# PKU Press Spring Edition

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- Recipes
- NEW! PKU Friendly restaurants
- NEW! Grocery Store Finds
- UPCOMING 2018 EVENTS
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# Letter from the Board

Hello PKU Families!

Our organization is a constant work in progress (aren't we all?) and I wanted to let you know about some improvements we're making to the PKU Press. First things first: we want to hear from you! We've been updating our website, social media channels and this newsletter to become more accessible to our community. We want you to engage with us and want to provide you content that you can use.

Second, we are as committed as ever to provide tools, support, and encouragement through creative means. Our board is comprised of a group of volunteer individuals who have been impacted by PKU or another allied disorder in some way, and we pledge to bring you more relevant information, tools, and events in the coming year. With that, we are excited to announce that we've added some new 'columns' to our PKU press, such as "Low-Pro Friendly Restaurants to try" and "Grocery store finds!" to help you find new, delicious, and EASY sources for low-protein foods

We'll also keep giving you the 'daily word on the street' on the newest products, clinical trials, medical enhancements, and recipes to try. Over the course of the year, you'll also see the addition of some new features and even a fresh look to our PKU Press.

In the meantime, I hope you are enjoying the content we are sharing and hope to see you at all the amazing events we have planned for this year

# HELLO

**MEET YOUR 2018 BOARD MEMBERS** 



kim kowalczyk





kathleen bianculli

TREASURER



pam kowalczyk

**VENDOR REPRESENTATIVE** 



alex siedler

MEMBER-AT-LARGE



grant smith

VICE PRESIDENT



eric halvorsen

WEBSITE ADMINISTRATOR



ami vanderhoof

PKU PRESS EDITOR



krista engen

MEMBER-AT-LARGE



melinda halvorsen

SECRETARY



elena caro

NPKUA REPRESENTATIVE



sean haney

MEMBER-AT-LARGE



soo shim, ms, mba, and lcsw

MEMBER-AT-LARGE

# Meet the Board

### **KIM KOWALCZYK**

#### **PRESIDENT**

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 (currently on both a men's and women's team), running and weight-lifting, cooking, and traveling. Three 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. Last year, I took on an additional role as Secretary and organized the PKU Family Camp. This year, I am honored to accept the many nominations and move forward as President of the PKU Organization of Illinois. 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 6th year on the board and second year as Vice President. I have a 6-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 organizations in the past and is currently serving on the Board of Directors for the NAIW Legacy Foundation, a philanthropic organization providing financial assistance to insurance professionals as well as supporting the development of insurance education courses. Kathleen has been married to her husband Jim for 42 years and they have two fabulous daughters and two wonderful sons-in- law. They enjoy traveling, golf and spending time with their family, especially their grandchildren, Giavanna and Vinny!

## melinda Halvorsen

#### **SECRETARY**

I am excited to serve as the Secretary and member of the 2018 board, my goal is to participate in other roles as I become more familiar with the organization. I have a background in Special Education and a Masters in Reading Education. Previously, I worked as an educator for high school students with learning and behavioral disorders. Currently, I am a stay at home mother of two boys, Emmett who is three years old and Elliot who is one. We found out one week after Elliot's birth that he had PKU. Before his diagnosis I was unaware of PKU and since then have tried to immerse myself in information, current research and events hosted by the PKU Organization of IL to build a support network for myself, my son, and my family. I have learned so much in such a short time and have made many connections through the organization. I look forward to helping raise awareness about PKU and hope to give back to the community that has already made a huge impact in my life.

# Meet the Board

## Pam kowalczyk

#### **VENDOR REPRESENTATIVE**

I am an adult with PKU and have recently adopted my daughter Kelsey who also has PKU. Kelsey joined our family on July 31st and was untreated for PKU however has been doing great with her formula and PKU diet! I am a special education teacher and a skating coach. This year I will be serving as the Vendor Rep for the PKU Organization of IL. Previously, I have served on the PKU Board as a voting member, shared the Vice President seat and was also President. I have been involved with the Board in some day for nearly my whole life when my parents first joined and helped get the board up and rolling in 1985! Since then, the Organization has been near and dear to my heart. I am looking forward to playing a more vital role with the organization again and also getting Kelsey involved with all of the great PKU events and activities that we offer!

## amı vanderhoof

#### PKU PRESS EDITOR

I'm excited for my third year on the board planning the Parent Cafe, and PKU Press Editor. As mom to a very happy, healthy, (and stinking CUTE!) 4-year-old, Logan who has PKU, my primary goals while serving the board include providing fun and positive experiences for PKU families, encouragement and support to new parents, elevating resources and knowledge to our Members. I've met so many amazing people and made lifelong friends for both Logan and myself thanks to this organization, and I hope to encourage others the same way.

#### elena caro

#### NPKUA REPRESENTATIVE

I am a pediatric registered nurse and a doctoral student studying Advanced Population Health Nursing at the University of Illinois at Chicago. I also have Classical PKU. This is my first year on the PKU Board, and I look forward to contributing by dedicating myself to learning more about disparities in PKU treatment and quality of life, and how health outcomes can improve among patients and families affected by PKU.

#### eric Halvorsen

#### **WEBSITE ADMINISTRATOR**

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 giving 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.

# Meet the Board

## alex siedler

#### MEMBER-AT-LARGE

This will be my first year serving on the board. I graduated with a bachelor's degree from Eastern Illinois University and I wanted to become more involved with the PKU community. Growing up with PKU I had lots of support from my family and friends and now I want to provide that support for others. I'm particularly interested in meeting families with PKU and learning how it's impacted their lives. I'm excited for the opportunity to give back to this community.

#### sean Haney

#### **MEMBER-AT-LARGE**

I have thoroughly enjoyed this last year of volunteering with the PKU Organization of Illinois and connecting with all the different members of our PKU community! I'm particularly interested in mentoring young adults with PKU at programs such as the PKU-palooza and the Annual Meeting. The organization and all the events that it sponsors have already provided me with a wealth of new experiences and I look forward to expanding on those in this upcoming year!

