



Prader-Willi Family Newsletter

Winter Edition



Developmental Behaviorist's Corner

From Dr. Grover & Dr. Chung

Families have been undergoing tremendous levels of stress during the pandemic, whether learning from home, participating in a hybrid model, or attending school in person. Below are some links to resources that may be helpful for you and your family.

- choc.org/coronavirus
We know how frightening the spread of the 2019 novel Coronavirus (COVID-19) must be for parents. Get answers to your frequently asked questions from CHOC experts.

- cde.ca.gov/ci/cr/dl
The website for the California Department of Education has a list of resources, guidelines, and recommendations regarding distance learning. The information is written for educators and professionals, so it is somewhat more technical in its language.

- connectionsacademy.com/tips/resources-for-families
This website has a number of tips, tricks, and resources for parents to use when conducting learning from home. It includes resources specific to students who are receiving special education support as well.

- who.int/campaigns/connecting-the-world-to-combat-coronavirus
The World Health Organization's website has a number of videos and articles on how to educate children about COVID-19 as well as strategies on healthy parenting during the pandemic.

- childmind.org
The Child Mind Institute has created a hub of resources available in English and Spanish that include articles and blog posts on a variety of topics related to developmental, behavioral, and mental health.

- store.samhsa.gov/product/Coping-with-Stress-During-Infectious-Disease-Outbreaks/sma14-4885
- store.samhsa.gov/product/Talking-With-Children-Tips-for-Caregivers-Parents-and-Teachers-During-Infectious-Disease-Outbreaks/PEP20-01-01-006
- store.samhsa.gov/product/Taking-Care-of-Your-Behavioral-Health-Tips-for-Social-Distancing-Quarantine-and-Isolation-During-an-Infectious-Disease-Outbreak/PEP20-01-01-007

The Substance Abuse and Mental Health Services Administration has a number of free tip sheets that address topics like how to cope with stress, how to talk to children, and how to balance behavioral health and social distancing that could be helpful for parents and their children.

CHOC Family Recipe Corner

With every issue of our PWS newsletter, we want to share a recipe suggested by one of our Prader-Willi families. Consider sending healthy, low calorie and delicious ideas to Laura Clapper, RD at Lclapper@choc.org.

QUICK & EASY LOW CARB NOODLES

Recipe submitted by Karen Koo, mom of Kaylen Kim.

Ingredients

- 2 tbsp gluten-free oyster sauce
- 3 tbsp avocado oil
- 1 cup organic marinara pasta sauce
- 2 tsp sesame oil
- 2 tbsp light soy sauce
- Vegetables of choice
- Protein of choice (chicken, shrimp or tofu)
- Low carb noodles (or rice)

Directions

Combine all ingredients together in a bowl and toss with a variety of vegetables, chicken, shrimp or tofu. Serve with a side of tasty low carb rice or noodles.

Our families recommend:

- Miracle Noodles (10 cal per serving)
- Better than Pasta Spaghetti (15 cal per serving)
- Well Lean Organic Fettuccine (5 cal per serving)





Nutrition Update: Vitamin D & COVID-19

From our Dietician, Leah Blalock

With the COVID 19 infecting many, families are seeking to boost their immune systems. Several recent studies have looked at the impact of Vitamin D on COVID 19.

Quick Facts about Vitamin D:

- Vitamin D is a fat-soluble vitamin that acts more like a hormone than a vitamin
- Vitamin D has several important functions. The liver and kidneys convert it into a hormone that is vital for brain function.
- Vitamin D helps regulate the amount of calcium and phosphate in the body. These nutrients are needed to keep bone, teeth, and muscles healthy.
- Studies suggest that Vitamin D also helps support normal immune system function. It also may play a role in alleviating depression and prevention of Type 2 Diabetes.

Vitamin D Deficiency & COVID-19:

Vitamin D is sometimes called the sunshine vitamin because it's produced in your skin in response to sunlight. Between October and early March, people experience less light exposure. Paired with the fact that fewer families go outdoors during quarantine, it's important to get Vitamin D from other sources such as food like eggs, salmon, tuna, shrimp, mushrooms, fortified cereal and fortified dairy products.

Recent studies have found a link between low Vitamin D levels and an increased risk of COVID-19 infection. One study found that the risk of COVID-19 infection in people with Vitamin D deficiency was nearly two times higher than in people with sufficient levels of the vitamin.

Vitamin D deficiency is more common in people with darker skin tone, the elderly, obese and people with high blood pressure. These factors may also increase the risk of severe COVID-19 symptoms.

There isn't enough data to recommend the use of Vitamin D to prevent or treat COVID-19 infection as further research is needed. In the meantime, if you are concerned about your Vitamin D level, ask your health care provider about getting your levels checked and whether a supplement may be right for you.

