

The PKU PRESS

FALL | WINTER 2019

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the PKU

Organization of
Illinois
&
Allied Disorders

Letter from the Editor

It is now "autumn". It is a lovely word to describe a season of beauty. Not only is the temperature more to my liking, but autumn offers the opportunity to bring new, hearty flavors into our diets. Fall and winter can be seasons of comfort. Like the comfort found in a warm slice of pumpkin bread, the welcoming aroma of a Crockpot at the end of the day or the delight I take in shuffling around in my slippers on a Saturday morning. Let's make the most of this season as we transition into the winter months. *-Meredith*



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pinterest.com/PKUillinois

Follow our Pinterest Boards for NEW PKU tools, Low Protein recipes, and adaptable dinner ideas!



Mary's Corner

Don't let pku stop you! I'm doing a lot. I just had another idea: I'm going to make my newsletter a book and have a designer!



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When balance is everything, you have to stay a step ahead!

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Dear PHE-bea,

WHAT DO I DO WITH CANDY AND TREATS THAT I GET ON HOLIDAYS, LIKE HALLOWEEN, THAT MIGHT NOT BE OKAY FOR MY SPECIAL DIET?

-A CANDY-CONSCIOUS CONSUMER

Dear Candy-Conscious,



For kids, Halloween is a magical night when they can dress up as their favorite superhero and go trick-or-treating to get tons of candy from their neighbors. However, for children with special diets and their parents, a little extra work has to be done to ensure a safe Halloween. This holiday can be nerve-wracking because many popular treats handed out contain high amounts of PHE.

While trick-or-treating, parents can keep their kids from eating goodies containing PHE by gently reminding them of the foods they can and cannot eat. Parents could also tell their children to wait until they're home before eating any candy. This way, their "loot" can be sorted and the High-PHE foods can be weeded out.

Some families make sorting into a game with their kids. For instance, you can offer to 'buy' unwanted candy for an alternative, like a small prize. Or you can trade each piece out for candy that is safe for your child to eat. This is known as the "Switch Witch".

I've included some responses from other readers to share with you how they handle this sweet holiday conundrum!

Happy Halloween!

PHEbea

WE HAVE CANDY
and
NON-FOOD TREATS



Teal Pumpkin Project

The **Teal Pumpkin Project**, created by the Food Allergy Research & Education (FARE) organization, promotes inclusion for those who have food allergies or other health conditions that could prevent them from eating certain foods. If you would like to let trick-or-treaters know you are promoting a safe Halloween by giving out non-allergic candy or other non-food treats, place a teal pumpkin by your door step!



Karen Dent

You can also donate the non pku friendly candy to teachers to use as prizes, to a nursing home as a treat for residents, or to a food pantry - always appreciated.

Marlene D'Ambra

We always did the switch witch. Any candy we got that couldn't be eaten was left in the black plastic cauldron and the witch came and left all pku friendly candies in its place. It was sort of 'elf on the shelf' like. My son loved the witch 🧹 We ate the non-pku 'switched' candy lol



Felicia Abrahamson

My parents always bought an extra bag of candy that we can have and set it to the side. When we got back, we sorted it out and kept the candy we could have and traded all the candy we couldn't. So we still got the same amount of candy that we collected

Jennifer Lanteigne

The switch witch. Child leaves all candies that they cannot have in a bucket for the switch witch and then the switch witch brings either candy or a small toy as a replacement for said candy. The unusable items are then donated to the food bank

Lesha Pku

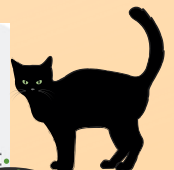
Well I have pku not my daughter but we do candy tax lol mom gets to pick out candy as a tax for taking her trick or treating lol for pku kids just pick out unsafe candy as the "tax"

Tracie 'Riker' Raitz

My kids come home and they all sort and trade candy (we have 5 kids- 2 oldest non and 3 youngest CPKU). We've done this since my oldest PKUers first Halloween and it's just now part of the Halloween fun for all!! And of course I get to implement 'mom tax' on any candy stash I see fit to 😊

Danielle Baker




My kids school collects candy and sends it to the military so we have always sorted it and given away what she can't eat. Also there is the "switch witch". A witch that comes and takes the extra candy and switches it for something else.