## Krista engen

#### **CLINIC LIAISON FOR UIC**

I am one of the three metabolic dietitians at the University of Illinois Medical Center. I have been working at UIC since November 2016 and have been a dietitian for 6 years. This is my first year on the PKU Board and I am very excited to be a part of this wonderful organization. I see patients in Chicago, Naperville, Peoria, and Springfield, and really enjoy working with my patients and their families. I am always learning something new in this job! I am looking forward to learning even more as a clinic liaison on the PKU Board in 2018.

## SOO SHIM, MS, MBA AND LCSW

# CLINIC LIASON FOR LURIE'S GENETICS DIVISION

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 2017 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.

# TEACH YOUR CHILD TO TRACK & COUNT PHE

A common concern is how and when to start teaching kids to count or track their daily PHE intake. We're here to take some of the pressure off with a fun craft project to help count and makes it easy to understand for the little ones.

First step is to find something that they really love – is it animals? Pirates? Princesses? Letters? As an example, let's say barnyard animals.

If Johnny's tolerance is 300 PHE per day, we would have 30 barn animals in the yard, each signifying 10mg PHE. For every 10mg PHE Johnny eats, he gets to move an animal into the barn! This will show how much he has in his budget and will help him make smarter decisions! It could be as easy as printing a picture of a barn, and putting it on a magnetic board, and each animal could be a magnet.

Some fun ideas could be:

- Your little princess can put 'diamonds on a tiara
- Your pirate can put the pirate booty into the treasure chest.
- Your Lego Lover can earn a piece for every 10 mg, and build a different 30 piece figure each day!
- Using skittles (or jellybeans) as a reward for when they count correctly each day.

One idea is to draw a Tree – and fill the tree with 30 apples (or PHE allowance divided by 10), and for every 10mg, they can place an 'apple' (red skittle) in the tree. When they get all 30, they can eat the skittles!

As they get a little older, you can use the same counting and tracking tools to teach budgeting. If you're going to dinner, and you think you'll need a higher allowance for the fries you have been craving all day, you can start setting those skittles aside and plan your day around it. Or different skittles colors can signify different phe numbers (i.e. purple is 100, Red counts as 50, orange is 30, yellow is 20, green is 0). Check out Pinterest 'spending' or 'budgeting' ideas for teaching kids about money - it's a similar concept! Whatever you choose, have fun with it! The more customized it is to your child's interest, the more excited they will be about it



#### MARY'S CORNER: DON'T LET PKU STOP YOU

I was diagnosed with PKU at the age of 1 ½ years old.

The doctors told my mom and dad there was no hope of me walking or talking. I was made fun of as a child, I got beat up to the point where I bled. [But]
I was no match for these bullies

in grammar and high school, [and] if those doctors were here, they would see me in a different light because I am walking and talking. Then they took me off the diet when I was 14 years of age, they didn't know it was a lifetime thing but then they found out it was.

I drink Periflex LQ orange cream. I have three jobs; I'm a receptionist here at Garden Center Services, I volunteer at Christ Hospital, and I'm a hostess at the Original Pancake House. I love them all, this is why I say don't let PKU stop you or you will regret it. I'm successful at what I do and I have Dr. Burton to thank for that, and Katie my dietician. They are the best at what they do, I have a lot of support from my family members. As for me I'd like everyone to learn from me.

> mary lovski



#### Dear Phe-Bea,

My son just turned 3 and is getting more curious about foods. Its exciting to expand his palate, trying new combinations - but also challenging to keep him within the limits of his tolerance. Enter the grandparents. They continuously challenge me and my husband to "just let him try it" or "one bite won't hurt." We've even caught them sneaking him some off-limits foods like chocolate and cheese and bacon. We want our son to have a close relationship with his grandparents, but we feel undermined and don't want him to try foods he cannot have as he gets older. We don't feel comfortable with them being alone with our son without us present, and we're always on edge. How do we communicate to them that this cannot happen and teach them the importance of the diet? - Frustrated in Frankfort, IL

## Dear Frustrated,

Grandparents often joke that it is their job to spoil the grandchildren, and then send them home, but some grandparents take their right to spoil very seriously. When it comes to food, especially the PKU diet, grandparents and family members must be especially careful to stick to the rules. Giving a grandchild a forbidden food is not only a serious breach of parental authority, it is likely to result in family conflict. It doesn't matter if they agree with the dietary rules, if they care for their grandchild, its important to remind them that this is what is best for their health and long-term effects when it comes to remaining on diet. Here are some ways to help get your family to grasp the importance of the diet, and help them feel involved:

- 1. Education- a lot of the miscommunication can come from not understanding why a person with PKU must follow a special diet. A person with PKU looks the same as anyone else, so it may be hard for a relative to understand that there is something different about their grandchild/niece/nephew and why they must follow a special diet. Taking time to educate relatives on PKU, and the dangers of consuming high protein foods, is a important conversation to have. Encourage relatives to do their own online research about how important it is to treat PKU, and why we treat PKU.
- 2. Support- asking for support of family members to help teach children/teens with PKU how to follow their diet is also important. This makes people feel like they are contributing to their grandchild/niece/nephew's health and is important for that child as they grow up and have such a great support system in place.
- 3. Respect- it sends mixed messages to the child when a relative allows the child with PKU to have something that is not on their diet. This both undermines the parents and causes a lot of confusion for a child as they are learning about PKU and why they can't eat the same as other family members.
- 4. Involvement- attending a low protein cooking class, accompanying mom or dad to a clinic visit with the child, learning to cook a low protein recipe, etc.- all of these are wonderful things for a relative to do. It's wonderful for the child/teen with PKU to feel like they have a relative who is "in their corner" and understands their condition. Give them recipes to try (like cookies or cupcakes from Cook For Love website), which allows them to 'treat' the child, and also shows that PKU food can be super yummy!

