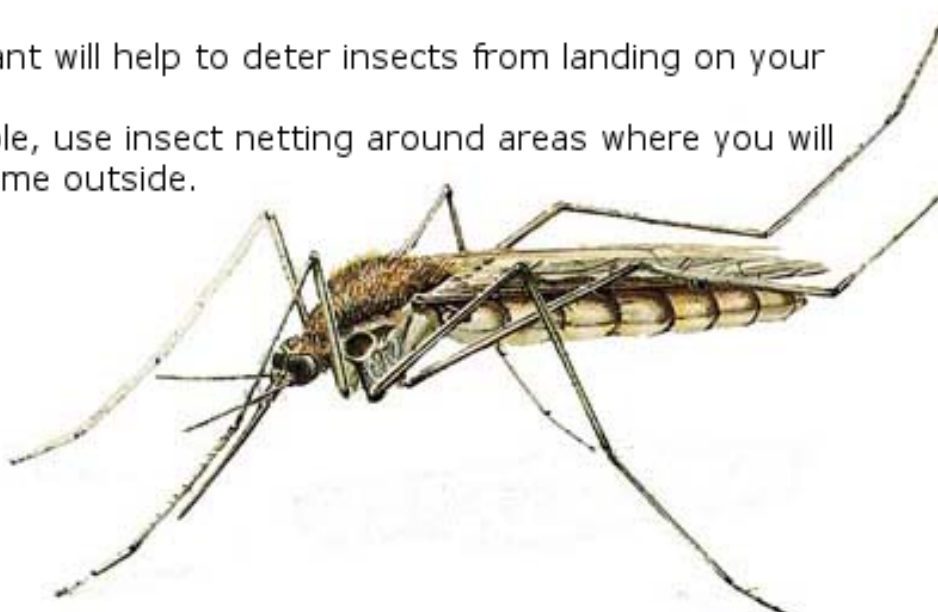
Insect Bites

Insect bites can lead to welts and sores that are itchy and a huge temptation to skin pick.

*Long sleeves and pants help to cover skin and protect from insects.

*Insect repellent will help to deter insects from landing on your skin.

*When possible, use insect netting around areas where you will be spending time outside.



2018 On The Move Walkathon!



On May 12th the Wisconsin PWS community (and a bunch of friends from other states as well) descended upon Roosevelt Park in Oconomowoc. 340 individuals walked for PWS awareness, enjoyed a nice low calorie lunch, and danced the afternoon away! Mother nature was very kind to us as rain had been in the forecast all week but we didn't get a drop!



MUNICIPAL
WELL & PUMP



LAWN CARE LLC.
262-719-7420



Check out our website pwsaofwi.org for more walk pictures.



GLOBAL PRADER-WILLI SYNDROME REGISTRY

WWW.PWSREGISTRY.ORG

ANXIETY IN PWS



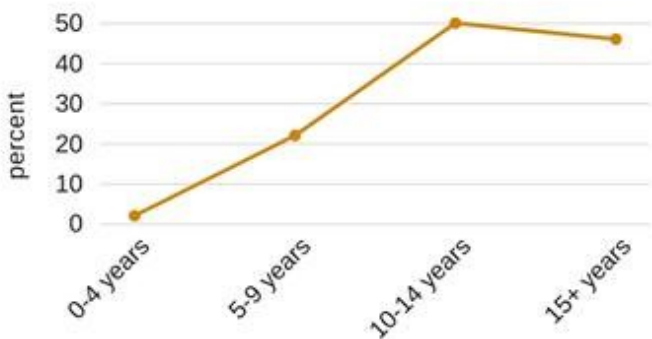
48%

OF REGISTRY PARTICIPANTS AGES 10 and up REPORT

ANXIETY

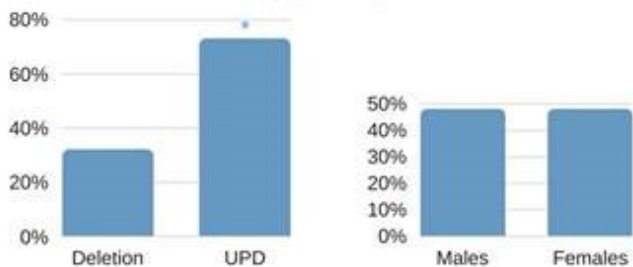
PREVALENCE OF ANXIETY

The reported rate of anxiety is highest in ages 10-14 years.



PREVALENCE BY SUBTYPE

In the Registry sample, males and females have similar rates of anxiety. While anxiety occurs in all genetic subtypes of PWS, there is a significantly higher rate of anxiety reported in individuals with PWS by UPD, compared to those with deletion. (* p < .01)



* p < .01

Data as of April, 2018



GLOBAL PRADER-WILLI SYNDROME REGISTRY

WWW.PWSREGISTRY.ORG

PARTICIPANTS BY COUNTRY



33

countries represented



73%



10%

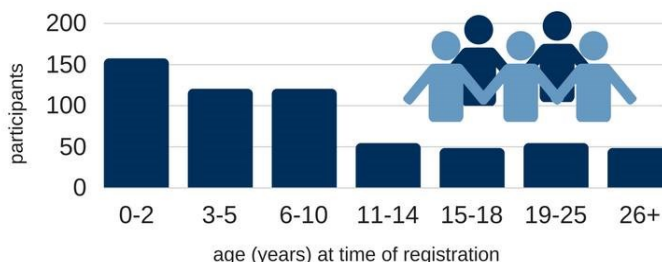


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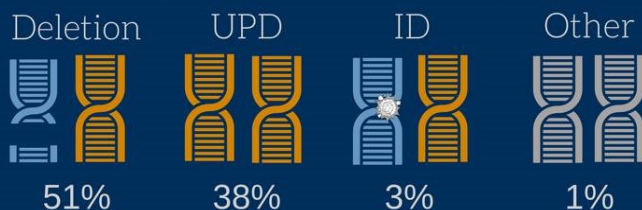


3%

PATIENT AGE



DIAGNOSIS SUBTYPE



TOPIC HIGHLIGHT: GROWTH HORMONE

91%

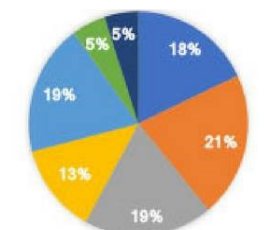
of registry participants have used GH



93%

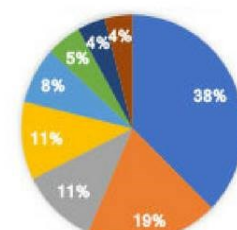
of registry users who have used GH perceive a benefit

AGE STARTED



Legend for Age Started: 0-3 mo (blue), 4-6 mo (orange), 6-12 mo (grey), 13-24 mo (yellow), 2-5 yrs (light blue), 6-10 yrs (green), 10+ yrs (dark blue)

BRANDS USED



Legend for Brands Used: Genotropin (blue), Norditropin (orange), Omnitrope (yellow), Nutropin (light blue), Saizen (green), Humatrope (dark blue), Don't know (brown)

Data as of November, 2017

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PWSA of WI, Inc.'s Event Calendar		
Aurora Medical Center Summit, Oconomowoc, WI	Oh No Five-O, A guide to prevention and education with Law En- forcement	June 23rd, 2018
Windwood of Watertown, Watertown, WI	18th Annual Golf Benefit	August 18th, 2018
AMF Bowlero Lanes, Wauwatosa, WI	Strike Out PWS Bowling Event	September 22nd, 2018