

# PWS Family Newsletter

## SPRING 2025 Edition

### Endocrine Corner: New Study

Sarah Hu, PNP

UCI is currently enrolling subjects for its study of intranasal carbetocin for the treatment of hyperphagia in Prader-Willi Syndrome (PWS).

This is a 12-week, multicenter, randomized, double-blind, placebo-controlled, parallel-group study comparing carbetocin nasal spray 3.2 mg TID with placebo (matched placebo nasal spray TID) in subjects with PWS.

One prior study for carbetocin use was the CARE-PWS Phase 3 trial which evaluated the safety and efficacy of intranasal carbetocin in individuals with PWS. This randomized, double-blind, placebo-controlled trial included 130 participants aged 7 to 18 years. The study found that the 3.2 mg dose of carbetocin was associated with clinically meaningful improvements in hyperphagia, anxiousness, and distress behaviors compared to placebo, although the primary endpoints did not reach statistical significance due to premature enrollment cessation caused by the COVID-19 pandemic.

Another study published in JCI Insight in 2018 also investigated the effects of intranasal carbetocin in adolescents with PWS. This study demonstrated that carbetocin significantly reduced hyperphagia and

improved behavioral symptoms compared to placebo over a 14-day period.

These studies suggest that carbetocin may be a promising treatment for managing hyperphagia and associated behavioral symptoms in PWS

The current study at UCI is a phase 3 trial that may help to confirm prior findings and establish long-term efficacy and safety.

Subjects who can apply for this trial

1. Male or female and 5 through 30 years of age
2. Prader-Willi syndrome with a documented disease-causing mutation
3. Increased appetite with decreased satiety accompanied by food seeking (consistent with PWS Nutritional Phase 3)
4. HQ-CT total score of  $\geq 13$  at Screening and Baseline
5. CGI-S score for hyperphagia in PWS of  $\geq 4$  at Screening and Baseline
6. Lives with a caregiver who understands and is willing and able to adhere to study-related procedures and is willing to participate in all study visits

There are exclusion criteria as well so please reach out to our Prader Willi team if interested in enrollment or have additional questions.

## Recipe Corner:

### Berry Delicious Yogurt Bark



Servings: 6

Serving Size: 2.7 oz

Nutrition – Calories: 64

kcal | Carbohydrates: 5g | Protein: 6g | Fat:  
2g | Fiber: 1g

#### Ingredients:

- 1 ½ cup low-fat Greek yogurt
- 1/3 cup fresh or frozen strawberries (sliced if fresh, chopped if frozen)
- 1/3 cup fresh or frozen blueberries
- 1 tablespoons unsweetened coconut flakes
- 1 teaspoon vanilla extract
- ¼ teaspoon ground cinnamon

#### Instructions:

1. Line a baking tray with parchment paper. Mix yogurt and vanilla extract until well combined.
2. Spread the yogurt onto the paper in a square, about 15 cm.
3. Add cinnamon and swirl.
4. Top with berries and unsweetened coconut flakes and freeze for at least 2 hours



## **Social Services Updates:** Department of Rehabilitation

Bobbi McGann, LCSW

The California Department of Rehabilitation (DOR) works in partnership with consumers and other stakeholders to provide services and advocacy resulting in employment, independent living, and equality for individuals with disabilities.

DOR administers the largest vocational rehabilitation and independent living programs in the country. Vocational rehabilitation services are designed to help job seekers with disabilities obtain competitive employment in integrated work settings. Independent living programs can help your child with potential skills to living as independent as possible.

### **Student Services:**

You and your PWS child should become involved with the DOR when your child is in high school at age 16. The Department of Rehabilitation (DOR) can attend IEP meetings to help plan for your child's future.

DOR Student Services are activities that support your child in exploring and preparing for the world of work. Services are based on your child's interest. To qualify you need to be between the ages of 16 and 21. Have an IEP or 504 plan at your school, and a disability.

