

spring/summer 2019

the **pku press**

INSIDE

- meet the board
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- meet amber gibson
- seasonal featured recipes
- upcoming 2019 events

THE **PKU**

Organization of
Illinois
&
Allied Disorders

"NATURE'S FIRST GREEN IS GOLD" LETTER FROM THE EDITOR

-Robert Frost

When I think of spring, I think of vibrant fresh flowers, bright blue skies, and a fresh pep in my step. Every new season brings us opportunities to make positive changes that can propel us closer to our goals. This year we celebrate success, no matter how small. There are great things happening in the scientific community. The first quarter of 2018 brought with it the FDA approval of *Palynziq*. The middle of the year we celebrated Dr. Burton of Lurie Children's Hospital with her receiving the Lifetime Achievement Award. In the fall several of our metabolic community gathered to enjoy delicious wine. We ended the year together at the Annual Meeting and the Holiday Cookie Exchange. I am excited to welcome a new beginning in my life as the Editor of the PKU Press. I hope that 2019 brings success into your own lives, no matter how big or small. I look forward to celebrating with you at our events in 2019!

-Meredith Stutzman

Dear PheBea, 

mary's corner

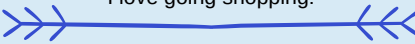
WITH MARY LONSKI



1st PKU Patient Diagnosed in
Illinois through Newborn Screening

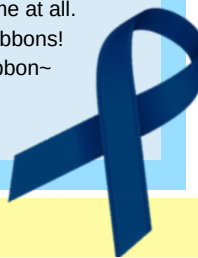
PKU Part 3

I'm doing everything! I love singing, I'm a hostess at the Original Pancake House, and I volunteer at Christ hospital. I'm a receptionist here at Garden Center Services, and I love going shopping!



I think I would make a good president for our board in my spare time. I love having a concert at any time! That is why I don't let PKU stop me at all. I love selling PKU ribbons! ~\$5 dollars per ribbon~

Love, Mary



I've had a difficult time with communication with my 7-year-old son's school, letting me know in advance when special treats will be available for the kids, and the teacher doesn't give very much notice, if at all.

Is there a way I can get her to understand the complications of making these treats and for him to not feel excluded from his peers?

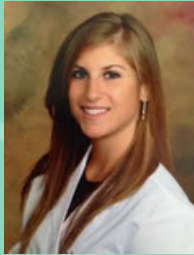
Dear Mama,

You're a great mom to be worried about your son's inclusion and wanting him to feel like his peers! I think this is a common issue that many parents encounter at some point of their children's schooling, and super important to address early and head on. Each school manages it differently, so I'm taking a page out of the NPKUA Binder on npkua.org to help provide some insight to how others address the issue: Letting your child's school and teacher know about his or her PKU is the first step. It is important for teachers and other staff to understand why your child needs a special diet, and why careful supervision is needed. Anyone who comes in contact with your child will need a basic understanding of your child's dietary restrictions. When my little guy was young, I had a separate meeting with the school principal, the teachers, the nurse, and food service team, to ensure they understood the necessity for him to stay on track. In some cases, a school might set up a 504 plan (a plan developed to ensure a child who has a disability identified under the law and is attending elementary or secondary educational institution receives accommodations that will ensure their academic success and access to the learning environment). If you're having consistent challenges that they are unable to meet, I suggest advocating for the school to implement one, as the repercussions for not being on diet will directly impact his ability to learn. Since there were many unannounced birthday cupcakes or cookies that we were not able to plan for, I kept a container of food items in my son's classroom that were in separate baggies. He could pick from these if he was unable to have the unannounced food. Each baggy had a label of the food item and then the teacher would send it home so I would know what he had. You are his biggest advocate, and you're right to address this early on! The sooner you get his accommodations met, the longer he (and you!) will be set up for success!

Best, PheBea

Meet Your 2019 Board Members

HELLO



Kim Kowalczyk
PRESIDENT



Grant Smith
VICE PRESIDENT



Kathleen Bianculli
TREASURER



Melinda Halvorsen
SECRETARY & VENDOR REPRESENTATIVE



Sean Haney
NPKUA REPRESENTATIVE



Meredith Stutzman
PKU PRESS EDITOR



Eric Halvorsen
WEBSITE ADMINISTRATOR



Meghan Fido
MEMBER-AT-LARGE



Shannon Razo
MEMBER-AT-LARGE



Nick Ferguson
MEMBER-AT-LARGE



Elena Caro
MEMBER-AT-LARGE



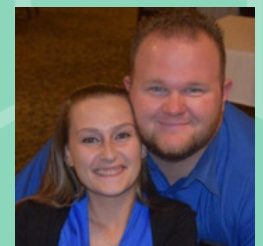
Mary Lonski
HONORARY MEMBER



Katie Ingle
UIC CLINIC



Soo Shim
MS, MBS, LSCW
LURIE CLINIC



Krystal Al-Haj
MEMBER-AT-LARGE

Meet Your 2019 Board Members

HELLO



KIM KOWALCZYK MHS, PA-C

PRESIDENT

My name is Kim Kowalczyk and I am the President of the PKU Organization of Illinois. I also currently work as a Physician Assistant in Emergency Medicine. Growing up, I have always enjoyed attending PKU conferences and functions with my older sister who has PKU. Listening to the doctors and researchers speak about the latest advances in PKU science and medicine have inspired me continue my involvement in this field. I am further connected to the PKU community as I have recently been blessed with a newly adopted niece from China, who also has PKU!

