



THE WISCONSIN CONNECTION

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Website: www.pwsausa.org

The Newsletter of the Prader-Willi Syndrome Association of Wisconsin, Inc.

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.



Notes from the Office

Program Director Joshua Escher

I feel like a broken record but it sure has been a crazy year. We have seen so many changes to our usual flow and we all know how changes are for folks with PWS! This just means it is that much more important for all of us to do our best to stay level headed and make the best of it.

On page six you will see an article about self care for parents of kids with disabilities. I encourage everyone to give it a read. It can sometimes feel selfish to take care of ourselves when we are responsible for others, but if we don't we aren't much good to anyone.

As many of you will have noticed, PWSA of WI has had to cancel both of our big fundraisers for the end of the year (golf and gala) as well as our family bowling event. As an organization we operate 100% on money brought in via fundraisers and donations. We have come up with what we hope will be some really fun alternate events that we will hold virtually. First of which will be a virtual Pub Quiz event hosted by yours truly! More information will be coming very soon so keep an eye out.

Now that school has started, a lot of folks have a better grasp on what their children's school year will look like. Likely you have developed a plan (and hopefully it was added to the IEP). This year will require much more active tending to that plan. I encourage you, if you haven't already, to communicate even more with your child's school team. Proactive is going to be the name of the game. As always, if you are having problems, I am here to help! I can provide education for the school team, advocacy if need be, and even just a supportive ear when you are frustrated.

Fall is here, stay warm!

Making a donation? Check with your employer, many companies have employee matching programs to encourage their employees to donate to charities!

2020 has been a crazy year and the word unprecedented gets used a ton and for good reason. This means there are tons of situations where you might not know your rights or how to handle them. We are here to help. Contact our Program Director Josh via phone/email/Facebook and he will provide you with the support you need!

Levo Therapeutics Announces Top-line Results from Phase 3 CARE-PWS Study of LV-101 (Intranasal Carbetocin) for the Treatment of Prader-Willi Syndrome

CHICAGO--(BUSINESS WIRE)--Levo Therapeutics, Inc., a biotechnology company dedicated to using genetic insights to advance treatments for Prader-Willi syndrome (PWS) and related disorders, announced today top-line results from the Phase 3 CARE-PWS clinical study evaluating LV-101 (intranasal carbetocin) for the treatment of PWS. This syndrome is a complex, neurodevelopmental disorder that occurs in approximately 1 in 16,000 births and is characterized by a false state of starvation and associated hyperphagia (unrelenting hunger), to which a deficiency in oxytocin is believed to be contributory. LV-101 is a selective oxytocin-receptor agonist. CARE-PWS tested two doses of LV-101 versus placebo with an even randomization (1:1:1), specifying the 9.6 mg dose as the primary endpoint and the 3.2 mg dose as the first secondary endpoint. After consultation with the U.S. Food and Drug Administration (FDA), enrollment was closed early due to COVID-19 with 119 evaluable patients in the Primary Analysis Set.

While the study did not meet its primary outcome measurements evaluating the 9.6 mg dose of LV-101 (intranasal carbetocin), statistical significance was achieved with the 3.2 mg dose as evaluated by the Hyperphagia Questionnaire for Clinical Trials (HQ-CT) score ($p=0.016$) as the first secondary endpoint. When pooling the two dose arms of LV-101, per a pre-specified analysis, the change in HQ-CT score from baseline to week 8 resulted in a p-value of 0.055. Consistency in benefit/response was observed in the 3.2 mg dose arm across other key secondary endpoints, including clinical global impression of change (CGI-C; $p=0.027$) and anxiety and distress behaviors, as evaluated by the PWS Anxiety and Distress Behaviors Questionnaire (PADQ; $p=0.027$). Neither dose demonstrated a statistically significant effect on the Children's Yale-Brown Obsessive Compulsive Scale (CY-BOCS). LV-101 was generally well-tolerated in the study.

"This is a long-awaited step towards addressing the substantial needs of individuals living with PWS," said Sara Cotter, CEO of Levo Therapeutics. "We are excited by these important results that were achieved after decades of interest in addressing the oxytocin deficiency in PWS. We are also pleased that our efforts to develop new tools for clinical evaluation of this rare, neurodevelopmental disorder have enhanced our understanding of the real-world impact LV-101 has on anxiety and distress behaviors."

"With no approved therapies to address their most challenging symptoms, patients with PWS continue to suffer from insatiable hunger and anxiety, which are debilitating and can be life-threatening if left untreated," said Jennifer L. Miller, M.D., Pediatric Endocrinologist, University of Florida. "These positive results of the Phase 3 CARE-PWS study strengthen the belief that intranasal carbetocin appears to be an effective treatment for patients living with PWS."

