



# Prader-Willi Family Newsletter Fall / Winter 2023 Edition

## Endocrinologist's Corner: Navigating The Growth Hormone Shortage

By Sejal Kadakia, M.D.

Dear families,

We are all familiar with the benefits of growth hormone in PWS: improvement in tone, body mass index, body composition, and even cognition. It is the mainstay of current medical treatment in PWS. These reasons – and more - are why the nationwide growth hormone shortage has been particularly worrisome to those in our community. The reasons for the shortage described by the manufacturers are due to manufacturing delays. Currently, we do not have any more information on the specifics of this.

Our team shares the frustration many of our families have had in securing a stable growth hormone supply. The good news is that there seems to be some light at the end of this (seemingly long) tunnel. Two of the biggest companies Novo Nordisk (Norditropin) and Pfizer (Genotropin) both anticipate being able to increase production capacity by the end of 2023 and anticipate growth hormone availability to stabilize in 2024.

Being off growth hormone is certainly not ideal, but we want to reassure you that short amounts of time without growth hormone should not significantly affect your child's health. Please keep our team updated on any issues that you may be having in accessing growth hormone. We may be able to authorize a different brand or formulation and we can try to help locate pharmacies that do have current stock. Occasionally, we may be able to access samples to help bridge any short gaps. Thank you for your patience during this time.

## Recipe Corner: Egg Roll Noodle Bowl

- 1 tablespoon sesame oil
- 1/2-pound ground pork or turkey
- 1 tablespoon low sodium soy sauce
- 1 garlic clove, minced.
- 1 teaspoon ground ginger
- 1/2 teaspoon salt
- 1/4 teaspoon ground turmeric
- 1/4 teaspoon pepper
- 1 bag of shredded cabbage (or try the Trader Joe's Cruciferous Crunch Bag for an extra boost of veggies)
- 2 large carrots, shredded (or about 2c pre-shredded)
- 4 ounces rice noodles
- 3 green onions thinly sliced.

1. In a large cast-iron or other heavy skillet, heat oil over medium-high heat; cook and crumble pork until browned, 4-6 minutes. Stir in soy sauce, garlic, and seasonings. Add cabbage and carrots; cook until vegetables are tender, stirring occasionally, 4-6 minutes longer.

2. Cook rice noodles according to package directions; drain and immediately add to pork mixture, tossing to combine. Sprinkle with green onions. If desired, serve with additional soy sauce.

1 cup: 200 calories, 8g fat (3g saturated fat), 22g carbohydrate, 9.4g protein.





## Social Worker's Corner: Challenging Behavior- The ABC's

By Bobbi McGann, LCSW

We have all experienced challenging behaviors from our children. Challenging behavior usually has a function and purpose to the child. Children may be trying to communicate something or be trying to get something. In any case, it can be frustrating for any parent to manage these events. Many experts in the field have discussed the ABCs of behaviors and it might be helpful to review these ideas which may help you the next time your child challenges you.

- **A=Antecedents**

The way to look at this is to try and determine what happened right before the behavior. It could be something in their environment such as instruction from a teacher or a parent taking the IPAD away. It could be a transition or a denial of some kind. Other internal states such as your child being tired or not feeling well can serve as an antecedent.

- **B=Behaviors**

These can be behaviors you observe like external or internal behaviors. Internal behaviors can be pain or daydreaming. External behaviors can be avoidance of a task, self-injuries, or tantrums. Most behavioral interventions focus on external behaviors.

- **C=Consequences**

A consequence is anything that immediately follows the behavior. It could be as simple as your child asking for a snack and you giving a snack or when a baby cries, picking up the baby to comfort them. Any consequence can increase the likelihood of the behavior happening again or decrease the likelihood of the behavior happening again or have no effect.



Through observation you can start to evaluate your child's behaviors by using these principles. In some cases, if you can figure out the antecedents which cause the behaviors, you may be able to intervene and prevent the behaviors in the future. Make sure you also look at what consequence is happening to be able to refine this. Once the reason for the behavior can be defined, effective interventions can be put in place to change the behavior in the future.

You can also work with a trained BCBA (Board Certified Behavior Analyst) by receiving a referral to an ABA (Applied Behavioral Analyst) Agency that can help you work on these challenging behaviors. Parent training from a specialist can help you effectively work with your child to change behaviors. The key to success is to be consistent with **your** interventions even when the therapist is not around.