In my spare time, I enjoy playing ice hockey, running, weight-lifting, cooking, and traveling. Four years ago, I joined the board of directors as the Illinois Representative for the NPKUA, and became involved in important matters regarding PKU legislation and research. Between then and now, I have also served on the board as Secretary, interim Treasurer, and event coordinator for the PKU Family Camp. This is my second year as President of the PKU Organization of Illinois and strive to continue to make a positive impact within the organization.

I am so grateful to have been given these opportunities and I look forward to giving back to the very same PKU community who positively influenced my career goals in medicine.

GRANT SMITH

VICE PRESIDENT

This is my 7th year on the board and third year as Vice President. I have a 7-year old son with PKU. In conjunction with organizing our Family Fund Day, I'm also in charge of our Facebook, Twitter, and Constant Contact messaging to the community.

KATHLEEN BIANCULLI

TREASURER

Kathleen is owner of Sterling Insurance Consulting, LLC. She has been treasurer of several not-for-profit organizations in the past. She is currently serving on the Board of Directors for the NAIW Legacy Foundation, a philanthropic organization which provides financial assistance to insurance professionals in addition to supporting the development of insurance education courses.

Kathleen is married to Jim and they have two fabulous daughters, two wonderful sons-in-law and two incredibly smart and talented grandchildren! They enjoy traveling, golf and spending time with their family. Kathleen's connection with PKU is her granddaughter, Giavanna.

SEAN HANEY

NPKUA REPRESENTATIVE

My name is Sean Haney and this will be my third year serving on the board. I have PKU and completed my undergraduate studies at the University of Illinois at Urbana-Champaign and graduate coursework at Loyola University Chicago. This year I will be serving as the NPKUA representative for our organization and am excited to be advocating for individuals with PKU on a national level. As always, my favorite part of being a member of the board is getting to connect with the members of our wonderful community!

MELINDA HALVORSEN

SECRETARY & VENDOR REPRESENTATIVE

My name is Melinda Halvorsen; this will be my second year on the board. I received my Bachelors Degree in Special Education with endorsements in Learning Disabilities, Behavioral/Emotional Disabilities, and Cognitive Disabilities through the University of Wisconsin-Eau Claire. I spent five year as a special education teacher at the high school level in Wisconsin and one year as preschool teacher in Illinois. I also have a Masters Degree in Reading Education from Concordia University. I have been married to my husband, Eric, for six years and we have two very active little boys, Emmett (4) and Elliot(2). Elliot was diagnosed with PKU at just a few days old, and this diagnosis led us to the PKU Organization of Illinois.

Last year my husband and I both volunteered to join the board and actively participated in planning and helping run events. I am happy to serve a second term where I will remain secretary and I will also be acting as vendor representative. I look forward to helping raise awareness about PKU and I am especially excited to continue meeting new people in the PKU community through our events.

Meet Your 2019 Board Members

HELLO



MEREDITH STUTZMAN

PKU PRESS EDITOR

Meredith is a Clinical Laboratory Scientist at Unity Point Health Methodist in Peoria. She currently works Per Diem in Hematology, Coagulation, and Urinalysis. Part of her job includes sending out the filter papers drawn for the IDPH Newborn Screening Program. She also helps educate laboratory science students in their clinical rotations at the hospital. This is her first year as the editor of the PKU Press.

Meredith is married to Alan and they have two very active sons, ages 7 and 4. Her sons, Aaron and William, both have Classical PKU. Her family enjoys camping, hiking, and visiting zoos. Meredith is excited to be volunteering as the new PKU Press Editor.

ERIC HALVORSEN

WEBSITE ADMINISTRATOR

My name is Eric Halvorsen and I am the Web Administrator for the PKU Organization of Illinois. I am a software engineer by trade and currently work at a major national retailer as an IT Solution Architect. My wife, Melinda, and I live in Plainfield and have two young boys – Emmett and Elliot. Elliot, the younger of the two, was born with PKU. Shortly after finding out his diagnosis, we began attending events and networking with other families of those impacted by PKU.

The PKU Organization has been there to support us since the very beginning, and I look forward to give back to the community by making information on news and events easier to access and more readily available online. In addition, I hope to assist wherever else I can be helpful in the operation of the organization and the support of the wider community.

MEGHAN FIDO

MEMBER-AT-LARGE

Meghan is an Assistant Principal for Chicago Public Schools. She has worked in public education her entire career with the majority of it being on Chicago's south side as an Early Childhood Educator. Recently, she became certified as a learning behavior specialist to assist families with the 504 and/or IEP process. As an administrator, she manages the school budget by disbursing funds to designated budget lines to cover salaries, materials, and professional development. She is versed in grant writing, which is used to add supplemental programming to the school. She serves as the secretary on the school board where her children attend and participate in their fundraising events. Meghan is married to Janusz and they have two beautiful children, ages 3 and 5. They enjoy traveling, theater, basketball games, and spending time with their family. Meghan wants to be more involved with PKU through advocacy and raising funds for research, given both of her children have PKU and has a genuine love for children and social emotional health.

