

The PKU

PRESS

IN THIS ISSUE

NEW & UPCOMING	2
PHENOMENAL PEOPLE	3
WHATS IN STORE	3
VARY YOUR VEGGIES	4
TIPS & TRICKS	5
CULINARY CORNER	6
PHONE A FRIEND	7

Liquid smoke

WHAT IS IT
AND HOW TO
USE IT

lets chat...

TIPS FOR TEENS
STRUGGLING
TO STAY ON
DIET

**VARY
YOUR
VEGGIES**

OUR MONTHLY VEGGIE
SPOTLIGHT: CAULIFLOWER

*note
from the
editor*

Hello! Welcome to the reinstated newsletter, The PKU Press, published by the PKU Organization of Illinois! We look forward to sharing upcoming events within the global PKU community, new products, and many delicious recipes for both the PKU'er and family. We will also feature a "phone a friend" section where we encourage readers to submit questions or personal advice on navigating a PKU diagnosis throughout the life span. We hope this newsletter serves as a source of inspiration and collaboration for all those involved in our PKU and rare disease communities!

Sincerely,

Kirsten Frankfort & The PKU Organization of Illinois



we want to hear from you!

- need help navigating a unique or challenging situation?
- looking to share your experiences or advice
- want to share your favorite PKU recipe?

email us: thepkupress@gmail.com

UPCOMING
EVENTS

LEARN TO COOK: LOW PRO FOCACCIA

This class will allow a hands-on opportunity for participants to learn the art of PKU bread making by measuring, shaping, cooking, and topping a delicious and versatile low pro focaccia bread.

presented by Kimberly Gralen & PKU Org of IL |
July 15 2023
&
August 5 2023

FAMILY FUN DAY

Enjoy a picnic lunch while mingling and playing with other PKU families.

presented by PKU Org of IL | July 29 2023

LEARN ABOUT 504 PLANS

Learn about 504 plans and accommodations for children with PKU.

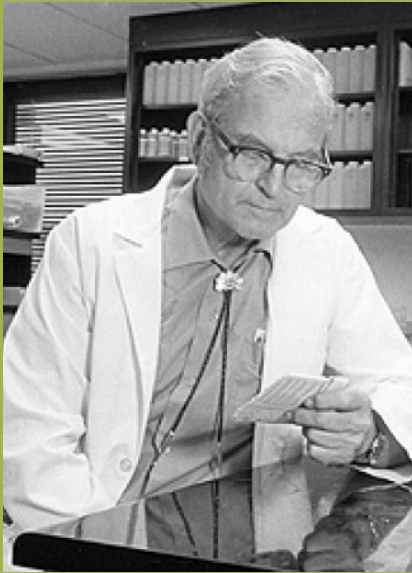
presented by NPKUA | July 11 2023

special thank you to
all the contributors:
Kimberly Gralen
Soo Shim
Anne Kozek
Brooke Kurkijan

new

&

noteworthy



PHE-NOMENAL PEOPLE

Dr. Robert Guthrie is considered the father of the newborn screening test. He dedicated his career to determining causes and prevention of intellectual disability. As a microbiologist, Dr. Guthrie developed a specially designed filter paper that tested bacterial growth when it came into contact with high phenylalanine levels from the blood sample. The former 'Guthrie test' became the pioneer for early diagnosis of PKU and other inborn errors of metabolism and ultimately prevented irreversible neurological damage with early detection and subsequent treatment. The newborn screen is required in the US and in some states, tests up to 80 different conditions. June 28th, Guthrie's birthday, is recognized as the International Neonatal Screening Day. Happy birthday Dr. Guthrie!

PKU IN THE NEWS

PTC THERAPEUTICS: APHENITY TRIAL

In May 2023, PTC Therapeutics, a global pharmaceutical company, released the results from the phase 3 portion of the APHENITY study - a global double-blind, placebo-controlled, registration directed study. The study enrolled 156 children and adults with PKU who were then randomized to receive sepiapterin or placebo for six weeks.