The bottom line is letting them know if they want to "spoil" the grandchildren, make sure whatever it is they are doing or giving them, it is always first and foremost keep them healthy and on-track for success.

# **2017 EVENT RECAPS**



#### **PKU FAMILY CAMP**

Last August, the PKU Organization of Illinois hosted our PKU Family Camp at Great Oaks Campground in Lacon, IL. The theme was "Around the World." On Friday, we kicked off the weekend with an All-American BBQ and enjoyed a favorite Cook For Love recipe "Not Dogs" followed by tie-dying T shirts, and coloring in our PKU Camp passports. We ended the night with some PKU-friendly smore's by the fire.

## WINE TASTING AND SILENT AUCTION

Nothing like a little fun rivalry, and things certainly got exciting last October at our annual Wine Tasting and Silent Auction. Some new and familiar faces were present throughout the fun filled night of drinks, PKU friendly food and a generous assortment of silent auction baskets.

CONTINUED ON NEXT PAGE

ANNUAL WINE TASTING & SILENT AUCTION 2017

The rain did nothing to slow down the vibrant interactions and a little healthy competition between our friends, parents and supporters. The auction basket values ranged from \$50 upwards of \$1000 value, and included getaway weekend trips, chocolate, coffee, original artwork, Chicagoland family-friendly activities, keeping fit, beer and

wine (of course!), various concert tickets, and so much more. For the second year, we incorporated the 'cork pull', where guests donate \$20, and pull a cork to reveal their winning bottle, with values ranging from \$15 - \$250. From this event we were able to raise over \$5,000 towards our scholarship funds.









## PKU FAMILY CAMP

Saturday morning, we had a hearty breakfast including some French pastries, in our lodge to give us energy for an action-packed day! We participated in archery, canoeing, paddle boating, ziplining, and fishing! A few of us even caught frogs and toads!

We went to the camp cafeteria for lunch and ate an Asian inspired stirfry. In the afternoon we played kickball, volleyball, played on the tire swing, and the best part.... the swimming lake!! After our Latino taco dinner, we made some friendship bracelets and other arts and crafts, followed by an intense game of glowstick "ghost in the grave-yard," and yet again ending with some old-fashioned campfire smore's.



# 2017 Low Protein

# HOLIDAY COOKIE EXCHANGE

We closed out 2017 with our third annual Holiday Cookie Exchange. With 15+ guests in attendance, everyone brought 2 dozen servings of their favorite cookie or holiday recipe to share. Recipes, PHE content, and festive beverages, and 'doggie bags' were provided to bring the treats home to indulge later. The delicious treats came in many assorted styles, and all were enjoyed by families and friends. This event also brought together current and new board members before we geared up for another successful year. We hope to have you join us in 2018!

Enjoy a fan favorite recipe from the event, Spritz Cookies from Cook for Love









# Spritz Cookies

From CookForLove.org Yield: 82 3 mg PHE / Cook<u>ie</u>

## INGREDIENTS

- · 260 gm (2 cups) wheat starch [21 mg]
- ½ teaspoon xanthan gum [0 mg]
- $\frac{1}{2}$  teaspoon salt [0 mg]
- ¼ teaspoon baking powder [0 mg]
- 50 gm (1/2 small box) vanilla flavored instant jell-o pudding mix [0 mg]
- 15 gm (1 large) egg yolk [102 mg]
- · 30 gm (2 tablespoons) heavy cream [30 mg]
- ·1 teaspoon vanilla extract [0 mg]
- 12 tablespoons (1½ sticks) unsalted butter, softened [72 mg]
- · ½ cup sugar [0 mg]

## **INSTRUCTIONS**

- 1. Heat oven to 375 degrees. In a medium bowl, whisk starch, gum, salt, baking powder, pudding; set aside. In a small bowl, beat yolk, cream, and vanilla with fork until combined; set aside.
- 2. In standing mixer, cream butter and sugar at medium-high speed until light and fluffy, 3 to 4 minutes. Scrape down bowl with rubber spatula. With mixer running at medium speed, add yolk/cream mixture and beat until incorporated, about 30 seconds. Scrape down bowl. With mixer running at low speed, add starch mixture until the dough is formed, about 1 to 2 minutes. (If too dry add an extra tablespoon of heavy cream.)
- 3. Following the instructions on your cookie press, fill with dough. Press cookies onto ungreased baking sheets, spacing them about 1-1/2 inches apart. Bake one sheet at a time until cookies are light golden brown, 10 to 12 minutes, rotating baking sheet halfway through baking time. Cool cookies on baking sheet until just warm, 10 to 15 minutes; using metal spatula, transfer to wire rack and cool to room temperature.
- 4. TIPS: To make these cookies in advance, freeze unbaked cookies right on the baking sheet. Once frozen transfer to a Ziploc bag. When ready to bake, place frozen cookies on baking sheet and bake for an extra 2 minutes. To lower the phe content, replace the egg yolk with an extra tablespoon of heavy cream.







# 2017 Annual Meeting

RECAP AND UPDATES

## mission: possible

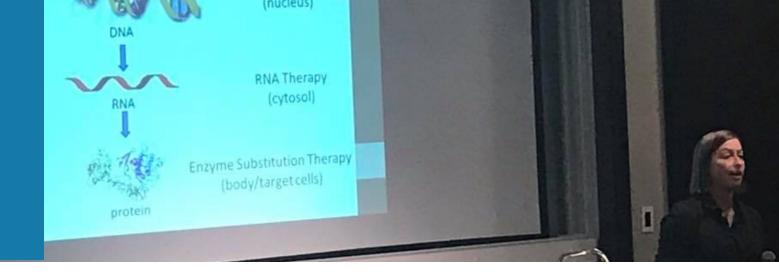
The PKU Organization of Illinois Annual Meeting took place on November 4, 2017 in Downers Grove.