Upon completion of the placebo-controlled period (i.e., after week 8), all patients were transitioned into the long-term follow-up period and received intranasal carbetocin. Greater than 98% of patients enrolled in CARE-PWS elected to enter the long-term follow-up period. Of note, further improvements in scores were observed and subsequently maintained after week 8 in both dose arms.

Safety data show that LV-101 (intranasal carbetocin) was generally well-tolerated. Treatment emergent adverse events (TEAEs) occurring in 5% or more of participants during the placebo-controlled period (TEAEs $\geq 5\%$) at the 3.2 mg dose include headache (16.3% vs. 7.0% for placebo), flushing (14.0% vs. 0.0% for placebo), diarrhea (9.3% vs. 2.3% for placebo), nasal discomfort (7.0% vs. 2.3% for placebo), pyrexia (7.0% vs. 0.0% for placebo), and upper respiratory tract infection (7.0% vs. 4.7% for placebo), all of which were considered mild or moderate. TEAEs $\geq 5\%$ at the 9.6 mg dose include flushing (20.5% vs. 0.0% for placebo), epistaxis (13.6% vs. 2.3% for placebo), and headache (9.1% vs. 7.0% for placebo), all of which were also mild to moderate in severity.

"The results from the CARE-PWS study have brought hope to the PWS community as together we pursue effective therapies for these patients in need," said Theresa V. Strong, Ph.D., founding member of the Foundation for Prader-Willi Research. "We look forward to continuing to partner with Levo Therapeutics to help bring LV-101 expeditiously to the PWS community."

"The impact that PWS has on parents and caregivers is incredibly burdensome, beginning with diagnosis in infancy and continuing as individual symptoms worsen over time. The unfortunate reality is that there is currently no treatment for the most life-limiting symptoms of PWS," said Elizabeth Roof, M.A., Vanderbilt University. "As clinical researchers, we are thrilled to see the results from CARE-PWS and that treatment with LV-101 showed meaningful improvements in hyperphagia and anxiety in patients with PWS, two hallmark symptoms of this rare and unique syndrome."

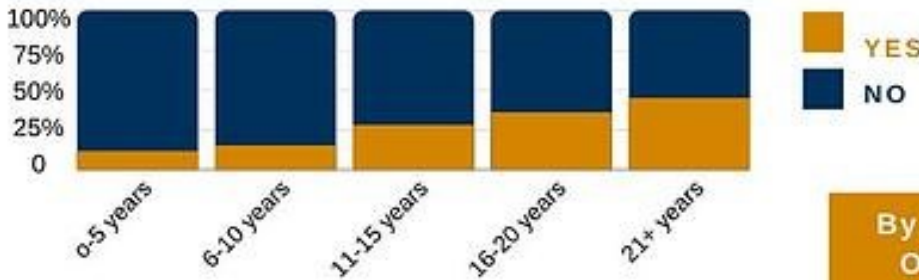
With these results in hand, all patients actively participating in CARE-PWS will be transitioned to receive the 3.2 mg dose of LV-101 for the remainder of their long-term follow-up and extension periods.

"We would like to thank the CARE-PWS participants, their families, our partners, and the entire PWS community for their support and ongoing contributions to this research," added Sara Cotter. "We look forward to working closely with regulatory authorities in the United States and abroad to bring this promising therapeutic to patients as quickly as possible."

DERMATOLOGY & PWS

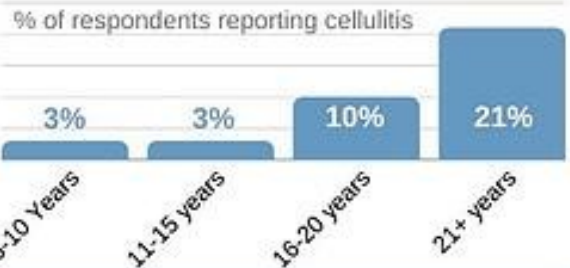
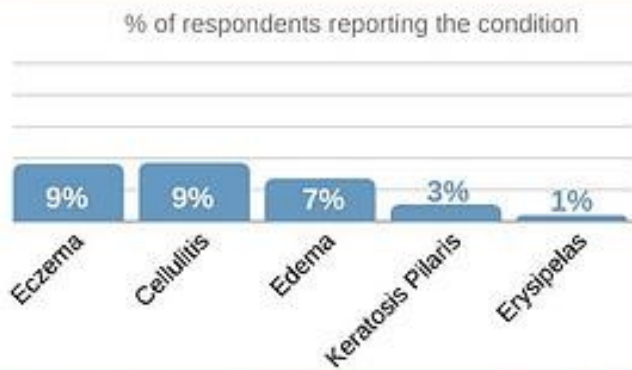
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Registry Participants Are More Likely to See a Dermatologist as They Get Older



By Adulthood, More Than 20% Of Participants Have Had A Cellulitis Infection.