Sepiapterin is a precursor to intracellular tetrahydrobiopterin (BH4) and has been found to have increased circulating BH4 in comparison to sapropterin. The end goal was a reduction in phe levels and the study had very promising results. They found a 63% mean phe reduction in sepiapterin treated patients and in the subset of classical PKU patients the mean phe reduction was 69%. Furthermore, no serious adverse events were noted and the drug was well tolerated.

PTC Therapeutics announced "they look forward to discussing the path to approval!"

WHAT'S IN STORE?

THE LATEST UPDATE ON PKU FRIENDLY PRODUCTS AVAILABLE NEAR YOU

RELIEF THERAPEUTICS: PKU GOLIKE

PKU GOLIKE is the latest innovation for medical formula. Rather than typical powder formula, GOLIKE is in tasteless, odorless granule form. The granules can be added to food or smoothies and readily absorb similar to natural proteins. PKU GOLIKE can be incorporated in gradual amounts and added to a variety of dishes. Request a sample with your dietician or online at www.pkugolike.com !





VARY YOUR VEGGIES

OUR MONTHLY VEGGIE
SPOTLIGHT: CAULIFLOWER

Grilling season is upon us -

With the (eventual) return of warm weather, many of us turn to outdoor cooking. Grilling out adds a new flavor to our foods which can pull us out of our winter food rut. The only problem with grilling season for those on a low protein diet - it's all meat! This month, we're highlighting cauliflower as a tasty option to try out on the grill.

EASY GRILLED CAULIFLOWER STEAK

recipe by: spend with pennies

PREP TIME 10 minutes
COOK TIME 15 minutes
TOTAL TIME 25 minutes
SERVINGS 4 servings

Ingredients

2 heads cauliflower leaves removed
¼ cup fresh parsley chopped, optional
Marinade Ingredients
¼ cup olive oil
1 teaspoon garlic powder
1 teaspoon smoked paprika
½ teaspoon onion powder
½ teaspoon liquid smoke
¼ teaspoon salt
¼ teaspoon black pepper

Instructions

1. Preheat grill to medium heat.
2. Cut the cauliflower in half from top to bottom, cutting through the stem. (Do not remove the stem.)
3. Cut each cauliflower half into 1 ½ - 2 inch slices (steaks). You should have 4 cauliflower steaks from one head of cauliflower depending on the size of the cauliflower.
4. Arrange the cauliflower on a baking sheet or tray. Set aside.
5. In a small bowl, whisk together the marinade ingredients.
6. Coat both sides of the cauliflower steaks with the seasoned oil using a pastry brush.
7. Place the cauliflower steaks on the grill and cook for 4-5 minutes.
8. Carefully flip the cauliflower steaks over with a spatula and continue grilling for 3-4 minutes or until tender.
9. Sprinkle with chopped parsley, if desired, and serve immediately.

Notes

1. Cauliflower can be cut into steaks up to 8 hours ahead of time. Cauliflower steaks can be roasted in the oven at 425°F for 25 minutes or until tender-crisp. Broil 1 minute before serving.
2. Ensure you cut the steaks at least 1 ½-inches thick or they may not hold together.
3. The bits of cauliflower that are too small to be steaks can be grilled in a grill basket, added to a stir fry, a casserole, or roasted.
4. Leftover roasted cauliflower is great served chilled in salads, added to potato salad, or reheated.

TIPS *and* TRICKS

TO SPICE UP YOUR PKU TABLE!

FEATURED RECIPE:

VEGAN CAULIFLOWER SANDWICH

recipe by: Kirsten Frankfort

Ingredients:

- roasted cauliflower florets (cold)
- bread of choice (gluten free, vegan, white, Italian, sourdough)
- mayonnaise
- tomatoes (thinly sliced)
- cucumber (very thinly sliced)
- red onion (very thinly sliced)
- sprouts
- spinach
- celery salt
- avocado (optional)



1. spread mayo on both sides of bread, sprinkle with celery salt
2. assemble sandwich with all ingredients
3. enjoy!