Our keynote speaker for the day was Daelyn Richards who is currently a doctoral candidate at Oregon Health and Science University in the Department of Molecular and Medical Genetics. She is working in gene therapy in the laboratory of Dr. Cary Harding, who's research focus is improving therapies for peoples with inborn errors of metabolism, including phenylketonuria (PKU), and is recognized for his efforts in translating these therapies into the clinic. Read her update on the following page!

Chef Rachel Merz served up a cooking demonstration for a PKU friendly taco, and gave tips and tricks for adjusting recipes. Merz was diagnosed with non-celiac gluten sensitivity four years ago and her focus is on gluten free/sensitive recipes.

The annual meeting had both a panel discussion and breakout sessions, to address PKU through transitions, such as early childhood, sports and PKU, and adulthood.

We'd like to thank those who were willing to partake in the panel and those that led discussions in the breakout sessions. Thank you as well, to all who attended and helped make this a successful event!



## UPDATES FROM DAELYN RICHARDS

Dear PKU Community of Illinois,

At the 2017 annual meeting I discussed two methods to improve PKU gene therapy. One approach included targeted integration of the phenylalanine hydroxylase (PAH) DNA into the genome with a means to select and expand those cells, and the other was to directly correct the mutation causing PKU in our mouse model using the revolutionary CRISPRcas9 system. Both methods were designed to produce a more robust, long-term therapy when translated into human medicine.

With regards to the former project, the selection of properly integrated DNA is harnessed by hijacking the strong selective pressure of hereditary tyrosinemia type 1 (HTI). Thus, we tested this gene therapy approach in HTI in a proof of principle study to show the selection process is effective. In all twelve animals treated, all were able to survive off HTI treatment, indicating proper integration and expansion. Further molecular tests are in process. The next step for this project is to test this gene therapy approach in PKU mice. The selection process will be facilitated by a drug that mimics HTI conditions. The drug is currently under synthesis, but these studies will commence as soon as this is completed. It is noteworthy to mention that while this project induced selection via HTI, other means of inducing selection are being developed in the field. These studies are expected to be completed this year.

For the CRISPRcas9 gene editing project, I presented a preliminary study which was overall unsuccessful. After systematically analyzing each molecular stage, a new study was developed to address the findings. The revised approach was tested in 3 mice and was found to be remarkably successful. In these animals, gene correction was found to be 12.7, 15.8, and 40.3%, yielding restoration of PAH activity to 5.4, 8.4, and 24.8% respectively. Serum Phe had decreased to 842, 393, and 883  $\mu$ M while on normal mouse chow, levels significantly lower than in untreated PKU mice (1647-2027  $\mu$ M; p = 0.002). While these results did not reveal a complete correction, they are certainly a step in the right direction. Since these mice were analyzed, more have been treated to elucidate the effectiveness of this therapy. More studies will need to be performed to make this therapy more broadly applicable to all human PKU mutations, but these data are encouraging to achieve the goal for a more robust, long-term treatment of PKU.

It was a sincere pleasure meeting all of you in the PKU community in Illinois last year. Thank you all for being so warm and welcoming. A special thanks to the National PKU Alliance, without whom, none of this research would be possible.

# Your FUTURE'S so BRIGHT, you have to wear shades!

CONGRATS, TO THE 2017 ANDREW CRAIG SCHOLARSHIP AWARD WINNERS!

PKU Organization of Illinois has elected to award scholarships for education to qualified individuals with PKU or Allied Disorders.

### HEATHER RICCA

For as long as I can remember, I have wanted to be a teacher and I am proud to say I am in my eleventh year of teaching. I've taught fifth grade for seven years, with the last two years teaching gifted and talented students. It's been a huge learning experience for me and allowed me to find my "niche" in education, finding my passion in coming alongside and supporting these exceptional learners who are often overlooked in our current education system. Through my graduate studies at Northeastern Illinois University, I've found great purpose as I develop myself professionally to meet the diverse needs of this student population. In 2019, I will have completed the first Masters of Gifted Education Program offered in the state of Illinois. I know this program is advancing me as a teacher, and in turn supporting our family for years to come. My family and I are beyond grateful for the 2017 Andrew Craig Memorial Scholarship, which has helped fund my graduate courses. This endeavor would not

have been possible without the generous support of the PKU Organization of Illinois.



## HALEY JARVIS-WALSH

Having PKU has inspired me to view the world in a different manner. This has helped me in many ways with my focus in school. I am currently finishing my last semester at George Williams College of Aurora University and will be graduating with a bachelor's degree in applied psychology. My psychology program has entailed being able to explore all the aspects I am interested in, including; forensic, police, personality,

clinical and counseling psychology. These were further explored first-hand through my internships. I have had the honor of interning my fall semester with my professor and clinical counselor, Jenn Pagone, who has taught me countless valuable skills in the psychology field and as a professional. My current internship is at the Walworth County Police Department and Jail, where I am seeing all aspects of an officer's job as well as the social work and psychology aspects at play in the jail. My experiences and education have prepared me for a promising future. I was honored to be chosen for the Andrew Craig scholarship which has helped me get to where I am today. I will be graduating at the top of my class with high honors and have been inducted into the National Honors Society. Always follow your dreams!

continued on next page...

Haley Jarvis-Walsh

### SARAH MARSHALL

Sarah Marshall is a PKU adult living in Chicago with her husband Chris and her two cats. She is the CEO of North Side Community Federal Credit Union, a community development credit union. Most of her career has been spent working in and studying community development. Previous work includes youth programming, community organizing, and working on environmental responsibility at a social enterprise. She is also a speaker and advocate for the PKU community. Sarah holds an MBA from North Park University and is using her scholarship to work on her Master of Liberal Arts degree at The University of Chicago. She hopes to study poverty relief policy and use her story of living with PKU to help people better connect with social issues and explore misconceptions created around cultural barriers. Her personal passions also include health and nutrition, from years of trying to figure out how to be healthy while enjoying the PKU diet. You can follow her food adventures on Instagram under the name 'plantbased\_pku.'