### **Assistive technology:**

Assistive technology (AT) is anything that is used to increase, maintain, or improve the

functional capabilities and independence of persons with disabilities.

### **Independent Living:**

DOR contracts with county independent living programs and there are eight core services provided by California's Independent Living Centers.

- Information and referral
- Independent Living Skills
- Transition
- Housing
- Peer counseling
- Person assistance services
- Assistive technology
- Advocacy

Please contact the DOR through their website, flyer attached. Your CHOC PWS team will be encouraging you to connect with these programs during your appointments. We all want your children to be as productive and independent as possible.





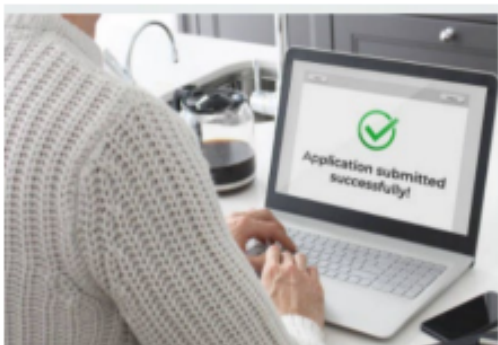
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## Calling Job Seekers

### LEARN HOW DOR CAN HELP YOU GET A JOB OR GROW IN YOUR CAREER!

The Department of Rehabilitation (DOR) works with Californians to help them get a job, live independently, and have the same rights and opportunities as everyone else. We have added new features on our website that let you request information and apply for services easily.



VISIT THE DOR WEBSITE TODAY TO COMPLETE OUR SIMPLE ONLINE FORM AND FIND OUT HOW WE CAN HELP YOU REACH YOUR CAREER GOALS.



Go To: <https://dor.ca.gov/Home/GettingStarted>

### Who We Serve

- Individuals with disabilities
- Individuals getting services from Regional Centers or Independent Living Centers
- Individuals who are blind/visually impaired or deaf/hard of hearing
- Students (ages 16+) with an IEP, a 504 plan, or a barrier to employment

### What We Do

DOR can help you with:

- Connect job seekers with disabilities with hiring employers
- Job training and tools
- College and textbooks
- Assistive technology
- Services like childcare or transportation to support your career goals
- Disability and benefits counseling (SSI/SSDI benefits to return to work)



## **Dietitian's Corner: Why it's essential to take Multivitamin for Prader-Willi Syndrome**

**Kimberly Lopez, Cal Poly Pomona Dietetic Intern**  
**Reviewed by: Christina Wright-Yee, MPH, RD, CSP**

Children with Prader-Willi Syndrome (PWS) should follow a low-calorie diet to help manage weight and prevent obesity, but a low-calorie diet might be missing important vitamins and minerals such as vitamins A, D, E, K and minerals like iron, calcium and zinc. A multivitamin with minerals helps make sure children get the vitamins and minerals they need to grow healthy and strong. According to the Nutrition Guidelines: Adolescence through Adulthood for Persons with PWS, a multivitamin is recommended when the daily caloric content of the diet is less than 1200 calories. Before taking multivitamins with minerals, please consult your child's dietitian to determine their needs.

### **Iron and Vitamin C**

Iron is a mineral that helps our red blood cells carry oxygen through our bodies and helps a child's ability to learn. Adequate amounts of iron will help prevent iron deficiency and iron deficiency anemia. If your child needs more iron, look for a multivitamin with minerals, additional iron, and vitamin C. Vitamin C helps absorb iron better.

### **Zinc**

Zinc helps kids grow and develop and is a mineral that is important for immune function, healing wounds, and maintaining a child's sense of smell and taste. Children with PWS may be deficient in zinc, but multivitamins with minerals generally have sufficient zinc, and excess zinc intake is unnecessary.