HOW MUCH PHE HALLOWEEN CANDY GUIDE

 <p>FREE!</p>	<p>Airheads Bottlecaps Candy Necklaces Dots Fruit Runts Fun Dip Gobstoppers Hard Candy*</p> <p>Jolly Ranchers Hard Candy Laffy Taffy Lifesavers* Mike & Ike Nerds Pez Candy in Dispenser Pixy Stix Ring Pop</p>	<p>Salt Water Taffy Smarties (U.S. version) Sour Patch & Sour Punch Candy Suckers/Lolly-Pops/Dum Dums* Swedish Fish SweeTARTS classic</p> <p><small>*Make sure these are not sugar-free & contain only phe-free sweeteners</small></p>
 <p>less than 10mg</p>	<p>PER PIECE Licorice, Bites Marshmallow Ghosts Sugar Daddy, Junior Tootsie Roll Midgees Tootsie Roll Pops, Caramel, Chocolate, or fruit flavors</p>	<p>PER PACKAGE Candy Corn Jelly Beans, all flavors Skittles, all flavors Sprees Chewy Candy Starburst Fruit Chews, all flavors SweeTARTS Chewy</p>
 <p>10-20 mg</p>	<p>Hershey Hugs Hershey Kisses Kraft Caramels Red Vines Black Licorice Twists Red Vines Original Red Twists Rolo Caramels in Milk Chocolate Sugar Babies, Fun Pack</p> <p>Twizzlers Licorice Twists Twizzlers Strawberry Twists</p>	
 <p>20+ mg</p>	<p>MINI CANDY BARS \$100 Grand, 3 Musketeers, Almond Joy, Baby Ruth, Butterfinger, Hershey's Minis, Kit Kat, Milky Way, Mounds, Snickers, Twix</p> <p>PER PIECE York Peppermint Patty Reese's Peanut Butter Cup, miniature</p>	<p>PER PACKAGE Haribo Gummi Bears Jolly Rancher Gummies Junior Mints, regular size Life Saver Gummi Savers M & M's, fun size Malted Milk Balls</p> <p>Milk Duds, 13 pieces Raisinets, 1.58 oz. bag Sugar Babies, regular size Sugar Daddy, regular size Whoppers</p>

IDEAS FOR HANDLING HALLOWEEN CANDY

-  Set aside higher-phe candy for the "switch witch" who comes & brings a present on Halloween night
-  Trade in higher-phe candy at the dentist or donate it at local firehouses or other organizations
-  Trade higher-phe candy with friends and siblings for lower-phe options

New Parent Cafe

May 4th, 2019



What a great day we had at the New Parent Café that took place on May 4th 2019 at Grounds for Hope in Lisle. We had SO MANY new faces! Our families of the older children (pre-school age) really came together during our group discussion to offer tips and suggestions for our new parents with PKU newborns. This discussion took place over piping hot coffee and scrumptious home made PKU pastries and dishes, while the children ran around and played on the supercool indoor playground in the next room over. We also are SO thankful to our sponsors who made this free event possible for our community: Vitaflo, Nutricia, Cambrooke, and BioMarin. Their services were definitely utilized as our families perused their products at their vendor tables and had all of their questions answered. New Parent Café was a HUGE success this year and we cannot wait for next year!



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Family Fun Day - North

June 23rd, 2019 at Wheeler Park



Family Fun Day took place on Sunday, June 23rd at Wheeler Pavilion in Geneva, Illinois. This free event was made even brighter with a beautiful, sunny day and 28 people in attendance! Our vendors from Vitaflo, Nutricia, and Cambrooke shared information and products with the families. There was a vast array of PKU friendly food for everyone to try (provided by the families) and we even fired up the Barbie! The playground was a big hit with the kiddos, as it kept them busy running around. Stories were shared by parents, old and new families connected, swapping recipes and tricks of the trade. Thank you to all who participated in making this event a huge success!