SHANNON RAZO

MEMBER-AT-LARGE

My name is Shannon Razo. I am 29 years old and have classic PKU. Life with PKU is most definitely a struggle for anyone who has it. When I was young and my mother was in control of what I ate, I always had great levels. My father told me before that I was the only child he's ever heard ask for "bean beans" (green beans) and water on a constant basis.

As I got older, I took more notice that other kids didn't eat the same things that I did. So, naturally, I got curious and started sneaking different foods... usually ones I had no business even trying. My levels usually stayed in range though my teenage years, however, were a struggle for me. There was a long period of time when I was basically completely off diet and it showed (ask my poor mother). I was almost always in a bad mood; my grades were slipping, and I wasn't processing class lectures anywhere near as well as I usually did in elementary school. After high school I was on and off my diet. I don't recommend that either.

In recent years I have taken a more active role in my PKU health. My husband and I got married last November and are looking forward to starting a family. So since the beginning of January I've been really trying to get my levels under control so we can have a healthy family.

Meet Your 2019 Board Members

HELLO



ELENA CARO

MEMBER-AT-LARGE

Hello, my name is Elena Caro. I am a pediatric registered nurse with a doctoral degree in population health. I also have Classical PKU. This is my third year on the PKU board. I have served as an at-large member, as well as the liaison between the PKU Organization of Illinois and the National PKU Alliance. This year I will again be an at-large member of the board. I look forward to spending time with families at various events, and contributing however I can!

NICK FERGUSON

MEMBER-AT-LARGE

As a PKU adult who grew up in the Chicago area, I can say that I am indebted to this organization for the work it has done, and continues to do. After graduating from the University of Illinois at Urbana-Champaign and earning a master's degree at the University of Iowa, I currently work as an analyst and transportation modeler in urban planning. With my wife, Kelly, and I set to become new parents in April, I hope to be a useful resource for the next generation embracing the challenge. In my free time, I am a so-so drummer, a guitar learner, a gamer (both video and board varieties), a movie buff, and a homebrewer. I am thankful for this opportunity to begin paying it forward as a new board member.

KATIE INGLE

CLINIC LIASON FOR UIC

My name is Katie Ingle and I am a metabolic dietitian at the University of Illinois Chicago (UIC). I see patients in Chicago, Naperville, Peoria and Springfield. I grew up outside of Boston, Massachusetts and studied nutrition and dietetics at the University of Vermont. I love skiing and hiking! I moved to Chicago for a clinical dietetics internship in 2015. This is my first year on the board of the PKU Organization of Illinois and I am excited to be involved in such a proactive organization.

KRYSTAL AL-HAJ

MEMBER-AT-LARGE

Hello! I am a cardiac registered nurse, pursuing my master's degree to become a family nurse practitioner. I also have classical PKU, receiving treatment with the new medication Palynziq. This is my first year on the board, I will be serving as a member at large. I am very excited to join and help others in need. I look forward to meeting new families and old friends along the way at all the events. I hope to be resource to all the families and give guidance to many adults struggling with PKU. I am grateful for this opportunity and can't wait to meet everyone.

SOO SHIM MS, MBS, & LSCW

CLINIC LIASON FOR LURIE'S

I have been in the Social Work field with twenty-seven years of experience working in medical Social Work. I am currently employed at the Ann and Robert H. Lurie Genetics Division. I have spent my career working in the medical field and as a social worker. I love supporting and advocating for patients and families. I have a Type 73 School Social Work Certification. I am involved as a member of the PKU Board liaison to the Lurie Genetics clinic. I am currently President for the Illinois Society for Social Work Leadership. I received my Master of Social Work degree from Columbia in New York and undergraduate degree B.S in Psychology from Washington University in St. Louis. My goal for the 2019 Board is to continue to educate PKU patients/families on all the events available and provide updates to the Board on relevant issues and needs in the clinics



A fabulous time was had by all who attended the annual Wine Tasting and Silent Auction event this past October! The Enoteca Roma really outdid themselves with a variety of delectable dishes and a lovely presentation of all plates.

We were able to solicit donations from more than 75 businesses and individuals allowing us to create 20 baskets for auction! These baskets included items such as passes to amusement attractions, spa treatments, museum certificates, sports tickets and accessories, home décor, yoga memberships and gear, restaurant and distillery certificates, coffee, golf outings, beauty supplies, and even a few yummy food and wine baskets.

Due to all our wonderful supporters, the organization was able to raise over \$5,000 through the auction baskets, the wine cork pull and individual donations! We look forward to an amazing event again this fall!

Wine & Tasting Silent Auction

EVENT RECAP

NOV. 2018

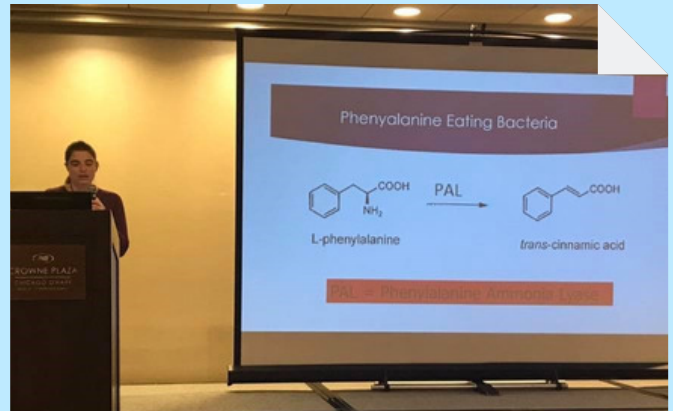
PKU Annual Meeting | Event Recap

The PKU Organization of Illinois Annual Meeting took place on November 10, 2018 at the Crowne Plaza Hotel and Conference Center in Rosemont.