#### **Use of behavioral Charts:**

- We encourage the use of behavioral charts. Children with Prader-Willi Syndrome often have difficulties with transitions and function better with routines and schedules.
- Start by targeting a few behaviors you want to improve. Don't try to overload the chart with too many tasks as the child will see this as overwhelming and not want to participate.
- Charts should be created and presented to the child before you start.
- Charts allow the child to see their progress and look forward to the reward which should be pre-established when making the chart.
- Never use food as a reward for children with PWS.
- The boxes can be checked off or you can use stickers to track their progress. If your child does not accomplish the task each day, still offer encouragement to keep going.
- The reward should be given if the child completes the items at least 80% of the time allotted.
- We have a sample of a chart below and you can print many off the internet.
- Often Susie, our volunteer, has your child create calendars in the playroom that can be used for these purposes.
- Your child will feel accomplishment and behaviors can change!

**Behavior Chart examples at the end of the newsletter.**



## Dietician's Corner: Encouraging Positive Behaviors

By Christina Wright-Yee, MPH, RD, CSP, RD

### Fun Non-Food Rewards for Encouraging Positive Behaviors in Kids and Teens

Do you want to know how to motivate your little ones and teens to behave well? Sometimes, using non-food rewards can be a great way to encourage positive behaviors, especially in children with PWS. Non-food rewards are treats or activities that make kids happy and proud without involving any edible goodies. In this article, we will explore some exciting non-food rewards for toddlers, adolescents, and teens, as well as provide a tracking log to help your family reinforce positive behaviors!

#### Non-Food Rewards for Toddlers:

1. **Sticker Charts:** Create a colorful chart and reward your toddler with a sticker for every good behavior they exhibit throughout the day. For instance, they could earn stickers for sharing toys, putting away their clothes, or using good manners. Once they collect a certain number of stickers, they can enjoy a special activity, like a trip to the park or a fun day at the zoo.
  - See other Rewards Charts you can download from here: <https://templatelab.com/reward-charts/>.
2. **Extra Playtime:** Encourage positive behavior by offering your toddler some extra playtime with their favorite toys or games. For example, if they finish their homework without any fuss, they can enjoy an additional 10 minutes of playing with their building blocks or coloring books.
3. **Art and Craft Supplies:** Kids love being creative! Reward your toddler with a new set of crayons, markers, or stickers when they show good behavior consistently. This way, they can have extra materials to explore their artistic side.
4. **Dollar Store Trip:** You choose how much you are willing to let your child spend (ex: \$3), and they can buy 2 items from the toy section, or buy a few toys to keep on hand!

#### Non-Food Rewards for Adolescents and Teens:

1. **Extra time privileges:** Reward teens with video games, watching TV or, art, music or computer time. This way, they'll have more opportunities to relax and enjoy their favorite activities guilt-free.
2. **Family/Friend Outings:** Plan special outings as rewards for adolescents when they achieve a positive behavior goal. This could include a trip to the movies, a visit to a local museum, or a day spent at a fun amusement park with the whole family, a specific family member or friend!
3. **Shopping Trip!** If your teen loves books or music, offer them a trip Target where they can choose a new activity (think exercise equipment, nail polish, toys, crafts, Brainteaser puzzles or books). This non-food reward can encourage both learning and creativity.



In conclusion, non-food rewards can be a fantastic way to motivate toddlers, adolescents, and teens towards positive behaviors. By utilizing sticker charts, art supplies, extra playtime or screen time, family outings, and visits to bookstores or music stores, you can encourage good behavior while fostering creativity, learning, and family bonding. By utilizing a tracking log, you can track and reinforce these positive behaviors consistently, leading to happier and more fulfilled family dynamics.

EXAMPLE:

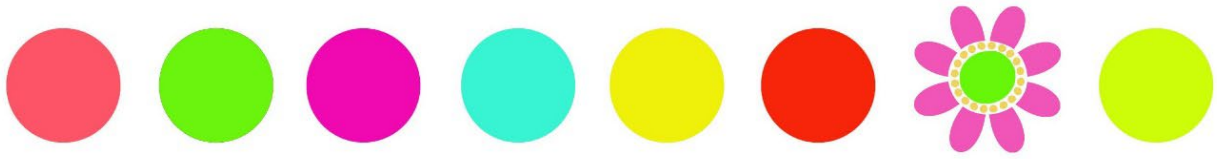
# Weekly Behavior Chart

**Weekly Behavior**  
For \_\_\_\_\_

BEHAVIORS	MON	TUE	WED	THU	FRI	SAT	SUN	POINTS

My Reward Is \_\_\_\_\_ Total:

☆☆☆



# Reward Chart for \_\_\_\_\_

	Mon.	Tues.	Wed.	Thurs.	Fri.	Sat.	Sun.
<input type="text"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<input type="text"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<input type="text"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<input type="text"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<input type="text"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

my reward will be:

