



Prader-Willi Family NEWSLETTER

Summer 2023 Edition

Endocrine Corner: Bariatric Surgery: An option for PWS?

by Sejal Kadakia, M.D.

Hello families!

Recently we have been receiving questions from many of you about the prospect of bariatric surgery or “weight-loss surgery” in PWS. So, I thought this would be a relevant topic to bring to this newsletter.

Though there are reports of some children that did have significant weight loss with bariatric surgery in the short-term, the longer-term data is less positive. The Obesity Society published a review article in 2022¹ showing that the benefits of bariatric surgery seem to be less significant and not as long-lasting in PWS compared to other individuals. While many PWS patients did have initial weight loss after surgery, they started to regain weight within just a few years.

There is a much higher risk of surgical complications² in PWS. There have been several patients with PWS who died after bariatric surgery and a very significant number who required a revision of their surgery or a second surgery. In addition, it is known that there is an increased risk of stomach rupture in PWS even without surgery. Having scar tissue (which is weaker and less flexible than surrounding tissue) increases this risk.

For all the reasons above, surgery is currently not recommended for children or adults with PWS. Our PWS team here at CHOC will continue to stay updated and keep you posted as more data emerges.

¹Gantz, M.G.; Driscoll, D.J.; Miller, J.L.; Duis, J.B.; Butler, M.G.; Gourash, L.; Forster, J.; Scheimann, A.O. Critical review of bariatric surgical outcomes in patients with Prader-Willi syndrome and other hyperphagic disorders. *Obesity* **2022**, *30*, 973–981.

²Scheimann AO, Butler MG, Gourash L, Cuffari C, Klish W. Critical analysis of bariatric procedures in Prader-Willi syndrome. *J Pediatr Gastroenterol Nutr.* 2008; **46**: 80- 83.



Social Worker's Corner: Tips from your Social Worker

By Bobbi McGann, LCSW

Respite- we all need to take breaks!

Most of you are too young to remember the Chicago song, "Hard to Say I am Sorry," from 1982, but I guess I am aging myself. The first line in the song says, "everybody needs a little time away" and I often find myself thinking about this and how true it is. Our PWS team are in awe of how much you as parents do for your children every day! Most of you never take any time for yourselves, and if you do it somehow it makes you feel guilty. I am here to tell you, we have to change our thinking on this.

Summer is the best time to take some time for yourself. Often, your children are not as scheduled with school and outside activities, so we want you to make efforts to do something for yourself. There are many studies that show we are better humans to ourselves and each other when we take time to do things away from our children. Here are some suggestions of what you can try, and we are hoping you will try to do them at least a few times a month. Use your respite hours from Regional Center or hire a staff person from school, many of the aides in the classrooms love to babysit during the summer. Or don't be afraid to ask for help from your extended family. Or if you do not have family, take turns with your spouse. Kids love special days with their mom or dad, and this gives the other parent a break.

- Take a walk on a trail you have never been on; nature does wonders for our souls
- Schedule a manicure or pedicure
- Take a yoga class
- Go to a paint and sip class, or pottery painting class
- Have lunch with a friend
- Watch a new movie in the theatre
- Take a cooking class

Tips Continued

- Go to the beach and read a book
- Take a nap

You get the picture, but the hardest part is making an effort to schedule this and keep doing it consistently. Don't feel guilty. You got this, trust me you will feel better and able to manage the stressful days a little easier.

Get Help:

Did you know our CHOC website can link you to resources in your community? We have partnered with Find Help which is an online directory that lists free or reduced cost services like, food, housing, and other resources. You just have to go to www.choc.org and enter community resources directory in the search bar. Or if you need our social worker to help you, let us know .

Dietitian's Corner: Surfing Through Summer Food Challenges

By Christina Wright-Yee, MPH, RD, CSP



Over the summer, schedules tend to loosen and there may be more variability in schedules. For children with PWS, we know how important a schedule can be to reduce the hope or expectations for more food. Here are some tips

to help you navigate this summer:

- Consider creating a “summer” schedule, to adapt for later wake up times, camps, or other events. Plan for at least 60 minutes of physical activity every day and make it fun!
- If your child will be going to day camps or another family member’s house, consider

packing snacks and/or meals and give it directly to that friend or family member. Come up with a plan to prevent sneaking, for example, purchasing temporary locks for that person’s home such as U-Shaped Child Locks for Cabinets or Cabinet Latch Locks

- Plan for family get-togethers and events by letting family and friends know your child has diet restrictions and can only eat the food you provide for your child.
- Give lower calorie meals and snacks if you know a higher calorie dinner or snack will be served later in the day.

Recipe Corner: Cauliflower Rice Summer Salad (Tabouleh)

Total Time: 12minutes **Serves:** 4 (about 1 cup each)

Ingredients

- 10 oz bag riced cauliflower
- 1 chopped red bell pepper
- 1 chopped yellow bell pepper
- 1 cup chopped English cucumber
- 1/2 cup chopped tomatoes
- 1/2 cup chopped flat leaf parsley
- 2 tbsp fresh mint (chopped), optional
- 2 Lemons
- 1 tsp. salt
- 1 tsp garlic powder



Instructions

1. Preheat a cast iron or stainless-steel skillet over medium heat. Once hot, add the riced cauliflower to the skillet and cook 5-7 minutes with a lid over the skillet.
2. While the cauliflower rice is cooking, chop all veggies and add to bowl.

3. After cauliflower rice is done cooking, add it to the bowl with the rest of the veggies. Add the lemon juice, salt, and garlic powder. Stir to combine.
4. Store the cauliflower tabbouleh in the fridge for up to 4 days.

Nutrition Facts	
Amount per Serving	
Calories	81
Fat	1g
Carbohydrates	18g
Fiber	6g
Sugar	6g
Protein	5g

Recipe and nutrient analysis credit: Bites of Wellness:
<https://bitesofwellness.com/cauliflower-tabbouleh/>

Healthy Barbeque Food Swaps

<i>Instead of</i>	<i>Try ...</i>
Butter on corn	Squeezing a lime on your corn
Mayonnaise/Sour Cream	Greek yogurt
Hamburgers, sausages, or hot dogs	Marinated portobello mushroom, or kabobs made with vegetables, chicken, or tofu
Pasta, potato, or rice salads	Use spiralized vegetables instead of noodles Try a leafy green salad, cauliflower rice or quinoa.
Bread buns or rolls	Wrap your protein of choice in butter leaf or romaine lettuce.
Oranges, bananas, mangoes, or pineapple	Watermelon, strawberries, melon, jicama and/or cucumber.
High calorie sodas, juices, or sports drinks	Bringing your own diet drink or sparkling water, so you know your child will have something they can enjoy.
Frozen desserts like ice creams, gelato, popsicles	<ul style="list-style-type: none"> • Lower sugar options such as: Outshine No Sugar Added bar, Sugar Free Popsicle or cut a Yasso or Enlightened Greek yogurt bar into cubes for a smaller portion. • Freezing a single serving Greek yogurt • Make our healthy banana ice cream recipe featured in our Spring '22 Newsletter *Note: portion size for the almond milk in recipe should be 1 cup.