Most Commonly Reported Skin Issues (other than skin picking)



29% of cellulitis infections required hospitalization

WWW.PWSREGISTRY.ORG

JUNE 2020



Do you know someone with Prader-Willi who no longer has family to provide them with gifts on their birthday or Christmas?

PWSA of WI has a gift giving program for these folks! Please contact us for more information so we can make their day.



PWS Hero!



Handling the coronavirus crisis has been stressful for many of us including individuals with Prader Willi Syndrome. Michael Girdaukas, a resident of Prader Willi Homes in Oconomowoc, decided to do something about it. Michael spent an extended weekend home visit sewing specialty themed face masks for all his house mates and for the staff at Margaret Ruth House. The most popular versions were the Bucky Badger and Green Bay Packer face masks. When asked why he wanted to do this he replied, "I'm just trying to spread a little love!"



Do you have a teacher, doctor, care provider, or other professional that you think deserves to be recognized for their service to the PWS community? We want to reward them! Visit our website at <https://pwsaofwi.org/ProRecognition> and fill out an application today! Each winner will receive a certificate, a card, and a \$50 gift card.

Write it, Share it, Post it, and Use it: Tips for Creating a Positive Behavioral Plan

Challenging behaviors are a feature of Prader-Willi syndrome (PWS). When responding to these behaviors, it is important to remember that negative consequences (which include responses such as shaming, threatening to take things away, etc.) are not typically effective in helping a person with PWS to manage their behavior more appropriately. The cognitive and impulse control deficits caused by PWS inhibit the ability to understand what a negative consequence is trying to teach so it does not alter future behavior. And most often it leads to a power struggle which rarely helps to improve a challenging behavior. So what does work?

People with PWS are successful behaviorally when a positive behavioral strategy is developed and consistently employed. This is a tried and true strategy that is effective for people with PWS of all ages. A positive behavioral strategy uses incentives and rewards to move a person successfully through the day by mixing preferred and non-preferred activities. For example:

If Tommy, who has had a problem getting up and ready for school in the morning, is able to accomplish this task in the designated half hour time period he will receive a sticker. If he earns 10 stickers during the week, he will be able to pick a movie he wants to watch.

In this example, Tommy’s desire to watch a movie of his choice is used to motivate him to successfully accomplish a nonpreferred activity – getting ready for school on time.

How to get started?

1. Create a list of challenging behaviors. These are the behaviors you want your plan to help change.
2. Prioritize the list by identifying one or two behaviors to be addressed first. Behaviors that are most disruptive could be at the top of the list or you could start with behaviors that will improve more quickly so the person begins to earn rewards and feel successful more quickly which can increase ongoing commitment to the plan.
3. Create a list of rewards or incentives that will motivate the person. When possible, invite the person with PWS to help you create this list. This creates a good opportunity also for you to begin to explain the purpose of the new plan you are creating in a positive way.
4. Create the plan for the initial behaviors you want to target. As with the example above, create a strategy for each challenging behavior that includes the preferred behavior you want to encourage and how and when the reward will be applied to motivate the behavioral change you want to help create. Pay attention to how often the reward is applied. For some people a weekly reward works well but for others the positive reinforcement might need to be daily or even hourly. Find what works for the person you are supporting!

Tip: Before beginning step three, do some research. You can find many helpful resources on positive behavioral strategies by searching online. If you are working with a counselor, social worker, or school professional they also might be able to assist you with ideas. And don’t forget to contact PWSA (USA) for helpful behavioral resources (video and written) for supporting people with PWS. The more you know the better your plan will be!

Once you have a written plan designed, share it with the person with PWS and others involved in their life so they understand the expectations of the plan and how it works, post it where you both can see it every day, and use it consistently. A good positive behavioral plan is an essential foundation for diminishing challenging behaviors experienced by a person with PWS.

Written by: Farrar/ Ziccardi

For more resources like this one, visit our website’s resource page pwsaofwi.org/pwsinfo.

To purchase PWSA of WI merchandise visit pwsaofwi.org/merchandise



Did you know PWSA of WI has a card club for individuals with PWS?!



Contact our program director at progdir@pwsaofwi.org to have birthday cards and seasonal cards sent to your loved one with PWS!

The Importance of Self-Care for Special Needs Parents

Caravel's autism health specialists work every day in the homes of families living with autism. They know firsthand how much is required of these parents – who need to bring more than the average amount of strength, perseverance and resourcefulness – day after day.