Liquid Smoke

WHAT IS IT AND HOW TO USE IT



liquid smoke enhances ordinary dishes, marinades, and sauces into a natural smokey flavor with just a few drops!

Try adding to

- jarred marinara sauce
- your favorite BBQ sauce
- marinade for veggies

.... or make your own vegan bacon!

PLEASE CONSULT YOUR DIETICIAN FOR EXACT PHE/PROTEIN CONTENT

Try our 'Vary you Veggies' featured recipe, grilled cauliflower steak using liquid smoke!



Quick

WEEKNIGHT DINNERS

CAULIFLOWER TACOS

recipe by: Kirsten Frankfort

- cauliflower florets
- taco seasoning
- low protein taco shell
- non-creamy slaw
- vegan mexican cheese
- corn
- avocados
- tomatoes
- limes + 1 tbsp lime juice
- 1/2 tsp red wine vinegar
- garlic (minced to paste)

higher phe / non-PKU options

- beans
- cheese
- corn or flour tortillas



CULINARY CORNER
MASTERING PKU COOKERY

cauliflower

- toss cauliflower florets with olive oil + taco seasoning. roast / grill / air fry seasoned florets at 400 for 15-20 minutes

slaw

- toss cabbage / slaw with lime juice, red wine vinegar, avocado (diced / mashed), garlic, fresh cilantro & salt to taste



taco

- assemble taco, sprinkle with lime juice, & enjoy!

CAULIFLOWER RICE

recipe by: Yotam Ottolenghi adapted by Kimberly Galen

- riced cauliflower
- lemon juice
- olive oil
- dried currants
- scallions (sliced)
- fresh parsley (minced)

1. Combine rice + lemon juice + salt - set aside for 20 minutes
2. Stir in olive oil + currants + scallions
3. Top with parsley

optional higher phe add ins

- white beans
- feta cheese
- vegan meatball



BAKED DONUTS

recipe by: Kimberly Galen

- 114 g rice milk
- 1/2 tsp apple cider vinegar
- 120 g wheat starch
- 2 g xanthan gum
- 1 tbsp plain metacul
- 1 tsp baking powder
- 1/4 tsp baking soda
- 72 g granulated sugar
- 1/4 tsp salt
- 1/2 tsp nutmeg
- 2 tbsp melted coconut oil
- 2 tsp vanilla extract
- 1 tsp poppyseed *optional*

dessert time!



Combine rice milk and apple cider vinegar in a small bowl. Set aside.

Stir dry ingredients: wheat starch, xanthan gum, plain metacul, baking powder, baking soda, granulated sugar, salt, nutmeg

To the milk mixture, add coconut oil and vanilla extract. Add to dry ingredients, and stir until mixed. Scoop by spoonfuls to a greased mini donut pan, and bake at 350 for 15 - 17 minutes.

Let rest 5 minutes, then carefully run a butter knife around each donut to loosen, and transfer to a wire rack to cool. Top with your choice of cinnamon sugar or powdered sugar.

Nutrition for total recipe: 552 calories, 0.5 G protein / 13 mg phe, 20 mg leucine
*optinoal poppyseed additional: 0.5 G protein / 21 mg phe, 37 mg leucine

PHONE A FRIEND

Tips for helping a teen stay on diet

Written by: Soo Shim, LCSW & Anne Kozek, RD

From day 1 the focus on teaching your child about their diet is that “we eat to live. We do not live to eat”. Life is about activities and sharing time with others. Do not make the focus of events or outings about the food. Planting the seed early on that the diet is for life and that food is not the focus, carries over thru the years. However, as your child grows, he/she will experience temptations from peers. Work with your child to be prepared how to handle situations that may tempt them to stray from the diet. Being prepared with answers for situations will help lessen the stress when in a tempting situation.

Also as teens are having growth spurts or burn calories with sports or activities they are often hungry. Make sure to have plenty of low pro snacks on hand. Encourage your teen to shop with you to help select foods he/she prefers. This also provides learning opportunities for label reading and discussions of appropriate foods.

need help navigating a unique or challenging situation? looking to share your experiences or advice?

email us: thepkupress@gmail.com