The recommended daily intakes of Vitamin D are as follows:

- **Infants 0–12 months:** 400 IU (10 mcg).
- **Children 1–18 years:** 600 IU (15 mcg).
- **Adults up to 70 years:** 600 IU (15 mcg).
- **Adults over 70 years:** 800 IU (20 mcg).
- **Pregnant or lactating women:** 600 IU (15 mcg).

CHOC Family Recipe Corner

SALMON STREET TACOS

Approximately 100kcal, 150IU Vitamin D per taco

Ingredients for Salmon

- 1 tbsp paprika
- 1 tsp cumin
- 1/2 tsp onion powder
- 1/2 tsp garlic powder
- 1/4 tsp black pepper
- Two 4-ounce pieces salmon, pin bones removed, skin-on
- 2 tbsp olive oil

Ingredients for Tacos

- 8 street size flour tortillas
- 1 cup red cabbage shredded
- 1 cup diced tomato
- 1/2 cup diced red onion
- 2 tbsp minced cilantro
- 1/4 cup tomatillo avocado salsa (or fat free sour cream)
- 1 lime cut into small wedges

To make salmon: In a small bowl, combine the spices. Put the mixture on a plate or other flat surface and coat the portions of salmon, one at a time, on the flesh side only. Heat a large heavy-bottomed pan or cast-iron skillet over medium heat and add the oil. Add the salmon flesh side down. Cook for 2 to 3 minutes per side or until the skin is crispy. Once the salmon has slightly cooled, peel the skin away with a fork and shred into large chunks.

To assemble: Char the tortillas on the stove-top (gas stoves only) until the edges are lightly burnt. Fill each tortilla with cabbage, tomato, onion, about 1/4 of each salmon fillet, a sprinkle of cilantro, a drizzle of fresh lime and a drizzle of fat free sour-cream or salsa. Enjoy!



CHOC PWS Parent Support Network

We would like to create a new parent support network for parent's here at CHOC PWS Clinic. If you are interested in being included on an email list for parents to connect with each other, please send an email to bmcgann@choc.org including your name, child's name and age, city you reside in and your email address. The list will be sent out to those who are interested. Thanks for supporting each other!

Volunteer Update

As you know, due to COVID restrictions, our CHOC Volunteers are not able to come into CHOC facilities until further notice. We are not sure how long these restrictions will be in place, but we have started zoom parties with Susie and will continue until Susie can come and coordinate the playroom in our new clinic space. You will continue to receive flyers with the zoom party dates and link to join!

Are you a member of the PWS CA Foundation?

The CHOC PWS team encourages all of you to join the Prader-Willi California Foundation. Why? You will have a support network who will provide you the latest in research, educational materials, community partner programs, committees, blogs, articles and you will make connections with other families who have children with PWS.

Prader-Willi California Foundation

www.pwcf.org

1855 First Avenue Suite 201

San Diego, CA 92101

Ph: (310) 372-5053

Toll-free phone within CA: (800) 400-9994

info@pwcf.org



Good Vaccination News for Our Families

STATE OF CALIFORNIA--HEALTH AND HUMAN SERVICES AGENCY

GAVIN NEWSOM, Governor

DEPARTMENT OF DEVELOPMENTAL SERVICES

1600 NINTH STREET, Room 240, MS 2-13
SACRAMENTO, CA 95814
TTY (916) 654-2054 (For the Hearing Impaired)
(916) 654-1897



January 13, 2021

To Whom It May Concern:

California has a large population of people with intellectual and/or developmental disabilities. Recent COVID-19 studies have identified several groups within this population as being at high risk of COVID-19 complications and related fatalities. The purpose of this letter is to clarify that family members of certain people are “health care workers” pursuant to the State of California’s [Vaccination Plan \(https://covid19.ca.gov/vaccines/#When-can-I-get-vaccinated\)](https://covid19.ca.gov/vaccines/#When-can-I-get-vaccinated), and thus are prioritized for COVID-19 vaccination within Phase 1A.

These family members include those who care for people with any of the following conditions. This list is not necessarily exhaustive:

- Cerebral palsy
- Down Syndrome
- Epilepsy
- Specialized health care needs, including dependence upon ventilators, oxygen, and other technology

The eligibility of these family members can be ascertained by documentation from their California regional center, verifying the qualifying condition of the member of their household who has an intellectual or developmental disability. A list of regional centers is available here: <https://www.dds.ca.gov/rc/listings/>. Alternatively, a family member may choose to present medical documentation of the qualifying condition of the member of their household who has an intellectual or developmental disability.

We hope this letter clarifies the eligibility of certain family members for the COVID-19 vaccine pursuant to Phase 1A of the State’s Plan, and thereby assists in protecting the health of Californians most at risk from COVID-19 impacts.

Sincerely,

NANCY BARGMANN
Director

“Building Partnerships, Supporting Choices”