### SARAH LOEWY

When I was younger I let being different define who I was as a bad thing. As I have grown up and the world as evolved, shaping the environment in which we all live, I have learned that my PKU makes me. I can't say that I still love PKU, but I have learned that it has helped me and made me stronger than many others. I love it now when friends balk at the idea of never being able to eat meat but then give me credit for being on such a strict diet! Currently, I am going to Eureka College in Illinois for an Art major psychology minor degree. I will be transitioning to online school after to get my CDA for preschool education shortly after I graduate in 2020! I have always been drawn to kids and I hope to find someone, not specifically with PKU, who has felt like an outcast and let them know I've been there and will help them through the tough times. I am so grateful that I was chosen for this scholarship and want to thank the board again for the ability to keep doing what I love: Helping



Sarah Marshall



Sarah Loewy

# **ASHLEY GINTER**

PKU has given me ups and downs throughout my life so far. When I was younger, I always thought I was too different from everyone else. Now that I am almost 19 years old, I have learned to embrace that I am unique. Although it was always a struggle finding a meal to eat at parties, sport meets, and school functions I was always fortunate enough to have family and friends who always have been very supportive. As of right now I am enrolled in cosmetology school at Cosmetology and Spa Academy (CSA). School has been a fantastic opportunity, giving me the ability to learn new things every day. Every day I am in school I attempt to make sure that I attempt to learn something that I hadn't known the day before. As of today, my graduation date is 7/11/18. My plans after school are to continue my education in cosmetology, and to strive for my license to teach. I am very thankful to have earned the Andrew Craig Scholarship, and it has been put to good use furthering my education. In the future I hope to gain a greater experience in my field and become more educated about PKU to help me manage it.

## SPECIAL PERSON: Significant Other Edition

Christian Villanueva Significant other of person with PKU Age: 25

Occupation: Registered Nurse, Doctoral

**Nursing Student** 

Time dating person with PKU: 6 years

## WHAT IS YOUR FAVORITE PART ABOUT DATING SOMEONE WITH PKU?

"The challenge itself. It includes being open to a whole new lifestyle. You have to evaluate how blessed you are and the simplicity in not having to be concerned with everything you consume, because your partner does not have that luxury. I also love trying new low-protein foods with her. I get excited when she gets excited in the Lil's Dietary Specialty Shop food aisles-Shoutout Lil's! I love seeing her geek out like a toddler at age 24 when new low-pro foods come out. It's quite a sight to see."

## WHAT IS THE HARDEST PART OF DATING SOMEONE WITH PKU?

"Formula breath. Just kidding. Always needing to step back and evaluate food options that would be best for her. Also, being selfless as much as possible when making decisions about where we go out to eat. Another delicate balance lies between being supportive enough to not make her feel bad or reprimand her before, during, or after high phe meals, and respectfully reminding her when she is about to eat too much phe. I care about her cognitive health and want her to have success with her diet and in her life."



## WHAT DO YOU WISH SOMEONE HAD TOLD YOU ABOUT DATING SOMEONE WITH PKU?

"I wish someone told me in detail what PKU is. I'm a nurse and even in nursing school it was glossed over very quickly in curriculum. After learning the ins and outs of PKU, it has made me a more compassionate nurse and human being towards others with dietary restrictions and genetic disorders. I also wish someone had told me what it would be like to experience the mood changes that can occur with high phe levels, as well as what it would be like to travel domestically and internationally with someone who's carrying formula. I always have Camino Pro formula in my car in case of emergencies. I think she appreciates that."

## WHAT IS ADVICE YOU'D GIVE TO OTHER SIGNIFICANT OTHERS OR SUPPORT PERSONS OF THOSE WITH PKU?

"Do your own research. Do your best to understand what living with PKU is by putting yourself in your significant other's shoes. The more you know about PKU, the better able you are to relate to and understand what they are going though-- they can't turn their PKU off because it is a diet for life. Also, be flexible in meal and diet choices. She loves when we normalize low-pro choices, and make them something we can both enjoy, like making Ratatouille with vegan cheese, or baked macaroni and cheese with low-pro pasta and cheese that we can both devour. I would also suggest immersing yourself in the PKU community by attending conferences, events, and even PKU clinic appointments. Your significant other will appreciate your efforts and you will be surprised at how much you learn!"

# save the dates

UPCOMING EVENTS IN 2018
VISIT PKUIL.ORG TO REGISTER OR FOR
MORE INFORMATION

MAY 05 JUNE 16

JULY 20-22 OCT 13

## NEW PARENT CAFE

Free event in Lisle, IL for parents, kids, and families of those with PKU. All ages welcome!

#### FAMILY FUND DAY

Family outing for everyone at Blackberry Farm in Aurora. Food and drinks provided.

# PKU FAMILY CAMP

3 days of fun in Lacon, IL. Outdoor activities for the whole family all weekend long.

#### ANNUAL WINE TASTING & SILENT AUCTION

Our top fundraising event of the year combines great wine, great food, and bidding for great prizes with friends and family

NOV 10







#### 2018 PKU ORG. OF ILLINOIS ANNUAL MEETING

A one-day conference in Rosemont, IL, sharing the latest in PKU studies, and breakout sessions by age group



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

#### HOLIDAY COOKIE EXCHANGE

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

#### BD'S MONGOLIAN BBQ FUNDRAISER

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

# NEW PARENT CAFE

meet. brunch. learn. play.

# FREE FUN FOR THE WHOLE FAMILY!

- Meet new friends in the PKU community
- LOW Protein Brunch ASSOFTMent
- SPEAK WITH VENDORS & CLINICS
- Free samples and tools





# **GROUNDS FOR** HOPE CAFE

Saturday, May 5, 2018 9:30 - 11:30 am

2701 Maple Avenue LISLE, IL 60532

LOW PRO FOOD SWAP

Have PKU FOODS YOUR CHILD HAS TRIED BUT WON'T EAT? (YEP, US TOO) DON'T THROW IT away! Bring to parent case, and swap with soods from another samily! Must not be expired or stale, but can be open, or frozen.

New





# GREAT OAKS CAMPGROUND

ARCHERY, SWIMMING, CANOEING, PADDLE BOATING, FISHING, CAMPFIRES & MORE!

JULY 20 - 22, 2018

COST INCLUDES
ALL MEALS, ACTIVITIES AND
LODGING ARE INCLUDED!

GREAT OAKS ADDRESS 1380 CR 900 N - LACON, IL MORE INFO COMING SOON!! SAVE THE DATE

# STEPPING STONES TO SUCCESS

**JOIN US FOR THE 2018 ANNUAL MEETING** 



#### Saturday, November 10, 2018

Crowne Plaza 5440 N. River Road Rosemont, IL, 60018

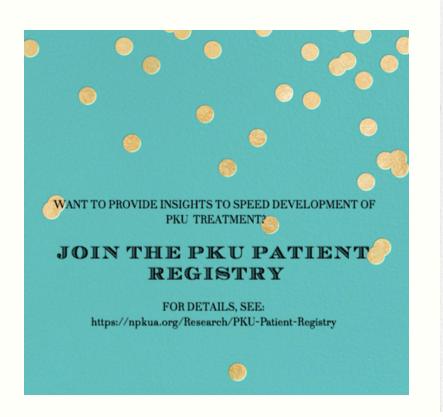
\$35 Adults \$25 children Join us for the Annual PKU Organization of Illinois Conference, where we will have keynote speaker Dr. Durrer- Deming, as she presents her latest study on a probiotic which would essentially lower serum PHE levels.

There will be breakout groups that focus on the various age groups, and workshops to teach children how to track and measure PHE.

Our overall theme will focus on PKU through adulthood and getting children set up for success.



Dr. Katherine Durrer-Deming at the University of North Texas Health Science Center is continuing her research into the ability of a genetically engineered probiotic to lower blood Phe levels in PKU mice. The creation of a human safe version of a genetically engineered probiotic to treat PKU is nearly complete. This human version is a Lactobacillus strain engineered to carry a Phenylalanine Ammonia Lyase (PAL) gene. PAL enzyme activity has been verified in cell culture extracts. To confirm efficacy and safety, a large group of mice will be fed the treatment probiotic for several months. Animals will be monitored for up to three months post treatment to determine potential long term residency in the gut. The data generated from these experiments will assist in working towards FDA approval for human clinical trials. (Source: NPKUA.org)



SAVE THE DATE!

2018 NPKUA
CONFERENCE
"ADVANCE THE
DREAM"

JULY 5TH-8TH ATLANTA, GEORGIA

ATLANTA BOTANICAL GARDENS/HILTON DOWNTOWN
ATLANTA
FOR DETAILS VISIT:

https://npkua.org/News-Events/Conferences

# TASTING AND SILENT AUCTION

#### SAVE THE DATE

Grab a glass of your favorite red or white and start bidding at a silent auction benefiting PKU

SATURDAY, OCTOBER 13, 2018 5:30 -9:00 IN THE EVENING

Enoteca Roma 2146 W Division Street Chicago, Illinois 60622

INFORMATION COMING SOON VISIT PKUIL.ORG FOR UPDATES

# **SPOTTED!** Low protein grocery store finds

Often, we hear "what can I find at a local grocery store" or "heading to whole foods – what should I look for?" Going forward, we're going to feature a few yummy finds from our local grocery stores, to shop smarter and delicious for the whole family!



#### SIETE CASSAVA & COCONUT TORTILLAS

17.4 MG PHE / TORTILLA (HOWMUCHPHE.ORG)

If flour tortilla and corn tortilla had a baby - it would taste like this! These have excellent reviews for both taste and pliability. Available at Whole Foods, Fresh Thyme, Tony's finer Foods, and Fruitful Yield - or, visit sietefoods.com/pages/store-locator to find near you



#### FIELD ROAST CHAO CREAMERY CHEESE

0.8 MG PHE / SLICE (HOWMUCHPHE.ORG)

This rich and creamy vegan cheese is coconut-based and seasoned with a fermented tofu. Chao Slices have bold flavors and a cheesy bite right out of the package or melted on your favorite hot sandwich. Comes in three flavors: Creamy Original, Tomato Cayenne, Coconut Herb. Found at Whole Foods, Meijer, Fruitful Yield, and Walmart, or visit Fieldroast.com/where-to-buy



#### **UPTON'S BAR-B-QUE JACKFRUIT**

28.5 MG PHE / SERVING (HOWMUCHPHE.ORG)

Readymade BBQ Jackfruit needs a quick heat and is ready to serve! A delicious meat alternative for the whole family, has the texture of pulled chicken or pork. Makes a great sandwich, on a salad, in a wrap, or over rice. Also available in Original, Sriracha, Chili Lime Carnitas, or Thai Curry flavors. Found on Amazon, Whole Foods, or visit uptonsnaturals.com/where-to-buy to find a location!



#### CECE'S VEGGIE NOODLES CO. -SPIRALIZED VEGGIE NOODLES AND RICE!

PHE AMOUNTS VARY BY VEGETABLE

You can eat 'em raw, sautéed as an alternative to pasta, sauced, sidelined, in a salad, or as a soup. Organic spiraled and riced veggies include sweet potato, butternut, zucchini, beet, spirals and veggiccine, sweet potato hash (homemade hash browns!??) and riced cauliflower and broccoli! This will make veggies fun for adults and kids with unique textures and shapes convenient for any recipe. Less prep work. Less clean up. More veggies. More fun. For recipes or where to buy (hint: Whole Foods is one!), visit cecesveggieco.com

# Let's go out to eat towight

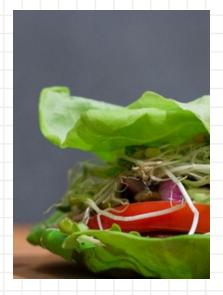
We're excited to bring you a new feature to the PKU Press: Restaurants to try! As much as we all love to order a Side of veggies with our salad (and a French fry, of course!), sometimes we want to order off the menu, alongside our company. We've done the dirty work and have will share with you some restaurants that have PKU friendly options to make your meal out easy, delicious, and sizeable!