We started our morning off with a continental breakfast consisting of fresh fruit, pastries and bagels (sponsored by Cambrooke's), and freshly brewed coffee and tea. We gathered in the main room to meet the board members, and to hear about the updates within the PKU Organization of Illinois and also within the clinics. We were so honored to present Hazel Vespa with a well-deserved lifetime achievement award just prior to welcoming our key note speaker.

We had the privilege of hosting Dr. Katherine Durrer from the University of North Texas Health Science Center as our keynote speaker. Everyone listened intently as she outlined her research and the latest advances in her genetically engineered probiotic to lower blood Phe levels.

While we digested all of Dr. Durrer's fascinating information, we took a break for a delicious Italian-themed lunch buffet served up by our guest chef, Michael McGee, who traveled all the way from Oregon to be with us!



After lunch, we went our separate ways to join one of 5 different breakout sessions and discussed strategies and tactics for tackling the PKU diet and management depending on the age bracket that pertained to us.

We then reconvened in the main conference hall as the children all came back from their all-day program and presented all of their artwork, projects, and goals to the rest of the group.

We capped our day with a measuring demo and sneak peek at how to effectively use howmuchphe in order to track our daily intake and progress, followed by our raffle drawing.

We are so so so thankful to all of our vendors and their unwavering support for our community! We enjoyed visiting their tables, learning about their products and even tasting some samples during every break and opportunity throughout the meeting! We are looking forward to yet another successful Annual Meeting this November!



Event Recap

holiday cookie exchange

The fourth annual cookie exchange was in jeopardy of being a cancelled event this year until the gracious Anderson family came to the rescue. Volunteering to host the event in their home, the Andersons arranged to have a variety of low protein treats available when the first guests arrived including the very loved CFL coffee cake and individual jars of hot chocolate mix. They prepared an arts area with coloring pages and crafts for the kiddos and even had little goodies to send home. The event attracted 5 families who were able to sit around the Christmas tree in the living and enjoy engaging conversations while watching the children run around and play. Everyone brought scrumptious treats and recipes to share and also left with a generous helping of snacks to try at home.

FEBRUARY 8TH, 2019 | RECAP MCCORMICK PLACE

Over the past 27 years, the Chicago Auto Show's First Look for Charity Event has raised nearly \$48 million for local Charities.

One of Chicago's largest single-day charitable events, First Look, has become the premier fundraiser for many local charities. This year, the money raised at First Look will benefit 18 local organizations.

Thank you!



**We raised \$3825 through
First Look for Charity for our
Genetics patient fund!**



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The annual First Look for Charity benefiting Lurie Genetics was held at the beginning of February. Our hope is to have a PKU patient attend each year to share about their PKU journey! Heather Bausell organized the event benefiting Lurie's and helped raise \$3825! This money will help PKU/Genetics patients and their families.

The clinic continues with successful group education classes for children and adolescents. We are adding adult support group sessions and parent/infant groups.

The Division of Genetics continues to expand. Our newest addition is Kirsten Havens, RN BSN. Kirsten joined the Division of Genetics, Birth Defects, and Metabolism in February 2018. She is a graduate of North Park University and worked for over 7 years in the level 3+ Neonatal Intensive Care Unit at Lurie Children's and the former Children's Memorial Hospital. Kirsten briefly left Lurie to work as a travel nurse in the NICU, PICU, and Cardiovascular ICUs at Children's Hospital of Los Angeles. Since returning to Chicago and transitioning to the Division of Genetics, Kirsten has helped develop Lurie's Palynziq program and will be joining the PKU clinic as a RN coordinator. She is a member of the Genetics Task Force of Illinois, and plans to attend the University of Illinois at Chicago (UIC) this fall to pursue her doctorate of nursing practice and pediatric nurse practitioner certification.



Kirsten Havens, RN BSN



thank you, shoppers!

\$112.04



Dear Charity Administrator,

This email is to notify you that PKU Organization of Illinois () has been issued a \$112.04 donation from the AmazonSmile Foundation as a result of AmazonSmile program activity between October 1 and December 31, 2018. The donation was deposited to your organization's bank account on or before February 15, 2019. It may take several days for the donation to appear in the account.

Add us as your AmazonSmile Charitable Organization!

- Sign in to smile.amazon.com on your desktop or mobile phone browser.
- From your desktop, go to Your Account from the navigation at the top of any page, and then select the option to Change your Charity.
- Select a new charitable organization to support.
- ***WHEN YOU PLACE AN ORDER it needs to be from the actual WEBSITE and NOT THE MOBILE APP*** or we get no credit. Thanks!

CLINIC UPDATE



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



follow us!

WE'RE ON PINTEREST

pinterest.com/PKUillinois

Follow our Pinterest boards for new PKU tools, Low Protein recipes, and adaptable dinner ideas!

MEET



AMBER GIBSON

OUR FEATURED PERSON OF INTEREST

- "I love doing this to help everyone ...
I love that my daughter has shown me how"

My name is Amber Gibson. I live a wonderful life in Brownsburg, Indiana with my husband, Ben, and my two kids- 6-year-old Denon and 3-year-old Samantha. We also have a cat named Indy.