“The challenge can be daunting,” according to Nan Huai, Ph.D., Licensed Psychologist, BCBA-D, of Caravel Autism Health. “Many parents want to invest every possible minute into helping their child. But if you're emotionally and physically exhausted,” says Dr. Huai, “it likely will make the challenge even greater.”

Dr. Huai says that self-care for parents is crucial to the wellbeing of the entire family. “The more you nurture yourself, the more you will be able to care for your child and increase your family's overall quality of life,” according to Dr. Huai. Here are five ways to practice self-care that will have a positive impact on your entire family.

Make a habit of scheduling “me time”

The demands of parenting can seem never-ending, especially for those who kids need extra attention and support. It is a journey. You will need some rest along the way so that you can go on the next leg with more energy and strength. By carving out a small amount of time for yourself every day, you will get much deserved and needed rest for your journey.

This “me time” doesn't have to be one big block. It can be broken up into smaller pieces. Take the scenic route and enjoy the view when you can spare a few extra minutes. Keep a routine of “me time” such as taking a walk or doing other exercise every day. Treat yourself to your favorite beverage. Settle into a comfy chair and do a few minutes of reading once your kids are in bed. Allow yourself to disconnect from your care-taking routine so that you can rest and recharge.

Move your body

It's hard to beat exercise as a mood-booster. Keep that in mind anytime you try to convince yourself that there's no time for it in your schedule. Take a brisk walk, even if it's just around the block. Spend five minutes stretching. Turn up the music when you can and dance while you cook or do housework.

Explore meditation or yoga

Many find that yoga and meditation help decrease stress. At the same time, these practices can help you cultivate mindfulness and tap into your own personal strength and sense of power. The quiet reflection associated with brief meditation breaks can also boost your immune system and improve your focus. In addition to local classes, there are lots of videos and apps that can help you explore these disciplines.

Tap into the kindness of your village

They say it takes a village to raise a child, but when you're a parent with a special needs child, others in your village don't necessarily know how to help you. “Don't be afraid to ask for help,” says Dr. Huai. “Most people are surrounded by people who are willing to step up. Help them help you by getting specific,” she explains. “Ask your neighbor if she'd be willing to pick up a few things for you at the grocery store. If your friend loves to cook, ask if he'd mind making you a dish that you can freeze. If you've got a few errands that need running, put the request out there to people who live nearby.”

Find community support

Connecting with other parents who know what it's like to walk in your shoes is invaluable. They can provide peer support, group therapy, counseling, stress management and opportunities to share stories and resources.

This article originally appeared on caravelautism.com July 30th, 2018

Healthy Turkey Chili

Ingredients

- 2 teaspoons olive oil
 - 1 yellow onion, chopped
 - 3 garlic cloves, minced
 - 1 medium red bell pepper, chopped
 - 1 pound extra lean ground turkey or chicken (99%)
 - 4 tablespoons chili powder*
 - 2 teaspoons ground cumin
 - 1 teaspoon dried oregano
 - 1/4 teaspoon cayenne pepper
 - 1/2 teaspoon salt, plus more to taste
 - 1 (28-ounce) can diced tomatoes or crushed tomatoes
 - 1 1/4 cups chicken broth
 - 2 (15 oz) cans dark red kidney beans, rinsed and drained
 - 1 (15 oz) can sweet corn, rinsed and drained
- For topping: cheese, avocado, tortilla chips, cilantro, sour cream*

Instructions

- 1) Place oil in a large pot and place over medium high heat. Add in onion, garlic and red pepper and saute for 5-7 minutes, stirring frequently.
- 2) Add in ground turkey and break up the meat; cooking until no longer pink. Next add in chili powder, cumin, oregano, cayenne pepper and salt; stir for about 20 seconds.
- 3) Next add in tomatoes, chicken broth, kidney beans and corn. Bring to a boil, then reduce heat and simmer for 30-45 minutes or until chili thickens and flavors come together. Taste and adjust seasonings and salt as necessary.
- 4) Garnish with anything you'd like. Makes 6 servings, about 1 1/2 cups each.

Servings: 6 servings

Serving size: 1

Calories: 336kcal

Fat: 3.7g

Carbohydrates: 46.7g

Fiber: 17.4g

Sugar: 9.5g

Protein: 31.8g



The 2021 PWSA | USA National Convention

June 22nd – 26th, 2021 | Lake Buena Vista Palace

Save the Date!

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TBD	In your home!	PWSA of WI's Virtual Family Bingo Night
TBD	Wherever you are!	PWSA of WI's Virtual Pub Quiz
PWSA of WI, Inc's Event Calendar		