#### HANDCRAFTED PIZZA

#### MOD PIZZA, BLAZE PIZZA, OR RISE PIES

When it comes to the menu - you can be your own Chef! With Gluten Free and Dairy Free Cheese available - everyone can have the pizza they crave - whether you like to load it with veggies, or a olive oil and cheese lover - make your way through the pizza bar and create as you desire



## **FUN ON A "BUN"**

#### RED ROBIN GOURMET BURGERS & BREWS

Have you been to Red Robin lately? You must head over and Create your own 'Burger' - go bun less and wrap some sautéed mushrooms, tomatoes, caramelized onions, and some dill pickle planks in a lettuce wrap at no charge! Need I mention... bottomless steak fries?



#### **ASIAN STIR FRY**

#### BD'S MONGOLIAN BBQ, STIR CRAZY, OR BIG BOWL

A customized bowl of stir-fry is a good, satisfying option if you're hoping for a healthier meal, too.

Take a trip to Big Bowl's stir-fry bar, load up your bowl with fresh vegetables, get saucy with a kung pao (spicy) or a sweet orange ginger, and let the chefs do the rest. Many offer lettuce wraps (in lieu of a tortilla) or Cauliflower 'rice' instead of steamed rice.

#### **UNIVERSITY OF ILLINOIS, CHICAGO**

The University of Illinois Genetics and Metabolic clinic continues to have strong outreach program through the satellite clinics. In addition to our Chicago based clinic, we see patients in Rockford, Oak Lawn, Naperville, Springfield and Peoria. Our physicians include Dr. George Hoganson, Dr. Zohra Shad and Dr. Rhonda Spiro, who is a new geneticist on our staff. Our team of dietitians includes, Shannon O'Brien, Katie Ingle, and Krista Engen in Chicago, and Diane Simon in Rockford. Our genetic counseling team includes Maria-Renee Coldagelli and three new genetic counselors who will be joining us this spring, as well as Jen Burton in Peoria and Gina Morley in Rockford. Our clinic coordinator is Andie Jones Jackson. We look forward to continuing to grow our team this year!





# ANN & ROBERT H. LURIE CHILDREN'S HOSPITAL

The Lurie Children's Division of Genetics continues to expand and service patients throughout the Midwest. We see patients at our downtown location and at the Westchester. II. satellite. In addition to our team of Dr. Barbara Burton, Andrea Paras Clinic Coordinator/Genetic Counselor, Shanna Widera APN, Favth Kalb Genetic Counselor, Vera Shively Educator, 3 Dieticians Heather Bausell, Katie Arduini and Amanda Johnson, we added two RN Nurses Teresa Philipp and Kirsten Havens. Kirsten was a Lurie NICU nurse prior to coming to Genetics Division and Teresa worked in various roles including outpatient Orthopedics. I continue to serve the clinic in my role as the Genetics Social Worker. There are three research staff members on the Lurie Genetics team: Rachel Katz (Manager), Carolyn Ries and Roxanne Del Rosario. The team continues to prepare for Pegvaliase. This summer the clinic will have special PKU educational sessions for parents, children and teens in age cohorts.

# CLINIC UPDATES



# MINT OREO ICE CREAM

• YIELD: 4 CUPS

• SERVING SIZE: ½ CUP

(100 GM)

• PHE PER SERVING: 30 MG

#### **INGREDIENTS**

- 360 gm (1½ cups) rice milk [32 mg]
- 120 gm (1/2 cup So Delicious Coconut beverage\*), plain, vanilla or unsweetened [20 mg]
- $\bullet$  120 gm (1/2 cup) heavy cream [122 mg]
- 30 gm(2 tablespoons) macadamia nut oil [0 mg]
- ¼ teaspoon xanthan gum [0 mg]
- <sup>2</sup>/<sub>3</sub> cup sugar [0 mg]
- 1/4 teaspoon salt [0 mg]
- 1⁄2 tablespoon crème de menthe [0 mg]
- 1/4 teaspoon peppermint oil (1 teaspoon if peppermint extract) [0 mg]
- 6 chocolate kinnitoos, crushed (gluten free "Oreos") [66 mg]

#### INSTRUCTIONS

- 1. Pour rice milk, coconut beverage, and heavy cream in a blender with xanthan gum, sugar, salt, crème de menthe, and peppermint oil. Blend for 60 seconds. While blending, add the macadamia nut oil gradually to emulsify.
- 2. Pour mixture into ice cream machine, and process according to manufacturer's directions. Once the ice cream is almost set, add the crushed cookies. Transfer to a container and freeze until firm, at least 4 hours or up to 3 days.
- .\* If unable to find So-Delicious coconut beverage, increase Rice Milk to 480 gm (2 cups). Pour rice milk and ¼ cup dried coconut into small saucepan. Bring to a simmer, and remove from heat. Let steep overnight in the fridge, or at least three hours. Strain coconut and add remaining ingredients to blender.



Just in time for grilling and BBQ season, we're sharing with you some favorite recipes from CookForLove.org! Everything you need for a PKU Friendly BBQ: a "Not" Dog, a side of "Faked" Beans, and a couple of summer friendly desserts (what is summer without Ice Cream and Apple Pie?!)

If you have not yet visited CookForLove.org, register on this FREE site containing dozens of family-friendly (and utterly delicious) Low Protein recipes for the PKU Community.