My husband and I met in culinary school in Indianapolis and graduated in 2010. From there I worked in a restaurant in a Marriott in downtown Indy for about 7 years. While there I gained experience in food service, quality control and food safety, and menu development. After my son was born, I wanted a job where I did not have to work so many hours and I could still be with him to care for him. I took a job doing some data entry for an accountant, who is also my father. While this job does get the bills paid, my strongest desire to cook and bake keeps me going back into the kitchen.

In 2015 our daughter, Samantha, was born. A week later we received news that her newborn screen test showed her homocysteine levels were too high. A few months later we got the rough diagnosis- she has homocystinuria (HCU). While we were terrified by the news, we were more bewildered. We were not sure how to make the foods for her, what her care was going to take, or what could possibly happen in the future.

Her first year was great and her levels were where they should be. Then the stomach flu hit her in fall 2016 as well as her older brother. Samantha began refusing her necessary formula. We tried everything- smoothies, mixing with baby cereal, flavorings, etc. As a few months went by she started to show signs of protein malnutrition. With the guidance of her metabolic doctor, we chose to try an NG tube. We did this for a few months, hoping it would trigger Samantha to drink her formula. Unfortunately it did not work, and we had to go the g-tube route. Now not only did we have to monitor her daily protein intake, but we have to give her formula through the tube three times a day. It is very stressful and time consuming through our day and her levels remain high, but she really is doing great. Samantha is very happy, sassy, silly little girl. We are thankful to God everyday for her and this condition.

When I first began making food for Samantha, some of the recipes I tried were just OK. The recipes really seemed to lack flavor and decent substance. As I looked at recipes online, I began to really think "how could I make this lower in protein?" I wanted to make recipes that are easy to understand, 2 grams of protein or less in a serving, and that do not require a lot of special ingredients that are hard to find. I began playing around in the kitchen. Some things turned out well, others needed a little more work. It is always trial and error in the kitchen. I love it!

One of the reasons I am driven to make the recipes I do is to try to make food that not only tastes good, but will also look very similar to our everyday family foods. I hope with these recipes my daughter will not feel she is missing out on something, but able to enjoy things just as we do. I wish the same for all of those in the allied metabolic disorders community. I have been able to execute what I learned in culinary school to create new foods and recipes that work well for the HCU community and the allied disorders community. I love doing this to help everyone and I love that my daughter has shown me how.

Amber's

OUR FEATURED PERSON OF INTEREST

PICKS

I got involved in this whole process by posting pictures of food I made for my daughter on the Facebook Cook For Love Site. I had others in the community start asking for my recipes, so I began to type them up and posting them for the community in the files tab. I was asked to add my recipes to the new Cook For Love site, which felt like such an honor!

IN THE KITCHEN

- I highly recommend the stand mixer. I use mine all the time!
- I also like my food processor. It helps with a lot of food prep, especially if you need to meal prep for the entire week. It makes things a breeze!
- A bread machine can be a great small appliance, too. There are some low protein bread mixes that work well in the bread machine.
- If you cook frequently, I do recommend getting a decent chef's knife and a honing steel to sharpen the blade. A good knife can help a great deal with food prep.
- As we all know, a scale with a toggle between gram and ounces is great to help measuring portion sizes and ingredients properly.

WHAT'S NEXT

One recipe I have not perfected yet is a low protein Angel food cake. I have tried it a few times and came close once, but it is just not quite there yet. I will need to come back to it in the future and try again. Grilling recipes are coming up next in the spring!

I plan to start a YouTube cooking Channel for the Allied Metabolic Disorders Community. My husband even got me an induction burner to encourage me. I have not begun yet, but I really want to do this! This is my biggest dream right now!



amber gibson

RECIPES · LOW PROTIEN · GOOD FOOD

COOK FOR LOVE

THE NEW COOK FOR LOVE SITE HAS LAUNCHED!

The wonderful work of Virginia Schuett and Dorothy Corry, the talented Malathy Ramanjuan of Taste Connections and pastry chef and up-and-coming low-protein rock star Amber Gibson have joined forces with little old me and PKU News/HowMuchPhe.org (HMP) to expand your culinary options.

All of the recipes have gone through HMP so you know the PHE, protein and calorie counts are accurate. If values change, the recipes will automatically update.

Search options abound: pick a chef or a meal type, enter an ingredient, and build a list of your favorites.

In the coming months we will be opening up new features including the rating system, comments & questions, sharing your own images and, for HMP users, creating and sharing your recipes with the entire community!

Since CFL originally launched 10 years ago, my goal was to eventually create a community driven recipe site. All of the incredible ideas and recipes that all of you have posted on this Facebook page have cemented that desire. It never could have happened without the technology behind HMP and Sarah Chamberlin's ridiculous work ethic, organizational skills and drive to help this community. Thanks Sarah, you rock!

As always, access to the site is free. Happy Cooking!

BRENDA WINIARSKI

COOK FOR LOVE IS COMMITTED TO CREATING
LOW PROTEIN FOODS THAT TASTE DELICIOUS.