-Meghan Fido



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Family Fun Day - South

June 22nd at McGraw Park/Bloomington



The southern Family Fun Day was held on Saturday, June 22nd at McGraw Park in Bloomington, Illinois. We had an excellent turn out of 38 guests! Vendors in attendance shared products and samples with our guests. Many "big kids" and little kids really enjoyed the playground and Splash Pad! A huge THANK YOU to our friends and families who helped make this event a success by bringing dishes to share. Our PKU attendees were able to enjoy food just for them including low-PHE miniature chocolate cupcakes and taco-cauliflower! Yum! It was wonderful being able to spend a day with old and NEW friends!

- Meredith Stutzman



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EVENT RECAP

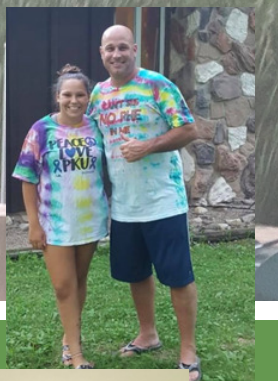
Family Camp!

July 19th - 21st Great Oaks Campground/Lacon, Illinois

The annual Family Camp was held the weekend of July 19th through the 21st at Great Oaks Campground. Campers began arriving Friday evening at the air-conditioned lodge in Lacon, Illinois. We had families from Missouri and Wisconsin travel to camp this year! The warm-weekend fun kicked off with tie-dyeing, a meal that included "Kelsey's Chinese American Pasta Salad" (see the recipe in this edition of the press!) and capped off with PKU friendly s'mores by the fire.

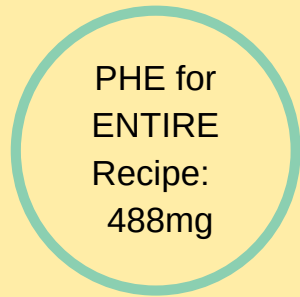
On Saturday, even more campers arrived to join in the fun! Activities included zip-lines, swimming at the lake, paddle boats, and even a climbing wall! It was great to see some of the *big kids* get in on the activities. Lunch at the large pavilion was taco-themed. PKU and NON-PKU foods were enjoyed by everyone.

We want to say THANK YOU to our fearless leader, Kim Kowalczyk, for organizing the majority of the camp this year. Also, THANK YOU to our FAMILIES and FRIENDS who brought low-protein food to share. We can't wait to see everyone at camp again next year!



Kelsey's Chinese-American Pasta Salad

- 300g Saifun Bean Thread Noodles
- 295g Carrots (raw, shredded)
- 495g cucumbers (raw, diced)
- 665g Tomatoes, roma (diced/chopped, raw)
- George Washington's Golden Seasoning and Broth (find on amazon!)
- Italian Dressing, one bottle



Boil the noodles with a packet of George Washington's seasoning and broth. While boiling, shred carrots, dice cucumbers, and chop tomatoes. Combine vegetables in large bowl. Set aside. Once noodles are translucent and soft, strain off broth. Toss noodles with veggies, pouring italian dressing over all.

THIS MAKES A LARGE BOWL OF PASTA!



Cornbread Holiday Stuffing

FROM THE APPLIED
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COOKBOOK

HOMESTYLE COOKING:
RECIPES THE WHOLE
FAMILY WILL ENJOY

Nutrition Per Serving: 3/4 cup

Pro 0.82g | LEU 65.5mg
PHE 31mg | kCal 123

Cornbread Cubes:

- 1 ½ cups Loprofin All-Purpose Baking Mix
- ½ cup cornmeal, self rising
- 2 teaspoons sage, dried
- 2 teaspoons thyme, dried
- 3 teaspoons baking powder
- 1 teaspoon baking soda
- 1 teaspoon rosemary, dried
- 1 teaspoon salt
- ¼ cup Miracle Whip® Original
- ½ cup non-dairy creamer, liquid
- ¾ cup water

Stuffing:

- 2 tablespoons margarine, non-dairy
- ⅓ cup onions, diced
- ½ cup celery, diced
- ½ cup apple, peeled, diced
- ½ cup fresh cranberries
- 1 teaspoon sage, dried
- 1 teaspoon thyme, dried
- ½ teaspoon rosemary, dried
- ¼ teaspoon white pepper
- 1 ¾ cups water*
- 2 packets G. Washington's® Golden Seasoning and Broth*

Cornbread Cubes:

1. Preheat oven to 425°F.
2. In large bowl, mix all dry cornbread ingredients.
3. Add Miracle Whip® with fork, then non-dairy creamer and water.
4. Pour batter into 9"x 9" baking pan, bake for 12 minutes.
5. Cool few minutes then remove from pan and cut into 1 inch cubes.
6. Transfer cubes back into 9"x 9" baking pan, bake at 300°F for 1 hour to dry cornbread pieces.