# HANDHELD APPLE PIES

- YIELD: 12 MINI PIES
- SERVING SIZE: 1 MINI PIE
- PHE PER SERVING: 22 MG

#### **INGREDIENTS**

- 490 gm (½) flaky pie pastry prepared [221 mg] o Visit COOKFORLOVE.ORG for the recipe
- 4 tablespoon butter [24 mg]
- 515 gm (4) Granny Smith apples, peeled, cored, and cut into ¼ inch squares [36 mg]
- ¼ cup dark brown sugar [2 mg[]
- 1/4 cup sugar
- 1/4 tsp salt
- •1teaspoon ground cinnamon
- 1 tsp tapioca starch dissolved in a tablespoon of water or apple juice



#### **INSTRUCTIONS**

- 1. Preheat oven to 400 degrees.
  2. Heat butter a large skillet over medium-high heat until sizzling. Add apples, brown sugar, sugar, cinnamon and salt. Cook, stirring frequently with heat proof rubber spatula, until apples are golden brown, about 10 minutes. Add the tapioca starch slurry to thicken the juices, cooking for about a minute. Off heat, stir in lemon juice. Set aside, or in the fridge, to cool completely.
- 3. Meanwhile, roll the pastry dough to % inch thick. Using a biscuit cutter, cut out 3 ½ inch circles. Take the leftover bits and re-roll as needed. In the end you should have 24 circles, each weighing about 20 gm.
- 4. Dip your fingers in a small bowl of water and moisten the edges of the rounds. Place a heaping tablespoon (30 gm) in the center of half of the rounds. Place the other rounds on top, pinch the dough together and then use a fork to seal. Make four slashes with a sharp knife on top. Freeze what you are not eating today.
- 5. Bake for 15 to 18 minutes.



# BOSTON "FAKED" BEANS

- YIELD: 3
- SERVING SIZE: 113 GM (1/2 CUP)
- PHE PER SERVING: 81 MG

#### **INGREDIENTS**

- 28 gm (2 Tbsp) butter [12 mg]
- 24 gm (2 Tbsp) onion, chopped [6 mg]
- 4 gm (1 clove) garlic [7 mg]
- 2 tbsp brown sugar [0 mg]
- 120 gm (1/2 cup) vegetable broth, preferably Swanson [5 mg]
- 5 gm (1 tsp) yellow mustard [7 mg]
- 240 gm (1 can) hominy, drained [183 mg]
- •1tsp salt [0 mg]
- ½ tsp cider vinegar [0 mg]
- 1/4 tsp smoked paprika [1 mg]
- ½ tsp ground white pepper [4 mg]
- 30 gm (2 Tbsp) ketchup [18 mg]
- 15 gm (1 Tbsp) maple syrup [0 mg]
- 15 gm (1 Tbsp) BBQ sauce [8 mg]

#### **INSTRUCTIONS**

- 1. Melt butter in a skillet. Add the onions and cook until soft, about 5 minutes.
- 2. Add minced garlic and sauté 30 seconds.
- 3. Add vegetable broth and drained and rinsed hominy.
- 4. In a small bowl, combine remaining ingredients and add to the skillet.
- 5. Bring to a boil and then reduce to a low simmer. Cover and cook for 30 minutes.
- 6. Remove the cover. Cook for an additional five to ten minutes if the sauce is too thin. Add a splash of vegetable broth if it is too thick. It should be a syrupy consistency. Add additional salt and pepper to taste.



#### "NOT" DOGS

- YIELD: 10 NOT DOGS
- SERVING SIZE: 1 CARROT
- PHE PER SERVING: 17 MG

#### **INGREDIENTS**

- 10 large carrots, peeled and cut down and shaped to resemble hot dog, each weighing about 55 gm after shaping.
- BRINE:
- 120 gm (½ cup) water
- 30 gm onion juice (1/4 onion)
- 30 gm beet juice (1 beet)
- 180 gm (¾ cup) apple cider vinegar
- 1½ tablespoons salt
- 1 tablespoon mustard seed
- 1 tablespoon white pepper seed
- •1teaspoon coriander seed
- •1teaspoon celery seed
- 1 tablespoon liquid smoke
- 1 teaspoon smoked paprika
- 1/4 teaspoon mace
- 2 teaspoons sriracha hot sauce
- 1 teaspoon Worcestershire sauce
- 20 gm garlic, rough minced



#### **INSTRUCTIONS**

- 1. Place a quart sized mason jar and lid in boiling water to sterilize.
- 2. Blanch the shaped carrots in a large pot of rapidly boiling salted water for 5 minutes. Drain in a colander and rinse under cold water to stop cooking.
- 3. In a small pot, bring the water, beet juice, onion juice and vinegar to a boil, stirring occasionally.
- 4. Reduce to a simmer. Add the salt, mustard seed, white pepper seed, coriander seed and celery seed and stir the ingredients.
- 5. Turn heat off and add liquid smoke, smoked paprika, mace, sriracha and Worcestershire sauce. Stir.
- 6. Add the rough chopped garlic to the bottom of the mason jar. Add in the carrot dogs.
- 7. Pour the brine over the carrots.
  Allow to cool slightly uncovered. Once it is cool enough to handle, put the lid on the jar and shake. Place in the fridge for at least one week. The longer they sit in the brine, the more flavorful they become.
- 8. To serve: lightly brush carrot with olive oil and put on the grill for 3 minutes to heat up and get those lovely grill marks. Serve on a low protein bun with relish and mustard and a side of Faked beans.

  If you do not have a juicer, just grate
- If you do not have a juicer, just grate the onions, place on a cheese cloth and squeeze the liquid out. Same with the beets - but wear a glove because those suckers stain.



# Cambrooke Therapeutics' latest breakthrough!

The lowest Phe GMP medical food available for PKU!



COMING SOON!

- Lowest Phe
- Natural!
- Lowest calorie GMP nutritionally complete formula
- Low volume
- Low carbohydrates
- Zero total sugars
- No artificial sweeteners, colors or flavors
- Synbiotic combination of probiotics & prebiotics to support gut health

The lowest Phe and lowest calorie complete GMP product available!



Request a sample today! cambrooke.com or 866 456 9776, opt 2





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