### **Vitamin D and Calcium**

Vitamin D helps your child build strong bones and prevents rickets, a condition that softens the bones of a growing child. Vitamin D and calcium deficiencies are common in PWS, as is osteoporosis. Osteoporosis may begin earlier than adolescence due to hormonal abnormalities that can affect bone mineral density.

### **How to Choose a Multivitamin: Supplement Safety**

**Disclaimer:** Just because a product has been Third Party Tested does NOT mean it is safe for your child. It can be harmful to take vitamins and/or supplements that are not approved by your provider. Please talk with your child's medical team to find out what vitamins and supplements your child needs and how much your child should take for their health.

1. Third-Party Testing:
  - a. Vitamins and supplements are not controlled by the Food and Drug Administration (FDA) in the United States. Safety is a concern when there is no regulation. You should know that what you are taking is reliable and harmless.
  - b. Third-party testing company approval tells you that the products you buy:
    - Contain what they say on the label
    - Are not contaminated with heavy metals, bacteria, or toxins.
  - c. Seals to look for on your products:

NSF International		Tests samples provided by the manufacturer once a year.
Consumer Lab		Test products once every 1-2 years at the manufacturer's request.
U.S. Pharmacopeia		Tests products 1-6 times per year from store-bought samples.
CVS Pharmacy		CVS Pharmacy pledges that all vitamins and supplements have been tested by a third-party
UL Solutions		Tests samples provided by the manufacturer at least once a year

## Pill vs. Chewable vs. Gummy Multivitamin

The table below lists the pros and cons of each type based on your child's needs and their preference for taking a vitamin. Parents should consult with their dietitian and/or physician to know which vitamins they need to focus on.

Form of Multivitamin	Pros	Cons	Tips and Suggested Brands
Pill	<ul style="list-style-type: none"> <li>Provide the highest concentration of vitamins and minerals</li> <li>Most effective</li> <li>Lower risk of overuse</li> </ul>	<ul style="list-style-type: none"> <li>Can be difficult for your child to swallow</li> </ul>	
Chewable	<ul style="list-style-type: none"> <li>Higher vitamin content than gummies and contains iron.</li> <li>A great option if you are concerned your child isn't getting enough of a specific vitamin.</li> </ul>	<ul style="list-style-type: none"> <li>Chalky texture</li> </ul>	<ul style="list-style-type: none"> <li>Flintstones Complete (chewable tablets): contains zinc, copper and iron.</li> </ul>
Gummy	<ul style="list-style-type: none"> <li>Tasty and easier for kids to eat.</li> </ul>	<ul style="list-style-type: none"> <li>Overall lower vitamin and mineral content than chewables and pills, and does not contain iron.</li> <li>Contain high amounts of added sugars and need to take more gummies per day to meet the same amount of nutrients in a chewable.</li> <li>Can be dangerous if your child consumes more than what is recommended.</li> <li>The sugar and citric acid in gummies can contribute to cavities.</li> <li>Limited shelf life and work less effectively overtime</li> </ul>	<ul style="list-style-type: none"> <li>Eat them with food.</li> <li>Store these vitamins away from children so they can't accidentally eat large amounts of them. Contact your PCP or</li> <li>For female teens: Bayer One A Day Women's Formula, otherwise you may need to supplement with additional iron and calcium supplements once they start their menstrual cycles.</li> <li>For male teens: Kirkland Signature (Costco) Daily Multi.</li> </ul>
Liquids	<ul style="list-style-type: none"> <li>Easier to modify the dose</li> <li>Easy to add into other food/drink</li> </ul>	<ul style="list-style-type: none"> <li>Limited shelf life, but longer than gummy vitamins.</li> </ul>	<ul style="list-style-type: none"> <li>Mix with small amount of water or other beverage to ensure the full dose is taken.</li> <li>Store away from direct line and avoid keeping in a bathroom or kitchen where it can be exposed to heat from shower steam/cooking.</li> <li>Some brands need to be refrigerated. Look at the bottle to learn more.</li> </ul>

## References

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