THINK SPRING

Carrot Cake

BY BRENDA WINIARSKI

INGREDIENTS

1 1/6 c (227g) Crushed pineapple in juice
1 small can 5 carrot(s) (305g) , shredded
1/2 c (60g) Dried cranberries
1/4 c (60g) Orange Juice

2 1/2 c (325g) Cook for Love Baking Mix
2 tsp (10g) Baking Soda
1 tsp (5g) Baking Powder
1/2 tsp (3g) Salt
2 tsp (6g) Cinnamon, ground
1/2 tsp (1g) Nutmeg, ground
1/2 tsp (1g) Ginger, ground
1/4 tsp (1g) Cloves, ground
1/2 unit(s) (43g) Jell-o Instant Vanilla Pudding

1 egg(s) (50g) Large Egg 1 c (200g)
Sugar 1/2 c (110g)
Brown Sugar 1/4 c (60g)
Mayonnaise 113g
Small jar pureed baby food carrots 1 tsp (5g)
Vanilla Extract 1 TBSP (6g)
Orange Zest
1 c (240g) Canola Oil

NUTRITION

24 SLICES

SERVING SIZE 1 SLICE

30 MG PHE PER SLICE

220 CALORIES EACH

Step 1: If you are making the Browned Butter Sour Cream Frosting, brown the butter now and refrigerate.

Step 2: Preheat oven to 350. Grease a 9 x 13 inch pan.

Step 3: Place craisins in a small pot with 1/4 cup of orange juice (use the orange you will need to zest). Bring to a boil and simmer for a few minutes to plump up the dried cranberries. Set aside.

Step 4: Sift the baking mix, baking soda, baking powder, salt, jell-o pudding and spices using a triple sifter.

Step 5: Place the egg in the large bowl of a mixer. Beat on medium high speed with wire whisk attachment for two minutes, or until light in color and thickened. Add the sugars 1 tablespoon at a time, taking about 4 minutes to add it all. Add the mayonnaise, vanilla, orange zest and baby carrots. Whip for another two minutes.

Step 6: Turn the mixer down to medium. Slowly pour the oil in a steady stream. Beat for one to two minutes until the oil is completely incorporated.

Step 7: Change to a paddle attachment. Add the starch mixture all at once, blending for about 30 seconds on a low speed. Add the pineapple with juice, blend again. Using a spatula, fold in the carrots and craisins. Pour the batter into prepared pan, smoothing the surface with the spatula.

Step 8: Bake for 50 to 55 minutes. A piece of raw spaghetti should come out clean when inserted in the center. Cool the pan on a rack. After 20 minutes, carefully invert the cake onto a cooling rack (place rack on top of pan and gently flip). When completely cool invert it back to serving plate and frost.

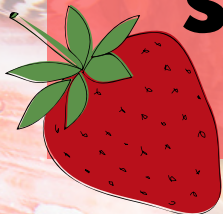
FOR COMPLETE NUTRITION INFO VISIT COOKFORLOVE.ORG

It's Summer Time!



strawberry mango salsa

AMBER GIBSON | COOK FOR LOVE



WHAT YOU'LL NEED

- 145 g Small Diced Strawberries 28mg
- 100 g Small Diced Mango 17mg
- 1 TBSP Lime Juice 1mg
- 1/2 tsp Juice from jar of Pickled Jalapenos
- 1/4 tsp Salt, Table
- 1/2 tsp Cilantro, raw chopped

NUTRITION INFO

Makes five 1/4 cup servings

Phe Per Serving: 9 mg

Protein Per Serving: 0.3

Exchanges Per Serving: 0.6

Calories Per Serving: 22

Phe mg/g: 0.17

Combine all ingredients in a glass bowl and lightly toss to combine. Cover with a lid and refrigerate until ready to use.

NOTE:

You can add one diced jalapeno if you want a little extra kick. For the pickled jalapeno juice- you can use mild or hot depending on your tastes

VISIT COOKFORLOVE.ORG

LET'S SOCIALIZE



WWW.PKUILLINOIS.ORG

SUBSCRIBE TO OUR EMAILS

[/PKUILLINOIS](https://www.youtube.com/channel/UCkUillinois)

Chili with Roasted Sweet Potatoes & Jicama

by Chef Andy Broder

Ingredients

- 3 Tbsp olive oil
- 1 medium onion, diced
- 1 cup peeled diced sweet potato (5-6oz)
- 2 cups diced celery
- 4 zucchini, diced (1 pound)
- 2 cups jicama, dice small
- 1 pound potatoes, diced
- 1 chipotle in adobo sauce, minced or ground
- 3 Tbsp chili powder
- 1 Tbsp garlic powder
- 1 Tbsp ground cumin
- 1 c. water + 1 Tbsp cornstarch
- Salt & Pepper to taste

Makes 12 servings

Directions

1. Preheat oven to 375 F
2. Place diced onion, sweet potato, carrots, and celery in a baking sheet and drizzle with the olive oil. Roast in the 375 F oven for 25 minutes.
3. Transfer potatoes and onions to a large stockpot. Add zucchini, tomatoes, jicama, chipotle in adobo, chili powder, garlic powder, and cumin. Stir to combine and add water and cornstarch to mixture.
4. Cook over medium high heat for 30 minutes, stirring occasionally.
5. After 30 minutes, season to taste with salt and pepper. Cook for 10-15 minutes longer. If necessary, you can add a little water to thin.

Nutrition Information

	Per Recipe	Per Serving
Phe, mg	723	60
Met, mg	986	82
Leu, mg	241	20
Protein, g	19.5	1.6
Calories	914	76

Jicama... What's That?

Jicama is a globe-shaped root vegetable with papery, golden-brown skin and a starchy white interior.



Its flesh is juicy and crunchy, with a slightly sweet and nutty flavor. Some think it tastes like a cross between a potato and a pear. Others compare it to a water chestnut.

EGGPLANT 'MEAT' BALLS

GENEVIEVE LAFRANCE | DIETICIAN & NUTRITIONIST

Low protein recipes: simple, attractive and tasty to help people with inherited metabolic disease in their daily lives.

YIELD: 24 SERVINGS
1 SERVING = 1 "MEAT" BALL

Ingredients

- 1 Tbsp olive oil
- 2 Tbsp chopped onion
- 2 garlic cloves, minced
- 1 medium eggplant (550 g) cubed
- 2 cups low-protein bread crumbs (10 crackers Aprotin reduced to crumbs)
- 1 tsp dried oregano
- 1 tsp dried parsley
- 1 Tbsp Country Sunrise egg substitute
- Salt and pepper



Preparation

- Preheat oven to 375 F.
- In a large pan, heat the oil. Sauté the onion for a few minutes. Add garlic and cook for 2 minutes. Add the eggplant cubes and cook for 15 minutes, until the eggplant becomes gray.
- Meanwhile, place the crackers in the food processor and reduce to crumbs. Add herbs, egg substitute, salt and pepper. Keep aside.
- When cooked, put the eggplant mixture in the food processor and puree. Add crumb mixture and mix well.
- Take 1 Tbsp (15 ml) of the mixture and form a ball. Place it on a baking sheet covered with parchment paper. Repeat until you've used all the preparation.
- Bake for 20-25 minutes, taking care to turn halfway through cooking.
- Note: Freezes well!

Nutrition

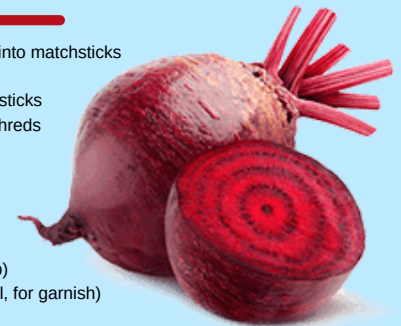
Energy: 26 kcal
Protein: 0.3 g
PHE: 13 mg
TYR: 8 mg
LEU: 21 mg
VAL: 17 mg
ILE: 14 mg
MET: 4 mg
LYS: 14 mg

<http://www.lowprorecipes.com/recipes/category/main-course/eggplant-meat-balls>

Borscht

Ingredients

- 1 pound beets (beetroot), peeled and cut into matchsticks
- 2 medium onions, sliced into half-moons
- 2 large carrots, peeled and cut into matchsticks
- 3/4 pound white cabbage, cut thinly into shreds
- 2 tablespoons olive oil
- 5 cups vegetable stock
- Juice of 1/2 a lemon
- Salt to taste
- Coarsely ground black pepper
- Sour cream (optional, omit for vegan soup)
- Finely chopped parsley or chives (optional, for garnish)



Directions

1. Peel and cut the onions, carrots, and beets (alternatively, shred the carrots and beets using the shredding blade of a food processor) and sauté over medium heat in the olive oil with a pinch of salt in a large soup pot. Reserve a small amount of beet to grate and add near the end to enliven the color.
2. In the meantime, bring the vegetable stock to a boil. When the vegetables are soft (about 5 minutes), add the shredded cabbage and the hot stock. Bring to a boil and simmer 15-25 minutes, until the vegetables are tender. With a few minutes left, add the reserved grated beet.
3. Season to taste with salt and pepper, then squeeze in the lemon juice, aiming for a pleasing but subtle sour taste. Serve with freshly grated black pepper, a dollop of sour cream, and chopped parsley, if desired.



FUN

/FƏN/

Save the Dates

noun | 1. amusing, entertaining, or enjoyable

UPCOMING EVENTS IN 2019

VISIT PKUIL.ORG TO REGISTER
OR FOR MORE INFORMATION

May
4th

New Parent Cafe

Free event in Lisle, IL for parents, children under age 5, and families of those with PKU & allied disorders.

June
22nd

Family Fun Day Central/South

Free family outing for everyone at McGraw Park, Bloomington Illinois There's a splash pad! Bring a dish to pass.

June
23rd

Family Fun Day North

Free family outing for everyone in Geneva, Illinois. Meet us at Wheeler Park for a fun day! Bring a dish to pass.

July
19 - 21st

PKU Family Camp

3 days of fun in Lacon, IL. Outdoor activities for the whole family, all weekend long. Lodging and meals are included in reservation fee.

September
7th

Uncorked @ Enoteca Roma

Our TOP fundraising event of the year at Enoteca Roma in Wicker Park. This event combines great wine, great food, and bidding for great prizes with friends and family.

November
9th

Annual Meeting

Annual event in Rosemont, IL at the Crowne Plaza. Food and vendors included in pricing. Children's program for ages 6 and up.

TBD

Holiday Cookie Exchange

More information coming later this year! Check PKUIL.org or follow us on facebook for updates!

New Parent Cafe

MEET. BRUNCH. LEARN. PLAY.



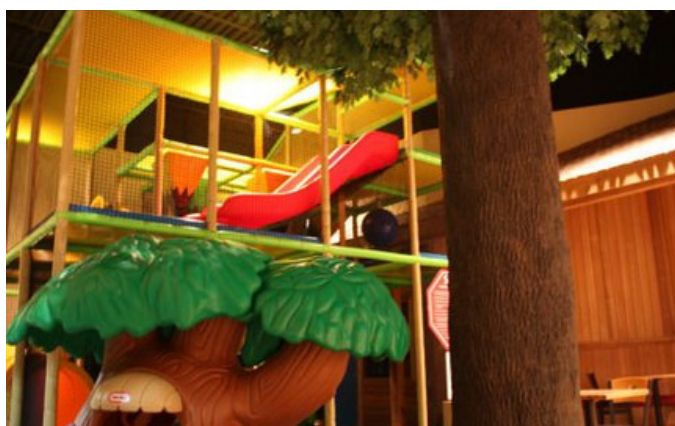
May
4th

presented by
the pku organization of illinois

** age limit of children for this event is under 5 years old **

a free fun event for the whole family!

- MEET NEW FRIENDS IN THE PKU & ALLIED DISORDERS COMMUNITY
- LOW PROTEIN BRUNCH ASSORTMENT
- SPEAK WITH VENDORS & CLINICS
- FREE SAMPLES AND TOOLS



Grounds for Hope Cafe

2701 Maple Ave.

Lisle, IL 60532

Saturday, May 4th, 2019

1:00 - 3:00pm

FOOD
SWAP

Have PKU Foods your child has tried but won't eat? (Yep, us too) Don't throw it away! Bring your items to Parent Cafe, and SWAP with foods from another family! Must not be expired or stale, but can be open or frozen.

Family Fun Day!

CENTRAL/SOUTH

@ MC GRAW PARK
Bloomington, IL

June
22nd
12 - 2pm

PRESENTED BY
THE PKU

Organization of
Illinois
&
Allied Disorders

Free!

Bring a dish
to share



...there's a
Splash Pad!

Where?

3202 Cornelius Dr.
Bloomington, IL
61704

Two Free Events!

**ONE GREAT
WEEKEND**

JOIN US!

Family Fun Day!

NORTH

@ WHEELER PARK

PRESENTED BY
THE PKU

Organization of
Illinois
&
Allied Disorders

June
23rd
12 - 2pm



Free!

Bring a dish
to share

Where?

Wheeler Park
822 N 1st St
Geneva, IL 60134



With two pavilions, easy access to a playground, Stone Creek Miniature Golf*, and The Links Disc Golf Course*, Wheeler Park has something for everyone!

*golf courses require small fee to play, not included

CENTRAL/SOUTH

**June
22nd**

NORTH

**June
23rd**

pk organization of Illinois

FAMILY CAMP

Lacon, Illinois | July 19 -21st

Great Oaks Camp
The fun begins now!

Archery

Swimming

Disc Golf Course

Canoeing

Paddle Boats

Fishing

High Ropes Course

Basketball

Sand Volleyball

Gagaball

Hiking

Carpet Ball

Camp Fires

Field Games

Save the date!

July
19-21st

Join us this July at Poplar Lodge! This building sleeps up to 60 guests in four dorm rooms. Poplar Lodge is air conditioned. The lodge also houses a kitchen, a common room, bathrooms with shower facilities, a tv/dvd system, and outdoor fun! High and low protein meals, activities, & lodging are all included in your registration fee. Ready to take a dip in the lake and enjoy s'mores by the campfire? Then bring your family to the great outdoors for this PKU friendly event!

THE PKU ORGANIZATION OF ILLINOIS

& ALLIED DISORDERS

PRESENTS



Uncorked

SILENT AUCTION

SEPTEMBER 7, 2019

WINE TASTING

&

APPETIZERS



JOIN US AT *ENOTECA ROMA* FOR OUR
PREMIER ANNUAL FUNDRAISING
EVENT!

PLAN ON AN EVENING OF GREAT WINE
AND DELECTABLE PKU & NON-PKU
FOOD ALIKE.

GRAB A GLASS OF YOUR FAVORITE
RED OR WHITE AND START BIDDING
AT OUR SILENT AUCTION BENEFITING
PKU & ALLIED DISORDERS.

ENOTECA ROMA

2146 W DIVISION ST
CHICAGO, IL 60622

RESERVATION
INFORMATION
COMING
SOON!!!

\$75/PERSON

\$125/COUPLE

Celebrate...

EVERY TINY VICTORY

NOVEMBER 9, 2019

2019 ANNUAL MEETING

THE PKU ORGANIZATION of IL & ALLIED DISORDERS

RESERVATIONS

More information
coming soon!

LOCATION

CROWNE PLAZA
5440 N RIVER RD
ROSEMONT, IL

WHAT TO EXPECT

- KEYNOTE SPEAKER
- BREAKOUT SESSIONS
- RAFFLE
- SCHOLARSHIP WINNERS
- VENDOR TABLES
- CHILDREN'S PROGRAM (6-12y)
- LIGHT BREAKFAST & LUNCH

VENDORS

NUTRICIA
BIOMARIN
LIL'S DIETARY
CAMBROOKE FOODS
FLAVIS
VITAFLO

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PhenylAde® GMP Ready is a medical food for the dietary management of proven Phenylketonuria (PKU) and must be used under medical supervision.

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