Veggie Bolognese

CHEF JEFF MASSE

Adapted from "The Spiralizer by Jennifer Williams"

- 2 tbsp olive oil
- 4 c mushrooms, chopped
- 1 c yellow onion, chopped
- 4 cloves garlic, minced
- 2 - 28oz cans crushed tomatoes
- 1/4 c tomato paste
- 1 tsp. dried basil
- 1/2 tsp. dried thyme
- 1 tsp. dried oregano
- salt & pepper to taste
- 6 - small to medium zucchini, spiralized

1. In a large saucepan, saute mushrooms over high heat for 8-10 minutes, until browned.
2. Add 1 tbsp olive oil and saute onions 5 minutes longer
3. Add garlic, tomatoes, paste, basil, thyme, and oregano and bring it to a boil. Reduce heat and simmer 30 minutes or until it thickens.
4. While sauce cooks, in a separate pan, saute zucchini spirals in 1 tbsp olive oil for 5 minutes until tender al dente.
5. Divide zucchini pasta onto plates and top with sauce.

Will make 4 servings

Serving Size: 1/2 cup sauce over zoodles
 Protein (gm): 10g
 PHE (mg): 380mg

gourmetjeff@msn.com

Spicy Pumpkin Cake

Chef Brenda Winiarski | Cook for Love

Moist, sweet and spicy, this cake is a perfect welcome for the Fall. The fact that it is both low in phe and so easy to make gets me doing a little happy dance. It is the perfect ending to your Thanksgiving feast.



- 3 c (390g) Cook for Love Baking Mix
- 1 unit(s) (85g) Jello Instant Pudding (Vanilla)
- 1 c (200g) Sugar, White Granulated
- 1 c (220g) Packed Light Brown Sugar
- 2 tsp (10g) Baking Powder 2 tsp (10g) Baking Soda 1 tsp (6g) Salt 2 tsp (6g) Cinnamon, ground 1 tsp (2g) Ginger, ground 1/2 tsp (1g) Allspice, ground 1/4 tsp (1g) Cloves, ground 1 c (240g) Apple Cider 1 c (244g) Canned Pumpkin, (NOT Pumpkin pie filling) 2/3 c (160g) Canola Oil 1 TBSP (15g) Apple Cider Vinegar

Preheat oven to 325 degrees. Generously grease a non-stick 10 inch bundt pan. Set aside.

In a medium sized bowl whisk the baking mix, pudding, sugars, baking powder, baking soda, salt, cinnamon, ginger, allspice and cloves; set aside.

In the bowl of your kitchen aid mixer with the paddle attachment, combine the pumpkin, cider and oil. Beat on medium-high for 1 minute.

Add the dry in ingredients and beat for 2 minutes on medium speed, scraping down the bowl at least once. Add in the vinegar, mix briefly (10 seconds) and quickly add the batter to the prepared bundt pan and get in the oven. (Remember the chemical reaction with baking soda and vinegar - which is what causes the cake to rise - is quick so it needs to get in the oven as fast as possible.)

Bake for 55 to 60 minutes. Place pan on a cooling rack and allow cake to cool in the pan for 10 minutes. Invert cake onto a serving plate and cool to room temperature.

GLAZE

- 1 c (120g) Sugar, Powdered (Confectioners)
- 1/4 tsp (1g) Cinnamon, ground
- 2 TBSP (30g) Apple Cider
- 1 TBSP (15g) Heavy Cream

To make the glaze: Combine the sugar and cinnamon. Stir in 1 tablespoon of apple cider and 1 tablespoon of heavy cream, whisk until smooth. Add the extra tablespoon of apple cider if the glaze is too thick. Spoon the glaze over the top of the cake.

PHE for entire 10" Bundt Cake: 360mg

LET'S DECORATE

Here's what you need:

- Cookie cutters - sometimes simpler is better!
- Couplers & Tips- just getting started? Stick with Wilton tips #1, #3, and #5 for easy flooding and decorating.
- Piping bags - disposable bags are great for easy clean-up!
- Gel food coloring - get the whole Wilton box set! I love these colors for royal icing, cake batter, frosting, etc. They're high pigmented so you don't need as much coloring. There is a chart right in the box that tells you how to get a color you'll love.



Shiny Decorator Icing

- 2 c. powdered sugar
- 4 tsp milk
- 6 tsp light corn syrup
- 1/2 tsp almond extract
- assorted gel food coloring

NOTE:

4 tsp = 20ml milk
36mg PHE

In a small bowl, combine sugar and milk until mixed. Beat in syrup with a fork until the icing is smooth. If your icing is too thick, add a bit more corn syrup. This icing will set and dry shiny and smooth. Separate frosting out if you want multiple colors before adding your gel coloring.

BITS & PIECES:

- I don't create intricate designs on my cookies because (1) I'm bad at it and (2) my hands are too shaky. Simpler designs are best if you're just starting out.
- Watch some online icing videos - you can learn a lot from them and get some ideas for your own creations.
- Always allow your cookies to COOL COMPLETELY. Hot cookies = Frosting disaster!
- Make your "border icing" thicker... this will help you when you flood your cookies later.
- Leave a fully decorated cookie alone to dry for 24 hours.
- LASTLY...even if your cookies aren't perfect, they'll still be just as delicious! So, have FUN!

One Mission:



The PKU Organization has partnered with OneMission to bring you one-of-a-kind shirts, sweatshirts, tank tops, mugs and more. The best part, no waiting! You no longer need to wait for an event to get your PKU gear. You can purchase online and the items are sent directly to you, with 40% of sales being directed to our organization. To date, we have raised almost \$700 with your purchases. If you have friends and family members that would like to help support our organization they can do so by making a cash donation through the site or purchasing one of the many other items available through OneMission. Visit the website here <https://onemission.fund/support/pku-illinois/>

Let's Celebrate... 

CELEBRATING 50 YEARS AS
THE PKU ORGANIZATION OF ILLINOIS & ALLIED DISORDERS

ANNUAL MEETING

Saturday, November 9th

WHAT TO EXPECT

- Keynote Speaker
- Cooking Demo
- Breakout Sessions
- Raffle
- Scholarship Winners
- Vendor Tables
- Children's Program (6-12y)
- Light Breakfast & Luncheon

LOCATION

CROWNE PLAZA
5440 N RIVER ROAD
ROSEMONT, IL

RESERVATIONS

MORE INFORMATION
COMING SOON!

Clinic Updates:



The clinic continues with successful group education classes for children, adolescents, adults and parent/infant groups. We have over 20 patients now on Palynziq and this number continues to expand monthly. We are excited for our patients who have responded to Palynziq therapy, and we remain committed to ensuring that all of our clinic patients are receiving the best treatment plan for their individual needs.

The Division of Genetics continues to expand with Research initiatives. We will begin recruiting shortly for a gene therapy trial in adult patients with PKU sponsored by Homology Medicines. A second gene therapy trial sponsored by Biomarin is also in development. Dr. Burton will be presenting on these initiatives at the Annual PKU of Illinois Conference in November 2019.

**THE
UNIVERSITY OF
ILLINOIS
AT
CHICAGO**



The division of Genetics and Metabolics at the University of Illinois Chicago continues to have a strong outreach program through numerous satellite clinics in Peoria, Naperville, Springfield and Oak Lawn. Our physicians include Dr. George Hoganson and Dr. Gifty Bhat. Christine Horne is our nurse practitioner and she works primarily with our newborn screening program.

The Chicago based genetic counselors include Katie Cobian, Lenika DeSimone, Beatriz Menendez and Alice Zalan. The metabolic registered dietitians include Krista Engen, Katie Ingle, and Shannon O'Brien. Our office coordinator is Andie Jones.

Our team in the Peoria office includes a genetic counselor, Jen Burton and registered nurse, Lauri Davis along with registered dietitian, Shelby Miller

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